

EAPC-RN / PRC
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Projects

Process Quality Indicators, quality of life and coss: a longitudinal study



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Cancer Palliative Care integrated early in the course of disease until death



delivered

- when
- what
- by whom
- how
- effect of palliative care interventions?

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When should palliative care interventions start?

Palliative Care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;

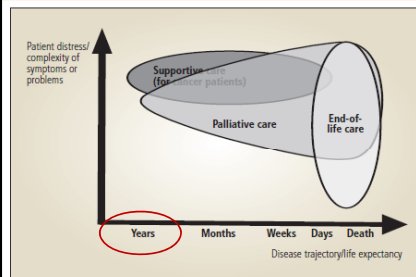
is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

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<http://www.who.int/cancer/palliative/definition/en/>

When should palliative care interventions start?



European Association of Palliative Care: year(s) before death

Main area of care provision for palliative care, supportive care and end-of-life care (using a narrow definition of end-of-life care)

Radbruch L et al. EUROPEAN JOURNAL OF PALLIATIVE CARE, 2009; 16(6)

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What are palliative care interventions?

TABLE 1. AMBULATORY PALLIATIVE CARE GUIDELINES

Illness understanding/education
 Inquire about illness and prognostic understanding
 Offer clarification of treatment goals
 Symptom management—Inquire about uncontrolled symptoms with a focus on:
 Pain
 Pulmonary symptoms (cough, dyspnea)
 Fatigue and sleep disturbance
 Mood (depression and anxiety)
 Gastrointestinal (anorexia and weight loss, nausea and vomiting, constipation)
 Decision making
 Inquire about mode of decision making
 Assist with treatment decision-making, if necessary
 Coping with life-threatening illness
 Patient
 Family/family caregivers
 Referrals/prescriptions
 Identify care plan for future appointments
 Indicate referrals to other care providers
 Note new medications prescribed

„Standard“-Interventions

- Illness understanding
- Symptom-Management
- Assist Decision-making
- End-of-life discussions
- Care plans - network

Temel J et al, NEJM 2010
 Jacobsen J, et al. J Pall Med 2011

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Who should deliver palliative care interventions?



Competence levels to be defined AND taught

Education

ESMO-ASCO Global Core Curriculum for Training in Medical Oncology Log Book

→ See updated version 2011

Communication with the patient and family
 Break bad news
 Act in difficult situations
 Communication and work with other health care professionals (eg. nurses, social workers, psychologists)

Palliative care and end-of-life
 Pain
 Assessment of location and severity of pain
 World Health Organization pain ladder
 Pharmacology and toxicity of the opiate
 Narcotics and other analgesics
 Management of cancer pain
 Recognition and referral for an invasive palliative intervention
 Other symptoms

Palliation of symptoms of respiratory tract
 Palliation of symptoms of gastrointestinal tract
 Palliation of neurologic symptoms
 Cutaneous and mucosal symptoms
 Anorexia and cachexia
 Dehydration
 How to handle end-of-life symptoms

Hansen NH et al. Ann Oncol 2004;15:1603 & J Clin Oncol 2004;22:4616

E-learning ESMO: Integration Oncology and Palliative Care 2012

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A lot of palliative care competencies in the curriculum of oncologists



Role of the Oncologist in delivering palliative care interventions: Chances & Challenges

Oncologist remains involved in care until patients death and beyond, responsible, committed, skilled, coordinates

Policy
 ASCO
 ESMO

Palliative Care Specialists needed:
 Co-Management (Shared-Care),
 Education, Academic
 Palliative Care

Challenge: assure both broad care AND high quality

- „Real“ Bio-Psycho-Social-Spiritual approach ?
- Multidisciplinary – multi-professional ?
- Focus also on community-based Palliative Care ?

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How should palliative care interventions be delivered by professionals involved?

Are there models of integrated oncology and palliative care?

Systematic review: 27 publications, 11 oncology

Three big types of models:

single specialist, multi-professional, inter-professional

Variable professionals: specialist palliative care teams, nurse-led consults, simultaneous or shared-care, oncologist-delivered

Variable practice settings: cancer centers, outpatient settings, private practice, community

Teunissen S et al., manuscript in prep.

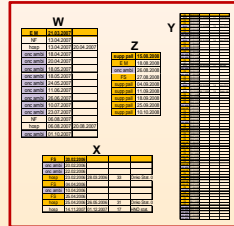
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**A model of integrated oncology and palliative care?
Oncology and oncological palliative medicine KSSG**

Analysis (visual graphic analysis) of all service points from 1st outpatient clinic contact

- Palliative Outpatient Pall Med
Inpatient PC Unit
Consult in-patient
- Oncology Outpatient
Inpatient
- „neutral“ Emergency Room



Results: Four patterns

W: Onc (30%), X: shared, Y: simultaneous, Z: Pall (40%)



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Cancer Palliative Care integrated early in the course of disease until death: Effects?

The research question:

What is the effect of [Palliative Care Interventions] on Patients' Outcomes [Quality of life] and [costs]?

- P Patients with oncologically defined situation (progression after 1st line treatment: lung, other?)
- I Evidenced-based components of [Pall Care Interv]
- C observational OR RCT with control?
- O Validated patient outcome tools
- Semistructured interviews with patients / proxies
- Costs

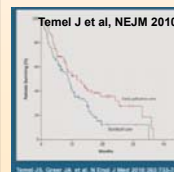


Cancer Palliative Care integrated early in the course of disease until death: Effects?

The research question:

What is the effect of [Palliative Care Interventions] on Patients' Outcomes [Quality of life] and [costs]?

Is there a need to ask this question (again)?



Formal focus groups with oncologists and palliative care specialist, representing the region eastern switzerland
→ Substantial need to improve
→ BUT: same setting, professionals?



PICO [Palliative Care Interventions]

This is a complex intervention along the trajectory of advanced, incurable cancer patients

Research question to prepare the study:

Can “key-interventions of cancer palliative care“ be identified, which are (high-level)

- evidenced-based,
- can be educated to different professionals, and
- can be measured with Process Quality Indicators?

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Example of Process Quality Indicator: Perceived management of physical symptoms

Example of a Quality Indicator Concerning Actual Care Experiences
Extent to Which Patients Receive Support for Their Physical Symptoms

Reason for indicator: Pain, fatigue, shortness of breath, and constipation are symptoms that frequently occur in the palliative phase. The quality of both

Do you receive support when you are in pain?
(never, sometimes, usually, always, not applicable)

Other symptoms same question (dyspnea, fatigue, ..)

Measurement of applied palliative intervention, Is not asking the outcome of the management

not applicable (because I have no pain)
 never
 sometimes
 usually
 always
 not applicable (because I am not tired)
Do you receive support when you have shortness of breath?
 never
 sometimes
 usually
 always
 not applicable (because I do not have shortness of breath)
Do you receive support when you are constipated?
 never
 sometimes
 usually
 always
 not applicable (because I am not constipated)

Claessen et al. JPSM 2011

PICO [Palliative Care Interventions]

The intervention: standard procedures

- Symptom management: routine, proactive, multi-dimensional, quantitative assessment
- Communication: proactive documented discussion about illness-understanding, prognosis, end-of-life preparation
- Anticancer treatment decisions: checklist
- Support network: care plans, family carers

Quality indicator publications
Lorenz JCO 2006; Twaddle JPallMed 2007; Gelfman JPSM 2008; Seow JPSM 2009; Zimmermann Jama 2008; Pasman JPSM 2009; Pastrana SCC 2010; Claessen JPSM 2011; Schenck JPallMed 2010
Research on Quality Indicators: IMPACT (Eu-consortium)

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PICO Patients' Outcomes [Quality of life]

- Validated patient-reported outcomes tools:
 - ESAS
 - Palliative Outcome Scale
 - EQ5D
 - Impact on Family? FAMCARE-P13
- Semistructured interview capturing quality time related domains (Prigerson's work)
- in depth interviews about lived experience

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PICO

Costs

- Ressource along the whole patient trajectory
- Collection of time spent of ALL providers
- Time on units, when patient could have been referred, but not able to get referred for space

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PICO

Trial design

Observational study or intervention trial?

Observational

- . Already existing interventions in the region
- . Contamination happens anyhow
- . Better to sell the stakeholders

Intervention

- . We should do it (SK)
- . Evidence stronger
- . Cluster randomisation of regions possible
- . Delayed intervention maintains motivation
- . Standard education

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The research question:

What is the effect of [Palliative Care Interventions] on Patients' Outcomes [Quality of life] and [costs]?

Many, many questions and open points

- Is it necessary to do first a phase II [Pall Care Intvt]?
- Can the Interventions sufficiently be standardised among professionals?
- Are the outcomes both relevant and robust?
- Should we use composite endpoints?
- Does contamination occurs randomizing regions?
- ..

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Secrets & Challenges to do such research

- Be part of the „gang“
- Talk their languages
- Motivate and incentives
- Make a difference AND relevant outcomes

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