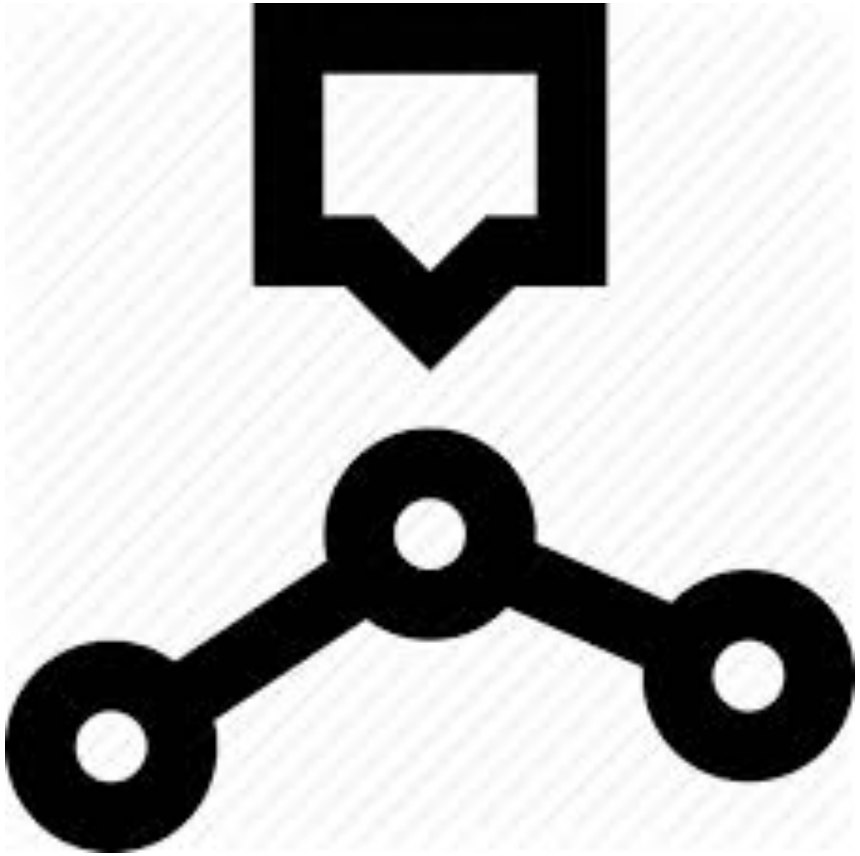


What Do We Mean by Palliative Care?

Mellar P Davis MD FCCP FAAHPM

Conflict of Interest

- I have no conflict of interest

Historical

Alfred Worcester 1934

- “ It matters much that we give ourselves with our pills”.
- Continuity and patient centeredness.

Cicely Saunders

- Total pain-1964
- Continuity-”caring for, being with and listening to” dying patient.
- Validated the experience of pain and suffering as worthy of qualitative study (1,100 patient ethnographic records) and quantitative study (diamorphine vs morphine).
- Interdisciplinary.
- Connecting physical, psychosocial and spiritual pain- “all of me is wrong”.
- Not disease centered nor age-limited.

Cicely Saunders

- ”the role of the physician is to stay with the dying patient in care” and to “relieve what cannot be healed”- palliative.
- Interdisciplinary team-”the doctor remains at the center of the interdisciplinary team”.
- The purpose-”to keep the patient’s struggles within his / her compass”- psychosocial, spiritual care.
- Goals-”to bring hope and consolation to the end”- quality of life.

Saunders C 1958

Palliative Care

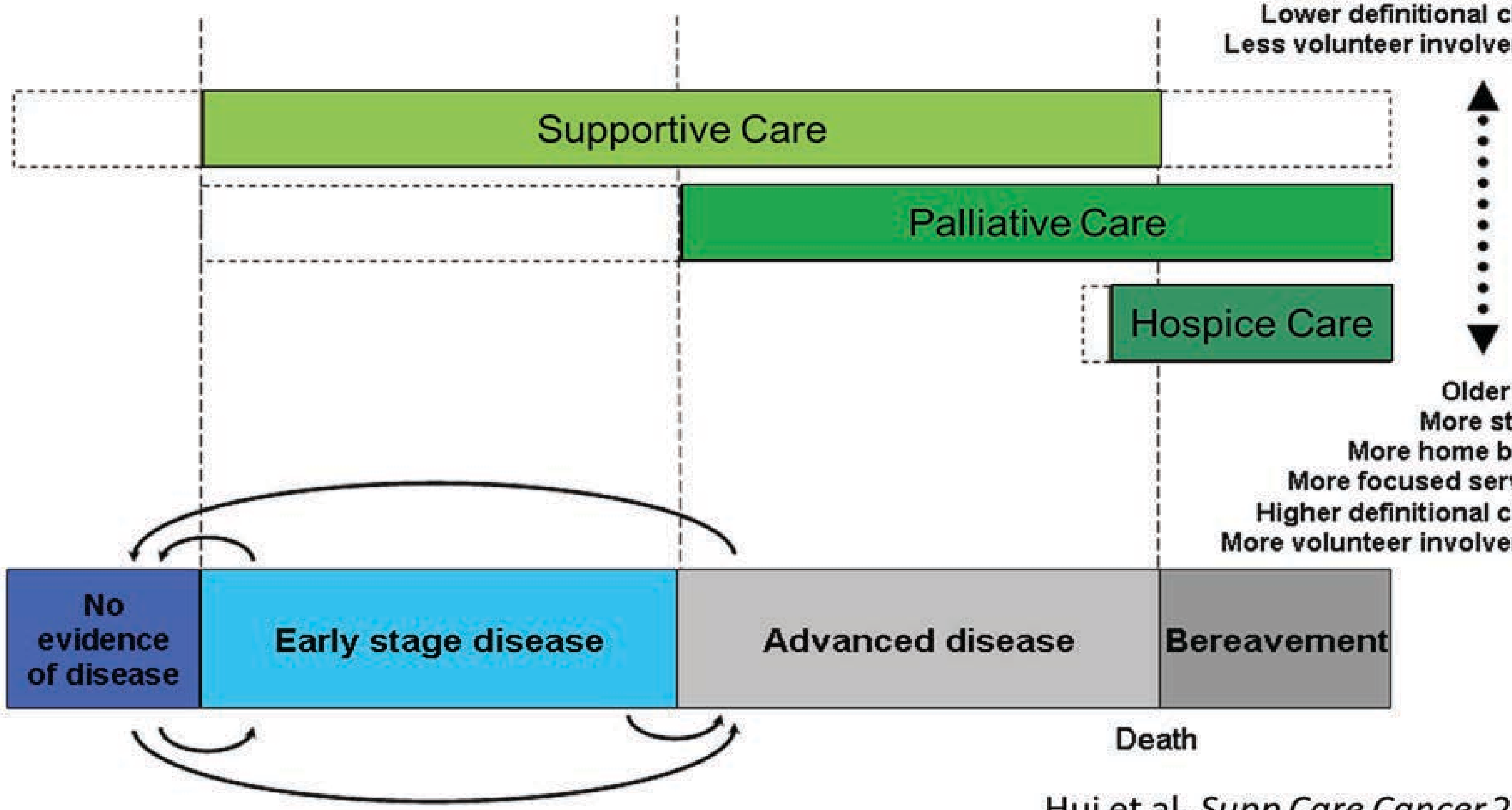
- 1976- hospital support teams for the terminally ill pioneered in the UK at St Thomas Hospital, London and Royal Victoria Hospital, Quebec ,Canada.
- Balfour Mount-“to die in most hospitals is still to experience isolation, inadequate treatment, and skills. Everywhere”.

Where are we now?

Supportive vs. Palliative Care

A Systematic Review

Newer term
Less stigma
More hospital based
Wider range of services
Lower definitional clarity
Less volunteer involvement



Supportive Care

Palliative Care

Hospice Care

No evidence of disease

Early stage disease

Advanced disease

Bereavement

Death

Older term
More stigma
More home based
More focused services
Higher definitional clarity
More volunteer involvement

Hui et al. *Supp Care Cancer* 2012

Common Elements in Definitions

- Quality of life and symptom management- though formal quality of life is measured in a minority of studies and is often substituted with symptom burden.
- Interdisciplinary structure remains but is a bit less hierarchical than defined by Cicely Saunders.

Hui D
2013

ASCO Statement

- “unanimous consensus regarding the need for…. definitions of palliative cancer care”.

Ferris F 2009

Differences

- Definitions of what is “early” and “late”
- Euphemistic terms are often attached to definitions (continued care, comfort care, supportive care).
- Palliative care is not formally defined in many research studies and not infrequently involves interventions from a single discipline.
- Differences in comprehensiveness- consulting services alone vs inpatient, outpatient, community, hospice and primary care.
- The largest evolution in the definition is the change in timeframe within disease course.
- Regional differences- by country and within country.
- Population differences- cancer only vs multiple chronic progressive illnesses.

Conceptualizations of Palliative Care

- Philosophy of care- patient centeredness, experience or “illness” centered
- Approach to care-palliative vs curative or disease modifying
- Program
- Service structure - limited or comprehensive
- Specialty- palliative medicine

Main Points of Contention in Definitions

- “The basic problems with palliative care are “whom” and “ when”.
- Clearly no study has addressed the best timing of palliative care in the management of heart failure, COPD, stroke, ALS.
- Timing needs to be based on best outcomes and cost effectiveness.
- In cancer care, only a few trials such as the Temel trial have demonstrated outcomes to timing of palliative referral.

Pastrana T

2008

Definitions in Chronology

Definitions

“ Language not only transmits meaning but constitutes what we do and how we do it”.

“The greatest confusion associated with palliative care is not the need for palliation but the timing in the spectrum of the illness”.

“ No sooner is a new service started anywhere in the world or a new professional palliative association formed, then people sit down and write a new definition”.

“Palliative care is extensively and variously described but the palliative care patient is not”.

There are 37 different definitions in the literature.

Pastrana T 2008

Doyle D 1993

van Mechelen 2012

UK Definition 1993

- Palliative Medicine is “ the study and management of patients with **active, progressive, far-advanced disease for whom the prognosis is limited** and the focus of care is on quality of life”.

Doyle, D 1993

Belgian Federal Knowledge Center

“Palliative care patients are patients suffering from **incurable, progressive, life-threatening disease with no possibility of obtaining a remission or stabilizing or restraining the illness**”.

WHO Definition (Old)

- “The active, total care of patients whose **disease is not responsive to curative treatment**. Control of pain, other symptoms and psychological and social and spiritual problems are paramount”.

WHO Definition (Recent)

- "An approach that improves quality of life of patients and families facing problems with **life-threatening illness** through the prevention and relief of suffering through assessment and treatment of pain and physical, psychosocial and spiritual…"

Centers for Disease Control

- Palliative care “ is a general term that includes treatment given to relieve pain and control symptoms when there is no reasonable expectation of cure. Individuals with **advanced chronic illnesses** or **life-threatening conditions** often benefit from palliative care”.

IAHPC

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life.

It aims to improve the quality of life of patients, their families and their caregivers.

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

Center for Advancement of Palliative Care

Center to
Advance
Palliative Care™
capc

“ Palliative care is specialized health care for patients living with **serious illness**. The care is focused on providing relief from symptoms and stress from **serious illness**”.

aahpm

AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

AAHPM

“ Palliative care starts **concurrently with life-prolonging care**”.

Consequences of Different Definitions , Timeframes and Structure

- There is a lack of generalizability of palliative randomized trials.
- Repetition of trials in independent settings to confirm results will require the same service structure, patient population, and stage of disease.
- Cost-effectiveness is timeframe and population dependent which is a moving target depending on referral.
- In 56% of RCT the stage of illness prognosis is not mentioned and in 49% of RCT patients with non-life threatening chronic illnesses were included.
- The problem with the Liverpool Pathway was not the pathway but the patient population in whom non-palliative care physicians were applying the pathway.

Keirse E 2009

Potential Populations Based on Definition

- Addiction- serious, chronic, symptomatic illness which can be life-threatening
- Cancer survivors- serious symptomatic illness with reduced quality of life, risks of second malignancies which can be life-limiting
- Chronic pain-symptomatic serious illness with reduced function
- Sickle cell disease- chronic, symptomatic, life threatening at times and life-limiting
- Fibromyalgia- painful, chronic illness with reduced quality of life
- Asthma- serious, life-threatening in a subset, symptomatic
- Inflammatory bowel disease-symptomatic, painful and serious

So what is MASCC definition of Palliative Care?

Summary

- There are common components to the definition of palliative care- symptom , management, quality of life and interdisciplinary.
- There has been a migration “ upstream” in defining populations and stage of illness which has confused referring physicians as to what we do and has impaired the generalization of clinical trial results.
- Palliative care has been seen as a philosophy of care which should inform all physicians, a program, service structure and specialty.
- Too often euphemisms have crept into definitions which can be interpreted in widely different ways.
- There is a great need to have a universal transparent workable definition of the field.