

INDIGENOUS CULTURAL PERSPECTIVES ON ADVANCE CARE PLANNING

Introduction

- Advance Care Planning (ACP) is a legally recognised approach record an individuals' end-of-life preferences.
- Aboriginal and Torres Strait Islanders peoples in Australia have specific, cultural ways of approaching death and dying.
- There can be reluctance to discuss death in Aboriginal communities, due to its complex impact on community and kin, the storied history of death in Aboriginal communities, and for fear of 'jinxing' oneself [1]
- Little is known about how Aboriginal peoples engage with ACP.
- Current generic ACP forms for the Australian population may be culturally appropriate Aboriginal peoples,
- This study investigated the perspectives of South Australian Aboriginal peoples toward ACP.

Methods

- The study design followed an Indigenist research methodology with Aboriginal co-design
- Qualitative data were collected from 35 South Australian Aboriginal community members and Aboriginal and non-Indigenous health professionals by an Aboriginal researcher, with Yarning methodology [2].
- Participants were recruited verbally or by letter through a network of contacts of the team from urban and rural communities.
- Transcripts were reflexively thematically analysed. [3]

Results

Demographic details + yarning locations			
Community	Engagement	Participants	Location
Aboriginal (35)	Yarning circle	8 Elders	Community Hall
	One on one yam	11 Urban	Home, workplace, cafe
	Yarning circle	13 rural	Motel conference room
	One on one yam	3 professional consultants (1 aboriginal)	Café, workplace

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Themes + sub-themes Of ACP experiences + perceptions	
Themes	Sub-themes
Cultural end-of-life practices	Cultural end of life practices
	Attitudes on life and death
	What matters at end of life
	State laws vs cultural law
Awareness and understanding of ACP	ACP vs EoL care plan vs will vs funerals
	Attitudes towards ACP
	Awareness
	Exposure methods to ACPs
	Understanding of ACP
Healthcare experiences	Traditional healers
	Aboriginal health workers
	Experiences with healthcare
	Care practices
	Cultural safety
Kinship and family dynamic	Kinship and family dynamics
	Substitute decision makers
	Financial elements
Information and resources	Accessibility
	Cultural accessibility and acceptability
	Language and literacy
	Mode on information and promotion
	How to increase access to ACP information
• ACP document	Storage of information
	Language and literacy
	Structure of ACP document
	Support with ACP
	Data sovereignty

Cultural practices

...in a traditional setting [...] our ancestors had an end-of-life care plan [...] But because we've been so disconnected from our cultural ways, there's no connection back to this ... [Elder participant]

Awareness and understanding of ACP

I'd heard of both of them [ACD and end of-life care plan], but [...], I don't know the difference. [Female participant]

Kinship and Family Dynamics

I would send it (ACP) out to, like copies out to family members ..., it'll save a lot of family chaos, I think, and distress [Female participant]

Discussion

- Aboriginal peoples face additional specific challenges in discussing death, related to culture, community diversity, communication barriers, trust and health service inequities,.
- Improving the cultural competency of service providers is essential to re-establish trust [4]
- ACP understandings were noted to intersect with other end-of-life concerns, including wills, palliative care and funeral arrangements.
- The range of current resources is limited and the current ACD was found to be lengthy, wordy and daunting to complete.
- Co-design approaches capture individual Aboriginal communities' perspectives on end-of-life issues and advance care directives

References

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- 2) Kennedy M et al (2022) Decolonising qualitative research with respectful, reciprocal, and responsible research practice: a narrative review of the application of Yarning method in qualitative Aboriginal and Torres Strait Islander health research. International Journal for Equity in Health 21(1), 134. <https://doi.org/10.1186/s12939-022-01738-w>.
- 3) Braun V and Clarke V (2019) Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health 11(4), 589-597. <https://doi.org/10.1080/2159676X.2019.1628806>
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