The future for palliative care: new care models and challenges now and in the future

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Outline

• Population based projections
• Projections for palliative care
• Preferences/priorities, now and the future
• Models of care
• Tools for general settings
• Evidence of effectiveness and cost-effectiveness?
• Discussion?
Future numbers of deaths is increasing

Projected number of deaths in 2030

Projected number of deaths in 2040

Actual number of deaths 2014

25% increase in annual deaths by 2040 in England and Wales. 54% will be ≥ 85 years

England and Wales data: Deaths and Palliative Care needs 2006 to 2040

- All deaths in England and Wales (ONS data and official mortality projections)
- Number of people who die estimated to need palliative care 2006 – 2014
- Projected palliative care need, the proportion of people who die that need palliative care remains as 2014
- Projected Palliative care need - palliative care need continues to rise as per the change from 2006 – 2014
- Projected Palliative care need - palliative care need continues to rise as per the change from 2011 – 2014

Future cancer in England & Wales, projected deaths to 2040

Cancer deaths increased from 2006 - 135,635
2014 - 143,638

Projected
2040 – 208,636

Layered above this
Increased multi-morbidity

Future dementia in England & Wales, projected deaths to 2040

Dementia deaths increased slightly to 2014 – 59,199

Projected 2040 – 219,409

Layered above this
Increased multimorbidity

Canadian population projections

Source: United Nations population projections
https://esa.un.org/unpd/wpp/Graphs/Probabilistic/EX/
The prevalence of multimorbidity rises with age

BUT, Rising tide of multimorbidity – at ALL ages

Source: Fefoyo et al, BMC Public Health 2015:15:415, data on Ontarians, Canada but relevant to UK & other countries
Multimorbidity also rises with deprivation

<table>
<thead>
<tr>
<th>Patients with this condition</th>
<th>Coronary heart disease (most affluent)</th>
<th>Coronary heart disease (most deprived)</th>
<th>Diabetes (most affluent)</th>
<th>Diabetes (most deprived)</th>
<th>COPD (most affluent)</th>
<th>COPD (most deprived)</th>
<th>Cancer (most affluent)</th>
<th>Cancer (most deprived)</th>
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</thead>
<tbody>
<tr>
<td>Coronary heart disease</td>
<td>19</td>
<td>23</td>
<td>21</td>
<td>24</td>
<td>15</td>
<td>24</td>
<td>12</td>
<td>17</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7</td>
<td>19</td>
<td>4</td>
<td>11</td>
<td>9</td>
<td>13</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>COPD</td>
<td>14</td>
<td>16</td>
<td>6</td>
<td>6</td>
<td>8</td>
<td>9</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Stroke/TIA</td>
<td>13</td>
<td>14</td>
<td>9</td>
<td>10</td>
<td>14</td>
<td>10</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>12</td>
<td>13</td>
<td>14</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>Painful condition</td>
<td>16</td>
<td>16</td>
<td>14</td>
<td>10</td>
<td>16</td>
<td>16</td>
<td>14</td>
<td>4</td>
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<tr>
<td>Depression</td>
<td>13</td>
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<td>13</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td>3</td>
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<tr>
<td>Anxiety</td>
<td>9</td>
<td>9</td>
<td>9</td>
<td>5</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>2</td>
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<tr>
<td>Dementia</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Figure 4: Selected comorbidities in people with four common, important disorders in the most affluent and most deprived deciles. COPD=chronic obstructive pulmonary disease. TIA=transient ischaemic attack.

The ‘new’ era of patient and family needs has implications for care

- Ageing, more oldest old
- More multi-morbidity
- More fluctuant trajectories of illness
- Treating later into course of illness

- More deaths in UK and many countries (due to post war boom in birth-rate and ageing)
- In older people physical illness has a greater social, functional and psychological effect
- MORE UNCERTAINTY – services and treatments need to respond to this
Palliative care has moved from rectangles to triangles

Modern concept of palliative care
Palliative care for the 21st century, bow-ties
(Hawley PH, J Pain & Sympt Manage 2014; 47 (1): e2-e5)

Modern Definitions of Palliative Care –
• an approach applying to life-threatening illness and applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (WHO)

• provides an extra layer of support with relief from the symptoms, pain, and stress of a serious illness (Meier, D)
Triggering referrals for palliative care in fluctuating diseases, Source: Maddocks et al Lancet. 2017 Sep 2;390(10098):988-1002.

Figure 3: Models of integrative working with palliative care for people with COPD
COPD=chronic obstructive pulmonary disorder.
Is there evidence to support this model of early integration of palliative care in cancer: randomised trial evidence (USA)

- 151 patients
- Primary endpoint, mean FACT QoL subscale – 98.0 v 91.5, p=0.03
- Also depression lower
- Temel et al, NEJM 2010; 363: 733-42
Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial

Camilla Zimmermann, Nadia Swami, Monika Krzyzanowska, Breffni Hannon, Natasha Leighl, Amit Oza, Malcolm Moore, Anne Rydall, Gary Rodin, Ian Tannock, Allan Donner, Christopher Lo

Findings 461 patients completed baseline measures (228 intervention, 233 control); 393 completed at least one follow-up assessment. At 3-months, there was a non-significant difference in change score for FACIT-Sp between intervention and control groups (3.56 points [95% CI -0.27 to 7.40], p=0.07), a significant difference in QUAL-E (2.25 [0.01 to 4.49], p=0.05) and FAMCARE-P16 (3.79 [1.74 to 5.85], p=0.0003), and no difference in ESAS (-1.70 [-5.26 to 1.87], p=0.33) or CARES-MIS (-0.66 [-2.25 to 0.94], p=0.40). At 4 months, there were significant differences in change scores for all outcomes except CARES-MIS. All differences favoured the intervention group.

Interpretation Although the difference in quality of life was non-significant at the primary endpoint, this trial shows promising findings that support early palliative care for patients with advanced cancer.

Effectiveness of early integration of palliative care: randomised trial evidence, UK evidence, NIHR funded

• 105 patients randomised to early palliative care integrated with respiratory services
  • Cancer, COPD, ILD
  • Significant benefit in primary outcome, a component of quality of life, 16% better in early palliative care group
  • Significant survival benefit
  • No difference in costs

Source: Higginson et al Lancet Respiratory Medicine, Dec 2014; 2(12): 979-987 DOI:10.1016/S2213-2600(14)70226-7
Illustrative quotes about valued interventions and mechanisms by which the BSS improved individual patient’s mastery over their breathlessness

‘It’s improved my ability to cope with it better; my breathlessness has improved [...] . Going to the clinic has done that because before I would get into a panic when I was breathless, but now I can sit down use my fan, wet my face, read my laminate (breathlessness poem) and I calm down pretty quick so, that’s is um, it’s funny how a laminate (breathlessness poem) could be so helpful (laughs). It’s embarrassing to know that just that, that writing, to be able to read it it calms me down so well.’ (Female, COPD)

“The advice they gave me which improved me mentally and my walking stick that helped me physically. It’s overall, its good overall, I’m happy. I’m glad. I’m glad I did come.’ (Male, Cancer)
Illustrative quotes…

‘I, I use that as my reference (patient points to the BSS patient tool kit) all the time (interviewer; do you?) When I’m having problems I go back and read it to see if I am doing the right thing. I find that very, very helpful. And, and, er, you gave me a fan (interviewer; yes), I find the fan is very helpful as well [...] The fan and the leaflets been very good to be able to handle the breathlessness. That was the most important thing because I was in a very bad state before I came to you (BSS clinic). I-I was thinking that I was about to be dying but now I know, err, one of the good things that happened on the course (BSS) and is that one of the, one of them or I call them tutors, (BSS staff) ... Breathlessness is not going to kill you. You can handle this and it, it will be awful but it not going to kill you. Take charge of it (patient laughs)’ (Male, ILD, Nursing Home)
‘Oh yeh, the little fan is alright. Um you see like um this morning, well this afternoon, midday, the sun shining out there so I went for a walk, there is a park up there, so I went for a walk up there. And um half way, you know, I started to slow, got no breath. And, you know, the water (interviewer; the spray?) yeh and the thing, you know, the fan. Yeh, it, it can get a little boost, man, like a good-a good shot of whiskey (both laugh). You feel your body move up, you know. Yes, you know, it works when I am outside. The park is just over the road there and um, and it works, when I do a little walking around, you know, when the breathlessness comes I use it and it works man.’ (Man, COPD)

‘It’s important to keep your confidence high when you’ve got something like that because it can knock you for six, if you can’t catch your breath then you can’t do the basics and that will erode your confidence (yeh) so anything that kind of helps you keep your confidence high or keep that level of self esteem up is important for people as well cos then you’re more likely to take your medication or look after yourself (mmhm) you’re more likely to turn up to that appointment more likely to keep, you know, keep going really.’ (Woman, Other diagnosis)
Does palliative care provision affect whether death is at home – YES more

How does home palliative care work?

What are the key ingredients?

Results of a meta-ethnography

Where will people die in future years?

Projections of place of death until 2040, assuming continued average trends between 2004-2014

235,000 more deaths in community?
Bed capacity?
Workforce?
Training and education?

Why does multimorbidity matter – different effects of where people are cared for

Example: England 2001-14, respiratory disease, n=380,232 (COPD (334,520), IPD (45,712))

Should palliative care also have a role when patients are entered into phase I trials?

• Experimental studies often in cases after conventional lines of treatment failed
• Higher risk of toxicity and challenges from treatment
• Often prognosis uncertain or poor
• Communication of risks and benefits of trial is difficult, needs expertise
• Should offering palliative care be standard ‘best’ care in both arms of the trial?
Palliative care as standard in phase I trials?

- Hui et al 2010
- Patients in phase I trials had similar symptom prevalence to non-phase I referrals
- Would referral to palliative care improve QoL and reduce side effects in phase I trials?
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)

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

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

*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 multiple morbidity..

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

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients live longer, higher Quality of Life</td>
<td>Temel NEJM 2010; 363:733-742, Higginson Lancet 2014; 2(1): 979-987</td>
</tr>
<tr>
<td>Greater patient / family satisfaction</td>
<td>Casarett Arch Int Med 2011; 171:649-655</td>
</tr>
<tr>
<td>Lower costs per day</td>
<td>Morrison Arch Int Med 2008; 168:1783-90 May et al 2016</td>
</tr>
<tr>
<td>Fewer ED visits and hospital admissions</td>
<td>Brumley JPM 2003; 6:715-724</td>
</tr>
<tr>
<td>Fewer hospital admissions</td>
<td>Brumley JAGS 2007; 57:993-1000</td>
</tr>
<tr>
<td>Fewer 30-day re-admissions</td>
<td>Enguidanos JPM 2012; 15:</td>
</tr>
</tbody>
</table>

Adapted from Egidio Del Fabbro, Massey Cancer Center, Virginia Commonwealth University
Latest evidence, WHO Review of service delivery models for older people to maximize quality of life

• A rapid systematic scoping review of systematic reviews. Searched MEDLINE, CINAHL, EMBASE and the Cochrane Database of Systematic Reviews from 2000-2017, supplemented by reference searching.

• Selected reviews that reported the effectiveness of service models that aim to optimise QoL for older people, where >50% of the population was aged >60 years and in the last 1 or 2 years of life.

• Search results were independently screened, and the selected reviews’ were quality assessed using AMSTAR.

• Data were described and synthesised narratively.

2238 reviews identified. Retained 72 (incl 9 Cochrane) 784,983 individuals

Identified 2 overarching classifications of service models intending to improve QoL, but with differing outcomes:
a) Integrated Geriatric Care, which targeted physical function, and
b) Integrated Palliative Care, which focused on symptoms and concerns.
Geriatric and Palliative models

- **Areas of synergy** included: care centred on the person; education for service users and providers; and the multi-professional workforce.
- The reviews assessed 117 separate outcomes, with the 21% used in meta-analysis demonstrating effectiveness for QoL (4/4 reviews) and individual symptoms (5/5 reviews).
- Economic analysis was poorly considered overall.
Figure 2. Overarching integrated service delivery models and processes to maximise quality of life for older people in the last years of life.

Integrated geriatric care

Multiple providers
Person-centred care targeting quality of life
Education of service users and providers

Integrated palliative care

Comprehensive Assessment, Case Management and Collaborative Working to integrate across the continuum of care

Adapted from Hawley [113]
Figure 3. Range of service packages to meet the needs of older people in the last years of life to be included within Universal Health Coverage

Modified from WHO Kobe Centre working framework [Ong, unpublished; Ong and Evans, 2014[134]].
Although they targeted different outcomes, service models classified as Integrated Geriatric Care or Integrated Palliative Care demonstrated effectiveness at improving QoL and symptoms for older people nearing end-of-life.

- Approaches highlight the imperative of their integration across the care continuum with service use triggered by patient need and intended outcomes.
- To inform scalability, we encourage economic analyses that span health and social care and an examination of all sources of finance are needed to understand contextual inequalities.

# Systems consideration for model of integration of palliative care

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<th>CATWOE</th>
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<tbody>
<tr>
<td><strong>Customers</strong></td>
</tr>
<tr>
<td><strong>Actors</strong></td>
</tr>
<tr>
<td><strong>Transformation process</strong></td>
</tr>
<tr>
<td><strong>Weltanschauung – (World View)</strong></td>
</tr>
<tr>
<td><strong>Owners</strong></td>
</tr>
<tr>
<td><strong>Environment</strong></td>
</tr>
</tbody>
</table>

- Beliefs and expectations of patients, nature of illnesses
- Workforce issues, who is trained, in what?
- Primary care, cancer centres, usual referral processes, availability of opioids, who can prescribe?
- Private v public v voluntary health care systems; views on opioids
- Who has the power in the systems – owners of hospitals, data?
- Rural versus urban, islands, mountains, potential role of telemedicine
Can we get better at triggering a palliative care assessment and reviewing our practice? - easy to use measures: E.g. Integrated Palliative care Outcome Scale (IPOS)

- Developed and validated in many countries, settings and disease
- 10 questions, rated 0 – 4
- Open question for patient concerns
- Time to complete 5 minutes
- http://pos-pal.org/
Example, Intensive care

- ICU is a dynamic, busy, high tech environment but where many patients die
- It is challenging to providing high quality end of life care particularly where there is prognostic uncertainty
- Research (mainly US) highlighted concerns about symptom control, decision making, communication and psychosocial support
- One-to-one nursing care

**Study aim:** to develop and evaluate a tool to improve palliative care in ICU
Design and Methods

• Mixed methods design following the MRC framework for development and evaluation of complex interventions

• Phase 0-1 exploring concerns and developing (Psychosocial Assessment and Communication Evaluation) PACE = literature review, qualitative interviews, focus groups with 40 staff and 13 family members

• Phase 2: Piloting, revising, implementing, preliminary evaluation = post-implementation survey of 95 ICU staff and 213 family members (two-thirds with PACE completed).

Decision: to develop PACE for all patients admitted to ICU

- Key details about family
- Social and cultural needs
- Patient preferences: treatment, place of care, advance directive
- Awareness of patient and family
- Information provision
- Communication update
- Useful contact numbers

To be completed within 24 hours of admission
### Example questions: PACE

If yes to any of the following, detail action taken below:

<table>
<thead>
<tr>
<th>Children under 18?</th>
<th>☐ Yes</th>
<th>☐ No</th>
<th>If yes, contact palliative care social worker to discuss supported visits (page KH6081)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guardianship issues of any children?</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td></td>
</tr>
<tr>
<td>Vulnerable adults?</td>
<td>☐ Yes</td>
<td>☐ No</td>
<td></td>
</tr>
</tbody>
</table>

#### 3. Patient Preferences

Has the patient previously expressed views about any treatment / care wishes:

- ☐ Yes  
- ☐ No  
Specify: __________________________

Has the patient expressed a preference for place of care?

- ☐ Yes  
- ☐ No  
Specify: __________________________

Does the patient have an advance directive / statement?

- ☐ Yes  
- ☐ No  
Details and action taken: __________________________

Names of people information about patient to be given to:

- __________________________
- __________________________

Has the ITU been explained to the patient / NOK?

- Visiting hours
  - ☐ Yes  
  - ☐ No  
- Who to ask for information
  - ☐ Yes  
  - ☐ No  
- Who the different staff members are
  - ☐ Yes  
  - ☐ No
PACE evaluation

95 staff responded to questionnaire

- Nurses mainly completed PACE
- 61% respondents reported completion within 24 hours
- 89% said it was very or generally useful
- Most useful sections: family details, social details and communication/information.

165 (of 213, 78%) family members completed questionnaire – two-thirds PACE. PACE group:

- significantly more satisfied with symptom assessment and treatment
- significantly more satisfied with honesty and consistency of information about patient

Post intervention: family members

Symptoms

“. when he’s been on the bed he’s sort of moved and he’s gone ‘Oh’, and he said he’s in pain. I’ve then called the nurse over and automatically she’s given him painkillers, or she’s checked the chart to see when he’s had his last painkillers and given him painkillers… (Relative of patient 5 Phase 2)”

Communication

“Because I do ask ... I said to them “is he under any sedation and have you taken him off this, have you taken him off that ... and they’re saying about his sodium level is a bit low and I asked them what that meant and they explained that to me so, you know, they are really good ... I’ve got no qualms with asking the nurses anything..”
Theoretical Model of how PACE may be acting to improve care

Information about family and social details requested and recorded in PACE and provides practical steps they can apply skills and attitude

Training on the ward of staff as part of PACE improves knowledge, skills and attitudes of staff

Collection of information on preferences facilitated in PACE, reinforcing attitude change

Enhanced patient/family/clinician interactions
Families feel a greater sense of continuity of information and honesty

Record of what has been discussed in PACE aids inter staff communication and care co-ordination

Details of useful numbers in PACE to aid staff when they need help underpin training

Support for dignity, respect and peace
Improved communication
Greater trust during difficult decisions
Attention to individual wishes
Improved symptom control

Timely referral and additional support gained from other services

Staff are aware of preferences to help them guide care and discuss these with patients

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## Take home thoughts: future for palliative care

<table>
<thead>
<tr>
<th>New era of palliative care: new landscapes</th>
<th>Ageing, multi-morbidity, fluctuating trajectories</th>
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<tbody>
<tr>
<td>Transformative models of care and treatment for new population</td>
<td>Palliative care to live well, as well as end of life care</td>
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<tr>
<td>Transformative research Methods to evaluate complex interventions</td>
<td>Potential for..</td>
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</tbody>
</table>
Acknowledgements

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• For resources go to:
  • www.csi.kcl.ac.uk
  • www.pos-pal.org