Evaluation of professionals' decision-making at end of life for frail older people

Dr Kim Stuart

University of Northampton

@KimStuartOT

kim.stuart@northampton.ac.uk

ELIZABETH CASSON TRUST

Aims of the session

To share the findings of doctoral research, evaluating care within a community setting provided to three (deceased) older people who experienced frailty

To gain a critical awareness of how occupational therapists can contribute to supporting older people experiencing frailty

To reflect on the organisation of end of life care within occupational therapy practice in supporting older people living with frailty

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Frailty

"Pragmatically, at some point, **the number of things** that people have wrong with them becomes more important than the exact nature of what they have wrong with them…"

Rockwood & Theou, Introduction to Frailty in Ageing, 2015

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Narrative accounts of frailty

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Temporality of participation

In constructing a life "well lived" gaining satisfaction from participation in everyday roles and tasks is essential

Rhythm and routine of everyday life

A satisfying routine and rhythm of everyday life provided a platform to accommodate continued participation, mediating the experience of frailty

Anticipating an aged death

Familiarity with death, as older people are exposed to their own ideas of mortality through the lives and deaths of those around them.

Grenier (2006;2008); Lloyd-Williams *et al* (2007); Hurd-Clarke *et al* (2011); Nicholson *et al* (2013); Bravell et al (2010), van Wijngaarden *et al* (2015)

Frailty and approaching an aged death

High quality of care indicators

- Personalised care (Kings Fund 2013; Age UK 2013, 2017)
- Familiar professionals (Rolland 2013; Haggerty 2012; Health Foundations 2011a)
- Integration (Ellins *et al* 2013; NHS England 2014;2019)
- Shared-decision making (Bunn *et al* 2017)
- Care planning that acknowledges end of life (Romo *et al* 2017; Gramling *et al* 2015)

Challenges in delivering care

- Fragmented, silo working practices (DoH 2012a, 2013a).
- Protocol and process driven care (Roland 2013; Haggerty 2012; Health Foundations 2011a)
- Complex and unpredictable trajectories of aged death (Nicholson *et al* 2013; Clegg *et al* 2013, Turner and Clegg 2015)

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Professional decision-making

Evaluate	Critically evaluate the process of end-of-life care for specific older patients' cases drawing out policy, practice and professional perspectives.
Review	Review the care of specific deceased older patients' cases through reviewing of medical notes and interviews to benchmark clinical practice against national policy and guidance.
Explore	Explore decision-making around end-of-life care of older people as retold through the narratives of healthcare professionals to inform service contexts.

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Method

- Three case reviews – **Albert**, **Brenda** and **Colin**
- Documentary review of case notes within episodes of care (community team) integrated into the story of care for Albert, Brenda and Colin
- **All** registered professional involved in care of Albert, Brenda and Colin within the community team invited to participate in a narrative interview to explore decision-making.
- **10** participants (Nursing, Occupational Therapy and Physiotherapy) across the 3 cases utilising narrative accounts and care mapping.
- Analysed data using Connelly and Clandinin (2000) interpretative **narrative framework**

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Grand narrative one

The clinical story of care providing a contextual account of frailty and end-of-life from professional perspective.

- Retold experience of frailty at end-of-life within the context of a community team.
- Importance of place in the experience of care at end-of-life for older people living with frailty
- The passage of care for the older person with frailty as they approach death

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Overview of case review

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Albert

- Albert was **91** years old when he died.
- He lived at home with his **wife** and has a small but close supportive family.
- During the last year of his life Albert had **multiple** admissions to hospital, during this period he was supported on discharge by the community team.
- Albert was diagnosed with COPD and IHD, he had **fallen** on several occasions resulting in a greater degree of **frailty**.
- Albert wanted to be at **home**
- Albert was admitted during out of hours to **emergency care**
- Albert **died** on an admissions unit within hours of transfer.

Brenda

- Brenda was **95** years old when she died
- Brenda lived **alone** in a small flat supported by her family.
- Brenda had **no** formal care support and was referred to **community services** on during the last year of her life.
- Brenda was initially referred for rehabilitation following the concerns identified by her family.
- Brenda declined support, refused to participate in the **rehabilitation** interventions.
- Brenda experienced **frailty**, several **falls**, low **mood** and **UTI** and was re-referred to the community team by her family one week later.
- Brenda declined admission to hospital on several occasions stating a preference for **no** medical intervention.
- Brenda wanted to die at home.

Colin

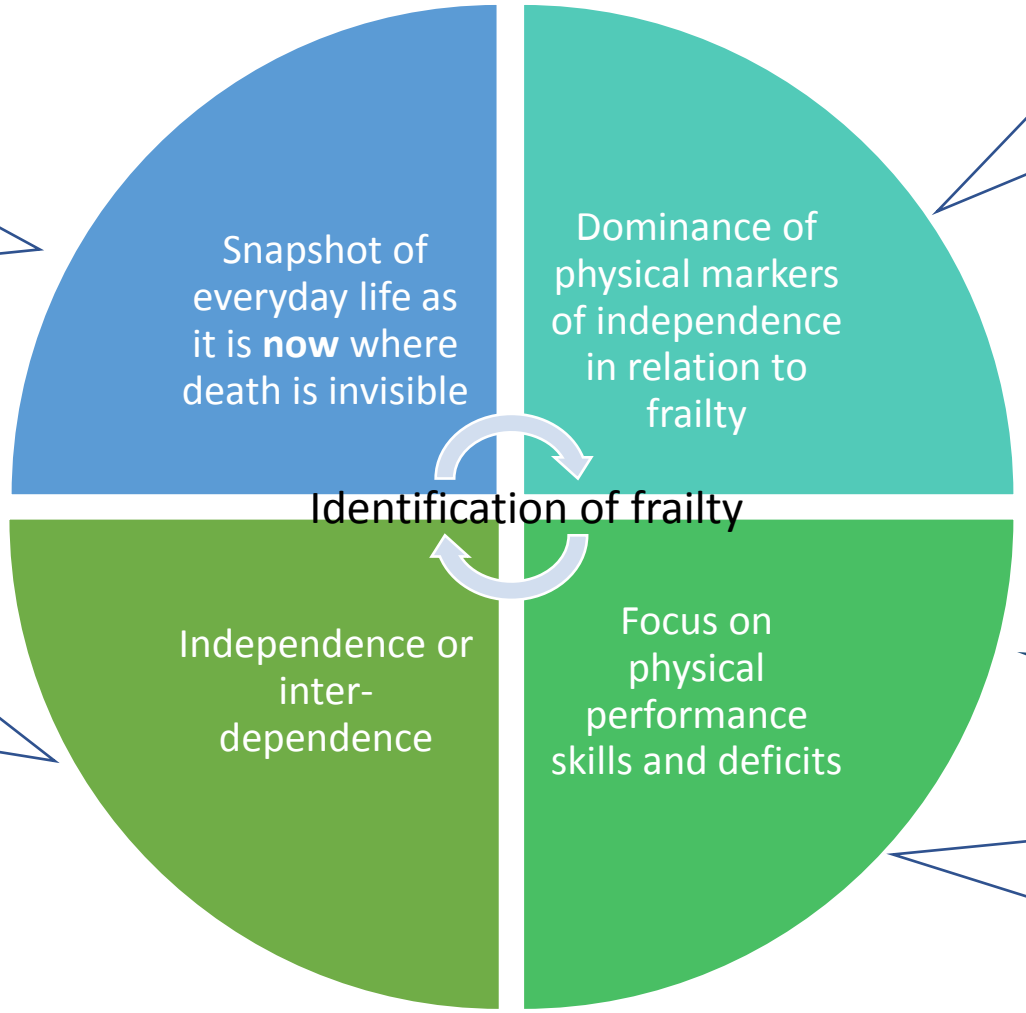
- Colin was **83** years old when he died
- Colin lived with his **wife** and had a large extended family supporting the couple.
- Colin had been discharged from hospital following a **prolonged admission** to an acute trust on a medical ward.
- Colin had **heart failure**, reduced **mobility**, fatigue, **SOBoE** and **frailty**.
- Colin was referred to community team to provide a period of **rehabilitation**.
- Colin had **intensive carer** input twice a day for personal care from a crisis response team.
- Colin wanted to be at **home** and did not to be readmitted to hospital.
- Colin had **fluctuating health** whilst being supported over the two-week period.
- Colin was re-admitted to hospital and **died** within 12 hours.

Retold experience of frailty at end-of-life

"I only met Albert on one occasion and at that time his physical health was the overriding impression was that he was quiet, he didn't communicate a great deal, very little verbal communication and actually appeared quite lethargic so any of the conversations that we had to have we tended to have with his wife who gave us and reported feedback on what we needed to know"

I tried to explain to Mrs A that because of these recurrent infections his baseline was shifting each time and each time [looking back at notes] that we were involved what four times, I think, he was getting worse and worse and worse and his baseline was shifting further back"

"I don't remember her looking particularly frail or thin".



"my impression is that the wife was doing a lot doing more than I realised and I think that was through conversation with her, I think she supported with all food, and I think she sort of although formal carers were going in twice a day I think it is just my impression of her over time was that she was doing more and more and I think that is something we don't always pick up on"

"my diagnosis was basically that he had got reduced lower limb strength and exercise tolerance due to a prolonged stay in hospital and required some exercises"

"we thought would be useful for Albert to be able to reposition, on the bed, it's about pressure care [as he was spending all day in bed due to fatigue and ill health] *and it's about maintaining muscle strength, joint integrity so that he can you know, keep a greater degree of independence."*

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Importance of place in the experience of care at end-of-life

Culture of care

Clinical world in the home

Place of death

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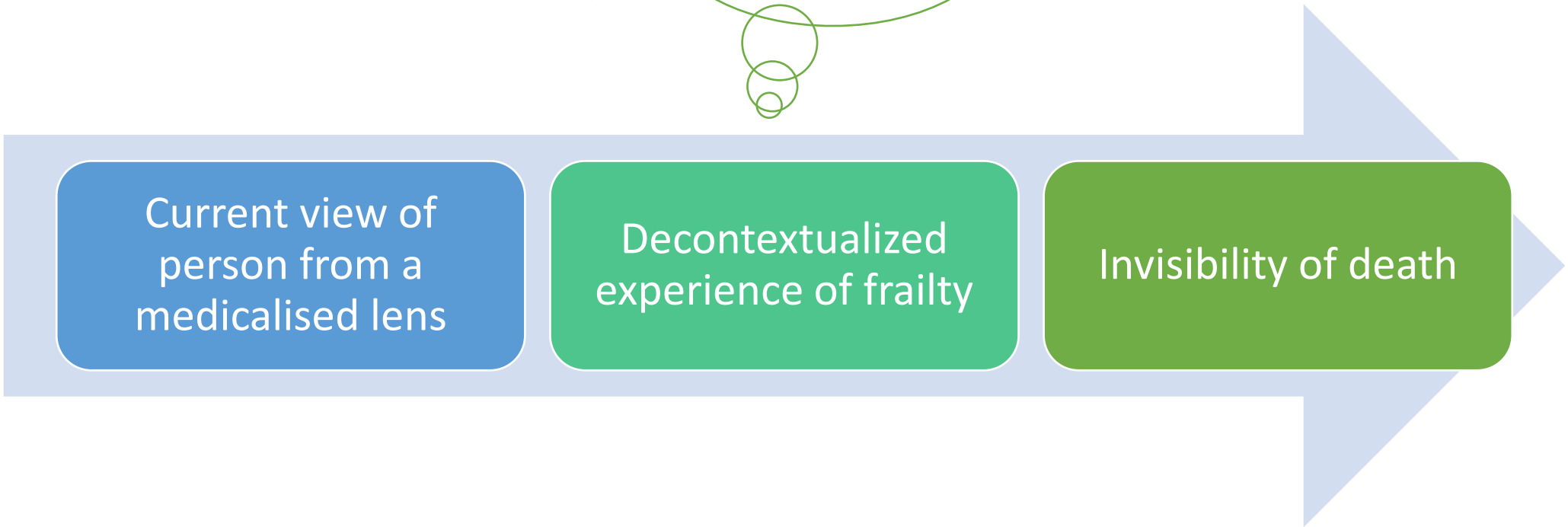
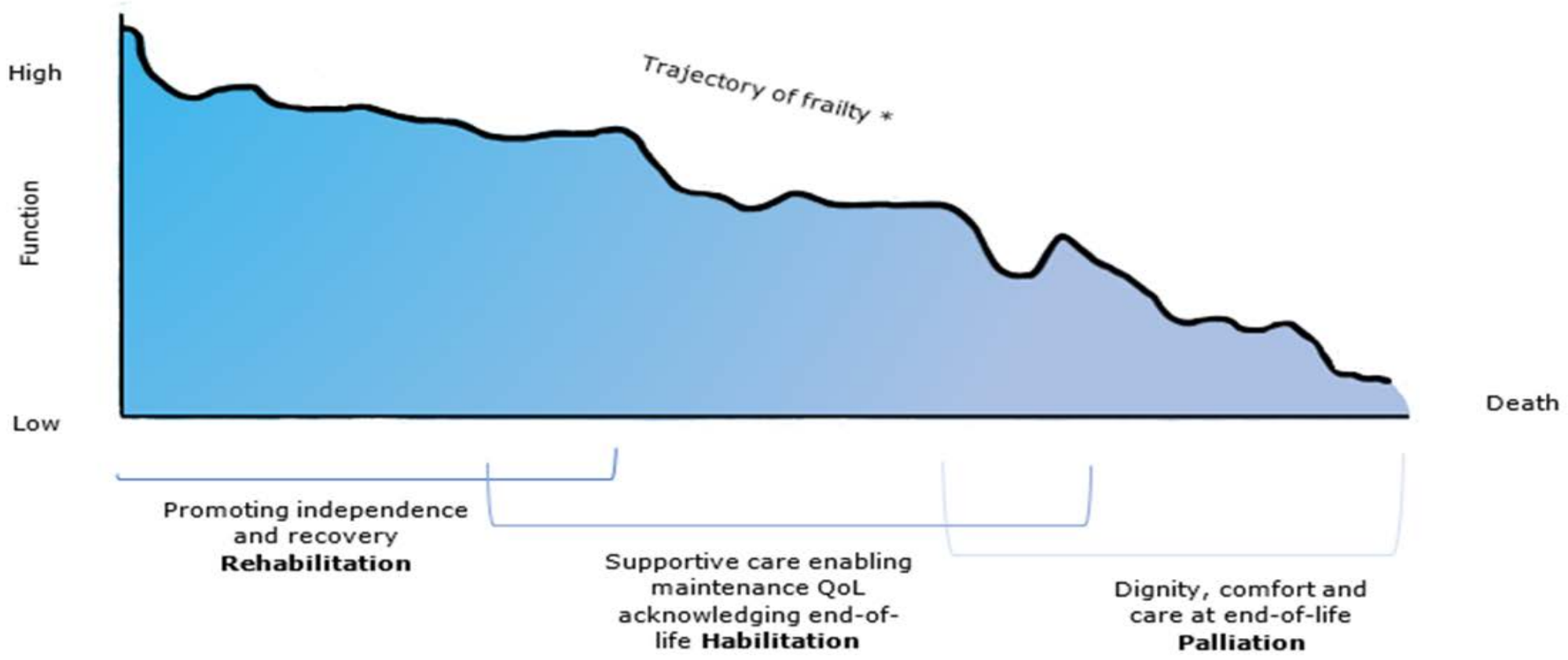
"I went in with that in my mind, and rather than looking at everything else that was going in, yeah I think it's very difficult but I think I was probably (pause) you know you have a snapshot in time to establish all this evidence"



The passage of care approaching death

Implications for occupational therapy – transitional lens of frailty to inform organisation of care



Ageing well
Pre-moderate frailty

Living well
Moderate to severe frailty

Dying well
Severe frailty - bereavement

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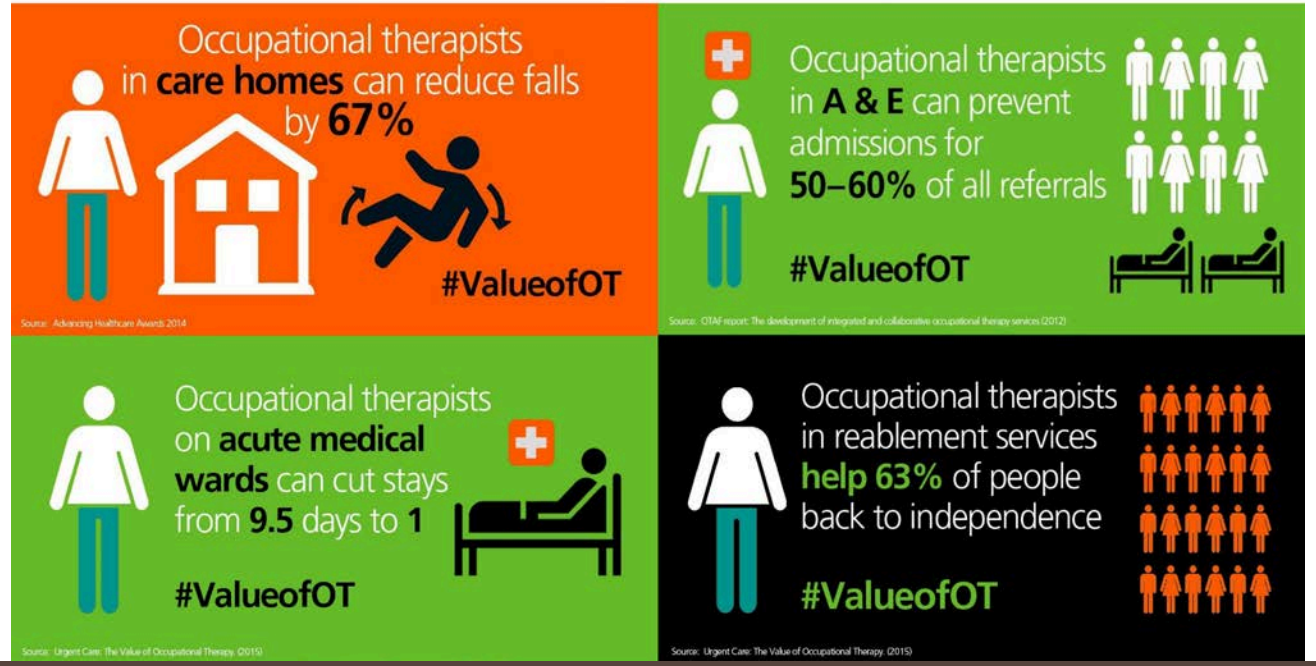
Occupational Therapy
Improving Lives Saving Money



The core business of our profession

We are well positioned to be the natural leaders in developing integrated pathways for frailty #AHP'sintoaction

Maintain a professional voice that is consistent with our values and ideology

Reflect on the service aims, who they are written by and whose needs do they meet – integration is key (NHS England 2019)

Anticipate death as part of the natural cycle of everyday life embedding this in the organisation of care (Barrett and Nightingale 2014)

Support older people to make decisions about what roles and occupations important – asset based approach

Be ready and prepared to have open conversations about advance care decisions beyond medical issues.

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