

What do people with dementia perceive as a good death?

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

Karen Harrison Dening

24 November 2021

CHSS
University of Kent

uff Universidade Federal Fluminense

KU LEUVEN

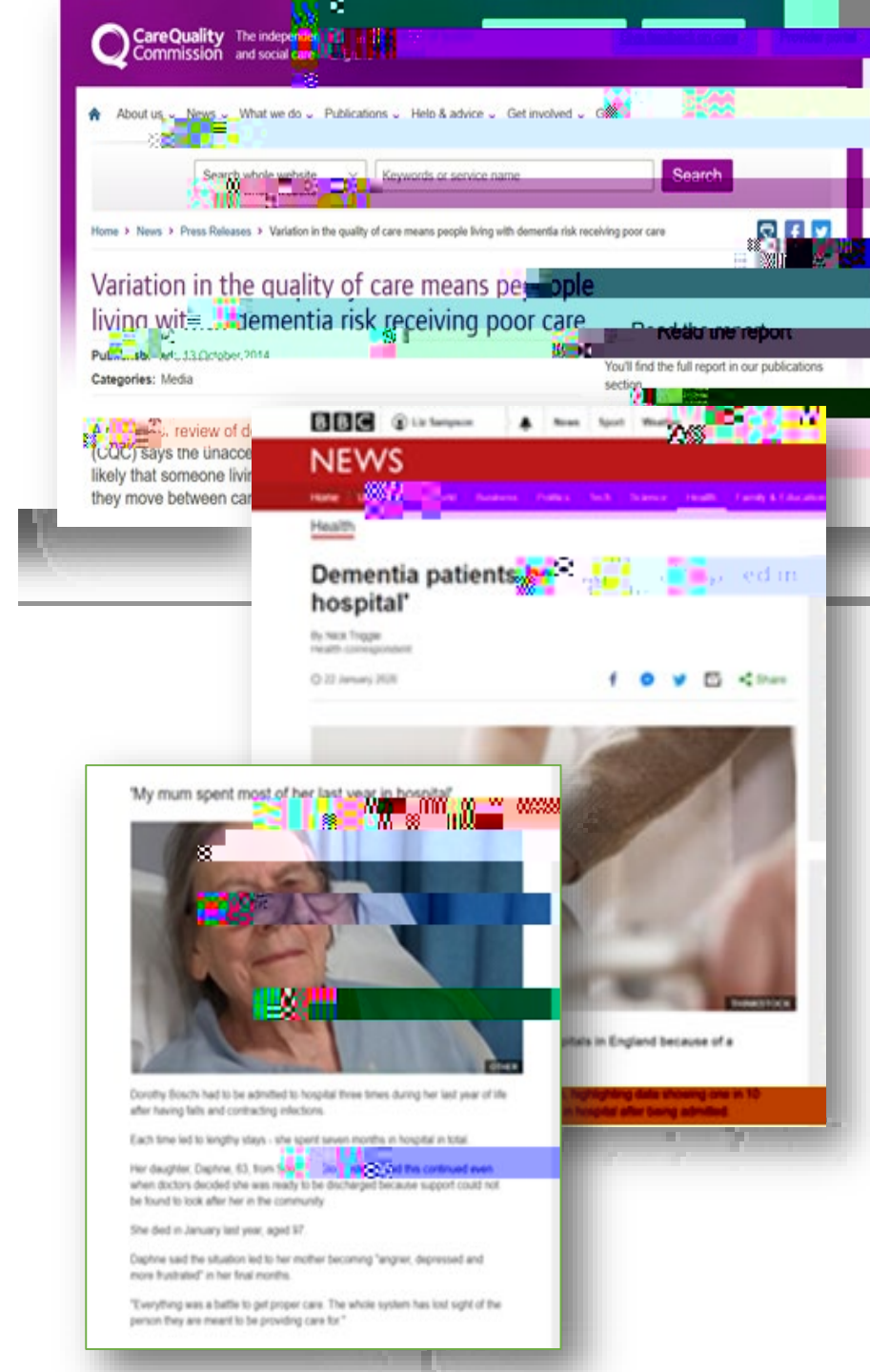
unesp

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.



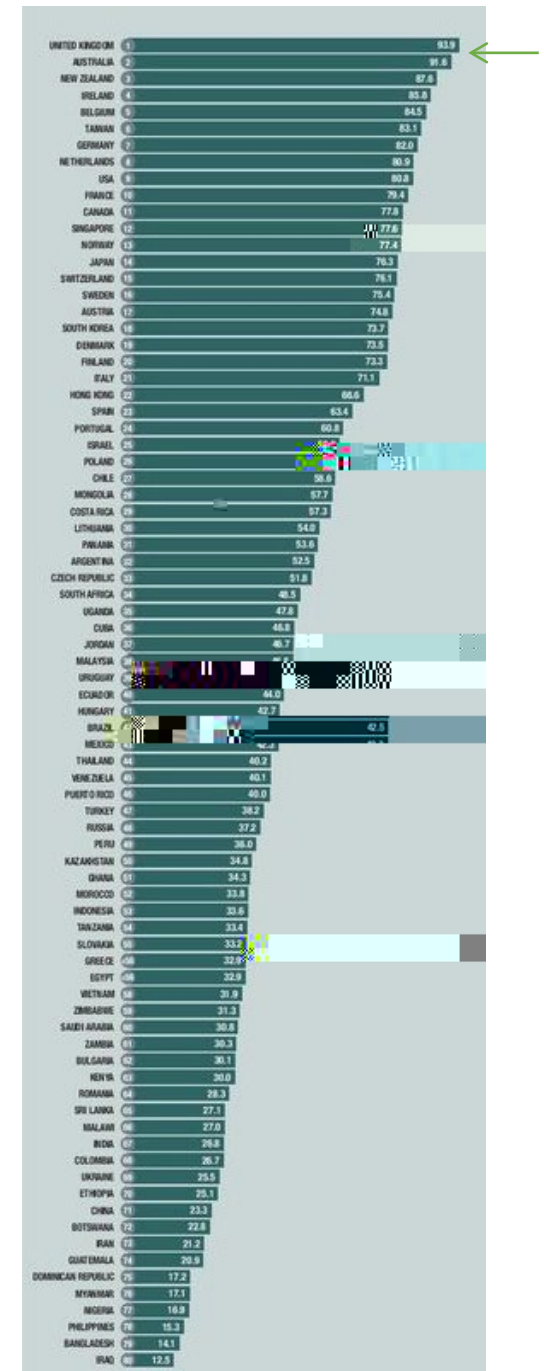
Why is this research important? (2)

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

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)



What's next?

Complete analysis in each country

Contrast and compare findings

Publish

Consider next steps for research collaboration



Any questions



Karen.Harrison-Dening@dementiauk.org

Karen.harrison-dening@dmu.ac.uk



References

Brayne, C., Gao, L., Dewey, M., & Matthews, F. E. (2006). Dementia before death in ageing societies—the promise of prevention and the reality. *PLoS medicine*, 3(10), e397.

Boff, M. S., Sekyia, F. S., & Bottino, C. M. C. (2015). Prevalence of dementia among brazilian population: systematic review. *Rev Med (São Paulo)*, 94(3), 154-161.

EtkindM (o)-2 (p)-r4 (s)4 ()10h4 (,)1 ()T-0, F. .0 Td[(,)1 (M)-4M.6 4 (.)3 ()4 (2)-2 (0)-7 (1)-2 (5)-2 ())Hps,1Sek p (&)3 (2 (v)-1 ()9)-2 4 (o)-le2 (n)6 (:)-w (s)ill (ic)4 (in)-4 0 Td[(me)-6 (:)-



What is it?

job for

analysis

for the world

in the UK

Za Ag

Aid Nat Rab Fov

PD 0

DeMfU

-Dm UK

RgICaIAid(ith)

-NHS EgdadNHS I pn

p_ag@dmu.ac.uk

PfKayDev's

PfJayBov

DeMfU





TM Full time PhD at De Montfort University Leicester, commenced May 2018

TM Supervisors: Prof Kay De Vries & Prof Jayne Brown

TM Supported by Dementia UK



- 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)

- 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

Chg

- Poor prognostication
- Multiple trajectories
- Perception of deterioration
- Medical model vs relational care model
- Professional values - ageism and inequality
- Resources - service configurations
- Relationships -

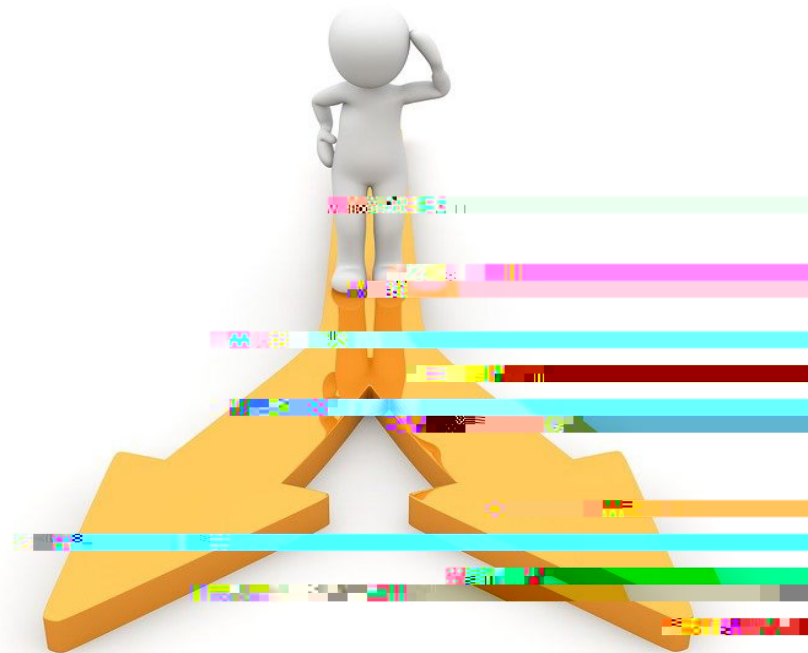
Mal Cans





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

....involving a
a ba gal th



Fa
id

-ang



Stacy



- Doing their best
- Demonstrating Moral Courage

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

contact



zena.aldridge@dementiauk.org