GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

ESMO SUMMIT AFRICA 2019

End of Life Care

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February 16th 2019

CONFLICT OF INTEREST DISCLOSURE

- Personal financial interests

  Stockholder: Eir Solution

  Research funding: Nutricia

CRITERIA TO BECOME AN ESMO DESIGNATED CENTERS FOR INTEGRATED ONCOLOGY AND PALLIATIVE CARE

- Patient symptom and function management
- Support of family members
- Coordination of home care
- Offer - In patient specialized palliative care
- Conduct research
- Offer - Education programs
- End of life care program

- “optimal end of life care starts early in the disease trajectory”
- “early integration of palliative and supportive care may improve end of life care”
- “ an integrated and systematic approach is needed”

- …”relevant for patients with sarcoma?”

WHAT TYPE OF COMPETENCE IS NEEDED AND WERE TO DELIVER?

- For oncologists
- For palliative care specialists
- For GPs/ familiy medicine

Panel 15: Three levels of palliative care

Basic

(Level A; undergraduate and postgraduate)

Advanced

(Level B; postgraduate)

Specialist

(Level C; postgraduate)

Adapted from panel 15, Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a *Lancet Oncology* Commission. *Lancet Oncol* 2018; published online Oct 19

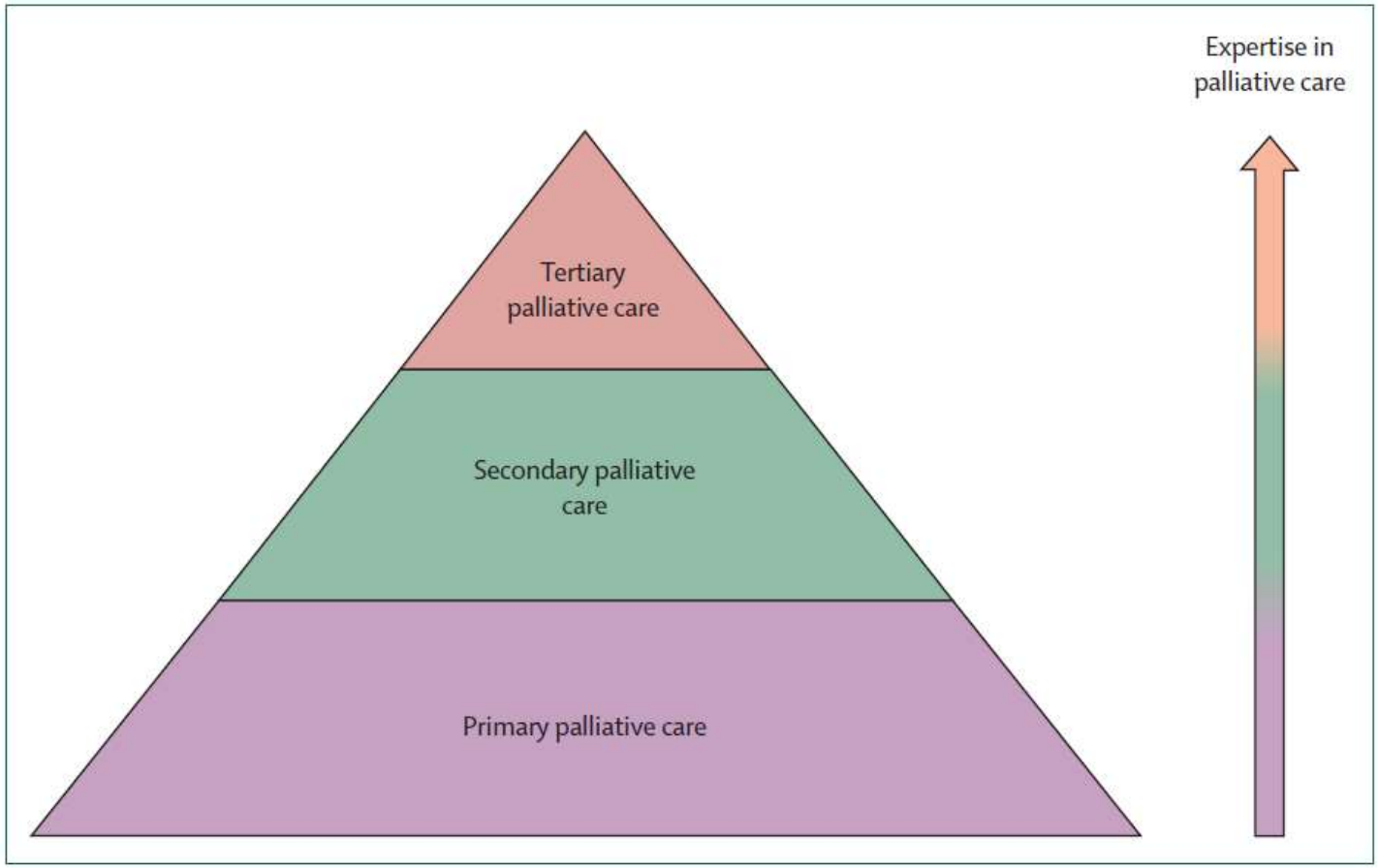


Figure 3: **Conceptual model of palliative care delivery based on provider expertise**

NEED SOME CLARIFICATIONS
WHAT IS:

- Integrated?
- Early?
- Palliative care…..and Supportive care?
- Patient centred care?
- The evidence for ?
- …and how are the models?

What is integrated care?

«The organization and management of health services, so that people get the care they need when they need it, in ways that are user-friendly, achieve the desired results and promote value for money»

WHO 2008

The concept of early integration

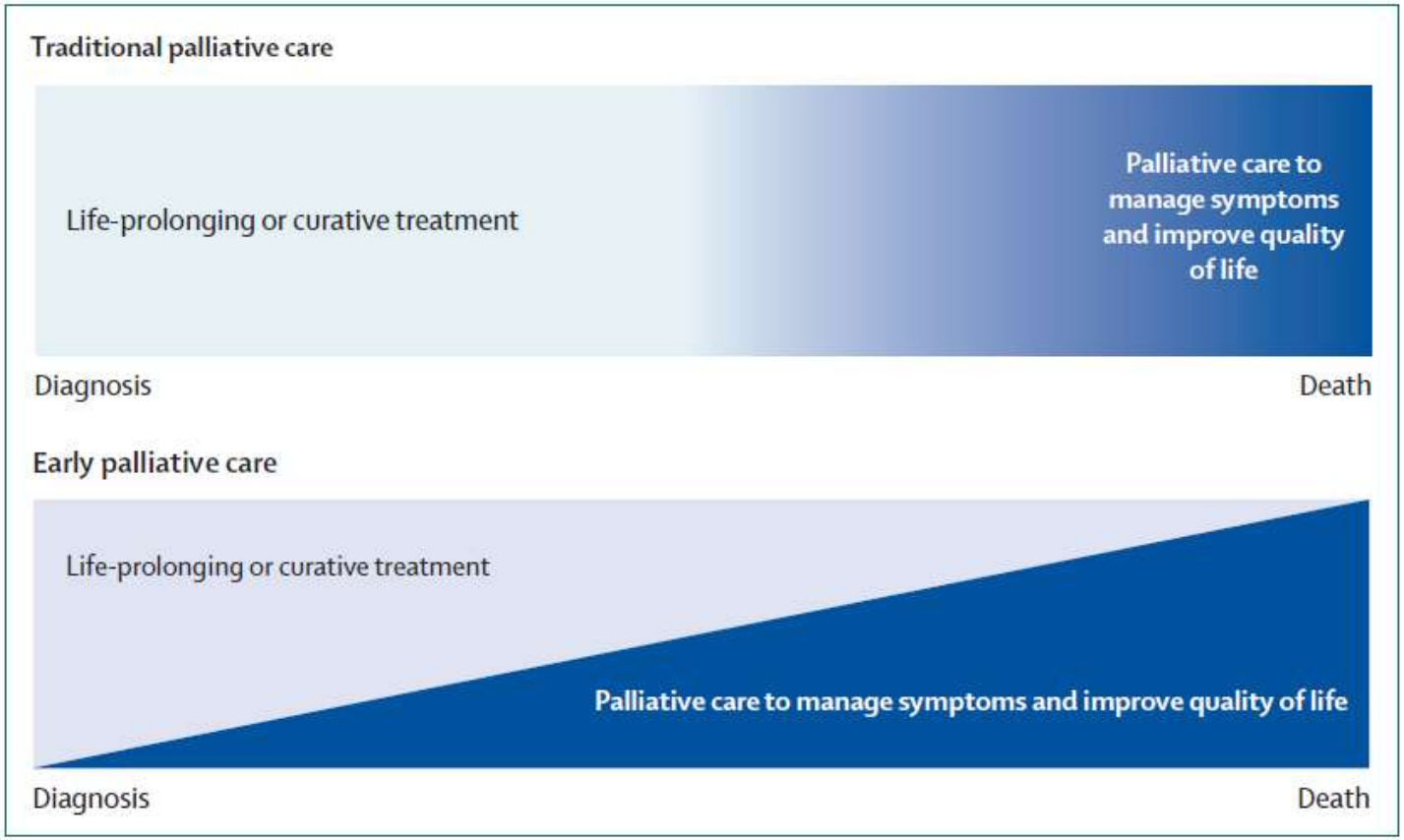


Figure 1: Traditional versus early palliative care

What is patient centeredness ?

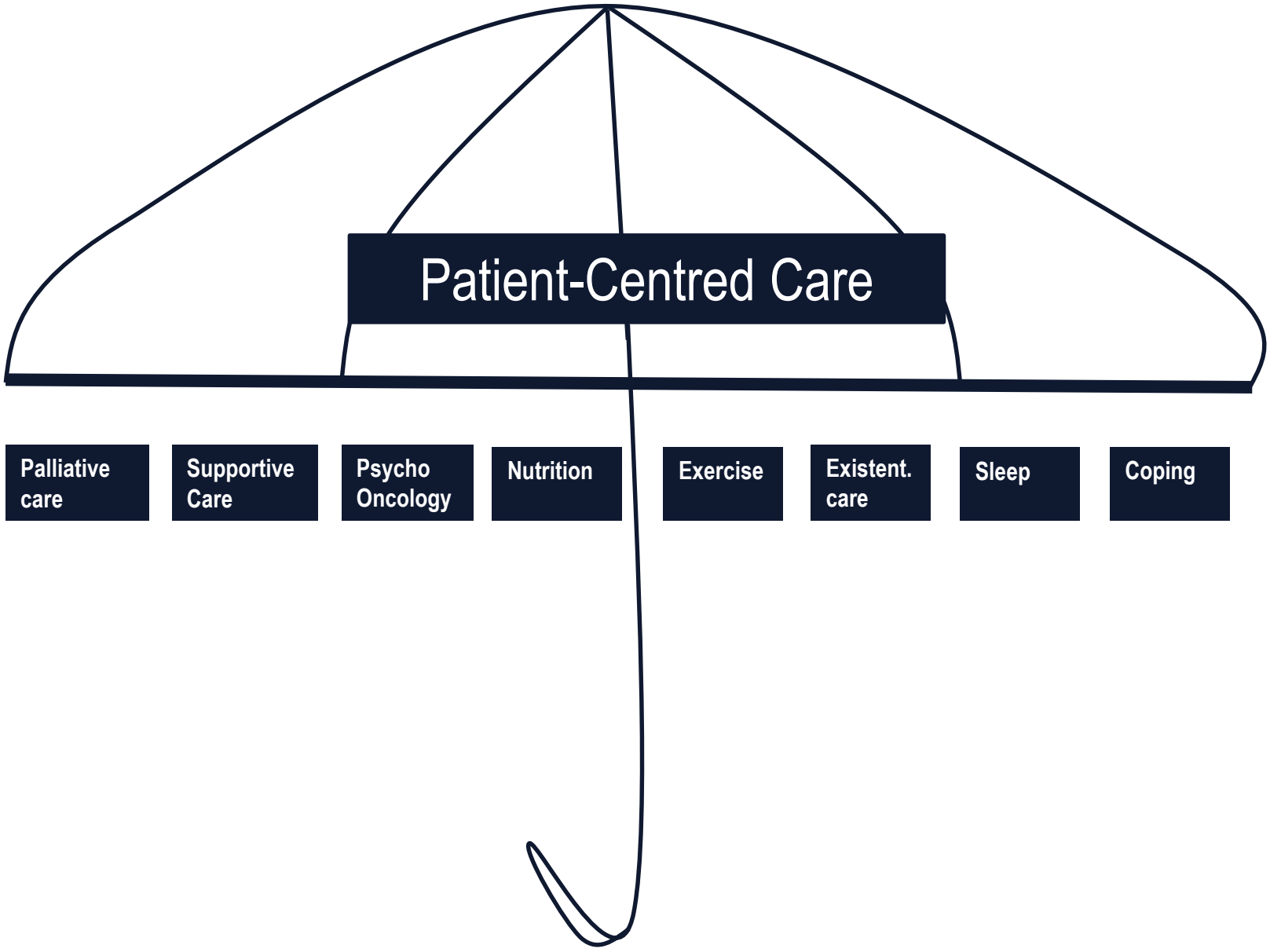
«Care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions»

Institute of Medicine (US) 2001

Panel 7: Main elements of patient-centred care

- Respect for patient's values
- Coordination and integration of care
- Information, communication and education
- Physical comfort
- Emotional support
- Involvement of family and friends

Adapted from panel 7, Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a *Lancet Oncology* Commission. *Lancet Oncol* 2018; published online Oct 19


Patient-Centred Care
Palliative care
Supportive Care
Psycho Oncology
Nutrition
Exercise
Existent. care
Sleep
Coping

Palliative care and oncology care – development over the past four decades

- The two paradigms – understood as two different cultures?
- Oncology – coming from mainstream medicine
- Palliative care – coming from outside mainstream health care
- WHO recommended integration many years ago
  - Of palliative care
  - Of health care in general

WHO recommended integration many years ago

- Did it happen?
- It did not - Why?
- Resistance is a basic barrier
  - In Palliative Care
  - In Oncology Care

Integration of oncology and palliative - supportive care

- Knowledge and skills in two models of care
  - Tumor-directed approach
  - The host-directed approach

- Palliative care is more than end of life care
- Palliative and supportive care – similar or identical?
  - Both are patient-centered care

What is the evidence for integrated oncology and palliative care? (1)

- Improved symptom control
- Improved patients' QoL
- Reduced "futile" chemotherapy last 30-60 days of life
- Improved survival

Bakitas 2009-2015
Temel 2010-2017
Zimmermann 2014
Vanbutsele 2018
Basch 2018

What is the evidence for integrated oncology and palliative care? (2)

- Satisfaction with care – patients are more satisfied with the health care delivered
- Family satisfaction and QOL is improved
- Place of care – place of death - more patients are at home

Jordhøy 2000
Ringdal 2002
Zimmermann 2014

European Society for Medical Oncology (ESMO) position paper on supportive and palliative care

K. Jordan[1*], M. Aapro[2], S. Kaasa[3,4,5], C. I. Ripamonti[6], F. Scotté[7], F. Strasser[8], A. Young[9], E. Bruera[10], J. Herrstedt[11,12], D. Keefe[13], B. Laird[14,15], D. Walsh[16], J. Y. Douillard[17] & A. Cervantes[18]

Table 1. Key patient-centred care interventions (examples)			
Assessment	Monitoring and intervention: regular changes in patients' health status preferably assessed with PROMs or other validated assessment tools	Management of cancer-related symptoms and other needs	Management of anticancer treatment-related toxicities and complications, including prevention

Jordan et al. ESMO 2018

Reference

Table 1. Key patient-centred care interventions (examples)

Assessment
• Cancer and anticancer-treatment related symptoms, toxicities, complications • Psychological disorders, distress • Sleeping problems • Spiritual and existential issues • Comorbidities • Nutritional status • Sexuality concerns • Prognosis and coping with cancer disease • Family and/or caregiver issues • Socioeconomic issues • Other unmet needs

Jordan et al. ESMO 2018

SYSTEMATIC USE OF PROMS

Reference

PROMs Can Be Applied With Several Goals

- Symptom screening
- Symptom monitoring
- To promote patient centered care

Greenhalgh J. *Qual Life Res.* 2009;18(1):115-123.

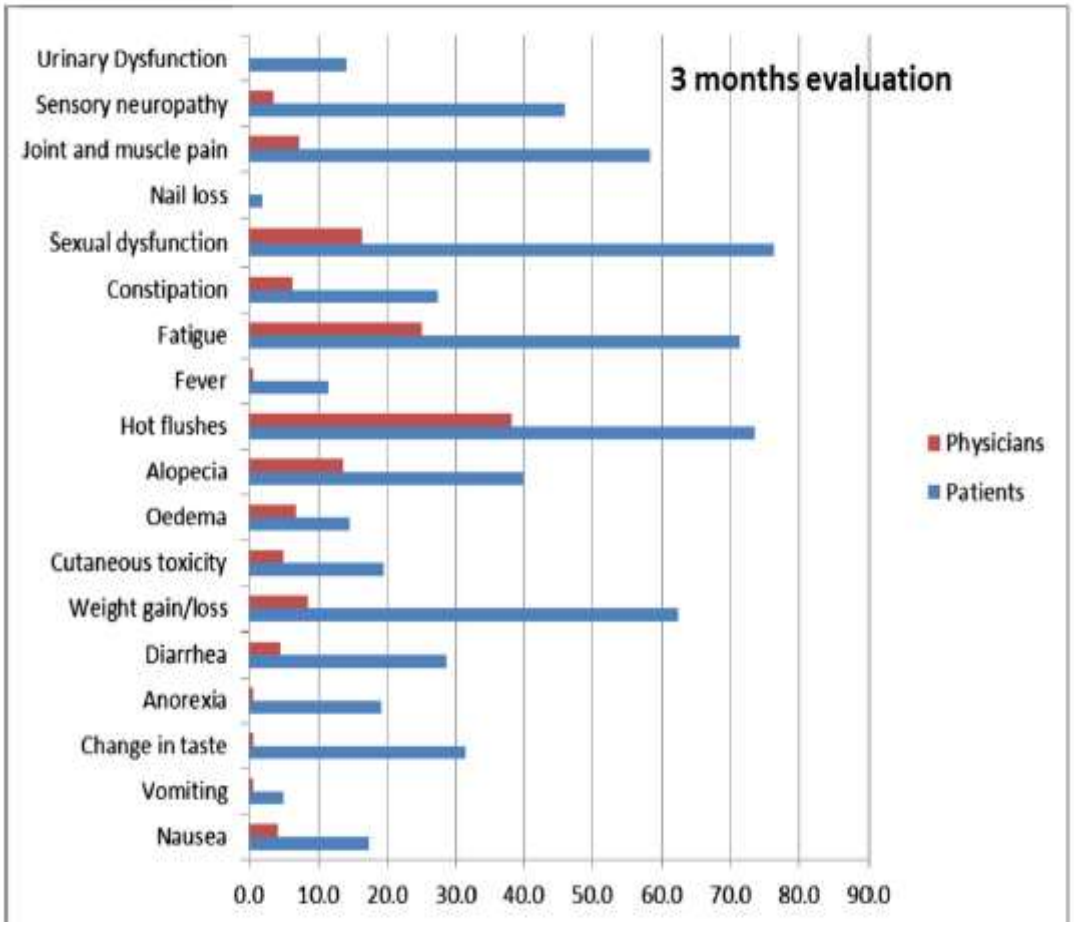
Completion of PROMs followed by presentation of the data for the health care personnel resulted in…

- Lower incidences of pain
- Lower incidences of constipation and vomiting
- Reduced fatigue

Kotronoulas G, et al. *J Clin Oncol.* 2014;32(14):1480-1501.

Why trust the patient?

Phase III trial (ADT ± docetaxel) in metastatic prostate cancer



Gravis, Eur J Canc 2014

RCT assessing the use of PROMS

- 766 patients at MSKCC during routine chemotherapy from metastatic solid tumors

Control Arm

"Standard" symptom monitoring

Intervention Arm

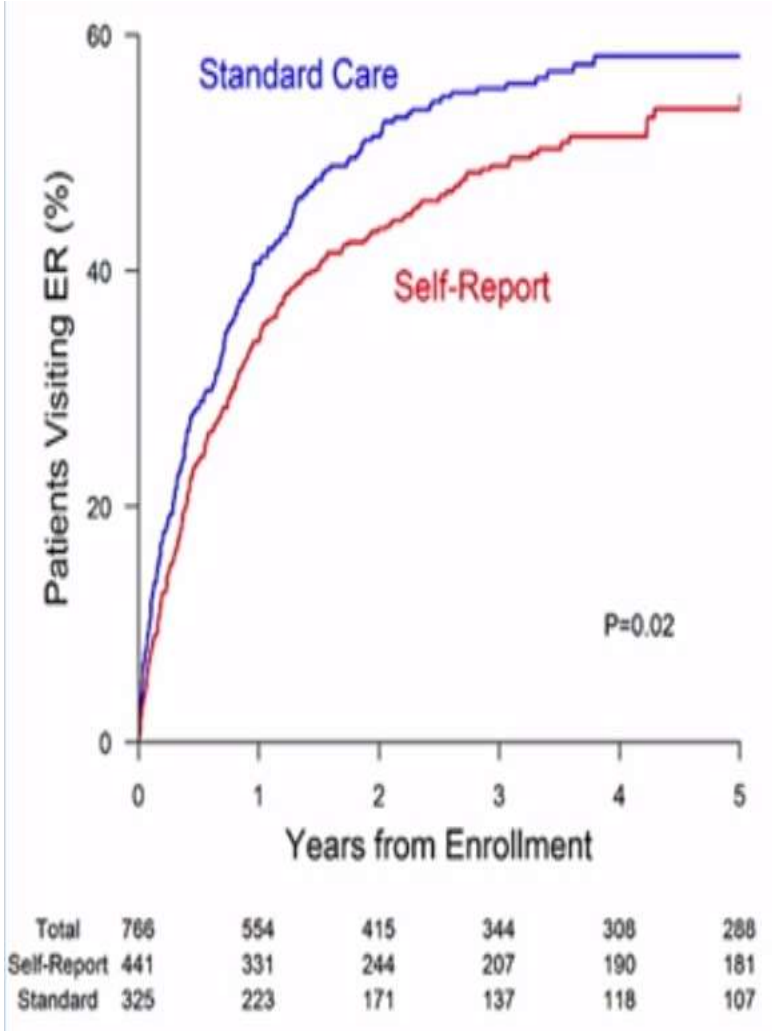
Self-report 12 common symptoms

- Prior to/between visits, by web
- Weekly email reminders to patients
- Alerts to nurses (by email)
- Reports to oncologists (at visits)

Basch E, et al. *JAMA.* 2017;318(2):197-198. Basch EM, et al. *J Clin Oncol*. 2017;35(suppl): Abstract LBA2.

Proportion of Patients Visiting Emergency Room

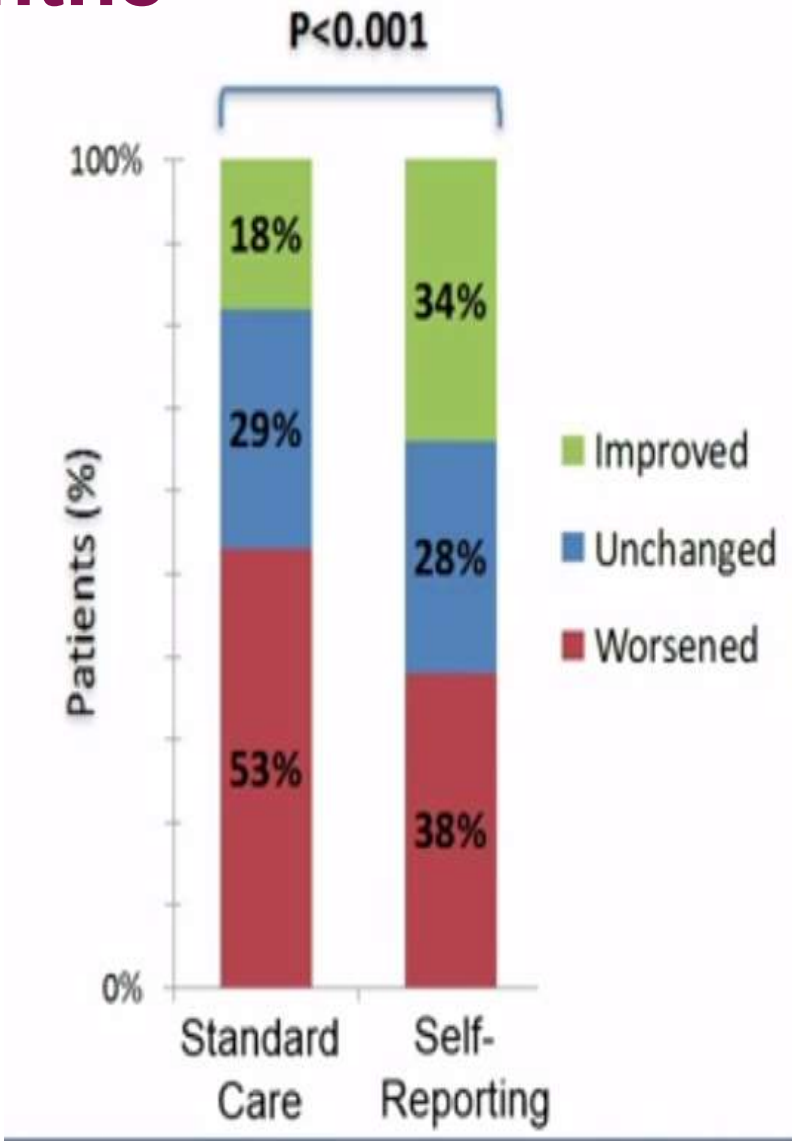
Compared to standard care, 7% fewer patients in the self-reporting arm visited the ER with durable effects throughout the study (*p*=0.02)



Basch E, et al. *J Clin Oncol.* 2016;3(6):557-565. Basch EM, et al. *J Clin Oncol*. 2017;35(suppl): Abstract LBA2.

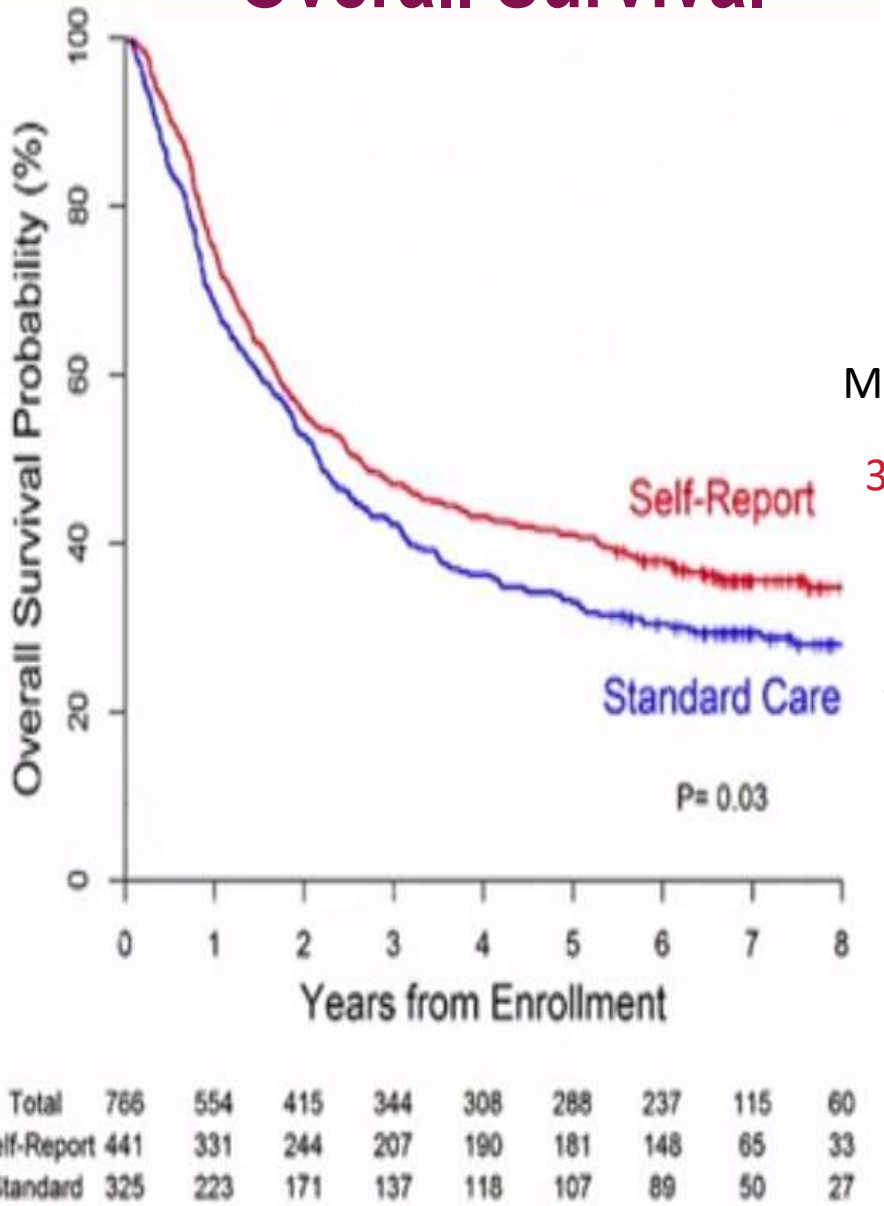
Quality of Life at 6 Months

Compared to standard care, 31% more patients in the PROMs arm experiences QoL benefits (p<0.0001)



Basch E, et al. *J Clin Oncol.* 2016;3(6):557-565. Basch EM, et al. *J Clin Oncol*. 2017;35(suppl): Abstract LBA2.

Overall Survival



Median Survival

31.2 months

26.0 months

Basch E, et al. *J Clin Oncol.* 2016;3(6):557-565. Basch EM, et al. *J Clin Oncol*. 2017;35(suppl): Abstract LBA2.

The key steps to achieve improvents in clinical practice

- Awareness: The physician must be aware of the evidence
- Agreement: The physician must agree with the evidence
- Adaptation: The physician must treat the patients accordingly
- Adherence: The physician must adhere to the evidence over time

Pathman DE, et al. *Med Care.* 1996;34(9):873-889.

Management of cancer pain in adult patients: ESMO Clinical Practice Guidelines†

M. Fallon[1], R. Giusti[2], F. Aielli[3], P. Hoskin[4], R. Rolke[5], M. Sharma[6] & C. I. Ripamonti[7], on behalf of the ESMO Guidelines Committee*

Table 2. Guidelines for the adequate assessment of the patient with pain at any stage of the disease
1. Assess and re-assess the pain
2. Assess and re-assess the patient
3. Assess and re-assess your ability to inform and to communicate with the patient and the family

Fallon et al. ESMO 2018

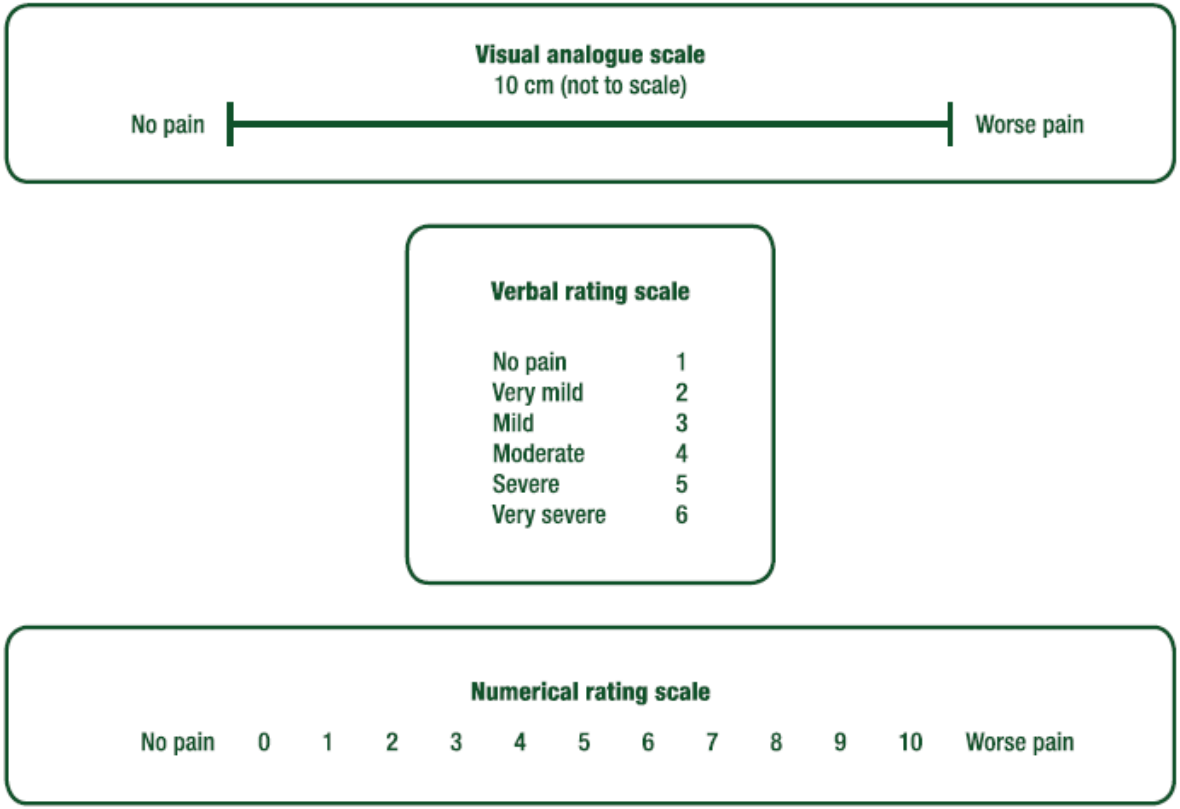


Figure 1. Validated and most frequently used pain assessment tools.

Fallon et al. ESMO 2018

ESAS – Edmonton Symptom Assessment System

Alberta Health Services

Affix patient label within this box

Edmonton Symptom Assessment System Revised (ESAS-r)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetitie
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Brea
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem *(For example constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

«Intelligent» use of electronic device

Eir for patients

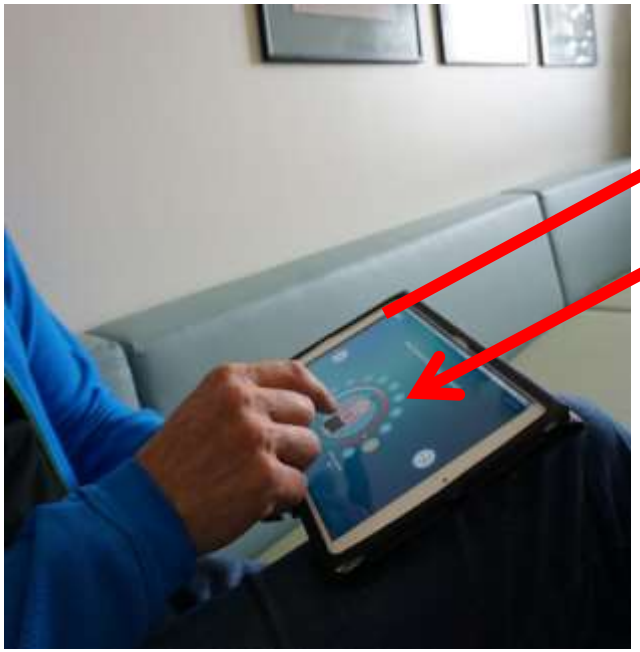
-Patients respond on an iPad

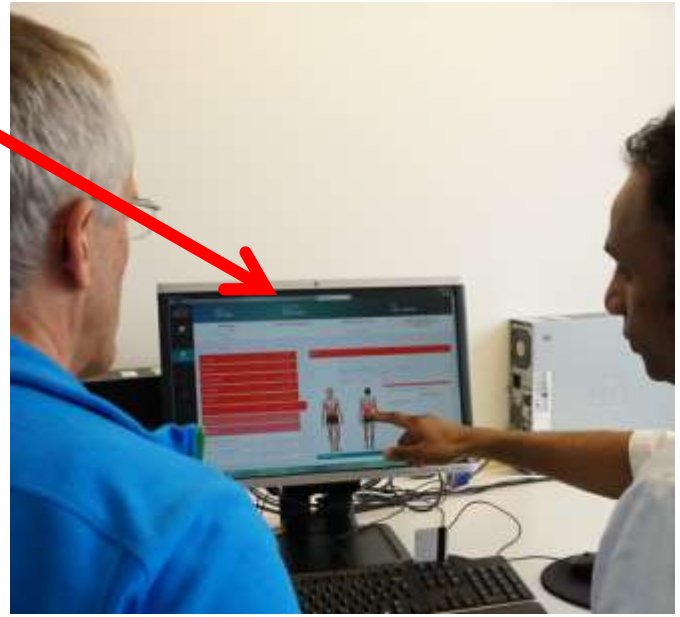
-iPad connected to web

Eir for health care personnel

-Summing up patients' responses

-Transferred to HCPs' PC via Internet





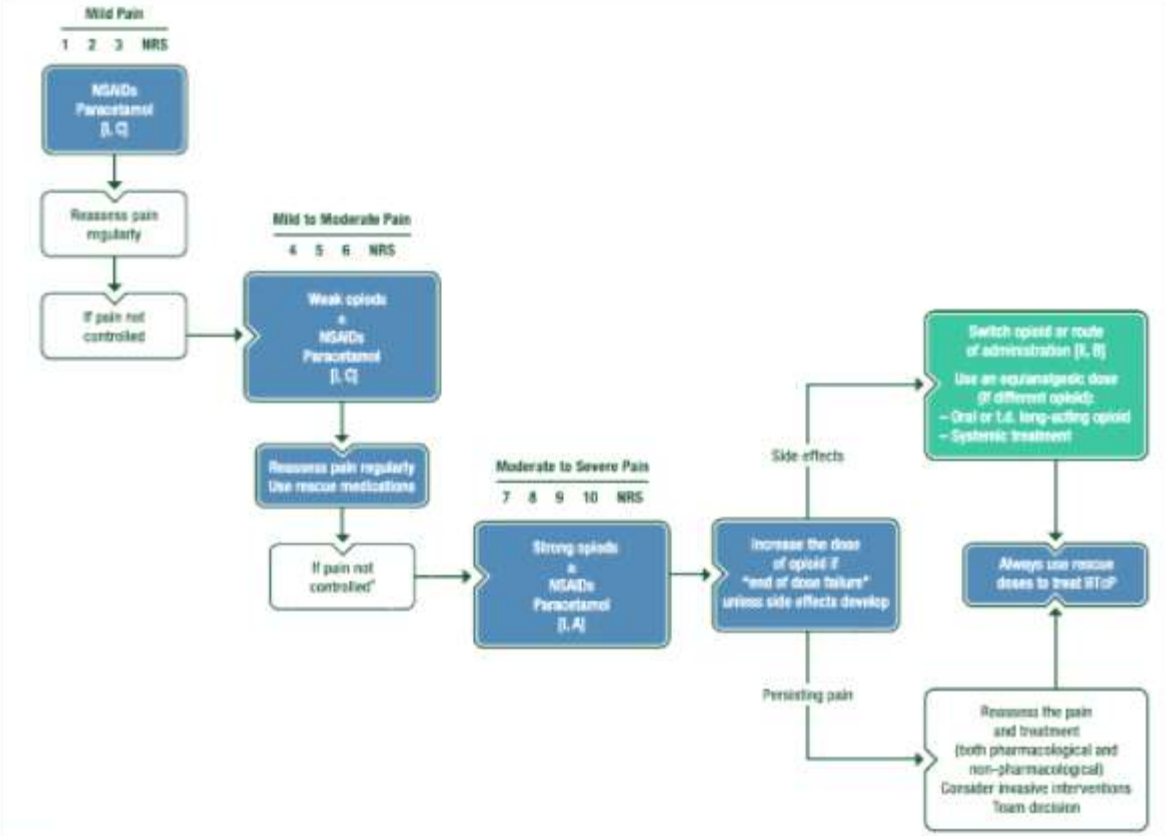


Figure 3. Treatment of cancer pain.
*Do not switch between weak opioids.
BTcP, breakthrough cancer pain; NRS, numerical rating scale; NSAID, nonsteroidal anti-inflammatory drug; t.d., transdermal.

Fallon et al. 2018

PALLIATIVE SEDATION (1)

- Before applied – assess all possible causes of suffering
- Multidisciplinary competence is needed

PALLIATIVE SEDATION (2)

- Appropriate drugs
- Dose titration
- Careful monitoring

END OF LIFE PAIN

- Alternative route of opioid administration
- Opioid rotation
- Hydration
- Aware of toxic metabolites
- Other symptoms often accompanied
  - Delirium
  - Dyspnea
  - Agitation
  - Anxiety

END OF LIFE CARE

- Advanced care planning
  - Adapted to patients and family members needs
- Communication
  - Understand and explain the natural course of the disease

FAMILY INVOLVEMENT

- CSNAT

The Carer Support Needs Assessment Tool (CSNAT)

Your support needs

We would like to know what help you need to enable you to care for your relative or friend, and what support you need for yourself. For each statement, please tick the box that best represents your support needs at the moment.

Do you need more support with...	No	A little more	Quite a bit more	Very much more
...understanding your relative's illness?				
...having time for yourself in the day				
...managing your relative's symptoms, including giving medicines?				
...your financial, legal or work issues?				
...providing personal care for your relative (eg dressing, washing, toileting)?				
...dealing with your feelings and worries?				
...knowing who to contact if you are concerned about your relative (for a range of needs including at night)?				
...looking after your own health (physical problems)?				
...equipment to help care for your relative?				
...your beliefs or spiritual concerns?				
...talking with your relative about his or her illness?				
...practical help in the home?				
...knowing what to expect in the future when caring for your relative?				
...getting a break from caring overnight?				
...anything else (please write in)?				

Please consider which of the above you **most** need support with at the moment.
A hospice nurse will then be able to discuss these support needs with you.

Table 3. ESMO resources for integrated patient-centred care education

- **E-learning modules**[a] on supportive and palliative care
- **ESMO Palliative Care Fellowships**[b] ESMO provides two palliative care fellowships allowing recipients observation or research at one of the ESMO Designated Centres
- **ESMO Clinical Practice Guidelines**[c] including guidelines on supportive care and palliative care.
- **ESMO Patient Guides**[d] include, e.g. how to deal with side-effects
- **ESMO Handbooks** for physicians[e]
- **ESMO Academy**[f] includes an overview of standards of care and future perspective in supportive care
- **ESMO Preceptorships in supportive care and palliative care**[g]
- **Oncology Pro Webcasts and Slides, Scientific Meeting Reports** (using search function) http://oncologypro.esmo.org/Slide-Resources
- **ESMO Congress track on supportive care and palliative care**
- **Core Curriculum** slide sets: http://www.esmo.org/Career-Development/Global-Curriculum-in-Medical-Oncology

Jordan et al. ESMO 2018

ESMO WILL ADVOCATE FOR AND CONTRIBUTE TO….

- Increased awareness
- Increased research
- Increased education
- Increased resources to be dedicated to supportive and palliative care