

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.^[1] Globally, about one in six deaths is due to cancer. Approximately 70% of deaths from cancer occur in low- and middle-income countries.^[2] There are estimated 2.5 million people living with cancer in India, with every year about 700,000 new cancer cases registered.^[3] 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.^[4]

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).^[5] 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.^[6] 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.^[7]

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Received: 01 October 2021 Accepted: 28 October 2022 E-Pub Ahead of Print: 12 January 2023 Published: XXXXXX DOI: 10.25259/IJPC.92_2021

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Quality Of Care For The Terminally Ill

Jay A. Levy, Claude Jasmin, Gabriel Bez



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 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 **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

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 **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

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

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

Assisted Dying for the Terminally Ill Bill (HL) Great Britain: Parliament: House of Lords: Select Committee on the Assisted Dying for the Terminally Ill Bill, 2005-04-28 The Bill was published as HLB 4 session 2004-05 ISBN 01084188390 This volume contains a selection of the 14 000 personal letters and other submissions received by the Committee with regards to their inquiry into the Bill

Quality Of Care For The Terminally Ill: Bestsellers in 2023 The year 2023 has witnessed a remarkable surge in literary brilliance, with numerous engrossing novels captivating the hearts of readers worldwide. Lets delve into the realm of top-selling books, exploring the fascinating narratives that have enthralled audiences this year. Quality Of Care For The Terminally Ill : Colleen Hoover's "It Ends with Us" This heartfelt tale of love, loss, and resilience has gripped readers with its raw and emotional exploration of domestic abuse. Hoover masterfully weaves a story of hope and healing, reminding us that even in the darkest of times, the human spirit can triumph. Quality Of Care For The Terminally Ill : Taylor Jenkins Reids "The Seven Husbands of Evelyn Hugo" This captivating historical fiction novel unravels the life of Evelyn Hugo, a Hollywood icon who defies expectations and societal norms to pursue her dreams. Reids compelling storytelling and compelling characters transport readers to a bygone era, immersing them in a world of glamour, ambition, and self-discovery. Discover the Magic : Delia Owens "Where the Crawdads Sing" This mesmerizing coming-of-age story follows Kya Clark, a young woman who grows up alone in the marshes of North Carolina. Owens weaves a tale of resilience, survival, and the transformative power of nature, captivating readers with its evocative prose and mesmerizing setting. These popular novels represent just a fraction of the literary treasures that have emerged in 2023. Whether you seek tales of romance, adventure, or personal growth, the world of literature offers an abundance of compelling stories waiting to be discovered. The novel begins with Richard Papen, a bright but troubled young man, arriving at Hampden College. Richard is immediately drawn to the group of students who call themselves the Classics Club. The club is led by Henry Winter, a brilliant and charismatic young man. Henry is obsessed with Greek mythology and philosophy, and he quickly draws Richard into his world. The other members of the Classics Club are equally as fascinating. Bunny Corcoran is a wealthy and spoiled young man who is always looking for a good time. Charles Tavis is a quiet and reserved young man who is deeply in love with Henry. Camilla Macaulay is a beautiful and intelligent young woman who is drawn to the power and danger of the Classics Club. The students are all deeply in love with Morrow, and they are willing to do anything to please him. Morrow is a complex and mysterious figure, and he seems to be manipulating the students for his own purposes. As the students become more involved with Morrow, they begin to commit increasingly dangerous acts. The Secret History is a brilliant and suspenseful novel that will keep you guessing until the very end. The novel is a cautionary tale about the dangers of obsession and the power of evil.

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Table of Contents Quality Of Care For The Terminally Ill

1. Understanding the eBook Quality Of Care For The Terminally Ill
 - The Rise of Digital Reading Quality Of Care For The Terminally Ill
 - Advantages of eBooks Over Traditional Books
2. Identifying Quality Of Care For The Terminally Ill
 - Exploring Different Genres
 - Considering Fiction vs. Non-Fiction
 - Determining Your Reading Goals
3. Choosing the Right eBook Platform
 - Popular eBook Platforms
 - Features to Look for in an Quality Of Care For The Terminally Ill
 - User-Friendly Interface
4. Exploring eBook Recommendations from Quality Of Care For The Terminally Ill
 - Personalized Recommendations
 - Quality Of Care For The Terminally Ill User Reviews and Ratings
 - Quality Of Care For The Terminally Ill and Bestseller Lists
5. Accessing Quality Of Care For The Terminally Ill Free and Paid eBooks
 - Quality Of Care For The Terminally Ill Public Domain eBooks
 - Quality Of Care For The Terminally Ill eBook Subscription Services
 - Quality Of Care For The Terminally Ill Budget-Friendly Options
6. Navigating Quality Of Care For The Terminally Ill eBook Formats
 - ePub, PDF, MOBI, and More
 - Quality Of Care For The Terminally Ill Compatibility with Devices
 - Quality Of Care For The Terminally Ill Enhanced eBook Features
7. Enhancing Your Reading Experience
 - Adjustable Fonts and Text Sizes of Quality Of Care For The Terminally Ill
 - Highlighting and Note-Taking Quality Of Care For The Terminally Ill
 - Interactive Elements Quality Of Care For The Terminally Ill
8. Staying Engaged with Quality Of Care For The Terminally Ill

- Joining Online Reading Communities
- Participating in Virtual Book Clubs
- Following Authors and Publishers Quality Of Care For The Terminally Ill
- 9. Balancing eBooks and Physical Books Quality Of Care For The Terminally Ill
 - Benefits of a Digital Library
 - Creating a Diverse Reading Collection Quality Of Care For The Terminally Ill
- 10. Overcoming Reading Challenges
 - Dealing with Digital Eye Strain
 - Minimizing Distractions
 - Managing Screen Time
- 11. Cultivating a Reading Routine Quality Of Care For The Terminally Ill
 - Setting Reading Goals Quality Of Care For The Terminally Ill
 - Carving Out Dedicated Reading Time
- 12. Sourcing Reliable Information of Quality Of Care For The Terminally Ill
 - Fact-Checking eBook Content of Quality Of Care For The Terminally Ill
 - Distinguishing Credible Sources
- 13. Promoting Lifelong Learning
 - Utilizing eBooks for Skill Development
 - Exploring Educational eBooks
- 14. Embracing eBook Trends
 - Integration of Multimedia Elements
 - Interactive and Gamified eBooks

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