



**Cicely Saunders
International**
Better care at the end of life

WHO Collaborating Centre
for Palliative Care, Policy and
Rehabilitation



KING'S
College
LONDON



You Matter Because You Are You: An Action Plan for Better Palliative Care

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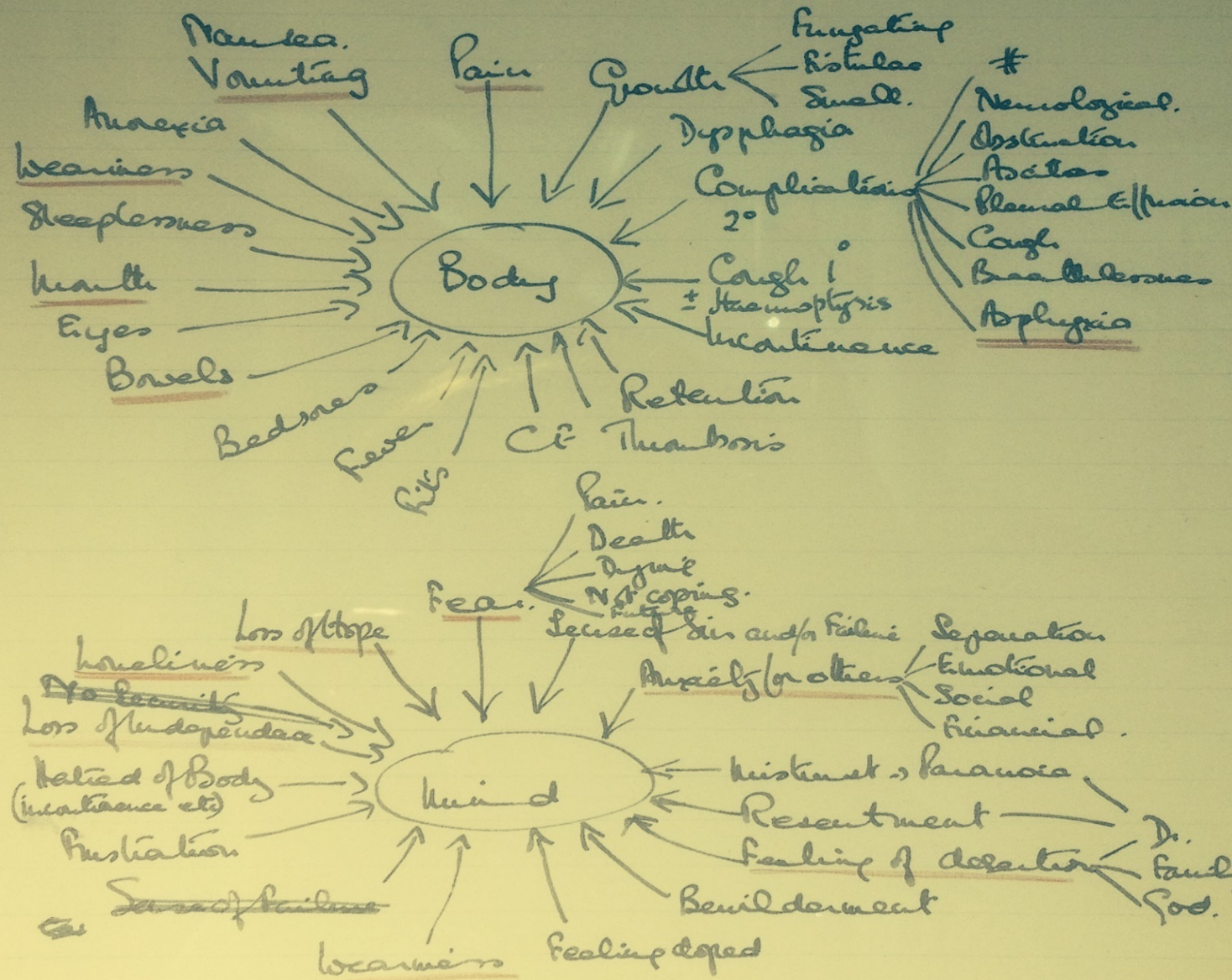
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 KING'S HEALTH PARTNERS

Attach.



Cicely Saunders model of palliative care

science, plus caring...

individualised (by culture, values, concerns)

In care and science (research, education)

Cicely Saunders
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Better care at the end of life

You Matter Because You Are You

**An action plan for
better palliative care**

<https://cicelysaundersinternational.org/action-plan-for-palliative-care/>

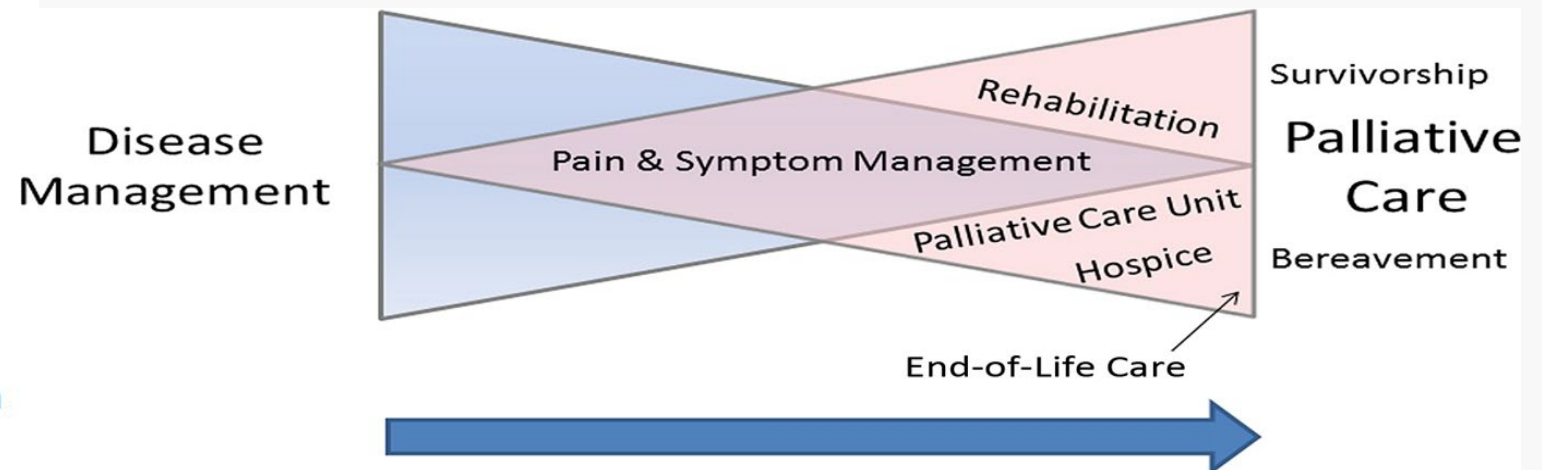
Modern Palliative care: 'Needs driven individualised care' – for those with life threatening, life limiting illness

Puts the person and those important to them before their disease. *The relief of suffering, with holistic and compassionate care is an essential component of care for those affected by life threatening illness.*

'We must somehow give everything we can to these people that says "you matter because you are you," everything to enable the patient to live up until he dies, and the family to go on living afterwards.'

Cicely Saunders 'A death in the family: a professional view' British Medical Journal, 6 January, 1973, p30-31.

Palliative care aims to add quality to remaining life. There is no evidence that it shortens life expectancy, if anything it's the opposite.



UK perspective - growing need for palliative care

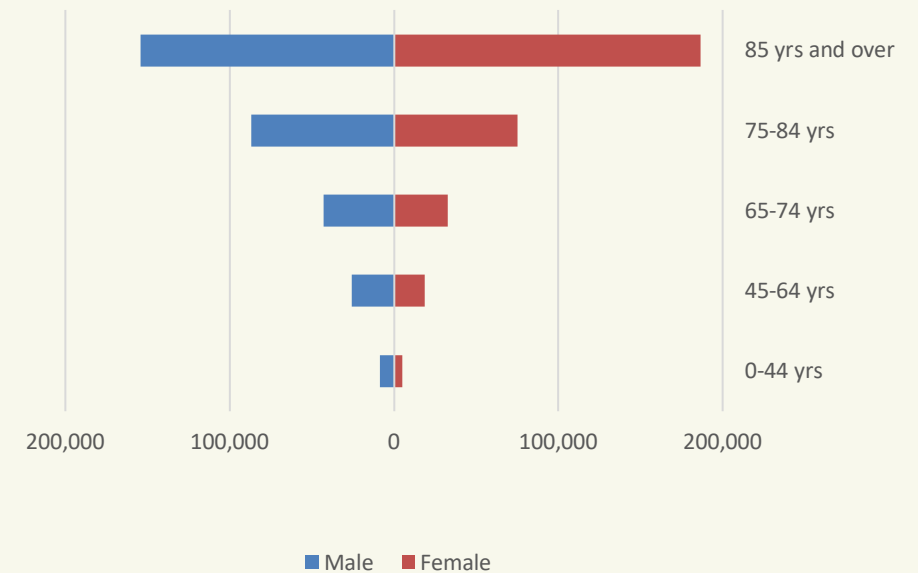
- **20% of healthcare resources** spent in last year of life
- **80%+ deaths from chronic & progressive conditions** with complex comorbid needs
- **PEoLC is central** element of the NHS's responsibility
- **By 2040, 25% increase in annual deaths, most over 85 years &**
- **>42% increase with people needing palliative care**

Yet:

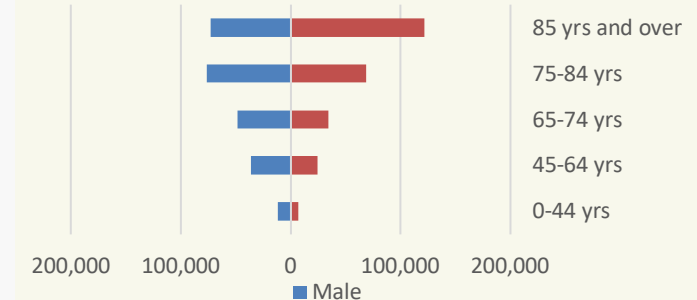
- Care quality at end of life often not optimal
- NHS budgets increasingly constrained
- Palliative care improves quality **without** increasing costs to NHS or society, and possibly saving money

Source: Bone et al *Palliat Med.* 2018;32(2):329-336.

UK: Projected number of deaths in 2040



Actual number of deaths 2014



1

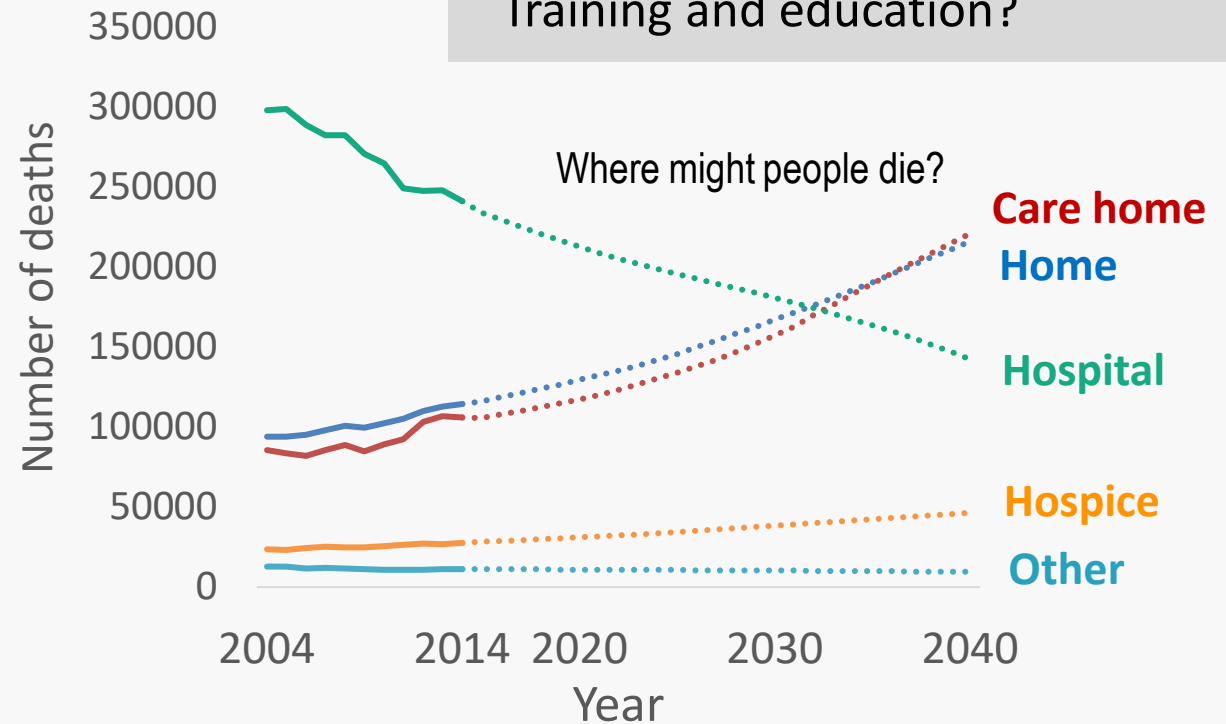
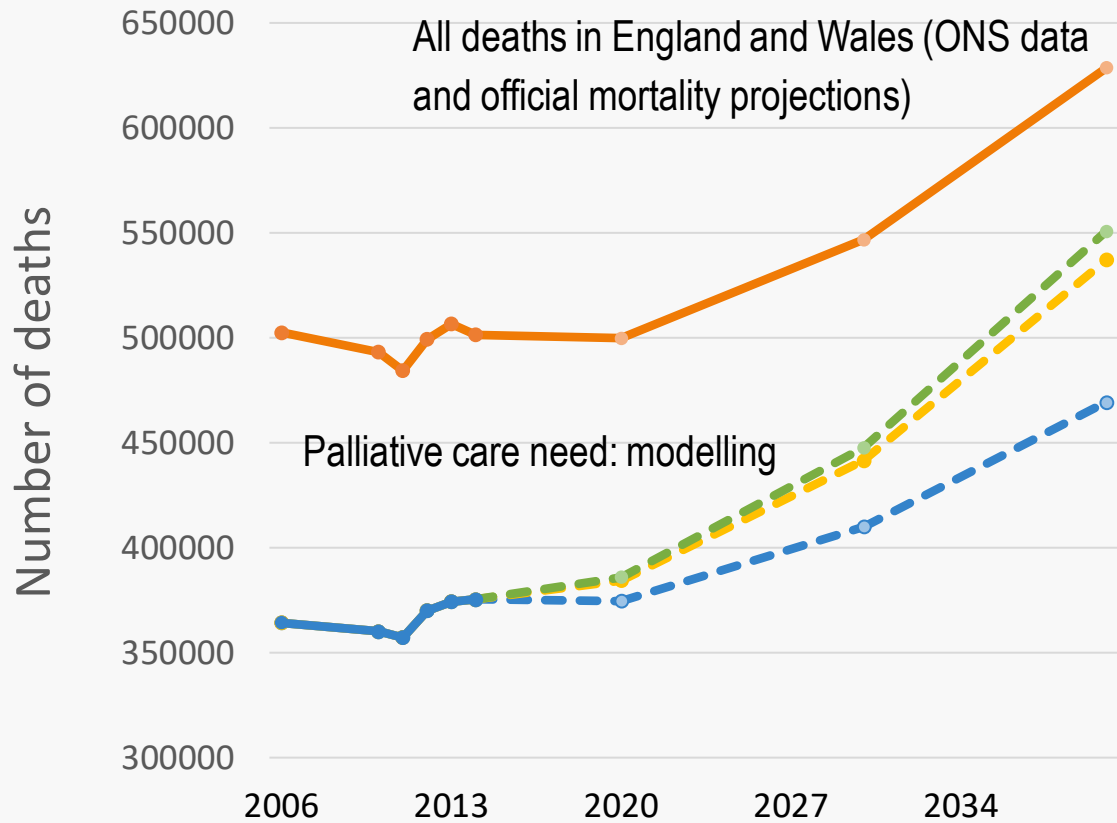
Provide palliative care expertise in places where people are cared for: hospitals, care homes, hospices and at home

CHALLENGE:

Patient surveys indicate that most of us – around 80% – would prefer to die at home or our place of residence, but in some parts of England and Wales, fewer than 50% do because the necessary services are not there to support them. Without expanding the resources and capacity to provide palliative care in all settings – whether home, community, hospital, hospice or care home – we will remain unable to meet the choices of patients and their families.

UK perspective – Projections: numbers & where will people be cared for ?

If trends continue (which they may not) 235,000 more deaths in community?
 Bed capacity? Workforce?
 Training and education?



Sources: Etkind et al. BMC Medicine (2017) 15:102
 Bone et al Palliat Med. 2017 Oct 1:269216317734435.

During the Covid-19 pandemic these projections were reached already

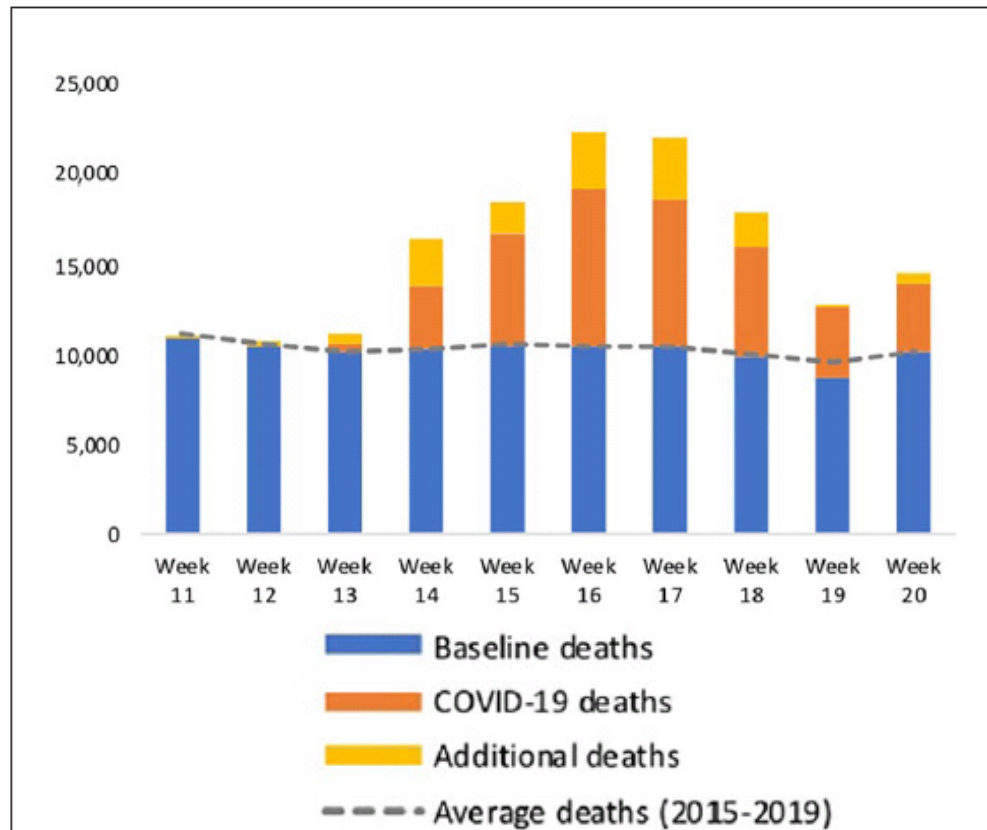


Figure 1. All registered deaths during the COVID-19 pandemic between 7 March and 15 May 2020 (weeks 11–20) in England and Wales.

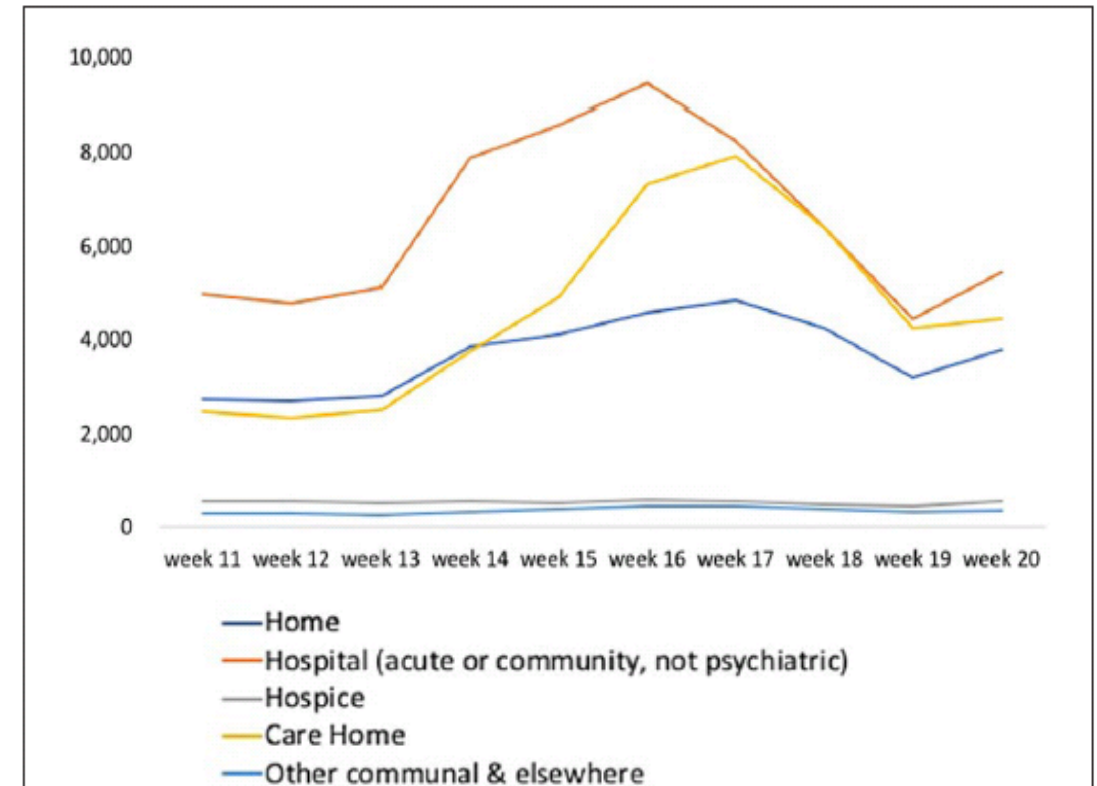
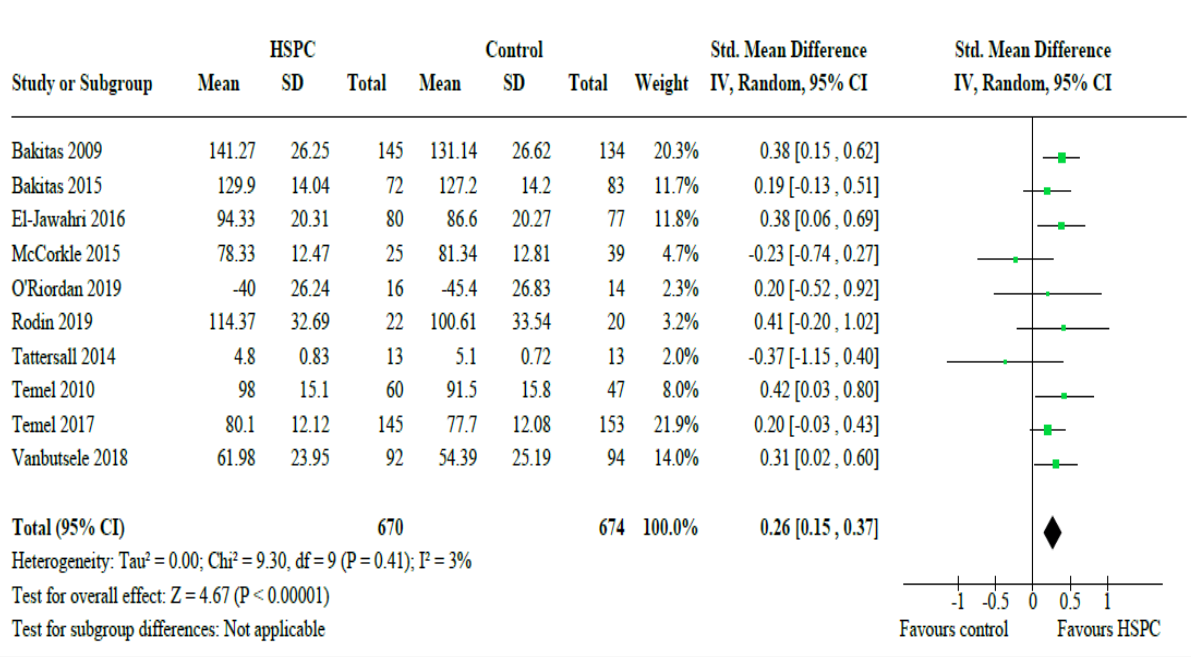


Figure 2. All registered deaths during the COVID-19 pandemic between 7 March and 15 May 2020 (weeks 11–20) in England and Wales by place of occurrence.

Consistence evidence in favour of palliative care on improving quality of life, symptoms, people being cared for where they wish

Hospital based palliative care teams

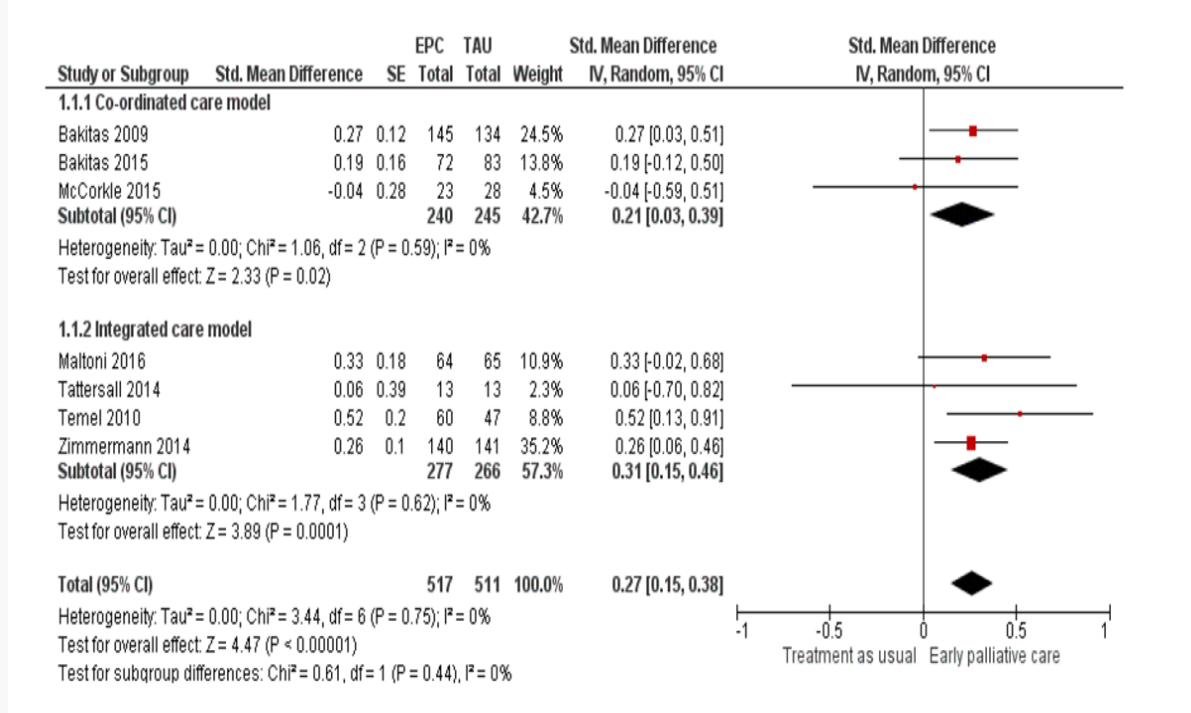
Analysis 1.1. Comparison 1: Patient health-related quality of life, Outcome 1: HSPC versus usual care on patient HRQoL: adjusted endpoint values



Bajwah S, et al Cochrane Database Syst Rev. 2020 Sep 30;9.

Early palliative care in cancer

Figure 4. Forest plot of comparison: I Health-related quality of life, outcome: I.I Health-related quality of life.



Haun MW, et al Cochrane Database Syst Rev. 2017 Jun 12;6.

2

Make joined up care a reality

CHALLENGE:

One of the restrictions on patient choice at the end of life revolves around coordination and information sharing between health and social care providers. Being unable to share information and coordinate care quickly enough in what is frequently an urgent situation can restrict patients' choices and impact their care.

SOLUTION:

- » Ensure all health and care partners have access to appropriate information and skills to provide the best care.
- » Facilitate greater joint working to identify people who may need palliative care or complex symptom management as early as possible.
- » Provide a named responsible senior clinician and care coordinator for each person who is experiencing severe symptoms or approaching the end of life.
- » Embed processes to support rapid discharge of patients to their preferred place of care at the end of life.

Effect of palliative care on health and social care costs...

- In hospital cost savings greater with earlier referral after admission to hospital (prospective cohort study with propensity matching, US data)
- *May P et al Clin Oncol. 2015 Sep 1;33(25):527-45*

Table 3. Estimated Treatment Effect on Total Cost, by Time to Consult

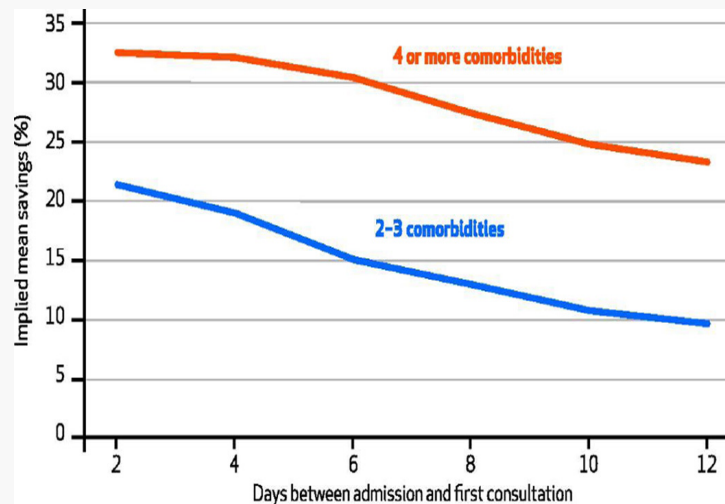
Treatment: Time of Consultation After Hospital Admission (percentile)	No. of Patients			Estimated Treatment Effect (\$) (95% CI)	P	Implied Saving (%)*
	UC	PC	All			
Any time (100th)	713	256	969	153 (-1,266 to 1,572)	.83	-2
Within 20 days (97.5th)	713	249	962	-706 (-2,007 to 596)	.29	7
Within 10 days (95th)	713	244	957	-927 (-2,283 to 429)	.18	10
Within 6 days (90th)	713	231	944	-1,312 (-2,568 to -56)	.04	14
Within 2 days (75th)	713	197	910	-2,280 (-3,438 to -1,122)	<.01	24

Abbreviations: PC, palliative care; UC, usual care.
*Implied saving in total cost of hospital stay from receiving treatment compared with receiving UC only.

Cost savings greater when patients have multimorbidity..

Receipt of a palliative care within two days of admission associated with:
 22 percent lower costs, comorbidity score of 2–3; 32 percent lower costs for those with a score of 4 or higher

May P et al, *Health Aff (Millwood)*. 2016 Jan;35(1):44-53.



Economics of Palliative Care for Hospitalized Adults With Serious Illness A Meta-analysis

JAMA Intern Med. doi:10.1001/jamainternmed.2018.0750
 Published online April 30, 2018.

Peter May, PhD; Charles Normand, DPhil; J. Brian Cassel, PhD; Egidio Del Fabbro, MD; Robert L. Fine, MD; Reagan Menz; Corey A. Morrison; Joan D. Penrod, PhD; Chessie Robinson, MA; R. Sean Morrison, MD

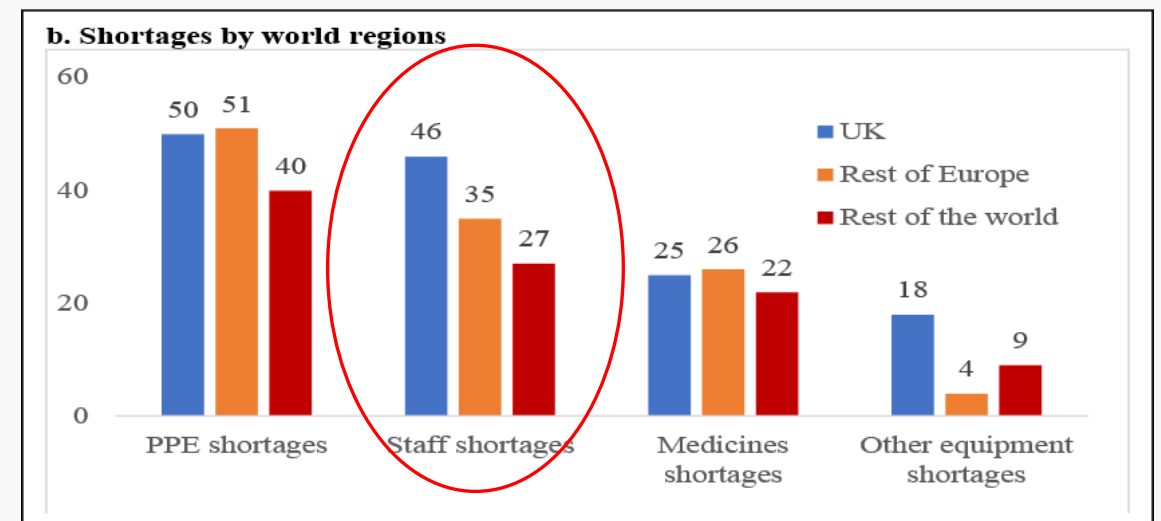
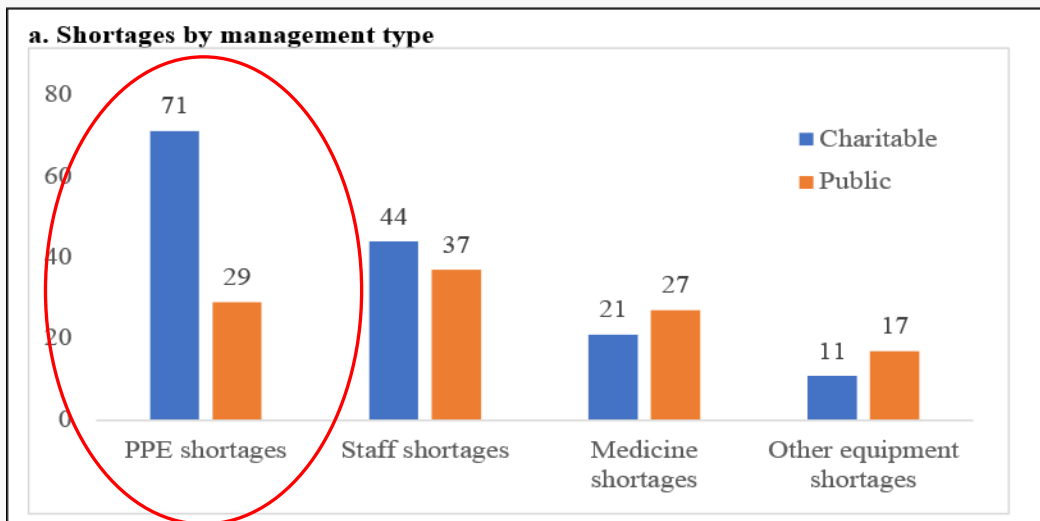
Table 3. Subsample Analyses: Pooled ATETs by Total Elixhauser Index at Admission^a

Diagnosis Group, Elixhauser Index	Pooled Sample Size			Pooled Estimated ATET, \$ (95% CI)
	UC Group (n = 121 943)	PC Group (n = 4580) ^b	All (N = 126 523)	
All				
≤1	34 755	1028	35 783	-2041 (-2425 to -1658)
2	28 697	968	29 665	-2524 (-3186 to -1862)
3	24 983	950	25 933	-3745 (-4401 to -3089)
≥4	33 508	1634	35 142	-4865 (-5553 to -4177)

CovPall - Improving palliative care for people with COVID-19 by sharing learning

See Oluyase et al. <https://www.medrxiv.org/content/10.1101/2020.10.30.20221465v1.full.pdf>

- Reduced inpatient palliative care unit activity in free standing units
- Increase in activity for home care & hospital teams
- Support from volunteers considerably reduced
- Financial concerns, some staff taking pay cuts, concerned for viability of the service, especially charitable sector services
- Shortages were common: especially of staff and personal protective equipment



3

Empower patients and carers to have greater choice and control over the things that are important to them

CHALLENGE:

While there may be many reasons why someone is not able to receive care in their place of choice, too many people are not given enough say in where they are cared for or die. The independent Review of Choice in End of Life Care, published in 2015, identified that delivering a national choice offer in end of life care required an additional investment of £130 million.

SOLUTION:

- » Allow patients to request and receive professional palliative care at the time of their choosing rather than having to 'wait' until they are referred or having to negotiate referral.


Results of the Multi-Speciality Holistic Service, triggered by Breathlessness

Higginson et al. *Lancet Respir Med* 2014;2(12):978-87

- Early palliative care integrated with respiratory services
- 16 % improvement in QoL
- No difference in costs to health care

	Breathlessness support service group (n=42)	Control group (n=40)	Difference between breathlessness support service and control (95% CI)	p value
Primary outcome (CRQ mastery)* †	4.15 (1.7)	3.57 (1.4)	0.58 (0.01 to 1.15)	0.048
Secondary outcomes				
NRS breathlessness average 24 h ‡	5.38 (2.2)	5.71 (2.1)	-0.33 (-1.28 to 0.62)	0.49

Fact sheet 2
Information for patients

King's College Hospital 
NHS Foundation Trust

Breathlessness Support Service

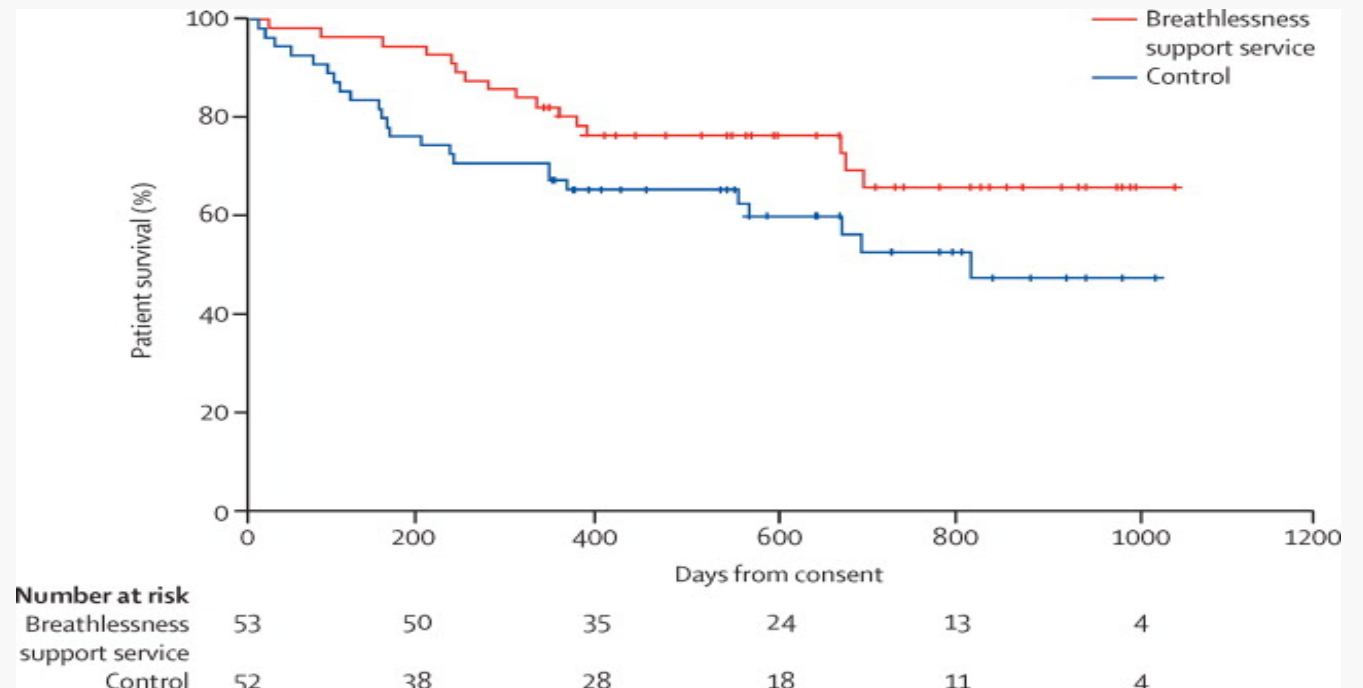
Managing breathlessness

This information sheet helps you manage your long-term breathlessness. If your breathing is getting worse or you are experiencing breathlessness as a new feeling, it is important to seek medical advice from your GP.

How are you breathing?
Make yourself aware of how you are breathing:

- When you breathe in, are you tensing your shoulders to lift your chest up?
- To exhale, do you force the air out?
- Are you breathing very rapidly?
- When you need to move, do you find yourself holding your breath?

What can I do to help my breathlessness?
Relax
When you are feeling breathless you may automatically start to use your chest, shoulder and neck muscles, hoping it will make breathing easier. These muscles are not meant to work continuously for long periods of time, so they will soon





OPEN ACCESS

ORIGINAL ARTICLE

Holistic services for people with advanced disease and chronic breathlessness: a systematic review and meta-analysis

Lisa Jane Brighton,¹ Sophie Miller,¹ Morag Farquhar,² Sara Booth,³ Deokhee Yi,¹ Wei Gao,¹ Sabrina Bajwah,¹ William D-C Man,^{4,5} Irene J Higginson,¹ Matthew Maddocks¹

- Meta-analysis of 37 articles; 18 different breathlessness support services or similar
- Improvements favouring intervention in
 - numeric rating scale distress due to breathlessness (n=324; mean difference (MD) -2.30, 95%ci -4.43 to -0.16, p=0.03) and
 - Hospital anxiety and Depression Scale (HaDS) depression scores (n=408, MD -1.67, 95%ci -2.52 to -0.81, p<0.001)

*Maddocks M, et al, NIHR Journals Library; 2019
Brighton LJ, et al Thorax. 2019; 74(3):270-281.*

Key messages

What is the key question?

- ▶ What are the outcomes, recipients' experiences and therapeutic components of holistic services for chronic breathlessness in people with advanced disease?

What is the bottom line?

- ▶ Overall these services reduce patient distress due to breathlessness and may improve psychological outcomes of anxiety and depression.
- ▶ Despite wide variability in content and delivery, recipients value tailored interventions and expert staff providing person-centred, dignified care.

Why read on?

- ▶ This is the first review to synthesise available quantitative and qualitative evidence around holistic services triggered by breathlessness, which may serve as an appropriate referral indicator for early integration of palliative care.

Breathlessness triggered service – *How did it work?*

- Patient and family holistic by palliative care / respiratory
- Home tool kit
 - Hand held fan / water spray
 - Information sheets
 - Breathlessness commonly asked questions
 - Managing breathlessness
 - Pacing
 - Hand held fan
 - Distraction techniques
 - Positions to ease breathlessness
 - Relaxation CD
 - Crisis plan
 - Breathlessness poem (Jenny Taylor)
- Home visit by physiotherapy/ occupational therapy; walking aids, home adaptations, exercise / muscle strengthening DVD or equivalent, reinforces clinic advice

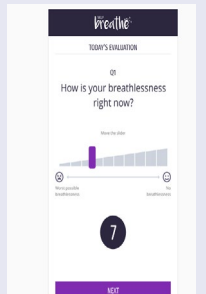
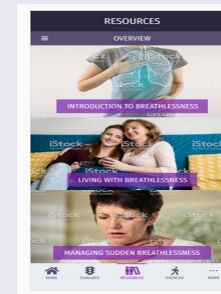


<https://www.kcl.ac.uk/cicelysaunders/research/symptom/breathlessness>

Next steps – moving to digital, self-help & support

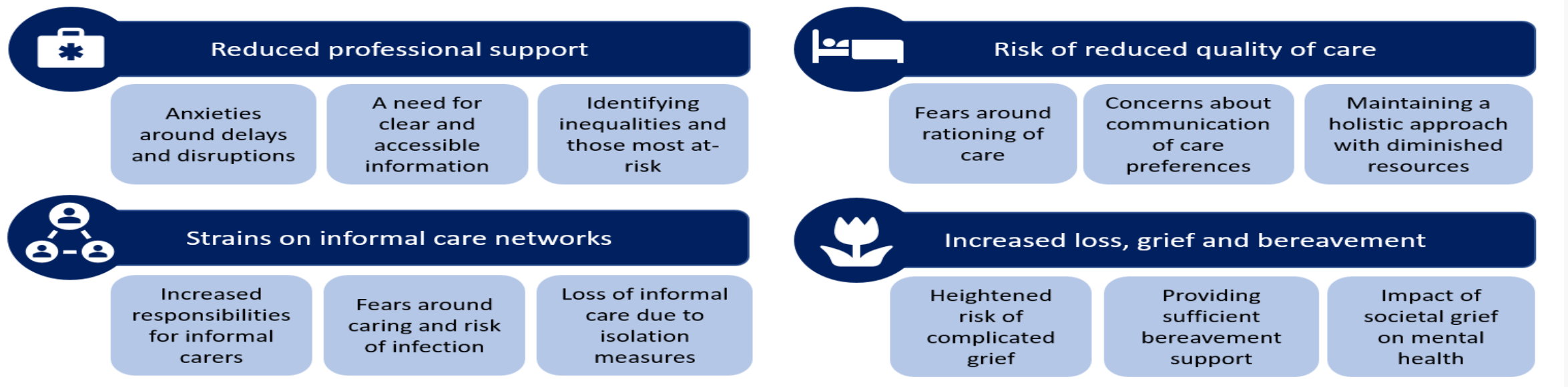
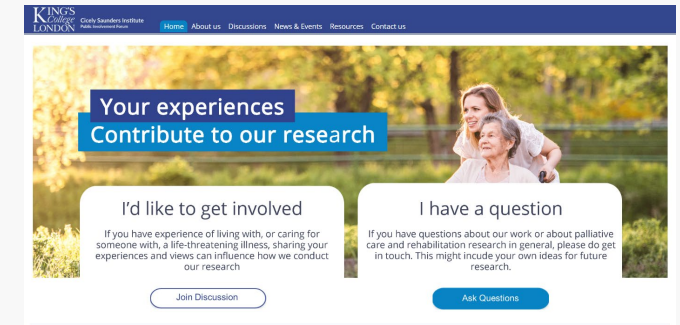
SELF
breathe

Self-guided, internet-based intervention:
Feasibility randomised controlled trial
NIHR funded (Reilly)



Bringing in the patient and family voice, these had been missing:

- Patient and family views were missing from the rapid guidance and advice being developed in response to COVID-19
- 54 responses received from people affected by serious illness across the UK via email, Cicely Saunders Institute online forum, phone call
- Conducted in collaboration with colleagues at Hull & York, Bristol and Sheffield



Johnson H, Brighton LJ, Clark J, Roberts H, Pocock L, Ogden M et al. Experiences, concerns, and priorities for palliative care research during the COVID-19 pandemic: A rapid virtual stakeholder consultation with people affected by serious illness in England. 2020. 31 p. <https://doi.org/10.18742/pub01-034>

4

Invest in community care services

CHALLENGE:

Too many people with life-limiting illnesses – as well as those approaching death – spend long periods of time in hospital, in part due to a lack of social or community care. Meanwhile, hospital admissions are rising to unsustainable levels across the country, something that was made all the more apparent as parts of the NHS risked being overwhelmed during the COVID-19 pandemic.

SOLUTION:

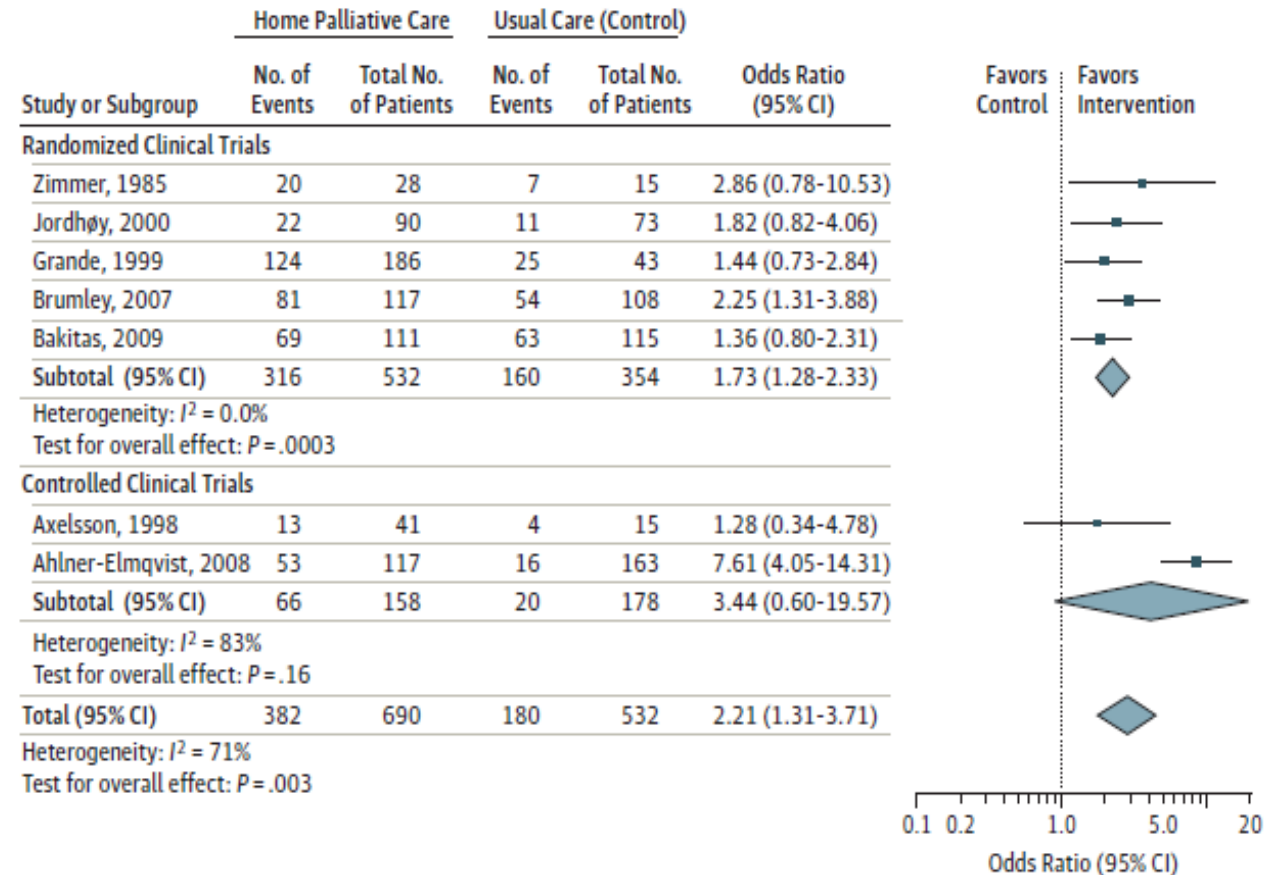
- » Invest in community care, including care homes, to reduce unnecessary hospital admissions for patients with life-limiting illnesses and those in the last months of life.
- » Target palliative care resources towards patients in high-risk groups to increase not only the benefit to those patients, but also the cost-effectiveness of resource allocation.
- » Ensure that home palliative care teams with symptom management expertise are widely available and provided with the necessary resources to provide high quality care.

Does palliative care affect whether death is at home, across diseases? – YES more likely



- OR 2.21 (95%IC 1.31 to 3.71) home death compared with conventional care
- Meta-analysis 7 trials,
- 1222 patients, majority cancer

Figure. Odds of Dying at Home With Home Palliative Care Compared With Usual Care



Gomes et al. Cochrane data base of reviews, 2013 Jun 6;6:CD007760.

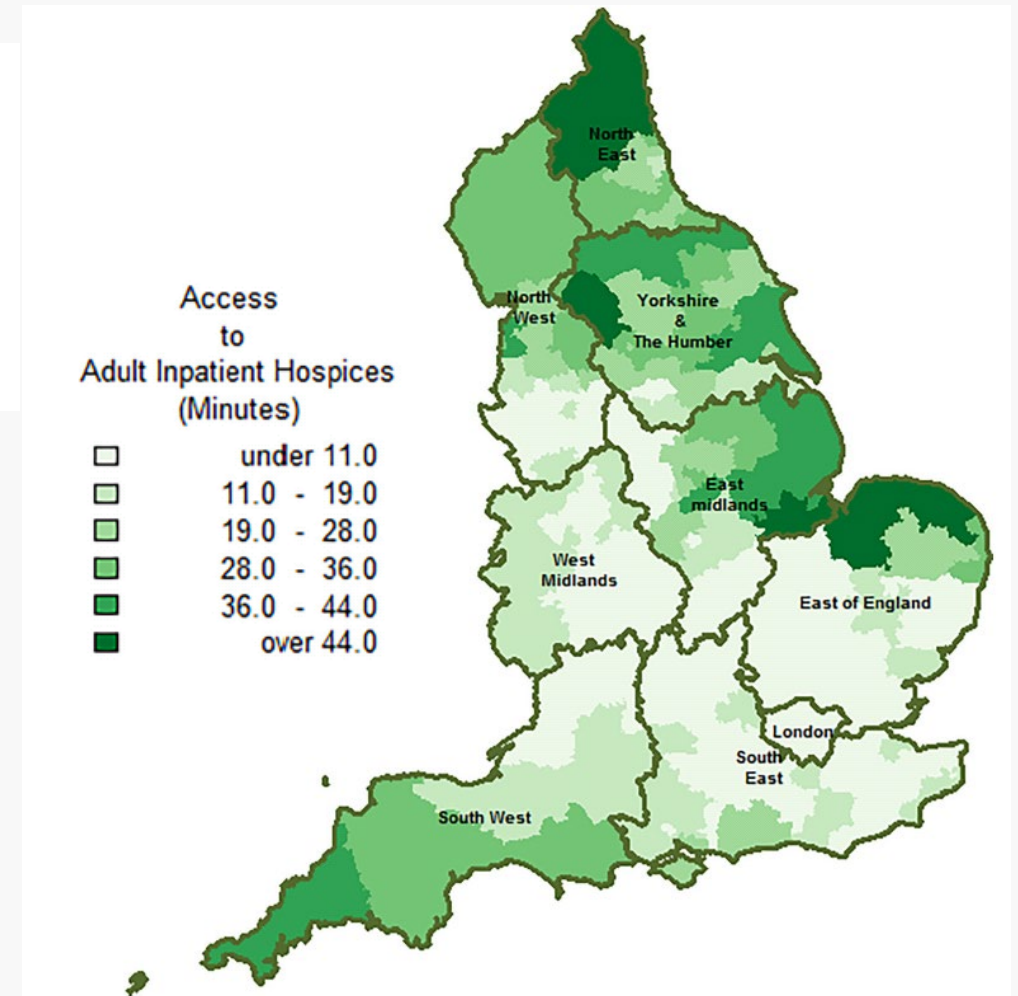
Inequity: Where you live and who you are affects whether and how you gain access to hospices

Regional variations in geographic access to inpatient hospices and Place of death: A Population-based study in England, UK

Emeka Chukwusa^{1*}, Peihan Yu¹, Julia Verne², Ros Taylor^{3,4}, Irene J. Higginson¹, Gao Wei¹

- Decedents who lived ≥ 10 minutes from hospices were less likely to die in a hospice
- There was a 'dose-response' with distance

Chukwusa et al, PLoS One, 2020 Apr 17;15(4):e0231666.



Inequity: Where you live and who you are affects whether and how you gain access to hospices

Original Article

The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012

Katherine E Sleeman¹, Joanna M Davies¹, Julia Verne², Wei Gao¹ and Irene J Higginson¹

PALLIATIVE MEDICINE

Palliative Medicine
1–9
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pmj.sagepub.com
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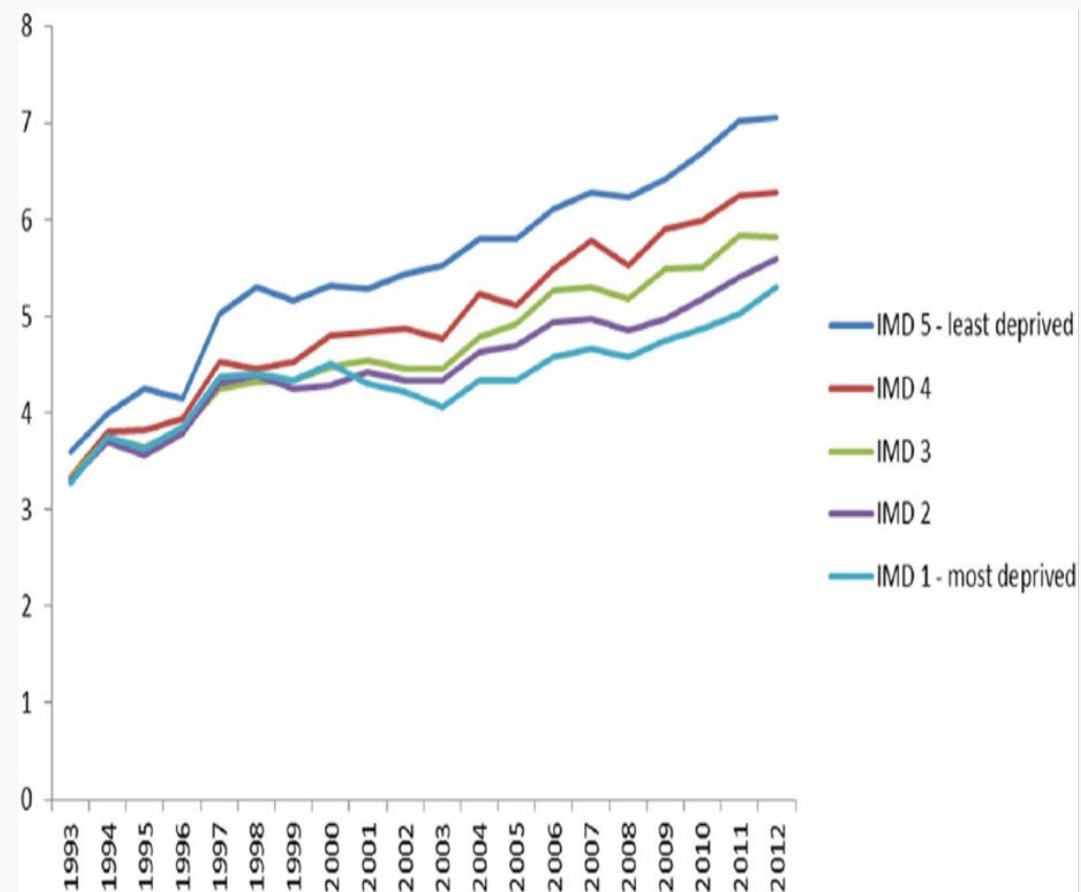
OPEN ACCESS Freely available online

Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10 Year Study

Jonathan Koffman*, Yuen King Ho, Joanna Davies, Wei Gao, Irene J. Higginson

King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, United Kingdom

PLOS ONE



Katherine E Sleeman et al. Palliat Med 2015;0269216315585064

5

Provide healthcare professionals and carers with high-quality palliative care training

CHALLENGE:

Health and social care professionals – including those who care for dying patients and patients with life-limiting illnesses – receive insufficient training on palliative care. The Royal College of Nursing’s most recent End of Life Care Survey found that only 1 in 10 nurses felt equipped to deliver good end of life care, citing lack of training as a contributing factor. The latest data for medical student training shows that the average number of hours of palliative care training is around 25 hours and varies greatly between medical schools – as little as 7 hours in some cases.

SOLUTION:

- » Provide all health care professionals with updated basic palliative care training, including symptom management and whole person assessment training.
- » Increase training for community health care professionals in symptom management, communication of difficult conversations and anticipatory care planning for older people with uncertain illness trajectories.
- » Develop additional training and education options such as an intercalated BSc in Palliative Care, as well as including palliative care in main health and social care curricula.
- » Develop an education strategy to underpin sustainable improvements in the quality of end of life care including a network of End of Life Care champions and link nurses.

CovPall - Improving palliative care for people with COVID-19 by sharing learning – Advance care planning:

See Bradshaw et al. <https://www.medrxiv.org/content/10.1101/2020.10.28.20200725v1.full.pdf>

Exacerbated already-existing challenges to high-quality, individualised Advance Care Planning
COVID-specific challenges: decision-making for a novel disease, communication in COVID-19, workload and time pressures

Services adapted local processes (prioritising specific components, integration into everyday practice) and structures (using technology, shifting resources, collaboration) of care



Implications:

- **The starting point to any discussion should always be the patient's values & priorities**
- Improve sharing information between services about wishes, keeping this up to date
- Parallel planning may be important
- High-quality Advance Care Planning needs to be resourced and better integrated into care across the health sector, ahead of pandemic waves and in routine care

6

Use outcome measures to embed a system of continuous learning and improvement

CHALLENGE:

Outcome measures are becoming more widely used on a national and international scale in order to improve the quality and cost-effectiveness of service delivery. Current barriers to implementation of outcome measures include a lack of time, resources and training.

7

Fund world-leading research into palliative care

CHALLENGE:

Palliative care education must be underpinned by scientific leadership and ongoing research. Some symptoms, such as breathlessness, complex pain, fatigue and depression, remain difficult to alleviate and need the same type of intensive and sustained research that discovered better treatments for more common health problems.

SOLUTION:

- » Increase the proportion of the medical research budget dedicated to developing better ways of caring for terminally ill people and their families; currently it stands at just 0.2 per cent, or 20p in every £100.
- » Research new ways to control common distressing symptoms, especially breathlessness, but also complex pain, fatigue and depression.
- » Support multidisciplinary, joined up research which brings together the health and social care disciplines involved in practice.

The importance of competence, skills and presence, especially in home care

model shows from research the 'key ingredients of being able to support people at home'

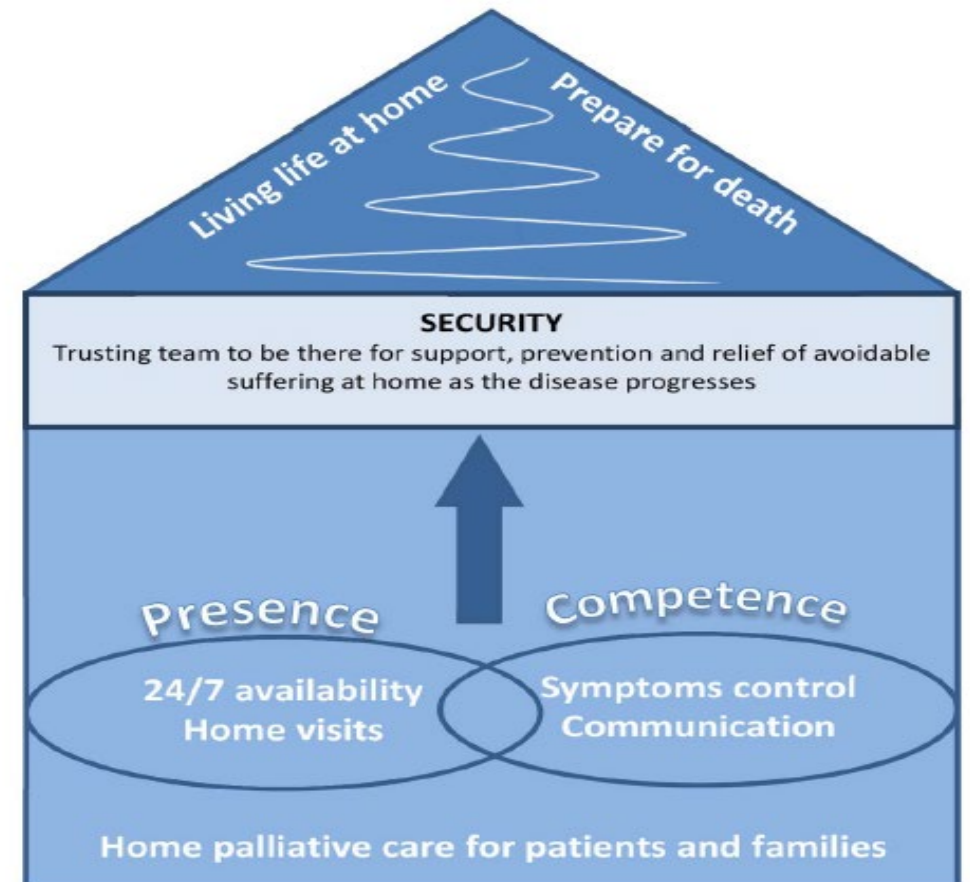
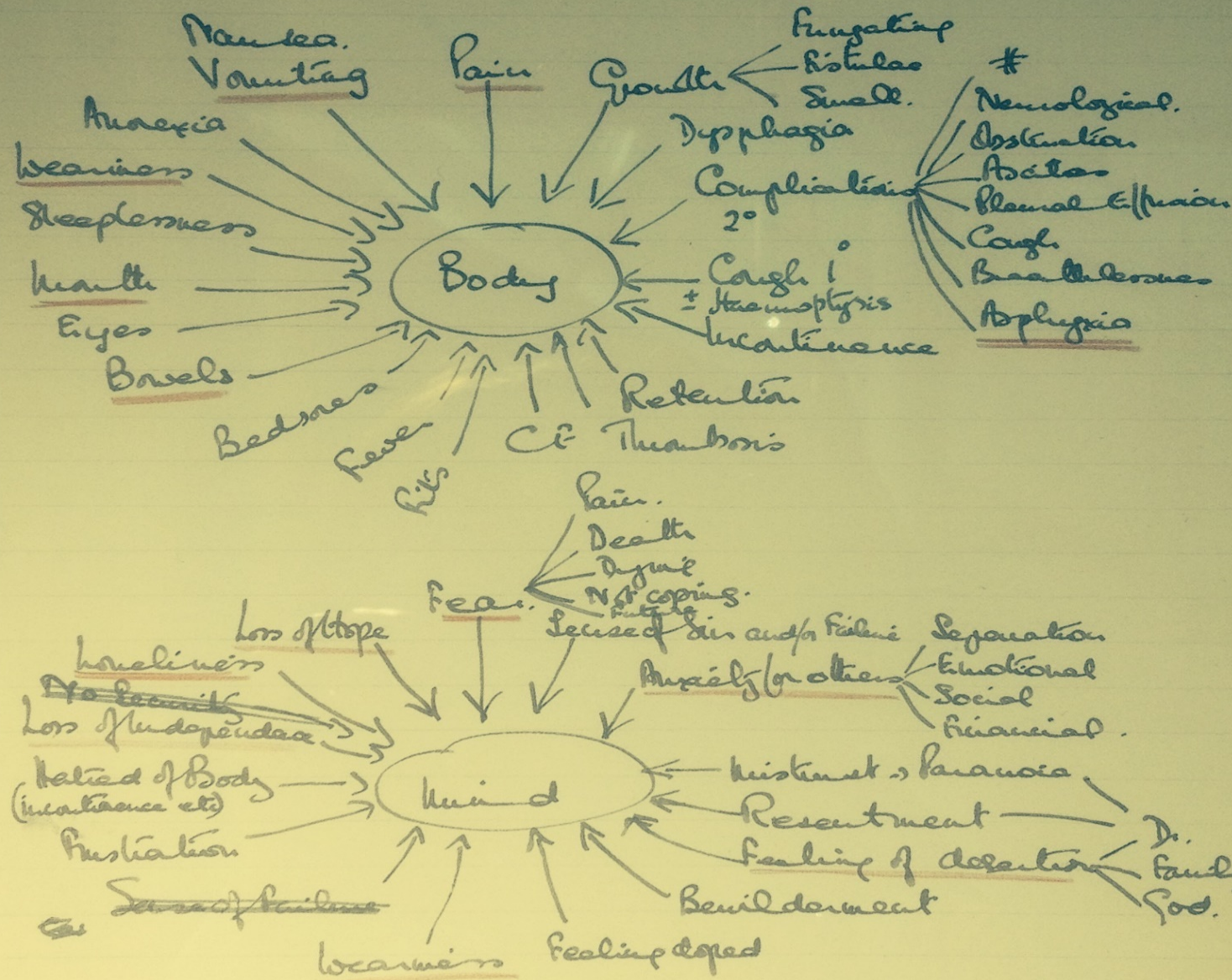


Figure 1 Lines-of-argument synthesis: simplified model of the experiences of patients' and caregivers' with home palliative care.

Results of a meta-ethnography
Source: Sarmiento et al *BMJ Support Palliat Care*.
2017 Feb 23.

Attach.



Cicely Saunders model of palliative care

science, plus caring...

individualised
(by culture, values, concerns)

In care and science
(research, education)

Improving care and treatment for patients with progressive illness to make high quality palliative care available to everyone who needs it.