Culturally appropriate online resources to support Aboriginal and Torres Strait Islander People at the end of life

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“We acknowledge the Traditional Owners on whose country we are meeting. We thank them for allowing us to meet on their country and acknowledge their Elders past and present.”

WARNING: This presentation may contain images of, or have references to, deceased people. There may also be words or descriptions that could be culturally sensitive. This could upset some Aboriginal and Torres Strait Islander people; however CareSearch wishes no disrespect or distress.
What will be covered today

- Cancer in Aboriginal and Torres Strait Islander People
- Culturally Appropriate Responses to Care
- Aboriginal and Torres Strait Islander Hub
- Resources
Cancer in Indigenous People

- Aboriginal and Torres Strait Islander (Indigenous) People are almost 36% more likely to die from cancer than non-Indigenous Australians.

- Higher death rates from cancers are in those often considered palliative at diagnosis (lung, liver and unknown primary, as well as breast cancer in women) or if there is late presentation or suboptimal treatment
  - Choice
  - Circumstance

- Not all Aboriginal and Torres Strait Islander People identify themselves as such and figures are likely to be higher

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Australian Institute of Health and Welfare & Cancer Australia 2013. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series no.78. Cat. no. CAN 75. Canberra: AIHW.

Respect for unique circumstances

- Indigenous people are likely to be:
  - Younger
  - With a higher prevalence of risk factors, most notably tobacco use
  - With a Greater burden of illness / complex co-morbidities
  - Over ten times more likely than non-Indigenous Australians to live in remote areas
  - Seen and cared for outside of specialist palliative care
  - Want to die at home

Respect for unique circumstances

- Culturally specific reasons for low participation in screening have been identified
  - programs and services that were culturally unsafe and/or insensitive
- What happens when services are not considered culturally safe?

“Indigenous patients with the same characteristics as non-Indigenous patients were a third less likely to receive appropriate medical care across all conditions as well as specifically for cancer (specifically lung cancer) and coronary procedures”.

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”

“When clients are not from the same culture(s) as the service provider, the metaphors, rituals, and meanings of the client’s cultures are absent”.

“A complexity of historical, economic, social and cultural factors, including past approaches to health care, have created a health system in which there is inequitable access to health care and wellbeing programs, and inequitable health and wellbeing outcomes between Aboriginal and Torres Strait Islander Australians and non-Indigenous Australians”.

Culturally appropriate online resources to support Aboriginal and Torres Strait Islander People at the end of life
CareSearch

- CareSearch is an online palliative care resource promoting evidence based practice and is developing a ‘Knowledge Hub’ of information and resources for those caring for Indigenous People at the end of life.
- In 2014, all of the relevant Aboriginal resources on the CareSearch website were collated and used to create a temporary ‘Aboriginal and Torres Strait Islander Resources’ section alongside the other hubs on the CareSearch website.
Aboriginal and Torres Strait Islander Hub

• Funding was made available in the current CareSearch contract to formally develop a Hub

• CareSearch has developed ‘hubs’ of information and resources that consolidate the knowledge base and practice issues for specific professional groups (Tieman, 2012)
  • Allied Health Hub
  • GP Hub
  • Nurses hub
  • Residential Aged Care Hub

• Rather than be specific to one professional group, this new Hub will provide information relevant for all health professionals who work with Aboriginal and Torres Strait Islander people, including nurses, doctors, allied health workers, and Aboriginal Health Workers.

Governance

- PEPA Aboriginal and Torres Strait Islander Reference Group
- provide CareSearch with:
  - Input and advice on ideas for the organisational structure and design of the Aboriginal and Torres Strait Islander Hub
  - Review of the current Aboriginal and Torres Strait Islander Resources pages
  - Advice re: suitable content and resources for the new specialist page
  - Suggest re: Aboriginal and Torres Strait Islander resources for the other CareSearch Hubs (where appropriate)
  - Provide advice on how to promote the Hub.

The PEPA reference group is represented by people from diverse backgrounds, organisations and roles. The experienced group includes representatives from CATSINaM, NATSIHWA, IAHA, PCA, and government departments from across Australia.
Cultural Considerations: providing end of life care
for Aboriginal peoples and Torres Strait Islander peoples

The Aboriginal and Torres Strait Islander demographic is a much younger population than the rest of Australia. So if they are not the ageing demographic, why is holistic end of life care important?

Aboriginal and Torres Strait Islander people have a greater burden of illness than other Australians. They die at younger ages and more frequently than other Australians. Multiple co-morbidities can complicate both understanding and the care pathway, along with a culture, communication styles, family structures and beliefs that are not always known or understood by other Australians.

In some instances these multifaceted factors can act as barriers to both accessing and providing services. Service providers can make a dramatic impact with open communication providing the right people with the right information, at the right time.

Supporting services and staff is integral to best practice. PEPA is dedicated to providing professional development & resources for health care providers.

This document outlines practical considerations for providing person-centered palliative care for Aboriginal peoples, Torres Strait Islander peoples and their respective families, while being respectful of intercultural variations and individual choices.

We hope you find our resource ‘Cultural Considerations’ a useful tool in your work practices.
Evidence

- In 2016, a systematic search for relevant resources for potential inclusion in the hub was commenced. This resource search has included:
  - literature searching for journal articles in formal literature databases, such as pubmed and informit
  - searching the grey literature for relevant policy documents and resources (including searching the content of over 100 websites, such as Australian national and state government sites, Australian health organisations and aboriginal organisations, and university websites.)

This has given us a sense of the different types of resources that exist.
Existing Evidence Sources on CareSearch

- Systematic Review Collection
- PubMed Topic Searches
  - Cancer, Aboriginal and Torres Strait Islander, Rural and Remote Health, nurses
- CareSearch Searchable Grey Literature Collection
Considerations

• Culturally sensitive issues such as the presentation of materials and the use of images need to be resolved
  • For example, visual representations of animals were decided to remain outside of the scope for the Hub. Certain animals hold special significance to different Aboriginal and Torres Strait Islander groups, and therefore choosing an animal representation that is appropriate for all aboriginal groups is very difficult.
  • A consensus was reached that the use of photographs in the Hub is permissible in certain circumstances

• Issues relating to strength of evidence, relevance and health literacy will be addressed.
Terminology

The use of terms in the Hub such as cultural awareness, cultural security, cultural safety, cultural responsiveness, and cultural competence were discussed. Position statements and standards by NACCHO, IAHA, and CATSINaM were highlighted. It was decided that it was important that the Hub include information on the following 3 areas:

1) ‘cultural safety’ (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, and drawing upon the AIHA cultural responsiveness framework, with permission sought from Donna Murray)
3) ‘cultural capabilities’ (at the organisational/service provider level, drawing on e.g., Queensland Health cultural capability framework).
Content

• Aboriginal and Torres Strait Islander Hub Home Page
  • Cultural Safety, Cultural Responsiveness, Cultural Capability in caring for Aboriginal and Torres Strait Islander People
  • Aboriginal Health Workers and Practitioners
  • Healthcare Professionals caring for Aboriginal and Torres Strait Islander People
  • Information for Aboriginal and Torres Strait Islander Patients and their families
  • Finding Research and Evidence
Patients, Carers, Family

In the section on information for patients and families, there will be information for patients as well as their families and carers, included where to get help, who can help, and links to online information and stories.

For example, the Cancer Council Queensland cancer fact sheets for Aboriginal people.

Another key message throughout the hub will be the need for person-centred care, and holistic care that takes into consideration the need not only for physical care, but also for clinical, social, emotional, psychological and spiritual care.

While the information to be provided in the Hub is relevant to care at the end of life it is also applicable for those with cancer.
Conclusion

• The Hub will consolidate the knowledge base and practice issues that nurses may not be familiar with.

• Nurses provide care to Indigenous people with cancer, often to the end of their life. Having culturally appropriate resources to inform and support care is vital.
CareSearch would like to thank the many people who contribute their time and expertise to the project, including members of the National Advisory Group and the Knowledge Network Management Group.

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We would also like to thank the members of the PEPA Aboriginal reference group.