Frailty and Care in the last phase of life

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IS Frailty relevant to you? The F word........

Our treatment of the frail elderly is a national scandal

The number of people over 85 will more than double to 3.4 million²

End of life care provision in care homes and the community needs to double by 2040²

Over one third of all deaths are people aged 85 and over²

How can practices fulfil the new frailty requirements?
Why does Frailty matter to Palliative Care? Imperatives:

Poor outcomes associated with Frailty:

Greater risk of disability, institutionalization and death

Fig. 1: Kaplan-Meier curves, adjusted for age and sex, for study participants (n) over the medium term (5–6 years), according to their scores on the CSHA Clinical Frailty Scale. Some scores were grouped. Top: Probability of survival. Bottom: Probability of avoidance of institutional care. Fried et al 2001

£10,207 per person is spent in the last year of life (average spending from 80+ years is £2,106 PA) Hazra et al 2017
I've seen terrible things as a paramedic. The worst isn't what you'd expect

Taking an elderly man to hospital while knowing his wife would probably never see him again is the job I've most agonised over

What if we offered older people honesty & choices as they approach the end of their lives? Would need reorganisation of services so they had help they needed
What is Frailty?

A clinically recognised state of \textit{increased vulnerability}.

- Age and morbidity related \textit{decline in the body’s physical and psychological reserves}.
- A long term condition, that can be identified and managed to improve quality of life
- \textit{At risk of dramatic deterioration} in their physical and mental wellbeing after an apparently small event which challenges their health.
- The degree of frailty of an individual is \textit{not static}; it naturally varies over time and can be made better and worse by \textit{our interventions (Modifiable)}
What is Frailty – clinically

“Frailty is a distinctive health state related to the ageing process in which multiple body systems gradually lose their in-built reserves leaving a person vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a change in medication or an infection” (Clegg et al 2013).

- Common around 10% of those over 65 (Clegg et al. 2013) increasing to around 65% of those 90 and above (Gale et al. 2015).
- Progressive (5 to 15 years) but not linear - interventions and to some extent can be modifiable (Maddocks et al. 2016).
- Episodic deteriorations (delirium; falls; immobility).
- Typical signs and symptoms of frailty include sarcopenia, anorexia, exhaustion and low mood.
- Frailty and cognition interact within a cycle of decline (Robertson et al 2013).
- Concept in evolution -
## Identifying Frailty complementary approaches

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<th>Identifying Frailty- Table Comparing the Frailty Phenotype and Frailty Accumulation of Deficit Index Approaches</th>
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<td>Fried et al 201</td>
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<td><strong>Frailty phenotype</strong></td>
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<td>5 pre-defined criteria: involuntary weight loss, exhaustion, slow gait speed, poor handgrip strength, and sedentary behaviour</td>
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A Life course perspective

Bergman et al 2014

Hanlon et al 2018-frailty in middle age (aged 37-73) - associated with multimorbidity, M/S, COPD, CFS and diabetes and with socio-economic deprivation, smoking, obesity
eFL score and categories

- **Fit (eFI score 0 -0.12):** No or few long-term conditions that are usually well controlled. Independent in day to day living activities.

- **Mild frailty (eFI score 0.13 –0.24):** Slowing up and in need help with activities of daily living such as finances, shopping, transportation.

- **Moderate Frailty (eFI score 0.25 – 0.36):** Limited outdoor activities and mobility problems or require help with personal activities such as washing and dressing.

- **Severe Frailty (eFI score > 0.36):** Dependent for personal care and have a number of co-morbidities. At risk of dying within 6 -12 months

X 5 more times likely to die than non frail person - but when? Stow et al 2018 - prognostication value of EFI
Clinical Frailty Scale*

1. Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.

5. Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7. Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally III - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.

* Canadian Study on Health & Aging, Revised 2008.

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What Frailty means to those living in late old age?

(Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age a narrative enquiry over 17 months 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
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.
Understanding what matters to older people Living and Dying with Frailty in Old Age

Maintaining Continuity-
Maintaining Personhood-
The continual work of keeping going 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_Y0XjL6Ws
Frailty.. Moving on

Shibley Rahman- 2019! Living with Frailty many sided-

The Frailty Fulcrum
https://www.england.nhs.uk/blog/dawn-moody/
How we talk about frailty

- Understanding and assessing
- Person-centred collaboration
- Managing frailty - PC choice in future care and support needs
- Underpinning principles

http://www.skillsforhealth.org.uk/services/item/60
7-frailty-core-capabilities-framework

https://www.bgs.org.uk/blog/the-paper-boat
End of life care and frailty- what do we need to do differently?

• Talking about a different phase of life where healthcare goals may change, balancing quality against quantity of life

• To encourage healthcare staff, families and patients to talk more openly about the last phase of life Opens up discussion to be more than end of life* and DNACPR

• “Adding life to years not just years to life”

• Dual approach- affirming life and preparing for death

• Talking about benefits and burdens of healthcare – understanding the impact of frailty on response to illness and recovery

• Understanding that just because we can does not mean we should- “managing risk” (Prem Fade 2018)
Age-attuned Hospice care
An opportunity to better end of life care for older people

Age Attuned Hospice Care- How can this best be organised and delivered?

Multi levelled approach:

• Working differently with older people as part of a clinical response (clinical uncertainty)
• Working in partnership across services and systems “Integrated care”
• Supporting Societal Change- community assets
Balancing continuity and adaptation to loss

Multi-Levelled Approach

‘It’s about getting through the day, just holding it together, as best you can, you fall down, you pick yourself up, you keep going as best you can, till you, and well you can’t keep it up for ever.’ (Nicholson 2012)
An optimal clinical response

Watchful Waiting: Proactive purposeful intervention to identify and respond to incremental change

- Negotiating and learning the best way to be involved
- Giving options and ways to best manage change

Enablement
- Rehabilitative palliative care
- Giving options and ways to best manage change

Parallel Planning
- Individual assessment
- Negotiating plans for care

Multimorbidity / Frailty
- Advanced symptom control
- Advice about when and where to seek help
Palliative care needs for older people with frailty

They are older, mostly dying with non-malignancy, yet with a similar overall symptom burden compared to those seen in a more standard specialist palliative care service. Currently, the population of older people with multimorbidity is not routinely recognized as having specialist palliative care needs. However, it would seem that whilst needs of referral might be similar, presentation and patterns of symptoms may differ over time.
St Christopher’s living well at home team: Extending rehabilitation into the community

http://www.stchristophers.org.uk/patients/allied-health-professionals

Anyone can volunteer and help people like Gladys achieve their goals
Parallel Planning

• Greater and intentional integration with Specialist teams e.g. heart failure, geriatrician.
• All possible outcomes are on the table and some become more obvious over-time than others
• Honest conversations including wider care network
• Benefit versus burden of treatment
• Personalising evidence based medicine
• Reducing the burden of medication
• Upstreaming palliative care involvement
Improving services and the system of care

- Utilise tools that support decision making for older people
- Find opportunities for shared learning between organisations and professionals
- Invest in education and information that develops confidence and competence
- Find opportunities to engage in trans-organisation and trans professional patient reviews
- Create relationships with commissioners and providers that help integrate the hospice into system wide networks and plans
- Engage in collaborative research projects that facilitate shared vision for future care
- Appreciate, collaborate with, and learn from local residential and social care agencies
- Develop patient related outcome measures across organisational boundaries that foster, and embed relational and effective care
- Learn to collect stories about lives of older people in order to better understand their values, aspirations and priorities for care
- Draw on the expertise and feedback from older people and their families to develop and improve services
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 health and social care
- Help people die with dignity in a place of their choice
- Provide support to their families and carers
- Reduce unnecessary hospital admissions

**Activity (Jan 2018)**

- **Daily caseload** averaging 303 and rising
- **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 model of care (current)

SPoC: all referrals triaged

RAG rated according to OACC and context of care

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

BCC CN's initial assessment and care needs identified via OACC

Appointing key worker linking into other services e.g. MC, DNs, residential care home teams, private care workers, Age UK

Rapid response
Access to equipment

16% die seven days post referral

24hr access to CNs/duty doctor
BCC Referral Criteria - Refined

Mainly GP’s
Local Hospital’s
Integrated Care Networks
Care homes

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.
Changes/Reflections

Working with Uncertainty

• Key working and watchful waiting- Change in our model greater skill mix - HCA's- but need to support and understand triggers for care

• Need crisis services for times other than actively dying including night care – Vital role of 24 hour access

• Keeping care close to home- Community interventions to prevent hospital admission e.g. first dose of IV antibiotics

• Patients live with debilitating symptoms and families live with anxiety and uncertainty over time - this leads to a fragile social system which unless supported will lead to admission to hospital (living alone second biggest factor in hospital admission for over 75s)

Rethinking Complexity

• OACC scores complex needs that require other St C resources e.g. rehab, functionality, falls prevention

• Greater working needed with Social care, volunteers and family carers- Long and uncertain dying trajectories with subsequent changes in physical and mental health and social support require on-going communication and facilitation to review ACP and goals of care

• Long and uncertain dying trajectories with subsequent changes in physical and mental health and social support require on-going communication and facilitation to review ACP and goals of care and different care systems- incremental gains
Shaping Society’s Response

- Encourage individuals, groups and communities to learn skills and engage in the care and support of others important to them who are approaching the end of life.

- Identify and promote opportunities in which the state of dependency can enhance lives of people who are more independent.

- Promote community participation in care.

- Embracing the ageing process and its opportunities.

- Building confidence to talk sensitively about death, dying & loss.

- Valuing older people.

- Recognise what older people bring to society, relationships, conversations and decisions.

- Encourage conversations on the part of citizens about legacy.

- Promote discussions related to plans regarding older life and its end.

‘It is surprisingly difficult to accept that dependency is a fact of life, from our first breath to our last.’ Dartington 2004
Changing the language – Legacy
Being held in Mind- before and after death...

C.N.: ‘Is there anything else you want to tell me Eli?
Eli: It’s very kind of you, tell, the whole story, the life story, it’s all recorded...
C.N.: Shall I turn it off now? (Picking up the recorder)
Eli: Yes, is it all recorded? (Reaches over to touch the tape recorder)
C.N.: Do you want to hear...?
Eli: Yes, yes, let me hear my voice.’

“People need recognition of their capability and strengths over a life long lived – this may help ease a conversation about their current or future vulnerabilities.”
Caroline Nicholson 2017

“The greatest gift is a portion of thyself.”
Ralph Waldo Emerson
Questions that matter to me…

• Where are we engaging well with older people with frailty?
• How can we do more of this?
• What partnerships do we need to attend to?
• How does our service reflect the needs and demographics of the community it serves?
• Are we changing as fast as the world around us?

“We live in the world our questions create”

( Cooperrider 2004)