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## Approaches in handling ethical challenges of cancer treatment and research in Nigeria

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### Summary

The diagnosis of cancer can devastate the physical, emotional, and socio-economic life of an individual. Caring for most cancer patients presents serious ethical challenges to physicians and other health workers. Inclusion of cancer patients in research could be no less challenging. These ethical problems become significantly magnified in the context of patients who have cancer in a low resource environment characterized by high illiteracy rate, poverty and poor health care infrastructure. Some of the ethical problems include: palliative care and end of life issues, particularly since most patients present in advanced stages, withholding or withdrawal of life support, global equity and justice in drug availability, drug pricing, cancer research and breaking bad news. Adherence to ethical guidelines in conducting cancer research would go a long way in reducing harms and unethical conducts. Similarly, the relevance of clinical and research ethics committees in resolving complex ethical issues in clinical practice has been suggested. However, where these are in place, the need for recourse to philosophical approach, especially virtue ethics in analyzing and resolving ethical concerns in clinical practice cannot be overemphasized. This paper highlights the burden of cancer in Nigeria and the ethical challenges of clinical management of cancer patients, using a case study. The role of clinical ethics and health research ethics committees as well as the justification for virtue ethics above principlism in handling ethical issues in cancer management and research in Nigeria were highlighted.

**Keywords:** *Cancer, health research, ethical challenges, ethics committees*

### Résumé

Le diagnostic du cancer peut désorganiser l'état physique, émotionnel et socio-économique de l'individu. Apporter les soins de santé à la plupart de ces patients présentent des sérieux défis éthiques

aux médecins et autres personnels de santé. L'inclusion de ce groupe de patients dans la recherche/étude pourrait être aussi difficile. Ces problèmes éthiques deviennent significativement dans le contexte que ces patients vivent dans un environnement à ressource faible caractérisé par un analphabétisme très élevé, pauvreté et des infrastructures de santé inadéquates. Quelques problèmes éthiques inclus : les soins de support, la décision de la mort ou euthanasie surtout que la majorité des patients sont à la phase très avancée. Maintenir ou arrêter les soins de support, l'équité globale et la justice dans l'accès aux médicaments, le coût des médicaments, la recherche sur le cancer et l'annonce des mauvaises informations. La compliance aux guides éthiques en recherche aidera à réduire les pratiques dangereuses et non-éthiques. De même, l'importance des comités cliniques et éthiques pour résoudre les problèmes éthiques complexes en clinique ont été recommandé. Cependant, Ou ces comités sont existant, le besoin des revues d'une approche philosophique spécialement l'éthique virtuelle dans l'analyse et la résolution des difficultés éthiques au Nigeria et les défis éthiques en soins clinique des patients ayant le cancer sont nécessaire. Le rôle de l'éthique clinique et des comités éthiques en recherche sur la santé aussi bien que la justification des éthiques virtuelles sur les principes à résoudre les problèmes éthiques dans les soins du cancer au Nigeria sont illuminés.

### Introduction

Cancer is a serious public health problem in Nigeria but regrettably, its management has not been satisfactory [1, 2]. The diagnosis of cancer destabilizes patients in dimensions greater than the impacts of other ailments including infectious diseases such as malaria and common cold, or surgical conditions such as appendicitis [3]. The family and social networks of the patient are often negatively impacted. The ensuing crisis could be so crippling with gross ethical challenges to the patient, their relatives and health care providers. Because many cancer patients present with advanced disease, they often have co-morbidities such as chronic and intractable pains, depression, nausea and vomiting which may be due to the disease, its treatment or complications. Cancers may also be associated with

prolonged hospitalization, reduced self-esteem and relatively higher cost of treatment [3, 4, 5].

In Nigeria, socio-cultural factors, and pervasive poverty reduce the accessibility and utilization of health care services [6, 7, 8]. Even the 6 percent average GDP growth rate that was reported during the 2002-2006 period still falls short of the National Economic Empowerment and Development Strategy (NEEDS) target rate of 10 per cent required to achieve many of the Millennium Development Goals [9].

Further, the power imbalance between clinicians and most breast cancer patients could reduce patients' autonomous power of making health decisions [10]. Gender stereotypes and religion could influence potential vulnerability of terminally ill patients in research and clinical relationships especially in developing countries [11, 12].

Cancer patients are less likely to have assurance of autonomous decision making under these conditions. A study revealed that one in five of 273 Finnish cancer patients feel that they are not encouraged to get involved in decisions about their treatment and that they have their wishes disregarded [13]. Cancer is perceived by most Nigerians as an extraordinarily devastating illness beyond the scope of both traditional and orthodox medical care [6, 8]. People perceive the diagnosis of cancer as a death sentence, a source of sorrow upon family members and anguish upon loved ones and well-wishers. A diagnosis of cancer induces fear, stigma, and depression to say the least [5]. Added to these in the society, the problem of fake medicine, quackery, and dependence on faith healing could retard progress in the diagnosis and treatment of cancers.

### **The burden of cancer in Nigeria**

In Nigeria, neoplastic diseases were well known to traditional medical practitioners long before the advent of modern medicine. Cancer was then, and is still believed to be incurable. It is described by the Yoruba speaking people of South-west Nigeria as "arun jejere" i.e. a disease that gradually eats up the body [3, 6].

The potential of cancer to provoke worries and the need to adequately respond to cancer patients' problems are found in literature. In a local study, cervical cancer patients had significantly worse psychosocial concerns than breast cancer patients. The commonest recurrent worries in both groups were depression about their condition (45%), thoughts of death (37%), insomnia (33.3%), bodily odour (30%), impairment of work efficiency (30%) terrifying

dreams (27%) and fear of illness being life-long [3, 6, 9, 13].

The estimated number of new cases of cancer in Nigeria was estimated to be 100,000 in 2003, and by 2010 it is predicted to be about 500,000. A critical review of published data from Nigerian cancer registries and several other publications have confirmed some changing trends in the relative incidence of major cancers [8, 13, 14, 15, 16, 17]. In the emerging trend, there are an estimated 100,000 new cancer cases in the country each year although observers believe the figure could become as high as 500,000 new cases annually by 2010. It is feared that by 2020, cancer incidence for Nigerian males and females may rise to 90.7/100,000 and 100.9/100,000 respectively. It is also anticipated that by 2020, death rates from cancer in Nigerian males and females may reach 72.7/100,000 and 76/100,000 respectively. Steadily improving economic and social factors, increasing consumption of westernized diets, reduced physical activity, increased rate of obesity will increase rates of cancer diagnosis [18].

Clinical services for cancer are grossly inadequate and poorly distributed. Only a few centres have functioning radiotherapy equipment. Radiologic services are generally available, but access is seriously limited by high cost. The same argument of high cost goes for chemotherapy. Pathology services are generally available, but the scope of services is limited. Molecular diagnostic methods are not widely available. Surgery is often performed by surgeons whose primary clinical practice is not oncology, and there is a very limited scope for multidisciplinary cancer care. Despite the increasing awareness of modern palliative care and pain management, which is particularly useful as patients often present with advanced disease, physicians have limited access to treatments that offer the prospect of prolonged survival [18].

The impact of cancer may be from the disease, its treatment or complication of the disease or of its treatment. This could translate into socio-economic and psychological losses through withdrawal, fatigue, reduced productivity, persistent drainage of resources, frequent hospital visits, altered family processes, and altered role performance. Others are pain management and enrolment of cancer patient in research [10]. In reality, issues like these could be very challenging to patients, relatives and health workers.

### A case presentation

Recently, Mrs. K. was admitted following the diagnosis of stage 4-breast cancer. She had stayed in a spiritual house for "divine healing," having earlier spent all her savings on herbal preparations that never worked. She was earlier minimally conscious and tolerated orally, but over the next fortnight, she became depressed with no related biological cause, and refused to eat. The physician commenced tube feeding - despite the family's opinion that it would be a futile effort. In anticipation of a possible cardiothoracic involvement, the physician suggested transferring Mrs. K to the very busy intensive care unit (ICU) with exacerbated cost.

Even in the ICU, Mrs. K's condition worsened and she became depended on oxygen through an oro-pharyngeal tube. When she became rousable, she pulled out the oro-pharyngeal tube. This prompted her husband who witnessed the event to request the physician to discontinue further treatment and terminate the administration of oxygen. The doctor taking care of the patient however objected claiming that it was his responsibility to keep his patients alive unless they were "overmastered by disease," as Hippocrates had put it [13, 19]. The possibility that the patient could benefit from an ongoing clinical trial was also offered by the physician.

### Inherent Ethical Challenges

This case illustrates many of the factors that make clinical ethics important and often difficult. Usually, caring for terminally ill patients as well as their inclusion in clinical researches present many uncertainties [19]. Although it is evident that it is necessary that a decision needs to be made about prolonging this patient's life, it is not clear which rules or principles should guide the physician and patient's relatives. There is an obligation to act in ways that are morally appropriate, not just medically sound. Many questions arise here. There is a question of decision-making authority. Is the physician in charge of the patient's care? Or does the patient's family speak for him? Who should speak about the patient's last wishes?

Secondly, what does the law say concerning "pulling the plug" or stopping feeding a patient to allow her to die? Is it legal for the physician to incur costs of treatment beyond what a patient's relative could afford? Lastly, should physicians prolong life endlessly even in futility when the family objects to it? Similarly how ethical is it to include the dying patient in a clinical trial? How should we respond

when our moral obligations conflict with our legal one [10]?

### The relevance of clinical ethics committees

Ethics committees involve groups of individuals from diverse backgrounds who support health care institutions with three major functions: providing ethics consultation, developing and/or revising select policies pertaining to clinical ethics (e.g., advance directives, withholding and withdrawing life-sustaining treatments, informed consent, organ procurement), and facilitating education about topical issues in clinical ethics.

The underlying goals of ethics committees are: to promote the rights of patients; to promote shared decision making between patients (or their surrogates if decisionally incapacitated) and their clinicians; to promote fair policies and procedures that maximize the likelihood of achieving good, patient-centered outcomes; and to enhance the ethical tenor of health care professionals and health care institutions. Ethics committees or select members often help resolve ethical conflicts and answer ethical questions through the provision of consultations. Whenever clinicians, relatives, and patients encounter challenges such as the one described above, referral to a clinical ethics committee would offer them the opportunity to be guided by broad based analysis of the inherent challenges upon which solutions that guarantee fairness to the interests of all the stake holders would be obtained.

### Ethical aspects of cancer research

Inclusion of patients in clinical investigations is increasingly becoming a feature of breast cancer management. The greater need to discover safer and more potent interventions to relieve the crippling effect of breast cancer makes this inevitable. However, it is extremely hard to distinguish between clinical research and the practice of good medicine. Many physicians conduct a small research project when they diagnose and treat a patient [17, 20]. Similarly, every time a physician administers a drug to a patient, he is in a sense performing an experiment [21].

Physicians' nuances and conflicts of interest are often explicated in the latter's dual role of care giver and researcher. The usual power imbalance between physicians and help seeking patients with terminal illness such as advanced breast cancer heightens patients' vulnerability to compromised autonomy in clinical decision making and research

endeavours. Further, both the process of managing breast cancer patients and their inclusion in clinical trials could be subtly coercive. It is easy for oncologists to unknowingly and unwittingly transgress ethical boundaries when recruiting cancer patients in a physician's care to participate in clinical research.

Clinical researches including oncological clinical trials should pass through an institutional research ethics review process. With these both the scientific and ethical validity of such investigations would be ascertained in an effort to protect human participants that may be included in such experiments.

### **Opportunities for collaborative research**

The need for collaborative approach to clinical investigations in the multi disciplinary approach to oncological research can not be over emphasized in gaining increased knowledge required for better cancer prevention, diagnosis and management. Having stressed that cancer affects the bio-psycho social lives of the patient and by extension the relatives, conducting scientific investigations in cancer prevention and management involves the domains of oncology, pathology, surgery, pharmacology, radiotherapy, nursing, and medical social work among others. Some of the relevant areas of collaborative research include investigations into genetic screening, community mammography, diet and cancer, cancer and clinical pharmacology, as well as socio-demographic and psychological correlates of cancer spread and management among others.

### **Handling ethical issues in cancer management and research: Virtue ethics as an alternative to principlism**

The best known approach to biomedical ethical problem solving that has developed over the past 30 years is principle ethics, or *principlism* [22]. This approach involves examining pertinent aspects of a troubling ethical situation from the point of view of each of the now canonical "four principles": autonomy, nonmaleficence, beneficence, and justice [9]. Despite its prominence in the canon of bioethics, principlism has its critics. Some argue that principlism by itself is insufficient for ethical problem solving [23], and others maintain that it is not a systematic method at all but rather a loose collection of principles with no structured process of decision making [24].

This exercise may not be sufficient to guide us to a resolution of an ethical problem, however, especially if we refuse to accept autonomy as a *de facto* trump principle. By themselves, principles can become mere abstractions, perhaps even sterile

nostrums for dealing with complex issues. The field clinical practice, especially medicine, if anything, is a human and humane practice; it concerns not only the care of others, but also the relationship of the healer with the sufferer [25]. Thus, the nature of that relationship is extremely important.

Virtue ethics, another bioethical approach that has received increased attention in recent years, addresses the nature of the relationship between patient and healer, with particular attention to the character of the physician. Pellegrino and Thomasma have presented a detailed analysis of how they interpret the virtues that are essential to medical practice [23]. These virtues include phronesis, compassion, fidelity, integrity, self-effacement, justice, fortitude, and temperance.

Phronesis is prudence, the kind of prudence that is defined as practical wisdom. It is the ability to choose right action with respect to all of the other virtues. Prudence is the virtue that shapes and guides the other virtues used in disposing one towards right action and good ends. It helps the agent address complex circumstances and discern the right and good in particular acts. In medicine, this means effecting a right and good healing action that is not only correct in terms of medical science, but also morally good in terms of all the interests of patients, their values, aspirations, needs, and beliefs. The character of physicians then depends on their ability to exercise prudence in the proper application of other virtues and principles. However, virtue ethics does not focus on what sorts of actions are morally permitted and which ones are not. But rather on what sort of qualities are to be fostered in order to be a good person [22].

### **Conclusion**

In Nigeria, steadily improving living standards coupled with increasing disposition to consume western diet and reduced physical activity among others have heightened the possibility of increased incidence of cancer [18]. To many, cancer is perceived as an intractable and lethal disease that tremendously impacts the entire bio-psycho-social lives of its victims [25]. The burden of cancer affects both formal and informal care givers.

Modern management and inclusion of oncology patients in research raise a plethora of complex issues: medical, ethical and legal. Physicians and other healthcare professionals increasingly must try to resolve these and may sometimes have to do so in the face of contrary opinion expressed by patients and/or their surrogates. Healthcare

professionals are seldom qualified to adjudicate on ethical or legal matters, or even, perhaps, to recognise them when they arise [26].

Even though recourse to the moral principles have been traditionally applied by physicians in resolving ethical challenges in oncology research and management, the limits of principlism and its conflict with peculiar socio-cultural values especially in non western societies make it less reliable. Virtue ethics, another bioethical approach that has received increased attention in recent years, addresses the nature of the relationship between patient and healer, with particular attention to the character of the physician, and by extension clinical investigators. Most cancer patients present late in hospitals for various reasons when already overwhelmed by the signs and symptoms of the disease. On many occasions, cancer patients would report in advanced stages of the disease when all other traditional modes of treatment have failed [8]. In such instances, the patients' physical and mental statuses would have sufficiently depreciated that their will-power, self esteem and assertiveness are often taken over by depression within the purview of exhausted financial and spiritual strength to negotiate care with physicians and health workers. Under such a condition, the individual's coping ability is exhausted while the physician is "crippled" by the challenge of medical futility. Ultimately, both patients and relatives await "divine intervention" or palliation of symptoms while waiting for inevitable death. At such times, neither the issue of patients' autonomous decision making nor moral relativism would count [8, 17,] but the virtues in the character of the intervening clinician or researcher.

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