

What do people with dementia perceive as a good death?

A qualitative study comparing views of people living with dementia in Brazil & UK

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Helping families face dementia

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Collaborators & acknowledgements

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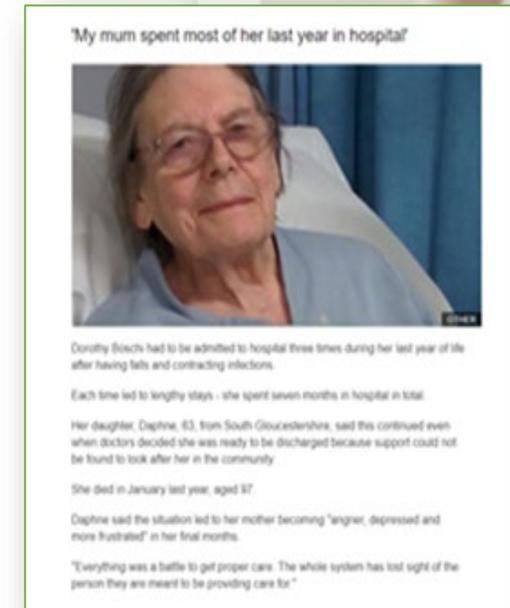


Why is this research important? (1)

There is still much to do to improve dementia care per se.

In the UK the total cost of care for people with dementia is currently £34.7billion. By 2040 this is predicted to rise to £94.1billion.

There is little consideration of the needs of people dying with dementia in UK health care policies, which leads to inequity in care.



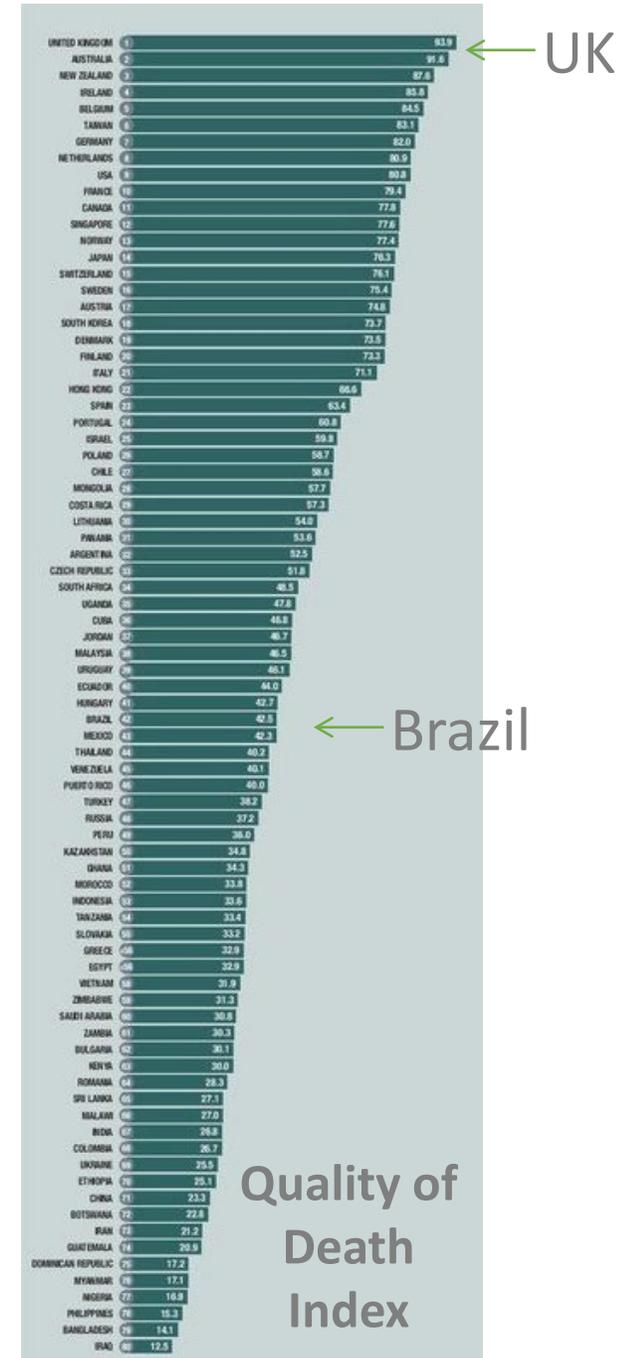
Why is this research important? (2)

Voices of people living/dying with conditions such as cancer have reshaped care delivery.

Voices of people with dementia are notably lacking from literature and decision-making.

Currently views on end-of-life in dementia are largely based on professional and clinical opinions. Tend to focus on clinical symptom management such as pain reduction.

Important to know how much perceptions of what a good death with dementia is depend on cultural/national context, and what might be universal.



What do people with dementia consider a good death in light of their dementia diagnosis?

Identify what constitutes successful dying or a good death for people with a diagnosis of dementia in Brazil and the UK.

To offer a more person-centered perspective for further development and refinement of recommendations on palliative care practice, policy and research.



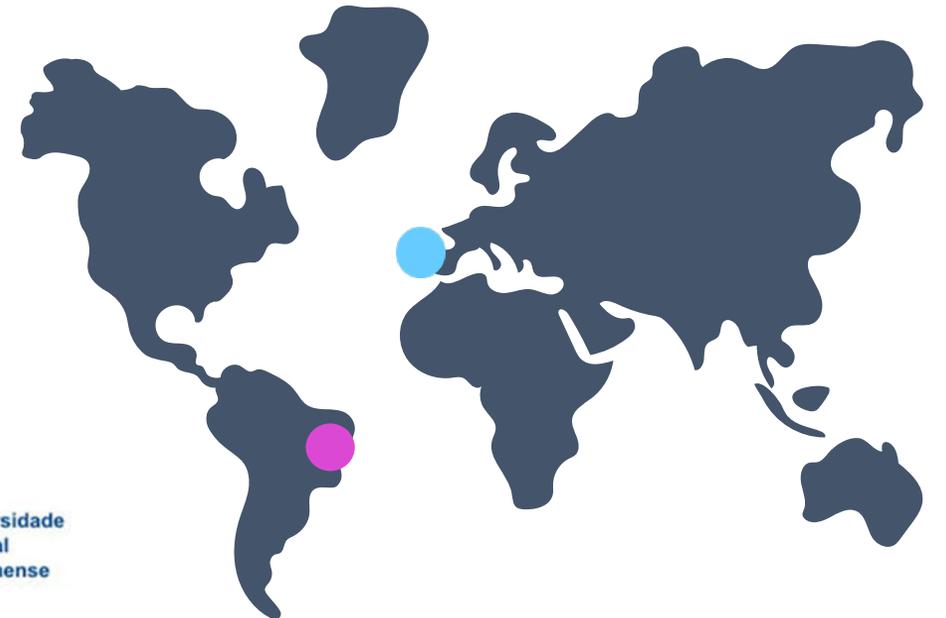
Interviews with people living with dementia

Study sample

A convenience sample of people who have a diagnosis of dementia (of any type) and are aware of their diagnosis.

People with dementia who have the capacity to participate in a semi-structured interview.
Pragmatic in identifying the two study locations as Kent (UK) and the state of São Paulo (Brazil) for ease of access to lead researcher university sites.

Sample size: UK (n=16); Brazil (n=16).
Saturation of themes.



Methods

Qualitative semi-structured interviews.
A structured topic guide.
Interviews audio-recorded with added detailed field notes.
Interview recordings transcribed and analysed.
Emergent codes and themes.



Ethical approvals from the University of Kent, UK & UNESP, Botacatu, Brazil



Early Findings:

UK

- Choice and control are a central concern
- Willingness to prepare for end of life
- Wishes largely based on personal experiences of death of others
- Clear expectations from and recommendations for professionals

Brazil

- Choice and control are not a concern; a more fatalistic outlook
- Resistance to prepare for end of life
- Lack of awareness of the role of professionals and greater reliance on family care

Both

- Worry about impact on family
- Fear of painful, prolonged death
- Wish for respect and relational comfort close to death
- Few conversations with professionals to prepare for end of life, but while UK interviewees wanted more information from professionals, this was less pronounced in Brazil



Participant quotes (UK)

“[Husband] will give me the best care that anyone can give me and he will look after me and I am 100% confident of that. If I go into a hospice or hospital they don't know me from anybody else...they don't know what I like, they don't know what I dislike, they don't know any part of me really so I'm a stranger to them and I just don't think I'd get anywhere near that same sort of care”

“... and they don't tell you what that is and they don't tell you what they're gonna do about it”

“I've not got a fear of dying. What I've got a fear of is either dying in pain or living a life where I am not me...like that empty shell...”

“oh ... it was like a sense of ... I don't really want to deal with this ... off you go...”

What's next?

Complete analysis in each country

Contrast and compare findings

Publish

Consider next steps for research collaboration



Any questions



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What are the experiences of nursing home staff when making decisions in the event of a person with advanced dementia deteriorating?

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The study

- ❖ Full time PhD at De Montfort University Leicester, commenced May 2018
- ❖ Supervisors: Prof Kay De Vries & Prof Jayne Brown
- ❖ Supported by Dementia UK

Why do we need to know ?

- There are currently in excess of 400,000 people living in care homes in the United Kingdom (UK) which equates to approximately three times the equivalent of hospital beds (Oliver 2016).
- It is estimated that around 69% of residents in residential and nursing care homes are likely to either have dementia on admission or develop dementia post admission, many of whom do not receive a diagnosis (Prince et al. 2014; OECD 2018)
- Of those 400,000 residents in care homes, it is estimated that 311,730 have dementia with 180,500 living in residential care homes and 131,230 living in nursing homes (Prince et al. 2014).
- In 2014 58% of dementia related deaths occurred in care homes and 32% in hospital (PHE 2016)

Complexity of the cohort

- Comorbidities
- Frailty
- Lack of parity in accessing specialist palliative care services
- Reduced mental capacity and ability to communicate wishes and preferences
- Lack of advance care planning

Challenges

- Poor prognostication
- Multiple trajectories
- Perception of deterioration
- Medical model vs relational care model
- Professional values - ageism and inequality
- Resources-service configurations
- Relationships- Perceived value of nursing home staff by wider health and social care system
- Leadership-Skills, experience & training

Moral Compass



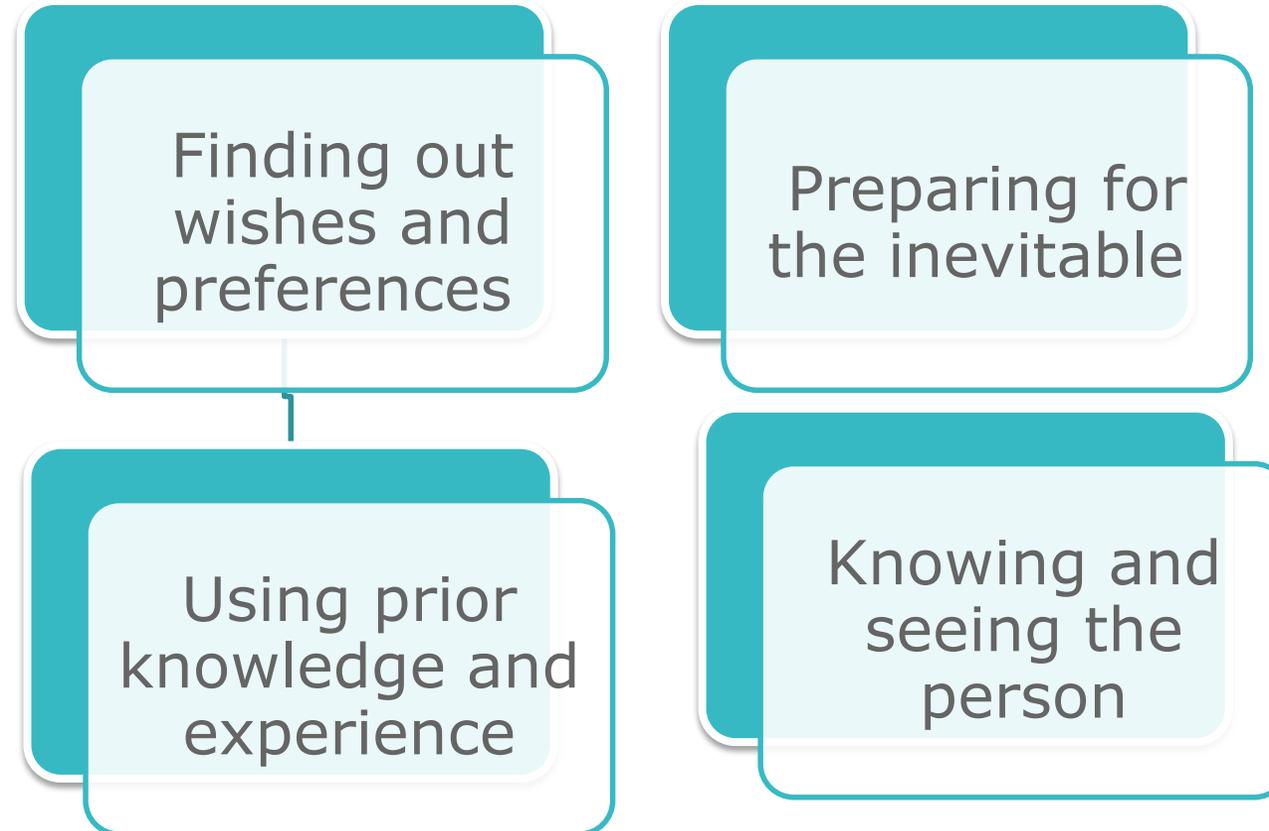


Balancing what is morally and ethically right with what is procedurally and clinically right.....

**....in order to do the right thing and
enable a good death**



Factors influencing decision-making



Moral Distress

"the experience of knowing the right thing to do while being in a situation in which it is nearly impossible to do it"

(Jameton 1984)

Strategies employed to reduce moral distress

- Doing their best
- Demonstrating Moral Courage

Thank you for listening and please feel free to contact me with any questions



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