Ali lahko govorimo o paliativnem pristopu kot doktrini ?

Mateja Lopuh
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SB Jesenice

Državna koordinatorica razvoja paliativne oskrbe

Zgodba o Ivanu Iljiču

- Klasična podpora učenju o biopsihosocialnem modelu
- 45 letni uradnik, padec iz lestve, bolečina v desnem boku, hira, hujša, oslabi, malodušen, prijatelji se ga izogibajo, draga zdravila ne pomagajo
- Najbolj ga bolijo laži, češ da bo vse dobro, da bo ozdravel; on pa se boji smrti, ne ve, kaj se bo zgodilo
- Nihče ne joka ob njem, ker misli na smrt svojci ne odobravajo, želi si, da bi ga kdo stisnil, objel, prijel za roko

Paliativna oskrba – sprememba vrednot

vsak človek je zase svet,
čuden, svetal in lep
kot zvezda na nebu

(tone pavček)

Življenje je eno samo neizprosno odločanje (Atul Gawande)

Paul Gaugin: Kje smo, kam gremo?

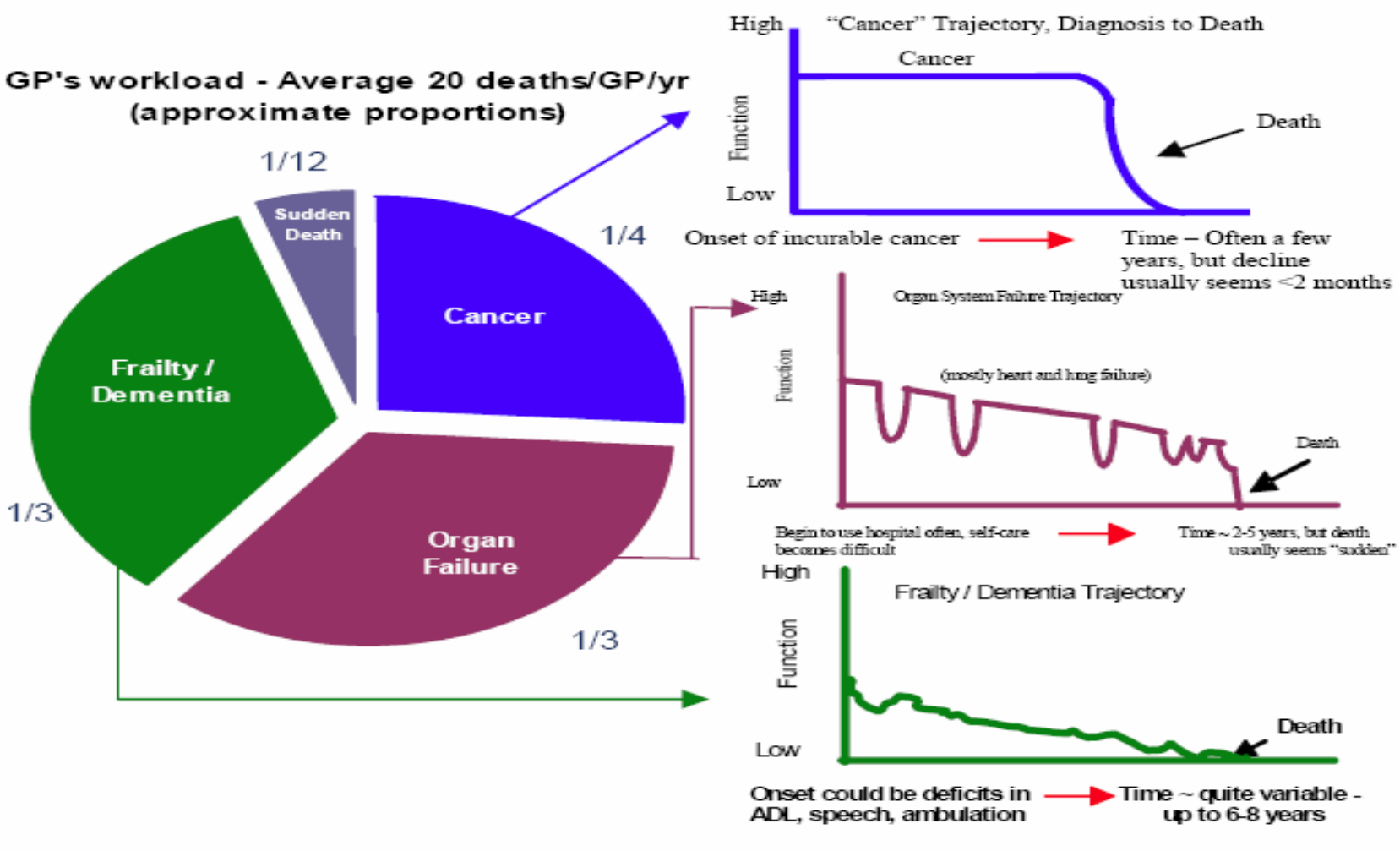
Definition of Palliative Care

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 problems, physical, psychosocial and spiritual.

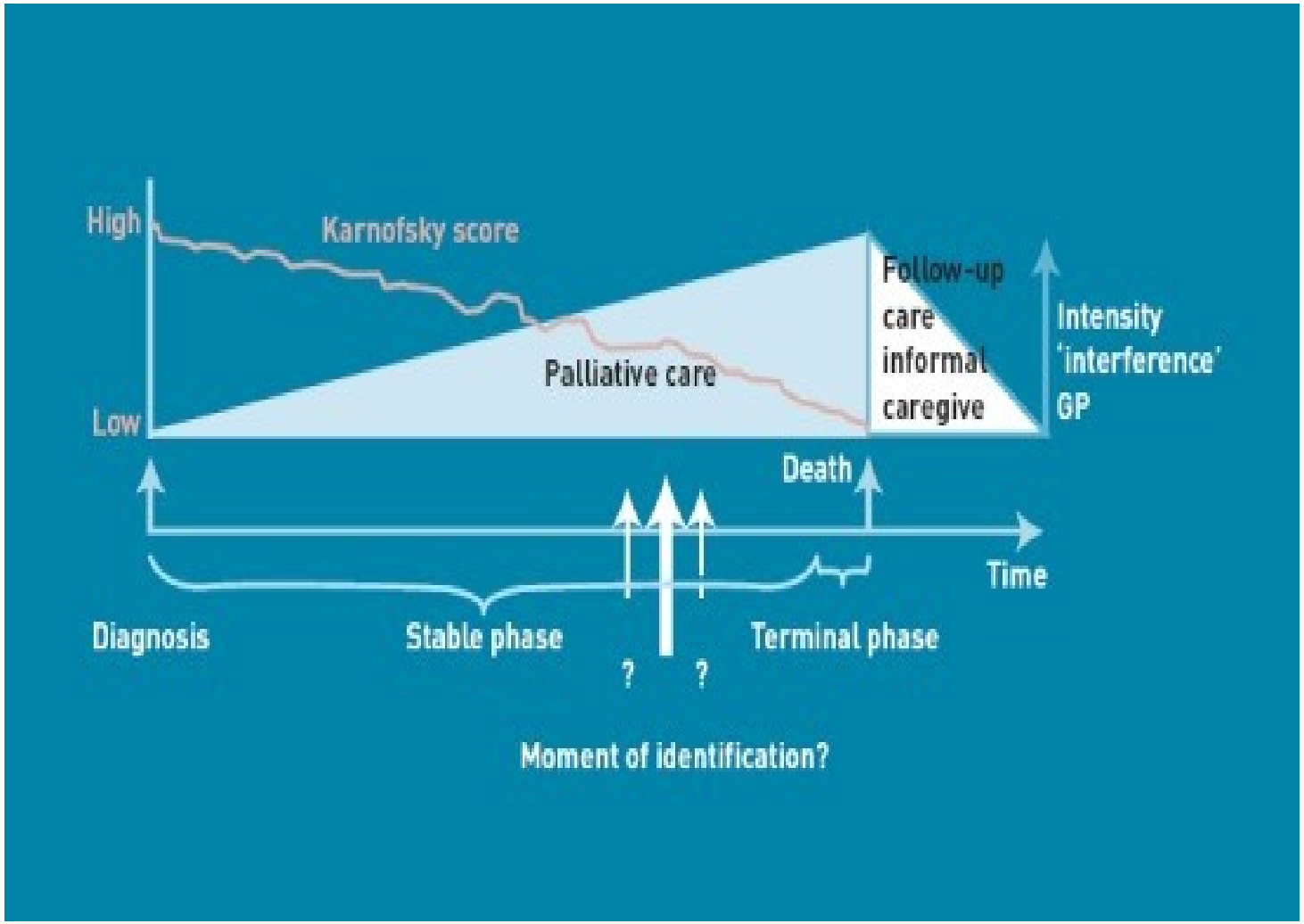
Različne ravni oskrbe

- Podporna oskrba - vključitev paliativnega pristopa v osnovne temeljne vede
- Paliativna oskrba v ožjem pomenu besede – kdo sodeluje s kom, vloga lečečih specialistov
- Oskrba ob koncu življenja

Trajectories & workload



Source: GSF NHS


High
Low
Karnofsky score
Palliative care
Follow-up
care
informal
caregive
Intensity
'interference'
GP
Death
Time
Diagnosis
Stable phase
Terminal phase
?
?
Moment of identification?

KDAJ ZAČETI ?

- PC 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**.

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assessment of unmet supportive and palliative care needs may be appropriate.

Look for two or more general indicators of deteriorating health:

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, unbeatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, incapacitating peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Supportive and palliative care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

Palliative register is the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, March 2014

skrbi

- Včasih nas je skrbelo, da bi ne naredili zadosti, sedaj nas skrbi, da bi ne naredili preveč

- Včasih so se ljudje bali navidezne smrti, sedaj se bojijo navideznega življenja

Kako torej učiti in se učiti paliativnega pristopa ?

- Ni terapevtski nihilizem
- Gre za drugačen način razmišljanja
- Gre za dopuščanje možnosti, da z zdravljenjem ne bomo uspešni
- Upoštevanje mnenja bolnika, ki ne sme temeljiti na strahu, ampak na jasnem pojasnilu
- Ni drugačna doktrina od klasične medicinske – gre samo za širše dojemanje medicine

Poglavitna etična dilema

- Ali lahko bolniku, ki preide v paliativno oskrbo v ožjem pomenu besede naredimo kakšno škodo ?
- LAHKO, če paliativni pristop razumemo v luči opuščanja

Zato je pomembno, da nikoli ne pozabimo, da smo medicinsko osebje in da moramo vedno poskušati delovati vzročno

Končne odločitve

- In dubio: pro vita
- Vedno je potrebno dovolj zgodaj z bolnikom pretehtati njegove vrednote in želje
- Medicina zmore veliko, ali si tega želi tudi bolnik ?
- Pri nezavestnih bolnikih, kjer povratka kognitivnih sposobnosti ni pričakovati v razumnem času: strokovno izpetost – želje svojcev (česa bi si po njihovem mnenju želel bolnik)
- Če smo v skladu z bolnikovo željo (ob razumevanju stanja), kljub strokovni indikaciji, nek poseg ali terapijo opustili, bolnika nismo ubili mi – ampak bolezen, katere potek je dopustil

Paliativna oskrba –upanje (Atul Gawande)

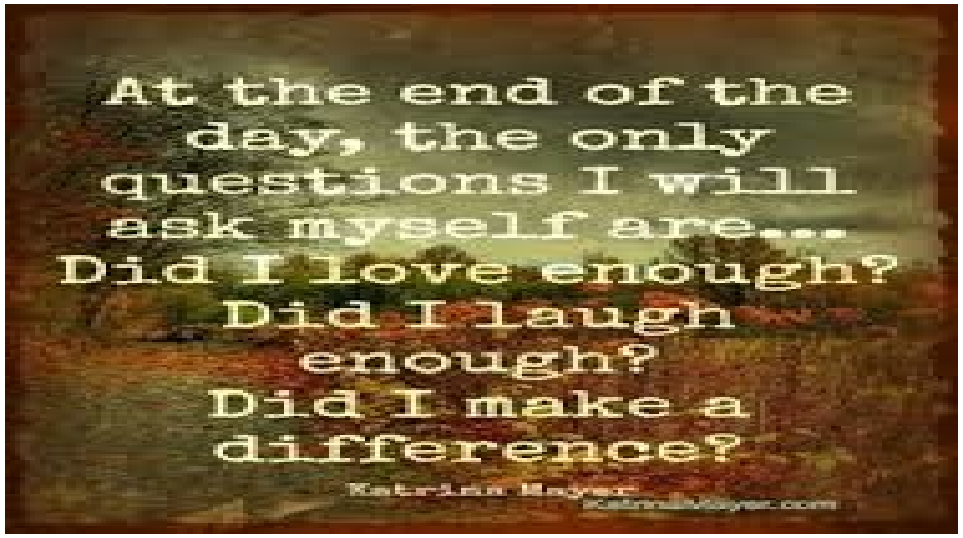
- Dlje živiš le, če se nehaš truditi, da bi živel dlje
- Temeljna konceptualna napaka: smrt je sovražnica. Vendar zmeraj zmaga.

  V vojni,kjer ne moreš zmagati, pa si ne želiš generala, ki se bojuje do popolnega uničenja.

Želiš si nekoga, ki se zna bojevati za ozemlje, ki si ga je mogoče priboriti, in se zmore predati, ko to ni mogoče, nekoga, ki razume, da je škoda največja, če ne počneš drugega, kakor da se vojskuješ do bridkega konca.

Paliativna oskrba - upanje

- Upanje ni prepričanje, da se bo nekaj dobro izšlo, ampak prepričanje, da je nekaj smiselno, ne glede na to, kako se izide. (vaclav havel)



Paliativna oskrba - smrt

- PO ne pomeni priprave na smrt – je pa pogovor o željah ob koncu življenja ključen
- PO pomeni iskanje neštetih možnosti, da izžamemo vse kar bolniku njegovo telo še ponuja in kar mu duh dopušča
- PO ne pomeni opuščati znanja, ki si ga je priborila medicina
- Za vse, kar je bolniku pomembno, se je vredno potruditi – ljudje umrejo samo enkrat


SMILE,
BREATHE,
AND GO
SLOWLY
THICH NHAT
HANH
katie daisy