Palliative Care Nursing
A well-known topic in modern times?

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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
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
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
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

- Social
- Psycho
- Bio
- Spiritual
Basic and Specialised Palliative Care

- Basic palliative care
- Specialized palliative care
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?

(Schulz and Schnell 2009; Schulz, Karger et al. 2010)
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

(Schulz and Schnell 2009; Schulz, Karger et al. 2010)
Definition of the incidence problem

Emerging or new symptoms
All symptoms of the palliative patient

Incidence
Prevalence
Reported and known symptoms

Illness progression / Transitions / Trajectories

e.g. Pain COPD

e.g. anxiety hopelessness

(Schulz and Schnell 2009; Schulz, Karger et al. 2010)
Diversity is not the problem of the others, is yours!

Diversity Problem
Attitude of the Palliative Care Professionals

(Schulz, Karger et al. 2010; Schulz and Schnell 2014)
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

(Schulz, Karger et al. 2010; Schulz and Schnell 2014)
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»

(Schulz, Karger et al. 2010; Schulz and Schnell 2014)
A German project to experience diversity at the end of life

www.30jungemenschen.de
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
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
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
Challenge on the part of the patiente

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

Maslow’s Hierarchy of Needs: A Framework for Achieving Human Potential in Hospice

ROBERT J. ZALENSKI, M.D., M.A. and RICHARD RASPA, Ph.D.
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
Vulnerability of researchers in palliative care

Ethical challenges embedded in qualitative research interviews with close relatives

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VIA University College, Bachelor Programme in Nursing, Denmark

Annelise Norlyk
Aarhus University, Denmark; Aarhus University Hospital, Denmark

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Aarhus University, Denmark
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
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!
Literature

Clemens, K. E., Kumar, S., Bruera, E., Klaschik, E., Jaspers, B., & De Lima, L. (2007). Palliative care in developing countries: what are the important issues? Palliative Medicine, 21(3), 173-175.
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Selected Webpages

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