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
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
“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
Narrative accounts of frailty

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.

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)

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<th><strong>Professional decision-making</strong></th>
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<td><strong>Evaluate</strong></td>
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<td>Critically evaluate the process of end-of-life care for specific older patients’ cases drawing out policy, practice and professional perspectives.</td>
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<td><strong>Review</strong></td>
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<td>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.</td>
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<td><strong>Explore</strong></td>
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<td>Explore decision-making around end-of-life care of older people as retold through the narratives of healthcare professionals to inform service contexts.</td>
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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
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
Overview of case review

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”

“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.”

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

Culture of care

Clinical world in the home

Place of death
“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”
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
The core business of our profession

We are well positioned to be the natural leaders in developing integrated pathways for frailty #AHP’s into action

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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