Closing the Gap for Indigenous Cancer Survivors

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Survivorship

‘The term cancer survivor refers to a person who has been diagnosed with cancer, from the time of diagnosis for the balance of life. The impact of cancer on family members, friends, and caregivers of survivors is also acknowledged as part of survivorship.”

- Centres for Disease Control and Prevention (CDCP)

“Survivorship encompasses those who are undergoing primary treatment, those who are in remission following treatment, those who are cured and those with active or advanced disease.”

– National Cancer Survivorship Initiative (NCSI)

“From the moment of diagnosis and for the remainder of the life, an individual diagnosed with cancer is a survivor.”

– National Coalition for Cancer Survivorship Charter (NCCS)
How to better understand survivorship in the Indigenous setting?

- What is the extent of the issue? How many people have cancer?
- What is the current state of health and wellbeing of cancer survivors?
- What specific problems, concerns or needs do cancer survivors report at different times after diagnosis and at different phases in the pathway of care?
- What are the risks of survivors experiencing adverse consequences from cancer treatment?
- What care are people receiving and how do cancer survivors perceive the care they are receiving?
- What has worked to improve the health outcomes for cancer survivors?
- How can survivorship care best be delivered?

Richards, Corner & Maher, 2011
Cancer is the 2nd leading cause of death (approx. 840 cases per year)\(^1\)
Pattern of incidence of specific cancers varies for Indigenous people
- 2.8 x higher liver cancer;
- 2.3 x higher cervical cancer;
- 1.7 x higher lung cancer
Overall mortality rate for all cancers is significantly higher for Indigenous Australians (221 vs 172/100,000)
- 3.4 x higher cervical cancer
- 3.0 x higher liver cancer
- 1.7 x higher lung cancer
Five-year survival between 1999-2007 was lower for Indigenous people diagnosed with cancer (40% vs 52%)
Current state of health and wellbeing of Indigenous cancer survivors?

Assessing quality of life, well-being and wellness and the associated factors is essential as a means of identifying and improving the length and quality of cancer survivorship, especially in groups that have significantly poorer cancer outcomes, such as Indigenous Australians.
Current state of health and wellbeing of Indigenous cancer survivors?

Health

“Aboriginal health means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life.”

- National Aboriginal Health Strategy, 1989
Current state of health and wellbeing of Indigenous cancer survivors?

Wellbeing

Wellness?

‘The optimal state of health of individuals and groups’

- Culture, heritage & leisure
- Family, kinship & community
- Health
- Education, learning & skills
- Customary, voluntary & paid work
- Income and & economic resources
- Housing, infrastructure & services
- Law & justice
- Citizenship & governance

ABS, 2010
Cancer care pathway – specific problems, concerns or needs?
Risks? Experiences?

Patients:
- patients’ view and understanding of cancer and cancer treatment
- financial problems
- transportation attitudes towards service providers out of town / country previous experiences
- access to supportive care services
- shame and fear of disease
- housing remoteness
- literacy
- patient disability
- co-morbidities
- family and community commitments

Socio-Cultural:
- disempowerment
- language (interpreter)
- historical implications
- lack of respect
- collective society mistrust
- discrimination
- cultural and spiritual beliefs
- traditional healers
- experience of others
- support person (the right person)

Health Care Systems:
- access to supportive care services
- appropriateness of service / service providers
- lack of confidence in system, staff and treatments
- late diagnosis (stage at diagnosis)
- communication (misunderstanding)
- medical practitioner (gender, technical, and communication skills)
- reduced uptake of treatment
- attitudes of staff
- (language, body language, tone of voice, how questions are asked)
- short consultation
- time
- no holistic treatment
- location of health facilities
- un- or under-insured
- (high co-pays)
- one system to fit all (no valuing diversity)
- waiting times for appointments when there
How can survivorship care best be delivered?

- Holistic approach to health and well being
- Diversity of Aboriginal and Torres Strait Islander peoples
- The social and cultural determinants of health
Indigenous cancer survivors: community awareness activities

National Aboriginal and Torres Strait Islander Cancer Framework
Priority 1
Improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members (across the continuum)

2015 Brisbane NICaN Annual Cancer Walk
Moving forward...

Take home messages
More research is necessary to better understand survivorship in the Indigenous setting

Survivorship models and plans need to consider Indigenous concepts of health and well-being and the social determinants of health

Current models of survivorship care require refinement to deliver effective and culturally-relevant healthcare
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Thank-you!

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Additional references
