Indigenous Australians and Cancer Care

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In recent years cancer mortality increased by 16% for Indigenous Australians while at the same time dropping by 10% for non-indigenous Australians.

The average life expectancy of Aboriginal and Torres Strait Islander people remains approximately ten years (10.6 years for men and 9.5 years for women) less than that of non-Indigenous Australians with leading causes including cancer.

Indigenous Australians are less likely to have screening tests for cancer.

Smoking within the Indigenous population is higher than for the rest of the population, which may contribute to the fact that Indigenous Australians are 1.9 times more likely to get lung cancer.

Indigenous Australians are more likely to be diagnosed at more advanced stages of cancer.

Higher levels of co-morbidity’s, poorer access to treatment and less complete treatment.
Barriers to Healthcare

- Indigenous Australians have a collective experience of racism and marginalisation, which can result in patients saying they understand when they don’t or remaining silent if they do not want to communicate.

- Limited understanding of how the health care system works which can result in them experiencing difficulty in navigating the cancer care system.

- Poorer housing and overcrowding in the housing that they do have.

- May live in rural and remote areas and face significant financial burden to get to treatment centres, as well as facing higher living costs in general due to their remoteness.

- Research suggests that the further away that a person lives from the treatment centre the poorer the cancer outcome.

- The concept of time used by Indigenous Australians can effect cancer outcomes.
Contributing Factors

Limited understanding of what cancer is or fears of attending clinics due to negative experiences in the past

Traditionally cancer has been viewed through Aboriginal cultural and spiritual beliefs. May see cancer as a payback, punishment or curse.

Cancer can be seen as incurable and cancer treatments seen as excessively toxic or not effective.

In many Aboriginal languages there is no word for “cancer”

Cancer can also be seen as a contagious disease that needs to be avoided, adding shame to the diagnosis and a reluctance to talk about experiences of cancer within the community.

Often lack knowledge on the type and symptoms of cancer and the treatment options available.
Patient Reflections

“I Did not understand the ways in which cancer care was organised and this lack of knowledge could present a significant barrier to cancer treatment and care of other Aboriginal people”

Desley.

“I felt that the racist practices of antenatal care that my mother had received (being made to wait outside the hospital until all non-Aboriginal patients had been seen) has resulted in my family being ‘fearful’ of hospitals.”

Zeta.
“I think...there needs to be a ...a person...not necessarily a case worker but a, a support worker, ideally an Aboriginal person who has...some awareness about cancer, has an awareness about the referral pathways that they can support. So I would like to see someone...who has the empathy or understanding about Aboriginal people and culture and that they can...it’s not the right kind of work but almost mentor you through that whole...you know, that knows the journey...often it’s a journey you travel once and ...you don’t know where you are going”.

Loretta.
“Being Aboriginal has nothing to do with the colour of your skin or shape of your nose. It is a spiritual feeling, an identity you know in your heart. It is a unique feeling that may be difficult for non-Aboriginal people to fully understand”.

Linda Burney.
Aim of Aboriginal Liaison Nurse

The number one priority of the 2015 Cancer Australia National Aboriginal and Torres Strait Islander Cancer Framework is to improve knowledge, attitudes and understanding of cancer by individuals, families, carers and community members.

Enhance the quality of care for Indigenous patients to increase screening, compliance and completion rates of chemotherapy and radiotherapy.

Make it easier for the Aboriginal patient to trust that the health system is there to help them.

Provide a link between services.

Provide a better understanding of the patient’s needs and circumstances to other health professionals through education to empower them to provide culturally sensitive care.

Those patients who have identified themselves as Aboriginal and/or Torres Strait Islander are supported in a culturally appropriate manner, through their cancer journey.

Allow effective engagement with Aboriginal communities; which in turn allows effective and sustainable solutions to be created.
Referral Process

Referral received from GP

Initial Contact from administration - Patient identifies as Aboriginal

QCL sent to Aboriginal Liaison Nurse

Patient contacted by Liaison Nurse
Consulted with 37 patients compared to half that number being identified in previous years.

Interactions have included, phone support, face to face Nurse Consultations, support during Medical consultations, Liaison with other health services for transport and home care, Referral to palliative care, social work and allied health care members as required.

Patients have expressed increased satisfaction and comfort through their cancer care journey by having an identified and experienced Nurse to help support them.

Nurse able to assist in the coordination of their care in a culturally sensitive manner and there has been more patients comply with and complete treatment.
Has the liaison position helped you to understand your cancer and treatment?

“"Yes, it was the best thing... she came to appointments and explained what to expect, set me up with palliative care and still checks up on me”.

“Yes, she picked up things I might have missed”.

“Indeed, she helped me fill out forms, made things understandable and made me feel at ease”.

“"Yes, she is wonderful, sits down and explains things to you, Doctors tell you things but she explains it to you so you can understand”."
What was done that made you feel safe during your treatment?

“She has a comforting presence and just by being there she helps”.

“She has always acknowledged me when I was there which helps”.

“She has been beside me when I am at the unit, she sits with me and explains things, she is my rock”.

“Just having her around makes me feel assured”.

16/09/2014
Have you shared your experience with the community?

“Yes, everything is a Facebook post”.

“Yes, I shared the treatment and information I got, having advice from the liaison she gave me the information I needed”.

“I talk about what is happening with friends and family so they understand”.

“I show them the information I got and talk to them all the time, it helps give them an idea what I am going through”.
How has follow up during your cancer treatment made a difference?

“Through the Liaison I helped to reconnect with my sister, before this my family was all over the place”.

“She always has a yarn and has always acknowledged me when I was there which helps”.

“She has put me in contact with palliative care, given me information and explained different things to me helping me think about a plan when it happens”.

“It was good to have her there to talk things through and give us another way to understand”.
Has your family been given support and information during your treatment?

“Always plenty of written information that they talk to you about as well”.

“Yes, a mile of information”.

“I was given heaps of information which helped a lot and I share with family and friends...well anyone really”.

“Yes and the Doctors gave me a lot of information”.

16/09/2014
Patient surveys were gathered in person with an independent Aboriginal health care worker to gauge patient satisfaction and highlight the need for any further requirements of the role.

A report on the program has been submitted to request funding and increase the role to 0.5 FTE to enable the Liaison Nurse to further embed the position within the community.

This would allow the Liaison Nurse to participate in screening and prevention programs in conjunction with local Aboriginal Medical Services and build rapport within the local community.

With increased community awareness of the role and the cultural security it can provide to patients having oncology therapies it is anticipated that compliance and completion rates will continue to increase.
References


Cancer Australia. (2010). Aboriginal and Torres Strait Islander Cancer Control Project. Cancer Australia. Author


