ETHICAL CASE DELIBERATION INVOLVING THE END OF LIFE DECISION

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ABSTRACT: End of life decisions involving the patients who are in unbearable, intense suffering are often not easy to make especially when there are moral dilemmas or conflicts. The patient, physician and care givers may have to come together to decide on a reasonable course of action. However, in arriving at a moral course of action a moral conflict may arise between all concerned parties. In resolving such a conflict there is a need to adopt a method. Here, a brief set of questions has been used as a method that can help to structure a case deliberation following a set of carefully separated steps. This paper adopts the Nijmegen method of case deliberation to analyse a case that involves a moral conflict. In addition to the method adopted the paper gives a careful consideration to the cultural underpinnings of the case. The choice of this method does not indicate that it is the best of all existing method but that the whole exercise is an attempt to point out how a moral conflict may arise in a case and how such conflict can be resolved by using a structured method.

Key Words: Moral conflict, ethical case deliberation**,** method of deliberation

INTRODUCTION: There are a lot of dilemma that faces patients, family and the medical professions towards the end of life. For example a physician may be faced with taking decisions concerning the life of a patient who may be suffering from an incurable disease and whose case is seen as hopeless and in intense suffering as he is expected to save life at all cost and at the same time to do their best to relieve suffering and pain. Since the days of the Hippocratic Oath the doctors have always been in a dilemma not to harm a patient and doing their best to relieve suffering. Besides, there are some principles that tend to be a guide to health care providers, care givers and family in an attempt to help a patient. The principles of autonomy, beneficence, non- maleficence and justice add fidelity to it[1]. These principles though appear very easy to understand but their applications are not the easy because they are thick concepts that require careful analysis and applications to particular issues and situations. The context of each case thus matters in ethical deliberations and decision making in all medical procedures. Thus as Cavalieri[2] rightly observed, physicians and other healthcare professionals providing care for dying patients will confront many ethical dilemmas and challenges. Providing good care to dying patients requires physicians to be knowledgeable of potential ethical dilemmas and be aware of strategies and interventions aimed at avoiding conflict. Cavalieri[2] further states that it is important for the physician to be proactive with regard to decision making and have good communication skills. Keeping the patient central in all decision making, that is, respecting patient autonomy is thus very essential.

It follows that ethical issues may arise at end of life of a patient when the attending physician thinks that treatment if futile and the family or care givers may differ and hold the view that treatment is not futile as such both parties differs on the next line of action. The idea of futility thus may give rise to conflict because there is no consensus between the doctors' opinion and the family or even between members of the family. In some other cases the financial and monetary aspect is given a priority in moral considerations especially when the family cannot afford to continue with treatment.

The cultural underpinning of a case also is of paramount important when a case is another factor that is of paramount importance in a case of moral conflict or dilemma. This paper thus tries to analyse a case of Chief Mrs Omojakande, a 90 year old Yoruba woman using the Nijmegen method of ethical

deliberation. In order to put the case in its proper cultural perspective the paper will give a brief analysis of the Nijmegen method of ethical deliberation and how an ethical conflicts in the case can be solved given the various cultural factors that underscores the case .

THE YORUBA ON DEATH: The Yoruba are from the Western part of Nigeria, West Africa. They have a rich culture and they are deeply rooted in their idea about life and death. For the Yoruba death can be either good or bad depending on the age, situation and circumstances surrounding a person's life and death. Examples of bad death include when a young person dies or a woman who dies in child birth or during pregnancy, and accidents. Bad death is regarded as *'Iku ofo'* – mourning death. So, young age is one of the main characteristics of bad death. Misfortunes, accidents, unpalatable events in life are also included in the factors that label a death as bad.

Good death is characterised by old age, accomplishment of dreams, hopes and aspirations in life. If a person lived to old age, living behind lots of children and grandchildren then he will be seen as having lived a good life and dying a good death[3]. The death of this nature is an occasion for celebration and grand burial ceremonies. In this case, the children of the dead do take their time before they bury the corpse. They make adequate preparation so as to give the dead a befitting burial. In the traditional Yoruba thought it is the belief that people that fall under the group of "bad death" will not be accepted in the abode of the ancestors, it is said that, they become wandering spirits and some may reincarnate. However, those who die a "good death" live on in a blissful life in the company of the ancestors. Thus, among the Yoruba, death is the means of transforming from mortality to immortality[3]. These are traditional ideas and meaning of life that shapes the people's perception about life and death even despite the exposure to Christianity, Islam and Western values and ideals. They are cultural markers that can be described as lived experiences that affect decisions in end of life.

THE NIJMEGEN METHOD OF CASE DELIBERATION: Several methods such as the Socratic Dialogue, the Hermeneutic Method, the Clinical Pragmatism can also be proposed in solving ethical conflicts and moral uneasiness concerning a case. The Nijmegen method of case deliberation is also one of the methods developed to discuss ethical conflicts on the ward. It was developed for the use of clinical practices in cases of moral conflicts and uneasiness. In this method, case deliberation is seen as a team based multidisciplinary endeavour, with a professional ethicist as both a critical tutor and a facilitator[4]. The Nijmegen method consists of a brief manual of questions, which can be used to enact the method, and to help structure a case deliberation following a set of carefully differentiated steps[4]. It is designed to integrate the process of argumentation and the structure of ethical judgement with each other. In the deliberation consensus is thus seen as a relative value[4]. While not denying that there may be immoral consensus the method considers of very seriously that the most important criteria of the rightness of a judgement are coherent, acceptable ethical reasons. Common sense, consciousness and consensus are important aspects in ethical case deliberation. However they claim that even this cannot be the criteria for the rightness of actions nor can the responsibility of a physician in charge be replaced by a procedure of democratic decision making[4]. It follows that in the deliberation, instead of taking on the responsibility of health care providers they are being supported in deliberating about the moral problems they endeavour in patient treatment. The major concern of this method then is on team deliberation and consensus without jeopardising moral uprightness. The basic paradigm of a Protocol of the Nijmegen method thus comes in four major steps which comprise of the following: The moral problem, the facts of the case, the assessment and decision making.

The first crucial question is: what is the moral problem in this case? In consideration of the moral problem it is important to make an inventory of the problems that may emerge from the team and decide on which one is the most important. In other words, the team needs be specific so as not to lose focus in the midst of the varying problems that may emerge. This will help to make a concrete

formulation of the most important problem that may emerge in the case. The formulation usually takes the form of a question.
Following the identification of the moral problem, there is a need to take an inventory of the facts starting from the medical dimension that is, the diagnosis, therapy, and prognosis of the patient. Next is the nursing dimension which includes the perspective of the nurses and activities of daily living of the patient. Having considered the nursing dimension there is a need to consider the patient's values and social dimension, the organisational and juridical dimension. The third step consist of considerations of the various assessment starting from the well-being of the patient, respect for autonomy of the patient and informed consent, respect for life, representation by proxy, responsibility of the health care professionals and the team. The final step involves the conclusion and decision making. In this step, the moral problem has to be recapitulated and other unknown details given to help in the deliberation and decision making. The various relevant arguments will then be summarised and an evaluation that can lead to a decision will be made. It is important to have a consensus within the team[4].
The advantage of the Nijmegen method is that it is not based on a single philosophical approach. It is a combination of clinical practice, hermeneutic reflection, and analytical bioethics. It also reflects patients' treatment in the clinic and the multidimensional team spirit. It is also facilitated by a moderator who is from outside the team and can provide a structure, guidance and procedural authority. As a result this method improves communication, creates space for deliberation, improves decision making and it develops reflection as an attitude that is paramount for deliberations on ethical conflicts in cases[4].
In addition to the procedure of the Nijmegen method this paper considers it appropriate to give the cultural dimension an important attention in the ethical case while not been unmindful of the problems that moral relativism can generate. This is because some moral conflicts may have cultural underpinnings which cannot be ignored and which may lead to communication break down between patients and the care providers. Such cultural assumption may shape the judgement of care givers and even health professionals directly or indirectly and this will arouse conflicting moral judgements of a case. The cultural factors determine the lived experiences of the people and they cannot be ignored in understanding, evaluation and decision making in a case. Thus, in using the Nijmegen to evaluate the case below, attention will be given to the cultural issues that may emerge in the course of deliberation.

THE CASE OF MRS OMOJAKANDE: Chief (Mrs) Adetutu Omojakande, a 90 year old Yoruba woman from Nigeria and a mother of four children (three of which are female and one male), having several grandchildren and great grandchildren, has lived a very normal life till her 85th birthday when she developed diabetes mellitus, renal insufficiency, anemia, cerebrovascular accident, coronary artery disease and Parkinsonism. Besides, she broke her hip. Prior to surgery, she experienced multiple grand mal seizures. Afterwards, was posturing, rigid, unresponsive to noise or pain. Reviewed by a neurologist, it suggests a slim chance of reasonable recovery. Her children are of the opinion that their mother had lived a very good life and her life should not be full of indignity at the latter stage of life. To die at this moment will be most dignifying to their mother as she has done quite a lot of fulfilling things in life especially the birth of the new great grandchild which she witnessed before hospitalization. Their mother also was fond of telling them that she will rather die in dignity than lose her dignity. Her point of reference most times is the Yoruba adage that it is better to die than to lose one's dignity *(Iku ya j'esin)* She kept on asking for prayers as a support from her children.
Mrs Omojakande's doctor came to discuss with relatives about treatment options and their challenges and that some medication could be terminated. The following day before Adetutu was brought into discussion for her decision, she went into coma. Mrs Omojakande, was moved to Intensive Care Unit

being sustained with ventilator and maintained on total parenteral nutrition, but more seizures, arrhythmias, gastrointestinal bleeding, disseminated intravascular coagulopathy where muscle wasting also occurred. Her chance of neurological recovery was nil.
The doctor insisted on doing his best for Mrs Omojakande as she is a woman that deserves to die in dignity because of her status in the society. He said she can continue with the ventilation and other medication until she comes into partial consciousness, after 6 months may be to full consciousness but her muscular activities won't be sustained. The first son wanted their mother weaned off ventilator so she can die peacefully and in dignity as she had wished before. The other daughters reacted to the elder one after noticing something can still be done for their mother having in mind she was a bit confused before going into coma. The insisted that whatever could be done should be achieved so that their mother will still live a more dignified life and invariably death.
They discussed with the nurses on the possibilities of retaining their mother in the hospital. However, the nurses commented that after ventilation, Mrs Omojakande will only need palliative care which can be done at home otherwise it will be a waste of money keeping her in the hospital. The children of Mrs Omojakande are praying for her with a faith that she will be doing well. They have decided to continue with medication. The first son withdrew himself from the plan and commented that they are putting their mother in more unnecessary pain, suffering and indignity.

ETHICAL ANALYSIS OF THE CLINICAL CASE:
Following the Nijmegen protocol of case analysis we shall then analyse the case of Mrs Adetutu Omojakande as follows:

What is the moral problem?
Should the doctor preserve the life of the patient?

Inventory and interpretation of facts:
1. Medical dimension (diagnosis, therapy and prognosis): The patient had diabetes mellitus, renal insufficiency, anemia, cerebrovascular accident, coronary artery disease and Parkinsonism. Besides, she broke her hip and had a surgery. Prior to the surgery she experienced multiple grand mal seizures and afterwards, was posturing, rigid, unresponsive to noise or pain. From this assessment the patient is in intense suffering and pain.
The Neurologist was invited to assess her and a review shows that there is a slim chance of reasonable recovery. Hence, from the experts view her case was futile medically and it was not something to be discussed within the limits of curative treatment. After this, she went into coma and was moved to Intensive Care Unit being sustained with ventilator and maintained on total parenteral nutrition, but with more seizures, arrhythmias, gastrointestinal bleeding, disseminated intravascular coagulopathy where muscle wasting also occurred. All indications based on the experts' advice shows that the chance of neurological recovery was nil. The co-morbidity assessment at this point shows that she is in great pains and her medical condition is not within curative limits.
However, the doctor thought the best method of dealing with Mrs Omojakande's case is to continue ventilation and other medication until she comes into partial consciousness, after 6 month may be to full consciousness. At this stage her muscular activities won't be sustained. On the whole the well-being of the patient is not within the limits of curative treatment because the trajectory of the illness and the comorbidity indicate that doing everything possible to cure the patient is a kind of misdirection and will lead to therapeutic obstinacy. Her quality of life is thus decreasing rapidly.

2. Nursing dimension: The nursing team seem to have a different opinion from the doctor. They are of the view that after ventilation, Mrs Omojakande will only need palliative care which can be best

achieved at home. They foresaw the therapeutic obstinacy in the patient's case and are of the opinion that palliative care at home is a better option. In short, the nurses have a plan for the patient but they seem not to want to disagree with the doctor because he has the professional duty to take a decision.

3. Patient's view (values, religious, cultural and social dimension): The patient is a deeply religious person. She kept on asking that her children should pray for her. This could be interpreted in two ways bearing in mind the Christian nature of the average Yoruba and the cultural underpinnings. It could mean that the prayers will bring a miracle and heal her, or it may be that the prayers will hasten her towards dying a painless death. In this case, bearing in mind the cultural underpinnings the latter is likely to be the case. Mrs Omojakande as the case indicates is a great grandmother, with a lot of life fulfilling ambitions. For example, her last wish was to see the great granddaughter and she did. When a Yoruba woman of her age has accomplished so much it will bring a sense of fulfilment and she will pray that death should take her speedily without pains and suffering or deterioration of the body. Her Chieftaincy title indicates that culturally and socially her status is high. Such a title indicates that she is a public figure. The life and death of such a person is expected to be couched in social dignity.

4. Social dimension: This is a very important aspect of the case in that the children of the patient did not agree on their views. There is a conflict in the decision of the family. The ladies suggest continuation of the treatment as long as this can still be done as this will lead to dignity. The son is against such a decision because in his view it will cause pain and indignity to their mother. However, a critical look will show that the argument from both ends can be reduced to the concept of dignity though interpreted from different perspectives. This then gave rise to a communication problem in the family.

Secondly, the division between the daughters and the son gives a very interesting cultural dimension. In the Nigerian culture the first son has a prerogative of decision making. If he happens to be the first child then this duty becomes stronger. So considering this aspect of the culture the decision of the first born who happens to be the first son should prevail. Since both parties rely on the concept of dignity though from different perspectives, the doctor should have taken a professional position in the interest of the patient along a dignified death.

The Nigerian Yoruba culture also recognises futility of medical treatment. In this case the concept of death is better than loss of dignity will apply (*iku ya j'esin*). Life as the Yoruba view it should not be preserved at all cost especially when the treatment is futile and when prolongation of life will lead to great and intense suffering. Thus, the Yoruba will advise that optimising quality of life and a painless death will be a more dignified death for a woman of her social status and age. For a woman who has accomplished so much in life, and considering her age which will be described as a "ripe age" for the Yoruba, if she dies the burial will be tinged with rejoicing and feasting to express her fulfilled, accomplished and dignified life. So not prolonging her pains will make the process and state of dying a dignified one. It will be interpreted as a fulfilled life, dignified life, dignified process of death and dignified state of death will follow with the burial ceremonies. If the doctor continues prolonging her life with intense suffering and pain then apart from the somatic suffering and harm he will bring a social harm to her. At such a ripe age the Yoruba fear illness and suffering not death. Most Yoruba people in such a situation would seriously object to being kept alive on life support or have life prolonged at all cost.

The financial aspect also comes in because the nurses implied that her prolonged stay in the hospital will lead to wasting of financial resources. In the Nigerian context it will be more prudent to take a patient home for palliative care if the illness trajectory shows that the patient cannot be cured. This will then be morally acceptable.

Organisational dimension:
The patient's need would be better met at home as the nurses indicated.

The juridical aspect:
There is no law in Nigeria that suggests euthanasia or physician assisted suicide both the Nigerian Criminal Code and the Penal Code prohibit killing of human being no matter the intent, as a result suggesting both procedures will not be an option. However, medical care recognises futility of treatment and that end of life care should be beneficial and proportionate. In this case the doctor's action is not proportionate. Since there is no legal procedure to follow and considering the futility of the illness the doctor should have used the available professional training and medical ethics to take a decision in the interest of the patient.

Moral values and norms:
1. Well-being of patient: There is intense pain and suffering and loss of dignity. The concept of dignity in death which matters to the patient and her children even with their disagreements is been violated by the actions taken by the doctor. The well-being of the patient is not taken into consideration by the physician.
2. Autonomy of the patient and informed consent: Up to the point that the patient was conscious she was well informed of her prognosis but just before the final decision was to be taken she went into coma. It can then be argued that the patient's autonomy is not very clear. It is clear from the statements of the daughters that she considers dignity in death as not suffering and been in pains. She can be said to have given a verbal advanced directive. Since the patient's autonomy could not be explicitly decided before she went into coma and given the communal nature of the Yoruba, her children should give proxy consent based on her earlier wish.
3. Representation by proxy: There is no doubt that this case needs a representation by proxy since she is in coma, consequently, the family in this case, the children of Mrs Omojakande are the next of kin. There is an obvious disagreement between the children and this has created a communication gap between them. Coincidentally the two sides are trying to protect the interest of their mother by respecting her dignity but from two different perspectives. The need to have a consensus between the children is very important as this may help the doctor and the team take a decision in the interest of the patient without a conflict.
4. Responsibility within the team of health care professionals: There does not seem to be a good team approach between the health care professionals. The doctor did not consider the neurologist's expert advice in his decision making. There is also a subtle indication of disagreement between the doctor and the nurses. This indicates that there is lack of team work in care giving between the nurses and doctors and other professionals.

Conclusion and decision making on the case:
Given all the facts at hand, it can be argued that the doctor did not consider `the expert advice of the neurologist in his actions. He should have based some of his decisions on the early assessment of the neurologist. Furthermore, Mrs Omojakande's case can be interpreted on one hand as a moral problem on the duty of the doctor not to prolong life in the face of medical futility and communication problem on the side of the children thus not making a concrete proxy consent upon which the doctor could have acted possible. The doctor should have frankly discussed the trajectory and prognosis of the illness of Mrs Omojakande with the family and advise them professionally on the medical futility of the case. A realistic dialogue between the doctor and the family may have given a better focus on the quality of life and not prolonging life at all cost. The continued over zealousness on the path of the

doctor invariably may not be a beneficent for the well-being of the patient but may be maleficent in that her life was been prolonged in pain and unnecessary suffering. She would have died a more dignified death in terms of less suffering and pain than the on-going and future suffering. The patient should have been given a comfort therapy with the intention to reduce her pains. Dying should not be the intention of such a therapy but the avoidance of harm and pain. Conclusively, the patient should have been taken outside the context of curative care to palliative care with the aim of giving her comfort and ensuring a more dignified death. If invariably she dies the principle of double effect and wish to die with dignity would have been a good moral justification for the action.

CONCLUSION: This paper has identified a method that is the Nijmegen method of case deliberation among several methods in deliberating upon a case that posed a moral conflict on the ward. The preference for this method does not foreclose the efficiency of other methods and the line of deliberation and decision making is not just the only one that can be arrived at by other committees that try to evaluate the moral problem another ethical committee may deliberate on the case and come up with different ethical question as the most important. Consequently, their line of deliberation will shift. The most important idea is that a case deliberation follows a protocol that can be used to structure a case deliberation following a set of carefully differentiated steps[4] and following the suggested steps that they come out with a moral course of action or a useful moral action guide.

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REFERENCES:

1. Beauchamp TL, Childress JF. The principles of biomedical ethics. New York: Oxford University Press; 2001,57-272.
2. Cavalieri TA. Ethical issues at the end of life. J Am Osteopath Assoc 2001; 101(10): 616-22.
3. Labeodan H. Death is not the end: a review of the concept of immortality among the Yoruba. Kinaadman 2008; 19(2).
4. Steinkamp N, Gordijn B. Ethical case deliberation on the ward: a comparison of four methods. Med Health Care Philosophy, 2003; 6(3): 235-46.