# Supportive and palliative care: Core elements of quality cancer care

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# Palliative and supportive care

- There has been much confusion regarding the definitions of supportive care and palliative care and many authorities use the terms interchangeably.

*Original Article*

The Lack of Standard Definitions in the Supportive and Palliative Oncology Literature

David Hui, MD, MSc, MSc, FRCPC, Masanori Mori, MD, Henrique A. Parsons, MD, Sun Hyun Kim, MD, PhD, Zhijun Li, MS, Shamsha Damani, MSLS, and Eduardo Bruera, MD

# Different Relational Models PC+SC

- Conflating
  - Equivalence:
    - Supportive care = Palliative Care
  - Subsumed:
    - Palliative Care includes all aspects of Supportive Care
    - Supportive Care includes all aspects of Palliative Care
- Distinct
    - Complimentary important disciplines

# Equivalence: Supportive care = Palliative Care

- Is it just a less threatening name for palliative care
  - Raise referral rates
  - Less association with EoL
  - Advocated by MD Anderson
  - Adopted by several other centers

# Supportive Versus Palliative Care: What's in a Name?

## A Survey of Medical Oncologists and Midlevel Providers at a Comprehensive Cancer Center

Nada Fadul, MD, Ahmed Elsayem, MD, J. Lynn Palmer, PhD, Egidio Del Fabbro, MD, Kay Swint, MSN, BSN, Zhijun Li, MS, Valerie Poulter, BSN, OCN, and Eduardo Bruera, MD

Cancer 2009;115:2013–21.

## DISCUSSION

Our preliminary study revealed that medical oncologists and midlevel providers stated more likelihood to refer patients at earlier stages of the cancer illness trajectory to a service named *supportive care* compared with *palliative care*. They were as likely to refer symptomatic patients at the *end-of-life* to a service named *supportive care* compared with *palliative care* (

# Hospitals that have labeled their palliative care programs SC

- City of Hope
- MD Anderson
- University of Sheffield
- Dartmouth General Hospital
- University of Illinois Hospital & Health Sciences System
- Children's Hospital Pittsburgh

STANFORD MEDICINE

# What is supportive care?

Supportive, or palliative, care is aimed at comfort versus cure. The decision to accept such care versus aggressive treatment is often difficult for family members. It means accepting a poor prognosis, but it also means providing a very special kind of care to a loved one. It means a new goal of providing a peaceful, pain-free death in the presence of loved ones.

# Subsumed

- PC begins from diagnosis till death
  - All aspects of care that contribute to quality of life
  - Includes SC to minimize treatment burden and adverse effects
  - Minimizes distinct issues
    - related to treatment delivery
    - related to patients with curable disease
- SC begins from diagnosis till death
  - All aspects of care that contribute to quality of life
  - Includes PC to relieve physical and psychosocial/spiritual distress
  - Minimizes distinct issues
    - related to advanced incurable disease
    - related to end of life care

# WHO Definition of Palliative Care

- Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:
  1. provides relief from pain and other distressing symptoms;
  2. affirms life and regards dying as a normal process;
  3. intends neither to hasten or postpone death;
  4. integrates the psychological and spiritual aspects of patient care;
  5. offers a support system to help patients live as actively as possible until death;
  6. offers a support system to help the family cope during the patients illness and in their own bereavement;
  7. uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
  8. will enhance quality of life, and may also positively influence the course of illness;
  9. 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.

# MASCC: special case

- Supportive Care in cancer is the prevention and management of the adverse effects of cancer and its treatment. *This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care.*

Conflationary

- **Supportive Care:**
  - alleviates symptoms and complications of cancer
  - reduces or prevents toxicities of treatment
  - supports communication with patients about their disease and prognosis
  - allows patients to tolerate and benefit from active therapy more easily
  - eases emotional burden of patients and care givers
  - helps cancer survivors with psychological and social problem

Distinct

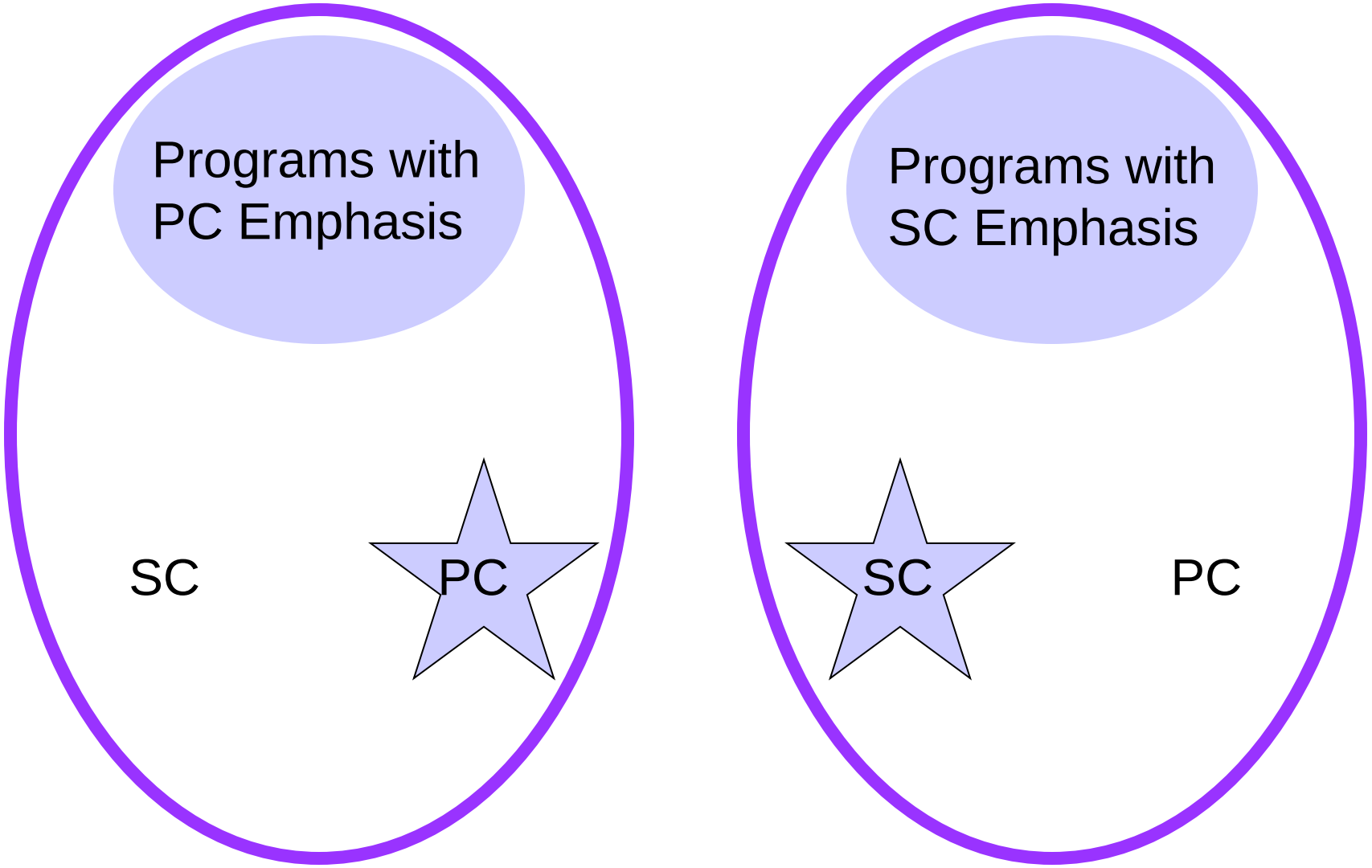
# Distinct but related

- Supported by ESMO +/- MASCC
- Separate but related
- Distinct
  - Focus
  - Body of knowledge

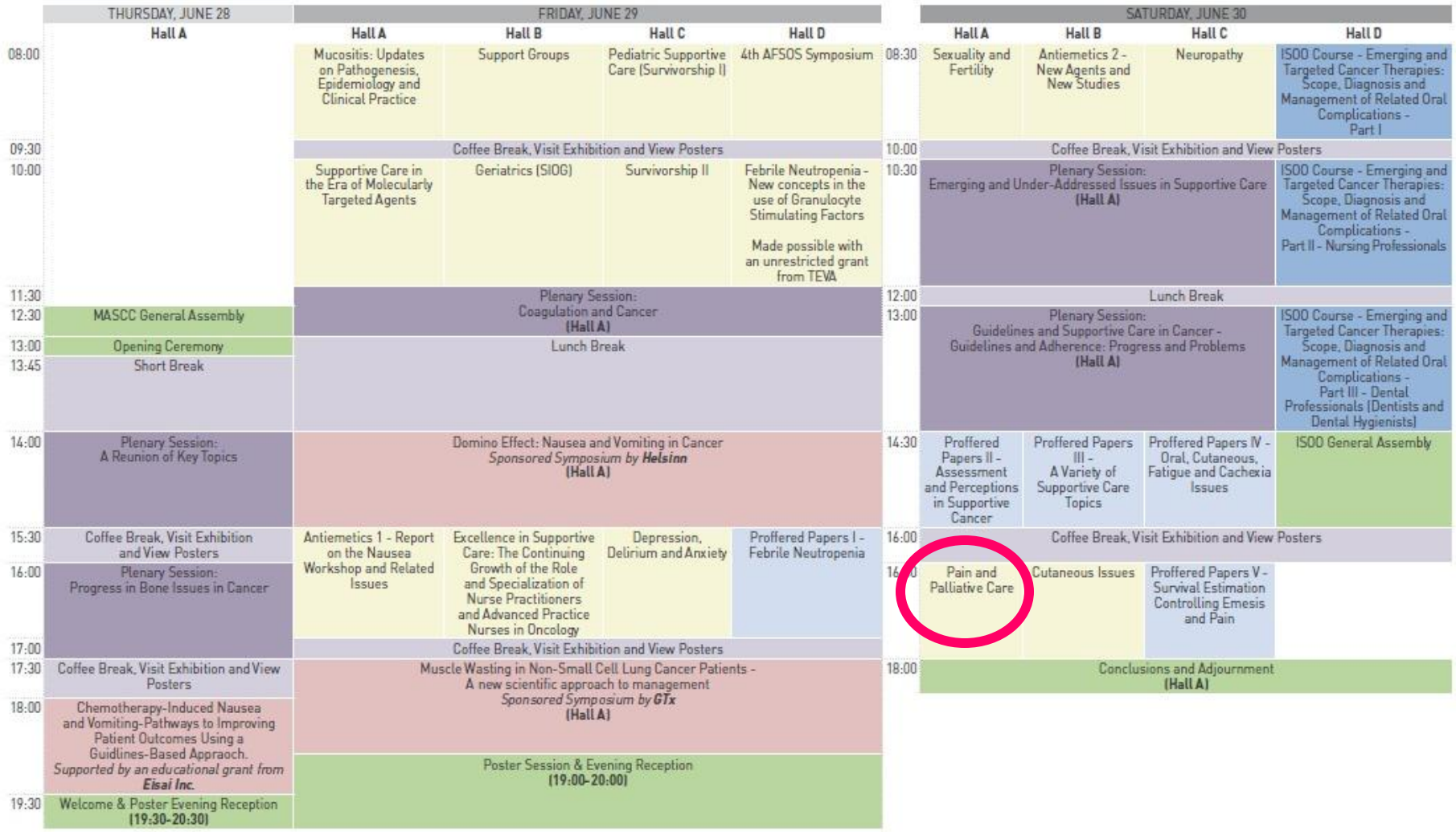
# Centers offering Supportive AND Palliative Care

- Cleveland Clinic
- Milan NCI

# Problems of conflation



# MASCC 12 Program at Glance



| | THURSDAY, JUNE 28 | FRIDAY, JUNE 29 | | | |
|---|---|---|---|---|---|
| | Hall A | Hall A | Hall B | Hall C | Hall D |
| 08:00 | | Mucositis: Updates on Pathogenesis, Epidemiology and Clinical Practice | Support Groups | Pediatric Supportive Care (Survivorship I) | 4th AFSOS Symposium |
| 09:30 | | Coffee Break, Visit Exhibition and View Posters | | | |
| 10:00 | | Supportive Care in the Era of Molecularly Targeted Agents | Geriatrics (SIOG) | Survivorship II | Febrile Neutropenia - New concepts in the use of Granulocyte Stimulating Factors<br><br>Made possible with an unrestricted grant from TEVA |
| 11:30 | | Plenary Session: Coagulation and Cancer (Hall A) | | | |
| 12:30 | MASCC General Assembly | | | | |
| 13:00 | Opening Ceremony | Lunch Break | | | |
| 13:45 | Short Break | | | | |
| 14:00 | Plenary Session: A Reunion of Key Topics | Domino Effect: Nausea and Vomiting in Cancer *Sponsored Symposium by* ***Helsinn*** (Hall A) | | | |
| 15:30 | Coffee Break, Visit Exhibition and View Posters | Antiemetics 1 - Report on the Nausea Workshop and Related Issues | Excellence in Supportive Care: The Continuing Growth of the Role and Specialization of Nurse Practitioners and Advanced Practice Nurses in Oncology | Depression, Delirium and Anxiety | Proffered Papers I - Febrile Neutropenia |
| 16:00 | Plenary Session: Progress in Bone Issues in Cancer | | | | |
| 17:00 | | Coffee Break, Visit Exhibition and View Posters | | | |
| 17:30 | Coffee Break, Visit Exhibition and View Posters | Muscle Wasting in Non-Small Cell Lung Cancer Patients - A new scientific approach to management *Sponsored Symposium by* ***GTx*** (Hall A) | | | |
| 18:00 | Chemotherapy-Induced Nausea and Vomiting-Pathways to Improving Patient Outcomes Using a Guidlines-Based Appraoch. *Supported by an educational grant from* ***Eisai Inc.*** | | | | |
| 19:30 | Welcome & Poster Evening Reception (19:30-20:30) | Poster Session & Evening Reception (19:00-20:00) | | | |

| | SATURDAY, JUNE 30 | | | |
|---|---|---|---|---|
| | Hall A | Hall B | Hall C | Hall D |
| 08:30 | Sexuality and Fertility | Antiemetics 2 - New Agents and New Studies | Neuropathy | ISOO Course - Emerging and Targeted Cancer Therapies: Scope, Diagnosis and Management of Related Oral Complications - Part I |
| 10:00 | Coffee Break, Visit Exhibition and View Posters | | | |
| 10:30 | Plenary Session: Emerging and Under-Addressed Issues in Supportive Care (Hall A) | | | ISOO Course - Emerging and Targeted Cancer Therapies: Scope, Diagnosis and Management of Related Oral Complications - Part II - Nursing Professionals |
| 12:00 | Lunch Break | | | |
| 13:00 | Plenary Session: Guidelines and Supportive Care in Cancer - Guidelines and Adherence: Progress and Problems (Hall A) | | | ISOO Course - Emerging and Targeted Cancer Therapies: Scope, Diagnosis and Management of Related Oral Complications - Part III - Dental Professionals (Dentists and Dental Hygienists) |
| 14:30 | Proffered Papers II - Assessment and Perceptions in Supportive Cancer | Proffered Papers III - A Variety of Supportive Care Topics | Proffered Papers IV - Oral, Cutaneous, Fatigue and Cachexia Issues | ISOO General Assembly |
| 16:00 | Coffee Break, Visit Exhibition and View Posters | | | |
| 16:30 | Pain and Palliative Care | Cutaneous Issues | Proffered Papers V - Survival Estimation Controlling Emesis and Pain | |
| 18:00 | Conclusions and Adjournment (Hall A) | | | |

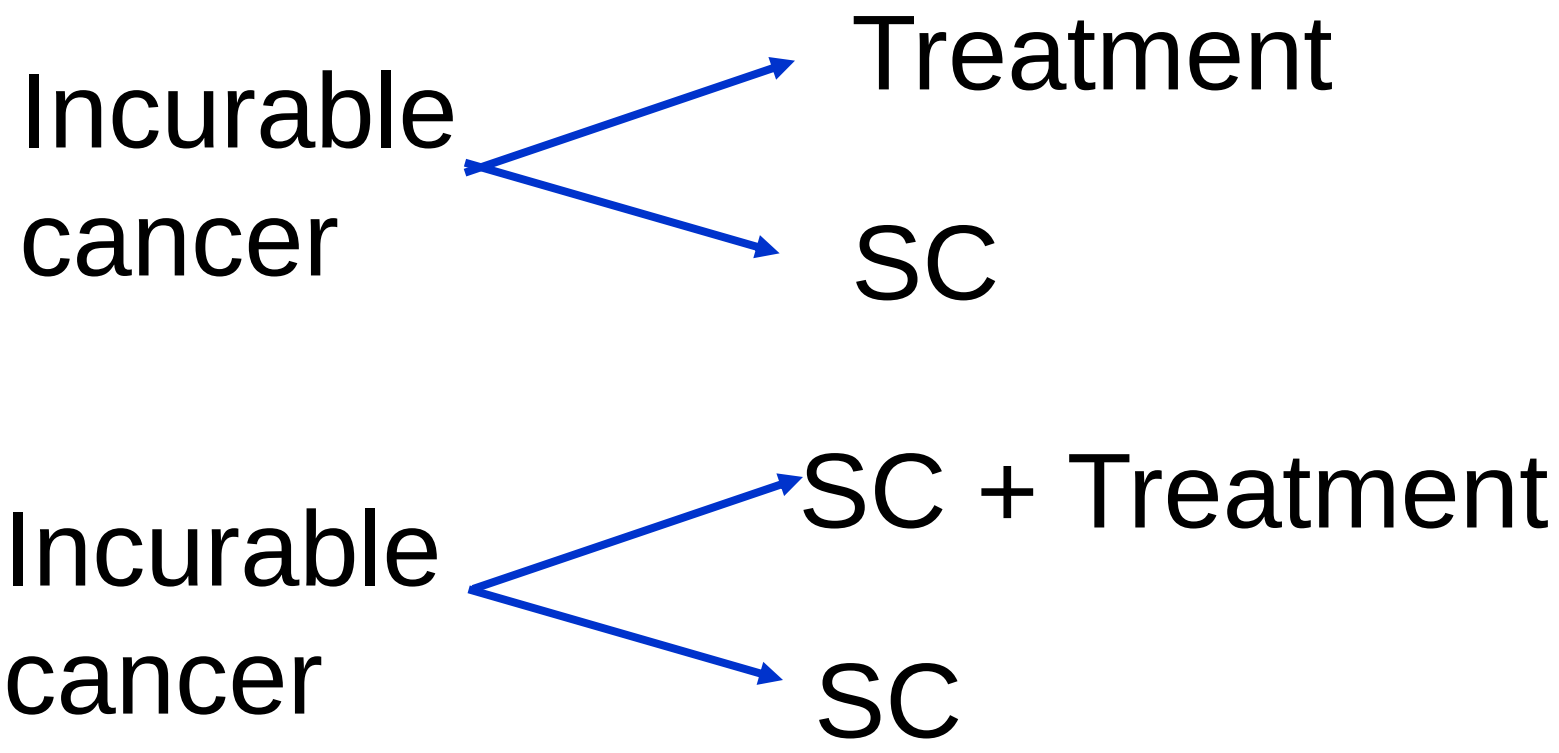
# EAPC Research Meeting 2012

| Time | Olavshallen<br>*1204 seats* | Olav Tryggvasson<br>*325 seats* | Haraldsalen<br>*140 seats* | Tavern/ Brattøra<br>*210 seats* | Lillesalen<br>*350 seats* | Cicignon/ Sverresborg |
|---|---|---|---|---|---|---|
| **0800-0845** | | Meet the experts: *Opioid addiction (10)* | Meet the experts: *How to read and write papers (11)* | Meet the experts: *Palliative care indicators (12)* | Meet the experts: *Polypharmacy (13)* | Poster viewing |
| **0900-1030** | **Plenary II (14)** | | | | | |
| **1030-1100** | | *Coffee break and poster viewing* | | | | |
| **1100-1230** | | *FC: Symptoms other than pain I (15)* | Poster discussion session I (16) | *FC: End of life care I (17)* | TS: *Research in action (18)* | |
| **1230-1300** | | *Lunch and poster viewing* | | | | |
| **1300-1400** | | Satellite symposium: ProStrakan | *Lunch and poster viewing* | | | |
| **1400-1430** | | *Lunch and poster viewing* | | | | |
| **1430-1600** | | *FC: Symptoms other than pain II (19)* | *FC: Research methodology I (20)* | TS: *Palliative sedation (21)* | *FC: Assessment I (22)* | |
| **1600-1630** | | *Coffee break and poster viewing* | | | | |
| **1630-1800** | | TS: *Cognitive impairment (23)* | | *FC: Health care services II (24)* | *FC: Pain II (25)* | |

# Best Supportive Care (BSC) studies

- Since the mid 1980s
- Dominant research paradigm for RCT of new treatments for diseases hitherto unresponsive to treatment when the current standard of care is the provision of PC.
- Euphemism for treatment vs. no treatment studies

# 2 Designs BSC studies



JOURNAL OF CLINICAL ONCOLOGY SPECIAL ARTICLE

# Improving the Methodological and Ethical Validity of Best Supportive Care Studies in Oncology: Lessons From a Systematic Review

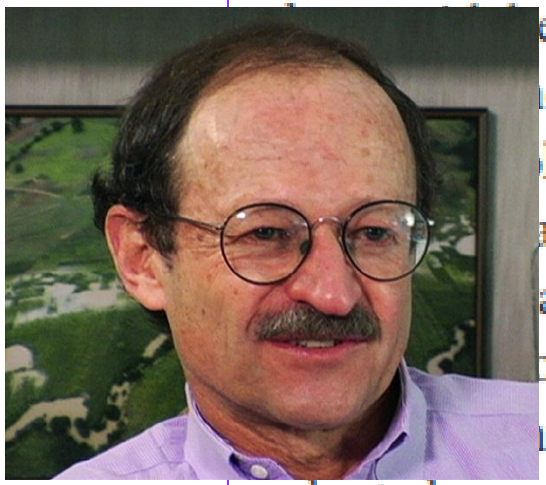
- Systematic review 43 BSC studies published between 1966-2008
- researchers failed to review the contemporaneous standards for supportive care no recognized practice standards for the supportive care elements of the studies were invoked.
- Not compliant with Helsinki Declarations.
  - Studies not predicated on a “thorough knowledge of the scientific literature”
  - control arm of randomized studies; From 1975-2008 the requirement was for a “best current care” standard and since 2008, “best current proven care”
- Methodologically unsound
  - Noncompliant with multiple CONSORT requirements for complex on pharmacological studies
  - High likelihood of bias

# 7 Universal Criteria for Ethics in Human Studies

Emanuel EJ, Wendler D, Grady C. What makes clinical research ethical? JAMA. 2000 May 24-31;283(20):2701-11.

| | Criteria | Evaluation |
|---|---|---|
| 1 | **Social Value** | Will this research derive knowledge or promote ends that will improve health, well being. |
| 2 | **Scientific Validity** | Does the research apply valid methodology to generate reliable valuable data |
| 3 | Fair subject selection | No targeting of vulnerable for risky research or favor for potentially beneficial research |
| 4 | **Favorable risk benefit ratio** | Minimization of risks, enhancement of potential benefits |
| 5 | Independent review | By appropriately staffed IRB |
| 6 | Informed Consent | Informing participants of risk benefit and alternatives. Voluntary decision |
| 7 | **Respect for potential and enrolled participants** | Permitting withdrawal, confidentiality, informing subjects of discovered benefits or risks, maintaining the welfare of participants |

The converse of social value is social harm. Although we acknowledge the value of research that has proven or disproven the merit of various anticancer therapies, we believe that the lack of standards applied to the SC delivery of this body of research may have, simultaneously, contributed to social harm by modeling ad hoc care as an acceptable standard of practice. Rather than conveying the message that palliative and supportive care should be administered in accor-



*"Experience shows that high quality health care and research go hand-in-hand. Organizations that conduct research are generally viewed as providing the best care."*

Testimony to Senate Subcommittee on Public Health and Safety on "The Value of Clinical Research" 1997

est practice standards, this body of research implies that e care, bereft of any recognized standards, is a reasonable le standard of practice. As emphasized by Harold Varal practitioners look to the medical research community andards of best contemporaneous practice. If Varmus is ble modeling provided by these studies may be one of the y cancer clinicians and treatment centers have not adopted recognized standards of practice for their routine administration of SC.[19,98-100] The ad hoc SC modeled in most of these studies neglects important evidence that adherence to standards of SC can reduce patient and family suffering[80,81,86,101-106] and is contrary to the efforts of the American Society of Clinical Oncology (ASCO)[107-109] and the European Society for Medical Oncology (ESMO)[110] to promote professional rigor to the delivery of this aspect of care. The

# Routine “supportive care” in oncology practice

Often involves:

1. inadequate evaluation of pain
2. failure to appreciate the presence and/or severity of symptoms
3. lack of consultation with experts in pain or palliative care
4. sub-standard pain treatment
5. poor symptom control
6. lack of attention to psychological or existential distress
7. lack of attention to family support

Zafar SY et al Consensus-based standards for best supportive care in clinical trials in advanced cancer. The lancet oncology. 2012;13(2):e77-82.

Cherny N. Best supportive care: a euphemism for no care or a standard of good care? Semin Oncol. 2011;38(3):351-7.

Cherny NI et al Improving the methodologic and ethical validity of best supportive care studies in oncology: lessons from a systematic review. J Clin Oncol. 2009;27(32):5476-86.

# Case for recognition of separate but related entities

- Share
  - Emphasis on humanism and quality of life
- Different
  - Focus
  - Primary target population
  - Academic priorities
- Overlap issues
- Independently important

# Supportive Care

- Defined
  - elements of care that facilitate safe and effective anti-cancer care, minimizing toxicity and optimize physical, psychological and social function of patients undergoing disease management strategies.
- Goals
  - Optimizing chances of cure/disease control
  - Optimizing treatment and post treatment quality of life
- Focus
  - All patients undergoing disease management strategies.
  - Major focus
    - side effect prevention and management
    - facilitation of effective treatment
    - prevention and management disease related symptoms at all stages
  - Strong focus
    - on optimizing physical, psychological and social function
    - prevention, optimization and rehabilitation
    - post treatment survivor issues

# Palliative care

- Defined
  - elements of care that optimize the comfort, function and social support of the patient and their family when cure is not possible.

- Focus
  - Patients with incurable illness
  - Major focus of care
    - prevention and  relief of distress caused by incurable illness.
    - The context of incurability, with all of its implications for the patent and family, that grounds palliative care as a special entity.
  - "End of life care" or "terminal care"
    - PC when death is imminent. End-of-life care
    - acknowledges that the intensity of physical, psychological, existential, spiritual and family issues may be magnified by the patient's approaching death.

# Patients undergoing treatment with curative intent

- Goals
  - Optimizing chances of cure
  - Optimizing treatment and post treatment quality of life
- Supportive care including
  - SC to help patients get through treatments as well and as effectively, safely and comfortably as possible
  - Management of physical and psychological and spiritual issues
  - Survivorship issues

# Patients with incurable cancer

- Goals
  - Often complex and changing
  - Changing focus: survival, function , comfort
- Needs
  - Goal flexibility
  - SC to help patients get through treatments as well and as effectively, safely and comfortably as possible
  - PC to focus on the of physical, psychological, existential, spiritual and family consequences of the cancer, both during the period patients receive disease modifying treatments and until the end of life.

# Conclusions

- Both PC and SC are vital elements of quality cancer care
- Conflation often has negative effect of de-emphasis of one or the other
- Both need emphasis and prioritization in
  - practice
  - training
  - research
  - publications
  - professional meetings