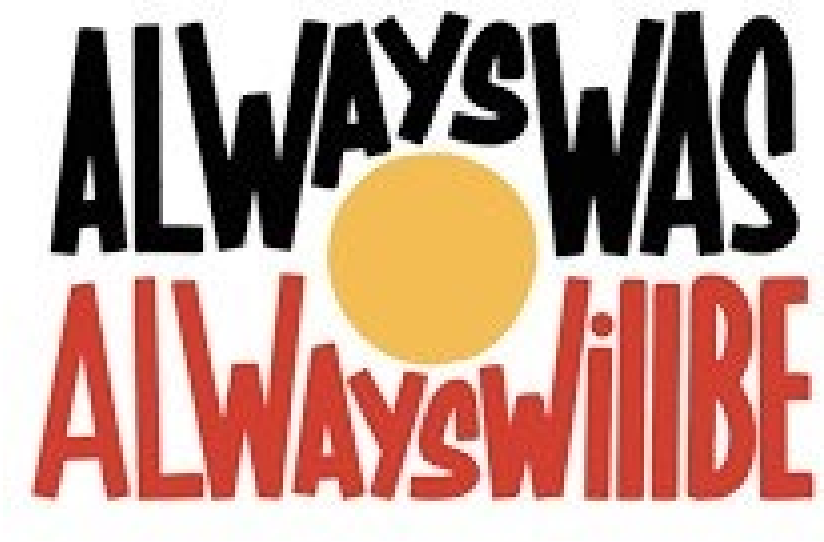
Palliative care and advance care planning considerations for CALD communities

MAC Symposium

Dr Georgia Rowley, Grant-funded Researcher,
School of Public Health, University of Adelaide

November 2023

Acknowledgement of country



Born on Meru land

Living and working on Kaurna land

My background

- 3rd generation Greek Australian
- First language: Greek
- Honours in Psychology, PhD in Public Health
- Grant-funded researcher (University of Adelaide)

A note on CALD diversity

- Older Australians speak over 260 different languages
- Many older CALD adults are not proficient in English
- Older CALD populations are growing faster than the older Australian-born, English-speaking population
- Needs and preferences across different CALD communities vary, as well as **WITHIN** communities / across individuals
- Duty to recognise and respond to individuals of all backgrounds
- Challenges faced by older CALD adults in accessing and engaging with services and supports. Barriers can be individual, cultural, structural and service related
- Impacts on health, wellbeing and quality of life

An intersectional lens

- Older CALD Australians are not a uniform group. There is much ‘diversity within diversity’, known as ‘intersectionality’
- Intersectional risk means some individuals face more vulnerability and discrimination than others
- Each person requires a tailored approach. Services must understand and be responsive to individual needs and preferences, and respect a person’s identity and diversity
- Preferences and beliefs about religion, culture and language can differ between families, communities and even individuals
- Avoid assumptions Re: individuals’ preferences based on cultural, linguistic, or religious background
- Care should reflect and respond to all individual needs across the following domains:
    - **social**
    - **cultural**
    - **linguistic**
    - **religious**
    - **spiritual**
    - **psychological**
    - **physiological**
    - **medical**
- Human rights and person-centred approaches to care ensure the needs of all individuals are met. Ask people whether there are beliefs, practices, or customs which may affect their care.

What does culture shape?

(EVERYTHING!)

Cultural background and lived experience shape many factors which can impact access and use of palliative care, including:

- language, communication, English skills
- literacy
- ageing, disability
- caring, carers
- religion, ethnicity
- pre-migration, migration, settlement, post-migration experiences
- trauma
- prejudice, racism
- war, conflict, persecution
- childhood, families, familial involvement, children, relationships
- community
- perceptions, assumptions, beliefs, roles, norms, attitudes, expectations
- reluctance and opposition
- interactions
- decision making
- health beliefs, illness

Barriers for CALD individuals accessing services

Cultural barriers can impact older CALD adults' access to appropriate palliative care. Some of these include:

- lack of awareness and knowledge of available services
- attitudes to family and caring responsibilities
- communication barriers in English
- cognitive impairment and/or dementia
- illiteracy in the native language
- difficulty expressing needs
- PTSD / other trauma
- feeling 'foreign' or excluded in society
- specific gender preferences and role expectations
- privacy concerns
- mistrust of authority or health care professionals
- cultural importance of ageing in place and dying at home
- taboo nature of, or resistance to, residential care
- difficulties associated with caring for family at home
- burden of care for CALD women
- loneliness and isolation experienced by older CALD carers
- digital literacy
- food preferences
- returning to the home country to care for others
- particular responsibilities as elders
- privacy and consent issues when using family as interpreters
- access to accredited interpreters and translators (rather than family)
- importance of maintaining cultural identity
- intergenerational culture change
- diverse health beliefs
- expectations of the health system
- lack of familial support
- isolation and fewer peers in older age

Service barriers

- cultural appropriateness
- lack of training in providing culturally appropriate / safe care
- high staff turnover
- assumptions that CALD adults pose added costs and workload
- avoidance of using translating and interpreting services
- rural and remote barriers

Structural barriers

- systems difficult to navigate
- lacking awareness of available services or information
- information not being shared or marketed appropriately
- English language barriers
- institutionalised and overt racism
- inadequate cultural training for staff
- lacking understanding of the nuanced health needs of CALD individuals
- diminished use of other services

Palliative care considerations for CALD individuals

- National Palliative Care Standards: *'specific attention is paid to the needs of people who may be vulnerable or at risk, to support communication, goal setting and care planning'*
- CALD adults (especially those from lower SES backgrounds) are underrepresented in palliative care, and may be more likely to die in non-hospice settings compared with the wider population
- Stigma around hospice care, especially where strong cultural and familial expectations of support exist. Palliative care often misunderstood, due to lack of awareness about services and supports
- Research required to better understand older CALD adults' needs and preferences for EOL care

How does culture impact death and dying?

- Beliefs, values and preferences around death and dying differ across cultures
- Western notions of patient autonomy, decision-making, self-determination, informed consent, truth telling and control over dying are not universally accepted values and may compete with other beliefs.
- Significant and varied death and mourning rituals
- Ask about personal EOL preferences, including beliefs and values around family, spirituality, care, dying, and palliative care
- Some believe discussing death is disrespectful, brings bad luck, eliminates hope, is akin to 'giving up' and causes depression or anxiety

Cultural background impacts many factors associated with EOL experiences, inc.:

- preferred foods
- assumptions around care responsibilities
- familial care and involvement
- whether decision making is individual or shared
- advance care directive preferences
- the meaning of life
- the meaning of suffering
- preferences for sharing and receiving bad news
- disclosure of diagnosis to the dying individual and others
- whether speaking about death is taboo
- pain and symptom expression
- attitudes and practices about pain relief
- beliefs about complementary or alternative medicine
- life support preferences
- preferences around place of death
- practices around immediate care after death
- autopsy preferences
- organ donation preferences
- burial or cremation preferences
- bereavement responses
- grieving practices and rituals

Advance care planning (ACP) considerations for CALD individuals

ACP guided by Western values of autonomy and self-determination

ACP is not universally accepted. Values may not be applicable to more collectivist groups

CALD adults less likely to complete ACP documents, more likely to seek life-sustaining treatment than others

Mistrust in the system or particular religious beliefs can influence ACP decisions. Some may see it as being intrusive or interfering with their sense of identity and family caring responsibilities

Staff should acknowledge different viewpoints about ACP and help build trust and a respectful caring environment

Increased awareness and understanding of ACP among older CALD adults is required

Language and literacy barriers can make ACP forms and other self-report forms difficult for older CALD people

Advance Care Planning Australia has fact sheets and other resources available in 13 languages

Prior Research

- Associate Professor Jaklin Elliot led this research project on Advanced Care Directives and three CALD communities (Bhutanese, Italian and Vietnamese). Project findings in a nutshell:

low levels of community and professional awareness of ACP and ACDs, due to confusion …
- of ACDs with other end-of-life documents
- on when, where, how, and with whom advance care planning should occur
- about how ACP is or could be embedded in healthcare systems

multiple reasons for, and consequences of, completing ACP and ACDs, including …
- respecting patients' wishes and refusals
- reducing (familial) conflict, distress, and confusion at a difficult time
- streamlining patient and family interactions with health systems and providers

multiple problems or challenges in obtaining and completing the SA ACD form, because the form itself …
- is not easily accessible
- takes a blunt approach to sensitive topics about death and dying
- does not capture the complex social aspects of end-of-life planning that typically involves decisions made jointly within relationships of care
- is a long and complex document; completing it is confusing, exhausting, and frustrating especially when unwell, busy, anxious, or experiencing cognitive decline
- presents advance care planning as a 'do-it-yourself' process which obscures or minimises the support or help (including with computer access, health literacy, English language proficiency) needed by many to complete it
- emphasises *writing down* advance care plans, which undermines the greater importance that many place on *talking* about end-of-life care

one-size does not fit all
- unique trusting relationships between individuals (at the personal, professional, and institutional levels) are central
- tailored supports accommodating individual and community needs and preferences are needed to promote equity of access to advance care planning and ACDs

Conclusions:
- supporting principles of autonomy and person-centred care by improving ACP within vulnerable communities requires structures and processes that allow for end-of-life care needs to be raised, discussed, documented, and acted on.
- engagement with individuals and communities will need to use clear, accessible language and concepts, follow processes understood by patients, make space for culturally responsive end-of-life care communication. be scaffolded by resources to meet individual needs as shaped by culture, be embedded into healthcare systems through policy and practice standards, ongoing practitioner training, and streamlined mechanisms for storing, accessing, and enacting documented plans when and where they are relevant

Current Research

Visit the Palliative Care Research Collaboration website

x5 current projects funded by the Hospital Research Foundation Group.

DLI (Death Literacy Index) project

- Death literacy = the language, knowledge, and practical skills needed to make active end-of-life choices
- Working with communities to determine if providing materials using culturally appropriate and accessible language through culturally acceptable modes of delivery increases death literacy within communities
- Supporting community leaders to undertake various activities sharing information about death, dying, and grief within their community, assessing death literacy before and after
- Participants recruited across metropolitan and rural SA from three population groups:

1. **CALD communities**: Filipino, German, Italian and Vietnamese
2. **Rural communities:** Mount Gambier, Port Lincoln, and Whyalla
3. **Low socio-economic status communities:** City of Playford and City of Port Adelaide Enfield

- Conducting a survey using the validated Death Literacy Index (DLI) tool within community groups, before and after community-led interventional activities delivered over 6-months
- Assessing the effectiveness of community-led activities regarding discussions, accounting for local conditions and cultural factors
- This community-led research will strengthen community resources, providing participant communities with the language, knowledge, resourcing, and practical skills to make active EOL choices

Current Research

Visit the Palliative Care Research Collaboration website

Acute Care Study: Case-note Audit and Patient Survey

- Study involves a cross-sectional case-note audit of in-patients aged 55 years and above, within major SA urban and rural public hospitals, in partnership with LHNs
- Audit will identify patients with deteriorating health and increasing care needs (i.e., 'SPICT positive'), documenting presenting issues, admissions, treatment details, and evidence of need for and conversations about EOL care
- Survey will document prevalence of unmet need and awareness of palliative care within the target population, further capturing admission and mortality outcomes 12 months later
- Inclusion criteria: 55+ years and SPICT positive; in-patient

Current Research

Visit the Palliative Care Research Collaboration website

Prospective, Longitudinal, Mixed-Methods Study

- This study captures behaviours, experiences, and key moments over time that shape how and why people living with a life-limiting illness who need assistance with their care needs, and their chosen carers from underserved SA communities make decisions about care at EOL
- Enable development of resources to ensure timely provision of information to, and support for, patients, families, and carers negotiating and living with decisions about EOL care
- Participants recruited across metropolitan and rural SA
- Participants and their carers followed until the end of the study in 2026 (or 3 months into bereavement)
- Through three conversations, we will capture behaviours, experiences and key moments that shape how and why participants and their carers make EOL decisions, as well as how these change over time.

Inclusion criteria:

- A person approaching the end of life (likely to die within the next 12 months), and their chosen carer (a dyad)
- Aged 18 years +
- CALD, rural and/or low socioeconomic populations

Contact

Dr Georgia Rowley

georgia.rowley@adelaide.edu.au

UoA: https://www.adelaide.edu.au/directory/georgia.rowley

LinkedIn: https://au.linkedin.com/in/georgiapanagiotopoulos

Thank you