Exploring factors influencing advance care planning uptake across socially and culturally diverse communities in Australia

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Key concepts

- Advance care planning as cultural practice
- Gradual emergence of research on cultural factors in ACP
- Cultural worldviews and mortality salience
- Intersectionality and within group differences
- Case Study: community development approach aiming for cultural responsiveness and cultural safety
Culture

“the values, beliefs and behaviours that a people hold in common, transmit across generations, and use to interpret experiences” (Perkins et al. 2002, p48)
Culture and end-of-life care

- Views about appropriate communication of bad news
- Method and locus of decision-making
- Attitudes towards advance directives

(Searight & Gafford, 2005)
Cultural Worldviews & Mortality Salience

- Terror management theory - reliance on shared cultural worldviews as a way of staving off fear and anxiety triggered by awareness of own mortality

- Mortality salience
  - Associated with increased aversion for cultural dissimilarity (Bassett et al 2011)
  - Greater value placed on pro-social behaviour (Schindler et al 2012) and symbols of one’s own cultural worldview (Wirth-Petrick et al 2012)

- Theorised in the context of advance care planning by Johnstone (2012)
Intersectionality - Race... or place?

- 63.4% of ‘White’ and 27.0% of African-American long term care residents had at least one advance directive (OR=2.35, a 36% difference)

- But when controlling for geographic location (rurality and socio-economic status), facility characteristics and other demographic variables, this accounted for nearly half of the discrepancy (16 of the 36% difference percentage points)

  (Troyer et al. 2006)
### Intersectionality - Education?

<table>
<thead>
<tr>
<th>Type of ACP</th>
<th>Anglo Celtic</th>
<th>Mediterranean</th>
<th>Eastern European</th>
<th>Asia-Pacific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enduring Guardian</td>
<td>37.5%</td>
<td>15.5%</td>
<td>24.1%</td>
<td>13.3%</td>
</tr>
<tr>
<td>Advance Care Directive</td>
<td>14.3%</td>
<td>2.8%</td>
<td>3.4%</td>
<td>0%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Anglo Celtic</th>
<th>Mediterranean</th>
<th>Eastern European</th>
<th>Asia-Pacific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
<td>7.1%</td>
<td>74.6%</td>
<td>48.3%</td>
<td>60.0%</td>
</tr>
<tr>
<td>High school or tertiary</td>
<td>92.9%</td>
<td>25.3%</td>
<td>51.7%</td>
<td>40.0%</td>
</tr>
</tbody>
</table>

Jeong et al (2014)

Education associated with ACP uptake (Sinclair et al. 2017)
Feasibility studies

- Detering et al 2015 - similar uptake of facilitated ACP among Italian and Greek speaking inpatients compared to English speaking inpatients, when facilitated ACP intervention supported by trained interpreters.

- Frequent involvement of family members, including as interpreters.

- Importance of starting ACP discussion from a broad perspective “how would you like decisions made, if you became unable to make them yourself?”

- Enabling patient and family input into method and locus of decision-making.
Noongar community work

- Discussions over cups of tea
- Endorsement from management
- Meeting of Elders and community members
- Aboriginal Health Service reference group

Diagram:
- Advance care planning
  - Doing an Advance Health Directive
  - Doing an Enduring Power of Guardianship
  - Having yarns with people
  - Thinking about what you want

Logos:
- University of Western Australia
- University of Notre Dame Australia
- The Rural Clinical School of Western Australia
Cultural reflections on talking about death and dying

“...when [Aboriginal community corporation] first started making... these funeral plans, and a lot of them said ‘ay where you at, where you people making these funeral plans? Haven’t they got any sense this mob warra* they shame.’ But by breaking it down and going out into the community it makes sense.”

*warra: Noongar word for ‘bad’
Importance of family and kin

Family situations/contexts informed views about ACP

“...Well see, my family talk... my daughter you see, she’d know what to do. Like I said if I can’t make my own decision, well she’d make it for me... there won’t be no disagreements in my family because they’re always wanting to do what’s best for me.”

“I think you need to write it down. This having a yarn, well [other family members] could say ‘oh but she told me’...”
Appropriate communication

“I think doctors should really give you time to think about it too, not just chuck it on you and want you to answer that question straight away without explaining it... they should be good enough to explain everything to you there and then, so you can walk out the door feeling a bit better…”

“...you couldn’t get any better than this... just sitting around, having a feed, cup of tea... In a doctor’s office you’re more in a rush to hurry up and get in and get out... [but] now that you talked about this and then the doctor comes and asks you, you know what to expect then.”
Implications for research

- “Simplified, limited understandings of culture and cultural factors have repeatedly been shown to have greater political than interpretative power, and run the risk of stereotyping” (Menaca et al. 2012, p394)

- Combining ‘preferences and perceptions’ research with observation of actual practice in socio-cultural context

- Impact of intersectionality (intervening social factors) can contribute to within group differences
Implications for practice

- Awareness of the cultural worldviews which inform advance care planning
- Acknowledging power and histories of oppression of ethnic minority groups - implications for trust in institutions
- Advance care planning models which accommodate diverse approaches to
  - Communicating bad news
  - Methods and locus of decision-making
- Adopting community development principles in promoting advance care planning
- Respecting the role and expertise of cultural mediators
Key References


- Troyer JL and McAuley WJ. Environmental contexts of ultimate decisions: why White nursing home residents are twice as likely as African American residents to have an advance directive. *The Journals of Gerontology, Series B*. 2006; 61: S194.