



We acknowledge the Turrbal and Yuggera peoples as the traditional custodians of the Brisbane region and pay respect to Elders past, present and emerging.



Wardliparingga Aboriginal Health Research Unit – 'Research Right Way' | www.sahmri.com



Understanding the needs of Aboriginal adolescents and young adults impacted by cancer:

Utilising narratives to improve support services

Fiona McDonald^{1,2}, Pandora Patterson^{1,2}, Rebecca Walker¹,
Jasmine Micklem³, Paul Yerrell³, Kim Morey³, Harold Stewart³, and Rachel Reilly³,
 the CanDAD Aboriginal Community Reference Group¹,
 with Kyran Dixon from the CanDAD Aboriginal Youth Advisory Committee

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



CanTeen's Support and Service



- Online and in person counselling
- Website with information
- Free books with age appropriate information
- Fun days with other young people
- Overnight camps and programs
- Youth leadership development
- Research into the needs of young people impacted by cancer



CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Impact of Cancer on Young People

- High levels of unmet needs and psychological distress
- Distress 3-6 times compared with other youth
- Disrupts normal transition to adulthood
- Can feel disconnected from friends
- Young patients want age appropriate services



CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Unmet needs

- Information about their family member's cancer
- Time away from the cancer and recreation
- Help with dealing with difficult feelings
- Friends to understand what they are going through and know how to support them
- Connect with and be supported by other young people who have been through a similar experience
- Help with family relationships
- Help with daily living such as household chores

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Impact of Cancer on Young Aboriginal People



- Overall cancer incidence rate similar to other Australians(1).
- However, Aboriginal people entering the health system for cancer treatment tend to be **younger and have more advanced and lethal types of cancer**(2, 3).
- **Aboriginal population median age 21yrs** vs. 37yrs for other Australians(4).
- Aboriginal population <25yrs predicted to substantially increase by 2026(5).
- When diagnosed with cancer, Aboriginal people more likely to have children aged <25 yrs.
- **Aboriginal family members more likely to require psychosocial support** due to higher cancer-related mortality.

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Collaborative Project

- The Cancer Data and Aboriginal Disparities Project (CanDAD)
- School of Health Sciences, The University of South Australia



CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



CanDAD Aboriginal Community Reference Group



www.sahmri.com



CanDAD Project Stories



Cancer stories from:

- 28 Aboriginal patients/survivors
- 13 Aboriginal carers/family members
- 22 cancer service providers

Youth experiences of cancer:

- 7 young cancer survivors
- 3 parents of youth diagnosed with cancer
- 3 youth caring for their parents/grandparent with cancer
- Other references to youth experiences of cancer (including adult cancer patients talking about their children)

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



General Findings



- **Many don't talk openly about cancer:**

- Only tell family on a need to know basis

"It's down the list and that might just be for a range of reasons but I also think obviously we have enough grief in our life and to burden someone else with that grief would be unfair."

- **Young men often delay seeing doctors:**

- Supportive family members push for them to be seen

- **Concerns about access to and inflexibility of mainstream health systems**

- **Concerns about institutionalised racism**

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au





Young Survivors

Managing cancer treatment:

- Reliance on parents vs. asserting independence
- Shock and fear about unfamiliar treatment regime (e.g. chemotherapy)
- Worries about potential side effects of treatment
- **Feeling homesick**
- Isolation from family and friends
- Missing out on things
- **Ngangkari healing and traditional bush medicines**

Managing other commitments:

- School work
- Plans for school formal
- Couldn't play football grand final
- University studies
- Parenting young children



Sophie is a cancer survivor and a member of CanTeen in NSW

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Parents



Not enough information or support for parents of children with cancer:

Mother of 14yo with rare cancer:

"I didn't get no back up at all from when he was fourteen. I had nobody. I had to try and explain to the schools and everything about what was happening with him. I had to go to the schools to see the head mistress and head masters of some of the schools to try and explain that he had a problem and everything and they say oh, what is it? You can't explain to them what it is because you don't know."

Mother of 17yo rushed interstate to city hospital for urgent Leukaemia treatment where there was no Aboriginal Cancer Care Co-ordinator:

"We all met at the hospital, we were there for one week without accommodation. We were in the waiting room sleeping with all our swags 'cause we had no-one to organise for accommodation at that time."

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Young Offspring

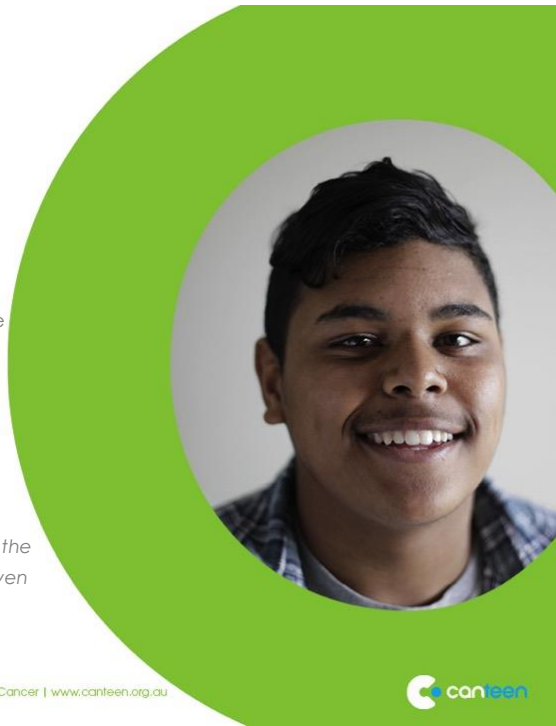
Kinship:

- Sometimes grandparents, aunts and uncles are considered like parents
- Not uncommon for grandchildren to be primary carers of cancer patients

Managing other commitments:

"When (my parent) was in hospital having radiotherapy or whatever, we'd always come home and then we'd go straight to the hospital. So year 11, I didn't do too well, even though I passed."

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Bereaved Offspring



- *"To be a young person and to realise that it's not necessarily the end of the end even though it might be the end of someone's life."*
- Concern that unresolved grief may have contributed to the suicide of a young bereaved offspring.
- Incarcerated and alone in grief - only able to visit parent once, under restricted conditions, and then attended funeral in handcuffs under heavy guard.
- *"My mum said to me that dad's in a better place now, he's no longer in pain. And even my uncle saying to me, 'You've got to look after your mum and your sister now.' When he said that, was just - well who's going to look after me?"*

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Help with Difficult Feelings



Family support:

- *"I think as Aboriginal people, we would do anything for anyone in our family and you'd probably do that first before you did something for yourself and I think we have to learn to look after ourselves before we can look after others. As selfish as that may seem, I think that's more what we need."*

Peer support:

- *"Going along to CanTeen really helped...it's always been a positive experience, and as you think - you're disappointed that other Aboriginal people aren't having the same experiences or for whatever reason, it would just be a bit disappointing."*
- *"It's allowed me to be a vulnerable person without the fear or worry of being ashamed or embarrassed about being – having had that experience because there are other people in the same boat and so when there are times of – when there are difficult times, you band together and you can get that support from friends who don't judge you, who don't question how you feel."*

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Improving Support Services



Recognise Aboriginal youth might not know much about their parent's cancer:

- Some Aboriginal people are beginning to talk openly about cancer, but it is still a private topic for many.

Recognise Aboriginal families often manage multiple stressors - cancer is but one:

- Family and community obligations, ongoing grief and trauma, institutionalised racism, incarceration, financial stress, housing concerns, isolation from homelands and community, other chronic illness in the family etc.

Recognise different kinship structures and family relationships:

- Extend support services to grandchildren, nieces and nephews where kinship relations warrant this.

Facilitate Aboriginal and Torres Strait Islander specific peer support:

- *"I was never asked, or was never aware of it, but how many other people within CanTeen were Aboriginal or Torres Strait Islander people?"*

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Other Support Services



- Youth Cancer Services
- Aboriginal Cancer Care Co-ordinators
- Cancer Council SA
- Kanggawodli
- Other NGOs (CanTeen, Leukaemia Foundation, Ronald McDonald House, Red Kite etc.)

CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Conclusion and next steps



- Continue to explore existing data to better tailor support services
- Better understand the support services available and increase awareness of these in Aboriginal communities
- With the CanDAD Aboriginal Youth Advisory Committee, develop a study to further explore the unmet needs of Aboriginal youth impacted by cancer



CanTeen - The Australian Organisation for Young People Living with Cancer | www.canteen.org.au



Acknowledgements

Dr. Micklem is employed part-time by Wardliparingga Aboriginal Health Research Unit, SAHMRI as a Post-Doctoral Research Fellow under the supervision of Professor Alex Brown under the following NHMRC grant:

The Cancer Data and Aboriginal Disparities Partnership Project

Dr. Micklem is employed as a casual Research Associate by the University of South Australia under the supervision of Professor David Roder, to research psychosocial impacts and supportive care for Aboriginal youth affected by cancer under the following NHMRC grant:

*Improving chronic disease outcomes for Indigenous Australians:
Causes, Interventions, System Change*

K O'Dea, R McDermott, K Rowley, J Lynch, L Segal



References



1. Australian Institute of Health and Welfare. Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. In: Australia C, editor. Canberra: Australian Government; 2013.
2. Australian Bureau of Statistics. Estimates of Aboriginal and Torres Strait Islander Australians, June 2011. Canberra2013.
3. Australian Bureau of Statistics. Estimates and Projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Canberra2014.
4. Australian Institute of Health and Welfare. Cancer in Australia: an overview 2014. Cat. no. CAN 75. Canberra: Australian Institute of Health and Welfare, 2014.
5. Roder D. Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory. Cancer Forum. 2005;29:7-9.