Palliative Care Basics and beyond

Session objectives

- Understand the principles of palliative care
- Introduction with the definition of good death
- Improve the general knowledge of symptom management strategies in palliative care
- Recognize our current stance in provision of palliative care services

(66)

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

-Cicely Saunders

WHO definition of palliative care:

"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 focuses on "caring" for the patient and family, not on "curing" the patient
- Can be valuable for any age and any stage of a serious, life-limiting illness
- Provides symptom relief and support to help patients function as well as possible
- Is used in hospitals, other community settings, or homes

- Which one of the following terms better define palliative care?
 - Comfort care
 - Supportive care
 - End-of-life care

- Comfort care: Enhance the quality of life for patients and their families
- **Supportive care:** Relieving the symptoms in order to improve the quality of life
- End-of-life care



Who Provides Palliative Care?

Nurse

Nursing Assistant

Physician

Social Worker

Psychiatrist/Psychologist

Dietitian

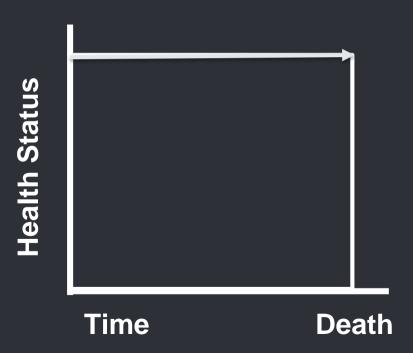
Chaplain

Physical/Occupational Therapist

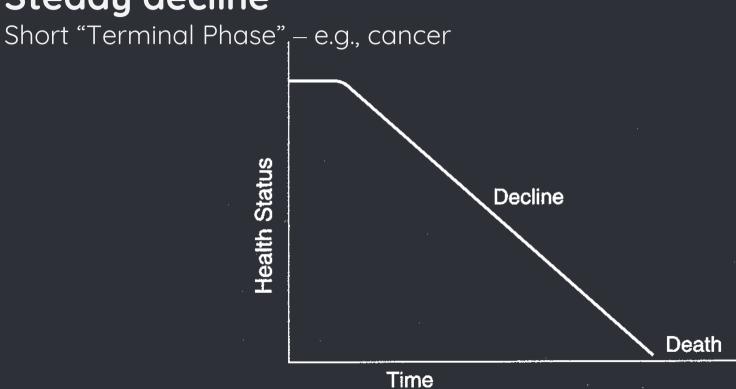
A good death is "one that is **free from** avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."

Sudden death, unexpected cause

MI, accident, etc. (< 10%)



Steady decline



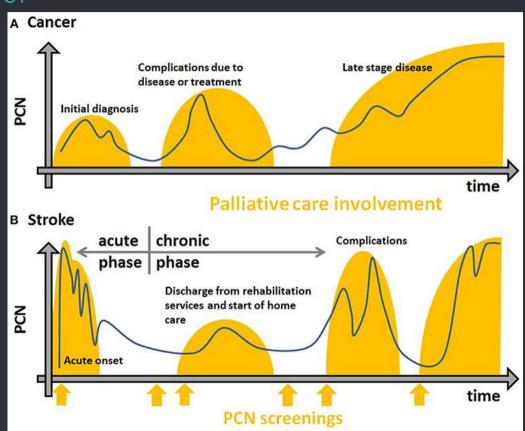
Slow decline

Periodic crises, sudden death – e.g., frailty, organ failure

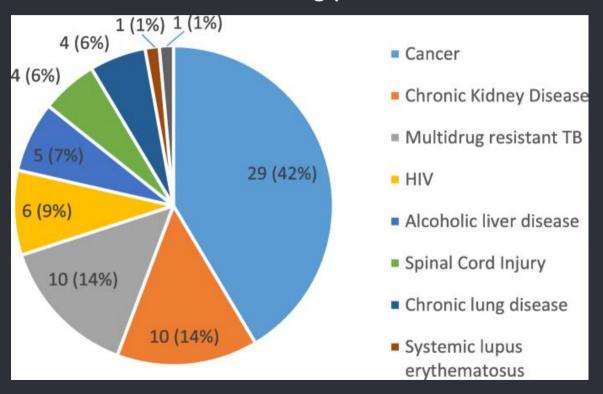


Exemplary trajectories of chronic diseases (A), e.g., cancer, heart failure, motoneuron disease, Parkinson's disease and acute diseases (B), e.g., stroke in terms of PCN (y-axis) over time (x-axis).

The blue lines are possible courses of SB over time. Orange orbs show PC involvement. Initiation in a timely fashion to achieve best results is based on regular standardized screenings for PCN (orange arrows).

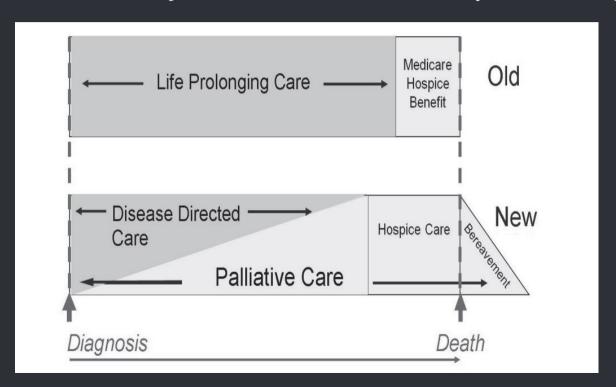


Palliative care needs among patients with advanced illnesses

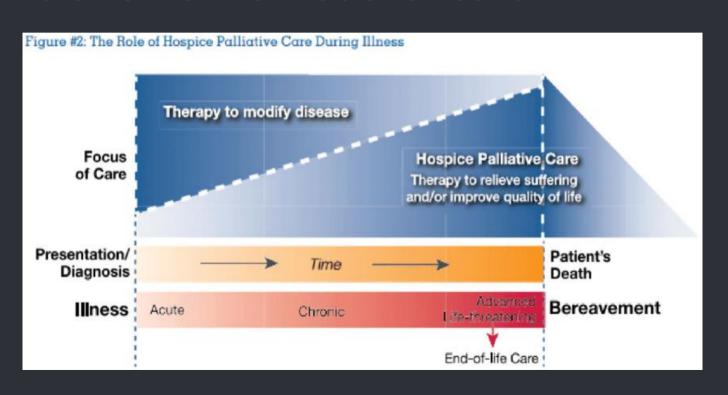


Laabar, T.D., Saunders, C., Auret, K. et al. Palliative care needs among patients with advanced illnesses in Bhutan. BMC Palliat Care **20**, 8 (2021). https://doi.org/10.1186/s129 04-020-00697-9

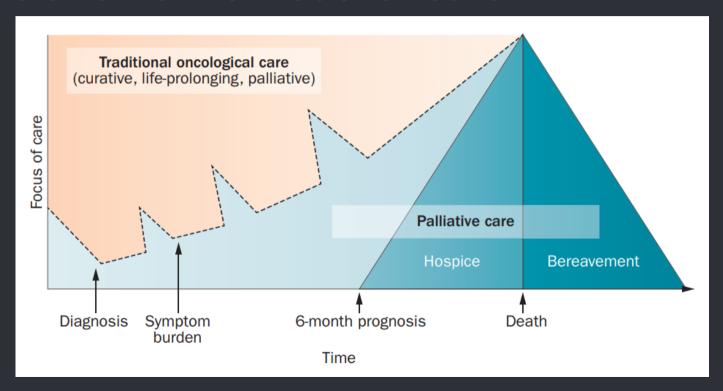
Historical trajectories of care pathways



The alternative model of care



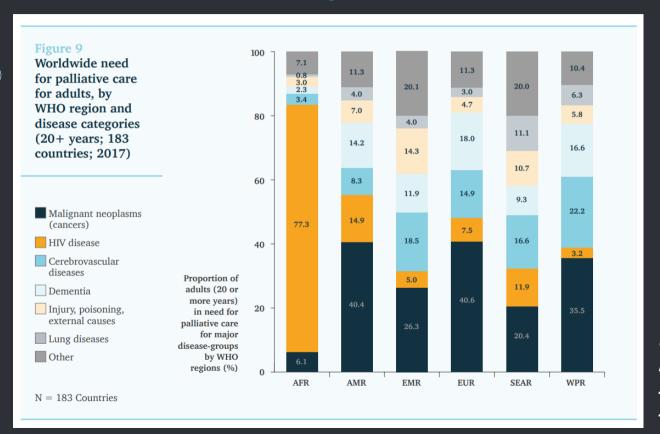
The alternative model of care



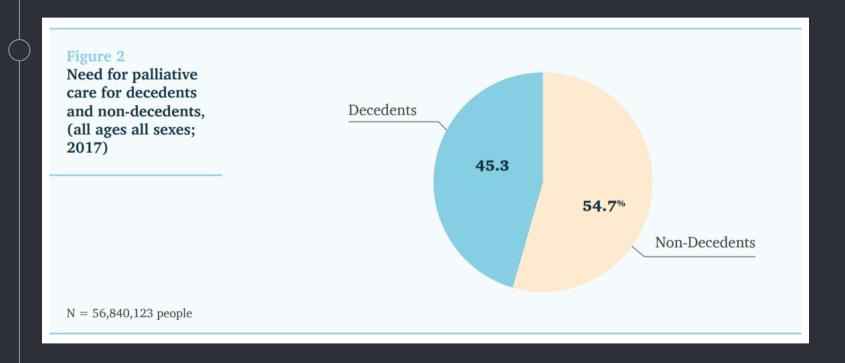
4 Where do we stand in PC provision?

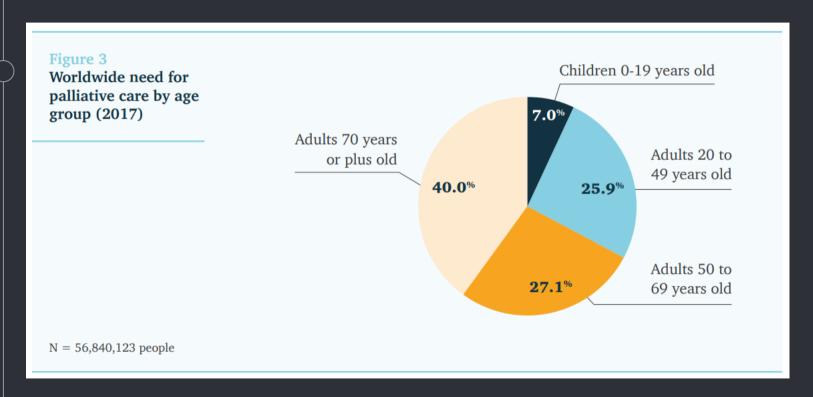
- Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care.
- Worldwide, only about 14% of people who need palliative care currently receive it.

WHO Fact sheet on palliative care, 2021



Global Atlas of Palliative Care, 2nd Edition, 2020





WHAT ARE THE GAPS?



86%

of people who need palliative care do not receive it



83%

of the world's population lack access to pain relief



98%

of children needing palliative care live in low and middle income countries

WHO Fact sheet on palliative care, 2019

WHAT ARE THE BARRIERS? Poor public awareness of how palliative care can help Cultural & social barriers, such as beliefs about pain and dying Cultural & social barriers and dying

WHO Fact sheet on palliative care, 2019

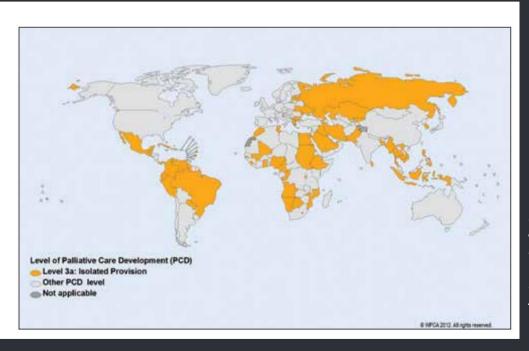
Barriers to address the unmet need for palliative care:

- Exclusion of palliative care form national health policies and systems
- Limited or non-existent training on palliative care for health professionals
- Inadequate access to opioid pain relief and fail to meet international conventions on access to essential medicines

Levels of palliative care development

Group 1) No known hospice-palliative care activity Group 2) Capacity building activity **Group 3a)** Isolated palliative care provision Group 3b) Generalized palliative care provision Group 4a) Preliminary integration of hospice-palliative care services into mainstream service provision **Group 4b)** Advanced integration of hospice-palliative care services into mainstream service provision

Figure 33
Countries with isolated provision of palliative care (Level 3a)



Global Atlas of Palliative Care at the End of Life, Worldwide Palliative Care Alliance (WPCA), WHO, 2010

Figure 37 Levels of palliative care development – all countries

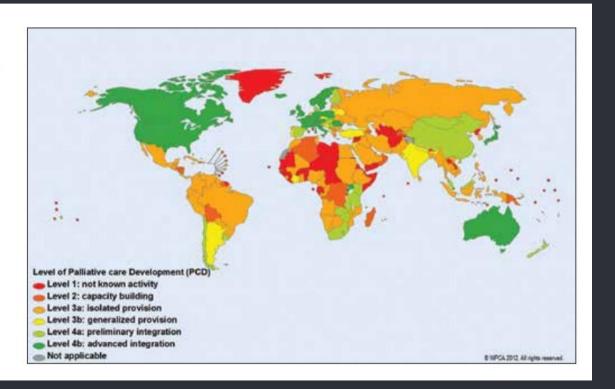
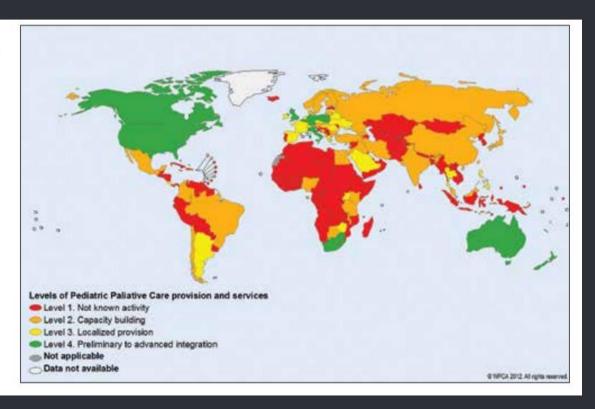


Table 2Changes in palliative care direction by country 2006–2011

Group	Changes in polliative care direction COUNTRY 2006, 2011 (±/)
Group	Changes in palliative care direction COUNTRY 2006–2011 (+/-)
Group 1	UZBEKISTAN (- from category 2)
Group 2	MONTENEGRO (+ from category 1)/ALAND ISLANDS (- from category 3)
	AZERBAIJAN (- from category 3) HONDURAS (- from category 3)
Group 3a	ANGOLA (+ from category 1) BAHRAIN (+ from category 2) BELIZE (+ from category 2) BRUNEI (+ from category 2) ETHIOPIA (+ from category 2) GHANA (+ from category 2) IRAN (+ from category 2) KUWAIT (+ from category 2) LEBANON (+ from category 2) LESOTHO (+ from category 2) MALI (+ from category 1) MOZAMBIQUE (+ from category 2) NAMIBIA (+ from category 2) NIUE (+ from category 1) PARAGUAY (+ from category 2) RWANDA (+ from category 2) SAINT LUCIA (+ from category 2) SUDAN (+ from category 2)
Group 3b	COTE D'IVORIE (+ from category 2) TURKEY (+ from category 2)/ ARGENTINA (- from category 4)
Group 4a	CHINA (including Taiwan) (+ from category 3) LUXEMBOURG (+ from category 3) MACAU (+ from category 3) MALAWAI (+ from category 3) PUERTO RICO (+ from category 2) SERBIA (+ from category 3) SLOVAKIA (+ from category 3) TANZANIA (+ from category 3) URUGUAY (+ from category 3) ZAMBIA (+ from category 3) ZIMBABWE (+ from category 3)
Group 4b	(New categorisation)

Figure 38
Levels of paediatric palliative care development – all countries





82.800.000

Population, 2021

.745.150

Surface, km²

Density, 2020 inh/km²

Gross Domestic Product per capita, 2018

Physicians per 1000 inhabitants, 2018

8.662

Health Expenditure total (% of gross), 2018

U**S\$**484.28

Health Expenditure per capita, PPP, 2018

Human Development Index. 2019

Human Development Index Ranking position, 2019

STATUS OF PALLIATIVE CARE



Outpatient Clinics



Mixed programs (community and hospital)



Consultation services (hospital support teams)



Hospital PC units



(inpatient)



education at the undergraduate level

nurses available

Nursing schools with PC education at the undergraduate level

Y	S

0/41

0/29

EDUCATION AND TRAINING Medical schools with PC.

NO
NU

Teachers of PC		4
Full professor	Medicine	0
	Nursing	0
Other professors	Medicine	1
	Nursing	3

Hospices (stand-alone inpatient units)

a section for PC



Community-based programs (home care)

Nursina home-based programs

Total

PALLIATIVE CARE POLICIES

National PC Law National plan IN PROCESS IN PROCESS or strategy for PC National cancer National standards IN PROCESS YES NO plan/strategy with and norms for PC

PAYMENT FOR PC PROGRAMS

Patients have to pay YES NO for PC? Patients have to pay for NO PC medications?

Health system

Universal Healthcare (Public) Private Radfar, A. (2022). Integrating Palliative Care into Primary Care: An Educational Project to Meet an Unmet Need. In: Schmidt-Straßburger, U. (eds) Improving Oncology Worldwide. Sustainable Development Goals Series. Springer, Cham. https://doi.org/10.1007/ 978-3-030-96053-7_15

Current health expenditure (% of GDP) - Iran, Islamic Rep.

Global Health Expenditure database, World Health Organization (WHO), uri: apps.who.int/nha/database, publisher: World Health Organization

License: CC BY-4.0 ①

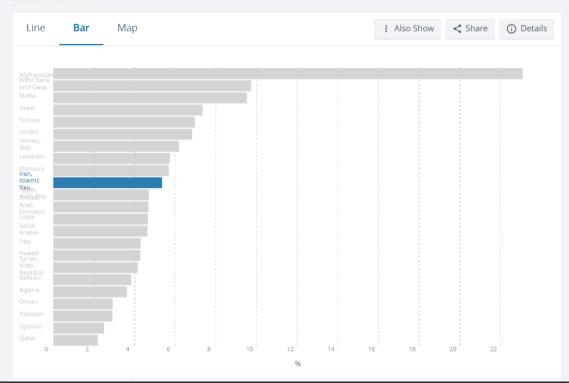


Current health expenditure (% of GDP) - Iran, Islamic Rep.
World Health Organization Global Health Expenditure database (https://data.worldbank.org, retrieved August 2025).

Current health expenditure (% of GDP) - Iran, Islamic Rep.

Global Health Expenditure database, World Health Organization (WHO), uri: apps.who.int/nha/database, publisher: World Health Organization

License: CC BY-4.0 ①



Current health expenditure (% of GDP) - Iran, Islamic Rep.

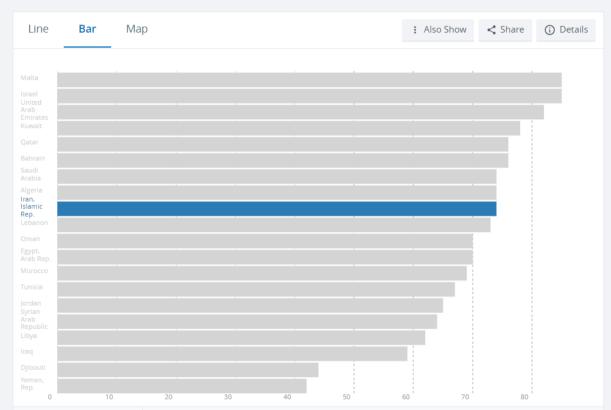
World Health Organization Global Health Expenditure database

(https://data.worldbank.org, retrieved August 2025).

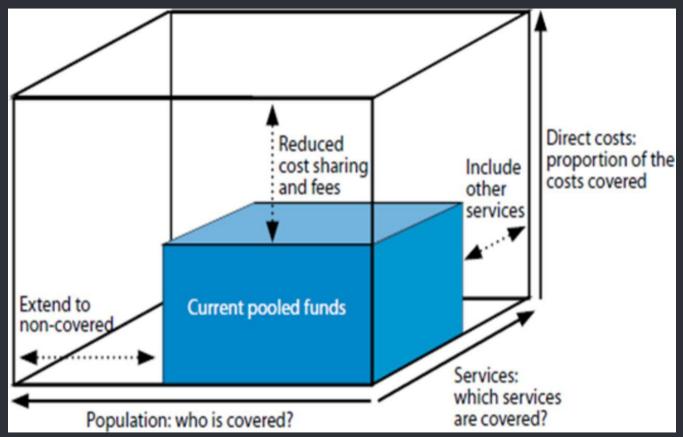
UHC service coverage index - Iran, Islamic Rep.

Global Health Observatory. Geneva: World Health Organization; 2023. (who.int/data/gho/data/themes/topics/service-coverage)

License: CC BY-4.0 ①

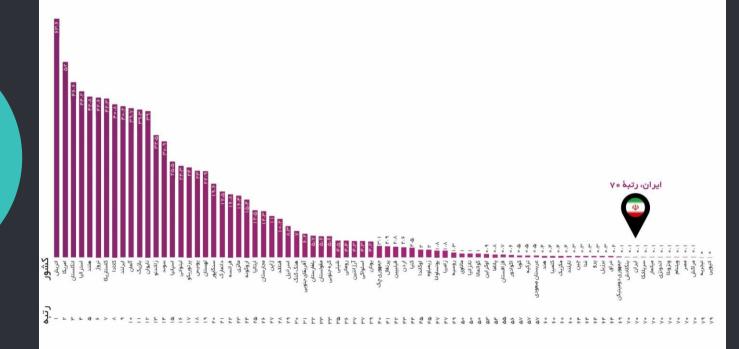


UHC service coverage index - Iran, Islamic Rep. Global Health Observatory. Geneva: World Health Organization (https://data.worldbank.org, retrieved on August 2025).



R Baltussen, M P Jansen, L Bijlmakers, N Tromp, A E Yamin, O F Norheim -Progressive realisation of universal health coverage: what are the required processes and evidence?: BMJ Global Health 2017;2:e000342.

چند درصد از کسانی که به مراقبتهای تسکینی نیاز دارند، به آن دسترسی دارند؟

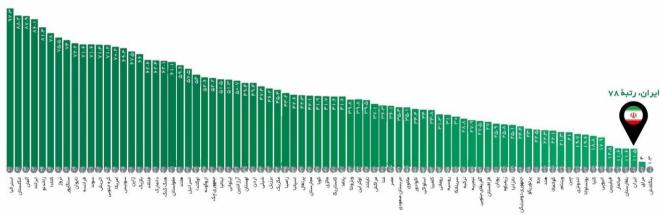






دانش پزشکان و پرستاران از مراقبت های تسکینی چقدر است؟

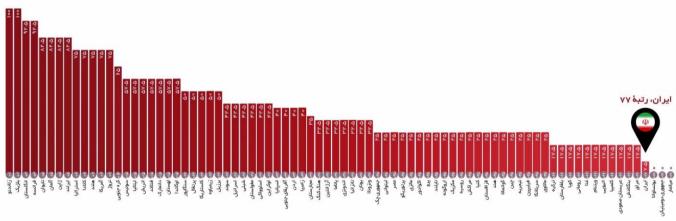




منبع: فهرست کیفیت مرگ: رتبه بندی کشورها در مر اقبتهای تسکینی (The ۲۰۱۵ (The Auality of Death Index. Ranking palliative care across the world) بنیاد لین (عام).

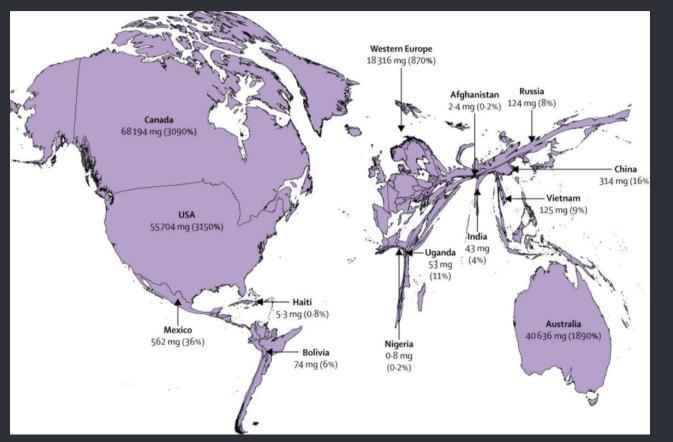
مردم چقدر در مورد مراقبتهای تسکینی میدانند و در ارائهٔ آن مشارکت میکنند؟





منبع: فهرست کیفیت مرگ؛ رتبه بندی کشورها در مراقبتهای تسکینی (Line Y و Liu) بنیاد لین (Line Y و این (The Y o la Quality of Death Index. Ranking palliative care across the world) بنیاد لین (طالعاتی مؤسسه اکونومیست، ۱۵ ه ۲۰

Where do we stand in palliative care provision?

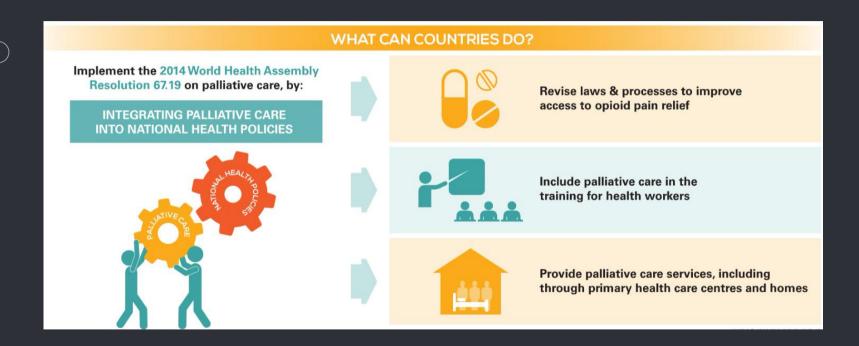


Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010–13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering

The Lancet
Commission on
Palliative Care and
Pain Relief—findings,
recommendations, and
future directions
Knaul, Felicia M et al.
The Lancet Global
Health, Volume 6, S5 S6

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Palliative Care in Global, Regional, and National Context



WHO Fact sheet on palliative care, 2019

Palliative Care in Global, Regional, and National Context

Policy

- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
 - Essential medicines

(Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)



Implementation

- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures

(Community & clinical leaders, administrators)

Education

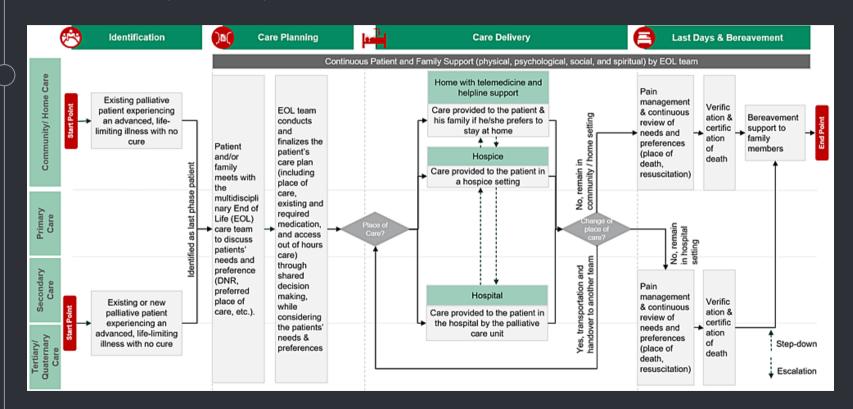
- Media & public advocacy
- Curricula, courses professionals, trainees
- Expert training
- Family caregiver training & support

(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

Public health model for palliative care development

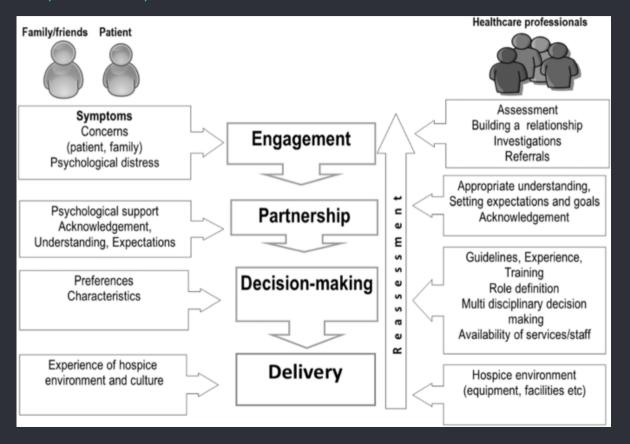
All these areas are related and will require education, essential medicines, policies, and the social and political support needed to make palliative care a priority and a reality throughout the world.

Stjernswärd, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. Journal of pain and symptom management, 33(5), 486–493. https://doi.org/10.1016/j.jpainsymman.2007.0 2.016



Alshammary S A, Punalvasal Duraisamy B, Salem L, et al. Integration of Palliative Care Into Primary Health Care: Model of Care Experience. Cureus 12(6): e8866.





Symptoms at End-of-Life

Pain: Common, complex

Respiratory Symptoms: Shortness of breath,

coughing, wheezing

Gastrointestinal Symptoms: Nausea, constipation

Psychological Symptoms: Depression, delirium,

anxiety

. . .

- Around the clock vs. PRN medications, especially for pain
- Oxygen, nebulizers, diuretics, antitussive w. codeine, prednisone
- Anti-nausea medications, gentle bowel stimulants
- Anti-depressants, anxiolytics
- Non-pharmacological therapies

. . .

Pain assessment
Types of pain

ТҮРЕ		NEURAL MECHANISM	EXAMPLE		
	V	sceral	Stimulation of pain	Hepatic capsule stretch	
Nociceptive	Somatic		receptors on normal sensory nerve endings	Bone metastases	
Nerve co		compression	Stimulation of nervi nervorum	Sciatica due to vertebral metastasis with compression of L4, L5 or S1 nerve root	
Neuropathic	Nerve injury	Peripheral	Lowered firing threshold of sensory nerves (deafferentiation pain)	Tumour infiltration or destruction of brachial plexus	
		Central	Injury to central nervous system	Spinal cord compression by tumour	
		Mixed	Peripheral and central injury	Central sensitization due to unrelieved peripheral neuropathic pain	
	Sympathetically maintained		Dysfunction of sympathetic system	Chronic regional pain syndrome following fracture or other trauma	

Pain assessment

Site	Where does it pain?
Frequency	Continuous or Intermittent If intermittent then, • How often in a day? • How long does it last?
Impact on activity	Does it affect your work/activities of daily living? Does it affect your sleep?
Medication history	What drugs did you take for the pain? What is the route? How often do you take? Does it give you relief? How long does the relief last? Are there any side effects?

Pain assessment

Pain History (OPQRST)	
O nset	When did the pain start?
Provocative/Palliative factors	What makes the pain worse?
	 What makes the pain better?
Quality	What exactly is it like?
	 Dull aching pain
	Sharp pain
	Burning pain
	 Lancinating pain, etc
Radiation	Does it spread anywhere?
S everity	How severe it is?
	 Mild
	 Moderate
	• Severe
Temporal factors	Does it come and go?
	Is it worse at any particular time of the
	day or the night?

Pain assessment

Numerical rating scale (for over 9 years old)

To assess the intensity of pain following pain scales can be used.

- Numerical rating scale (For adults)
- Wong-Baker FACES pain rating scale (For paediatric age group)
- Categorical scale

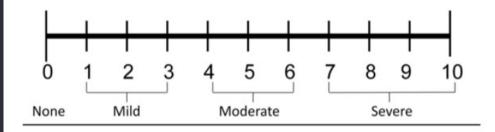


Figure 6: Numerical rating scale

Pain assessment

Wong-Baker FACES pain rating scale (for over 3 years old)



©1983 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission. Originally published in Whaley & Wong's Nursing Care of Infants and Children. ©Elsevier Inc.

Instructions for Usage

Explain to the person that each face represents a person who has no pain (hurt), or some, or a lot of pain.

Face 0 doesn't hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little bit more. Face 6 hurts even more. Face 8 hurt a whole lot. Face 10 hurts as much as you can imagine, although you don't have to be crying to have this worst pain.

Ask the person to choose the face that best depicts the pain they are experiencing.

Pain assessment

Critical Care Pain
Observation Tool (CPOT)
(assessment of pain in patients
who are critically ill or unable to
communicate verbally)

INDICATOR	DESCRIPTION	SCORE	
Facial expression	No muscular tension observed	Relaxed, neutral	0
	Presence of frowning, brow lowering, orbit tightening, and levator contraction	Tense	1
	All of the above facial movements plus eyelid tightly closed	Grimacing	2
Body movements	Does not move at all (does not necessarily mean absence of pain)	Absence of movement	0
	Slow, cautious movements, touching or rubbing the pain site, seeking attention through movements	Protection	1
	Pulling tube, attempting to sit up, moving limbs/thrashing, not following commands, striking at staff, trying to climb ou of bed		2
Muscle tension	No resistance to passive movements	Relaxed	0
Evaluation by passive	Resistance to passive movements	Tense, rigid	1
flexion and extension of upper extremities	Strong resistance to passive movements, inability to complete them	Very tense or rigid	2
Compliance with the	Alarms not activated, easy ventilation	Tolerating ventilator or movement	0
ventilator	Alarms stop spontaneously	Coughing but tolerating	1
OR	Asynchrony: blocking ventilation, alarms frequently activated	Fighting ventilator	2
Vocalization	Talking in normal tone or no sound	Talking in normal tone or no sound	0
(extubated patients)	Sighting, moaning	Sighting, moaning	1
	Crying out, sobbing	Crying out, sobbing	2
Total, range			0-8

Pain assessment

The Pain Assessment in Advanced Dementia tool (PAINAID)

PAIN ASSESSMENT IN ADVANCED DEMENTIA (PAINAID)					
	0	1	2	SCORE	
Breathing independant of vocalization	Normal	Occasioinal labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.		
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying		
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facia grimacing		
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.		
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distracg or reassure.		
			TOTAL		

Pain management

Non-opioid vs opioid options

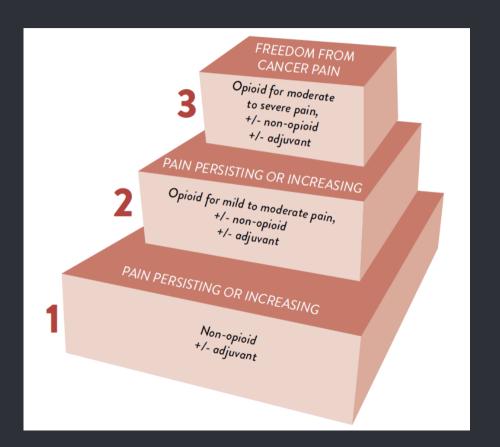
MEDICINE GROUP	MEDICINE CLASS	EXAMPLE MEDICINES		
	Paracetamol	Paracetamol oral tablets and liquid. Rectal suppositories, injectable		
Non-opioids	NSAIDs	Ibuprofen oral tablets and liquid Ketorolac oral tablets and injectable Acetylsalicylic acid oral tablets and rectal suppositories		
	Weak opioids	Codeine oral tablets and liquid and injectable		
Opioids	Strong opioids	Morphine oral tablet and liquid and injectable Hydromorphone oral tablets and liquid and injectable Oxycodone oral tablets and liquid Fentanyl injectable, transdermal patch, transmucosal lozenge Methadone oral tablet, liquid, injectable		

Pain management Adjuvants

MEDICINE GROUP	MEDICINE CLASS	EXAMPLE MEDICINES
Adjuvants	Steroids	Dexamethasone oral tablet and injectable Methylprednisolone oral tablets and injectable Prednisolone oral tablets
	Antidepressants	Amitriptyline oral tablets Venlafaxine oral tablets
	Anticonvulsants	Carbamazepine oral tablets and injectable
	Bisphosphonates	Zoledronate injectable

Pain management

The three-step analgesic ladder



Pain management

Approximate potency of opioids relative to morphine

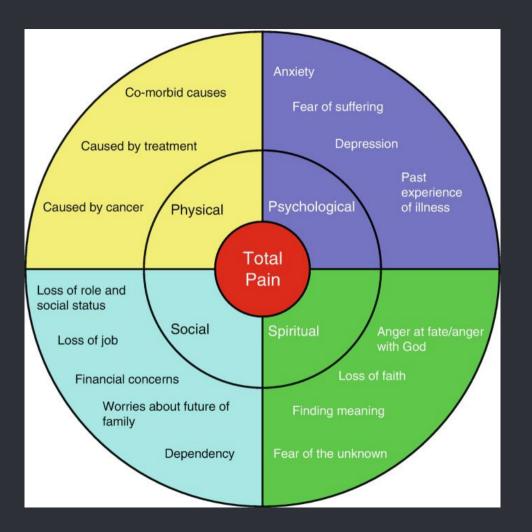
ANALGESIC	POTENCY RELATIVE TO MORPHINE	DURATION OF ACTION (HOURS) ⁶
Codeine	1/10	3-6
Dihydrocodeine	1/10	5-0
Pethidine	1/8	2–4
Tapentadol	1/3	4-6
Hydrocodone (not United Kingdom)	2/3	4-8
Oxycodone	1.5 (2)°	3-4
Methadone	5-10 ^d	8–12
Hydromorphone	4-5 (5-7.5) ^d	4-5
Buprenorphine (SL)	80	6–8
Buprenorphine (TD)	100 (75–115)°	Formulation dependent (72–168)
Fentanyl (TD)	100 (150)°	72

Drug	Conversion	Equi-analgesic	Example conversions
	ratio from	dose to 30 mg	(These apply to single
	oral	oral morphine	doses or total daily dose)
	morphine		
Morphine (oral)	1	30mg	1. To convert 60 mg of
Morphine (sc)	2 to 1	15mg	oral Morphine to
Morphine (iv)	3 to 1	10mg	subcutaneous Morphine
Diamorphine (sc)	3 to 1	10mg	divide by 2 to give 30 mg.
Oxycodone (oral)	1.5-2 to 1	15-20mg	
Oxycodone (sc)	3 to 1	10mg	2. To convert 30 mg of oral
Alfentanil (sc)	30 to 1	1mg	Morphine to oral
Fentanyl (sc)	150 to 1	200mcg	Oxycodone divide by 2
Hydromorphone (oral)	7.5 to 1	4mg	To give 15mg
Hydromorphone (sc)	15 to 1	2mg	

Opioid	Renal	impairment	Hepatic	impairment
	Moderate	Severe	Moderate	Severe
Morphine	Reduce dose	Avoid	Normal dose	Reduce dose
Diamorphine	Reduce dose	Avoid	Normal dose	Reduce dose
Oxycodone	Reduce dose	Avoid	Reduce dose	Avoid
Alfentanil	Normal dose	Normal dose	Normal dose	Reduce dose
Fentanyl	Normal dose	Normal dose	Normal dose	Reduce dose
Methadone	Normal dose	Normal dose	Normal dose	Reduce dose
Hydromorphone	Reduce dose	Reduce dose	Reduce dose	Avoid
Buprenorphine	Normal dose	Normal dose	Normal dose	Reduce dose

Total Pain

Cicely Saunders, the founder of the modern hospice movement, recognized this and applied the term **total pain** as having physical, psychological, social, and spiritual components interacting upon one another.



•	Total Pain
	The interaction among total pain components is often complex, yet evident in patients with serious illnesses. For example, loss of hope can have a spiritual, existential, and psychological dimension which may compound the intensity of physical pain if the patient attributes pain with impending death.

ts with serious illnesses. For loss of hope can have a spiritual, al, and psychological dimension ay compound the intensity of pain if the patient attributes pain ending death. Clinicians cannot fully care for patients

with life-limiting illnesses without assessing for all domains of total pain. Since no one person or discipline can manage total pain, interdisciplinary teams (IDTs) are vital to address total pain.

Anxiety. hopelessness, helplessness

Fear of

dependency on

family; loss of

to family (19):

Despair from

and without

meaning (16)

inner realization

that life is finite

role as provider

Description

Nociceptive.

visceral, or

from known

tissue injury (1)

neuropathic pain

PainComponent

Physical

Psycho-logical

Social

Spiritual

Manifestation

Pain leads to

from fear of

from home

Adjustment

Loss of dignity and

sense of worth (13).

Feelings of

disconnection and

abandonment by

community/God.

impaired function

and social isolation

exacerbations away

from medical uncertainty (15.18)

Disengaging from clinical care plan. spending reactions, despair.

Example

Epigastric pain

radiating to the

back from

unresectable

pancreatic cancer

addressing what to excessive time expect and how the searching the web natient defines quality of life.

Facilitate Family conflict as discussions the patient between patient declines and caregivers to recommended

home

help find solutions care and voices an for the patient's changing clinical urgency to return status and family role (2).

Questioning the meaning of life

me?" (20)

process - "Why

sets to enable

and the dying

psychologist, chaplain) with skill

(e.g., social worker,

Involve clinicians

exploration of the

patient's distress from dving (21).

Intervention

significantly

towards resolution

Celiac plexus block

improves patient's

pain and function

Meeting with the

IDT for a serious

illness discussion

Addressing spiritual needs:

- Don't wait until the last minute!
- Facilitate rituals
- Assist with funeral arrangements
- Implement cultural considerations (values, customs, behaviors and beliefs)

Supporting the Family:

- Address questions
- Provide information
- Give suggestions on how to support patient/resident
- Offer comforting items: chairs, tissues, drinks, etc.
- Offer interdisciplinary support

6 Case studies

Case study – Presentation

Mr. J, 69 y/o, father of four, with 1y history of stage IV NSCLC, is referred to ED with pneumonia. He is confused, hypoxic and tachypneic, and not responding to IV antibiotics. Family says "do everything". He has no ACP.

Case study – Discussion

- 1. What is the likely prognosis? List the suggestive clinical features.
- 2. What is "ACP", and why is it relevant here?
- 3. What is your immediate approach?
- 4. How would you clarify the goals of care?
- 5. Would you initiate CPR if he deteriorates?
- 6. What role can a palliative care team play at this stage?
- 7. When should you consider transitioning to a comfort-focused care plan?

7

References and additional resources

References and additional resources



The Lancet Commission on Palliative Care and Pain Relief—findings, recommendations, and future directions



Report of the Lancet Commission on the Value of Death: bringing death back into life



MJHS online continuing education material: Hospice & Palliative Care

Thank you for your attention! ANY QUESTIONS?

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