Improving end of life care for older people with frailty in the community - Attending to Living AND Dying

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Attending to people...
What Frailty means to those living in late old age?
(Nicholson 2012)

Seeing in a different way:

“But my confidence in life in general has gone, you know because you can't do things. I’m frightened to an extent, to a certain extent but it might be the wrong word but in a general sense, the way the world is going everything. I haven't got the confidence anymore”
(Jack)

Being seen in a different way:

“I hate it, I hate being treated differently I am the same on the inside as I have always been”
(Maureen)

A state of imbalance
• Dis-connects (Losses)

Loss of the future: more obviously inhabiting the space between living and dying-
“And then he doesn’t seem to be so strong-once we got nearly as far as nearly the pillar box (on a walk) but now I don’t know he doesn’t want to go as far as that. I’m just terrified he’s going to die.”
(Betty wife of Jo)

• Retaining connections and anchorage through the work of daily routines
• Creating connections- the creativity of older people with frailty relating to their worlds in a different way
Understanding what matters to older people Living and Dying with Frailty in Old Age

Maintaining Continuity-
Maintaining Personhood-
The continual work of balancing and adaptation to loss

The social networks/community “the glue” through which and in which lives are lived

The VIP Bundle [http://youtu.be/Qj_YOXjL6Ws](http://youtu.be/Qj_YOXjL6Ws)
Learnings - The Frailty Paradox

• Frailty- encompasses more than deficit  No-one in my doctoral study referred to themselves as frail-Older people with frailty living at home are the survivors-outliving the majority of their birth cohort. These are important considerations when considerable capability and resilience were evidenced as well as the difficulties of living with an increasing unreliable body

• Valuing continuity The ritualised and regulated practices that older people in this study undertook to create a sense of stability in their uncertain worlds were universally cut across when health and social care became involved-potentially leaving an older person feeling more frail

• Allowing yourself to be cared for as well as cared about revalidation of the hidden work of intimate care giving for older people

• The importance of Families

• Keeping the future in mind The prolonged period of living with increasing dependency and limited function can mean deterioration is missed and dying is unrecognised and unsupported- There is unnecessary suffering for older people of over and under treatment in ignoring or fighting against dying in old age
Commissioned by Bromley Clinical Commissioning Group. BCC is a nursing led service, with the GP taking medical responsibility for the patient. The team consists of Clinical Nurse Specialists, health Care Assistants and administrators. Other St Christopher’s services are available as necessary to meet patient needs. Those using the service can access advice and help 24 hours a day.

**Service Aims**
- Enable older people with advanced illness or frailty thought to be in their last year of life to receive timely and well co-ordinated care
- Help people die with dignity in a place of their choice
- Provide support to their families and carers
- Reduce unnecessary hospital admissions

**Activity**
- **Daily caseload** averaging 260
- **Home death rates** increased 23% to 67%
- **Time in service** 16% of patients die within 7 days of referral- 2% on the books for over 2 years
- **Not known to other** services - 56% in year one- 86% in year three
BCC Referral Criteria

Mainly GP’s
Local Hospital’s
Integrated Care Networks

Any older person thought to be in the last year of life.

Indications for referral include:
People with an EFI of severe frailty
Multiple admissions to hospital in the last year
  • Increasing uncertainty
  • Deterioration
  • Long term comorbidities
e.g.
  • Dementia
  • Endocrine (e.g. diabetes)
  • Neurological (e.g. MND, multiple sclerosis, Parkinson’s)
  • Renal failure
  • Respiratory
  • Cancer
  • Cardiac disease

Precarious social support network/carer burden and escalation of concern

Would benefit from advance care planning or discussions about the future

Requires a joined-up approach – currently falling between services and requires care co-ordination.
BCC- Model of Care (current)

SPOC-all referrals triaged

BCC CNs Initial assessment and care needs identified via OACC

RAG rated according to OACC and context of care

Appointing key-worker linking in to other services e.g. MC, DN’s, Residential Care Home teams, private care workers, Age UK

Care Co-ordination
- Care planning
- ACP conversations
- Advice to GP/DN re care
- Key working certain patients
- Watchful waiting

Red

Amber

Green

Blue

Rapid response
Access to equipment

24 hr access to CNs/Duty Dr

16% die 7 days post referral
The BCC population compared to conventional community palliative care patients

**Age**

- **BCC**
  - 57% 25 - 64 years
  - 10% 65 - 74 years
  - 31% 75 - 84 years
  - 3% 85 - 100 years

- **HC - BRO**
  - 26% 25 - 64 years
  - 21% 65 - 74 years
  - 34% 75 - 84 years
  - 15% 85 - 100 years

**Diagnosis**

- **BCC**
  - 12% Cancer
  - 88% Non Cancer

- **HC - BRO**
  - 13% Cancer
  - 87% Non Cancer

**Place of Death**

- **BCC team**
  - 63% Home
  - 17% Hospital (acute)
  - 13% Inpatient Unit
  - 4% Other

- **HC-BRO**
  - 46% Home
  - 29% Hospital (acute)
  - 19% Inpatient Unit
  - 5% Other
  - 1% Learning disabilities Care Home bed
  - 0% Residential Care Home bed
Using Patient Reported Outcomes to improve our understanding of need in older people with frailty

**AKPS:** measure of functional status; 0-deceased to 100 best possible function

**Phase of Illness** – describes four distinct clinical stages of a palliative patient’s illness: stable, unstable, deteriorating, and dying (and deceased).

**IPOS:** 17 items, common symptoms & problems in palliative population, 0 absent to 4 overwhelming

The Outcome Assessment and Complexity Collaborative (OACC) project - www.kcl.ac.uk/nursing/departments/cicelysaunders/research/studies/oacc/index.aspx

BGS EoLC 2018
AKPS: measure of functional status

Whilst indicative of care need and possibly carer distress this data suggests AKPS as a predictor of decline in BCC patients is of limited value.
Phase of illness

Over 6 months – deterioration phase seems slower - The nurses in BCC express this as a different momentum and pace – can be hard to know what we are doing and register change, – Care pathways and management pathways not so clear. ACP can be harder as people do not identify as ill (er) or dying. Variation in POI “practice dying”.

<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase...</th>
<th>This phase ends when...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</td>
<td>Patient problems are resolved; disease is stable and can be managed by usual oral medication and support</td>
<td>Patient is unlikely to improve and needs more support, care and medications.</td>
</tr>
<tr>
<td>Unstable</td>
<td>Patient is unwell and deteriorating; urgent changes are needed</td>
<td>Patient does not have a plan of care or is deteriorating</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>The patient is in a deteriorating phase; quick decisions needed</td>
<td>Patient is dying</td>
</tr>
<tr>
<td>Dying</td>
<td>Patient is dying and dying</td>
<td>Patient is dying</td>
</tr>
<tr>
<td>Deceased</td>
<td>Patient has died</td>
<td>Patient has died</td>
</tr>
</tbody>
</table>

Length of phase of illness (in days) in each setting

![Bar chart showing length of phase of illness in each setting]
“Keeping Going”

Proportion of BCC patients with symptoms & problems - identified using iPOS at first assessment

Specialist Palliative care focus is often on disease rather than on disability and resilience - importance of functionality and rehabilitation and falls prevention.
Learnings and Questions

• **Single disease focus is problematic** in determine need for this patient group - Multimorbidity - needs long term and ongoing partnerships with older people's services -

• **Care Co-ordination** – how do we maintain continuity of some low involvement

• **Advance Care Planning** - perhaps a different language or a different focus - uncertain futures as much as care in the last few days of life. –

• **What and How are we assessing need?** E.g. Mental health assessment - often overlooked yet physical And mental issues together are a sign of complexity and poor outcomes, symptoms rather than functionality

• **Workforce Development** - adapting our services to be less organised around dying and more around variable episodes of crisis and need -

• **Rehabilitation/Disability Models** – Partnerships with wider community services and voluntary sector

• **Palliative Care in the community mainly provided by social care agencies and families** - Carer needs and capability - who supports this and how do we enable people to support each other?
Connecting & Understanding where people are
Assessment
Proactive Intervention
Identify and possibly relieve distress

Developing Philosophy and workforce
Providing tools (resources) to enable flexible and competent EOL provision

Community participation
Responsibility
Adding Value

Appreciating different places of care eg care homes

Valuing older people – Social value and legacy

Confidence to talk sensitively about death, dying and loss

Embracing Ageing -

Rehabilitation - Watchful waiting

Optimize working with the person & their family
Shared learning

Working in Partnerships across sectors and specialties

Balancing Continuity and Adaptation to Loss

Age Attuned (Palliative) Care
(Nicholson, Seymour & Richardson 2018)
Summary- Older People with Frailty

• People need recognition of their capability and strengths over a lifetime-long lived-this may help ease a conversation about their current or future vulnerabilities

• It is as important to attend to accumulated losses and distress as to death and dying- this values the ageing process and dependency/ interdependency which are often ignored

• Knowing when someone is going to die (prognostication) may be less helpful than knowing what matters to a person (preferences and needs)
Services/Community

• Working with people in their own homes means letting go of being in charge, allowing more risk and uncertainty than is comfortable and knowing a person over time

• Communities are a hugely important and core in providing care, compassion and continuity for older people with frailty

• Know who and what “community” is for an individual older person and work with that community
In conclusion…

Living with and dying from Frailty moves beyond the dichotomies of independent/dependent or coping/requiring care, to a person-centred approach recognising both potential needs and capability. It seeks to recapture McCue's insight of life naturally moving towards closure in old age.

In this formulation, dying is engaged holistically and not, without careful thought, resisted biologically (Nicholson 2017)