Closing the Gap for Indigenous Cancer Survivors

Kalinda Griffiths^{1&2}

- 1. Sydney Centre for Aboriginal and Torres Strait Islander Statistics, University of Sydney
- 2. Menzies School of Health Research





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?

Research

policy

implementation

Cancer and Indigenous people

- 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;
 - 2.3x higher cervical cancer;
 - 1.7x 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?

<u>Health</u>

"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

Customary, Voluntary & Paid Wo

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

Physically
Psychologically
Socially
Spiritually
Economically

Family
Community
Place of
worship
Workplace

ABS, 2010

Cancer care pathway - specific problems, concerns or needs? Risks? Experiences?

disempor lap (inter implie colle (interpreter) historical implications lack of respect collective society mistrust and spiritual beliefs traditional healers experience of others support person (the right person)

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 car eservices shame and fear of **GISEASE** housing remoteness literacy patient disability co-morbidities family and community commitments

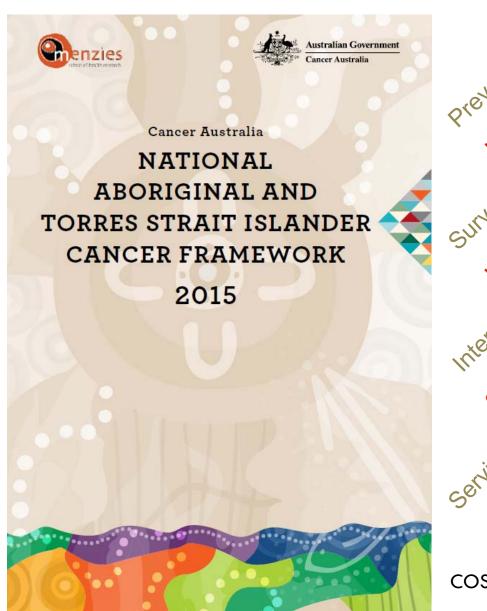
Health Care Si supportive care services, appropriateness of

service / service **Droviders** lack of confidence in system, staff and treatments late diagnosis (stage at diagnosis) communication (misunderstanding) medical practioner (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



Prevention
Surveillance
Surveillance
Intervention
Intervention
Service Coordination

COSA, 2016

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...

HEALTH EQUALITY AND A HUMAN RIGHTS APPROACH

ABORIGINAL AND TORRES STRAIT ISLANDER COMMUNITY CONTROL AND ENGAGEMENT

PARTNERSHIP

ACCOUNTABILITY

Commonwealth of Australia & Closing the Gap, 2013

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

Acknowledgements

- Gail Garvey and Joan Cunningham, Menzies School of Health Research
- Aboriginal and Torres Strait Islander Cancer Survivors
- Centre for Research Excellence in Discovering Indigenous Strategies to improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT)
- University of Sydney's Wingara Mura Leadership Program

Thank-you!

KALINDA.GRIFFITHS@SYDNEY.EDU.AU

References

- 1. Richards M., Corner J., Maher J. 2011. The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. BJC. 105:S1-S4
- 2. Centres for Disease Control and Prevention. Basic Information About Cancer Survivorship. Available from: https://www.cdc.gov/cancer/survivorship/basic_info/survivors/index.htm Last accessed: 16 Jan 2017
- 3. DH, Macmillan Cancer Support & NHS Improvement. 2010. The National Cancer Survivorship Initiative Vision. London: Department of Health.
- 4. National Coalition for Cancer Survivorship. Our Mission. Available from: https://www.canceradvocacy.org/about-us/our-history/. Last accessed: 16 Jan 2017
- 5. AIHW. 2014. Cancer in Australia: an overview. Cancer Series no.90. Cat. no. CAN88. Canberra: AIHW
- 6. AIHW & Cancer Australia. 2013. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series no.78. Cat. no. CAN75. Canberra: AIHW
- 7. Garvey. 2016. Personal Communication. Email. 01/02/2016.
- 8. World Health Organisation. 1946. Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June, 1946. Signed on 22nd July 1946, entered into force 1948. Geneva.
- 9. ABS. 2010. Framework for Measuring Wellbeing: Aboriginal and Torres Strait Islander Peoples, 2010. Cat. No. 4703.0
- 10.Clinical Oncology Society of Australia Model of Survivorship Care Working Group. 2016. Model of Survivorship Care: Critical Components of Cancer Survivorship Care in Australia Position Statement (draft). Clinical Oncology Society of Australia.
- 11.Commonwealth of Australia & Closing the Gap. 2013. National Aboriginal and Torres Strait Islander Health Plan 2013-2023.

Additional references

- Garvey G., Cunningham J., Yf He V., Janda M., Baade P., Sabesan S.,
 Martin JH., Fay M., Adams J., Kondamsamy-Chennakesavan S., Valery PC.
 2016. Health-related quality of life among Indigenous Australians
 diagnosed with cancer. Qual Life Res. 25:1999-2008.
- Cavanagh BM., Wakefield CE., McLoone JK., Garvey G., Cohn RJ. 2016.
 Cancer survivorship services for Indigenous peoples: where we stand, where to improve? A systematic review. J Cancer Surviv. 10:330-341.