

The anthropological approach challenges the conventional approach to bioethical dilemmas: a Kenyan Maasai perspective.

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Abstract:

Background: The cultural background, religion and societal norms have a huge influence on the decision making process for physicians, patients and their families, when faced with medical ethical dilemmas. While the medical professionals, through their training, can rely on the principles of autonomy, justice, beneficence and non-maleficence to guide them, the patients can only draw from their personal and cultural experiences.

Objective: To explore some of the challenges that face physicians when presented with ethical dilemmas.

Methods: A review of the literature on the principles of medical ethics and the cultural practices of the Maasai tribe, as well as, interview, interaction and observation of the patients and family during patient. management.

Results: In the Maasai community in Kenya, where family is the center of all attention and decision-making, the listed ethical principles and rules have a very different understanding of the self-determination, and autonomy becomes collective rather than individualistic. Medical practitioners when faced with ethical medical dilemmas are neither comfortable in adopting the conventional bioethical guidelines, nor in offering a health care purely based on cultural and historical practice.

Conclusion: In our set up, developing culturally relevant principles of bioethics appears to be the most effective solution in addressing medical ethical dilemmas.

Keywords: Bioethical dilemmas, Kenyan Maasai perspective.

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Introduction

The literature in biomedical ethics has identified several moral principles, such as respecting the wishes of the competent person which are, do no harm to others including a prohibition against killing and cruel treatment, benefit others, produce a net balance of benefit over harm, keep promises and contracts, disclose information, respect privacy and protect confidential information etc. Some of these obligations are regarded as primary and fundamental, whereas others are secondary and derivative. Amongst these Beauchamp & Childress have jointly recognized autonomy, non-maleficence, beneficence, and justice as primary principles, which have generally been accepted as the four basic principles of medical ethics.^{1,2}

The process of reasoning and decision making when it comes to bioethical problems is based on the premise

that individuals are rational human beings who should engage in a process of moral reasoning, based on normative rules or principles, to arrive at decisions in situations of conflict or ambiguity.³ In this regard, the decision making process is very contextual, influenced by the immediate environment and culture. There is a complex interaction of sociocultural, institutional, political and personal factors that contribute towards the precipitation/formation of the bioethical dilemma, and these must be taken into consideration if one is to fully understand the rationale of the moral decision making process by those faced with the bioethical dilemma.

The shortcomings of the principles of bioethics.

The principles of bioethics put forward by Beauchamp & Childress are neither foreign to Kenyans nor to the practice of bioethics in Kenya, yet in the application of these principles to actual situations, different interpretations surface, especially as concerns the principles of autonomy, justice, and decision making. One realizes that in the application of these principles in our set up, alot of complex factors and subtle ties of real life situations that are key to the evolution of the moral conflict are not taken into consideration. Such factors include gender, life stories, cultural identities, psychological sta-

tus etc. The principle-based ethics therefore ignore the impact that these factors may have in the decision making process and thus comes across as being abstract and removed from moral and psychological realities of the problem.⁴

The anthropological approach to bioethics.

We believe that the anthropological approach to bioethics may be best placed to address the shortcomings of the principle-based approach to solving bioethical dilemmas. The anthropological approach focuses on solving bioethical issues by use of local societal norms and cultural perspectives. Muller describes the anthropological approach to bioethical problems as having four overlapping dimensions. These pertain to a) the contextual nature of bioethical dilemmas, where the anthropological position sees the definition of a medical dilemma and the ways in which it is handled as inextricably bound to broad cultural conditions that influence health and illness behavior generally; b) the cultural embeddedness of moral systems, where different cultural systems have different standards for behavior and different expectations for relationships that are played out in health care arenas; c) the multicultural character of many bioethical dilemmas, where the anthropological approach places emphasis on the dilemmas resulting from cultural pluralism; and d) the challenge of examining the field of bioethics as a cultural phenomenon. This dimension explores the premise that bioethics is a social, cultural, and intellectual phenomenon that should be examined in its own right.³

Methodology

The methodology for this paper was carried out in two ways;

First by observation of the Maasai patients and their relatives while working at the hospital over several years. This was done mainly in the ICU because in the critical care setting a lot of decision making comes into play regarding the patients' treatment and end of life issues. Observation on how decisions were made on issues of life when it came to Maasai patients and their families prompted us to search electronically for any literature on the Maasai culture that would influence how they make decisions on bioethical issues.

Electronic searches were conducted in two main stages.

Stage one: electronic database searching in PubMed: through www.ncbi.nlm.nih.gov/entrez/. The Key

words used were Maasai, bioethics, anthropology. By using this site and its link to "related articles", several studies were produced. The titles and abstracts of the studies were examined and reviewed and the studies found to be applicable were used.

Stage two: Electronic searches were conducted for full text documents in HINARI-WHO-Kenya, as well as manual search through text books and journals. The studies that were used in this review included prospective, retrospective, case series and case reports.

Discussion

Using case studies from the Maasai culture in Kenya, we explore some of the challenges that we as Kenyan healthcare providers face in the application of the principle-based approach to bioethical dilemmas and how the anthropological approach may contribute to developing culturally relevant principles of bioethics that will help us resolve these bioethical dilemmas.

The anthropological approach to medial bioethics and its relevance to the maasai culture

In the Maasai culture, as in many non-western cultures, the family, or the doctor and the family, often make decisions about a patient's health care. This model, in which religious, cultural,spiritual beliefs and the extended family play a primary role in matters dealing with marriage, survival, and all aspect of life including terminal illness, is shared by many other Kenyan and Eastern cultures^{5,6}. However this contrasts significantly with the situation prevalent in many Western communities where a patient's individual autonomy, is generally accepted as the cornerstone of medical ethics particularly in decisions involving medical care and end of life.⁷

In secular Western societies, the competent patient is considered as an autonomous and rational agent who has full control over all choices regarding therapeutic interventions. The principle of autonomy has been extended to incompetent patients who do have advance directions through court ruling and legislature.⁷ Such an autonomy model is not without critics. Empirical research by Leslie Blackhall and colleagues has shown that "Korean and Mexican Americans feel that families, not patients, should be informed about a terminal diagnosis and be the primary decision makers". In recent years, medical, bioethical and legal literature has begun to address the need for family to have a greater role in medical decision-making.⁸

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Lieban uses the term ethno ethics to refer to the exploration of moral issues related to healing practices in non-Western societies. According to Lieban, ethno ethics should be informative not only about cross-cultural variation in ethical principles of medicine, but also about variations in the issues which in different societies come to be defined as morally relevant or problematic.⁹ The Analytic philosophy of bioethics, viewed culture as something extraneous to the rational core human, something that can be stripped away to reveal a universal human being, and until recently, the bioethics have concentrated the attention on the individual as the primary unit of analysis.¹⁰ The autonomous individual freely acts in accordance with a self-chosen plan, analogous to the way an independent government manages its territories and sets its policies. If we translate this definition to the health and wellbeing of a patient in our set up, it means that the patient himself is the primary decision maker with respect to his own health and medical care.

Deriving from this principle is the concept of “informed consent”. This refers to an autonomous authorization by an individual, of a medical intervention, where it implies that both doctors and patient must consent before a particular course can be followed. Patients have the right to decide whether to accept or refuse treatment even if it is not in their interest to do so. In this framework, medical ethical dilemmas are analyzed in terms of the Western philosophical principles of respect for individual autonomy, beneficence, non-maleficence, and distributive justice. However the strong relationship between new perspectives in bioethics and traditional concerns of the social sciences and humanities are evolving. As P. Marshall observes, bioethicists have begun to acknowledge the hermeneutical nature of clinical medicine, something that anthropologists and other social scientists have recognized for some time.¹¹ Lieban and Fabrega focused specifically on outlining a framework for studying questions of medical ethics across cultures. Fabrega described an "ethno medical" approach to medical ethics, which would encompass a broad range of areas, including the complex relationships that exist between healers and patients, among groups of healers, and between healers and the larger society.^{9,12}

The primacy of autonomy and individualism is especially problematic as it does not acknowledge the incommensurability between particular Western and non-Western cultural beliefs. Our dilemma as medi-

cal practitioners is that we are neither comfortable in adopting the conventional bioethical guidelines, nor in offering a health care purely based on cultural and historical practice. However we strongly acknowledge the fact that cross-cultural encounters between patient and health care providers are our routine daily experiences.

The Maasai: Origins, organization, culture and religious beliefs.

Origins, land and family

The Maasai are considered a hybrid between Nilotes and Hamites. They originated from North of Kenya. The land of Maasai is the property of the clan with all authority in the hands of the maternal elders, the heads of the homestead, village and territory. The Maasai family is a unit of varying size constituted by a man and his wife or wives. The family is characterized by shared residential and economic fortunes. One of the most significant areas of cooperation and subordination in Maasai kinship is the father-son relationship and it manifests the heritage between the past and the future.

Health and medicine

The Maasai live entirely on milk, blood, butter, honey and occasionally the meat of the black cattle and sheep. They use the cattle urine for medicinal purpose. The Maasai woman in the later stage of pregnancy is advised not to eat, and drink only water. Fresh milk is forbidden because it is thought to fatten the baby and thus, the delivery becomes more dangerous. When the child is 4-5 years the two lower-incisors will be removed which makes it possible to feed the child through the small opening should it get sick of tetanus. The Maasai believe that the youth who experience the pain of circumcision will emerge as individuals able to endure the challenge of life.

Religion

The Maasai believe in God, (Engai). Although they pray as a community during major ceremonies, their daily lives also incorporate many phrases expressing their awareness of God's presence like “*Engaitujapaki tooin-ai-puko inono*”- God, shield me with your wings or “*Engai ake naiyiolo*”- only God knows. The two most important things that the Maasai constantly pray for are the children and cattle. The most respected and feared of Maasai elders is the “Laibon”. He combines the functions of the spiritual leader, diviner, healer, expert on rituals, and provider of medicine. The Laibon is believed to have descended from God.^{13,14,15}

Ethical considerations and challenges in the context of the Maasai culture

The Maasai people have longstanding cultural traditions and spiritual beliefs that place the family and then the tribe at the center of the individual's existence. The individual is viewed as social centrically enmeshed in inextricable social bonds and ties, which make the interpersonal process the source of vital decisions in all aspects of life. A legal concept of advanced directives and living wills by an individual regarding his end of life care is unknown in the Maasai culture. They are against any attempt of physician assisted suicide or direct action that hastens death and the issue of a patient's right to request assistance or take steps to end his life is therefore not an option in this set up. Members of the family generally undertake decisions regarding terminal care for both competent and incompetent patients. Nursing homes for aged people, the terminally ill, or incompetent are unknown in most of the Kenyan communities and particularly for the Maasai. Such individuals are cared for at home by all members of the family.

In a society where family is the center of all attention and decision-making, the listed ethical principles and rules have a very different understanding of the self-determination, and the autonomy becomes collective rather than individualistic. In Maasai culture the center of each person's life is not himself but the family and the tribe. Thus, autonomy can only be spoken of as a collective right rather than an individual privilege.

This collective autonomy is commonly seen in our practice. When a young patient is diagnosed with terminal cancer, the first person to be notified is often the head of the family. He will then confer with the other members to see what decision is to be taken. After the decision is made, it is the duty of the family and physician to ease the patient's pain and anxiety. Furthermore, when considering a different treatment option, the family members are consulted first. If the patient is the eldest man, the family members, will then confer with another subcommittee, which normally consists of a group of elderly members.

In the codes of medical ethics the guidelines regarding disclosure of diagnosis are not unequivocal and may be interpreted in various ways. Doctors should practice their art with purity and holiness, which may imply veracity, in accordance with the restatement of the Hippo-

cratic oath, declaration of Geneva (1947), stating simply that the health of the patient should be the doctor's first consideration and in declaration of Lisbon (1981), the patient has the right to accept or refuse treatment after receiving adequate information.^{16,17} All may suggest that telling the truth about diagnosis is a mere prerequisite to the choice of treatment and the same is reinforced in the general and the hospital ethical guidelines.

Of course, the truth about our situation here is far more complicated. The physician and family may or may not provide the information to the patient, and in serious situations, the family prefers to handle the responsibility of informing the patient, because they think that their way is more “considerate”. How truthful should the considerate way be? Most of the times the family goes away with the patient without letting the patient know about the disease or the possible treatment. In a situation like this, the physician believes that the information offered is not sufficient, yet the family believes they are acting in the best interests of the patient. This model, in some ways is like consequentialism, which insists that the decision to tell or not to tell depends on the details of the clinical situation, and the physician should decide which course of action might be less harmful, and produce the best results for the patient. While on the other hand, our medical ethics guidelines follow deontology thoughts which assumes that lying and deception are wrong in themselves and that clinicians like everyone else, have a moral duty to tell the truth.

In the deontological approach, the word “competent” may cause reservations. In our situation, the dilemma is that the patient who is competent is in reality, considered as “incompetent” or a person of “diminished autonomy”. Although one may argue that there is probably no point in telling the truth to those whose cancer or HIV/AIDS disease is so advanced, as they may not be able to cope with it. The survey by Carrese and Rhodes reported a strong Navajo cultural belief that presenting such information to patients is detrimental to their health and welfare “negative words could hurt the patients”.¹⁸ However, in all other cases, the right of those who have presented as patients, to know what is thought to be wrong with them, should be respected. It remains controversial as to when, if ever, a person loses that right and whether it is ethical for a family or community to consider a competent person as incompetent, and not permit them to know or to understand their diagnosis.

In many situations we are unable to give clear guidance on when our action is professionally or theoretically justifiable. A 22-year-old HIV positive patient was diagnosed as having Pulmonary TB and Lymphoma. Later he developed respiratory, renal and hepatic failure. After 2 weeks in ICU, the medical team discussed the issue with the family for the possibility of removing life support system. The family was unhappy with the news, went back to the village and got their medicine man (laibon) who came to see the patient and advised the family “not to give up and that he is expecting an answer from God at any time”. After one week the patient died. We do understand and believe that requests based on deeply held religious and spiritual beliefs, or cultural ties should most often be honored. However, the decision to keep a patient on life support, and not allowing the patient to die with some sense of peace, and dignity, that purport to be based upon culture or spirituality, should be subjected to dialogue and evaluation.

The Maasai culture defines the familial and filial responsibilities, obligations of physicians, and decisions that involve end of life situations, and how death itself is to be viewed. To tell four grown up sons that their elderly father had metastatic cancer, and that radiation and chemotherapy will ease his pain and prolong his survival, the first thing they said was: “we do not want him to know that he has cancer”, “How long he lives is in the hands of God”, and “The best way to do it is to take him home”. In these words lies the essence of decision making when illness strikes the elder member of the family. In this situation, the family rather than the patient or the doctor, takes the central stage in this process.

Often the family will not allow the disclosure of terminal illness to the patient and they will always show concern about allowing the patient to die in peace and without any intervention, regardless of what the intervention will offer the patient. This is perceived as a form of caring, particularly towards the elderly, born of the concern to protect the patient from additional distress.

In this deeply cultural society, morality is rooted primarily in what is perceived as the cultural, religious or spiritual obligations of the family or tribe and the physicians towards the patient, rather than the legal right of the individual. This reflects the historically interconnectedness of the patient and the family, the dominant

role of the medicine cum spiritual man, the impact of cultural and spiritual belief and the socioeconomic situation on medical decision-making.

The economy, as in any other countries, plays a part in family decision-making. Most of this community has no third-party payers or health insurance scheme, and patients usually pay cash for medication. The socioeconomic situation in Kenya in general and in the Maasai community is such that there are limited resources. This forces families to make distressing choices depending on how much each situation is worth for the community. Most of the time, the survival of the entire family unit supersedes the interest of an individual member, which is an extreme example of family autonomy and a form of distributive justice. The cultural approach is to limit the amount of information given to the patient by the physician. This is in contrast to what is advocated for by Beauchamp & Childress in their primary principles of medical ethics. Therefore for the physician, the argument for telling the truth and disclosure is a vital one in almost every situation. Lies and deceit breach the autonomy of a person. Patients cannot make valid decisions unless they are fully informed.

The arguments about doctor’s action to withhold the information, and to limit disclosure particularly if the disclosure of information seems to be harmful to the patient, may be criticized as an example of an acceptable paternalism. However, in our case the paternalism, as we mentioned earlier, frequently appears to be unavoidable, and after all, the Laibon for the Maasai have done a far better job in relieving patients anxiety and depression than many of our staff members. It is very difficult to find a middle ground in these situations. The individual is not isolated and disconnected from many relationships within which he actually exists. The Maasai model of decision making is almost always strictly authoritarian and works on the premise that the family exists in mutually trusting and interdependent relationships that stress on caring and love, rather than individual rights. Thus, it always holds inherent risks for the individuals of that unit such as inadequate representation of interests and wishes of those individuals. Furthermore the unquestioned acceptance by the physician of implicit agreement to every decision can carry risks, and on occasions, undoubtedly occur, in which the concerns and wishes of a competent patient are ignored or overridden in a non-participatory process of decision making.

We believe that replacing the system of supportive-interdependent relationship within families with another that focuses on disconnecting individual’s rights exclusive of family interests is neither feasible nor desirable. However, in a few occasions, a shift to some kind of middle ground is possible although the room for flexibility is narrow and the dynamic balance, which can preserve the important culture values, is difficult to find. The major risk to the patient in such a set up lies in the potential abuse of this unchallenged power that physicians command in a country where the population is largely illiterate and economically disadvantaged.

Conclusion

In cultural societies like Kenya, our bioethics cannot ignore the fact that this community is deeply entrenched in religious and cultural norms that emphasize the primacy of the family with well-defined roles, and physicians have been expected traditionally to draw their professional morality from duty and obligations. In Kenya today skilled physicians and surgeons are no longer difficult to find, state of the art technology is already in the private and public sectors, thus the physicians are moving very fast towards an approach, which is distant and akin to the contractual model prevalent in the west, with its over emphasis on individualism, and with minimum cultural concern. Such a change needs a literate population and society with well established, effective checks and balances through institutional, professional and governmental bodies. Unfortunately, in our situation, these do not function and sometimes are absent. Thus such change can be extremely hazardous to the patient, who may end up paying such an unacceptably high price in the name of medical progress. Therefore developing culturally relevant principles of bioethics has remained the only solution and the anthropological approach to bioethics may help us achieve this.

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