Palliative Care for people with non-oncological disease

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EAPC Task Force for People with Heart Failure

Vision of Palliative Care

The active total care of patients whose **disease is not responsive to curative treatment**.

Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount.

The goal of PC is achievement of the best possible **quality of life for patients and their families**.

Many aspects of **PC** are also **applicable earlier in the course of the illness**, in conjunction with *active* (anti-cancer) treatment.

PC **affirms life** and **regards dying as a natural** process; it aims to neither hasten nor postpone death

http://www.eapcnet.eu/corporate/abouttheeapc/definitionandaims.aspx

Two persepctives of PC

End-of-life

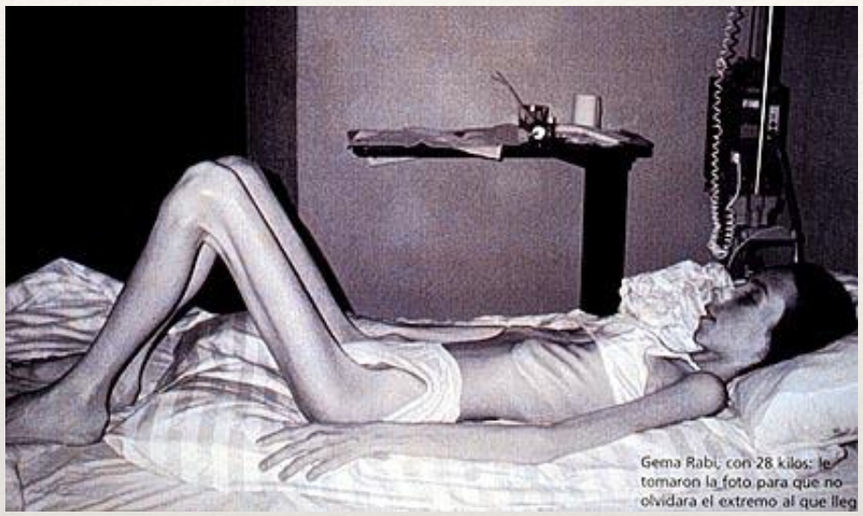
- Focused to provide care for those who approach death (the prediction of high risk of death is difficult for most patients)

Supportive, parallel care

- The prediction is not needed
- PC involvement according to needs

The way PC has gone

1967



Cicely Saunders established St. Christophers in London,
with a goal to improve the Q of **dying** (=remaining life), and not just **only to gather up dying people**

2019

Specialized medical care for **people living** with a serious illness, with the goal to improve QoL for both the patient and the family.

Understanding of PC

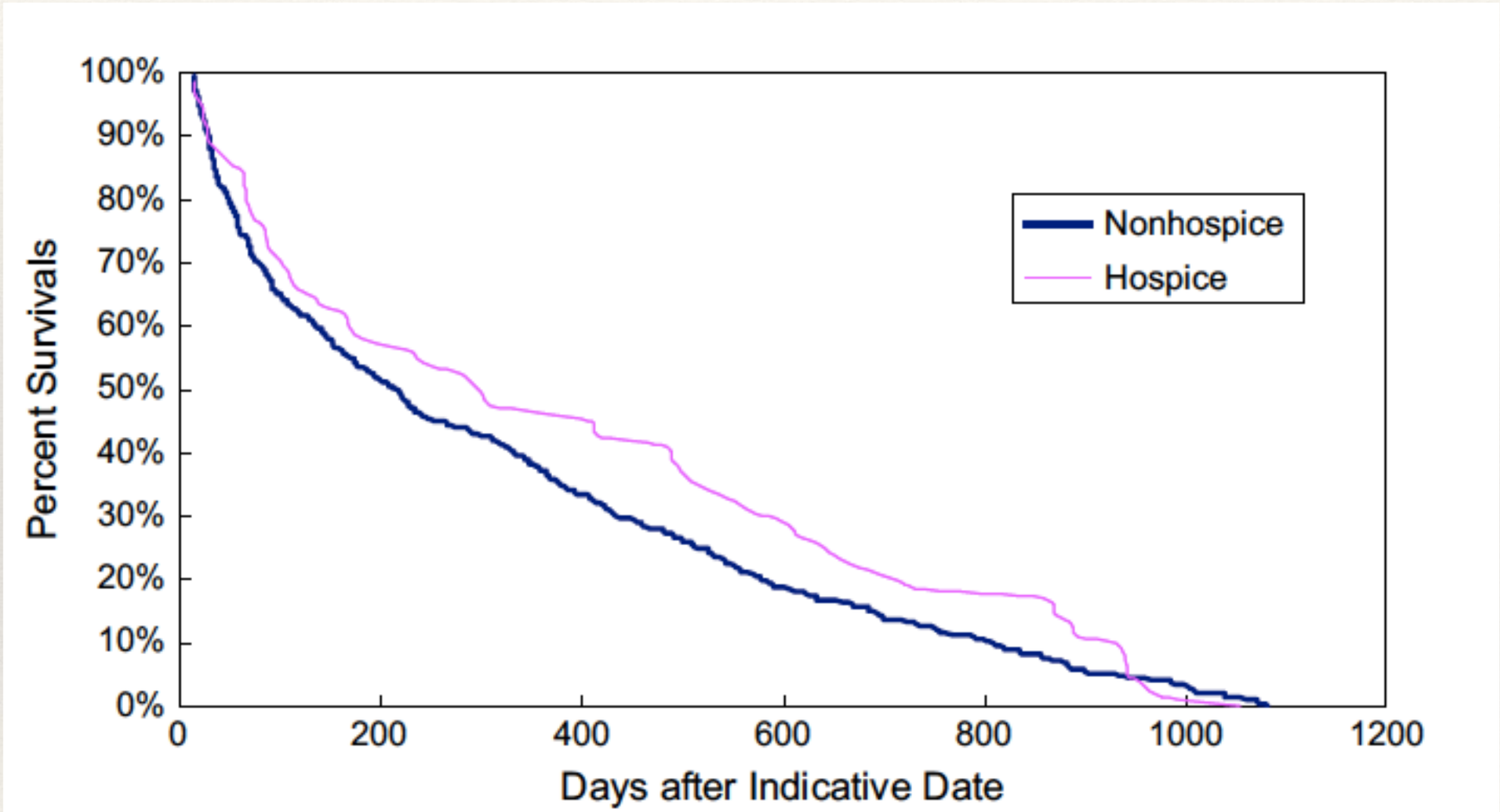
The reality **Should be**

- Despite substantial changes in the setting of PC, it is still strongly associated with cancer and "**preparing to die**" in the minds of patients, family caregivers and professionals[1].

- PC is **based on the needs of the patient, not on the patient's prognosis**[2].
- This care is appropriate at **any age and at any stage** in a serious illness[2].

[1.] Kendall M. *2015*; 2; [2.] https://www.capc.org/about/palliative-care/ accessed 09.2019

PC does not shorten the life of people

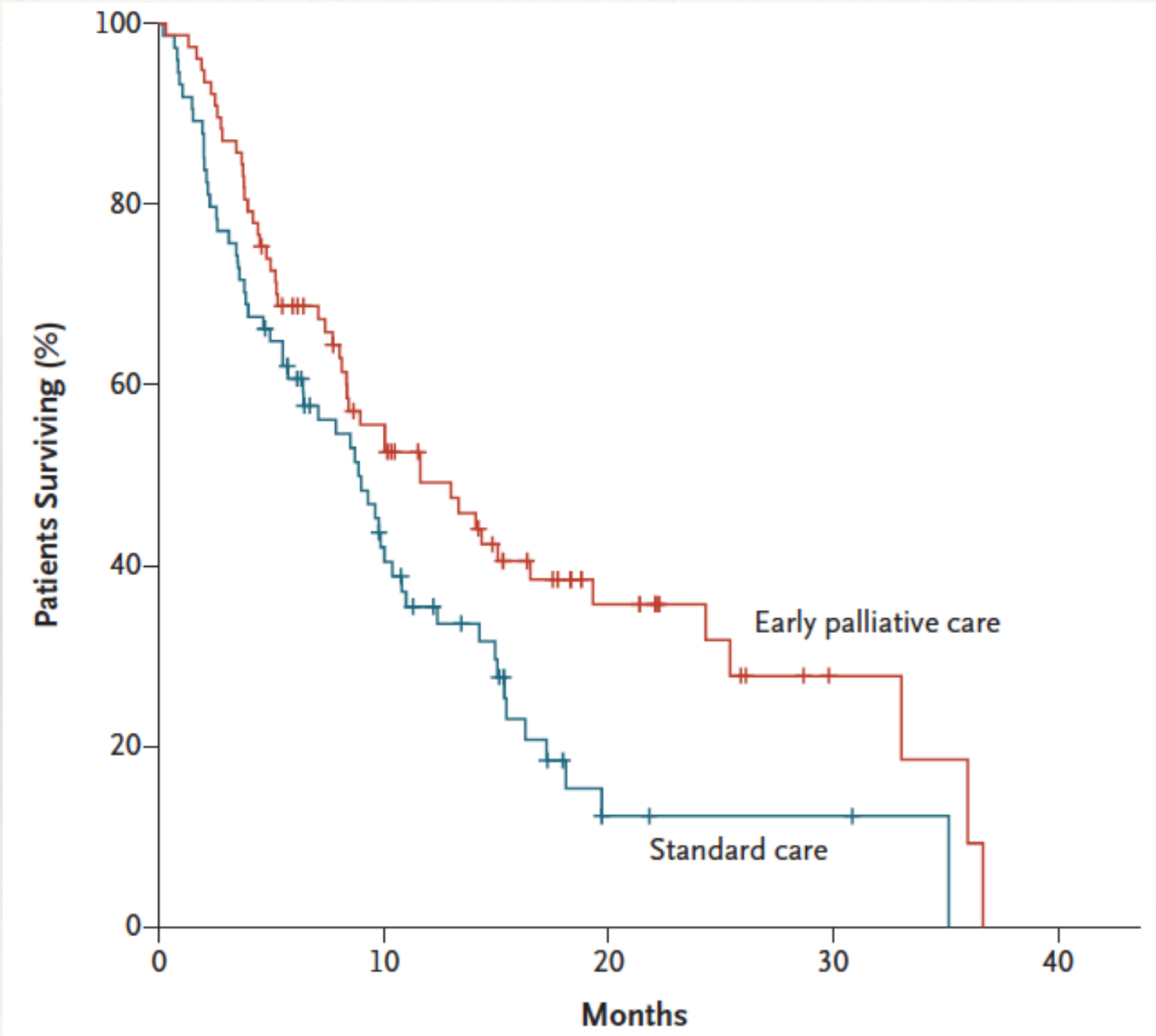


Description of Study Population (Sample Size)

Variable	Hospice ($n = 2095$)	Nonhospice ($n = 2260$)
Disease		
CHF	83 (4%)	457 (20%)

Connor, S. R. (2007). *J Pain Symptom Manage* ***33, 238.***

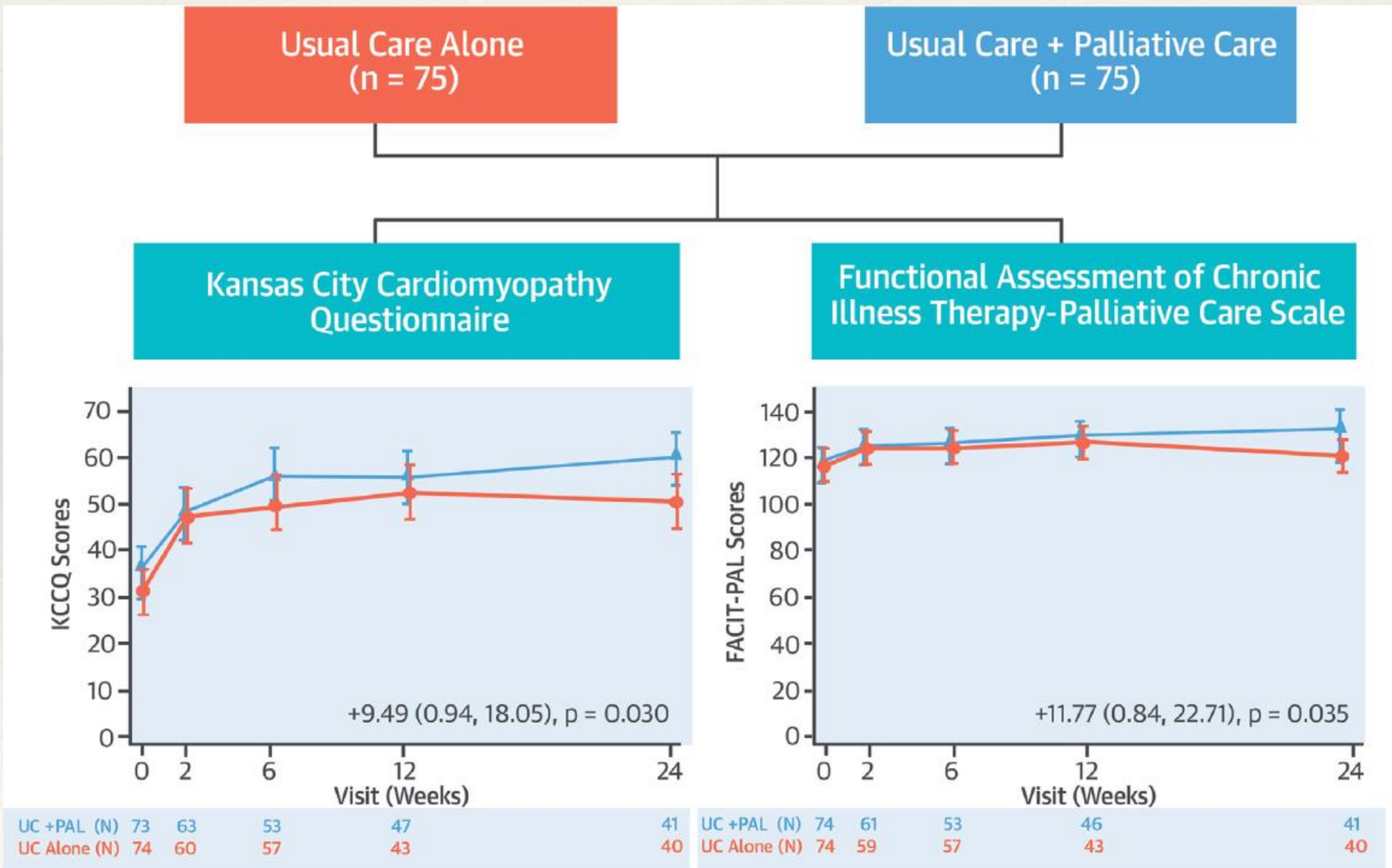
Early PC compared to best standard care



Temel JS. *N Engl J Med 2010;* 363: 733

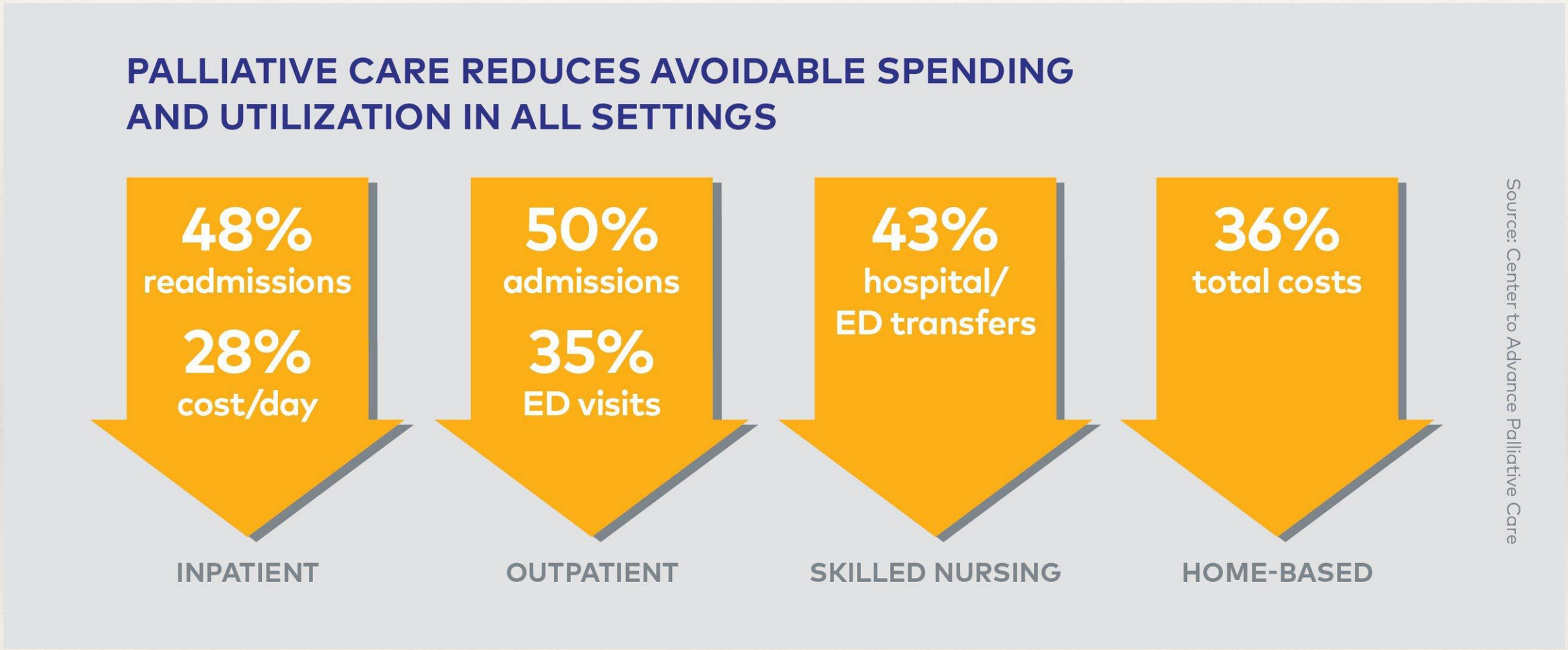
QoL as care - outcome

PAL-HF prospective, randomised, one-centre study; intervention PC for > 6 months added to standard, optimal cardiac care



Rogers, J. G. (2017). *JACC*

PC improves Q measures and resource utilization



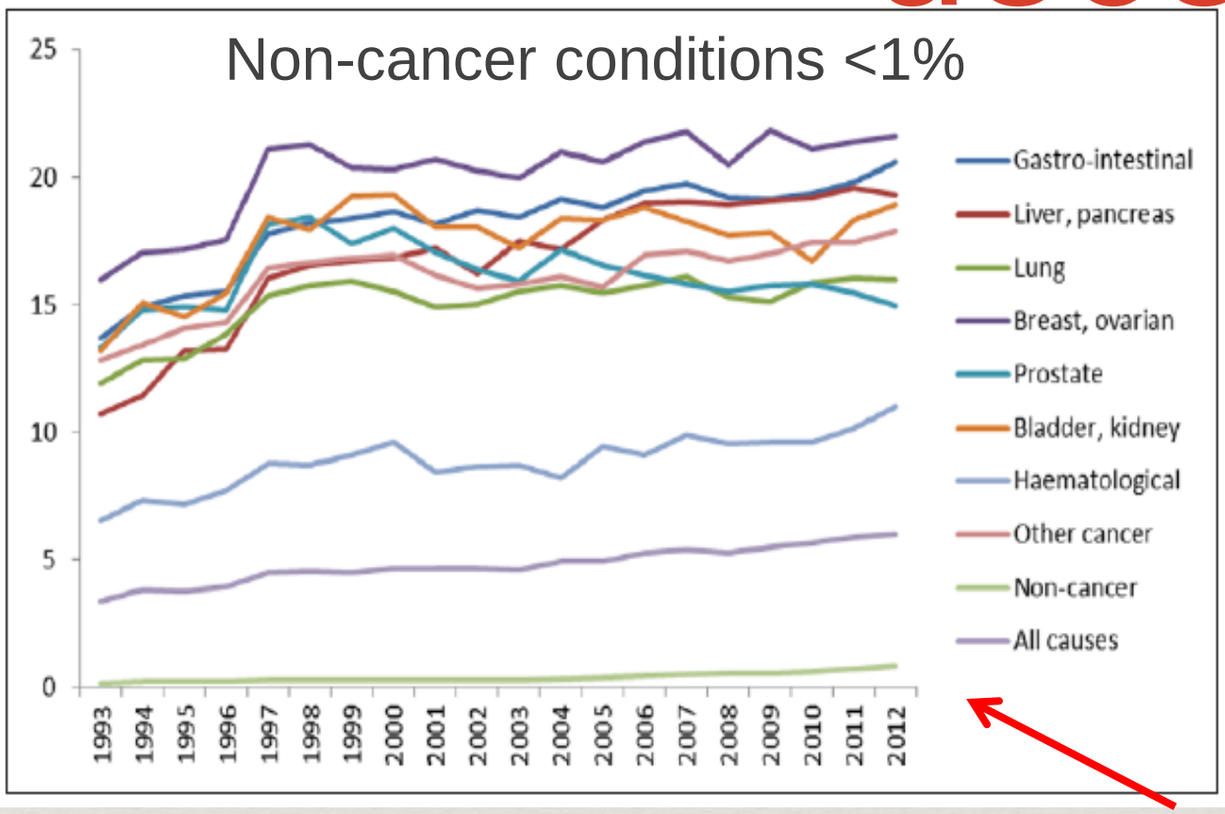
https://www.capc.org/about/palliative-care/ accessed 09.2019

Additional benefits of PC

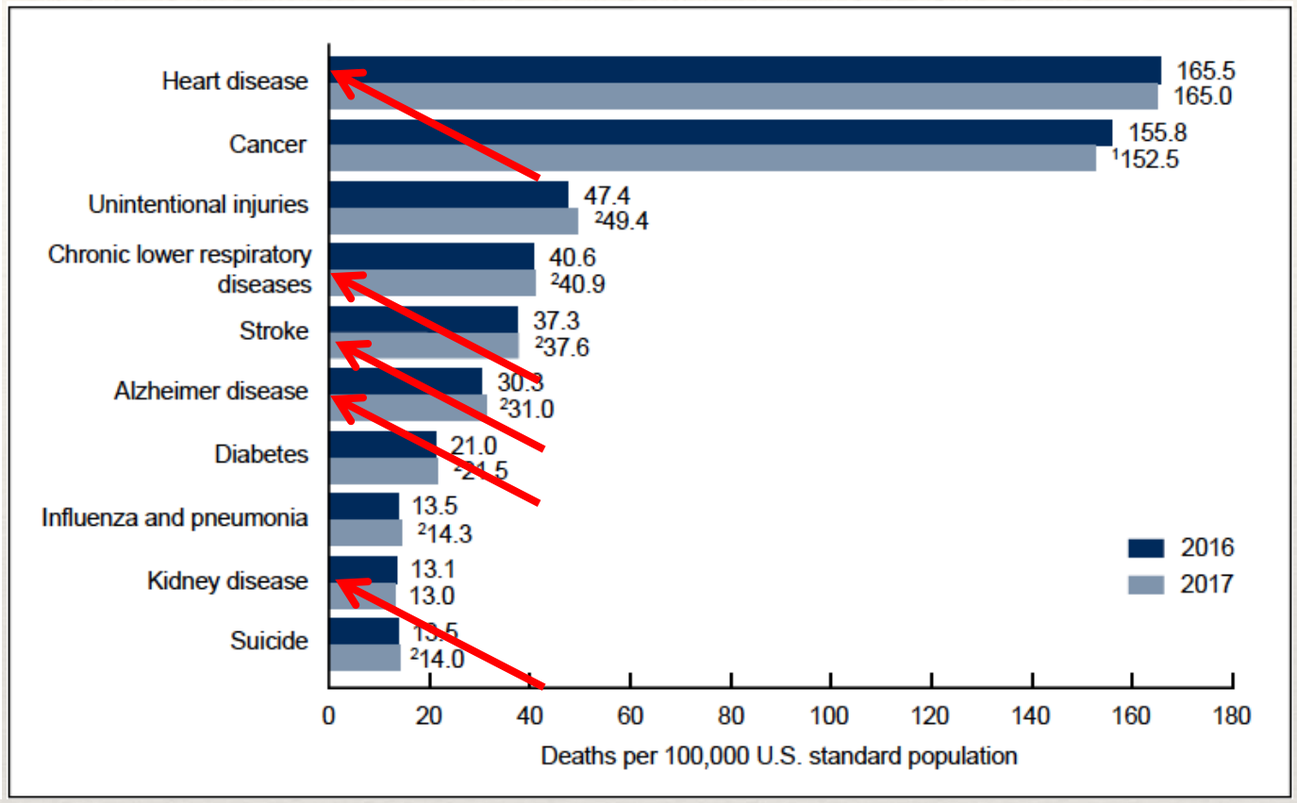
Improved:

- Patient's and relatives' **satisfaction** with care
- Communication
- **Bereavement morbidity**

Diagnoses of hospice decedents



Percentage of deaths in hospice by underlying cause, England 1993-2012

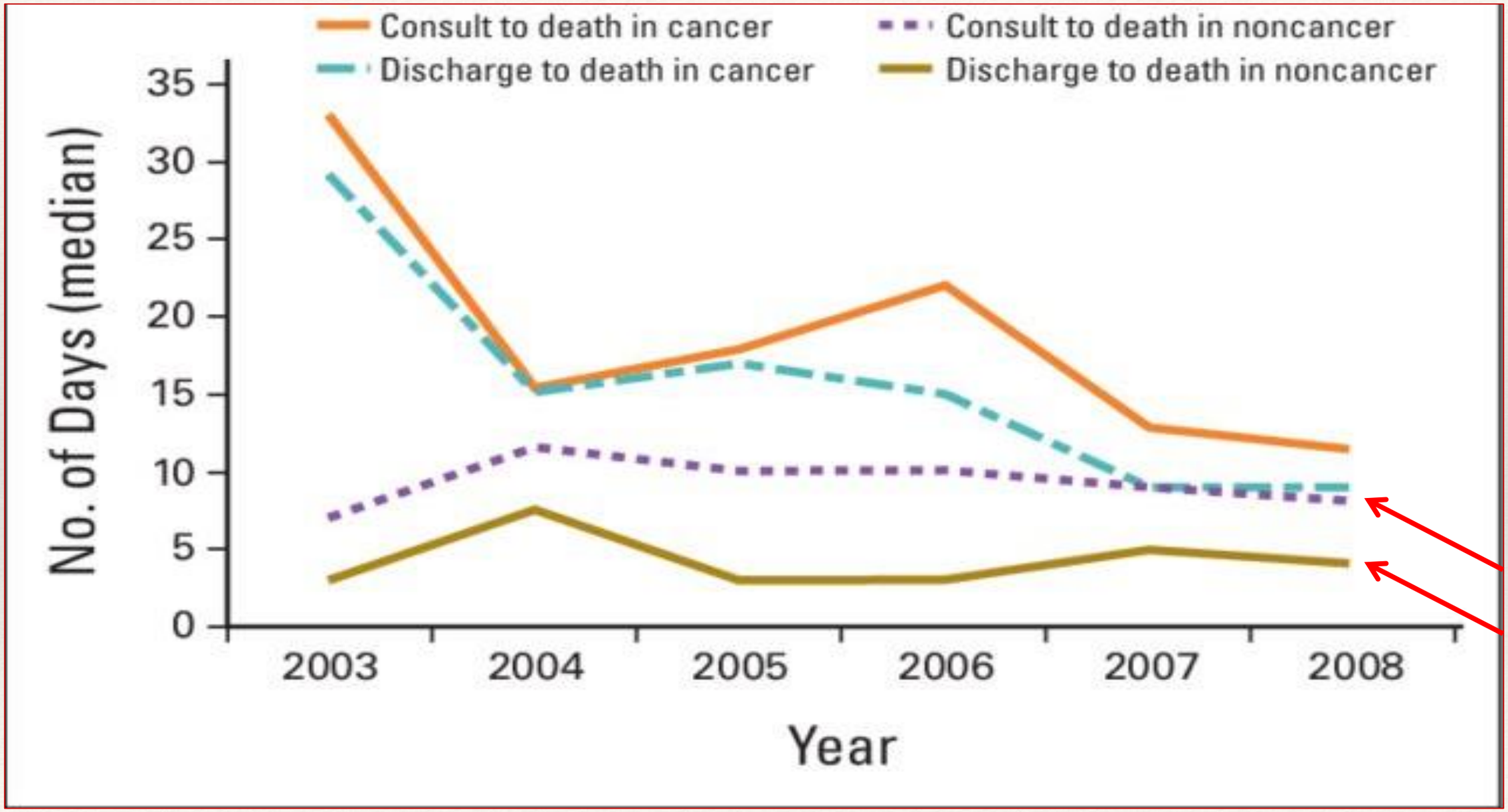


Age-adjusted death rates: United States, 2016 - 2017

Sleeman KE ,2016, 30:45

https://www.cdc.gov/nchs/data/databriefs/db328-h.pdf

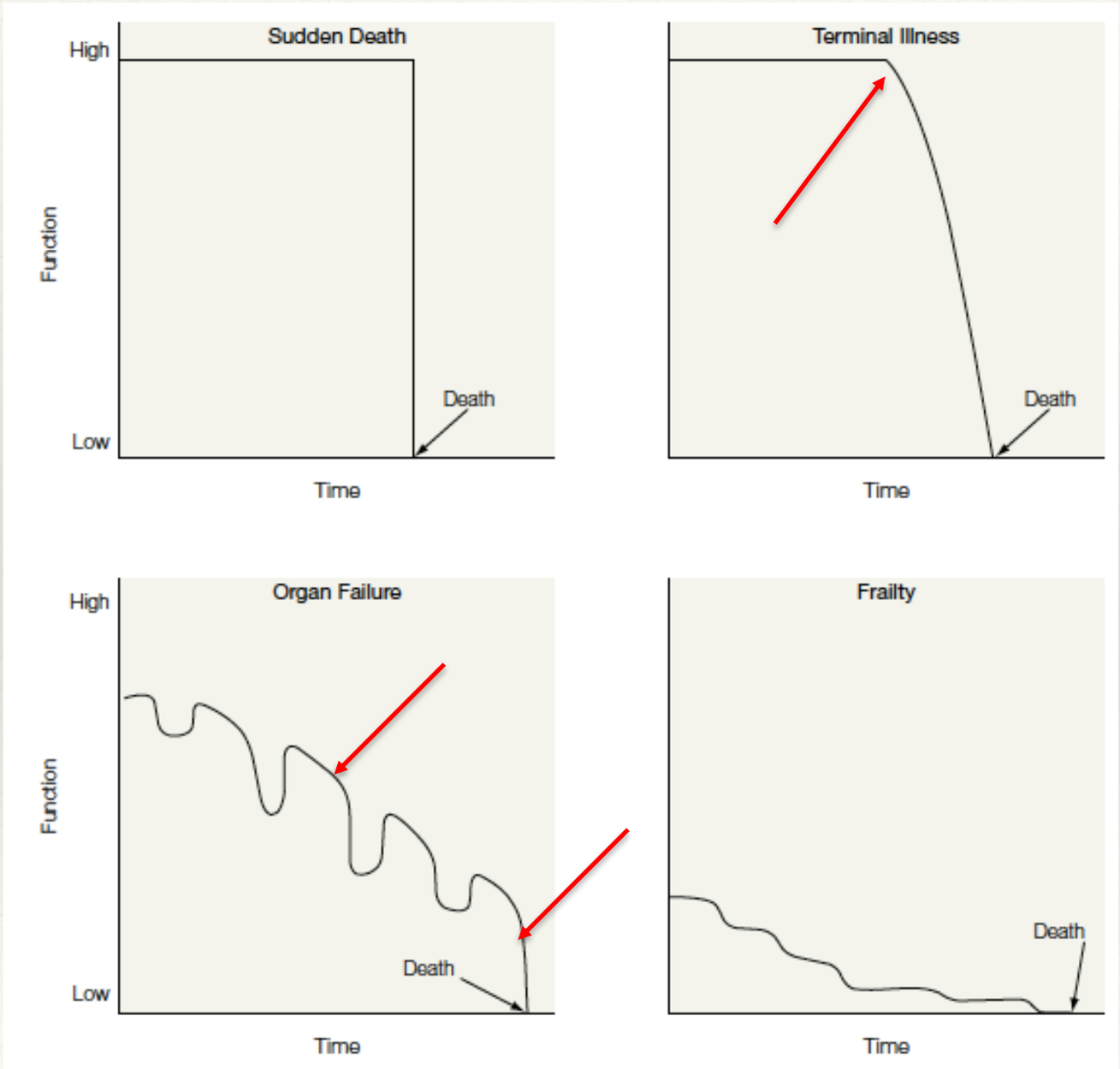
PC consultations – length of survival after first consultation



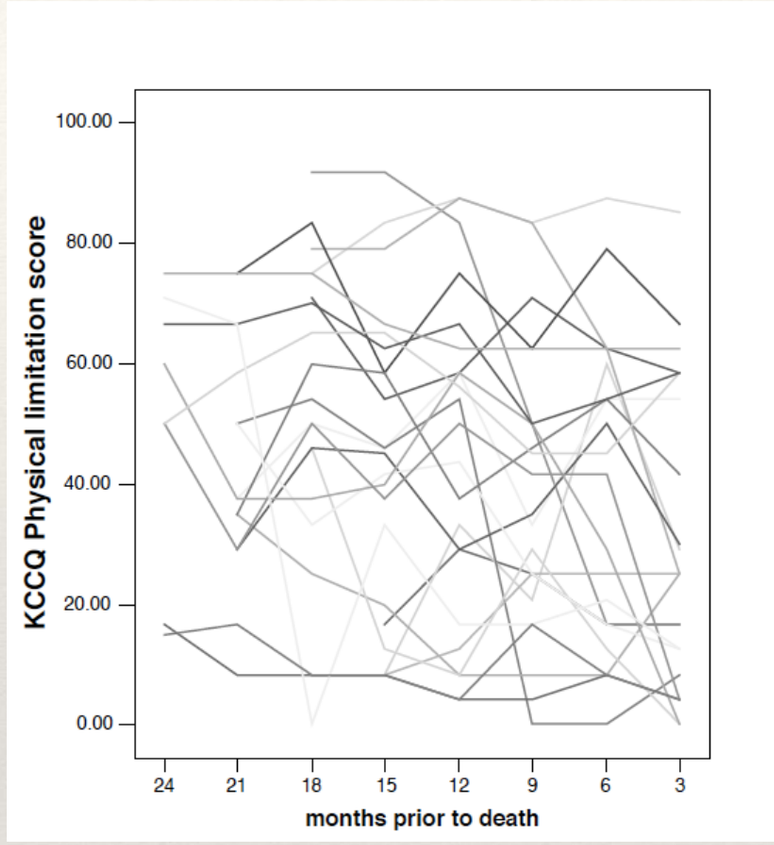
Kamal, A.H. J of Oncol Pract. 2011,

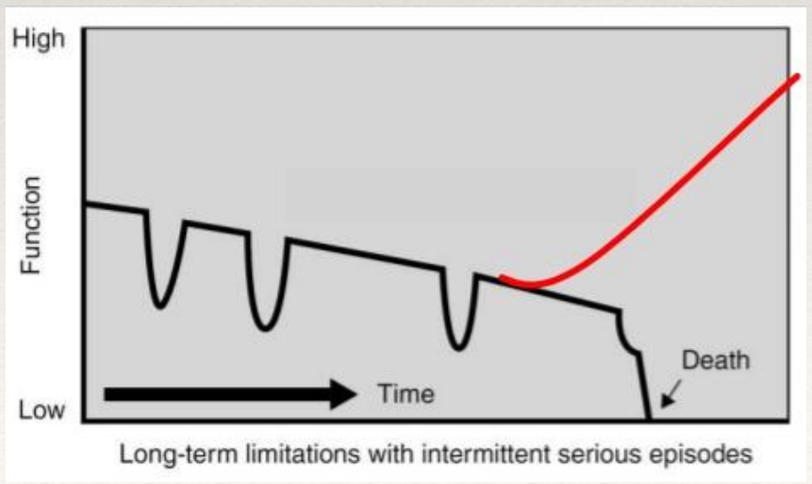
What are the areas of improvement?

Trigers to start implementation of PC



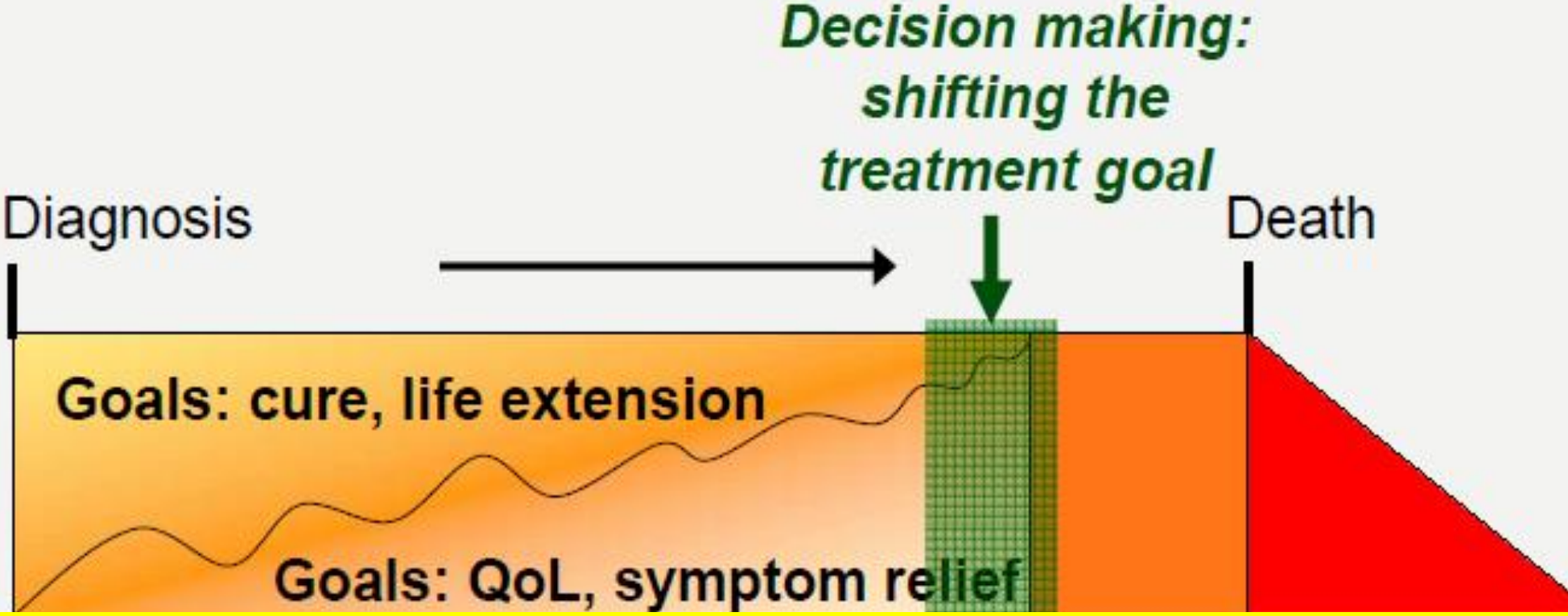
Lunney, J. R. 2003, 289





Gott, M. (2007). *Palliat Med* ***21, 95.***

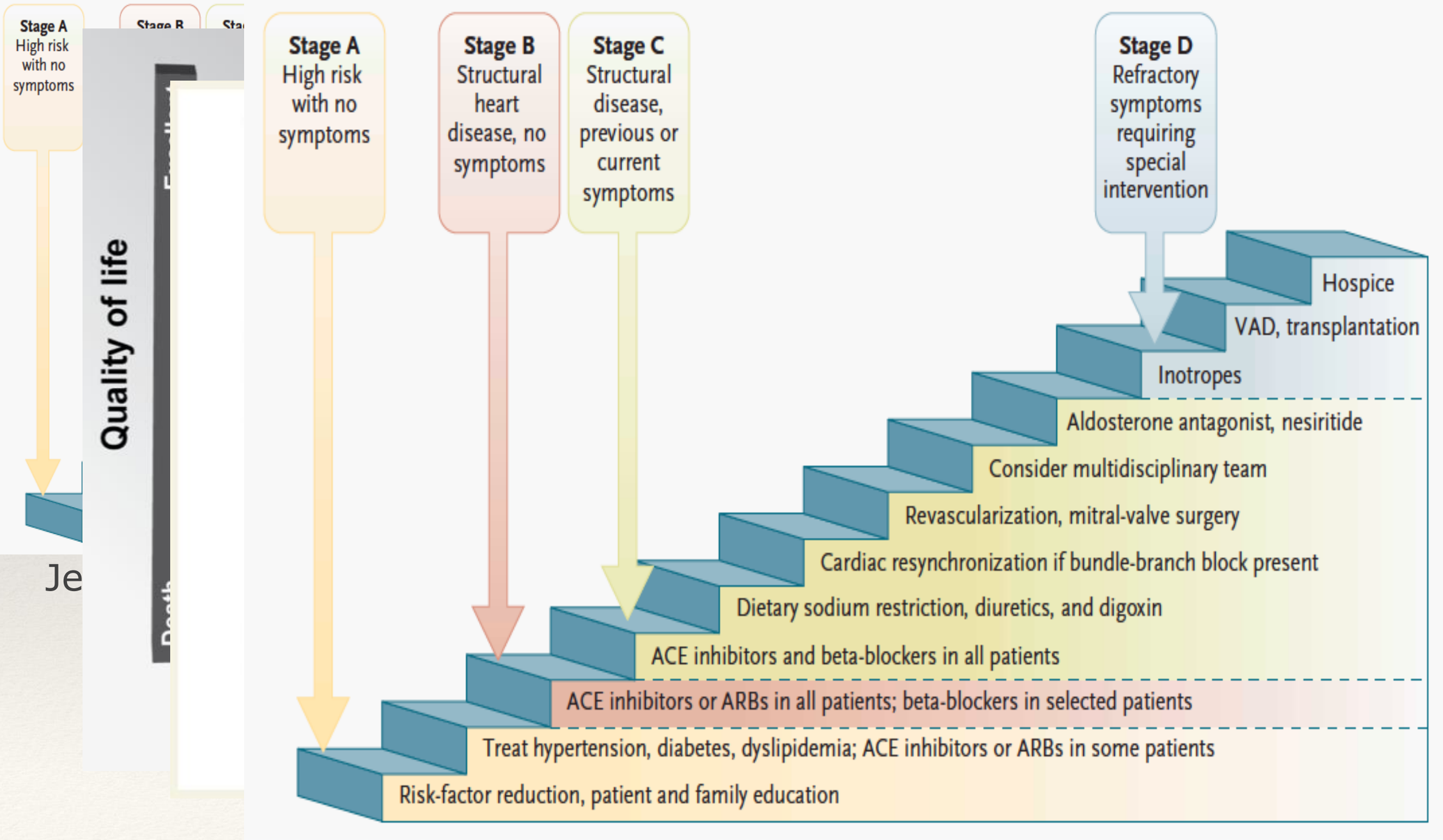
Implementation of PC – PC perspective



PC is common among people receiving EoL care, it **is not** necessarily **restricted to** people with **terminal illnesses**.

CAPC – Center to Advance Palliative Care

Implementation of PC – cardiologic point of view



Sobanski P. 2019: mod. from Allen LA. 2012

2016 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure

EUROPEAN SOCIETY OF CARDIOLOGY®

Table 14.5 Key components of palliative care service in patients with heart failure

Foc her	
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Acc spir	
Adv dea pac	

Therapies and actions to provide palliation of symptoms and improve QoL:

- **Morphine** (with an antiemetic when high doses are

ESC European Society of Cardiology

Cardiovascular Research
doi:10.1093/cvr/cvz200

REVIEW

Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement

Piotr Z. Sobanski [1]*, Bernd Alt-Epping[2], David C. Currow[3,4], Sarah J. Goodlin[5], Tomasz Grodzicki[6], Karen Hogg [7], Daisy J. A. Janssen [8,9], Miriam J. Johnson [10], Małgorzata Krajnik[11], Carlo Leget [12], Manuel Martínez-Sellés[13], Matteo Moroni[14], Paul S. Mueller [15], Mary Ryder [16], Steffen T. Simon[17,18], Emily Stowe [19], and Philip J. Larkin[20,21]

1. When to start PC provision (how to recognise those who could benefit with PC)

The most important & most difficult question

Surprise Question?

Would I be surprised if this patient were to die in the next 12 months

Second surprise Question?

Would I be surprised if this patient is still alive after 12 months”?

Weijers et al. BMC Palliative Care (2018) 17:64
https://doi.org/10.1186/s12904-018-0312-6

BMC Palliative Care

RESEARCH ARTICLE Open Access

Adding a second surprise question triggers general practitioners to increase the thoroughness of palliative care planning: results of a pilot RCT with cage vignettes

F. Weijers†, C. Veldhoven†, C. Verhagen, K. Vissers and Y. Engels*

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assess these people for unmet supportive and palliative care needs.

Look for general indicators of deteriorating health.

- Unplanned hospital admissions.
- Performance status is poor or deteriorating, with limited reversibility; (person is in bed or a chair for 50% or more of the day).
- Dependent on others for care due to physical and/or mental health problems.
- More support for the person's carer is needed.
- Significant weight loss over the past 3-6 months, and/ or a low body mass index.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- Person or family ask for palliative care, treatment withdrawal/limitation or a focus on quality of life.

Look for clinical indicators of one or more advanced conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

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

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

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 swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

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

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

Severe, inoperable 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.

Deteriorating and at risk of dying with any other condition or complication that is not reversible.

Review current care and care planning.

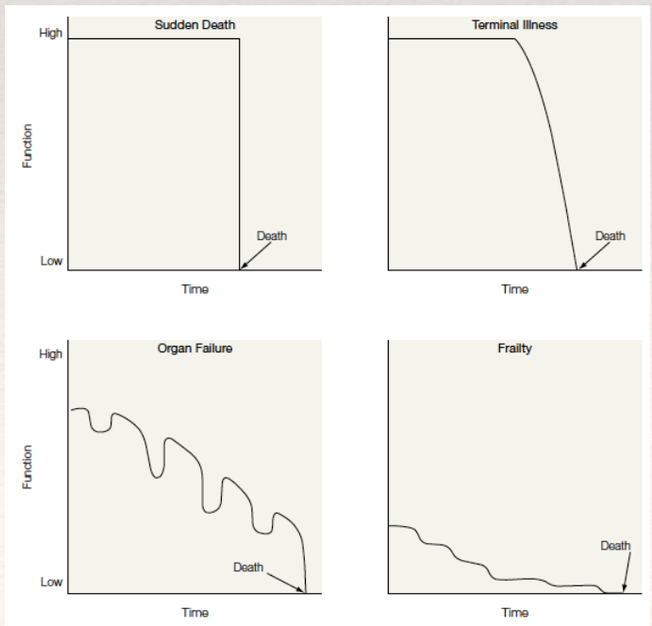
- Review current treatment and medication so the person receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the person and their family.
- Plan ahead if the person is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2016

Supportive and PC Indicators Tool

SPICT



the needs
the symptoms
the suffering

≠

the risk of deterioration
the risk of dying

Implementation of PC based on needs assessment

Needs Assessment Tool
Progressive Disease – HF

NAT: PD - HF

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

	Yes	No	If yellow boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?			
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?			
3. Do you require assistance in managing the care of this patient and/or family?			

SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the patient experiencing unresolved physical symptoms (including problems with breathlessness, pain, fatigue, nausea, oedema, insomnia or cough)?						
2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about how to manage his/her medication and treatment regimes?						
5. Does the patient have concerns about spiritual or existential issues?						
6. Does the patient have financial or legal concerns that are causing distress or require assistance?						
7. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						

8. Does the patient require information about: (tick any options that are relevant) ☐ The prognosis ☐ Treatment options ☐ Heart disease ☐ Advance directive/resuscitation preferences ☐ Medical/health/support services ☐ Financial/legal issues ☐ Social/emotional issues

COMMENTS: _____

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Is the caregiver have difficulty managing the patient's medication and treatment regimes?						
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						

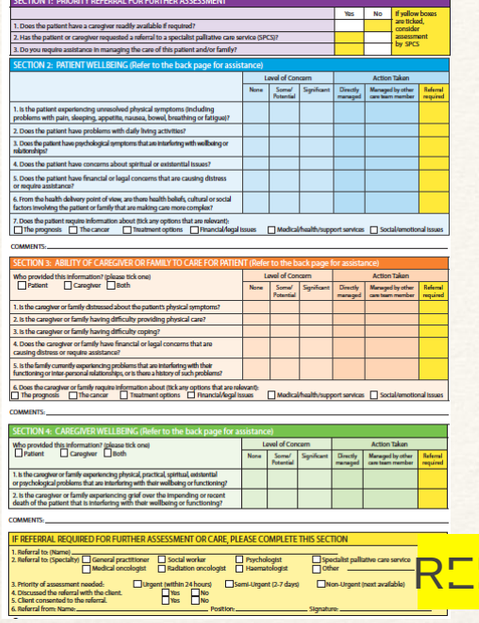
7. Does the caregiver require information: (tick any options that are relevant) ☐ The prognosis ☐ Treatment options ☐ Advance directive/resuscitation preferences ☐ What to do in event of patient's death ☐ Medical/health/support services ☐ Social/emotional issues ☐ Heart disease ☐ Financial /legal issues

COMMENTS: _____

SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?						

COMMENTS: _____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2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about spiritual or existential issues?						
5. Does the patient have financial or legal concerns that are causing distress or require assistance?						
6. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						

7. Does the patient require information about (tick any options that are relevant):
☐ The prognosis ☐ The cancer ☐ Treatment options ☐ Financial/legal issues ☐ Medical/health/support services ☐ Social/emotional issues

COMMENTS:

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both

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5. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						

6. Does the caregiver or family require information about (tick any options that are relevant):
☐ The prognosis ☐ The cancer ☐ Treatment options ☐ Financial/legal issues ☐ Medical/health/support services ☐ Social/emotional issues

COMMENTS:

SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)

Who provided this information? (please tick one) ☐ Patient ☐ Caregiver ☐ Both

	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly managed	Managed by other care team member	Referral required
1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?						

COMMENTS:

IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION

1. Referral to (Name): _____
2. Referral to (Specialty): ☐ General practitioner ☐ Social worker ☐ Psychologist ☐ Specialist palliative care service ☐ Medical oncologist ☐ Radiation oncologist ☐ Haematologist ☐ Other _____
3. Priority of assessment needed: ☐ Urgent (within 24 hours) ☐ Semi-Urgent (2-7 days) ☐ Non-Urgent (next available)
4. Discussed the referral with the client. ☐ Yes ☐ No
5. Client consented to the referral. ☐ Yes ☐ No
6. Referral from: Name: _____ Position: _____ Signature: _____

NAT: PD / HF

https://www.eapcnet.eu/eapc-groups/task-forces/heart-disease

REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE

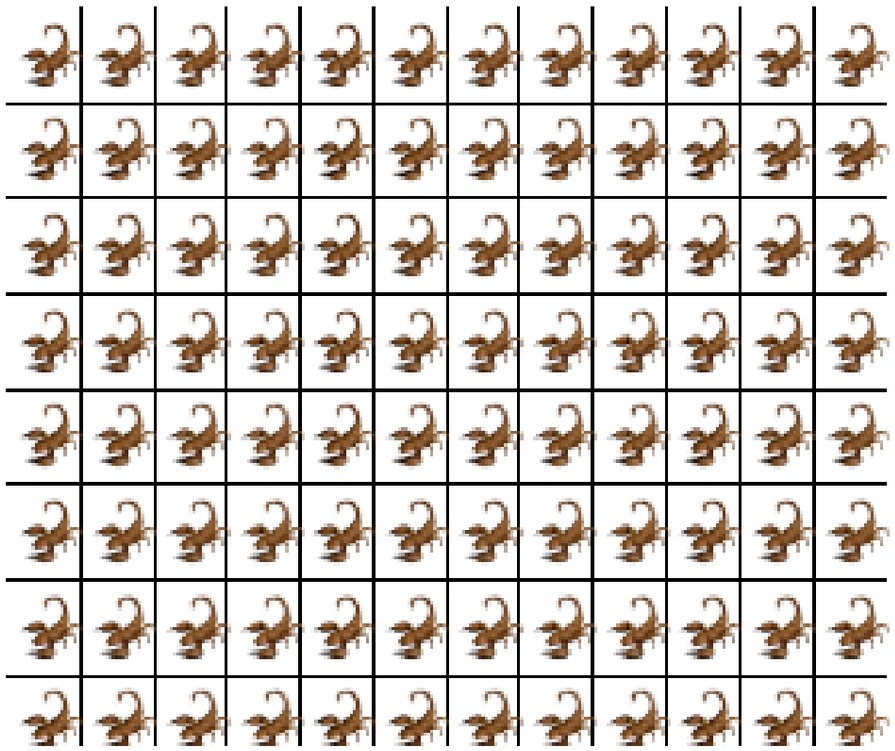
PRIORITY REFERRAL FOR FURTHER ASSESSMENT	PATIENT WELLBEING	ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT	CAREGIVER WELLBEING
• a caregiver readily available if required? • patient or caregiver requesting a referral to a specialist PC service? • assistance needed in managing the care of this patient and/or family?	• unresolved physical symptoms? • problems with daily living activities? • psychological symptoms interfering with wellbeing or relationships? • concerns about spiritual or existential issues? • financial or legal concerns? • health beliefs, cultural or social factors involving the patient or family that are making care more complex? • Information required (about disease, treatment, possible support…)?	• caregiver or family: • distressed about the patient's physical symptoms? • having difficulty providing physical care? • having difficulty coping? • financial or legal concerns that are causing distress? • problems interfering with functioning of family, inter-personal relationships, or a history of such problems?	•physical, practical, spiritual, existential or psychological problems interfering with caregivers wellbeing or functioning? •grief over the impending or recent death that is interfering with wellbeing or functioning?

2. What are the most appropriate models of PC

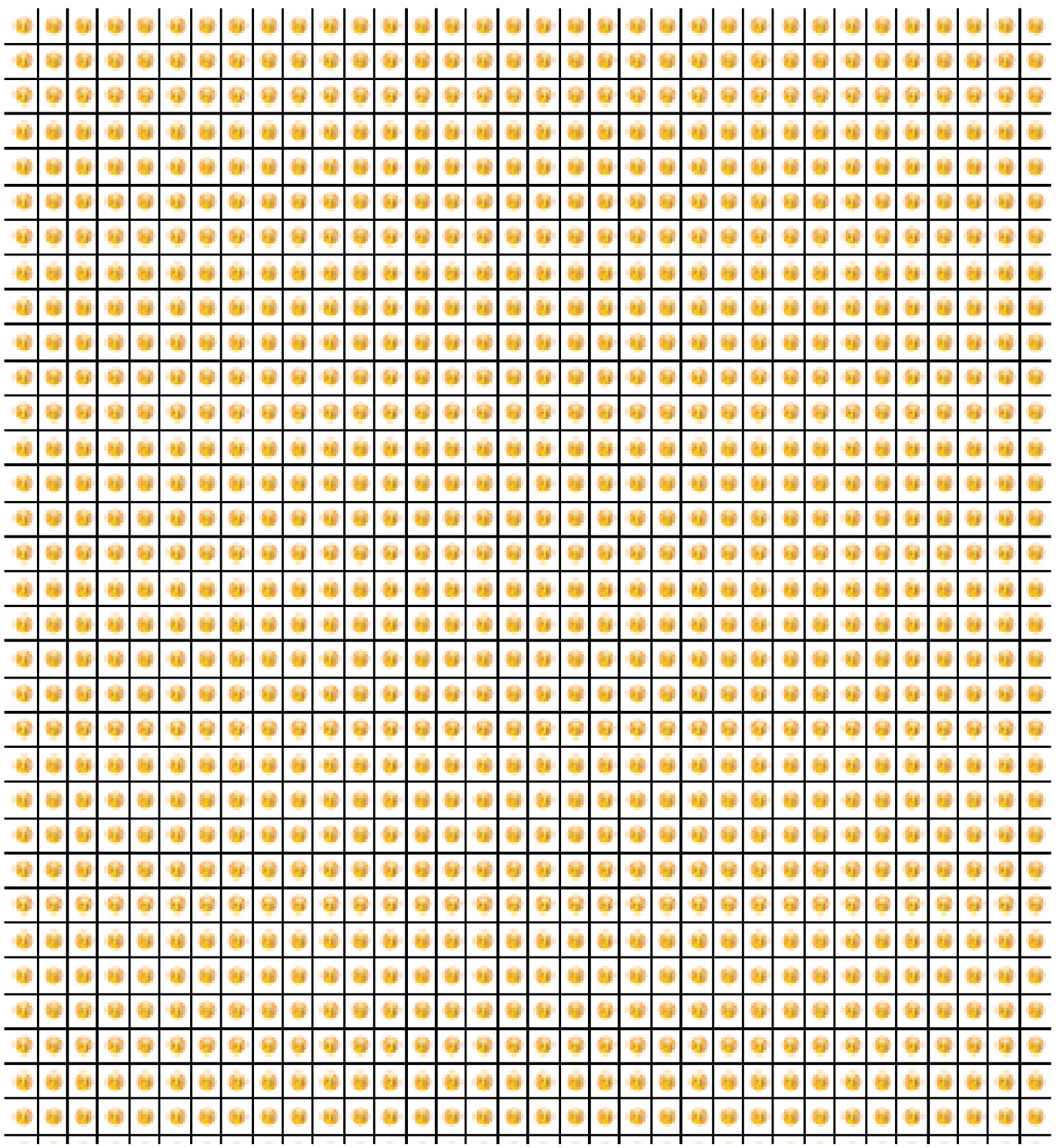
One specialist for every

cardiologist for 71 with AMI

oncologist for 141 with new cancer



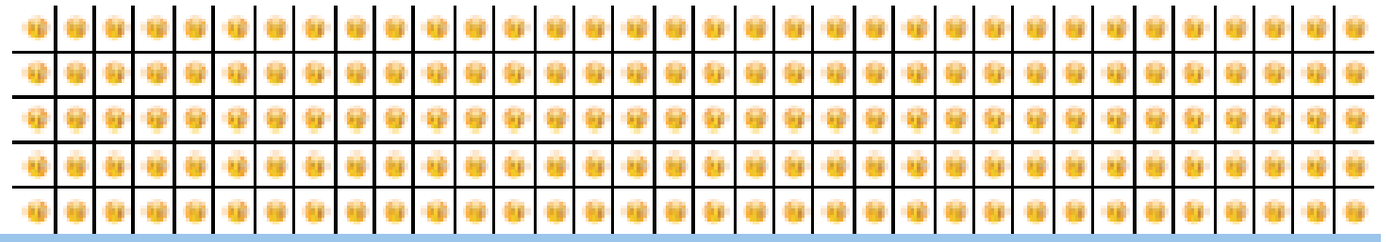
PC for 1200 with serious or life-threat. disease



Primary and Sepecialist PC

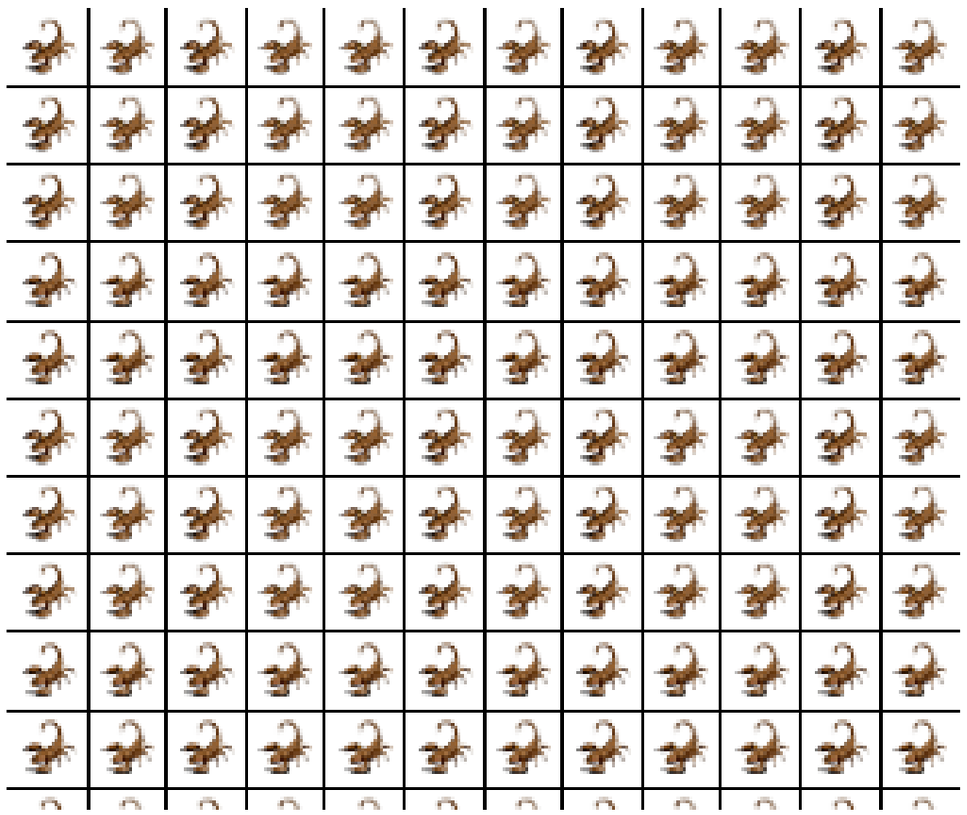
cardiologist for 71 with AMI

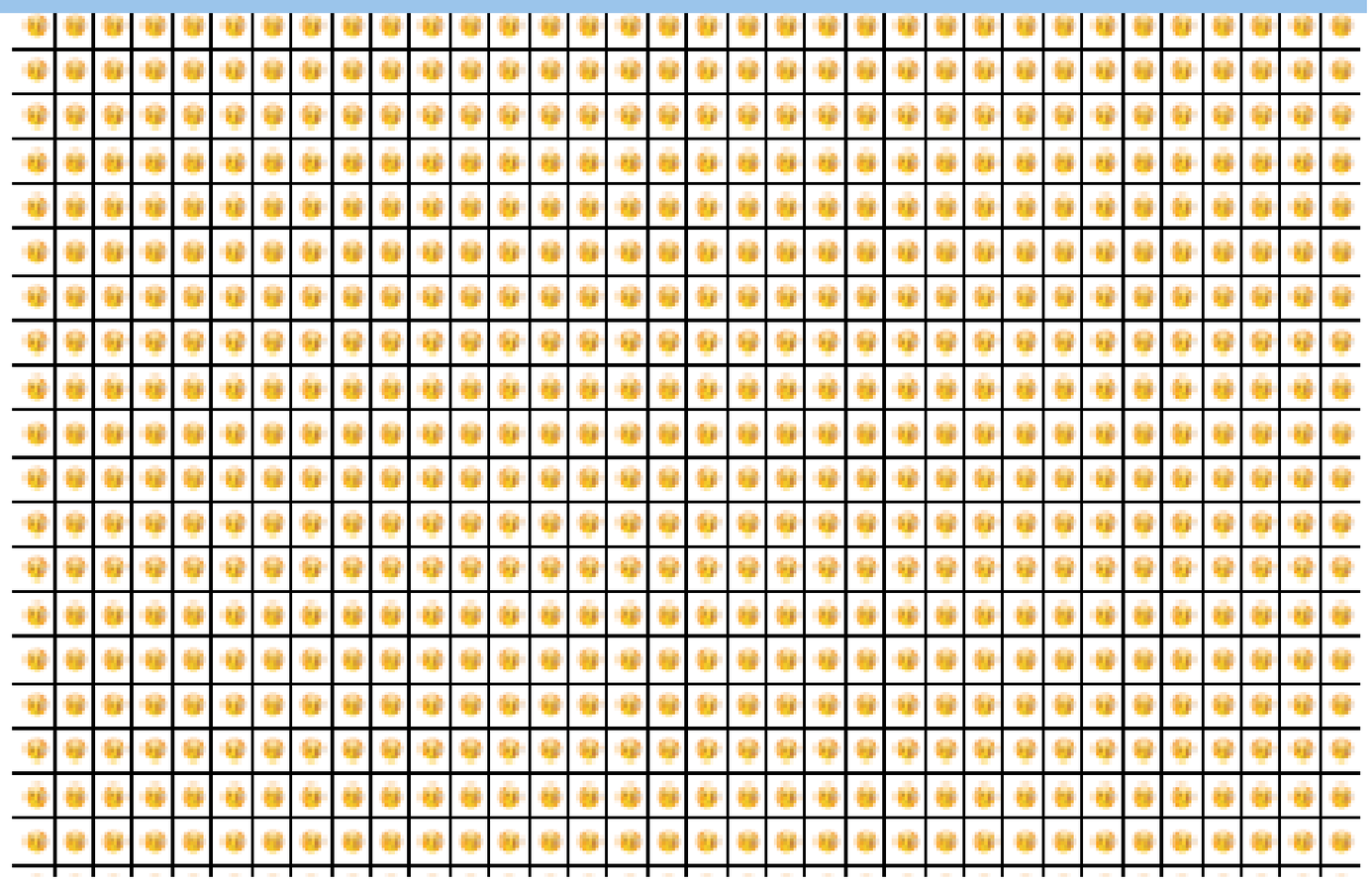
PC for 1200 with serious or life-threat. disease



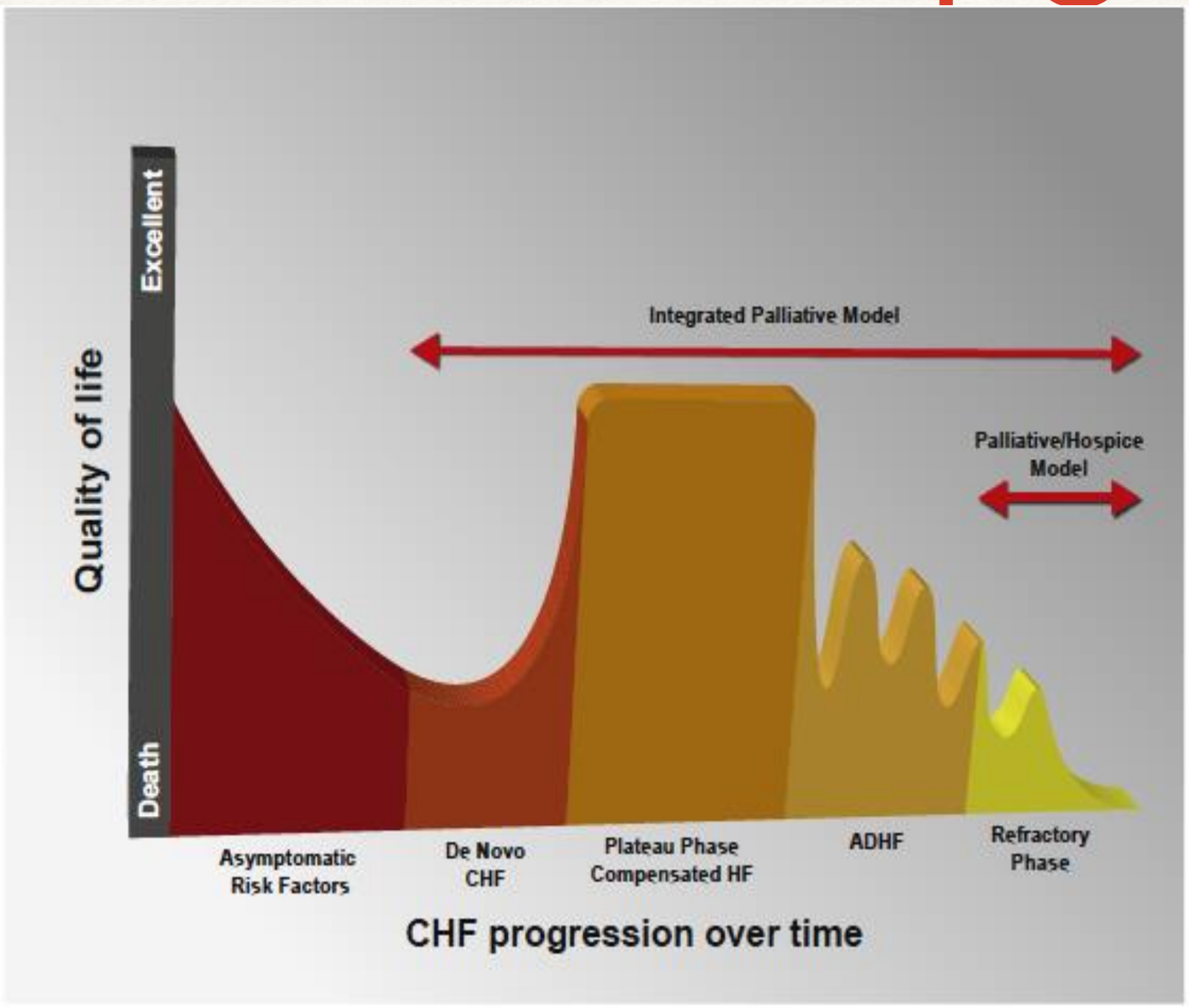
additional 18.000 PC physicians would be needed to meet inpatients consultation needs

oncologist for 141 with new cancer





How to integrated specialised PC

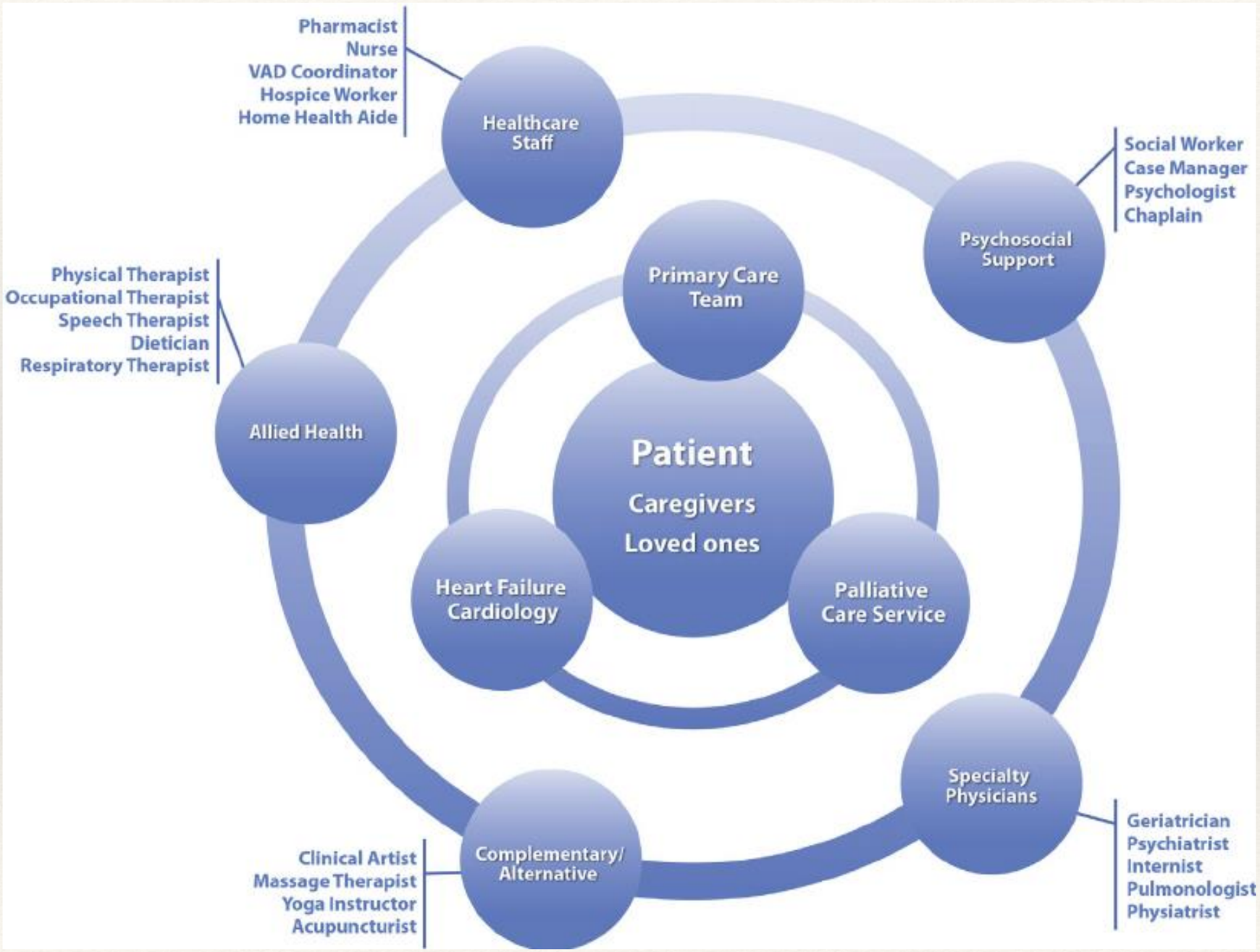


Possible forms of integration

- improvement of basic PC skills all healthcare professionals,
- delegating staff (HF nurse, physician) to get basic knowledge on PC
- cooperating with PC Team (supportive in hospital team)
- PC specialist liason
- fix PC specialist post (heart centers, cardiologic hospitals) dedicated to cardiology

Meyers, D.E. and S.J. Goodlin, Can J Cardiol, 2016. **32**(9)

Caring together



3. What need to be improved in the knowledge about the elements of PC

Symptom Management

Decision making

Network working

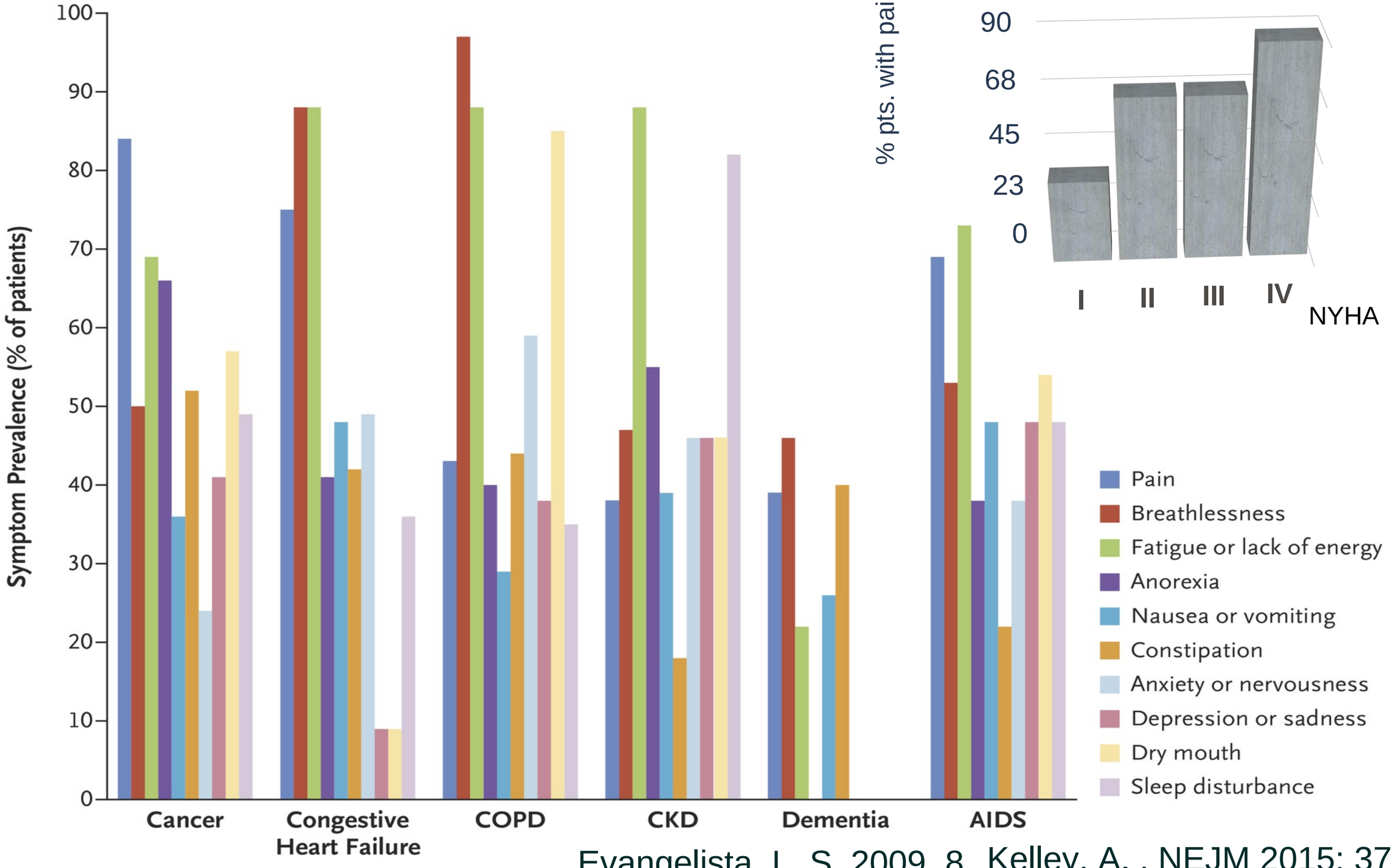
Support

End of life

Bereavement

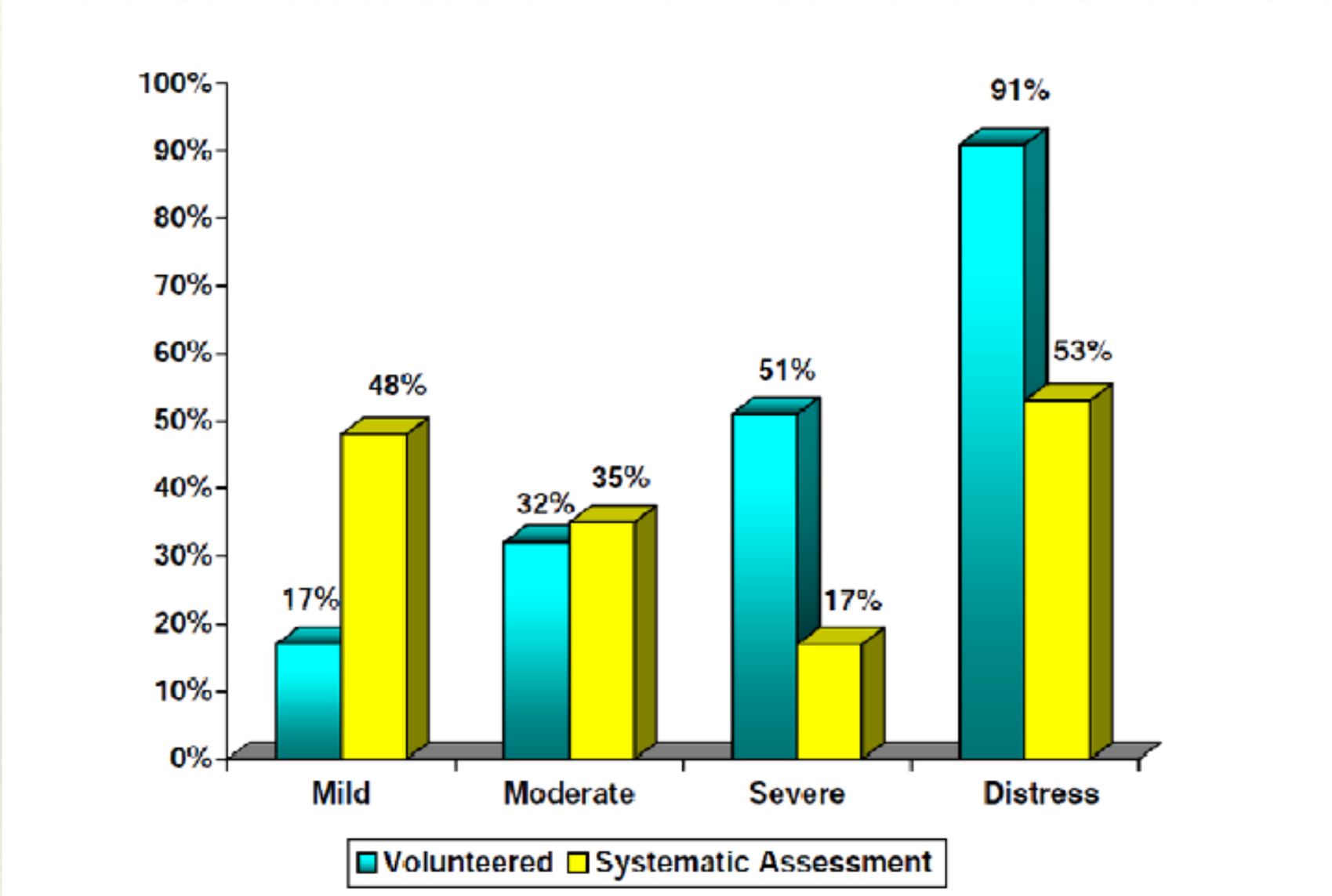
Palliative CARE Team

Symptom prevalence in serious disease



Evangelista, L. S. 2009, 8 Kelley, A. , NEJM 2015; 373

Symptom reporting



On average patients report spontaneously 1 symptom,
and 10 different symptoms – when assessed systematically

Homsi J. 2006 May;14(5):444

Elements of PC management most relevant in care for people with HF

Topic	Description	Clinical implications for care people with heart failure
Breathlessness—palliative management	Breathlessness (at rest or at slight exertion) persisting despite continuously optimized cardiologic treatment should be recognized as indication for symptomatic management.	Multi-modal PC management including breathing-relaxation training, cognitive-behavioural therapy, walking aids, hand-held fans, and low-dose oral morphine may improve breathlessness intensity, unpleasantness and/or its impact of the functional capacity.
Pain management	Pain is a common symptom among people with HF, often being caused by concomitant disease and requires symptomatic management.	Local and non-pharmacological therapies should be applied if applicable. Opioids should be considered for pharmacologic pain management in people with heart failure, taking into account renal function. Systemic non-steroid anti-inflammatory drugs are contraindicated. Paracetamol is considered as free of undesirable cardiovascular side effects.
Depression management	Depression as common comorbidity, increasing risk of rehospitalization, and limiting the QoL	Depression should be actively sought. The management should be based on multi-modal interventions (including cognitive behavioural therapy) with the pharmacotherapy based on selected SSRI or mirtazapine, as second line intervention.

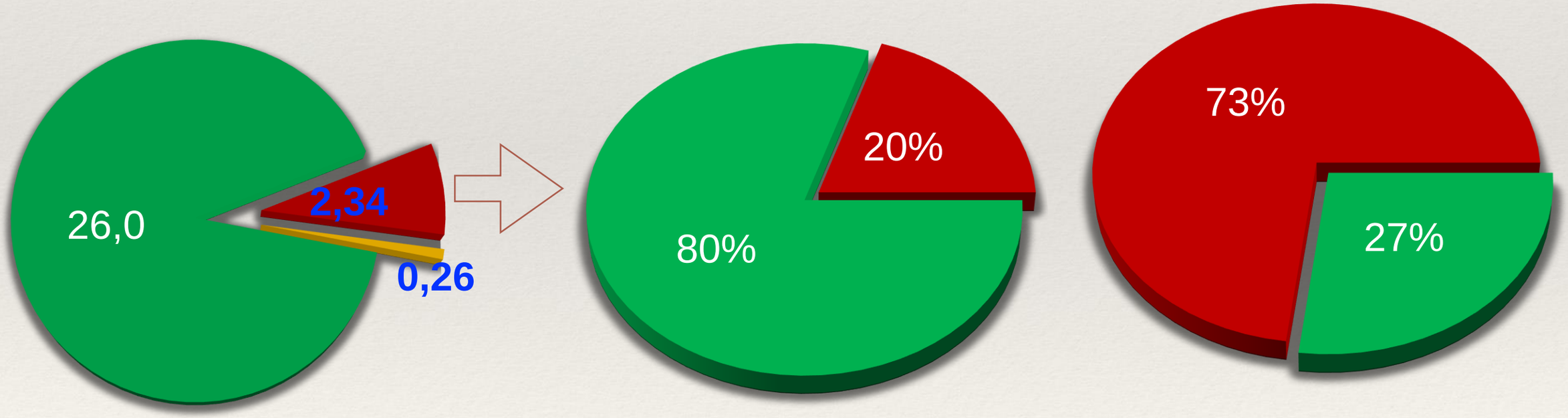
Sobanski, P Cardiovasc Res. 2019,

Breathlessness „invisible symptom”

Breathlessness at rest or at slight exertion (IIIB/IV NYHA)

Treatment gap chronic breathlessness related to HF

Treatment gap after HF related hospitalization



Mililions of people living with HF
2.34 Mio - AHF with breathlessness,
0.26 Mio – AHF without breatlessness

*Mozaffarian, D.(2016) Circulation
**Vicent, L. (2017) BMC Palliat Car

Patients` interpretation of breathlessness

- Patients rather adjust their activities as report breathlessness as a symptom
- Patients are rather explain breathlessness with aging or needing to slow down, as seek medical help

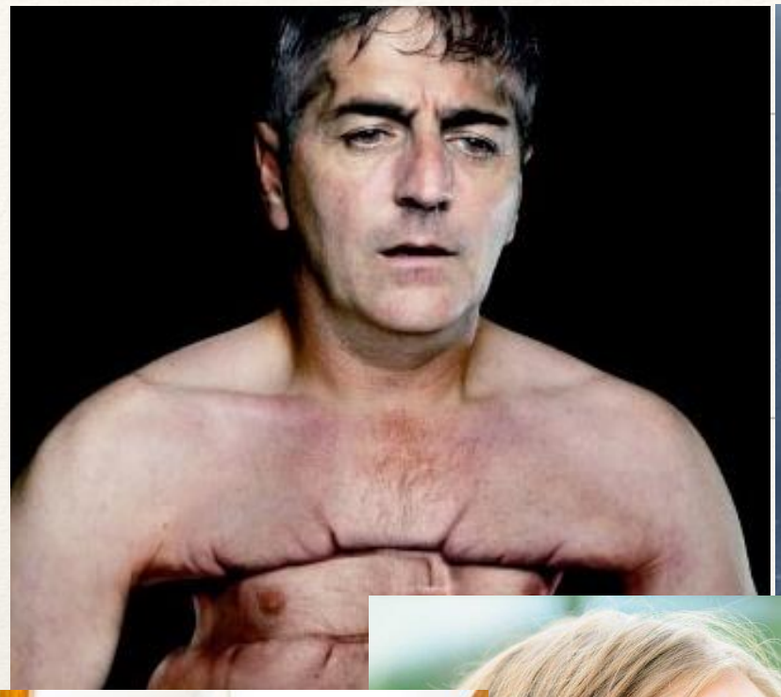
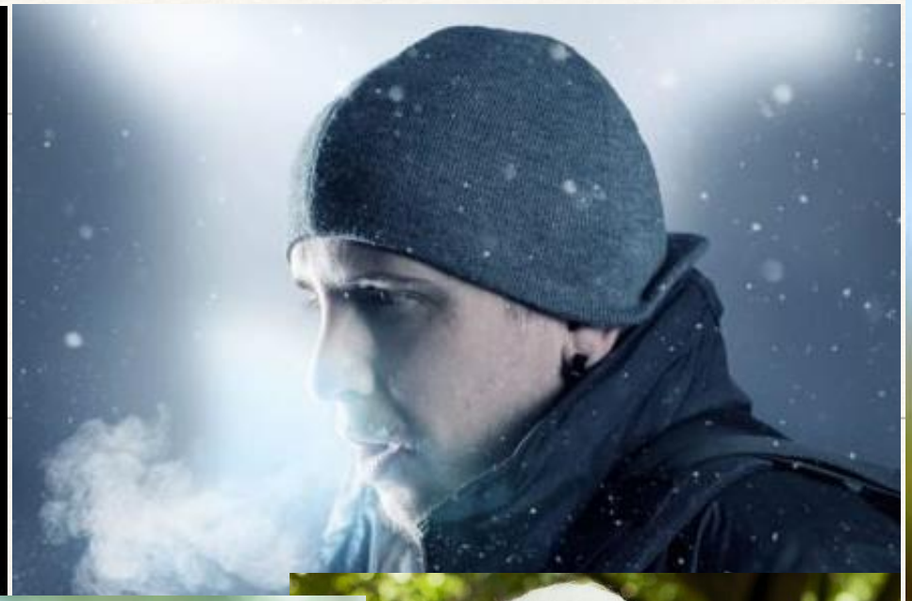
- Are you breathless? ✗
- How does breathlessness affect you at home? ✓

Episodic Breathlessness - dynamics of clinical presentation

Type	Characteristic / description
Trigged, normal level of breathlessness	Late onset, quick recovery. *Typical for heavy exertion*.
Triggered, predictable response*	**Certain level of trigger causes predictable severity of breathlessness, gradual increase and decrease. *Typical exertional dyspnoea, even moderate exertion can trigger severe breathlessness.***
Triggered, unpredictable response	Severity of breathlessness unpredictable, not proportional to intensity of trigger. Very limited exercise can evoke very severe dyspnoea.
Non-triggered, attack-like*	**Unpredictable, without warning, often rapid onset and severe breathlessness, sometimes very short lasting.**
Non-triggered or triggered, wave-like	Gradually onset, mostly severe. *Typical for COPD*.

* typical for HF

Simon ST, 2013;45:1019

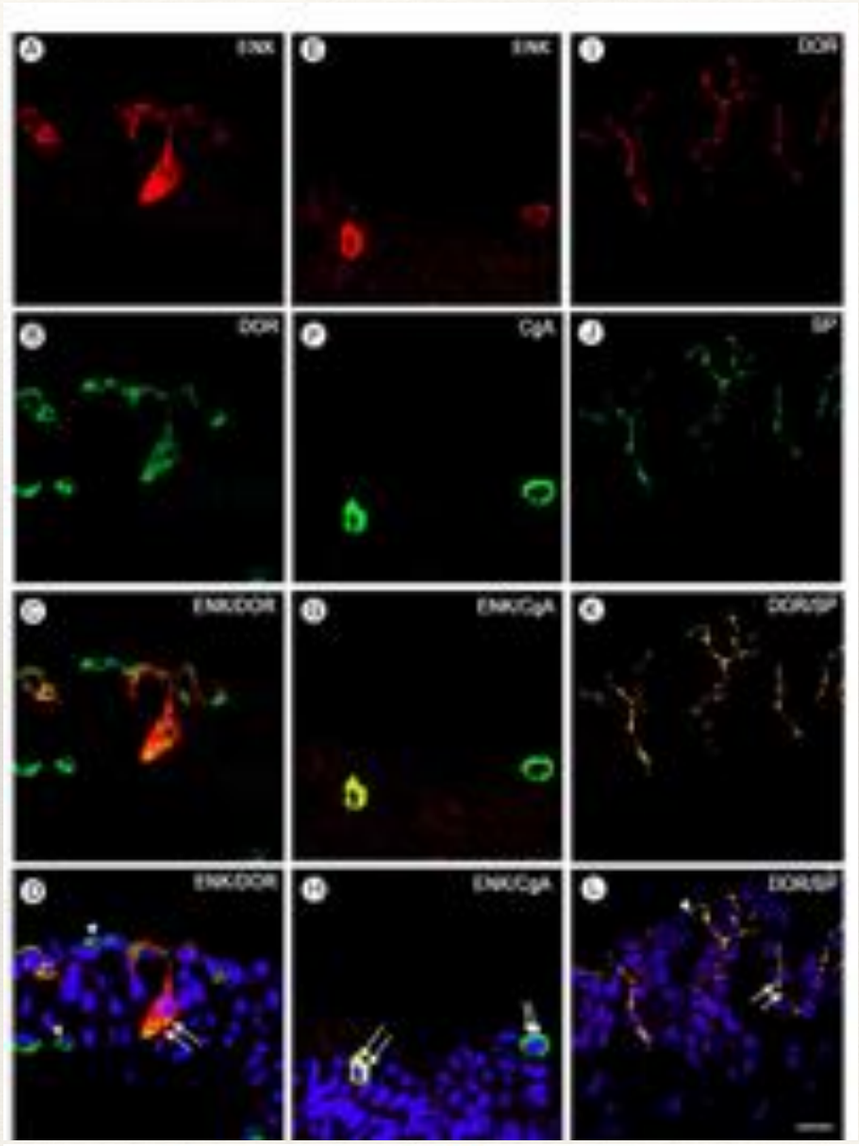



you for your at

There is no „the breathlessness“, and no „the pathophysiology“ - there will not be „the intervention“ to treat it

Pulmonary neuroendocrine cells (PNEC & NEBs)

- 1% of total airways epithelial cells
- Synthesise and release 5HT, ACh, CGRP, Chromogranin A, ATP
- Afferent innervation by n. vagus, dorsal booth ganglia dendrits



Enkephalin, its precursor, processing enzymes, and receptor as part of a local opioid network throughout the respiratory system of lung cancer patients

Malgorzata Krajnik MD[a,1], Michael Schäfer MD[b,1], Piotr Sobanski MD[c], Janusz Kowalewski MD, PhD[d], Elzbieta Bloch-Boguslawska MD[e], Zbigniew Zylicz MD, PhD[f], Shaaban A. Mousa PhD[b,*]

RESEARCH ARTICLE Open Access

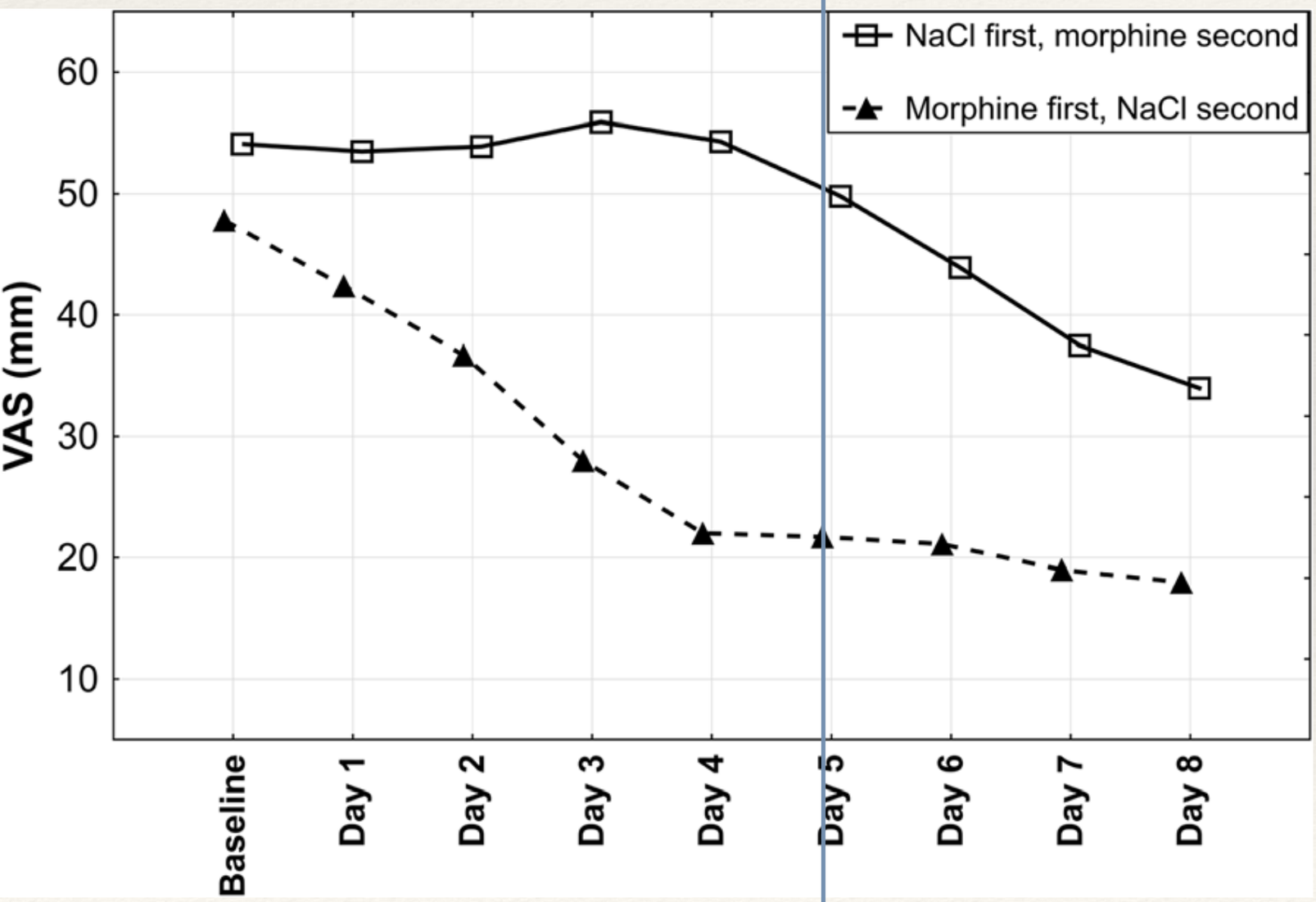
Dosimetrically administered nebulized morphine for breathlessness in very severe chronic obstructive pulmonary disease: a randomized, controlled trial

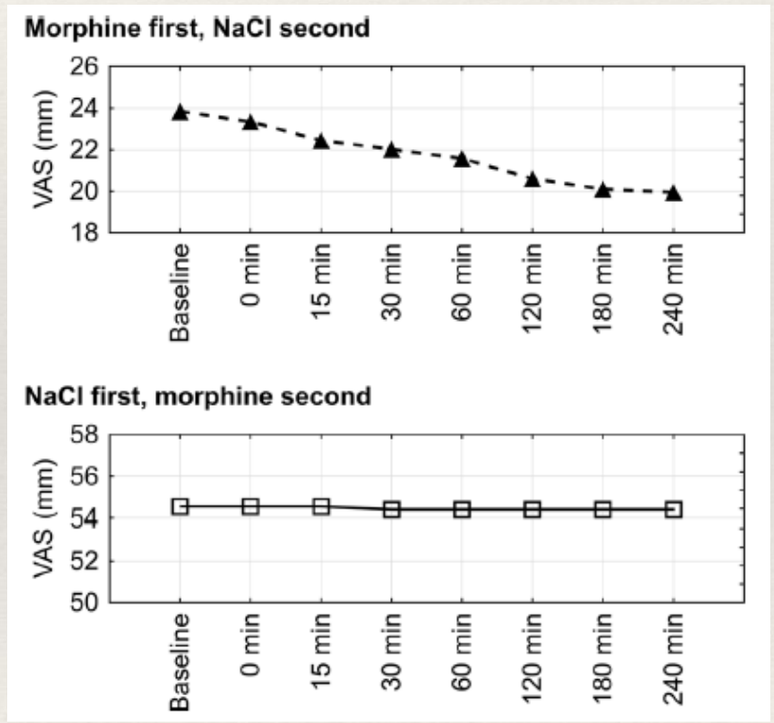
Piotr Janowiak[1], Małgorzata Krajnik[2], Zygmunt Podolec[3], Tomasz Bandurski[4], Iwona Damps-Konstańska[1], Piotr Sobański[5,6], David C. Currow[7*] and Ewa Jassem[1]

Morphine Inhalation OD

Dose escalation 1 →2 →**3** →5mg

Until 20 mm reduction in VAS





Cross over

PC interventions relevant for HF

Topic	Description	Clinical implications for care people with heart failure
Advance care planning (ACP)	Process of compassionate communication on disease progression, helping individuals to define goals of care and preferences for future medical treatment and care, especially life-sustaining treatments. The conclusions of the ACP can be: the recording of advance directives or the indication of a personal representative for medical decision-making.	Disease-specific aspects need to be addressed as part of ACP, such as fear of breathlessness or uncontrolled pain at the end of life or management of an implantable cardioverter-defibrillator in the dying phase.
Addressing ethical dilemmas	Four ethical principles guide decision making that arise during the care of patients with advanced HF: beneficence, non-maleficence, respect for patient autonomy, and justice. Ethical dilemmas that arise when caring for patients usually occur when two or more ethical principles are in conflict with one another.	Respect for patient autonomy requires that clinicians inform people with advanced HF about their disease, prognosis and the risks, benefits and alternatives to tests and treatments including, in those with implantable cardiac devices, the option of withdrawing device therapies or 'device deactivation'. Respect for patient autonomy also underlies the process of ACP. For situations in which such dilemmas cannot be resolved, ethics consultation and/or PC consultation should be considered.
Spiritual care	Address religious needs, values, and the existential quest.	Spiritual care involves a wide range of interventions from the therapeutic presence of clinicians to the professional help offered by specialists in spiritual care/chaplains and pastoral care workers.
Adjusting medical therapy	The validity of former indications for drugs use, after setting new goals, should be continually evaluated.	Adjustment of medical therapy is a dynamic process that might include reducing doses/withdrawing of ongoing medication if it is no longer beneficent especially if causing unpleasant side effects or restarting/up-titrating previously withdrawn/reduced doses of drugs after improvement of clinical situation. The rule is: harm, burden or long-term effect = stop; symptom improvement = continue/adjust dose.
Care for the dying	Dying is a medical diagnosis and diagnosing it should be neither neglected nor postponed. Dying is a dynamic process, with changing symptoms and signs, requires if complex intensive palliative care.	Patients and their families should receive appropriate counselling, support, and reassurance. All interventions and therapies that do not contribute to the aim of preserving the highest level of comfort should be discontinued or not initiated. This also includes the deactivation of ICDs and other devices (if not performed previously).

Sobanski, P Cardiovasc Res. 2019,

Deactivating …. Withdrawing ….Withholding ….

The primary aim behind the rationale for them must always be to **respect the patient's right to live**, or **at least to die with dignity**, while limiting any therapeutic action that increases the patient's level of stress, pain or anxiety'.

Wilkoff BL, Auricchio A, Brugada J, Cowie M, Ellenbogen KA, Gillis MA et al. HRS/EHRA expert consensus on the monitoring of cardiovascular implantable electronic devices (CIEDs): description of techniques, indications, personnel, frequency and ethical considerations. Europace 2008;10:707–25

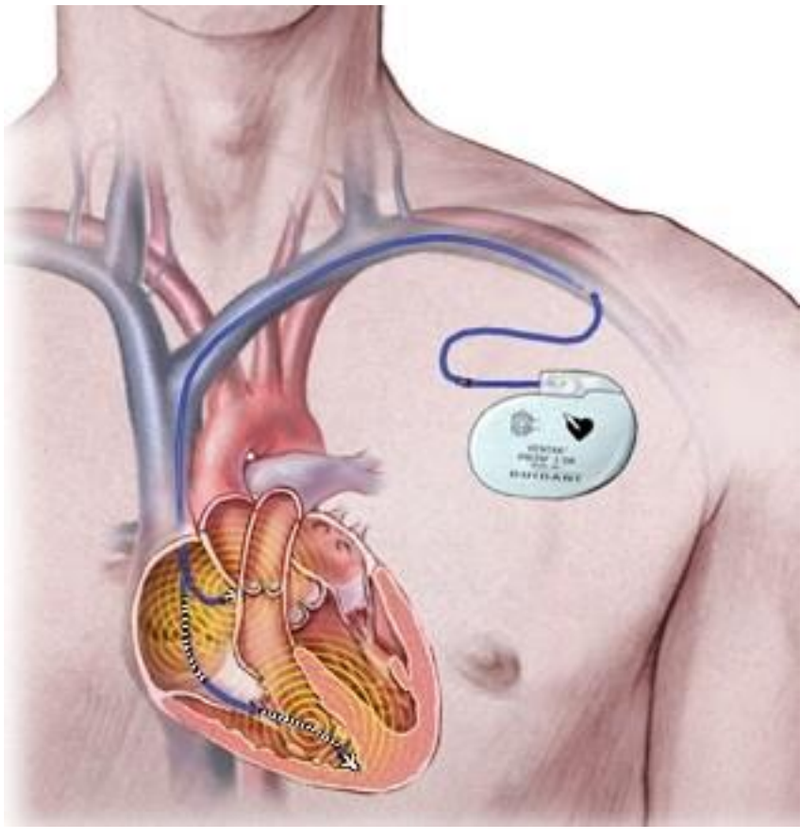
Withdrawing of disease-specific medicines as „palliative intervention”

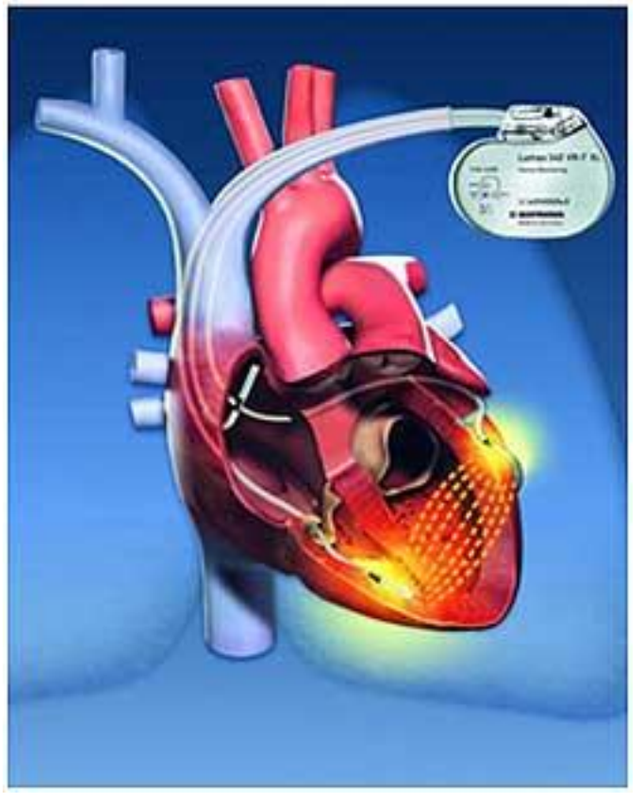
- Withdrawing of anticancer therapy improves **QoL** in people with **advanced cancer**
- This caused the bad pattern - stopping active treatment starting PC
- This is not completely true in the case of HF ….
  - the purely „**prognostic**” drugs, specially prescribed as **primary prevention** can be discontinued
  - the indications for **secondary prevention** – need to be carefully reverified
  - a significant proportion of HF-specific medicines play a role for improve **symptom-control** (dose adjustment may be necessary)
  - In **geriatric population** withdraw of in average 2.8 medicine/person: has reduced mortality (from 45% to 21%) und hospitalizations (form 30% to 12%). The most commonly stopped drugs: nitrates, lasix, BP-Medicines

The essence of PC is not to stopp or limit every ongoing treatment, but to verify its appropriateness for achievable goals?

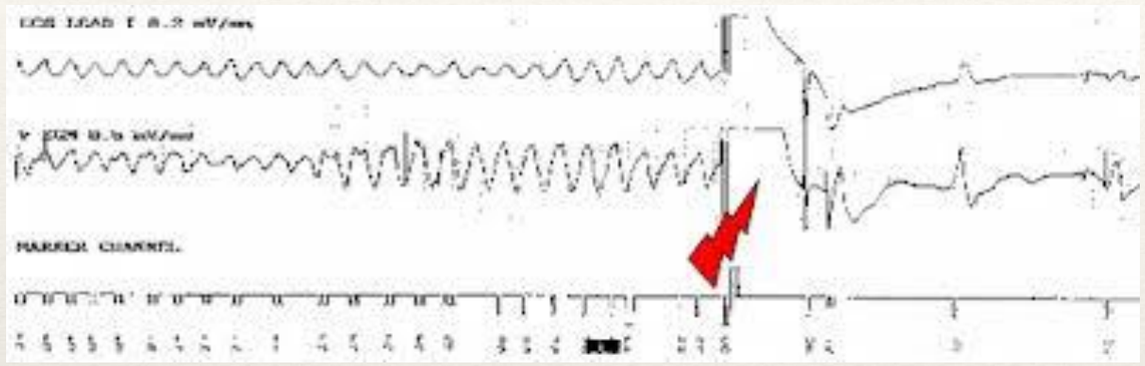
Garfinkel, D. (2007). *Isr Med Assoc J* ***9, 430.***

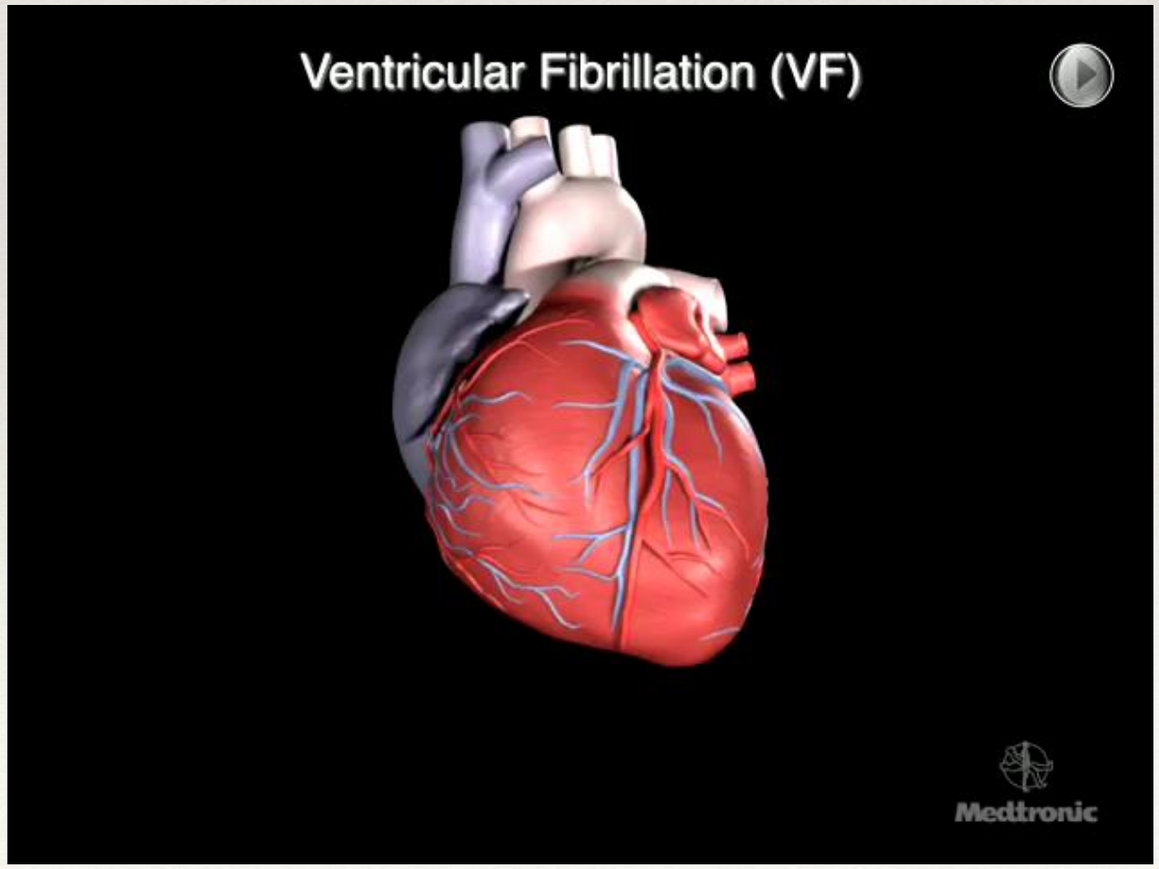
Pacemakers





ICD





Deactivation of ICD as an entry criterium for hospice care

- many hospices require the patients to have ICD switched off on the entry

- probably **not the deactivation, but communication** on ICD modification should be the pre-requirement for hospice admission

- but the possibility, that the shocks can be delivered is pointed against the most basic principle of PC - to assure a worthy death

4. Closing remarks

Measures to improve PC service for non-oncological patients

- Standardized criteria to trigger involvement of specialized PC
- Defining clear outcome and quality criteria of good care for people with non-oncological disease (comparison with and without PC)
- Reimbursement structures providing incentives for advance care planning and PC consultations early in the course of illness.
- Changing reimbursement from fee-for-service to fee-for-value (need to define the value or desired outcomes and their quality measures).*

*Kamal AH. *J Pain Symptom Manage 2015;* 49: 243

Bernacki RE. *J Palliat Med 2012;* 15: 192

Screening for those who can have PC needs

- Electronic screening tools (systems flagging patients with key words in free text).*
- Manual electronic data screening.
- Algorithm exerting educational effect for non-referring departments.

* Bernacki RE. *J Palliat Med 2012;* 15: 192

Criteria for aggressive treatment at EoL in cancer patients

1. Chemotherapy within 14 days before death.
2. Lack of hospice care.
3. Admission to hospice ≤ 3 days before death.

Early PC led to a decrease in aggressive treatment from 54% in the control group to 33% in the early PC group (p = 0.05).

Measure of health care use:

Documentation of patients' preferences in respect of resuscitation.

Temel JS. *N Engl J Med 2010;* 363: 733.

Summary

- The need for PC for people with non-oncological disese is becoming better known, however the implementation needs improvement
- PC ≠ hospice care.
- To get the improvement - teaching is needed, but is not enough
- Contemporary PC should be provided based on needs not on prognosis
- Needs/symptoms should be assessed using structural, validated tools (NAT PD-HF / ESAS).
- PC should be add to optimal cardiac care, not replace it if „nothing more can be done”
- The elements of PC - describes SENSE Model

Dialog between Palliative Care Societies and Cardiologic Societies

http://www.eapcnet.eu/Themes/Specificgroups/Heartdisease.aspx

We can achieve it together