

The Clinical Scientist

Volume II

A Compendium of
Faculty of Clinical Sciences Lectures
College of Medicine, University of Ibadan



Editors: Omolola M Atalabi & Ade F Adeniyi

© Faculty of Clinical Sciences, University of Ibadan, 2015

ISBN: 978-978-921-113-5

No part of this book may be reproduced, stored in a retrieval system or transmitted in any form or means, electronic, mechanical, photocopying, recording, or otherwise, without the prior permission of the copyright holder.

Faculty of Clinical Sciences

College of Medicine

University of Ibadan

Ibadan, Nigeria

email: fcs@comui.edu.ng

gsm: 02 2414425

Published in Ibadan, Nigeria by

BookBuilders • Editions Africa

2 Awosika Avenue, Bodija

Ibadan, Nigeria

email: bookbuildersafrica@yahoo.com

gsm: 0809 920 9106 • 0805 662 9266

Printed in Ibadan by OluBen Printers

GSM: 0805 522 0209

CONTENTS

Between Life and Death <i>Arinola A Sanusi</i>	1
May What We Consume Not Consume Us: An Update on Colorectal Cancer in Nigeria <i>David Omoareghan Irabor</i>	27
Alcohol: The Good, The Bad and The Ugly <i>Victor O Lasebikan</i>	53
Living While Dying <i>Adenike C Onibokun</i>	81
Snoring: The Untold Story <i>Ayotunde James Fasunla</i>	93
Diabetic Retinopathy: A Time Bomb, Everybody's Business <i>Tunji Oluleye</i>	121

LIVING WHILE DYING*

Adenike C Onibokun

Department of Nursing, College of Medicine, Ibadan

Quality of Life Issue

Given the incurability, the increasing chronic nature and prevalence of many forms of advanced cancer and other life-limiting illnesses, both the quality of life and the quality of death have become very important. Quality of life is more than the absence of dysfunction or distress; it includes a sense of well-being and life satisfaction.¹ Although scientists are yet to come up with a permanent cure for most cancers and other life-limiting diseases, something can still be done for everyone battling with health challenges. We should not feel helpless or hopeless just because every patient is not cured.² Though we may not cure all, but we can definitely care for all.

Quality of Death and Palliative Care

Quality of life is a common phrase among healthcare professionals, but quality of death is yet to gain well-deserved attention too. In Nigeria, like most parts of the world, open and free discussion about death and dying is still a taboo.³ Also, palliative and end-of-life care nursing is not yet fully embraced by the Nigerian professionals, despite its inclusion in the famous definition of nursing given by Virginia Henderson;

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

* This lecture was delivered at Paul Hendrickse Lecture Theatre, College of Medicine, University of Ibadan, University College Hospital, Ibadan, Nigeria on Tuesday, 25 July 2012.

peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.⁴

The definition of nursing given by Henderson emphasizes the unique role of maintaining both the quality of life and quality of death. Nursing is a profession in the healthcare sector that focusses on the care of individuals, families and communities, so that they can maintain, attain, or recover optimal health and quality of life. Apart from the many things that nurses do, they are also in a position to improve care for the dying patients and their families in their various settings. However, nurses report a lack of preparation in dealing with end-of-life (EoL) care in the intensive care environment.⁵

- Physical Well-Being
- Psychological Well-Being
- Social Well-Being
- Spiritual Well-Being

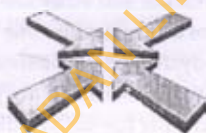


Figure 1. Quality of life model⁶



Figure 2. Domains of quality of life model.

Pain and Suffering: What is the Difference?

Definition of Pain

Pain is a subjective phenomenon. It is what the person says it is.⁹ The International Association for the Study of Pain (IASP) defined pain as an unpleasant sensory and emotional experience that is associated with actual or potential tissue damage or described in terms of such damage.¹⁰ The definition of pain proposed by IASP implies that pain is no longer simply nociceptive (that is activity produced in the nervous system by potentially tissue-damaging stimuli), but is recognized and accepted as a psychological one involving nociception, pain perception and pain expression.² Inadequate pain relief can hasten death. Pain relief is very essential at the end-of-life and it requires a multidisciplinary approach.

What Then is Suffering?

In most people's minds the concepts of pain and suffering are used as synonyms: both terms are frequently used to convey the reaction to any negative experience and emotion. But contrary to common belief, the fundamental philosophy that underlies the psychological approach to pain is that pain and suffering are not the same.¹¹ Suffering is a state of mind, and emotional experience that includes thoughts, meanings, and feelings that occur in response to many different causes. Pain is only one stimulus that does not necessarily cause emotional distress or suffering. Suffering is the mental experience of a person—pain is a sensory stimulus in a physical body.¹¹ Ferrell and Coyle made this distinction very clear and further defined the meaning of suffering:

Suffering is experienced when an impending destruction of an individual is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. It follows then, that although suffering often occurs in the presence of acute pain, shortness of breath or other bodily symptoms, suffering extends beyond the physical. Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person... suffering can occur in relation to any aspect of the person, whether it is in the realm of

social roles, group identification, the relation with self, body and family, or the relation with a transpersonal, transcendent source of meaning.¹²

Palliative Care Defined

Palliative care is an active total care of the body, mind and spirit.¹³ It is a form of comfort-giving care that recognizes cure or long-term control of disease as not possible. The primary goal of palliative care is quality of life. It is provided so that individuals who are dying can be helped to maintain the best possible level of physical, emotional, spiritual and social life during their remaining time. Palliative care, as a philosophy of care, uses a combination of active and compassionate therapies intended to comfort and support individuals and families facing a life-limiting illness. It may be combined with treatments aimed at reducing or curing the illness, or it may be the total focus of care. Palliative care strives to meet the physical, social, emotional, psychological and spiritual needs of patients, while remaining sensitive to personal, cultural and religious values, beliefs and practices. Above all, palliative and optimal end-of-life care focus on improving the quality of living to the fullest extent possible.^{14,15}

Providing palliative care successfully requires special knowledge and skill from a variety of healthcare professionals working collaboratively as an interdisciplinary team. Each team member has a role in paying close attention to controlling symptoms and providing psychosocial and spiritual support to both the patient and his or her family members. Healthcare professionals involved in the provision of palliative care must receive appropriate education if they are to be effective in helping the person who is dying feel supported and cared for. The education needs to include a range of specialties and focus on skill development in communication, clinical assessment, ethical decision-making and team work. All cancer nurses (in fact all nurses), regardless of the setting in which they practice, need to be knowledgeable about palliative care. However, the depth of the knowledge they require will vary from setting to setting. For example, the nurse working in a cancer-screening clinic may need to know (as an elective) what palliative care is as a philosophy of care; while a nurse in a palliative care unit must know a great deal about managing pain and other symptoms, talking about death and dying, and providing emotional support. Whereas the former nurse may learn about palliative care through

lectures, the latter nurse requires a more in-depth structured programme or course of study.

Goals of Palliative Care

1. To achieve good palliative care which ensures that people living with life-limiting illnesses live their lives with minimum discomfort and in the place of their choice.
2. Planning with the patient, rather than planning for the patient, issues relating to his or her care.
3. The involvement of family members and other unofficial caregivers in discussions relating to the disease process, line of management, with the consent of the patient if able, thereby respecting his or her rights.
4. The provision of effective support services for unofficial caregivers.
5. Fostering coping and nurturing hope when discussing the future with people living with life-limiting illnesses and their caregivers.

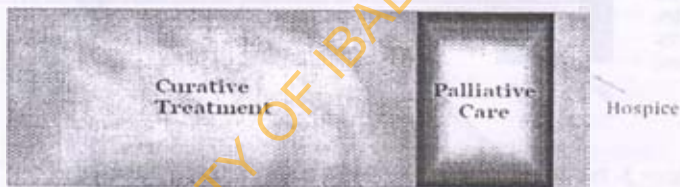


Figure 3. Current practice of hospice and palliative care.

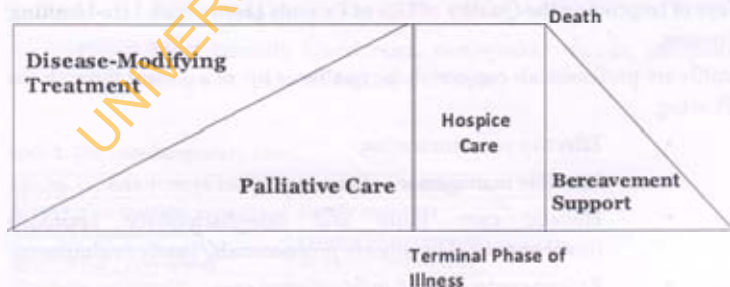


Figure 4. Continuum of care.³⁶

Major Problems of Terminal Illness

Individuals experiencing any life-limiting illnesses are faced with many physical, social and psychological problems. Some of the major challenges are pain and other symptoms such as anorexia, weight loss, fatigue, cough, anxiety and preparatory grief. Others include loss of income, broken marriages and altered family process, as well as dependency. A clinical audit of patients living with life-limiting illnesses conducted by Soyannwo, Olabumuyi, Ogeleye¹⁷ between 1 January and 31 December 2011, revealed the major physical problems faced by the patients, as shown in figure 5.

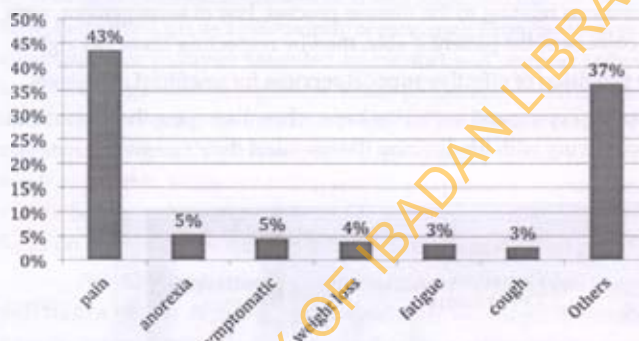


Figure 5. Percentage distribution of physical symptoms in UCH hospice patients in 2011.

Ways of Improving the Quality of Life of Patients Living With Life-Limiting Illnesses.

Healthcare professionals can enrich the quality of life of a patient through the following:

- Effective communication
 - Effective management of pain and other symptoms
 - Holistic care: multi and interdisciplinary approach (involvement of healthcare professionals/family/volunteers)
 - Patient-centred and family-oriented care
 - Respect of the patient's bill of last rights.

Patient's Bill of Last Rights¹⁸

- The right to be in control
- The right to have a sense of purpose
- The right to reminisce
- The right to be comfortable
- The right to touch and be touched
- The right to laugh
- The right to be angry or sad
- The right to have a respected spirituality
- The right to hear the truth
- The right to be in denial

Palliative Care Settings

Palliative care services can be provided in various settings such as:

- Hospitals
- Clinics
- Streets (among the homeless)
- Genocide
- Homes (home-based care)
- Nursing homes
- Battle fields
- Mass casualty (pandemics, earthquakes, floods, aeroplane disasters, tsunami, building collapse)

Table 1. The interdisciplinary team

Health-Related	Non-Health related
Nurses (Community-based/Hospital-based)	Family members (unofficial caregivers)
Doctors (GP/Specialists)	Religious counsellors
Psychologists (Health Psychologist/Clinical Psychologists)	Drivers
Social workers	Medical record staff
Pharmacists	Volunteers

Health-Related	Non-Health related
Pharmacists	Volunteers
Physiotherapists	
Nutritionists/Dietitians	

End-of-Life Care: Best Practices for the Provision of Quality and Culturally-Sensitive End-of-Life Care.

The Institute of Medicine defined optimum end-of-life (EOL) care as an experience that is free from avoidable distress and suffering for patients and their families, in accord with the patients' and families' wishes, and consistent with clinical, cultural and ethical standards.^{19,20} Standards for a good end-of-life care include symptom management, patient and family-focussed care, and spiritual well-being for both patients and families.^{16,19,21} According to the WHO, quality end-of-life care is the active total care of patients whose disease is not responsive to curative treatment. This definition includes meeting the psychological, social, and spiritual needs of both patient and family.^{16,19,21,22}

Healthcare providers need to be sensitive to the cultural and religious beliefs of their patients when counselling them on end-of-life care, bearing in mind that end-of-life beliefs, customs and values vary widely depending on the cultural and religious background and inclinations of individual patients. End-of-life care should recognize, assess and address the psychological, social, spiritual/religious issues and cultural taboos, realizing that different cultures may require different approaches. End-of-life discussions are particularly challenging in cross-cultural interactions because of the emotional intensity involved and high stakes of the situation. However, it is important to spend quality time to discuss these issues openly with the patient and/or family members in order to understand their own unique perspectives rather than make assumptions based on their culture or religion. Since every patient is unique, his or her personal views may be different from group traditions. Ultimately, these discussions and negotiations will help guide an end-of-life plan that provides the patient comfort and respect in his or her final days.²³

The following are a few tips for culturally-competent end-of-life care in general:

- Spend time to educate patients/families about the nature of palliative care (i.e., not 'giving up' on the patient), but do not attempt to convince them as this may heighten any underlying mistrust.

- The fear that costly treatment will be withheld may lead patients to pursue aggressive care at the end-of-life over palliative care. Try to build trust and be open and honest with patients about what is happening and explore their preferences.
- Do not assume that because a patient is from a particular cultural or religious background that their end-of-life decisions will reflect the customs and values of that group.
- Ask patients and families how they prefer to receive clinical information and make medical decisions (the patient may want to leave it to the family).
- It is important to inquire from the patient and family about any traditional end-of-life rituals that they may want enforced, e.g., religious ceremonies, planning one's funeral, last rights, etc.
- Patients often appreciate when healthcare professionals ask about spirituality, especially as related to end-of-life discussions.
- It is important to respect the patient's end-of-life wishes even though they may differ from personal beliefs.
- Always use professional interpreters (or telephonic interpretation where available) when there is a language barrier—ask patients if they need an interpreter, or use one if you feel one is necessary. Do not use family members as interpreters, as this could cloud the messages being passed.

Training Needs in Palliative Care

Since the goal of quality palliative care is to address quality of life concerns, it then becomes absolutely necessary for members of the palliative care team to possess adequate and current knowledge in this field. Also, the importance of interdisciplinary approach to care must be ensured.

The nursing curricula in most nursing education programmes in Nigeria (diploma and tertiary) are deficient in current global health and nursing issues like comprehensive and multidisciplinary pain management, and palliative and end-of-life care nursing. This gap has implications for stakeholders like the National Association of Nigerian Nurses and Midwives (NANNM), Nursing and Midwifery Council of Nigeria (N&MCN), Nigerian

Medical Association (NMA), Medical and Dental Consultants' Association of Nigeria (MDCAN), and other healthcare professionals who are responsible for medical education in Nigeria.

Fortunately, the University College Hospital (UCH), Ibadan, being the premier teaching hospital in Nigeria, was the first to have a comprehensive hospice and palliative care unit in Nigeria. The UCH management has also supported the training of many healthcare providers working in this facility. Many patients who need this specialized care and their families have benefited from the quality services provided by the staff of the UCH Hospice and Palliative Care Unit. The unit is also assisting in the training of students by providing them with hands on experience.

Recommendations

For quality palliative and end-of-life nursing care to be achievable in Nigeria, there are some basic factors which need consideration:

- Strengthening of nursing education through curriculum review.
- Continuing education and in-service education opportunities to improve end-of-life care.
- Public awareness on the benefits of palliative and end-of-life care should be intensified to educate patients and the general public on their rights to demand and receive a higher standard of care at the end-of-life.
- Healthcare system changes are needed to care and eliminate barriers such as regulatory constraints on prescribing opioids. Central to all healthcare reform is the need for educated professionals to direct this change.
- The National Association of Nigeria Nurses and Midwives should begin the revolution in end-of-life care by paying more attention to the education curricula of nurses at various levels.²⁴



Figure 6. UCH hospice & palliative care team members

References

1. Campbell A, Converse PE, Rodgers WL. *The Quality of American Life*. Russell Sage Foundation, New York, 1976, pp. 471.
2. Onibokun, A. The efficacy of non-drug therapy in cancer pain management. *Nigerian Journal of Health, Education and Welfare of Special People* 1999; 3(2): 1-9.
3. Economist Intelligence Unit. Quality Death Index Ranking End-of-Life Care Across the World, 2010. www.eiu.com/sponsor/liefoundation/quality_of_death (Accessed on 15 May 2012).
4. Henderson, V. *The Nature of Nursing*. Macmillan Publishing, New York, 1966.
5. Zormordi, M, Lynn MR. Critical care nurses' values and behaviors with end-of-life-care: Perceptions and challenges. *Journal of Hospice and Palliative Nursing* 2010; 12(2): 89-96.
6. Adenipekun A, Onibokun A, Elumelu TN, Soyannwo OA. Knowledge and attitude of terminally-ill patients and their family to palliative and hospice services in Nigeria. *Nigerian Journal of Clinical Practice* 2005; 8(1): 19-22.
7. Onibokun A, Ajayi B, Aiyemowa A, Ojo B. *Knowledge and Practice of Palliative and End-of-Life Care in University College Hospital, Ibadan*. In press.
8. Ferrell BR, Grant M, Padilla G, Vemuri S, Rhiner M. The experience of pain and perceptions of quality of life: Validation of a conceptual model. *The Hospice Journal* 1991; 7(3): 9-24.
9. Passero C, McCaffery M. *Pain Assessment and pharmacologic Management*. Mosby, Saint Louis, 2011.

10. International Association for Study of Pain. Pain terms: A list with definitions and notes on usage. *Pain* 1979; 6(3): 249-52.
11. Fishman SM, Carr DB. Clinical issues in pain management. *Contemporary Internal Medicine* 1992; 4: 92-103.
12. Ferrell BR, Coyle N. The nature of suffering and the goals of nursing. *Oncology Nursing Forum* 2008; 35, 241-247.
13. National Cancer Policy Board, Institute of Medicine, National Research Council. *Improving Palliative Care: We Can Take Better Care of People With Cancer*. The National Academies Press, Washington, DC, 2003.
14. Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA* 2000; 284:2476-2482.
15. WHO. WHO Definition of Palliative Care. www.who.int/cancer/palliative/definition/en/ (Accessed 2 January 2012).
16. National Consensus Project for Quality Palliative Care. *Clinical Practice Guidelines for Quality Palliative Care*, 2nd edition. National Consensus Project, Pittsburgh, PA, 2009.
17. Soyannwo AO, Olabumiyi AA, Ogeye BA. Clinical Audit of Patients Receiving Palliative Care between January 1-December 31. A Paper Presented at the Hospice and Palliative Care Association of Nigeria, Ilorin, Nigeria, 2011.
18. Barbus AJ. The dying person's bill of rights. *American Journal of Nursing* 1975; 75: 99.
19. Donalson MS, Field MJ. Measuring quality of life. *Arch Intern. Med.* 1998; 158(2): 121-128.
20. Lohr KN. *Medicare. A Strategy for Quality Assurance*. National Academy Press, Washington DC, 1990
21. Gazelle G, Buxbaum R, Daniels E. The development of palliative care program for managed care patients: A case sample. *J Am Geriatr Soc.* 2001; 49(9): 1241-1248.
22. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AG, Hood K, Douglas HR, Normand CE. Palliative care in hospital, hospice, at home: Results from a systematic review. *Ann Oncol.* 2002; 13(Supp14): 257-265.
23. Carrillo JE, Green AR, Betancourt JR. Cross-cultural primary care: A patient-based approach. *Ann Intern Med.* 1999; 130(10): 829-34.
24. Malloy P, Virani R, Kelly K, Munevar C. Beyond bad news: Communication skills of nurses in palliative care. *Journal of Hospice and Palliative Nursing* 2010; 12: 166-174.