

Original Article

# Exploring Perception of Terminally Ill Cancer Patients about the Quality of Life in Hospice based and Home based Palliative Care: A Mixed Method Study

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## ABSTRACT

**Objectives:** The objectives of the study were to evaluate the perceptions and performance of terminally ill cancer patients regarding the quality of palliative care at different settings and to measure their quality of life (QOL) at the end of life.

**Material and Methods:** This comparative, parallel and mixed method study was conducted at the Community Oncology Centre, Ahmedabad, among 68 terminally ill cancer patients as per inclusion criteria who were receiving hospice (HS)-based and home (HO)-based palliative care under 2 months permitted by the Indian Council of Medical Research. In this parallel and mixed method study, qualitative findings were supplemented by quantitative data with both components executed simultaneously. Interview data were recorded by taking extensive notes during interviews along with an audio recording. Interviews were transcribed verbatim and a thematic approach was adopted. QoL questionnaire (FACT-G System) was used for the assessment of QOL in terms of four dimensions. Data were analysed using the appropriate statistical test on Microsoft Excel.

**Results:** The qualitative data (primary component) analysed under five themes – staff behaviour, comfort and peace, enough and consistent care, nutrition and moral support, in the present study favours a HS-based setting more than a HO-based setting. Among all four subscale scores, physical well-being and emotional well-being subscale scores were statistically significantly associated with the place of palliative care. Functional Assessment of Cancer Therapy-General (FACT-G) total score was high among patients getting HO-based palliative (mean = 67.64) care than HS-based palliative care (mean = 56.56) and the difference between total FACT-G scores was statistically significant (unpaired t-test = 2.20, P = 0.03).

**Conclusions:** Overall, with the primary component favouring HS care and higher scores obtained in HO-based patients, the present study advocates the necessity for palliative services to expand their coverage regardless of whether they are provided at HS or HO, as it has improved the QOL of cancer patients significantly.

**Keywords:** Cancer, Home-based care, Hospice, Palliative care, Quality of life

## INTRODUCTION

Cancer is the second leading cause of death globally and is responsible for an estimated 10 million deaths in 2020.<sup>[1]</sup> Globally, about one in six deaths is due to cancer. Approximately 70% of deaths from cancer occur in low- and middle-income countries.<sup>[2]</sup> There are estimated 2.5 million people living with cancer in India, with every year about 700,000 new cancer cases registered.<sup>[3]</sup> The International Agency for Research on Cancer GLOBOCAN project has predicted that India's cancer burden will nearly double in the next 20 years, from slightly over a million new cases in 2012 to more than 1.7 million by 2035.<sup>[4]</sup>

It is estimated that over 40 million people require palliative care each year out of which over 20 million require palliative care near the end of life (EOL).<sup>[5]</sup> It is estimated that in India, the total number of people who need palliative care is likely to be 5.4 million people a year.<sup>[6]</sup> Although palliative care services have been in existence for many years, India ranks at the bottom of the Quality of Death Index in overall score and lacks the awareness and existence of hospice (HS) care. According to the Worldwide Palliative Care Alliance, although >100 million people across the world would benefit from HS and palliative care annually.<sup>[7]</sup>

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# Quality Of Care For The Terminally Ill

**Emily Jackson, John Keown**



## **Quality Of Care For The Terminally Ill:**

Quality of Care for the Terminally Ill Karen Gardner, 1985      The Effects of PPS on Quality of Care for Medicare Patients  
United States. Congress. Senate. Special Committee on Aging, 1986      *Cancer, AIDS, and Quality of Life* Jay A. Levy, Claude  
Jasmin, Gabriel Bez, 2013-06-29 This volume contains selected contributions from individuals who attended the Second  
International Conference of the International Council for Global Health Progress ICGHP held at UNESCO in Paris France on  
January 15-17 1996 This conference brought together experts in many disciplines that deal with the devastating diseases of  
cancer and AIDS with a focus on the concerns for quality of life The ICGHP fosters multicultural and multidisciplinary  
approaches to global health problems to help influence governments and other international health organizations to  
emphasize prevention and care of diseases and to understand their scientific social and cultural features The Council  
encourages the interchange of information on health problems and policy and supports educational funding for the public at  
large Its objective is to effect disease-free lives in the world community Participants of the conference included scientists  
sociologists government leaders physicians health care providers epidemiologists religious leaders company officials ethicists  
and philosophers They examined and discussed the many variables involved in quality of life for people affected with cancer  
and with AIDS The volume's text begins with introductory comments by officials attending the ICGHP conference  
Subsequently a chapter is dedicated to one aspect of quality of life be it definition scientific research evolution cultural  
changes ethics measurements or other issues dealing with health care and treatment survival The second part of the volume  
includes commentaries dealing with five aspects of quality of life which merit consideration      *Textbook of Palliative  
Medicine and Supportive Care* Eduardo Bruera, Irene Higginson, Charles F. von Gunten, Tatsuya Morita, 2015-01-15 the  
thoroughness of the text has to be admired It is an excellent starting point for students of palliative care which makes an  
important contribution to any library British Journal of Hospital Medicine covers a plethora of topics ranging from the  
development of palliative medicine in different countries to clinical topics and bioethics and      *Handbook of Death and Dying*  
Clifton D. Bryant, 2003-10 Dying is a social as well as physiological phenomenon Each society characterizes and consequently  
treats death and dying in its own individual ways ways that differ markedly These particular patterns of death and dying  
engender modal cultural responses and such institutionalized behavior has familiar economical educational religious and  
political implications The Handbook of Death and Dying takes stock of the vast literature in the field of thanatology arranging  
and synthesizing what has been an unwieldy body of knowledge into a concise yet comprehensive reference work This two  
volume handbook will provide direction and momentum to the study of death-related behavior for many years to come Key  
Features More than 100 contributors representing authoritative expertise in a diverse array of disciplines Anthropology  
Family Studies History Law Medicine Mortuary Science Philosophy Psychology Social work Sociology Theology A  
distinguished editorial board of leading scholars and researchers in the field More than 100 definitive essays covering almost

every dimension of death related behavior Comprehensive and inclusive exploring concepts and social patterns within the larger topical concern Journal article length essays that address topics with appropriate detail Multidisciplinary and cross cultural coverage      *Textbook of Palliative Medicine* Eduardo Bruera,Irene Higginson,Charles F von Gunten,2009-01-30 Textbook of Palliative Medicine provides an alternative truly international approach to this rapidly growing specialty This textbook fills a niche with its evidence based multi professional approach and global perspective ensured by the international team of editors and contributing authors In the absence of an international curriculum for the study of palliative medicine this textbook provides essential guidance for those both embarking upon a career in palliative medicine or already established in the field and the structure and content have been constructed very much with this in mind With an emphasis on providing a service anywhere in the world including the important issue of palliative care in the developing nations Textbook of Palliative Medicine offers a genuine alternative to the narrative approach of its competitors and is an ideal complement to them It is essential reading for all palliative care physicians in training and in practice as well as palliative care nurses and other health professionals in the palliative care team      *Supportive and Palliative Care and Quality of Life in Oncology* Bassam Hassan,Ali Mohammed,2023-01-11 This book examines supportive and palliative care and quality of life in cancer patients Chapters address such topics as anxiety depression and delirium in terminally ill cancer patients ethics in palliative care palliative care medications assisted suicide and euthanasia and much more      *Compassionate Person-Centered Care for the Dying* Bonnie Freeman,2015-02-23 A milestone resource for palliative care nurses that facilitates evidence based compassionate and humanistic care of the dying A valuable contribution to the evolving field of palliative nursing care It is authored by a model for this field Bonnie Freeman and brings to the bedside what her practice embodies evidence based clinically expert care The CARES tool is a long needed resource and we are all grateful to the author for moving her passion to paper It will touch the lives and deaths of patients families and the nurses who care for them Betty Ferrell PhD RN MA FAAN FCPN CHPN Professor and Director Division of Nursing Research and Education City of Hope National Medical Center From the Foreword This groundbreaking reference for palliative care nurses is the first to provide realistic and achievable evidence based methods for incorporating compassionate and humanistic care of the dying into current standards of practice It builds on the author s research based CARES tool a reference that synthesizes five key elements demonstrated to enable a peaceful death as free from suffering as possible comfort airway management management of restlessness and delirium emotional and spiritual support and selfcare for nurses The book describes step by step how nurses can easily implement the basic tenets of the CARES tool into their end of life practice It provides a clearly defined plan that can be individualized for each patient and tailored to specific family needs and facilitates caring for the dying in the most respectful and humane way possible The book identifies the most common symptom management needs in dying patients and describes in detail the five components of the CARES paradigm and how to implement them to enable a

peaceful death and minimize suffering It includes palliative care prompts founded on 29 evidence based recommendations and the National Consensus Project for Palliative Care Clinical Practice Guidelines The resource also addresses the importance of the nurse to act as a patient advocate how to achieve compassionate communication with the patient and family and barriers and challenges to compassionate care Case studies emphasize the importance of compassionate nursing care of the dying and how it can be effectively achieved Key Features Provides nurses with a clear understanding of the most common needs of the dying and supplies practical applications to facilitate and improve care Clarifies the current and often complex literature on care of the dying Includes case studies illustrating the most common needs of dying patients and how these are addressed effectively by the CARES tool Based on extensive evidence as well as on the National Consensus Project for Palliative Care Clinical Practice Guidelines

Aspen's Health Care Quality Review Jane Lowers,1999 Aspen s Health Care Quality Review 1999 compiles current real world examples of hospitals health plans physician practices and other organizations applying quality improvement theory and reaping reduced costs improved patient satisfaction and improved health outcomes as a result Each section organizational quality quality theory and practice quality tools and measurement quality in care profiles top health care providers around the country and tracks not only clinical improvements but also the organizational changes and philosophy that made them possible Contact information for each chapter allows readers to go straight to the source for more details and a wealth of statistics charts and easily replicated tools help readers apply the information at their own facilities With Aspen s Health Care Quality Review you ll get award winning articles from our other quality publications for example Russ Coile s Health Trends The Quality Letter for Healthcare Leaders QRC Advisor and Journal of Nursing Care Quality No more combing through various resources for the information you need We have done it for you

Debating Euthanasia Emily Jackson,John Keown,2011-12-02 In this new addition to the Debating Law series Emily Jackson and John Keown re examine the legal and ethical aspects of the euthanasia debate Emily Jackson argues that we owe it to everyone in society to do all that we can to ensure that they experience a good death For a small minority of patients who experience intolerable and unrelievable suffering this may mean helping them to have an assisted death In a liberal society where people s moral views differ we should not force individuals to experience deaths they find intolerable This is not an argument in favour of dying On the contrary Jackson argues that legalisation could extend and enhance the lives of people whose present fear of the dying process causes them overwhelming distress John Keown argues that voluntary euthanasia and physician assisted suicide are gravely unethical and he defends their continued prohibition by law He analyses the main arguments for relaxation of the law including those which invoke the experience of jurisdictions which permit these practices and finds them wanting Relaxing the law would he concludes be both wrong in principle and dangerous in practice not least for the dying the disabled and the disadvantaged

Chronic Illness Ilene Morof Lubkin,Pamala D. Larsen,2013 The newest edition of best selling Chronic Illness continues to focus on the various aspects of

chronic illness that influence both patients and their families Topics include the sociological psychological ethical organizational and financial factors as well as individual and system outcomes This book is designed to teach students about the whole client or patient versus the physical status of the client with chronic illness The study questions at the end of each chapter and the case studies help the students apply the information to real life Evidence based practice references are included in almost every chapter

**Foundations of Nursing: Enrolled Nurses** Susie Gray,Leanne Ferris,Lois Elaine White,Gena Duncan,Wendy Baumle,2018-08-31 Designed for the Diploma of Nursing Foundations of Nursing Enrolled Nurses Australia and New Zealand edition is mapped to the HLT54115 training package competencies and aligns to the revised Standards for Practice for the Enrolled Nurse Written to equip the enrolled nurse with current knowledge and basic problem solving and critical thinking skills to successfully meet the demanding challenges of today s health care the text clearly explains concepts and definitions and scaffolds knowledge The student friendly text provides a clear and fresh approach to the study of nursing it is straightforward and heavily illustrated with colour photos of procedures

**Fundamentals of Nursing E-Book** Barbara L. Yoost,Lynne R. Crawford,2021-12-07 NEW Clinical Judgment in Nursing chapter introduces the concept of clinical judgment and the six NCSBN Clinical Judgment Measurement Model Skills NEW Clinical judgment steps are integrated within the nursing process

**The Art of Dying Well** Katy Butler,2020-02-11 This comforting thoughtful The Washington Post guide to maintaining a high quality of life from resilient old age to the first inklings of a serious illness to the final breath by the New York Times bestselling author of Knocking on Heaven s Door is a roadmap to the end that combines medical practical and spiritual guidance The Boston Globe A common sense path to define what a good death looks like USA TODAY The Art of Dying Well is about living as well as possible for as long as possible and adapting successfully to change Packed with extraordinarily helpful insights and inspiring true stories award winning journalist Katy Butler shows how to thrive in later life even when coping with a chronic medical condition how to get the best from our health system and how to make your own good death more likely Butler explains how to successfully age in place why to pick a younger doctor and how to have an honest conversation with them when not to call 911 and how to make your death a sacred rite of passage rather than a medical event This handbook of preparations practical communal physical and spiritual will help you make the most of your remaining time be it decades years or months Based on Butler s experience caring for aging parents and hundreds of interviews with people who have successfully navigated our fragmented health system and helped their loved ones have good deaths The Art of Dying Well also draws on the expertise of national leaders in family medicine palliative care geriatrics oncology and hospice This empowering guide clearly outlines the steps necessary to prepare for a beautiful death without fear Shelf Awareness

**International Day of Persons with Disabilities - Children's Disabilities** Olaf Kraus de Camargo,Thorsten Langer ,Nihad A. Almasri,2024-10-29 The International Day of Persons with Disabilities IDPD serves to globally promote an understanding of disability issues and mobilize support for the dignity rights and well being of persons

with disabilities The theme of the most recent United Nations Day was transformative solutions for inclusive development the role of innovation in fuelling an accessible and equitable world It is in this spirit that Frontiers in Public Health is launching a new article collection inspired by this UN day with a specific focus on children with disabilities and how innovative public health solutions to support them can contribute to making the world a more equitable and prosperous world for all

**Federal Register** ,1983-11      **Introduction to Medical-Surgical Nursing - E-Book** Adrienne Dill Linton,2014-04-14

With just the right level of information to equip you to effectively care for adults and older adults Linton s Introduction to Medical Surgical Nursing 5th Edition is the leading LPN LVN text in its field Covering both med surg and psychiatric mental health conditions and disorders it addresses your role in a variety of care settings emphasizes culturally competent care and holistic nursing and thoroughly covers all relevant NCLEX PN Test Plan content Abundant real life case studies clearly show how to apply what you ve learned to clinical practice Features separate chapters on common high profile disorders including hypertension diabetes and shock providing an in depth understanding for patient care Offers foundational units on basic concepts related to the health care system care settings the nursing process leadership nutrition the older adult growth and nutrition legal ethical considerations evidence based nursing care and many more essential topics avoiding repetition later in the text Includes a separate comprehensive unit on the older adult and related disorders no other LPN LVN med surg text has as much coverage of this primary patient group Includes a separate comprehensive unit on psychosocial responses to illness psychiatric disorders and substance abuse eliminating the need for a separate psychiatric mental health nursing text Emphasizes content related to the NCLEX PN Test Plan including health promotion nutrition legal ethical issues HIPAA and prevention of medication medical errors Offers in depth pharmacology coverage the Pharmacology Tutorial covers drug classifications how drugs work and nursing responsibilities Pharmacology Capsules boxes provide medication information precautions for use interactions and side adverse effects and Pharmacology and Medications tables in body systems chapters include classification use action side adverse effects and nursing interventions all with the goal of reducing medication errors on the job and equipping you to pass the NCLEX exam Assists with assignment and supervision helping you assign tasks to nurse assistants patient care techs and unlicensed assistive personnel and making sure you understand the difference between delegation management supervision and assignment of tasks on the health care team Features Diagnostic Tests and Procedures tables for a quick reference to MRI CT Doppler flow lumbar puncture tests for neurologic disorders and much more Highlights timely information with Health Promotion boxes Cultural Considerations boxes Nutrition Considerations boxes and Complementary and Alternative Therapies boxes Provides bulleted lists of nursing instructions for Patient Teaching Plans stressing the role and responsibility of the LPN LVN to reinforce patient education Provides consistent Nursing Care Plans that reinforce the nursing process and focus on critical thinking and Put on Your Thinking Cap Critical Thinking boxes encourage you to pause and consider the practical implications of what you have just read      **The**

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