The meaning of a good death among people living with dementia in the UK and in Brazil: Opportunities for culturally-sensitive approaches in palliative dementia care

Presenting: Dr Rasa Mikelyte

Team also includes: Dr Edison Iglesias de Oliveira Vidal,
Prof Karen Harrison Dening , Dr Francelise Pivetta Roque,
Dr Deborah Oliveira, Dr Natashe Lemos Dekker, Ms Julia Maria Vanelli,
Dr Adriele Ferreira Neves

CHSS University of Kent · DementiaUK · unesp · uff Universidade Federal Fluminense · Universiteit Leiden · UNIFESP

Our Team

Dr Edison Iglesias de Oliveira Vidal

Dr Rasa Mikelyte

Prof Karen Harrison Dening

Dr Francelise Pivetta Roque

Dr Natashe Lemos Dekker

Dr Deborah Oliveira

Dr Adriele Ferreira Neves

Ms Julia Maria Vanelli

Backgrounds in: palliative medicine, geriatrics, nursing, anthropology, psychology, psychiatry, speech & language therapy

Defining a ‘good death’

- Importance of patient perspective
- Importance in palliative care education
- Potential to influence policy (eg place of death for people with cancer in the UK)

CLINICAL REVIEW ARTICLE

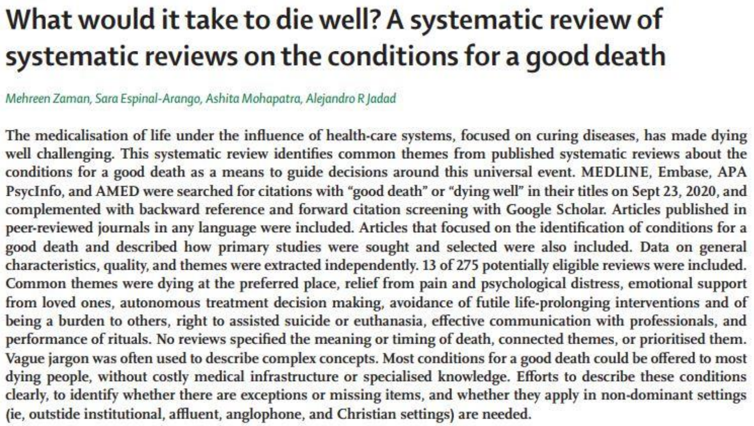
Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue

Emily A. Meier, Ph.D., Jarred V. Gallegos, M.A., Lori P. Montross-Thomas, Ph.D., Colin A. Depp, Ph.D., Scott A. Irwin, M.D., Ph.D., Dilip V. Jeste, M.D.

There is little agreement about what constitutes good death or successful dying. The authors conducted a literature search for published, English-language, peer-reviewed reports of qualitative and quantitative studies that provided a definition of a good death. Stakeholders in these articles included patients, prebereaved and bereaved family members, and healthcare providers (HCPs). Definitions found were categorized into core themes and subthemes, and the frequency of each theme was determined by stakeholder (patients, family, HCPs) perspectives. Thirty-six studies met eligibility criteria, with 50% of patient perspective articles including individuals over age 60 years. We identified 11 core themes of good death: preferences for a specific dying process, pain-free status, religiosity/spiritualty, emotional well-being, life completion, treatment preferences, dignity, family, quality of life, relationship with HCP, and other. The top three themes across all stakeholder groups were preferences for dying process (94% of reports), pain-free status (81%), and emotional well-being (64%). However, some discrepancies among the respondent groups were noted in the core themes: Family perspectives included life completion (80%), quality of life (70%), dignity (70%), and presence of family (70%) more frequently than did patient perspectives regarding those items (35%–55% each). In contrast, religiosity/spirituality was reported somewhat more often in patient perspectives (65%) than in family perspectives (50%). Taking into account the limitations of the literature, further research is needed on the impact of divergent perspectives on end-of-life care. Dialogues among the stakeholders for each individual must occur to ensure a good death from the most critical viewpoint—the patient's. (Am J Geriatr Psychiatry 2016; 24:261–271)

Key Words: successful dying, good death, aging, hospice, palliative care, caregivers

(Meier et al, 2006)



What would it take to die well? A systematic review of systematic reviews on the conditions for a good death

Mehreen Zaman, Sara Espinal-Arango, Ashita Mohapatra, Alejandro R Jadad

The medicalisation of life under the influence of health-care systems, focused on curing diseases, has made dying well challenging. This systematic review identifies common themes from published systematic reviews about the conditions for a good death as a means to guide decisions around this universal event. MEDLINE, Embase, APA PsycInfo, and AMED were searched for citations with "good death" or "dying well" in their titles on Sept 23, 2020, and complemented with backward reference and forward citation screening with Google Scholar. Articles published in peer-reviewed journals in any language were included. Articles that focused on the identification of conditions for a good death and described how primary studies were sought and selected were also included. Data on general characteristics, quality, and themes were extracted independently. 13 of 275 potentially eligible reviews were included. Common themes were dying at the preferred place, relief from pain and psychological distress, emotional support from loved ones, autonomous treatment decision making, avoidance of futile life-prolonging interventions and of being a burden to others, right to assisted suicide or euthanasia, effective communication with professionals, and performance of rituals. No reviews specified the meaning or timing of death, connected themes, or prioritised them. Vague jargon was often used to describe complex concepts. Most conditions for a good death could be offered to most dying people, without costly medical infrastructure or specialised knowledge. Efforts to describe these conditions clearly, to identify whether there are exceptions or missing items, and whether they apply in non-dominant settings (ie, outstide institutional, affluent, anglophone, and Christian settings) are needed.

(Zaman et al, 2021)

Research on 'a good death'

- ○ Findings limited by the dominance of research from high-income countries. None in Latin America
- ○ Limited attempts to ask people living with dementia about good death and dying
- ○ Further efforts required to generate knowledge about the extent to which the identified conditions for a good death would apply across political, religious, and cultural boundaries

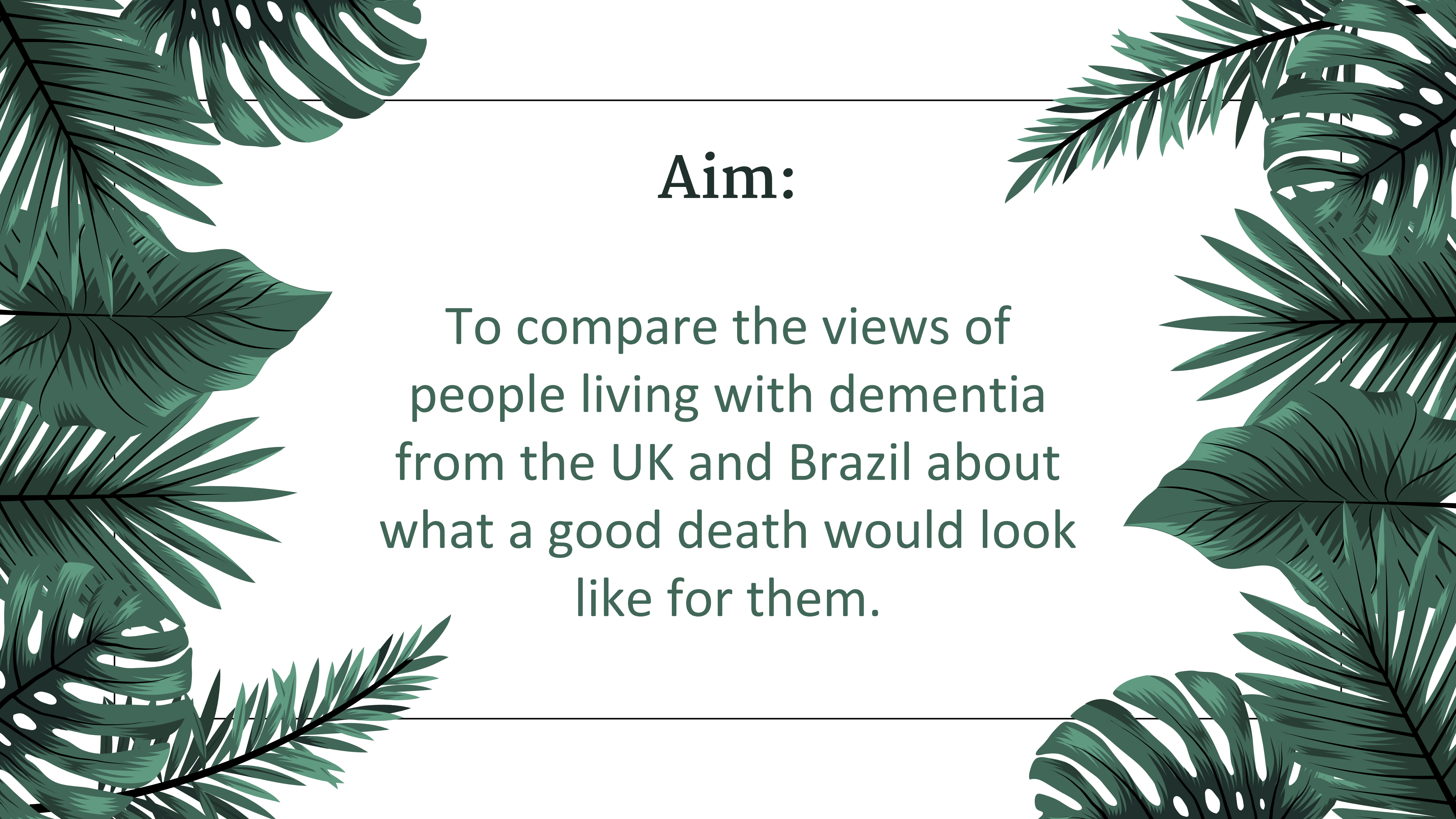
"While several studies and reviews have addressed the optimal time for a more palliative approach, none have done so from the perspective of the person with dementia, whose views should be paramount."

"There is an **urgent need for more research**, specific to the dementia field, regarding **preferences of people with dementia**, and how these can be elicited"

Alzheimer's Disease International
The global voice on dementia

World Alzheimer Report 2016
Improving healthcare for people living with dementia
COVERAGE, QUALITY AND COSTS NOW AND IN THE FUTURE

(Alzheimer's Disease International, 2016)



Aim:

To compare the views of people living with dementia from the UK and Brazil about what a good death would look like for them.

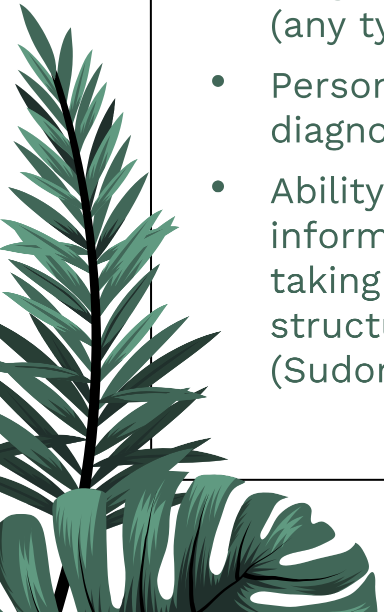
Recruitment

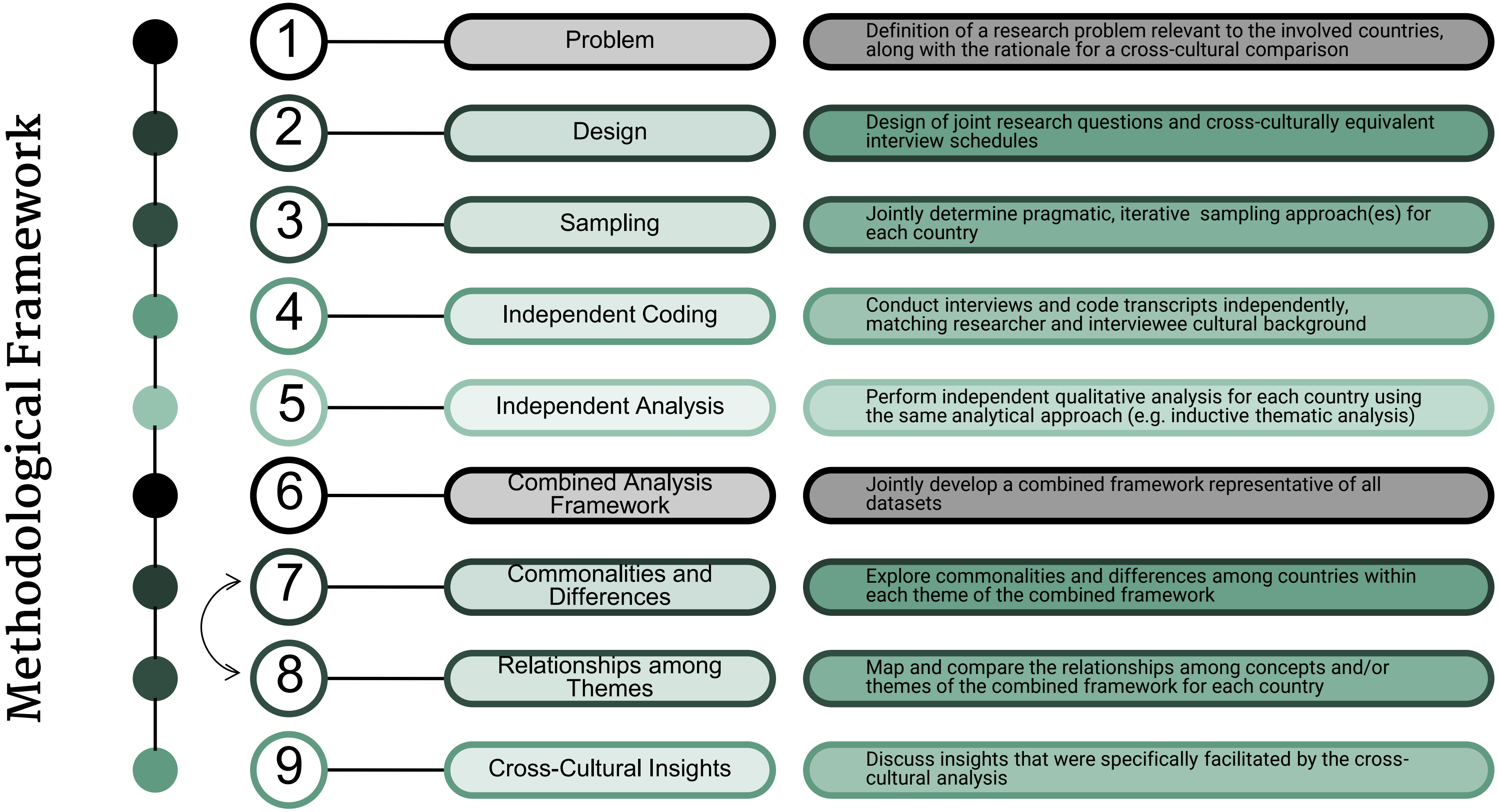
Inclusion criteria:

- Diagnosis of dementia (any type)
- Person aware of the diagnosis
- Ability to give informed consent to taking part in a semi-structured interview (Sudore et al, 2006)

Recruitment approach:

- Non-probability sampling
- **Brazil:** recruitment by health professionals from public and private healthcare organisations in the Southeast region of the country
- **UK:** recruitment by researchers from dementia peer groups in the South East, a Britain-wide dementia group and via social media adverts by a national dementia charity.
- Half of the interviews in person, half online
- Interviews in August 2019 – August 2021



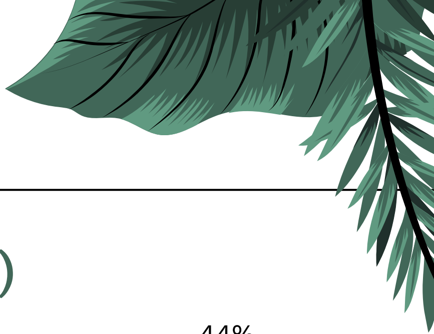


Methodological Framework

1	Problem	Definition of a research problem relevant to the involved countries, along with the rationale for a cross-cultural comparison
2	Design	Design of joint research questions and cross-culturally equivalent interview schedules
3	Sampling	Jointly determine pragmatic, iterative sampling approach(es) for each country
4	Independent Coding	Conduct interviews and code transcripts independently, matching researcher and interviewee cultural background
5	Independent Analysis	Perform independent qualitative analysis for each country using the same analytical approach (e.g. inductive thematic analysis)
6	Combined Analysis Framework	Jointly develop a combined framework representative of all datasets
7	Commonalities and Differences	Explore commonalities and differences among countries within each theme of the combined framework
8	Relationships among Themes	Map and compare the relationships among concepts and/or themes of the combined framework for each country
9	Cross-Cultural Insights	Discuss insights that were specifically facilitated by the cross-cultural analysis

Ethical Considerations

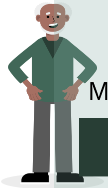
- In both countries, participants' capacity to consent was assessed in line with the principles outlined by Sudore et al (2006)
- Informed consent was taken either in writing, or verbally (the latter audio-recorded for evidence)
- We checked for ongoing consent throughout the interview
- Distress protocol designed for the study
- Ethical approval granted by Botucatu Medical School (#12370419.4.0000.5411) and by the University of Kent Research Ethics Committee (SRCEA222).



Participants

Brazil (16 participants)

69%



Age

Median = 81

68-90

75%
White

19%
Black

6%
Paro/Mixed

81%
Catholic

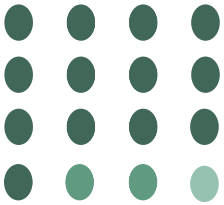
12.5%
Spiritist

12.5%
Other faith

Time since diagnosis

Median = 2yrs

1 mnth – 5 yrs



81%
Alzheimer's

12.5%
Lewy Body

6.5%
Vascular

Spousal carer	Filial carer	Paid carer	Other carer
25%	50%	12.5%	12.5%

Live with carer

UK (16 participants)

75%

Age

Median =62

49-76

81%
White British

12.5%
White Scottish

6.5%
Refused to state

44%
None

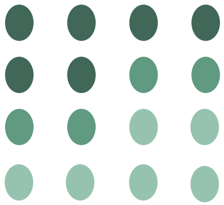
31%
Christianity

25%
Other faith

Time since diagnosis

Median = 4yrs

3 – 14 yrs



37.5%
Alzheimer's

25%
Mixed

37.5%
Other

Spousal carer	Filial carer	No carer	Paid carer
50%	12.5%	31.25%	6.25%

Live with carer

Choice & Control

- Central for UK interviewees; not considered conceivable for most interviewees in Brazil
- In the UK choice and control was a way of dealing with uncertainty (spirituality served the same function in Brazil)
- Euthanasia discussed frequently in the UK, but absent from Brazilian narratives.

"I really wish to die when I want to die, if dementia starts to get hold of me, which in this country euthanasia isn't allowed, you know. I'd have to go to Switzerland or somewhere. And I wish that before I need that decision to be made, that the laws here will change. Because that would be a good death for me to decide whether or not." (UK09)

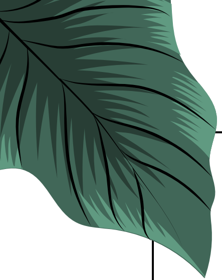
"No, I wouldn't like [to know what may happen when I'm dying], because I would, would be anticipating my death if I tried to know. No, I wouldn't like [to have control over my death]. Because, we have, have to let death be the way God wants it to be, right?" (BR09)

Spirituality

- ○ Majority of participants in both countries had some religious affiliation, but...
- ○ In Brazil, spirituality was the basis of participants' views around death, with some framing a good death as "being at peace with God and others feeling certain that god will provide them a good death
- ○ In the UK, role of God considered mostly for the afterlife; concern regarding religion of others leadin to lack of respect for choice

"God prepares everything for us. I have a huge faith. I am certain that I will have a peaceful death! I'm not afraid of dying! It is a crossing that we all must face! (...) I don't think about death. I know that I will have a wonderful death!" (BR1)

"I absolutely want to live as positively as possible for as long as possible. But, just as I don't see why, due to anybody's political or religious beliefs that I should be enforced to live beyond what I consider is a good standard of living." (UK08)

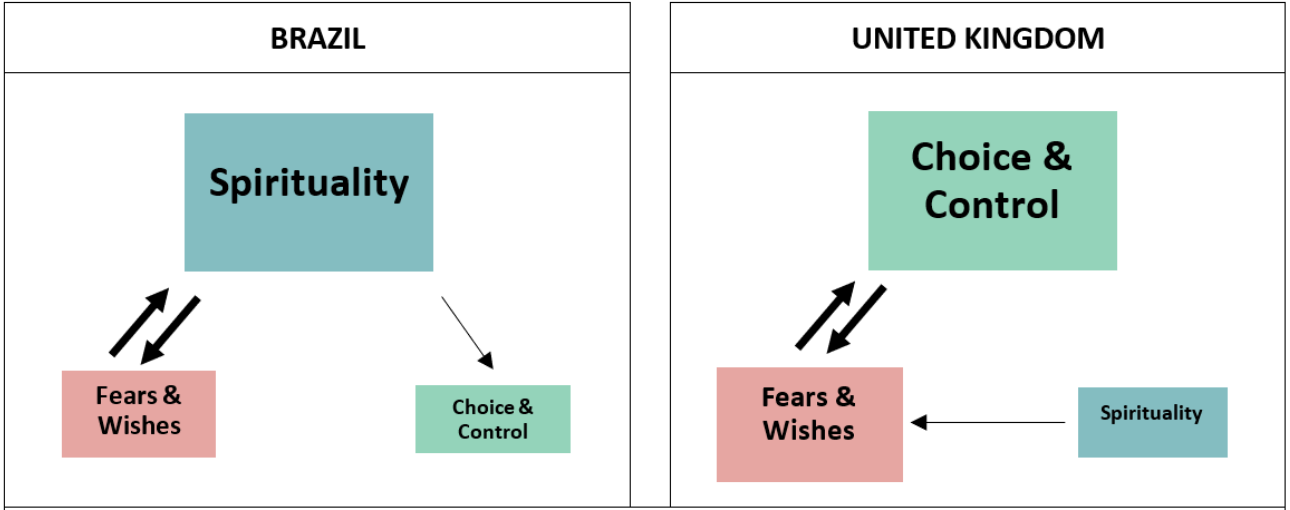


Fears & Wishes

- Fear of a painful, prolonged death shared in both countries
- In both countries, fears and wishes strongly linked to experiences of death of others
- Tension around own wishes and protecting loved ones
- Fear of loss of self and lack of access to or poor quality of health and social care only present in the UK

"[A good death] is that [we] don't suffer when dying. How do we say it? Dying quietly [laughs]. [...] Not suffering. [...] Feeling pain, like my mother [who] suffered to die, poor her, she suffered so much. [...] I think that death is suffering [...] it took my mother a long time to die, but [she] stayed in that agony trying to talk without being able." (BR15)

"I have been left vulnerable, through lack of local knowledge. And lack of someone to talk to that has the time, and it's their job. It's their space. Your GP, they're supposed to, but they don't have the time." (UK15)



BRAZIL

Spirituality

Fears & Wishes

Choice & Control

UNITED KINGDOM

Choice & Control

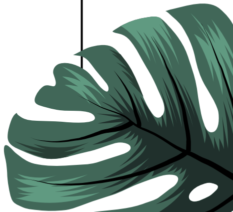
Fears & Wishes

Spirituality

Operating within country-specific contexts of societal and individual views on dementia; societal religiosity; language as a cultural, social and psychological phenomenon; and historical, as well as current state of Health and Social Care provision.

So what? (1)

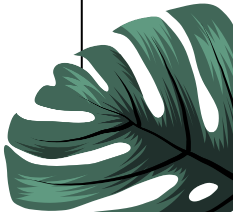
- By contrasting different cultural perspectives, our study offers **new opportunities for culturally-sensitive approaches to palliative care for people living with dementia**
  - In the UK, approaches that focus on choice and control (e.g. advance care planning) are likely to alleviate anxiety
  - In Brazil, drawing on spirituality may offer ways to address anxiety
    - encouraging advance care planning in Brazil may require a different approach (as choice *per se* is unlikely to be desired); focus on reducing concerns of / demands on family and friend caregivers may offer a better rationale



So what? (2)

- Asking about past **experiences around death of others** might be crucial in understanding differences in patient preferences and fears
    - More information on dying with dementia and available options may be relevant for some
    - But this will depend on cultural and other influences

- What a good death means to people living with a life-limiting condition should be taken into account when **assessing the quality of palliative care**
    - Including global indexes

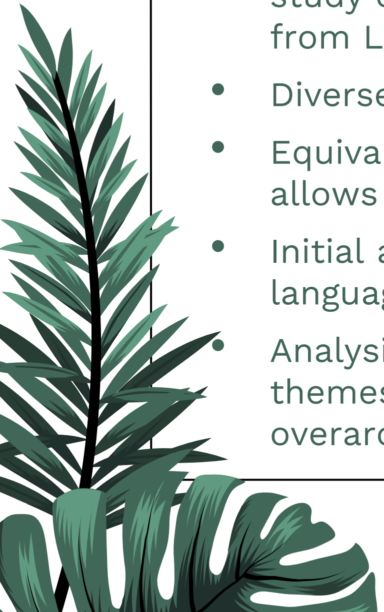


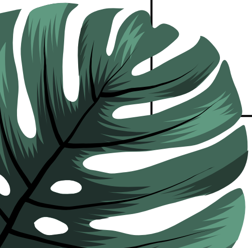
Strengths:

- First study to directly compare perceptions of people living with dementia on the meaning of a good death in 2 countries and the first study on a good death in dementia from Latin America
- Diverse samples
- Equivalent data collection procedure allows for stronger comparisons
- Initial analysis conducted in the language of the participant
- Analysis strategy allowed for specific themes for each country **AND** an overarching cross-country analysis

Limitations:

- Pragmatic sampling and participant self-selection meant that we interviewed people who wish to talk about death
- Participant geographic location did not cover both countries equitably
- Sample characteristics differ between the two countries
- As in all cross-cultural research, it is tricky to differentiate individual differences from cultural ones:
  - But clear differences in trends between UK and Brazil!





Thank You!

Do you have any questions?

R.Mikelyte@kent.ac.uk

CREDITS: This presentation template was created by **Slidesgo,** including icons by **Flaticon**, infographics & images by **Freepik**