

End-of-Life Care in Nigeria: *Preparing Nursing Students and Workforce to take the Lead*

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 ranging from physical, psychological, social and emotional issues contending with their existence. However, as their condition deteriorates they ought to be supported and cared for even as they progress towards the end-of-life. This care has been the unique 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. Nigeria is no exception and more challenging is the fact that nurses have little or no education regarding palliative and end-of-life care. Also, there is no specialty currently in the country either at the post basic nursing or university level to prepare nurses in this area. Hence, the need to prepare nursing students and possess a workforce with requisite knowledge, attitude and skills to adequately care for the dying has thus 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 the competence nursing workforce in order to bridge areas of needs as regards end-of-life care education and practice among nurses in Nigeria.

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

39 failure e.t.c.) has become prevalent; and are becoming the leading cause of death worldwide [3]. Sub-
 40 Saharan Africa bear a huge burden, having about 66% out of 54.6 million deaths in 2011 and over 29
 41 million people die from conditions requiring palliative care (The Global Atlas of Palliative Care at the
 42 End-of-Life, 2014).

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

53

54 **Dying Patient Bill of Right**

55 Health has been acclaimed a right for all and as such every individual irrespective of age, sex, creed,
 56 or religion deserves quality care from competent health professionals. Also, the type and stage of
 57 disease does not limit the amount and quality of care to be offered. There has been advocacy that
 58 everyone should have access to excellent care during the course of a serious illness and as they
 59 progress to the end-of-life (4, 5]. The Institute of Medicine (IOM) stated in its report (*Approaching*
 60 *Death: Improving Care at the End of Life*) that all patients with potentially fatal, advanced, chronic
 61 illnesses should receive competent care [6].

62 The patient who is actively dying or progressing towards the end-of-life has the following rights [7]:

- 63 1. I have the right to be treated as a living human being until I die
- 64 2. I have the right to maintain a sense of hopefulness, however changing its focus may be
- 65 3. I have the right to be cared for by those who can maintain a sense of hopefulness, however
- 66 changing this may be
- 67 4. I have the right to express my feelings and emotions and my approaching death in my own
- 68 way
- 69 5. I have the right to participate in decisions concerning my care
- 70 6. I have the right to expect continuing medical and nursing attention, even though "cure" goals
- 71 must be changed to "comfort" goals.
- 72 7. I have the right not to die alone
- 73 8. I have the right to be free from pain
- 74 9. I have the right to have my questions answered honestly
- 75 10. I have the right not to be deceived
- 76 11. I have the right to have help from and for my family in accepting my death
- 77 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.

The Nurse 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...”. [8] acknowledged that 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] assert that care of patients who are approaching the end-of-life occur in different care settings and this care has always been the responsibility of nurses [10]. 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 [11].

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. As a result, it is not only nurses with specialized training who come into contact with the palliative patients; recent nursing graduates must also be able to provide adequate care to them (De Vlieger et al., 2004). This goes to buttress the need to support and educate nurses for the provision of high quality palliative and end-of-life care.

A call for nurses to rise up to their responsibility

Globally, end-of-life care is posing serious challenge to health practitioners owing to the growing aging population and increased chronic terminal diseases. The recent change in demographic and disease pattern has brought about increase in chronic illnesses which is characterized by progressive deterioration in the health of the patient until the patient approaches the end-of-life.

Sadly, despite the strategic role nurses play in caring for patients with life limiting illness, 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 [12]. 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 [13, 14, 15, 16]. 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 [17, 18]. In Nigeria as well, studies have also shown gaps in knowledge about palliative or end-of-life care among healthcare workers [19, 5] and lack of experience was reported as a major factor influencing practice [5].

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.

Capacity building for nursing faculties in Nigeria

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 [10]. 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”.

Capacity building for nursing faculties 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 [20]. ELNEC Trainers are hosting professional development seminars for practicing nurses, incorporating ELNEC content into nursing curriculum, hosting regional training sessions to expand ELNEC’s reach into rural and underserved communities, presenting ELNEC at national and international conferences, coordinating community partnerships, and improving the quality of nursing care in other innovative ways [21]. 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 expertise 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.

Developing an innovative curriculum with robust end-of-life education content in nursing education programs

Nurses, more than any other health professionals, are the frontline caregivers for patients with life-limiting diseases or conditions (Cummings, 2008). However, obvious gaps are evident in undergraduate (Wallace et al., 2009), graduate (Paice et al., 2006), and continuing education (Murray, Wilson, Kryworuchko, Stacey, and O'Connor, 2009) programs. 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. [22] Posits that improvement in EoL 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 EoL. Similarly, [23] submits 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.

Although palliative care is beginning to feature in preregistration nursing curricula in some resource-rich countries [24, 16], there is still a significant lack in the curricula of resource-poor countries [25, 15]. 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 EoL education should involve a combination of both clinical experiences and didactic approaches for a comprehensive EoL care learning experience [26].

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. 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 programmes will have done their part in educating their students about end of life issues. [27] Supports this assertion and noted that 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.

Nursing workforce development

In Nigeria, a great percentage of nursing workforce 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 unlikely that

nurses have up-to-date knowledge, attitude and skills needed to effectively care for patients with life limiting illnesses that are near death or approaching the end-of-life. According to [28], competent and compassionate end-of-life care is the responsibility of all health professionals. Each discipline must determine strategies to educate its students and professionals in palliative 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 requiring end-of-life 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.

Competencies necessary for nurses to provide high quality care to patients and families during the transition at end-of-life

The recommended competencies and curricula guidelines for end-of-life nursing care [28] include:

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.

Preparation for and care at the time of death

Death and dying are natural and inevitable phenomena that each human being will eventually encounter. They are integral components in patients' care at the end of their lives. According to [7], 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. 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. Regardless of the setting, 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. 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.

Nursing care measures aimed at patient comfort should be continued: pain medications (administered rectally or sublingually), turning, mouth care, eye care, positioning to facilitate draining of secretions and measures to protect the skin from urine or feces (if the patient is incontinent) should be continued. The nurse should consult with the physician about discontinuing measures that no longer contribute to patient comfort, such as drawing blood, administering tube feedings, suctioning (in most cases), and invasive monitoring. The nurse should prepare the family for the normal, expected changes that accompany the period immediately preceding death. If family members have been prepared for the time of death, they are less likely to panic and are better able to be with their loved ones in a meaningful way.

REFERENCE

1. Kim S, Kim B, Yu S, Kim S, Park S, Choi S, et. al. The effect of an end-of-life nursing education consortium (ELNEC) course on nurses' knowledge of hospice and palliative care in Korea. *Journal of Hospice and Palliative Nursing*. 2011; 13: 222-231.
2. Jones M, Rattray J. (2010). Questionnaire design. In: Gerrish K. and Lacey A., (eds). *The Research Process in Nursing*, 6th ed. Oxford. Wiley-Blackwell.
3. World Health Organization (2010). *Global status report on non-communicable diseases* Geneva: WHO Press.

- 270 4. World Health Organization (2002). *National Cancer Control Programmes: Policies and*
271 *Guidance*, WHO, Geneva, Switzerland.
- 272
- 273 5. Ingwu JA, Ohaeri B, Nwaiku L. Knowledge and practice of end-of-life care among nurses in a
274 teaching hospital in Nigeria. *International Journal of Palliative Nursing*. 2016; 22(4):194-199.
- 275
- 276 6. Kuehn BM. IOM: Boost nurses' role in health care. *Journal of American Medical Association*.
277 2010; 304(21): 2345-2346.
- 278
- 279 7. Smeltzer SC, Hinkle JL, Bare BG, Cheever KH. *Brunner and Suddarth's textbook of medical-*
280 *surgical nursing*. 12th ed. Wolters Kluwer Health / Lippincott Williams and Wilkins; 2010
- 281
- 282 8. Gallagher O, Saunders R, Tambree K, Allie S, Monterosso L, Naglazas Y. Nursing student
283 experiences of death and dying during a palliative care placement: Teaching and learning
284 implications. *Teaching and learning forum* 2014
- 285
- 286 9. Wilson DM, Truman CD, Thomas R, Fainsinger R, Kovacs-Burns K, Froggatt K, et al. "The
287 rapidly changing location of death in Canada, 1994–2004," *Social Science and Medicine*. 2009;
288 68(10): 1752–1758.
- 289
- 290 10. Wilson DM, Goodwin BL, Hewitt JA. An examination of palliative or end-of-life care education in
291 introductory nursing programs across Canada. *Nursing Research and Practice*. 2011; Article ID
292 907172. doi:10.1155/2011/907172
- 293
- 294 11. Youssef HAM, Mansour MAM, Al-Zahrani SSM, Ayasreh IRA, Abd El-karim RAK. Prioritizing
295 palliative care: assess undergraduate nursing curriculum, knowledge and attitude among nurses
296 caring for end-of-life patients. *European Journal of Academic Essays* 2015; 2(2): 90-101
- 297
- 298 12. Barrere CC, Durkin A. Finding the right words: the experience of new nurses after ELNEC
299 education integration into a BSN curriculum. *Medsurg Nurs*. 2014; 23(1): 35 – 43, 53
- 300
- 301 13. Payne S, Ingleton C, Sargeant A, Seymour J. The role of the nurse in palliative care setting in
302 the global context. *Cancer Nurs Pract*. 2009; 8: 21–26.
- 303
- 304 14. Khader KA, Jarrah SS, Alasad, J. Influence of nurses' characteristics and education on their
305 attitudes towards death and dying: a review of literature. *Int J Nurs Midwifery*. 2010; 2: 1–9.
- 306
- 307 15. Prem V, Karyannan H, Kumar SP, Karthikbabu S, Syed N, Sisodia V. et. al. Study of nurses'
308 knowledge about palliative care: A quantitative cross-sectional survey. *Indian J Palliat Care*.
309 2012; 18(2): 122 – 127. PMC3477365
- 310
- 311 16. Cavaye J, Watt JH. An integrated literature review of death education in pre-registration nursing
312 curricula: Key themes. *International Journal of Palliative Care*. *International Journal of Palliative*
313 *Care*. 2014; Article ID 564619, <http://dx.doi.org/10.1155/2014/564619>
- 314
- 315 17. Leighton K, Dubas J. Simulated death: an innovative approach to teaching End-of-life care. *Clin*
316 *Simul Nurs*. 2009; 5: 223–230.
- 317
- 318 18. Mutto EM, Cantoni MN, Rabhans MM, Villar MJ. A perspective of End-of-life care education in
319 undergraduate medical and nursing students in Buenos Aires, Argentina. *J Palliat Med*. 2012;
320 15: 93–98.
- 321

- 322 19. Fadare JO, Obimakinde AM., Olaogun DO, Afolayan JM, Olatunya O, Ogundipe KO. Perception
323 of nurses about palliative care: Experience from South-West Nigeria. *Annals of Medical and*
324 *Health science research*. 2014; 4(5).
325
- 326 20. Grant M, Wiencek C, Virani R, Uman G, Munevar C, Malloy P. et. al. End-of-Life care education
327 in acute and critical care: The California ELNEC project. *AACN Advanced Critical Care*. 2013;
328 24(2): 121-129.
329
- 330 21. End-of-Life Nursing Education Consortium: Advancing palliative care. 15th anniversary, Fact
331 Sheet, Updated 2016.
332
- 333 22. Bahr DJ. "Evaluation of Impact of End-Of-Life Nursing Education Consortium (ELNEC)
334 Education on Registered Nurses". 2014; All Regis University Theses. Paper 173.
335
- 336 23. Lippe MP, Carter P. End-of-Life care teaching strategies in pre-licensure nursing education: an
337 integrative review. *Journal of Hospice and Palliative Nursing*. 2015; 17(1): 31 – 39
338
- 339 24. Dickinson GE, Clark D, Sque M. Palliative care and end-of-life issues in pre-registration,
340 undergraduate nursing programmes. *Nurse Education Today*. 2008; 28(2): 163-170.
341
- 342 25. Mwangi-Powell F, Dix O. Palliative care in Africa: an overview. *Africa Health*, 2011; 19–21.
343 Available at: http://www.africa-health.com/articles/july_2011/P_care_overview.pdf.
344
- 345 26. Gillan PC, van der Riet PJ, Jeong S. End-of-life care education, past and present: A review of
346 the literature. *Nurse Education Today*. 2014; 34(3): 331-342.
347
- 348 27. White KR, Coyne PJ. Nurses' perceptions of educational gaps in delivering end-of-life care.
349 *Oncology Nursing Forum*. 2011; 38(6): 710-711
350
- 351 28. Anila GD, Haseena TA. Knowledge and attitude of staff nurses regarding palliative care.
352 *International Journal of Science and Research*. 2013; 2319-7064
353
- 354 29. American Association of Colleges of Nursing (2005). Peaceful death: Recommended
355 competencies and curricula guidelines for end-of-life nursing care In: Matzo M, Sherman DW.
356 *Palliative care nursing: Quality care to the end of life*. 3rd ed. LLC New York, Springer publishing
357 company; 2010