Introduzione alle cure palliative non oncologiche

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4 situazioni cliniche

Sig. na T
78 anni
Cardiopatia ischemica, valvolare e ipertensiva
Accidente cerebrovascolare nel 2016
7 ospedalizzazioni nel 2016

Sig. G
67 anni
BPCO severa
3 sovrainfezioni polmonari con ospedalizzazione

Sig. V
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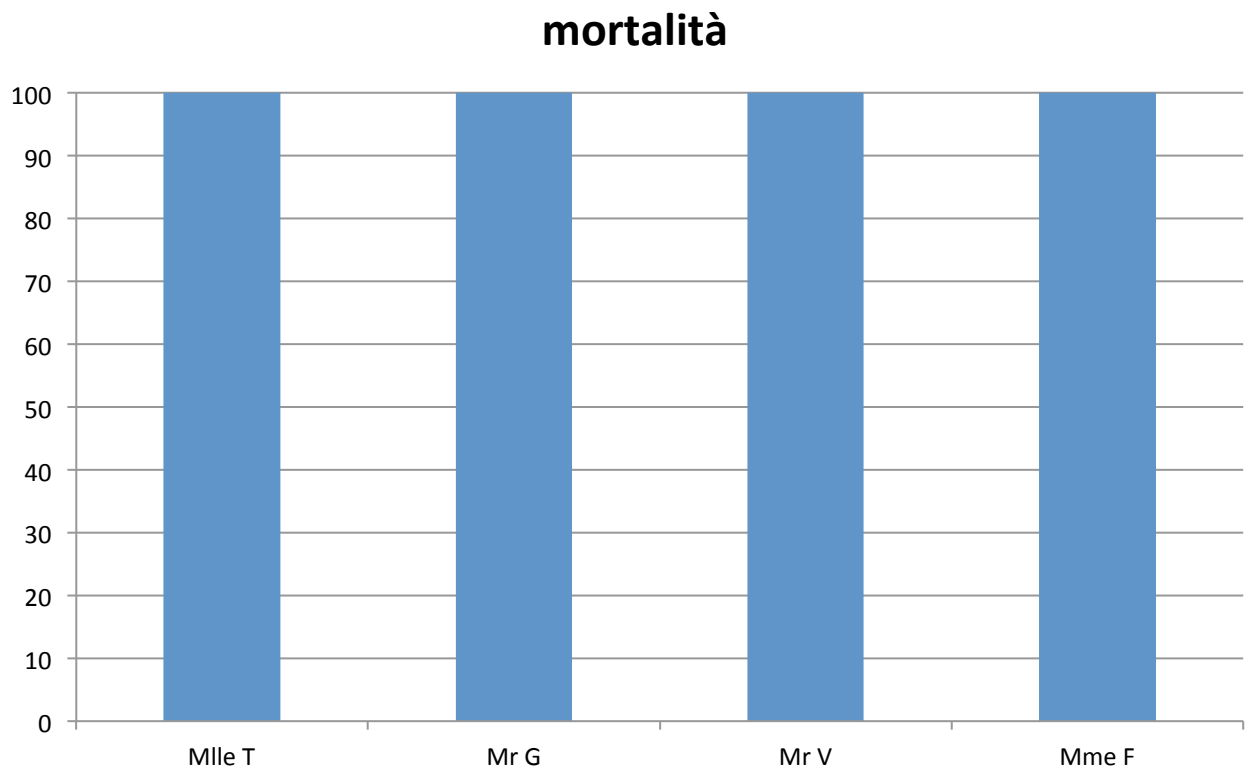
Ricoverato per frattura al collo del femore
Alzheimer moderato

Sig. ra F
83 anni
Tumore al seno multimetastatico
Divorziata, 2 figli, 5 nipoti

CERTEZZE

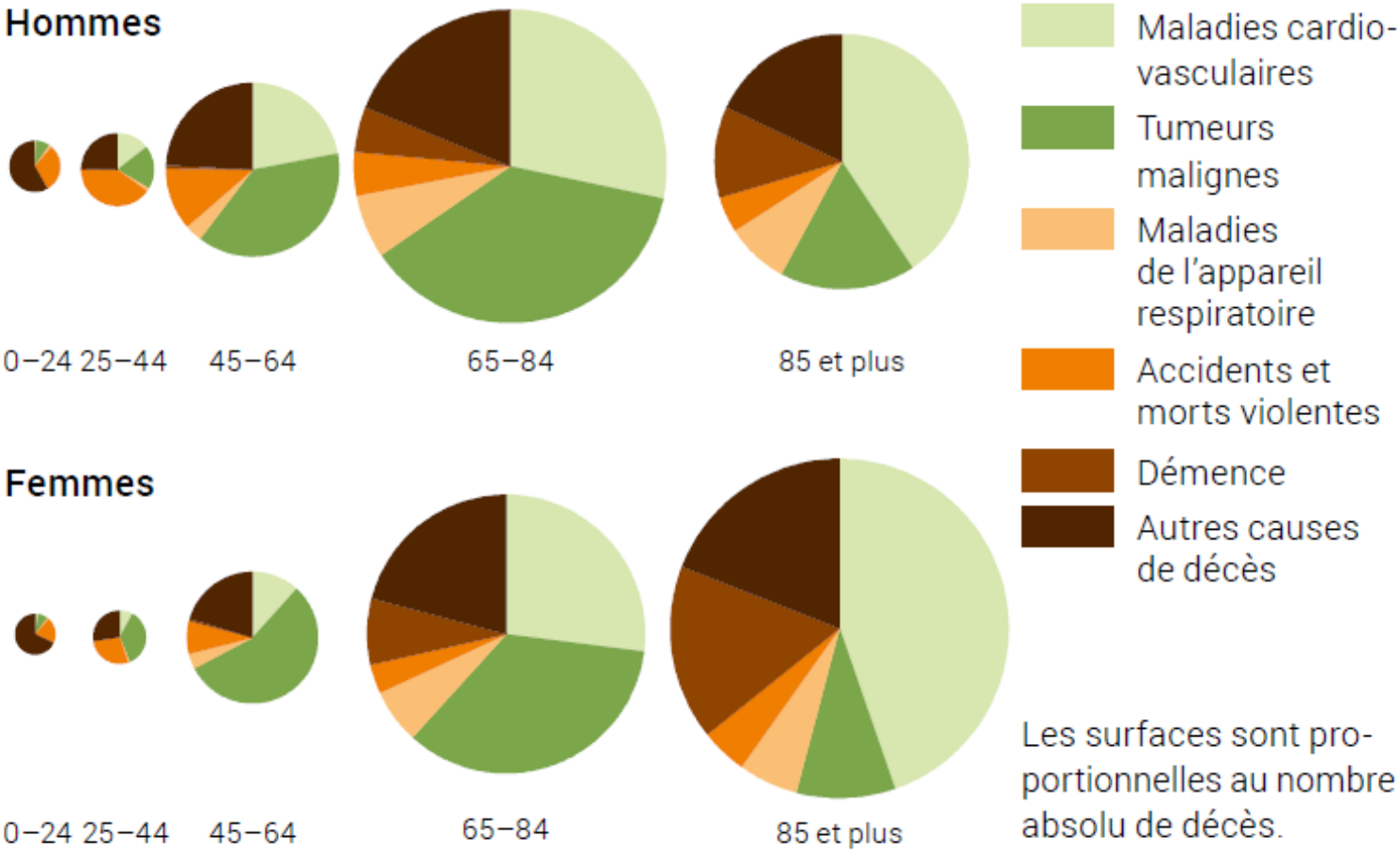


World Health Organization

Le cure palliative cercano di **migliorare la qualità di vita dei pazienti e dei loro familiari** nell'affrontare le conseguenze di una **malattia potenzialmente mortale**, grazie alla prevenzione della **sofferenza,** identificata precocemente e valutata con precisione e attraverso il **trattamento del dolore** e di altri **problemi fisici**, **psicologici** e **spirituali** legati alla malattia.

Da: *National Cancer Control programmes, policies and managerial guidelines,* 2ª edizione, Ed. WHO2002, pag. 84

Principales causes de décès selon le groupe d'âge G 2

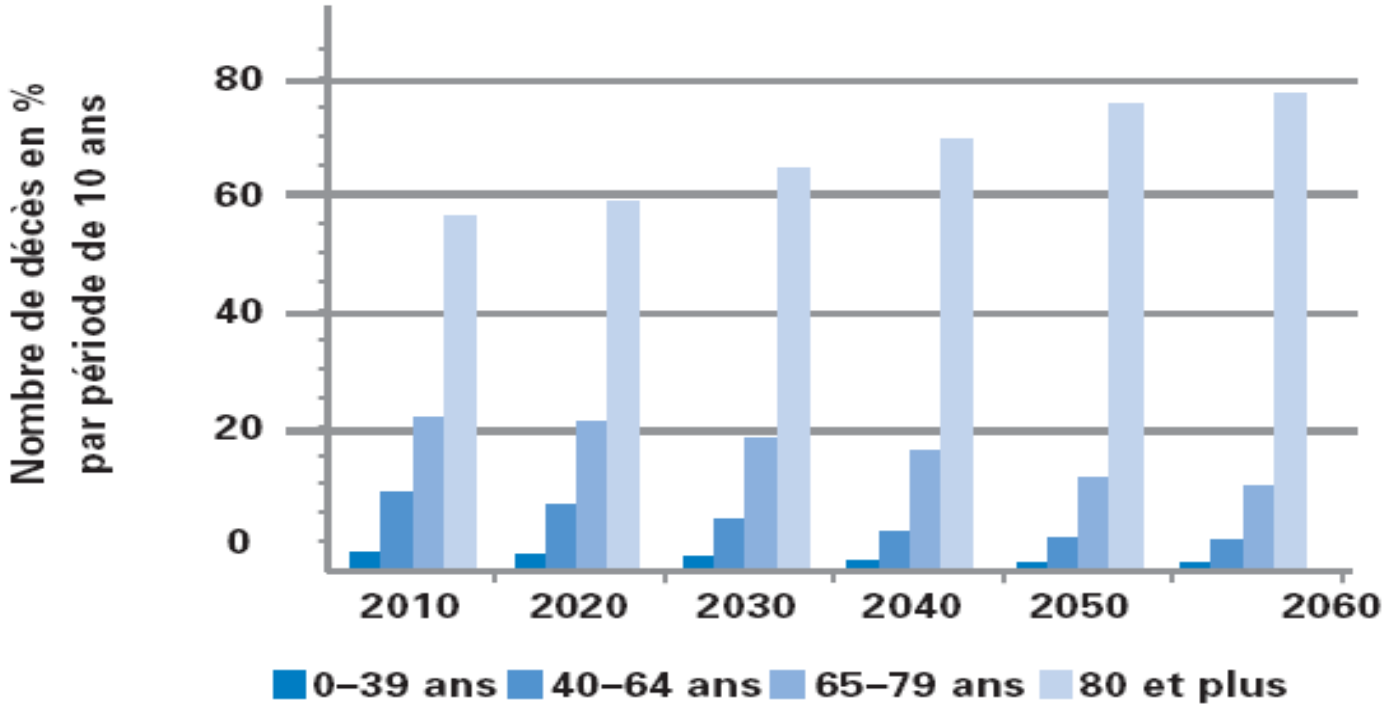


Les surfaces sont proportionnelles au nombre absolu de décès.

Source: OFS – Statistique des causes de décès

CERTEZZE (continuazione)

Fig. 3 : Evolution des décès par âge 2010-2060

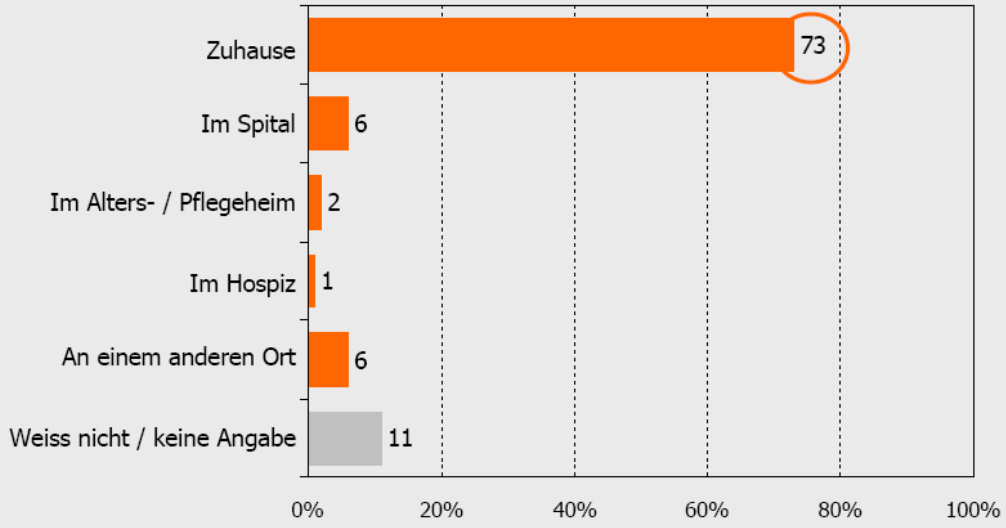


Source : Office fédéral de la statistique (OFS)

Sterbeort

F8: In der Schweiz sterben die Menschen am häufigsten im Alters- oder Pflegeheim, am zweithäufigsten im Spital und am dritthäufigsten zuhause oder an einem anderen Ort.
An welchem Ort würden Sie wünschen, sterben zu können?
Basis: n=1'600 / Angaben in %

Die grosse Mehrheit der Befragten wünscht sich, zuhause sterben zu dürfen. Gemäss öffentlicher Statistik sterben die Menschen jedoch am häufigsten im Alters- und Pflegeheim.



GfK

GLI ALTRI SINTOMI

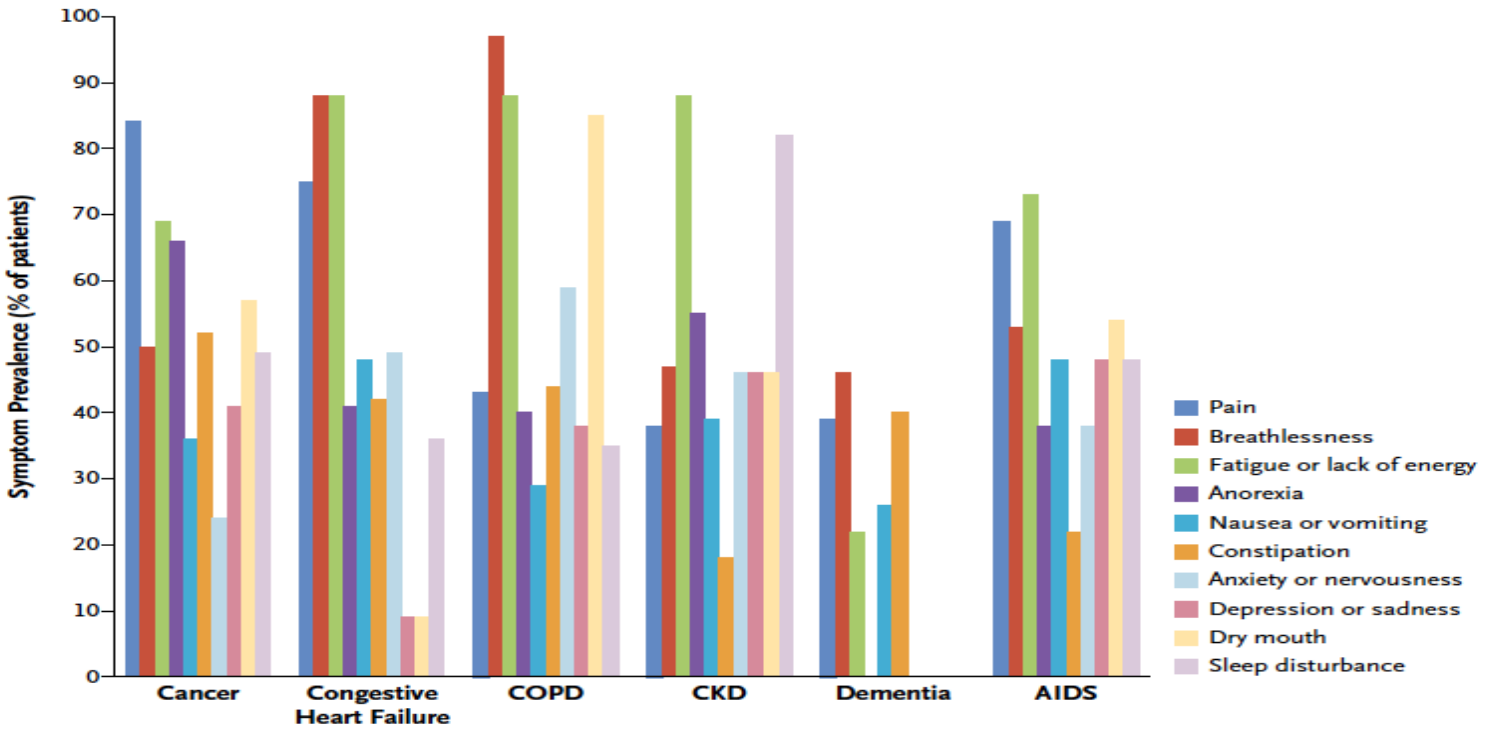


Figure 1. Symptom Prevalence in Advanced Illness.
Data are from representative studies of symptom prevalence among patients with cancer,[8-12] congestive heart failure,[13,14] chronic obstructive pulmonary disease (COPD),[15] chronic kidney disease (CKD),[13,14] or dementia[16,17] and among patients who received highly active antiretroviral therapy for the acquired immunodeficiency syndrome (AIDS).[18] Self-reported data regarding some symptoms were unavailable for patients with dementia.

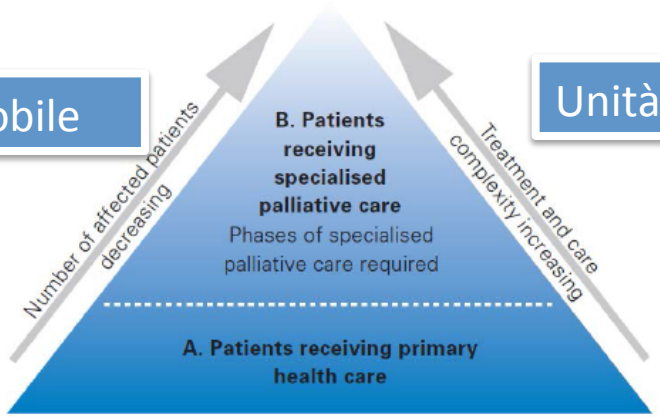
N Engl J Med 2015;373:747-55.

CURE PALLIATIVE

- QUALITÀ DI VITA
- PRESA IN CARICO DEI SINTOMI FISICI E PSICOLOGICI
- MANTENIMENTO DELLA FUNZIONALITÀ
- SOSTEGNO SOCIALE
- SOSTEGNO SPIRITUALE
- FAMILIARI
- PRESA DI DECISIONE - DEFINIZIONE DI UN ATTITUDINE
- PRESCRIZIONE MEDICAMENTOSA ADEGUATA
- ANTICIPAZIONE

Cure palliative generali-specializzate

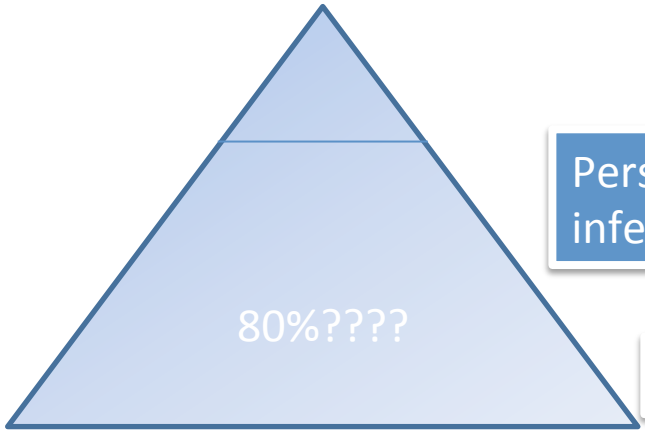
Fig. 1: Target groups for palliative care



Source: FOPH and CMH (2010): National Guidelines for Palliative Care

Equipe mobile

Unità di cure palliative



Medici curanti

Personale infermieristico

...

Identificazione

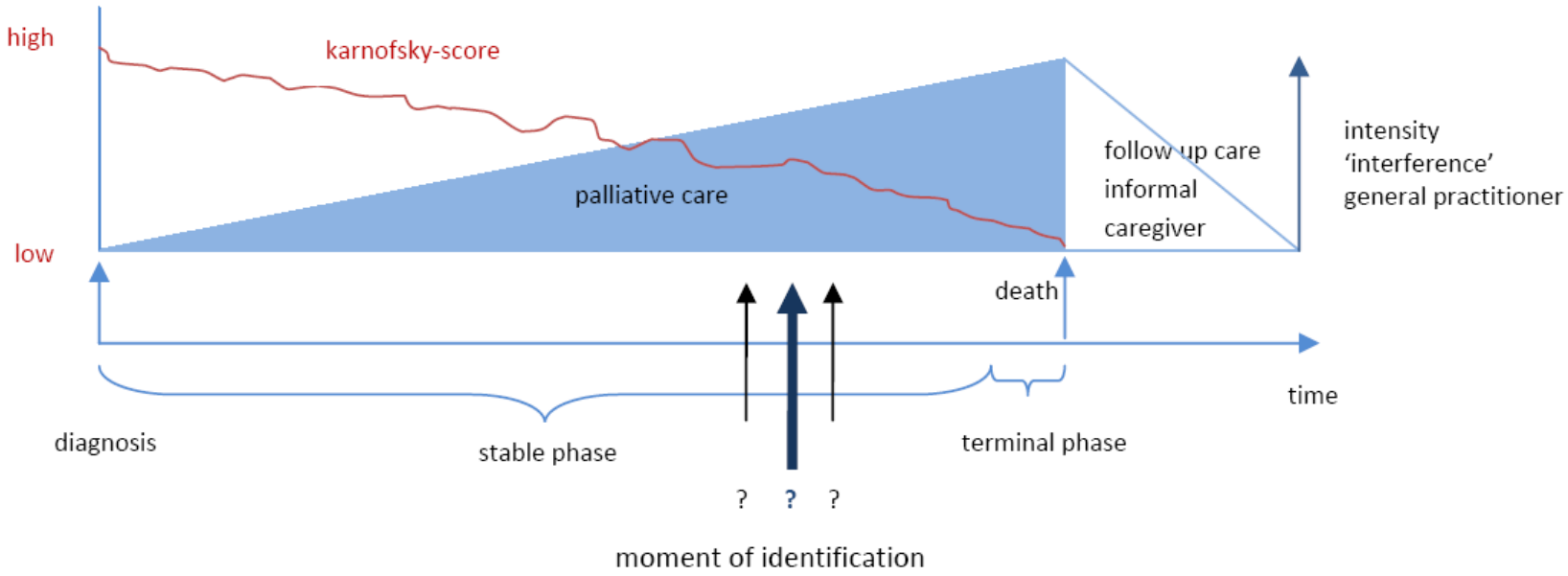
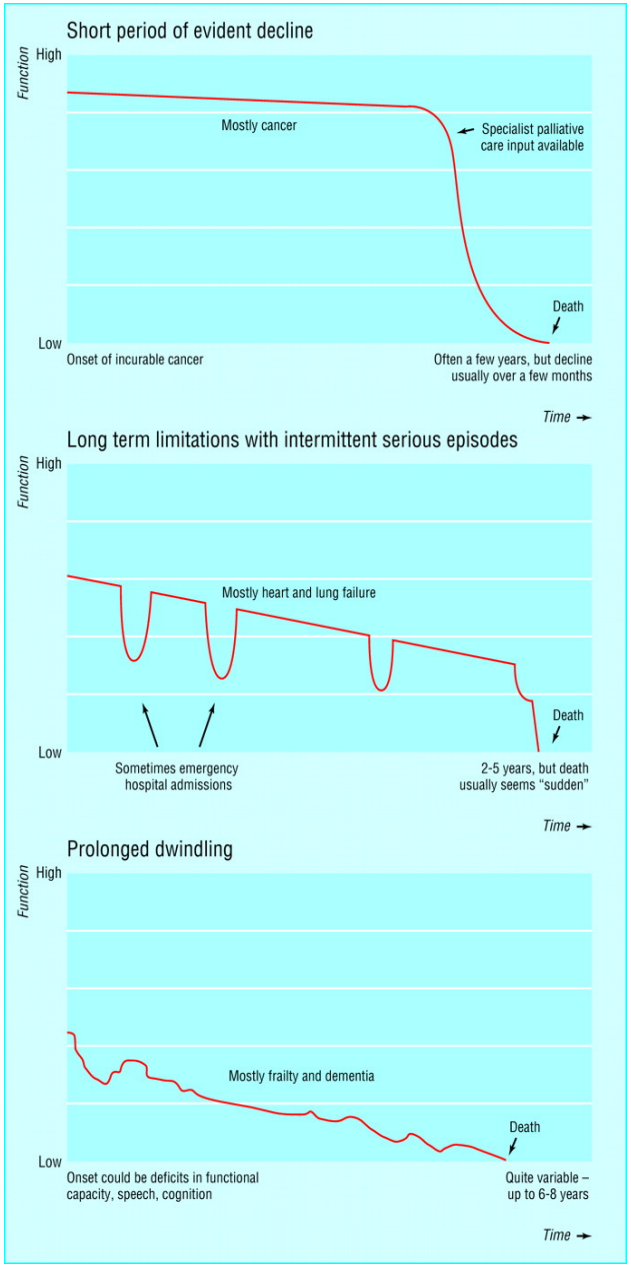


Figure 1 What is the moment to start palliative care?, a modified figure of Lynn and Adamson [37].

BMC Fam Pract. 2011;12:123.



Murray, S. A et al. BMJ 2005;330:1007-1011

Multimorbilità

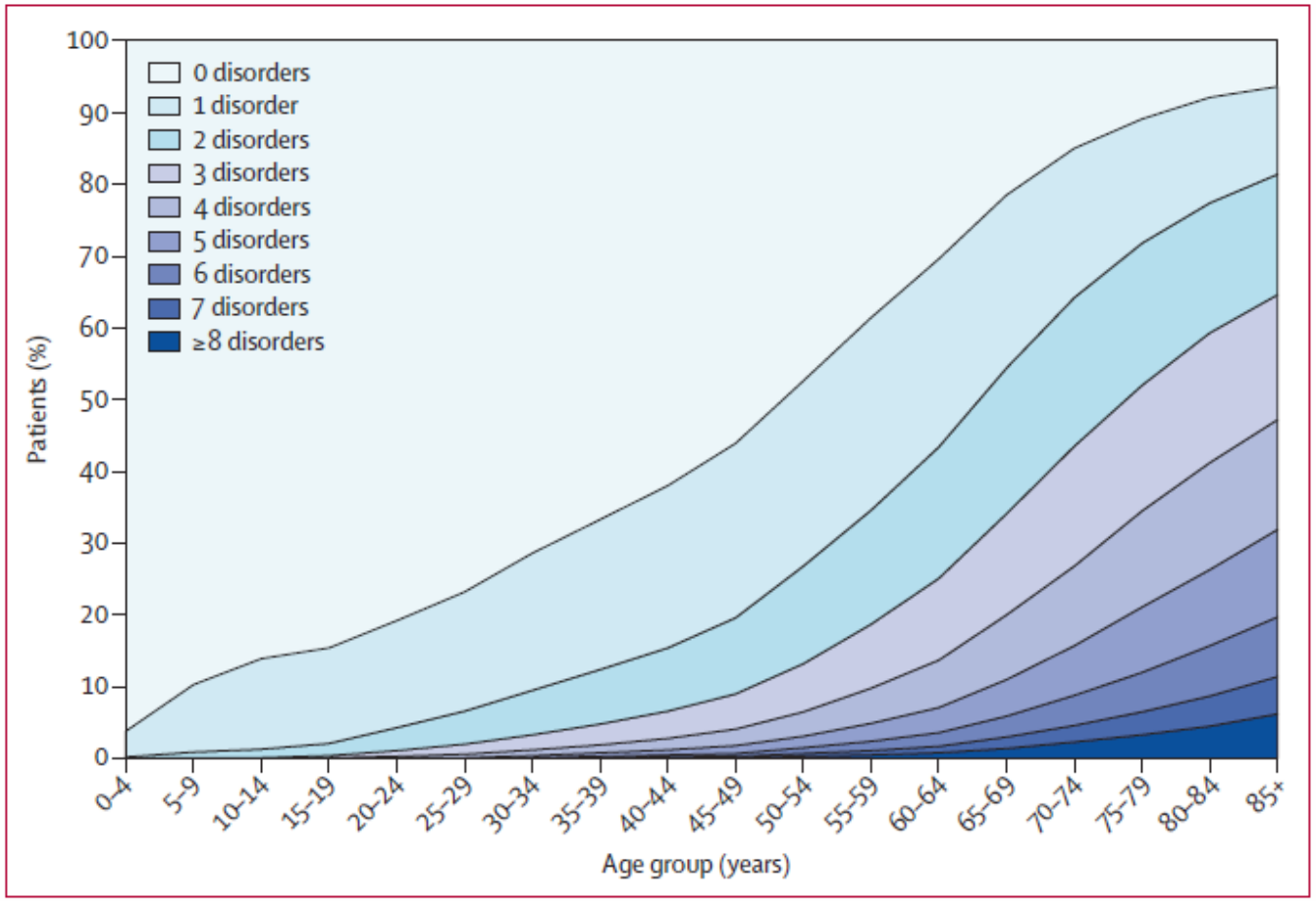
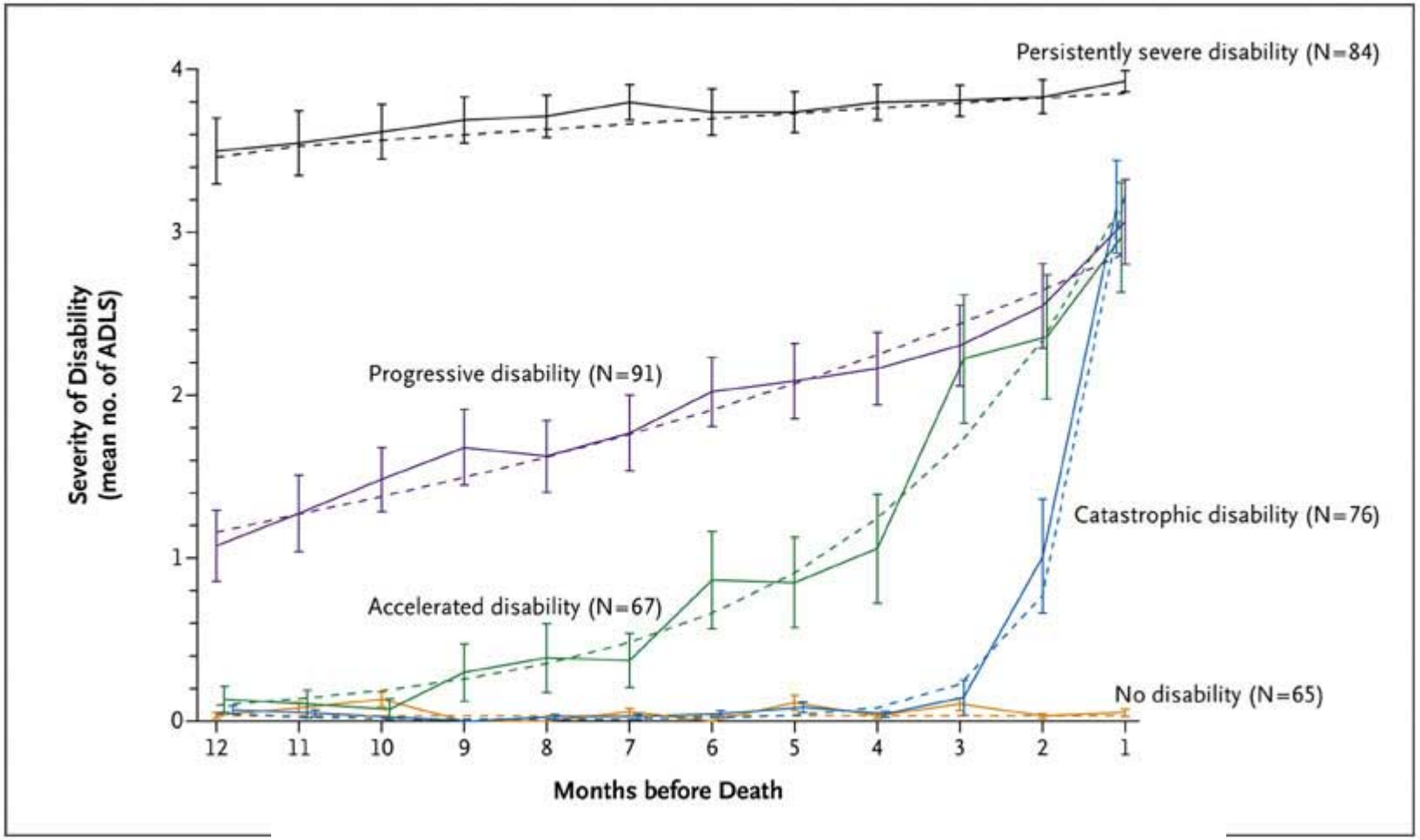
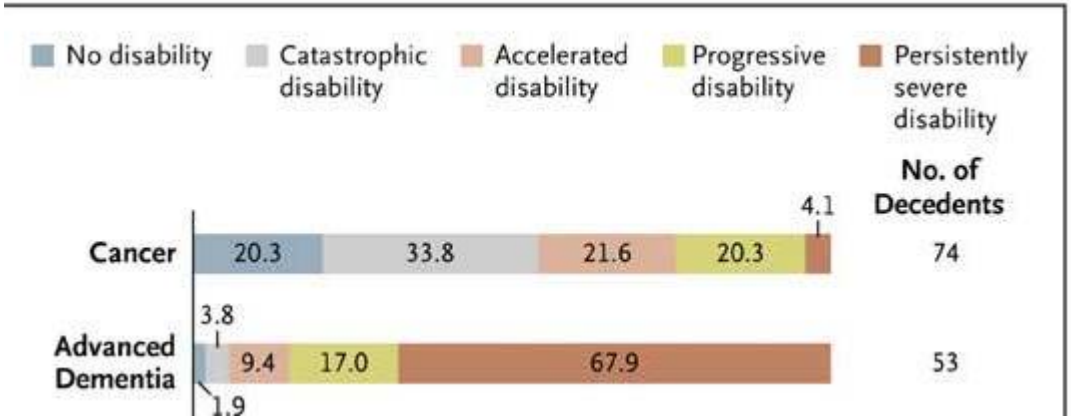


Figure 1: Number of chronic disorders by age-group

Lancet 2012; 380: 37–43





T M. Gill, NEJM, 2010;362:1173-1180

SPICT

Outil d'indicateurs de soins palliatifs et de support (SPICT-FR™)

Le SPICT-FR™ est un outil pour identifier les personnes dont l'état de santé risque de s'aggraver, ou risquant de décéder.
Evaluez leurs besoins en termes de soins palliatifs et de support.

Cherchez au moins deux indicateurs généraux de l'aggravation de l'état de santé

- *Performance Status* médiocre ou en voie de détérioration (la personne reste au lit ou au fauteuil plus de 50% du temps de veille), avec réversibilité limitée.
- Dépend d'autrui pour la plupart des besoins en matière de soins, en raison de problèmes de santé physique et/ ou mentale.
- Au moins deux hospitalisations non programmées au cours des six derniers mois.
- Perte de poids importante (5-10%) au cours des 3-6 derniers mois, et / ou faible indice de masse corporelle.
- Symptômes persistants et gênants malgré le traitement optimal des pathologies sous-jacentes.
- Le patient demande des soins palliatifs et de support, ou il demande l'arrêt d'un traitement.

http://www.spict.org.uk/

SPICT

Cherchez des indicateurs cliniques d'une ou plusieurs pathologies avancées

Cancer

L'état fonctionnel se détériore du fait d'un cancer métastatique progressif.

Trop fragile pour un traitement oncologique ; l'objectif du traitement est le contrôle des symptômes.

Démence / fragilité

Incapacité à s'habiller, marcher ou manger sans aide.

La personne mange moins et boit moins ; difficultés à avaler.

Incontinence urinaire et fécale.

N'est plus capable de communiquer en utilisant un langage verbal ; peu d'interactions sociales.

Fracture du fémur ; chutes multiples.

Épisodes fébriles récurrents ou infections ; pneumopathie d'inhalation.

Maladie neurologique

Maladie cardiaque / vasculaire

Insuffisance cardiaque classe NYHA III / IV, ou maladie coronarienne étendue et non traitable avec :

- dyspnée ou douleur thoracique survenant au repos, ou pour un effort minime.

Maladie vasculaire périphérique grave et inopérable.

Maladie respiratoire

Insuffisance respiratoire chronique sévère avec :

- dyspnée au repos ou pour un effort minime entre des décompensations aiguës.

Nécessite une oxygénothérapie au long cours.

A eu besoin de ventilation pour une insuffisance respiratoire, ou la ventilation est contre-indiquée.

Maladie rénale

Insuffisance rénale chronique au stade 4 ou 5 (DFG < 30 ml/min) et détérioration de la santé.

Insuffisance rénale compliquant d'autres pathologies limitant l'espérance de vie, ou compliquant certains traitements.

Arrêt de dialyse.

Maladie du foie

Cirrhose avancée avec au moins une complication au cours de l'année passée :

- ascite résistante aux diurétiques
- encéphalopathie hépatique
- syndrome hépatorénal
- péritonite bactérienne
- hémorragies récurrentes de varices oesophagiennes

Transplantation hépatique contre-indiquée.

http://www.spict.org.uk/

NECPAL CCOMS-ICO 3.0 2016©

PATIENT: ..... HC: .....

DATE: ..... / ..... / ..... SERVICE: .....

RESPONSIBLE(S): .....

Surprise Question (to/among professionals)	Would you be surprised if this patient dies within the next year?		☐ Yes ☑ No (-) (+)
"Demand" or "Need"	- Demand: Have the patient, the family or the team requested in implicit or explicit manner, palliative care or limitation of therapeutic effort?		☐ Yes ☑ No
	- Need: identified by healthcare professionals from the team		☐ Yes ☑ No
General Clinical Indicators: 6 months - Severe, sustained, progressive, not related with recent concurrent process - Combine severity WITH progression	- Nutritional Decline	• Weight loss > 10%	☐ Yes ☑ No
	- Functional Decline	• Karnofsky or Barthel score > 30% • ADLs >2	☐ Yes ☑ No
	- Cognitive Decline	• Minimental/Pfeiffer Decline	☐ Yes ☑ No
Severe Dependence	- Karnofsky <50 or Barthel <20		☐ Yes ☑ No
Geriatric Syndromes	- Falls - Pressure Ulcers - Dysphagia - Delirium - Recurrent infections	• Clinical data anamnesis - recurrent > 2 - or persistent	☐ Yes ☑ No
Persistent symptoms	Pain, weakness, anorexia, dyspnoea, digestive...	• Symptom Checklist (ESAS)	☐ Yes ☑ No
Psychosocial aspects	Distress and/or Severe adaptive disorder	• Detection of Emotional Distress Scale (DME) > 9	☐ Yes ☑ No
	Severe Social Vulnerability	• Social and family assessment	☐ Yes ☑ No
Multi morbidity	>2 chronic diseases (from the list of specific indicators)	• Charlsson Test	☐ Yes ☑ No
Use of resources	Evaluate Demand/intensity of interventions	• > 2 urgent or not planned admittances in last 6 months • Increase Demand/intensity of interventions (homecare, nurse interventions, etc)	☐ Yes ☑ No
Specific indicators	Cancer, COPD, CHD, Liver, Renal, CVA, Dementia, Neurodegenerative diseases, AIDS, other advanced	• To be developed as annexes	☐ Yes ☑ No

Classification:		
Surprise Question (PS)	SQ + (I would not be surprised)	√
	SQ - (I would be surprised)	
NECPAL Parameters	NECPAL + (de 1+ a 13+)	
	NECPAL - (No parameters)	√

Codification and Registry

Propose codification as Patient with Advanced Chronic Conditions (PCC)

Linee guida

11.3. Palliative Care for Patients With HF

The core elements of comprehensive palliative care for HF delivered by clinicians include expert symptom assessment and management. Ongoing care should address symptom control, psychosocial distress, HRQOL, preferences about end-of-life care, caregiver support, and assurance of access to evidence-based disease-modifying interventions. The HF team can help patients and their families explore treatment options and prognosis. The HF and palliative care teams are best suited to help patients and families decide when end-of-life care (including hospice) is appropriate.[30,885–888,904] Assessment for frailty and dementia is part of this decision care process offered to the patient and family.

Data suggest that advance directives specifying limitations in end-of-life care are associated with significantly lower levels of Medicare spending, lower likelihood of in-hospital death, and higher use of hospice care in regions characterized by higher levels of end-of-life spending.[905] In newly diagnosed cancer patients, palliative care interventions delivered early have had a positive impact on survival and HRQOL. This approach may also be relevant for HF.[906] Access to formally trained palliative care specialists may be limited in ambulatory settings. Therefore, cardiologists, primary care physicians, physician assistants, advanced practice nurses, and other members of the HF healthcare team should be familiar with these local treatment options. Evaluation for cardiac transplantation or MCS in experienced centers should include formal palliative care consultation, which can improve advanced care planning and enhance the overall quality of decision making and integrated care for these patients, regardless of the advanced HF therapy selected.[907]

Circulation. 2013;128:e240-e327

Original Article

PALLIATIVE MEDICINE

White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

Palliative Medicine
2014, Vol. 28(3) 197–209

DOI: 10.1177/0269216313493685
pmj.sagepub.com
SAGE

Jenny T van der Steen[1], Lukas Radbruch[2], Cees MPM Hertogh[1], Marike E de Boer[1], Julian C Hughes[3], Philip Larkin[4], Anneke L Francke[1,5], Saskia Jünger[6], Dianne Gove[7], Pam Firth[8], Raymond TCM Koopmans[9] and Ladislav Volicer[10] on behalf of the European Association for Palliative Care (EAPC)

Global Initiative for Chronic Obstructive Lung Disease

SUPPORTIVE, PALLIATIVE, END-OF-LIFE & HOSPICE CARE

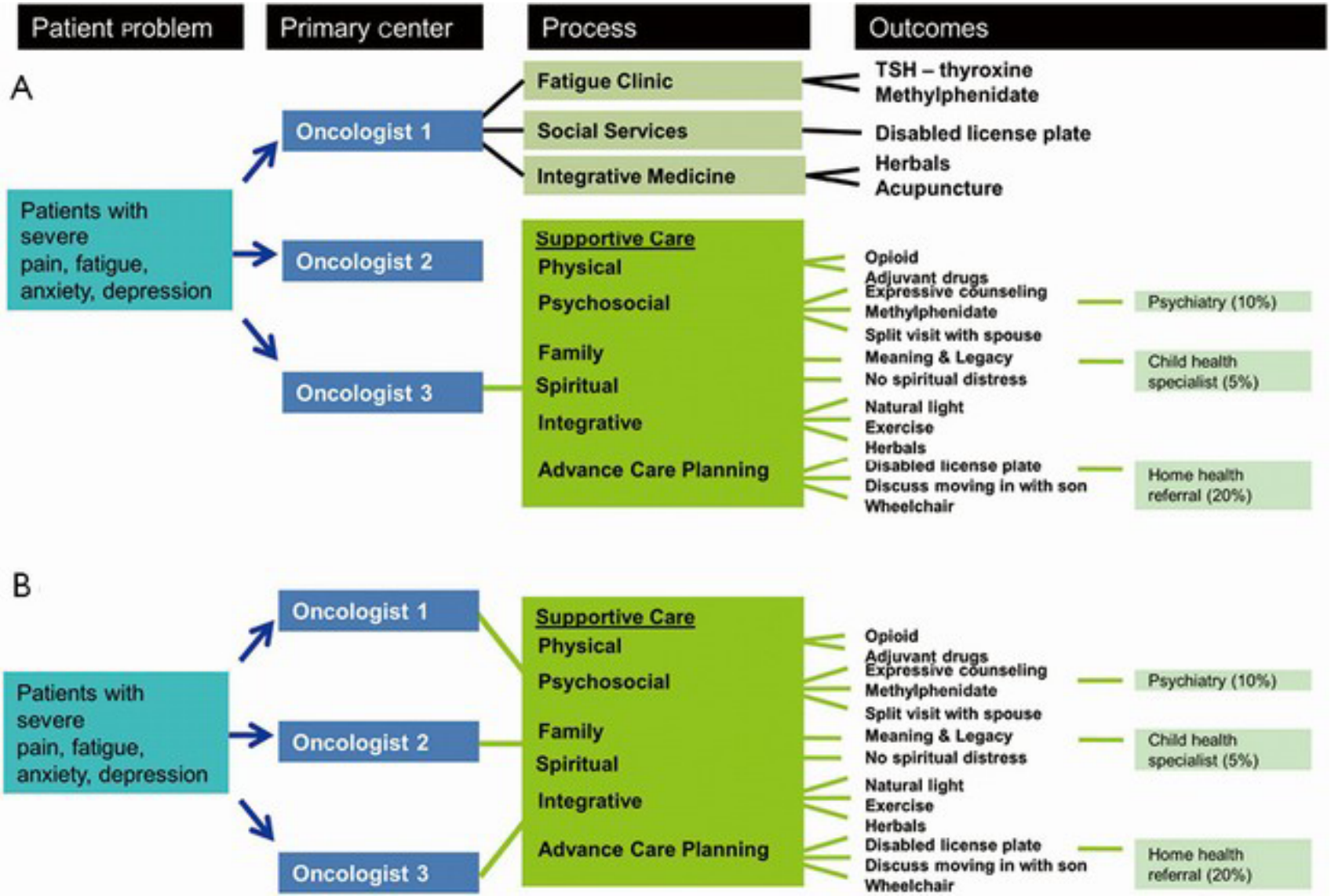
Symptom control and palliative care

- COPD is a highly symptomatic disease and has many elements such as fatigue, dyspnea, depression, anxiety, insomnia that require symptom-based palliative treatments.
- Palliative approaches are essential in the context of end-of-life care as well as hospice care (a model for delivery of end-of-life care for patients who are terminally ill and predicted to have less than 6 months to live).

Key points for palliative, end-of-life and hospice care in COPD are summarized in **Table 3.9**.

Table 3.9. Palliative care, end of life and hospice care in COPD

- Opiates, neuromuscular electrical stimulation (NMES), oxygen and fans blowing air onto the face can relieve breathlessness **(Evidence C)**.
- In malnourished patients, nutritional supplementation may improve respiratory muscle strength and overall health status **(Evidence B)**.
- Fatigue can be improved by self-management education, pulmonary rehabilitation, nutritional support and mind-body interventions **(Evidence B)**.


Patient problem
Primary center
Process
Outcomes
A
Patients with severe pain, fatigue, anxiety, depression
Oncologist 1
Oncologist 2
Oncologist 3
Fatigue Clinic
Social Services
Integrative Medicine
TSH – thyroxine
Methylphenidate
Disabled license plate
Herbals
Acupuncture
Supportive Care
Physical
Psychosocial
Family
Spiritual
Integrative
Advance Care Planning
Opioid
Adjuvant drugs
Expressive counseling
Methylphenidate
Split visit with spouse
Meaning & Legacy
No spiritual distress
Natural light
Exercise
Herbals
Disabled license plate
Discuss moving in with son
Wheelchair
Psychiatry (10%)
Child health specialist (5%)
Home health referral (20%)
B
Patients with severe pain, fatigue, anxiety, depression
Oncologist 1
Oncologist 2
Oncologist 3
Supportive Care
Physical
Psychosocial
Family
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Accidente cerebrovascolare nel 2016
7 ospedalizzazioni nel 2016

Attitudine generale, se si presenta una nuova complicazione: cure intensive, stent ecc.

Luogo di ospedalizzazione in caso di nuove complicazioni?

Chi partecipa alla decisione, nel caso in cui la paziente non fosse più in grado di comunicare?

4 situazioni cliniche

Sig. G, sposato
67 anni
BPCO grave
3 sovrainfezioni polmonari con ospedalizzazione nel 2016

Attitudine: rianimazione-ventilazione invasiva-non invasiva

Ospedalizzazione ogni volta?

In caso di presa in carico domiciliare: chi, cosa, come?

Sostegno alla moglie

4 situazioni cliniche

Signor V, vive con la sua compagna
78 anni
Ospedalizzato per frattura al collo del femore
Alzheimer moderato

Attitudine se si aggravano le funzioni cognitive:
-alimentazione artificiale
-antibiotici a ripetizione
-la compagna è nominata rappresentante terapeutica.

4 situazioni cliniche

Sig. ra F
83 anni
Tumore al seno multimetastatico
Divorziata, 2 adolescenti

Rifiuta un'altra ospedalizzazione, non vuole soffrire.
Presa in carico a domicilio: chi, quando, come?
Medicamenti di riserva in caso di esacerbazione dei sintomi, sedazione?
Presa in carico dei nipoti…

Le sfide che ci attendono

- Integrare questa presa in carico palliativa nella presa in carico dei pazienti non oncologici.
- Identificare i bisogni e le aspettative dei pazienti.
- Offrire una presa in carico personalizzata che risponda a tali aspettative.