

Palliative Care Nursing

A well-known topic in modern times?

SASRO 2018 – 31. Aug 2018

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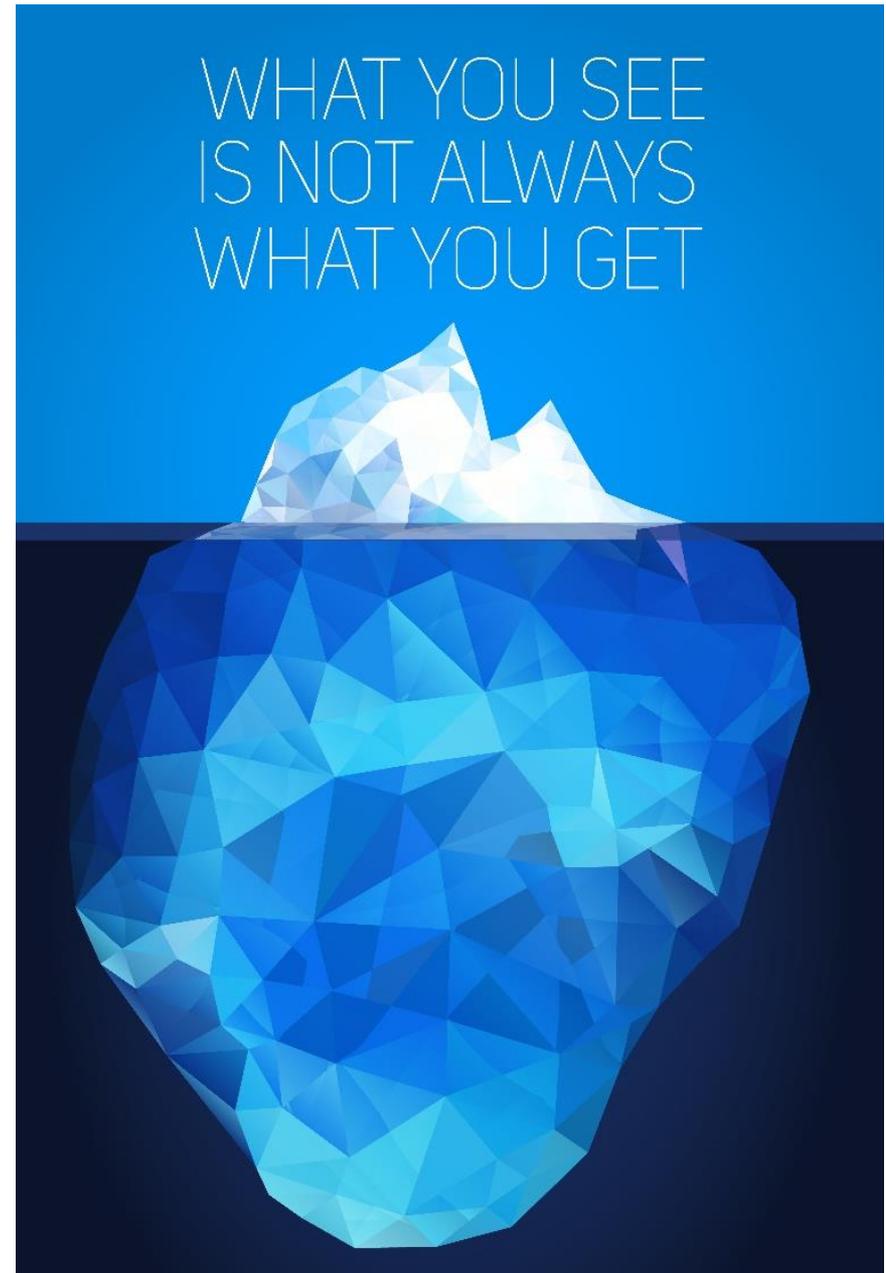
Overview

1. Background

2. Palliative Care Nursing

3. Research in Palliative Care

Background



Challenges of professional (palliative) care in Europa

- Increase in life expectancy
- Changes in the age structure of the population
- Displacement of causes of death
- Extending therapeutic and technical interventions
- Individualization of life
- Change of family structures
- Need for new forms of informal aid and support
- Increase in economic demands
- Market discovery «Palliative Care»



The beginnings of palliative care.

- Cicely Saunders
- 1967: Historical moment
- The estranged dying in the hospital
- Medieval hospice philosophy:
“assisting and accompanying”
- Interdisciplinary



Patient Education and Counseling 41 (2000) 7–13

Patient Education
and Counseling

www.elsevier.com/locate/pateducou

The evolution of palliative care

Cicely Saunders*

St. Christopher's Hospice, Sydenham, 51–59 Lavrie Park Road, London SE26 6DC, UK

The four „S“ Modell of Palliative Care

- «S» as **symptom** treatment, e.g. comprehensive, active and individualized patient care
- «S» - as **self-determination**, such as effective communication
- «S» like **security**, e.g. interdisciplinary teamwork
- «S» like **support**, such as family support



Palliative Medicine 2005; **19**: 619–627

‘Now nobody falls through the net’: practitioners’ perspectives on the Gold Standards Framework for community palliative care

Nigel King School of Human and Health Sciences, University of Huddersfield, Queensgate, **Keri Thomas** John Taylor Hospice, Birmingham **Nina Martin, Dennise Bell** and **Sharon Farrell** School of Human and Health Sciences, University of Huddersfield, Queensgate

Development of palliative care in Switzerland

- 1970 – 1990 Pioneering phase
 - 1990 – 2005 Differentiation phase
 - 2005 – 2015 Integration phase
-
- 1970: Sensitization (Rosette Poletti)
Geneva
 - 1991: Palliative Medicine
Cantonal Hospital St.Gallen
 - 2006: SAMW guidelines and
recommendations



Palliative Care in Switzerland

*Look Back, Current Endeavors,
and Outlook*

Elisabeth Spichiger, MSN, RN

Goals of Palliative Care

- The goal is to improve the quality of life for individuals who are suffering from severe diseases
- Palliative care offers a diverse array of assistance and care to the patient and involved persons
- Not a “one size fits all approach”: Care is tailored to help the specific needs of the patient
- Since palliative care is utilized to help with various diseases, the care provided must fit the symptoms.



Dimensions



Basic and Specialised Palliative Care

- Basic palliative care
- Specialized palliative care

494 *Journal of Pain and Symptom Management*

Vol. 33 No. 5 May 2007

Special Article

Palliative Care as an International Human Right

Frank Brennan, MBBS, FRACP, FACHPM, LLB
Calvary Hospital, Sydney, New South Wales, Australia



ELSEVIER

European Journal of Cancer 40 (2004) 2192–2200

European
Journal of
Cancer

www.ejconline.com

Position Paper

A new international framework for palliative care

S.H. Ahmedzai ^{a,*}, A. Costa ^b, C. Blengini ^c, A. Bosch ^d, J. Sanz-Ortiz ^e,
V. Ventafridda ^c, S.C. Verhagen ^f, on behalf of the international working group

Palliative Medicine 2007; **21**: 173–175

Palliative care in developing countries: what are the important issues?

Katri Elina Clemens Department of Science and Research, Centre for Palliative Medicine Bonn, University of Bonn, Malteser Hospital Bonn, Germany, **Suresh Kumar** Institute of Palliative Medicine, Calicut, Kerala, India, **Eduardo Bruera** The University of Texas M. D. Anderson Cancer Center, Houston, USA, **Eberhard Klaschik** Department of Science and Research, Centre for Palliative Medicine Bonn, University of Bonn, Malteser Hospital Bonn, Germany, **Birgit Jaspers** Department of Science and Research, Centre for Palliative Medicine Bonn, University of Bonn, Malteser Hospital Bonn, Germany and **Liliana De Lima** International Association of Hospice and Palliative Care, Houston, USA

Summary Background

- Complex
- Multifaceted
- Many points of view
- Many particular interests
- Medicine has the market power

➔ Well known but increasingly restrictive.

Palliative Care Nursing



Central topics in palliative care nursing

- *Professional Attitude*
- Care Settings
- Nursing diagnosis/assessment
- Pain management
- Full spectrum of symptoms
- Communication (mourning work)
- *Anticipatory grief*
- Culture, spirituality in Care
- Moral distress
- Quality and accessibility
- *Equal treatment*



Incidence Problem

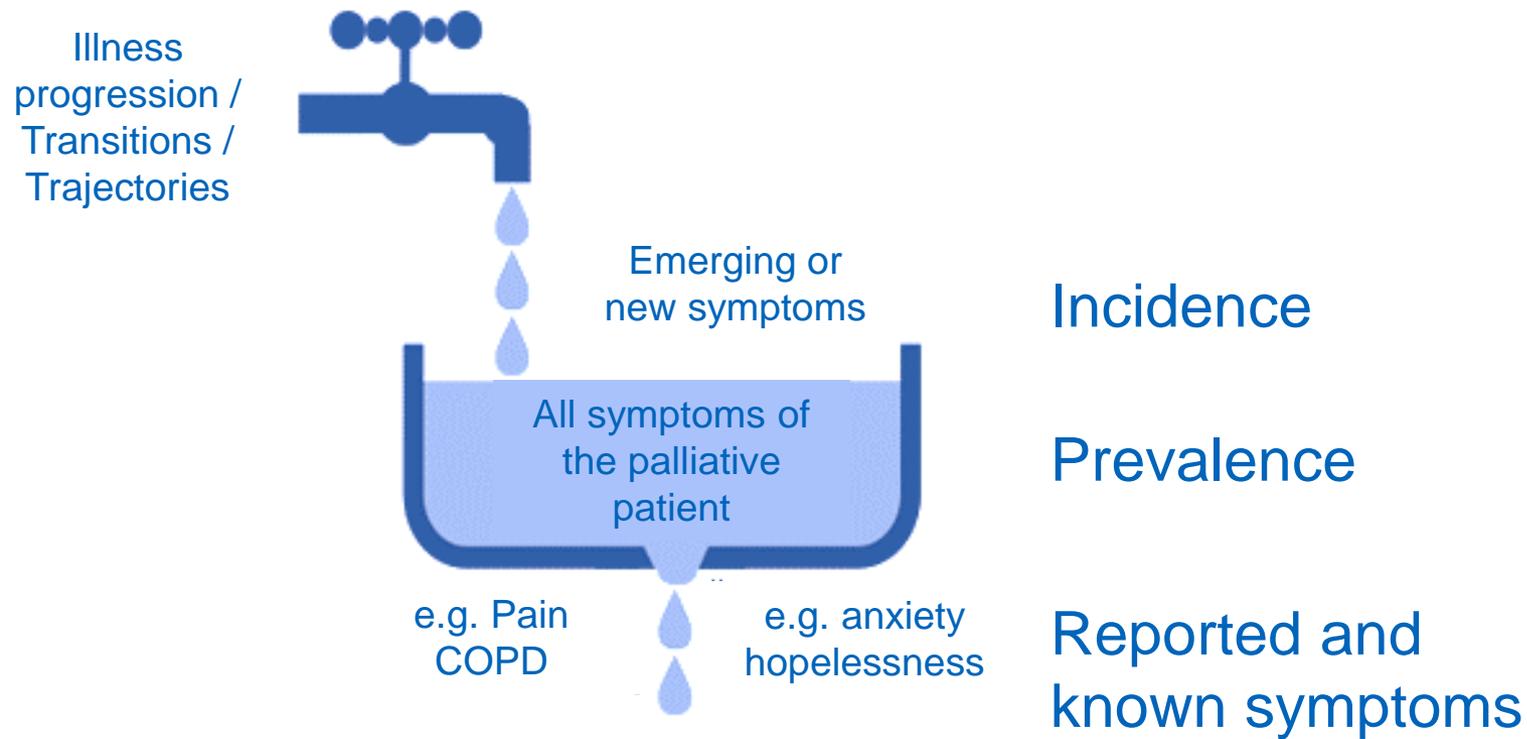
In How Far We Can Estimate The Dimensions Of Patients Its Symptoms?

Incidence Problem

- To develop awareness of the cause of incidence problem
- Symptom notification only with explicit inquiries
- There are low incidence values by unsystematic surveying
- There are high incidence values by systematic surveying and monitoring
- Commonly the symptoms with main personal load or suffering are reported

- To ask and again asking – to talk and again talking

Definition of the incidence problem



Diversity is in your hands.



Diversity is not the problem of the others, is yours!

Diversity Problem

Attitude of the Palliative Care Professionals

Professional attitude

- Part of professionalism not to neglect diversity
- Need to develop an attitude towards the diversity problem
- Diversity is the asymmetry between the survivors and the dying patient himself
- For this background the nurses and physicians needs to develop a specific attitude

Diversity **is in your hands.**



Diversity is not the problem of the others, is yours!

Attitude towards Diversity

Problem:

- «Total Pain» absorbs a lot of attention
- Palliative Care tends to be marginalised to a technological downturn

There is a need:

- That the patient report
- ... for Patient's narration and to let him tell
- ... for sharing experiences
- ... to ask how do they feel

Threats:

- Palliative Care degenerates to pure «pain management»

Diversity **is in your hands.**



Diversity is not the problem of the others, is yours!

A German project to experience diversity at the end of life

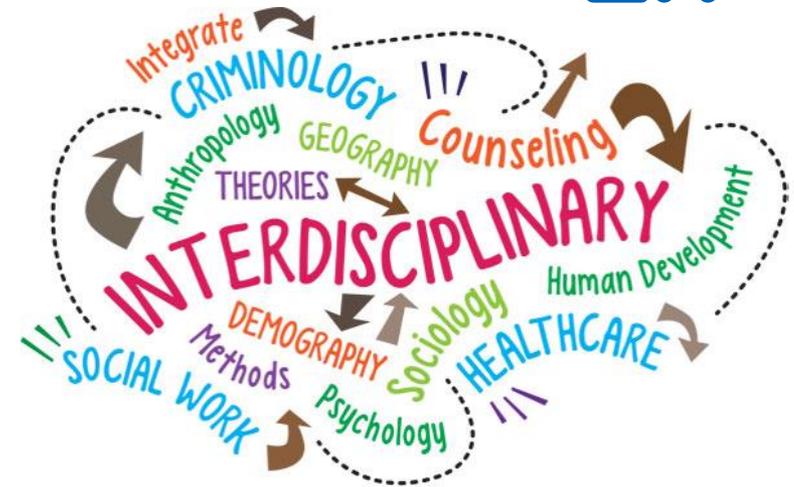
30 JUNGE MENSCHEN SPRECHEN
MIT STERBENDEN MENSCHEN UND
DEREN ANGEHÖRIGEN



PROJEKT PERSONEN PRESSE BLOG KONTAKT



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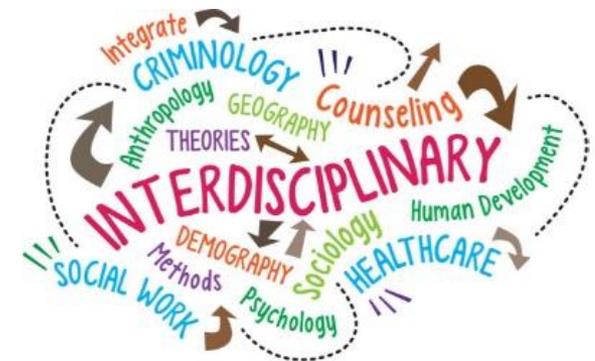
Interdisciplinary in Palliative Care

The Nurse's Role

The nurse`s role in interdisciplinary and palliative care

Characteristics of an effective interdisciplinary team:

- Collaboration
- Leadership
- Coordinated decision making
- Conflict resolution
- Attend the particular needs of the patient and the family
- Include specialists if needed
- Respect and trust in each team member`s skills
- Openness to diverse ideas and opinions



Summary

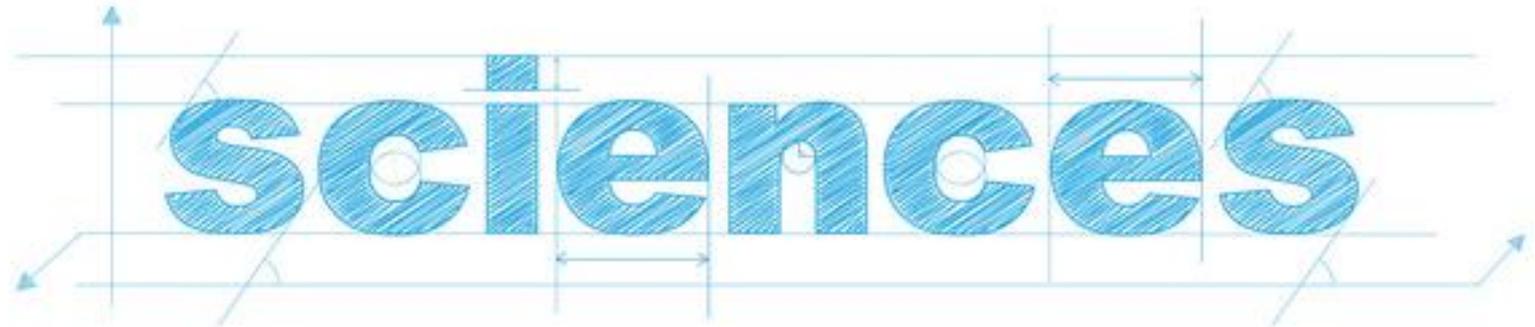
Palliative Care Nursing:

Soft paternalism

Interdisciplinary:

Primus*a inter pares

Research in Palliative Care: Misgiving and Challenges



Misgivings

- Vulnerability, dependence, limited autonomy
- Risk of unethical or borderline research objectives and research questions
- Difficulty or fluidity of the "informed consent"
- Professional attitude: Gentle or paternalism or protective paternalism
- Inappropriate or disrespectful behavior due to improper goals, questions and attitudes
- Danger of curiosity-oriented research
- Research can develop an aftertaste of intrusiveness and disrespect

Vol. 25 No. 4 April 2003

Journal of Pain and Symptom Management S53

Special Article

Maximizing Benefits and Minimizing Risks
in Palliative Care Research That Involves
Patients Near the End of Life

Perry G. Fine, MD

Palliative Medicine 2005; **19**: 532–537

Seeking new methodology for palliative care research:
challenging assumptions about studying people who are
approaching the end of life

Jane B Hopkinson, David NM Wright Macmillan Research Unit, University of Southampton, Southampton
and **Jessica L Corner** School of Nursing and Midwifery, University of Southampton, Southampton

Project external challenges

- Research in the field of palliative care is considered complex
- Involved professions tend to advocacy protectionism
- Ethics committees and review boards as additional hurdles
- Attitude that the vulnerability of dying people is an extended area of protection
- Financing problematic of complex research
- Social taboos as barriers

Palliative Medicine 2008; **22**: 913–920

The views of patients with advanced cancer regarding participation in serial questionnaire studies

C Shipman King's College London, Department of Palliative Care, Policy and Rehabilitation, London,
M Hotopf King's College London, Department Psychological Medicine, Institute of Psychiatry, London,
A Richardson King's College London, Florence Nightingale School of Nursing and Midwifery, London,
S Murray General Practice Section, Division of Community Health Sciences, University of Edinburgh,
Edinburgh, **J Koffman**, **R Harding**, **P Speck** and **IJ Higginson** King's College London, Department of Palliative
Care, Policy and Rehabilitation, London

Review

Conducting qualitative research with palliative care patients: applying Hammick's research ethics wheel

Lisa S Whiting, Peter S Vickers

Methodological challenges

- „Another powerful barrier to end of life research is the willingness of physicians to recognize patients as dying (Fine, 2003: S54).“
- Rapid disease changes, traits or transitions
- Emotional pain and psychological distress
- Concentration ability and duration
- Speaking, thinking and discussing about the future is considered most challenging

The views of patients with advanced cancer regarding participation in serial questionnaire studies

C Shipman King's College London, Department of Palliative Care, Policy and Rehabilitation, London,
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Special Article

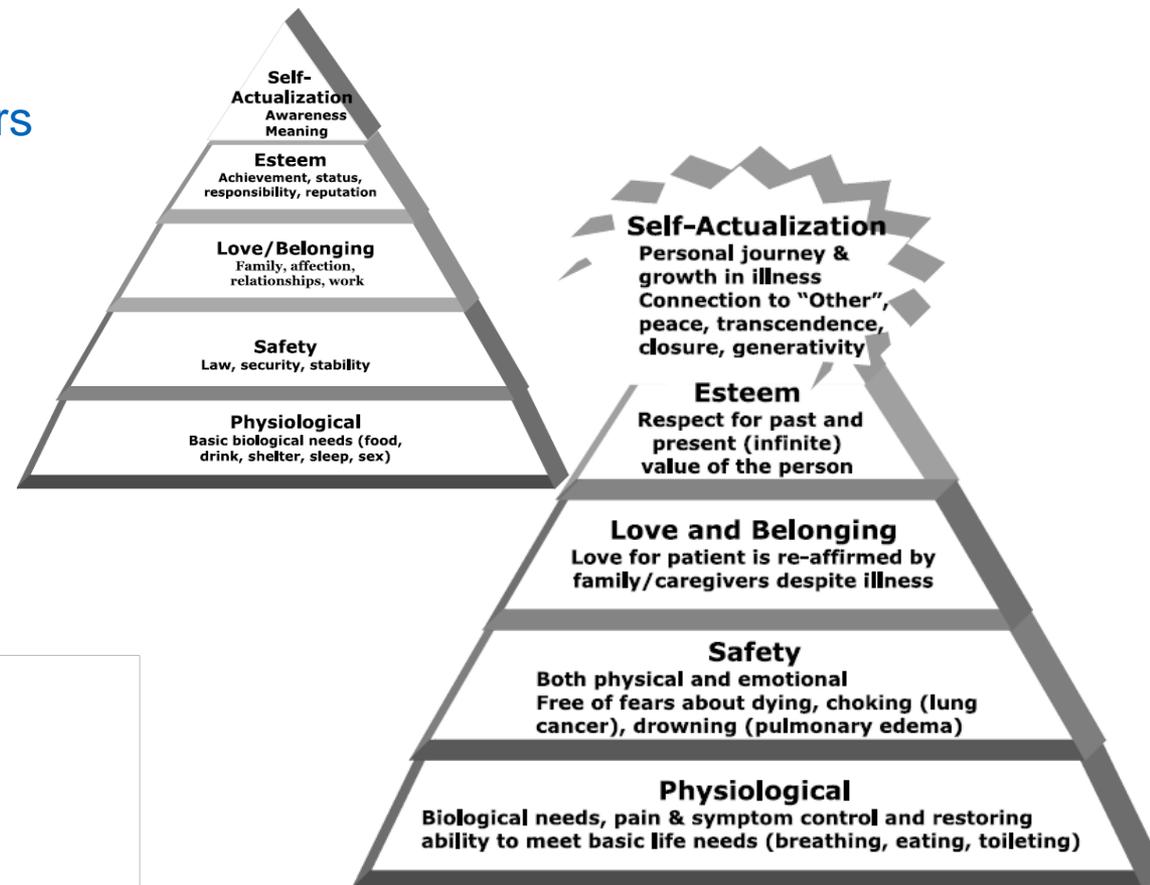
Maximizing Benefits and Minimizing Risks in Palliative Care Research That Involves Patients Near the End of Life

Perry G. Fine, MD

*Department of Anesthesiology, School of Medicine, University of Utah, Salt Lake City, Utah,
and VistaCare, Inc., Scottsdale, Arizona, USA*

Challenge on the part of the patiente

- Patient-related challenges:
 - symptoms and symptom-clusters
 - refractory symptoms
 - incidence problem
 - meaning of life and terminality



Vulnerability of participants in palliative care

- Patients have a higher need for protection
- Vulnerability of the target group as main argument for specificity:
 - Higher risk of unforeseen events
 - Not intentional side effects

Note:

- Not only palliative patients are vulnerable
- Vulnerability and research also apply to other groups

Special issue 2002

Research sensitivities to palliative care patients

J. ADDINGTON-HALL, PHD, *Department of Palliative Care and Policy, King's College London, Weston Education Centre, London, UK*

Vulnerability of researchers in palliative care



Article



Ethical challenges embedded in qualitative research interviews with close relatives

Nursing Ethics
2014, Vol. 21(1) 6–15
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10.1177/0969733013486370
nej.sagepub.com



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Palliative Care is Effective

- Successful palliative care teams require nurturing individuals who are willing to collaborate with one another
- Researchers have studied the positive effects palliative care has on patients
- Recent studies show that patients who receive palliative care report improvement in:
 - Pain and other distressing symptoms, such as nausea or shortness of breath
 - Communication with their doctors and family members
 - Emotional and psychological state



Review



Evidence on the cost and cost-effectiveness of palliative care: A literature review

Palliative Medicine
0011-21
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DOI: 10.1177/0269216313493464
jpm.sagepub.com



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REVIEW

CLINICIAN'S CORNER

Effectiveness of Specialized Palliative Care A Systematic Review

Camilla Zimmermann, MD, MSc

Rachel Riechelmann, MD

Monika Krzyzanowska, MD, MPH

Gary Rodin, MD

Ian Tannock, MD, PhD

Context Specialized palliative care teams are increasingly providing care for the terminally ill. However, the impact of such teams on quality of life, satisfaction with care, and economic cost has not been examined systematically using detailed criteria for study quality.

Objective To systematically review the evidence for effectiveness of specialized palliative care.

Summary and Outlook

Strength:

A (well-)known topic in modern times

... but ...

Threat:

A home loss of the initially intention



... is not always what should and could be!

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Selected Webpages

- <http://www.who.int/cancer/palliative/definition/en/>
- <http://www.who.int/cancer/media/FINAL-Palliative%20Care%20Module.pdf>
- <http://www.cancer.gov/cancertopics/factsheet/support/palliative-care>
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