Improving palliative & end of life care for older people in community settings

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Cicely Saunders Institute
www.csi.kcl.ac.uk
The meaning of “palliative care”

- Enhance the **quality of life** of patients and families
- Applicable **early in an illness course** alongside therapies intending to prolong life
- **Relief** from pain and other distressing symptoms
- Integrates **psychological & spiritual**
- A **support system** to help patients live as well as possible until death, and families in bereavement
- Provided by Generalists (eg GP, Care home manager) and specialists (eg Macmillan, hospice)
“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Dame Cicely Saunders
Nurse, Doctor, Social Worker and Writer
Founder of the Hospice Movement (1918-2005)
Palliative care for the 21st century, bow-ties
(Hawley PH, J Pain & Sympt Manage 2014; 47 (1): e2-e5)

- Applicable early in an illness course alongside therapies intending to prolong life
- Goal based care, not prognostication ‘last year of life’
- Focus complexity and phase of illness (unstable – distressing symptoms/concerns patient and/or family)
The concern? Palliative care is becoming a central element of health care responsibility

- 15-20% of healthcare resources are spent on the last year of life
- More than 80% of deaths are from chronic and progressive long-term conditions
- By 2020 40% of deaths people aged 80 years or over
- Patients with multiple co-morbidity experience complex symptoms and problems which increase as their illness progresses
- Their families often struggle with the burden of care

Mortality Predictions show the numbers will increase across the globe

Source: Office of National Statistics / GAD
• How people die remains in the memory of those who live on. 
  *Dame Cicely Saunders (1918 - 2005) founder of the modern hospice movement*

• Your chances of avoiding the nursing home are directly related to the number of children you have *Atul Gawande, Being Mortal:*

• The dissatisfied dead cannot noise abroad the negligence they have experienced. *John Hinton*

• At my age I do what Mark Twain did. I get my daily paper, look at the obituaries page and if I’m not there I carry on as usual. *Patrick Moore (1923 - 2012) British astronomer and television presenter*
May 2014 – World Health Assembly resolution on palliative care, to be integrated into health systems – UICC said – essential health care service for people with chronic and life limiting illness.
Concerns:
- 355,000 people EoLC is wanting
- Inadequate out of hours cover
- Reliance on hospitals at EoL
- Inequity of spend £600-6K per death

James Lind Alliance:
- Access to palliative care for all – non-cancer
- Care in patient’s home
- Well trained staff
- Out of hours provision

2015 Quality of Death Index
The biggest problem is that our healthcare systems are designed to provide acute care when what we need is chronic care.....That’s still the case almost everywhere in the world

Stephen Conor, Worldwide Hospice Palliative Care Alliance, 2015
Palliative care research in the Cicely Saunders Institute

Evaluating and improving care
- Cancer
- Complex disability
- Neurological
- HIV/AIDS
- Renal failure
- Organ failure
- Multimorbidity

Person centred outcome and assessment measures
- Palliative care Outcome Scale (POS)
- Goal attainment scales
- Rehabilitation scales
- Complexity & costs

Focused clinical research on symptoms
- Breathlessness
- Depression
- Pain
- Spasticity

Patients and Families

Methodological development

Policy and Guidance

Living and dying in society
- Ageing
- Caregivers
- Preferences / choice
- Place of care and death
- Ethnicity & culture
- Global health
- Spirituality

Collaboration

Dissemination

Education
– right place, right care and right time
Right place? – where older people die

**Centenarians** N=35,867 deaths 2001-2010

- 56% increase in deaths
- Little change place of death
- 27% died in hospital
- 61% died in a care home

Right care – what you die from changes with age

- Centenarians likely to die from pneumonia and ‘frailty’
- Outlived causes of death from cancer or heart disease commoner in ages 80-95 years
- To reduce reliance on hospital
  - Recognition centenarians risk to ‘acute’ decline from pneumonia
  - Wider provision of anticipatory care to remain usual place of care in the community

Dementia - right place?

Place of death 2001-2010 N=388,899

- Hospital deaths (40%)
- Reversal 2006
- Increase care home deaths (55%)
- Older age, availability of CH beds

Few died at home (5%) or hospice 0.3%

Right care, right time
OPTCare Elderly

• Optimising palliative care for older people in community settings

• To develop and evaluate the feasibility of a model of short-term integrated palliative and supportive care

• Joint study King’s College London and Sussex Community NHS Trust

http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/OPTCare/index.aspx
OPTCare Elderly-Optimising care; development and evaluation of short-term integrated palliative and supportive care (SIPS)

- **Development Phase 1a**: Mortality follow-back survey
- **Development Phase 1b**: Consultations on findings to inform SIPS (benefit; timing; integrated working) older people, carers, clinicians, researchers, commissioners.
- **Evaluation Phase 2**: Comparative feasibility evaluation of SIPS for older people and families in community settings – target N=52 patients
Phase 1 Intervention development

AIM

To identify factors associated with end of life transition to hospital from usual place of care for people aged 75 years or over.
RESEARCH METHODS

• Mortality follow-back survey QUALYCare (Gomes et al 2010)
• Last 3 months & week of life examines:
  Outcomes: Palliative care Outcome Scale (POS)
  Care receipt: Client Service Receipt Inventory (CSRI)

SETTING

• Two local authorities in England approx. 1 million residents
• Survey administered by Office for National Statistics

PARTICIPANTS (n=882)

• Registered the death of a person aged 75+ years
  (malignant/non-malignant disease) preceding 4-10 months
• Excluded deaths e.g. suicide/accident
Main outcome:

Transition to hospital as place of death  
versus  
No transition or transition to a community setting (care home or hospice)

• Multivariable regression analysis
EXPLANATORY MODEL

ILLNESS
- Cause of death
- Symptoms e.g. pain
- Psychological distress e.g. anxiety

INDIVIDUAL
- Demographic variables e.g. age, gender

ENVIRONMENTAL
- Area deprivation
- Health service contacts, e.g. GP, community nurse
- Type of health provision, e.g. key worker

Gomes & Higginson 2006 BMJ
RESULTS (1)

**Respondents**
- 443 (50.2%) participated
- Most were relatives (98.9%)
e.g. spouse, son/daughter
- Majority women (63%)
- Mean age 62.3 years (SD 10.7)

**Patients (decedents)**
- Mean age 87 years (SD 6.4; range 75 - 104 years)
- Majority women (59%) and widowed (54%)
- Died from **malignant (24%) and non-malignant conditions (76%)**
  (circulatory 33%; respiratory 20%;
dementia/frailty 15%/5%)
- 93% White British
RESULTS (3)
Patient and family preferences

• Only 2% of patients and 9.7% of families preference to die in hospital.
• Patients wished to die at home (68%)
• Family: home (42%)/care home (25%)
RESULTS (4)

Time spent in hospital before death N=144*

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<td>Less than 24 hours</td>
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<td>A day or more but less than a week</td>
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<td>A week or more but less than one month</td>
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<tr>
<td>One month or more but less than six months</td>
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*2 missing data

OPPORTUNITY
RESULTS (5) **Multivariable analysis (N=424)**

- EoL transition to hospital was…

<table>
<thead>
<tr>
<th>More likely for patients with:</th>
<th>Less likely for patients with:</th>
</tr>
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<tbody>
<tr>
<td><strong>Respiratory disease</strong> as cause of death vs cancer (PR=2.07, 95%CI 1.42-3.01)</td>
<td><strong>Identified key worker- a skilled doctor or nurse to rely on to get things done</strong> (PR 0.74; 95% CI 0.58-0.95)</td>
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<tr>
<td><strong>Breathlessness</strong> Severe/overwhelming in the last week of life vs. no breathlessness (PR 1.96; 95%CI 1.12-3.43)</td>
<td><strong>Discussion about EoL preferences with a health professional</strong> (PR 0.60; 95% CI 0.42-0.88)</td>
</tr>
</tbody>
</table>
Right care - implications for practice

Three key messages:

1. Improve management of breathlessness in the community (Higginson et al 2014 *Lancet Resp*; Farquhar et al 2014 *BMC Med*)

2. A skilled key worker to co-ordinate timely care e.g. nurse, doctor or social worker (Epiphaniou et al 2014 *Prim Care Resp J*)

3. Health care professionals provide opportunities for patients and families to discuss future care and wishes (Gomes and Higginson *BMJ* 2006)
OPTCare Elderly – Phase II
Comparative feasibility trial Short-term integrated palliative care
Short-term integrated palliative and supportive care; key components

- Delivered by integrated working between specialist palliative care and the main care providers - community nurses and GPs
- ‘An extra layer of support’ for frail elderly with advanced condition(s), unresolved concerns
- Multi-disciplinary review by palliative care
- 1-3 visits by the palliative care team – assessment, implement change and review.
OPTCare Elderly Phase 2 study flow diagram

- **50 patients and 26 carers recruited**
- **48 patients completed**
- **2 withdrawal – 1 death and 1 carer hospitalized**
- **20 qualitative interviews with patients and carers**
- **2 Focus groups with clinical teams experiences of delivery the intervention involving:**
  - Two community palliative care teams
  - Four community nursing teams
  - Four GP practices

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- **GP identifies patients in their practice who might benefit from a proposed new support service**
- **Continuing usual support from their GP**
- **Support from the specialist palliative care team alongside usual GP care**
- **All participants interviewed with researchers to understand the challenges older people face and their views on the support they have received to see what could be improved**
  - 3-4 interviews over 3 months
  - At a time and place to suit participant
  - With a family member or friend taking part if possible
  - With participants permission to look at their medical notes
  - All information gathered will be kept CONFIDENTIAL
- **After study completion ALL participants will be offered additional support from the specialist palliative care team**
Eligibility criteria

- Age 75+ and severely affected by non-malignant advanced illness and/ or frailty with or without dementia encompassing two or more unresolved:
  - Symptoms
  - Psychosocial concerns
  - EoL issues e.g. advance care planning
  - Progressive illness/frailty
  - Complex needs (i.e. palliative care needs)
    - Increasing health service use
  - Carer burden
- Rockwood Clinical Frailty Score 4-9
- Excluded if active cancer diagnosis or receiving specialist palliative care
Outcomes.....

PRIMARY OUTCOME
Total 5 symptoms from IPOS
1. Breathlessness
2. Anxiety or depression
3. Constipation
4. Pain
5. Weakness or drowsiness (fatigue)

SECONDARY OUTCOMES
• Additional IPOS items
• Carer Burden (Zarit)

ECONOMIC EVALUATION
• Client Service Receipt Inventory
• EQ-5D – quality of life
Phase 2 Feasibility Trial Update (2)

Cumulative Accrual

Number of patients recruited

Accrual
Target Accrual

1st August 2014
1st September 2014
1st October 2014
1st November 2014
1st December 2014
1st January 2015
1st February 2015
1st March 2015
1st April 2015
1st May 2015
1st June 2015
1st July 2015
1st August 2015
1st September 2015
1st October 2015
# Participants (n=50)

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<td>Mean age</td>
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<td>Male</td>
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<tr>
<th>CLINICAL FRAILTY SCORE*</th>
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<td>6</td>
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<td>7</td>
<td>5</td>
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<tr>
<td>Mean score</td>
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<td>Endocrine</td>
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<td>Frailty</td>
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<td>Dementia</td>
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<tr>
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<tr>
<td>Diseases of the Blood</td>
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*Clinical Frailty Scale
- 4= Vulnerable
- 5= Mildly frail
- 6= Moderately frail
- 7= Severely frail
- 8= Very severely frail
- 9= Terminally ill
Mean IPOS score over time for selected symptoms (preliminary findings)

Group A

Group B
Qualitative interviews with patients and carers – acceptability and benefit of receiving short-term integrated palliative and support care
We’re important, but means my ‘my last ditch’?
Well a friend of ours, her daughter …was a Macmillan Nurse …I can see that she was helping people and I thought it might be good, it might be Macmillan coming up to see me, change me or ask me things ….. thought I was going to be helped, but thank God I’m managing [01107-M]

.....Palliative Care Team was coming, I thought oh God, you know, that’s dreadful, it’s my last ditch. It wasn’t really, until I met her and found, you know, that it wasn’t quite like that really, just anybody who’s got a sort of incurable long term thing, like I have [renal failure] [01108-F].
Acceptability - Integrated working

We all want the same thing – ’keeping me on my feet’

They [the physio, OT, carers, benefit advisor, nurses] all want the same thing...what I want....to keep me on my feet [02409-F]

‘We've seen so many people’

..it’s been wonderful since the Palliative Care Team have got involved and we’ve had all these different things, but I do feel it could all be a bit more centralised. So we didn’t have to sit and answer the same questions I think that information should move on with dad with all the departments…(e.g. medication) [C2303-F].....
Benefits - Receiving palliative care

A ‘listener’ who understands ‘where you are’
…She (the palliative care nurse) was a listener…The nearest I’ve come to someone having an understanding of what you do, how you are and what could be of help…and one or two things have come out we hadn’t thought about, hadn’t even considered. You know – excellent. [01201-M]

Her (the palliative care nurse’s) manner towards dad and me, and the questions she asked…she was just very caring and trying to get...[C02303-F] ..Ease it out for us [02303-M]
Benefits - Symptoms and concerns

Emphasis on psychosocial care

‘A safety net' someone to turn to who listened

To me I feel that they’re in the background. It gives me a safety net. I feel that they were so caring and lovely that I could phone them if I felt I was worried or concerned more than I could his doctor.[C2303-F]

Well just made me feel buoyed- makes you feel buoyed [up]....someone you can talk to about every day things..to know you are doing the right things [01107-F]
Adapting and accepting ‘old age innit’

…I mean, it’s all down to old age innit? It’s like yesterday I was alright, all of a sudden I got a terrific pain down the back, in the middle of my back, right between the shoulder blades. Now, whether it was a muscle, it has gone today, still getting all these twinges...... I’m always uncomfortable [laughs] [01204-M]

‘If it gives me a little respite’

I was going to say no to that (18 month treatment for chronic lung infection). But now these anti-biotics...you might go in for a week or 10 days. It sorts it [lung infection] and they do the tests..If it gives me a little bit of respite. I will be delighted… [01207-M]
Benefits - Advance care planning

‘Close your eyes and not wake up again'
Most hoped to die at home in their sleep, but not seeking to plan future care:

- as place of future care often uncertain
- most feared increasing care needs - both reliance on carers at home, or moving to a care home
‘Flickers through my mind’ (ACP)

…it had sort of flickered through my mind sometimes..I’ve been on dialysis and I thought oh God what would happen if, you know, I couldn’t even go on like this at home, but I sort of dismissed the thought of it, cowardly, but then I did realise after she [CNS] started talking about it that I had to face up to that and think what would I do, or what I hope I would be able to do, and I hope that I would be able to go on here with somebody helping out if necessary, [that's] what I’d hope. [01108-F]
Right care, right place - Short-term integrated palliative and supportive care

- Acceptable to patients and carers
- GPs can identify eligible patients
- Community Palliative care can deliver
- Likely main benefits psychosocial e.g. anxiety, ‘safety net’, ‘feel valued’; connecting to services; and coordinating care
- Advance care planning acceptable (for most)
- Integrated professional working – how is this working (or not)? – emphasis skilled key worker to coordinate care
Thank you
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OPTCare Elderly Research team

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