بسم الله الرحمن الرحیم

Supportive & palliative care

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WHO Definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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 physical, psychosocial and spiritual problems

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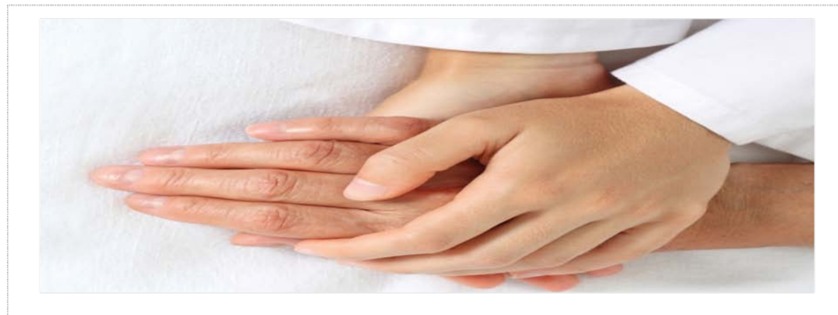

history

- The origins of palliative care go back centuries
- Looking back, it is easy to see a chain of events that led logically, indeed inexorably, to World Health Assembly Resolution 67.19

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- Palliative care is now recognized as a core public health issue.
- The need for palliative care is escalating, with rising numbers of deaths annually across the globe, population aging and changes in chronic diseases and multimorbidity.
- Estimates of growth in palliative care need range from 40% to 87% between now and 2060.
- Although palliative care is now recognized as a core human right, and should be part of universal health care (with a World Health Assembly declaration in 2014), there are still inequities in access.
- Inequities in access to palliative care in particular affect groups, such as those with socioeconomic disadvantage, non-cancer diagnosis, elderly, cultural minorities, those with lower education, homelessness, and those who are lesbian, gay, bisexual, or transgender.
- There is good evidence that palliative care is effective, cost-effective, and adds value (costs/ outcomes), but new models may need to evolve to respond to the populations of the future

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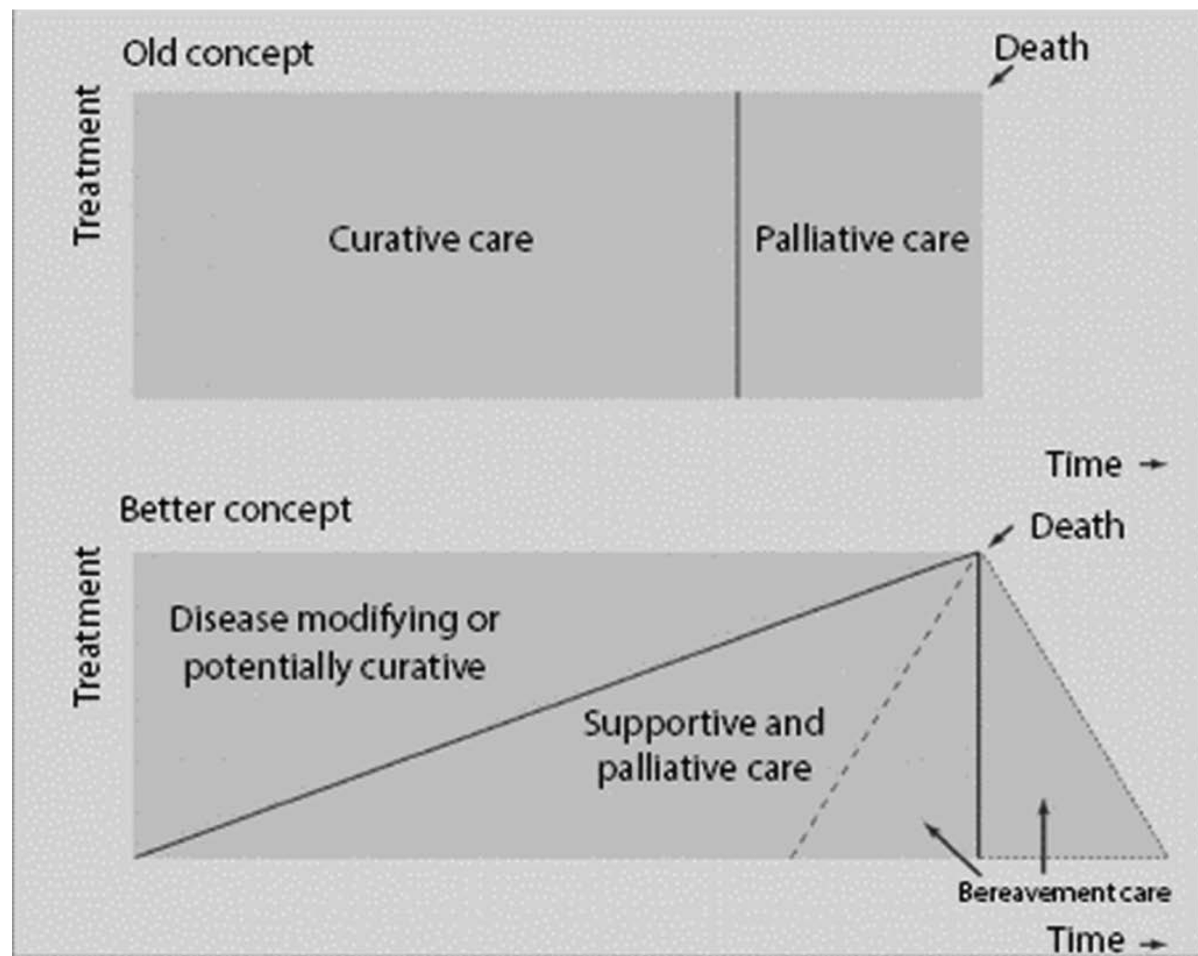

Old concept
Death
Treatment
Curative care
Palliative care
Time
Better concept
Death
Treatment
Disease modifying or
potentially curative
Supportive and
palliative care
Bereavement care
Time

Death

Terminal care

Palliative Care

Supportive Care

No evidence of disease

Early-Stage disease

Advanced Disease

Bereavement

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Palliative care programs developed with three main characteristics

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1) Multidimensional assessment and management of severe physical and emotional distress

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Patients with Advanced Illness

Advanced age
Comorbidities

COGNITIVE IMPAIRMENT
DELIRIUM

EMOTIONAL DISTRESS
Anxiety
Depression

SPIRITUAL DISTRESS

FAMILY/ CAREGIVER DISTRESS

SOCIO-CULTURAL ISSUES
FINANCIAL DISTRESS

DYSPNEA

CONSTIPATION
BOWEL OBSTRUCTION
ASCITIS

NAUSEA AND VOMITING

FATIGUE
CACHEXIA
Lymphedema

PAIN
somatic
Neuropathic

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Symptom assessment is very important because symptoms directly affect patients’ distress level, quality of life (QOL), and survival. Symptoms can be related to the disease itself, its treatment, and comorbid illnesses. Multiple physical, psychological, and spiritually distressing factors affect QOL, a multidimensional construct with specific emotional, physical, and social aspects.

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Table 2.1 Multidimensional Assessments of Patients with Advanced Illness Evaluated by Supportive/Palliative Care Teams

Dimension	Assessment
a. History	Stage of the cancer/illness Recent chemotherapy and/or radiotherapy or other disease-modifying therapy Self-rated symptoms scales Characteristics, intensity, location, aggravating factors of distressful symptoms
b. Performance status History of falls Use of assistant walking devices	Karnofsky Performance Scale or Eastern Co-operative Oncologic Group Scale scores
c. Activities of daily living (ADL) and instrumental activities of daily living (IADL)	Assessment of ADL (bathing, dressing and undressing, eating, transferring from bed to chair, and back, voluntarily control urinary and fecal discharge, using the toilet, and walking) Assessment of IADL (light housework, preparing meals, taking medications, shopping for groceries or clothes, using the telephone, and managing money)

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d. Assessment of distressful physical symptoms (pain, fatigue, anorexia, nausea, dyspnea, insomnia, drowsiness, constipation)	Edmonton Symptom Assessment System (ESAS) Abdominal X-ray to assess constipation vs. bowel obstruction (consider abdominal CT scan)
e. Assessment of psychosocial symptoms: anxiety/depression f. Family/caregiver's distress g. Cultural and financial status	Anxiety/depression (ESAS) Identification of mood disorder during interview Assessment for family/caregiver distress during the interview Sociocultural and financial issues evaluation
h. Assessment of delirium	Memorial Delirium Assessment Scale (MDAS) Mini-Mental State Examination (MMSE) Confusion Assessment Method (CAM)
i. Assessment of spiritual distress/spiritual pain of the patient and caregiver	Spiritual Assessment SPIRITual History; FICA Self-rated spiritual pain (pain deep in the soul/being that is not physical) Identification of spiritual distress during interview.
j. Assessment for chemical coping	CAGE questionnaire
k. Evaluation of medications and possible interactions (polypharmacy)	
l. Physical examination	

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Edmonton Symptom Assessment System:
(revised version) (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 Appetite
No Shortness of Breath	0	1	**2**	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
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 ___________

Patient's Name ______________________

Date ______________ Time ______________

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

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FICA Tool for Spiritual Assessment

FICA Tool

	Questions
F—Faith, belief, meaning	Do you consider yourself spiritual or religious?
	Do you have spiritual beliefs that help you cope with stress?
	What gives your life meaning
I—Importance and influence	What importance does your faith or belief have in your life?
	On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life?
	Have your beliefs influenced you in how you handle stress?
	What role do your beliefs plan in your health-care decision-making?
C—Community	Are you a part of a spiritual or religious community?
	Is this of support to you and how?
	Is there a group of people you really love or who are important to you?
A—Address in care	How would you like your health-care provider to use this information about your spirituality as they care for you?

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2) Emphasis on caring not only for the patients but also for their families

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3) Interdisciplinary care by multiple disciplines in addition to physicians and nurses

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Main medical and nonmedical disciplines that influenced the body of knowledge in palliative medicine.

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Palliative Medicine

Social Worker

Palliative nursing

Couselor

Patient and Family

Pastoral care

OT

Dietician

Physio-therapist

Pharmacist

Volunteer

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BOX 8.1 EUROPEAN ASSOCIATION FOR PALLIATIVE CARE AGREED LEVELS OF PALLIATIVE CARE KNOWLEDGE (FROM REFERENCE [4] WITH PERMISSION)

***PALLIATIVE CARE APPROACH**

A way to integrate palliative care methods and procedures in settings not specialized in palliative care. Should be made available to general practitioners and staff in general hospitals, as well as to nursing services and nursing home staff. May be taught through undergraduate learning or through continuing professional development.

***GENERAL PALLIATIVE CARE**

Provided by primary care professionals and specialists treating patients with life-threatening diseases who have good basic palliative care skills and knowledge. Should be made available to professionals who are involved more frequently in palliative care, such as oncologists or geriatric specliats, but do not provide palliative care as the main focus of their work. Depending on discipline, may be taught at an undergraduate or postgraduate level or through continuing professional development.

***SPECIALIST PALLIATIVE CARE**

Provided in services whose main activity is the provision of palliative care. These services generally care for patients with complex and difficult needs and therefore reuquire a higher level of education, staff, and other resources. Specialist palliative care is provided by specialized services for patients with complex problems not adequately covered by other treatment options. Usually taught at a postgraduate level and reduced through continuing professional development.

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- There is great potential for palliative care to be delivered in the community, by primary care doctors and community nurses.
- Primary care teams can reach many more people with palliative care needs than can specialists and also earlier in the course of the illness.
- Palliative care specialists should prioritize delivering training, advice, and support for hospital and community generalists.
- Primary care is well placed to provide high-quality palliative care for patients:
  - ✓ With all life-limiting conditions
  - ✓ From early in the course of the illness
  - ✓ With all dimensions of need
  - ✓ In care homes and at home
  - ✓ In all countries, including lower income settings
  - ✓ And to support family caregivers

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Places Of Care

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Hospice House

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Supportive and palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- 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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Conclusion

Caring for patients with advanced illnesses involves relieving distressing physical, psychosocial, and spiritual problems and empowering patients and their families to retain control while balancing the benefits and risks of treatments.

Recognizing these patients' distressing symptoms as multidimensional complexes and using appropriate and validated assessment tools help physicians manage these symptoms to improve patients' QOL and decrease caregiver burden.

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CONCEPTUAL MODEL OF PALLIATIVE CARE DEVELOPMENT

با تشکر از توجه شما

دکتر پونه پیرجانی

پالیتیویست

مدیر مراقبتهای حمایتی و تسکینی مکسا

بیمارستان شریعتی تهران

عضو کارگروه مراقبتهای حمایتی و تسکینی معاونت درمان وزارت بهداشت، درمان و آموزش پزشکی

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