An online resource to support culturally responsive palliative care for Aboriginal and Torres Strait Islander Peoples.

Lauren Miller-Lewis, Catherine Jacka, Deb Rawlings, & Jennifer Tieman.

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Acknowledgement of Country

CareSearch respectfully acknowledges the Kaurna people, the traditional custodians of the lands that we meet on today. We would like to acknowledge elders past and present and their spiritual relationship with the land.

WARNING: Aboriginal and Torres Strait Islander peoples should be aware that this presentation may contain images, voices, names and/or references to people who have since passed away.
Outline:

1. CareSearch Context
2. Why a CareSearch Aboriginal and Torres Strait Islander care section?
3. How was it developed?
4. What is in it?
5. Learnings and Conclusions
CareSearch Context

• Online palliative care resource promoting evidence-based practice and access to trustworthy information
• Funded by Australian Government Department of Health
• CareSearch includes ‘Hubs’ of information and resources that consolidate the knowledge base and practice issues for specific professional groups or care issues, e.g.,
  ➢ GP Hub
  ➢ Allied Health Hub
  ➢ Nurses Hub
  ➢ Residential Aged Care Hub

CareSearch Context

• Aboriginal and Torres Strait Islander care identified as issue requiring attention
• 2014: interim solution of collating resources on CareSearch website relevant to Aboriginal and Torres Strait Islander care into one section.
• Received funding to formally develop a new ‘Hub’.
• 2016: developed into a full ‘knowledge hub’ suitable for all health professional groups.
• Recognise the needs of the community and support the health workforce to provide culturally safe and responsive care.
Why an Aboriginal and Torres Strait Islander Section?

Understanding the care context

• Aboriginal and Torres Strait Islander people needing palliative care are more likely to be:
  ➢ Younger (life expectancy 10 years less)
  ➢ With greater burden of illness and comorbidities
  ➢ Possible connections to remote home
  ➢ Seen and cared for outside of specialist palliative care

Why an Aboriginal and Torres Strait Islander Section?

- Low participation in health services related to Aboriginal and Torres Strait Islander people having less access and not feeling culturally safe.

- What happens when services are not considered culturally safe?
  - “Compared to non-Indigenous patients with the same medical needs, Indigenous patients were about one-third less likely to receive appropriate medical care across all conditions” and much more likely “to die before getting old”.
  - e.g., higher likelihood of being considered palliative at diagnosis

Sources:
Culturally responsive approaches to care

• “Culturally responsive care can be defined as *an extension of patient centred care* that includes paying particular attention to social and cultural factors in managing therapeutic encounters with patients from different cultural and social backgrounds”.

• To create equity we need to implement palliative care strategies that integrate, respect, and accommodate the cultural needs of Aboriginal and Torres Strait Islander peoples.

How was the Hub developed?

1. Governance
2. Evidence
3. Cultural considerations
   - Terminology
   - Structure and Content Themes
   - Visual design
Governance

Major role of the Aboriginal and Torres Strait Islander Reference Group for PEPA and PCC4U:

• Expert advisory group of Aboriginal and Torres Strait Islander people representing key organisations within the Australian health sector
• Building on existing knowledge and expertise from key stakeholders
• Provided guidance on visual design, organizational structure, and suitable content and resources
• Stakeholder involvement essential to success of hub
Evidence

- Systematic search for relevant literature, evidence and resources
  - Formal Literature databases (e.g., Pubmed)
  - Systematic web search for grey literature; e.g., policy documents and publications from national and state governments, health organisations, Indigenous organisations.
- Compile and organise evidence and resources
- Draft and review content for hub pages
Cultural Considerations: Terminology

• Guided by position statements and standards by NACCHO, IAHA, CATSINaM, NATSIHWA and PEPA.

• Possible preference for ‘passed on’ or ‘finished up’ instead of ‘dead’

• ‘Aboriginal and Torres Strait Islander peoples’ preferred descriptor

• Focus on 3 cultural concepts:
  1. ‘Cultural safety’ (judged from the perspective of the client)
  2. ‘Cultural responsiveness’ (with health professionals working in a culturally responsive way to achieve cultural safety for their clients – drawing on IAHA cultural responsiveness framework)
  3. ‘Cultural capabilities’ (drawing on organisational level frameworks).

Cultural Considerations: Structure and Content Themes

• Critical to represent the importance of cultural safety and cultural responsiveness

• Person at the centre: Good quality palliative care is person-centred
  ➢ built on the specific needs of the individual (physical, social, spiritual, cultural)
  ➢ responds holistically to these needs, including cultural
  ➢ Culturally responsive care is an important part of person-centred care

• Focus to be on the patient journey to remind us the person sits at the heart of all care activity

• Health professionals have a role because of the patient’s needs
Cultural Considerations: Structure and Content Themes

• Importance of relationships:
  - The need to establish relationships to accurately identify patients needs
  - Highlight importance of inter-professional care and continuity across settings and providers
  - Valuable role for Aboriginal and Torres Strait Islander health workforce

• Need for content specifically for patients, family and community

• Need to showcase the sharing of real stories
The Importance of Real Stories

It's important for our elders to be cared for where their cultural needs are addressed ... We make sure they can get outside into the garden, that family can visit whenever they like and that the stories can be told.

Aboriginal Manager of aged care facility.

Cultural Considerations: Visual Design

- Graphic design played a key role within the Hub
- Unique visual presence to make immediately identifiable
- Indigenous artwork as centrepiece, representing a story
- Culturally sensitive issues such as the visual presentation of materials and use of images needed to be resolved
  - Particular animals may hold special meanings for different Aboriginal and Torres Strait Islander groups – abstract imagery better
  - Photographs considered permissible in certain circumstances:
    - With cultural warning at the website entrance
    - Perpetual image rights
    - Images representative of diversity in Aboriginal and Torres Strait Islander peoples
What’s in the Hub? - Graphic Design

• Leigh Harris of Ingeous Studios.
• Graphic artwork representing one’s journey of life and the care of our loved ones on their final journey.
What’s in the Hub? - Hub Content

Aboriginal and Torres Strait Islander Care Home Page

• Culturally Safe and Responsive Care
  ➢ Information about cultural safety and cultural responsiveness for the health care workforce

• The Care Journey
  ➢ Information for the health care workforce providing end-of-life care for Aboriginal and Torres Strait Islander people

• Patient, Family and Community Journeys
  ➢ Information for Aboriginal and Torres Strait Islander patients, their family and community

• Research, Evidence, and Practice
  ➢ Find and access relevant research and practice literature and resources
Aboriginal and Torres Strait Islander Care

This Hub brings together a range of resources and information to help the health care workforce and carers in providing palliative care with Aboriginal and Torres Strait Islander people. Culturally safe and responsive care is an essential part of good care.

Learn more about the Hub

Artwork by Leigh Harris of Ingeous Studios.
The Care Journey

This section provides information for the Health Care Workforce on providing palliative care with and for Aboriginal and Torres Strait Islander people.

In order to effectively meet the needs of Aboriginal and Torres Strait Islander patients requiring palliative care, health professionals need both clinical and cultural knowledge and skills to engage with Aboriginal and Torres Strait Islander patients and their family and community and provide the best possible end-of-life care journey for all involved.

Sharing stories is a valuable way to help show us how each person's journey to the end is different. We need to understand and acknowledge the role of the Aboriginal and Torres Strait Islander person's culture, family, and community in this journey. At this time many Aboriginal and Torres Strait Islander people provide care for their loved one requiring palliative care, and they learn and share the stories of that individual during this time of sadness.
Patient, Family and Community Journeys

Palliative Care - What's it about?

...it's about Quality of Life

Palliative care is provided for someone who is really sick and not going to get better. The goal of palliative care is to improve the quality of life of patients - to provide comfort, and to help them be as comfortable and active as possible. It can help with relief from pain, suffering, and other symptoms that may be affecting the person. Palliative care is not just about helping with physical concerns - it can also assist with social, emotional, cultural, and spiritual concerns. Supportive care for a person who is getting ready to finish up is about health professionals working together to do what the person wants. Palliative care services can help patients to remain in their community if that is what they wish. They can help family, carers, and community members learn how to care for someone who is finishing up.
Learnings and Conclusions

• The new Hub consolidates the knowledge base and practice issues, bringing it together into one place.
• The Hub provides access to resources that encourage culturally safe and responsive palliative care for Aboriginal and Torres Strait Islander peoples.
• Significance of the Hub greatly enhanced by partnership with key stakeholders in Aboriginal and Torres Strait Islander health.
Learnings and Conclusions

• Principles of palliative care resonate with principles in Aboriginal and Torres Strait Islander health
  - Emphasis is on the individual person who sits at the heart of care
  - Needs and care are individual
  - Patient and family and community all involved

• Health professionals and services need to recognise cultural and social contexts in the therapeutic encounter

• Health professionals can be active agents of change:
  - “Are there cultural or spiritual practices that affect the way you wish to be cared for?”
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