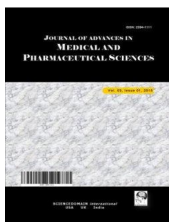

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End-of-life Care in Nigeria: Preparing Nursing Students and Workforce to Take the Lead

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Authors' contributions

This work was carried out in collaboration between both authors. Author PE designed the study, wrote the first draft of the manuscript and effected all corrections made by reviewers. Author UE managed literature searches, wrote the methodology and edited the first draft of the manuscript. Both authors contributed to discussion, read and approved the final manuscript.

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ABSTRACT

In this 21st century, several factors have informed the increasing need of end-of-life care globally. Notable amongst them are the global changes in both demographic and disease pattern; factors that have led to increasing number of chronic illnesses. Individuals suffering from chronic illnesses are faced with complex health challenges and thus, they ought to be supported and cared for as they progress towards the end-of-life. This care has always been a unique and important function of nurses irrespective of the work setting. Unfortunately, literatures in most parts of the world have shown that nurses are not adequately prepared to take on this role; demonstrating gaps in knowledge, attitude and skills in caring for the dying. The aim of this article is to increase awareness on the growing need for palliative and end-of-life care, review evidence to determine nurses' preparedness in terms of knowledge, attitude and competence to provide quality care to patients who are near death and their family, and to discuss evidence based strategies that will enhance nurses' knowledge, attitude and skills in providing quality and competent end-of-life care to patients approaching the end-of-life. The literature search related to the article was conducted from databases; google search, MEDLINE, Google scholars and Pubmed. Themes that emerge in

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literature suggest that knowledge, and competence of end-of-life care among nurses is lacking and the need to prepare nursing students and possess a workforce with requisite knowledge, attitude and skills to adequately care for the dying has become a priority.

Keywords: Palliative and end-of-life care; nursing faculty; knowledge; attitude and skills of end-of-life care; end-of-life care nursing education and practice.

1. INTRODUCTION

End-of-life care is a broad term used to describe specialized care provided to a person who is dying or approaching the end-of-life. It starts in the final stage of dying; involving care of the body, relief of suffering and improving the quality of living until death and continues into family bereavement. Palliative Care (PC) and End-of-life (EoL) care are relatively recent concepts, and the terms are often used synonymously. The concept of PC or EoL care originated with hospice movement and was developed to assist patients approaching the end-of-life and their families by offering psychological and spiritual support along with symptom management interventions [1].

In this 21st century, several factors have informed the increasing need of end-of-life care globally. Notable amongst them are the global changes in both demographic and disease pattern; factors that have led to increasing number of chronic illnesses. This increase in chronic diseases is expected to continue in the nearest future. It is projected that by the year 2030, 1 in every 8 of the earth's inhabitants will be 65years-and-older with the most rapid increases occurring at a rate of about 140% in developing countries, and the number of people over the age of 85 will double [2]. Likewise, the shift from communicable to non-communicable diseases (e.g. cancer, HIV/AIDS, end stage renal failure e.t.c.) has become prevalent; and are becoming the leading cause of death worldwide [3]. Evidence suggests that in 2011, there were approximately 54.6 million deaths worldwide; of which 66%, are due to non-communicable diseases. Shockingly, over 29 million (29,063,194) people died from diseases requiring palliative care and the estimated number of people in need of palliative care at the end of life is pegged at 20.4 million [4].

Unfortunately, individuals suffering from chronic or life limiting illnesses are faced with complex health challenges ranging from physical, psychological, social and emotional issues contending with their existence. At the beginning of the illness trajectory, curative focus may be the mainstay of management and palliative care may be provided alongside in order to relief pain and other symptoms as well as reduce patient suffering. However, as the disease progresses, patients may have their health continue to degenerate, making the individual progress towards death. As death becomes imminent, care interventions are likely to be more frequent and focused on palliation of pain and other symptoms rather than attempts to cure or otherwise extend a patient's life. Providing appropriate care and support for the terminally ill patient and his or her family; that allows the patient to live as fully as possible until death, is critical at this stage of life.

2. METHODOLOGY

The literature search on end-of-life care was conducted from databases; google search, MEDLINE, Google scholars and Pubmed were searched using the keywords; palliative and end-of-life care, end-of-life care nursing education, knowledge, attitude and skills of end-of-life care among nurses/nursing students, and end-of-life care education contents in nursing curricula. The search was extended by searching the reference lists of located papers for related articles.

The search was limited to papers written in the English language and published between 2000 and 2016. From the possible articles identified, common themes that emerged in literatures were identified and are discussed.

3. RESULTS AND DISCUSSION

Health has been acclaimed a right for all and as such every individual irrespective of age, sex, creed, or religion deserves quality care from competent health professionals. Also, the type and stage of disease does not limit the amount and quality of care to be offered. There has been advocacy that everyone should have access to excellent care during the course of a serious illness and as they progress to the end-of-life [5,6]. The Institute of Medicine (IOM) stated in its report (*Approaching Death: Improving Care at the End of Life*) that all patients with potentially fatal, advanced, chronic illnesses should receive

competent care [7]. The patient who is actively dying or progressing towards the end-of-life has the following rights [8] and these rights should be protected by health professionals. It is stated thus;

1. I have the right to be treated as a living human being until I die
2. I have the right to maintain a sense of hopefulness, however changing its focus may be
3. I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this may be
4. I have the right to express my feelings and emotions and my approaching death in my own way
5. I have the right to participate in decisions concerning my care
6. I have the right to expect continuing medical and nursing attention, even though “cure” goals must be changed to “comfort” goals.
7. I have the right not to die alone
8. I have the right to be free from pain
9. I have the right to have my questions answered honestly
10. I have the right not to be deceived
11. I have the right to have help from and for my family in accepting my death
12. I have the right to die in peace and dignity
13. I have the right to retain my individuality and not be judged by my decisions, which may be contrary to the beliefs of others.
14. I have the right to discuss and enlarge my religious and/or spiritual experiences, regardless of what they mean to others.
15. I have the right to expect that the sanctity of the human body will be respected after death
16. I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

4. NURSING AND END-OF-LIFE CARE

Caring for patients at the end-of-life is a cardinal function of a nurse as encapsulated in the definition of nursing by Virginia Handerson (1966). She defined nursing thus, “the unique function of the nurse is to assist the individual, sick or well in the performance of those activities contributing to health, or its recovery or to a peaceful death…”. This function of the nurse has been reiterated by several researchers. Nurses have a key role in caring for patients with a life limiting illness throughout the palliative care trajectory including end-of-life care, especially as they spend more time with patients than any other members of the health profession [9]. Care of patients who are approaching the end-of-life occur in different care settings [10] and this care has always been the responsibility of nurses [11]. Throughout the decades, nurses have been pivotal and remain indispensable in the care of dying persons and their families. They have played vital role in promoting responsible, competent, compassionate, appropriate, and ethically sound care [12].

Based on the above, the evidence clearly reveals that nurses’ responsibility in end-of-life care is not in doubt. Hence, the knowledge, skills and competence in end-of-life care is essential for effective care delivery.

5. KNOWLEDGE, ATTITUDE AND SKILLS OF NURSES IN END-OF-LIFE CARE

End-of-life care is posing serious challenge to health practitioners with a global call placing emphasis on enhancing quality of life among patients progressing towards the end-of-life and their families. Sadly, despite the strategic role nurses play in caring for patients approaching the end of their life, studies in most parts of the world have found that nurses’ report feeling unprepared and lacking the knowledge, attitude and skills needed to provide care at the end-of-life [13]. In addition, a lack of palliative care knowledge and skills among practicing nurses, both newly graduated and student nurses have also been reported from various quarters [14,15, 16,17]. Pre-registration students have also been found to have negative attitudes towards death and the care of the dying, expressing feelings of hesitancy, and anxiousness, and being unprepared and untrained to care for a dying person [18,19]. In Nigeria as well, studies have also shown gaps in knowledge about palliative or end-of-life care among healthcare workers [20,6] and lack of experience was reported as a major factor influencing practice [6].

Competent and compassionate end-of-life care is the responsibility of all health professionals. The recommended competencies and curricula guidelines for end-of-life nursing care is well documented [21] and includes:

1. Recognize dynamic changes in population demographics, healthcare economics, and

service delivery that necessitate improved professional preparation for end-of-life care.
2. Promote the provision of comfort care to the dying as an active, desirable, and important skill, and an integral component of nursing care.
3. Communicate effectively and compassionately with the patient, family, and healthcare team members about end-of-life issues.
4. Recognize one's own attitudes, feelings, values, and expectations about death and the individual, cultural, and spiritual diversity existing in these beliefs and customs.
5. Demonstrate respect for the patient's views and wishes during end-of-life care.
6. Collaborate with interdisciplinary team members while implementing the nursing role in end-of-life care.
7. Use scientifically based standardized tools to assess symptoms (e.g., pain, dyspnea [breathlessness] constipation, anxiety, fatigue, nausea/vomiting, and altered cognition) experienced by patients at the end of life.
8. Use data from symptom assessment to plan and intervene in symptom management using state-of-the-art traditional and complementary approaches.
9. Evaluate the impact of traditional, complementary, and technological therapies on patient- centered outcomes.
10. Assess and treat multiple dimensions, including physical, psychological, social and spiritual needs, to improve quality at the end of life.
11. Assist the patient, family, colleagues, and one's self to cope with suffering, grief, loss, and bereavement in end-of-life care.
12. Apply legal and ethical principles in the analysis of complex issues in end-of-life care, recognizing the influence of personal values, professional codes, and patient preferences.
13. Identify barriers and facilitators to patients' and caregivers' effective use of resources.
14. Demonstrate skill at implementing a plan for improved end-of-life care within a dynamic and complex healthcare delivery system.
15. Apply knowledge gained from palliative care research to end-of-life education and care.

The need to possess a workforce with requisite knowledge, attitude and skills in the care of the dying has thus become a priority especially among nurses who are front liners in the care giving of patients at this stage of life and even to their families. If nurses whose primary role is to provide compassionate and quality care and to enhance the quality of life of patients across all ages and stages of illness trajectory express this great shortfall in their professional duty, where then lies the hope of the populace? Nurses must therefore rise up to their responsibility by developing the knowledge, attitude and skills needed to care for individuals and families in this critical stage of life. An all-inclusive evidence based approach must be followed to the latter with unending commitment to bridge areas of needs as regards end-of-life care education and practice among nurses.

6. CAPACITY BUILDING FOR NURSING FACULTIES

How nurses are educated has great impact on the type and quality of care they bring to fore in their daily practice. The need for all nurses to be adequately prepared to care for dying persons and their families has been recognized by nurse educators [11]. However, it may be very challenging for nurse educators who lack education and clinical competence in palliative or end-of-life issues to be able to effectively deliver any curriculum or program that will transform nurses into qualified and competent practitioners; as the saying goes "one cannot give what he or she does not have".

One evidence based strategy to improving the quality of nursing care for patients who are approaching the end-of-life is ensuring capacity building for nursing faculties in Nigeria. It can be a useful evidence based strategy in addressing the gaps in the knowledge, attitude and skills of nurse educators regarding end-of-life care. For instance, in the US, the demonstration funding provided by Robert Wood Johnson Foundation and the End-of-Life-Nursing Education Consortium ELNEC-Core that entered a pilot phase with eight train-the-trainer courses — where five that targeted undergraduate nursing faculty and three directed to continuing education (CE) providers and staff development (SD) educators is a landmark research that has transformed end-of-life education provisions globally. The curriculum is evidence-based and highly rigorous: reaching approximately 4,500 nurses every year for the purpose of helping their

hospitals improve the care of dying patients in critical care [22]. This goes to show the extent of influence the train-the-trainer program can have on end-of-life education provisions.

Therefore, building the capacity of nursing faculties may provide for a wide range of nurse educators in the country to gain up-to-date knowledge, skill and expertize needed to deliver innovative end-of-life education contents that will prepare nurses to take the lead in end-of-life care. We therefore advocate for global and national support and grants that will initiate or establish an end-of-life nursing education consortium for nurse educators in Nigeria. Government, non-governmental organizations and nursing faculties can collaborate with significant bodies like the Robert Wood Johnson Foundation and the American Nurses Association to ensure the train-the-trainer program is instituted for nurse educators in Nigeria. Until this is done, end-of-life education and practice may continue to be challenged in this 21st century.

7. DEVELOPING INNOVATIVE CURRICULUM WITH ROBUST END-OF-LIFE EDUCATION CONTENT

Developing an innovative curriculum with robust end-of-life education content in nursing education programs will positively impact on outcome of nursing care among nursing students upon graduation. Several authors have lend their voices to the strategic influence end-of-life education content in nursing curriculum may have in promoting and enhancing nursing practice in end of life care. For example, it is stated that improvement in end-of-life care will occur by offering nurses an evidence-based program aimed at improving nurses' ability to provide compassionate care to patients at or near their end-of-life [23]. Similarly, it was opined that an essential factor to ensure provision of appropriate end-of-life care is that pre-licensure nursing students need adequate education prior to entering professional nursing practice [24].

Despite the known fact that nurses are frontline caregivers and are in the most immediate position to provide care, comfort and counsel to patients approaching death and their families [25], findings in some countries report obvious gaps in undergraduate [26], graduate [27], and continuing education [28] programs. Although palliative care is beginning to feature in preregistration nursing curricula in some resource-rich countries [29,17], there is still a significant lack in the curricula of resource-poor countries [30,16]. In Nigeria, there is no available specialty that is specially designed to educate nurses to provide end-of-life care and since the university produce nurse generalist upon graduation, there is need to prepare students to be competent, and be able to apply evidence based knowledge in providing quality care to these patients who they may come across while providing care in various work settings. Essentially, it has been advocated that end-of-life education should involve a combination of both clinical experiences and didactic approaches for a comprehensive end-of-life care learning experience [31].

In order to keep with the current realities and address the health needs of the populace, and to produce graduates of international standards and relevance, there is therefore the need to include robust end-of-life education contents in nursing education programs in Nigeria. The curriculum should give detailed attention to and offer varied exposure for the development of cognitive, affective and psychomotor skills in the students. As palliative care becomes more normative and is contained in the curricula of nursing and medical schools, included in textbooks and licensure examinations, and integrated into clinical practice guidelines, improvements will be made in nurses' competencies regarding end-of-life (EoL) care [32]. Upon graduation, if students feel comfortable educating the patient and family about the dying process, are ready to respond to patients who request assistance in dying, are ready to break bad news to a patient and family, then pre-registration nursing programs will have done their part in educating their students about end-of-life issues.

8. NURSING WORKFORCE DEVELOPMENT

Another strategy that may prepare the nursing community in Nigeria to take the lead in end-of-life care is to ensure a conscious national effort towards nursing workforce development. In Nigeria, a great percentage of nursing work force had little or no education on palliative or end-of-life care during their training and since there is no specialty on end-of-life care, it is likely that most nurses do not have up-to-date knowledge, attitude and skills needed to effectively care for patients approaching the end-of-life. Patients requiring palliative or end-of-life care are cared for not only on specialized units, but also at

home or on general wards of hospitals and nursing homes and as such, it is not only nurses with specialized training who come into contact with the palliative patients. This goes to buttress the need to support and educate nurses for the provision of high quality palliative and end-of-life care. With the current trends in healthcare; where patients with chronic life-threatening diseases requiring palliative or end-of-life care are cared for in virtually all settings, including intensive care units, accident and emergency wards, general wards e.t.c. it is eminent that nurses have no limits to their practice and are obliged to fulfill their professional duty of improving the quality of life of patients under their care. Therefore, interventions aimed at enhancing nurses' practice regarding end-of-life care must therefore target not only preregistrations nursing students but more importantly the nursing workforce who are caring for patients and their families in their practice settings. For example, hosting professional development seminars for practicing nurses has been proven to improve the quality of nursing care in innovative ways [33]. Also, palliative care units or departments should be created in hospitals and establishment of protocols that ensure synergy between other departments should be implemented.

9. CONCLUSION

Death and dying are natural and inevitable phenomena that each human being will eventually encounter. Patients and their families are understandably fearful of the unknown and the approach of death may prompt new concerns or cause previous fears or issues to resurface. As death approaches and organ system begin to fail, observable, expected changes in the body take place. When death is imminent, patients may become increasingly somnolent and unable to clear sputum or oral secretions, which may lead to further impairment of breathing from pooled or dried and crushed secretions. The sound ("terminal bubbling") and appearance of the secretions are often more distressing to family members than is the presence of the secretions to the patient.

Skilled practitioners can make the dying patient comfortable, make space for their loved ones to remain present when they wish, and can give family members the opportunity to experience growth and healing. Providing care to patients who are close to death and being present at the time of death can be one of the most rewarding experiences a nurse can have [8]. Themes that emerge in literature suggest the need to prepare nursing students and possess a workforce with requisite knowledge, attitude and skills to adequately care for the dying has become a priority. Nurses must therefore rise up to their responsibility and employ an all-inclusive evidence based approach such as capacity building for faculty members, designing and implementing an innovative curriculum with robust end-of-life education contents in nursing education programs as well as developing competent nursing workforce in order to bridge areas of needs as regards end-of-life care education and practice among nurses in Nigeria. Nurses can make the difference in the health sector and take the lead in caring for patients approaching the end-of-life if end-of-life care is given significant attention and the evidence-based strategies to ensure knowledge, attitude and competence of nurses are implemented. This will in no small measure contribute to improvement in quality of life of patients who are approaching the end-of-life and their family.

CONSENT

It is not applicable.

ETHICAL APPROVAL

It is not applicable.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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