



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



Complexities of head and neck cancer:

Health-related quality of life concerns reported by Aboriginal patients in South and Central Australia

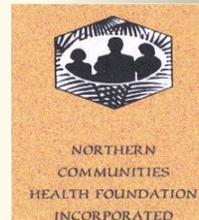


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NORTHERN
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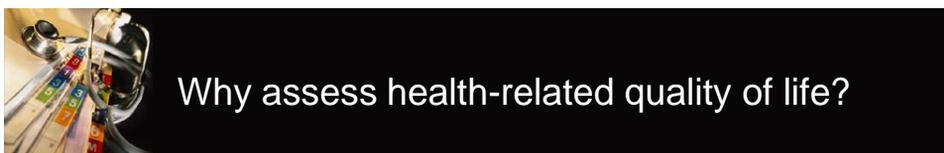
Dr. Syd Selva-Nayagam
Senior Medical Oncologist, Royal Adelaide Hospital

Thank you!

To all the cancer patients, survivors, carers and service providers who so generously share their experiences and wisdom during challenging times

And thank you to the CanDAD Aboriginal Community Reference Group and staff at Wardliparingga for continuing to guide my work in this area

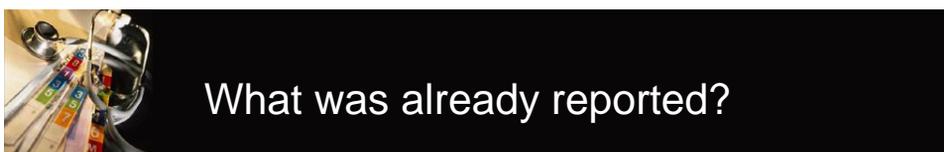




Why assess health-related quality of life?

Understand impacts of different cancer treatments:

- Enhance clinical decision making:
 - Surgery vs. radiotherapy? (Where there is choice...)
 - Palliation... Active treatment vs. supportive care only?
- Improve delivery of information and counselling



What was already reported?

...not much about the impact of head and neck cancer (HNC) or related treatment on Aboriginal or Torres Strait Islander peoples' lives

For further details see:

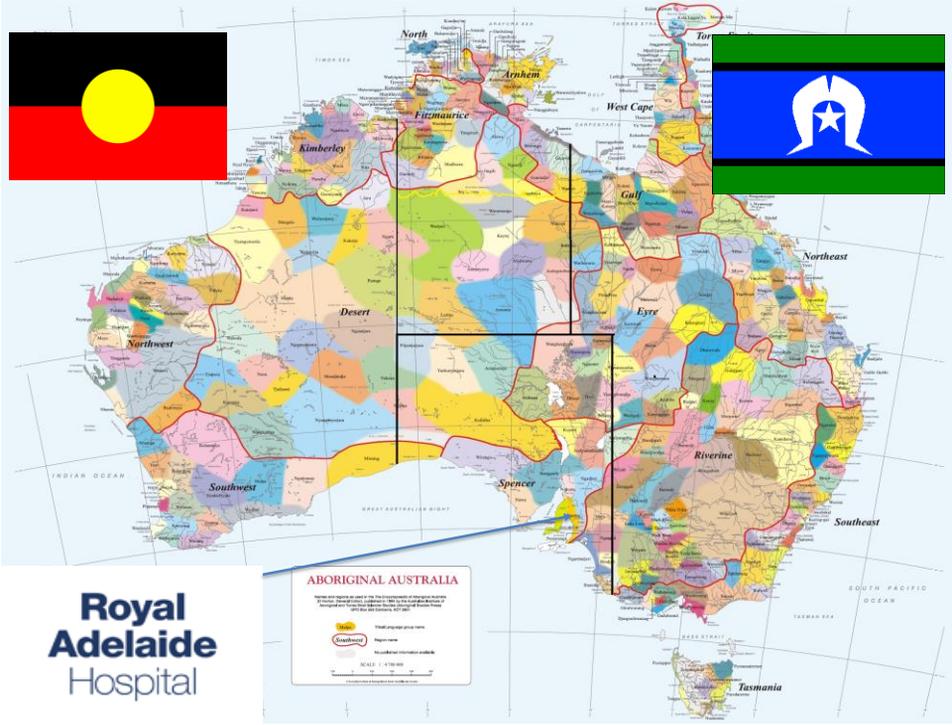
LITERATURE REVIEW

Self-reported health-related quality-of-life issues for Aboriginal and Torres Strait Islander patients with experience of cancer in Australia: a review of literature

Jasmine M. Micklem PhD

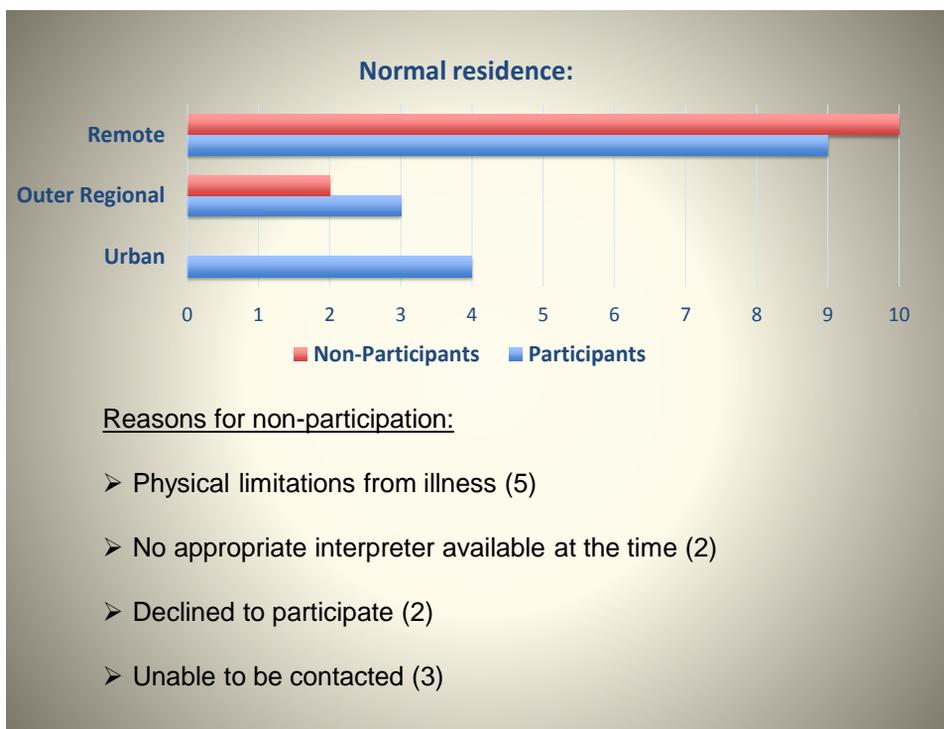
The University of Adelaide, Adelaide, Australia

International Journal of Evidence-Based Healthcare, 13 (4), June 2015

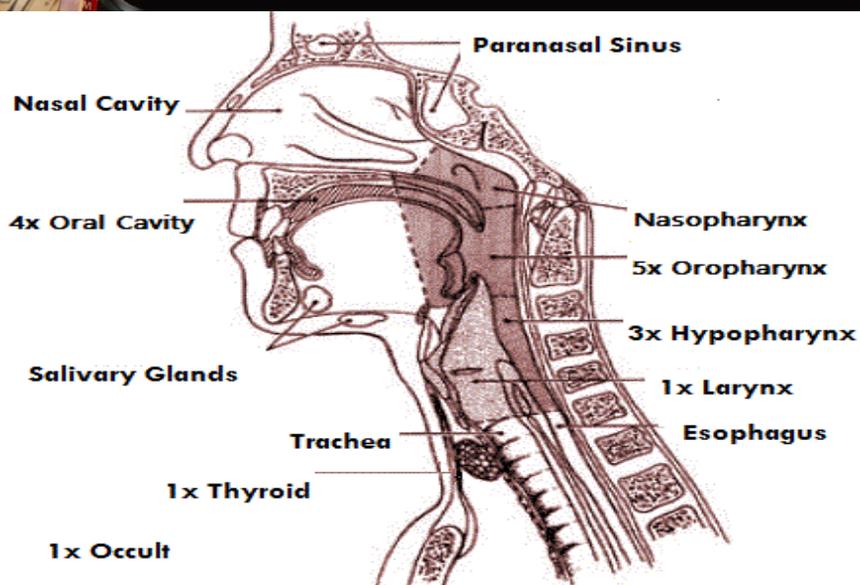


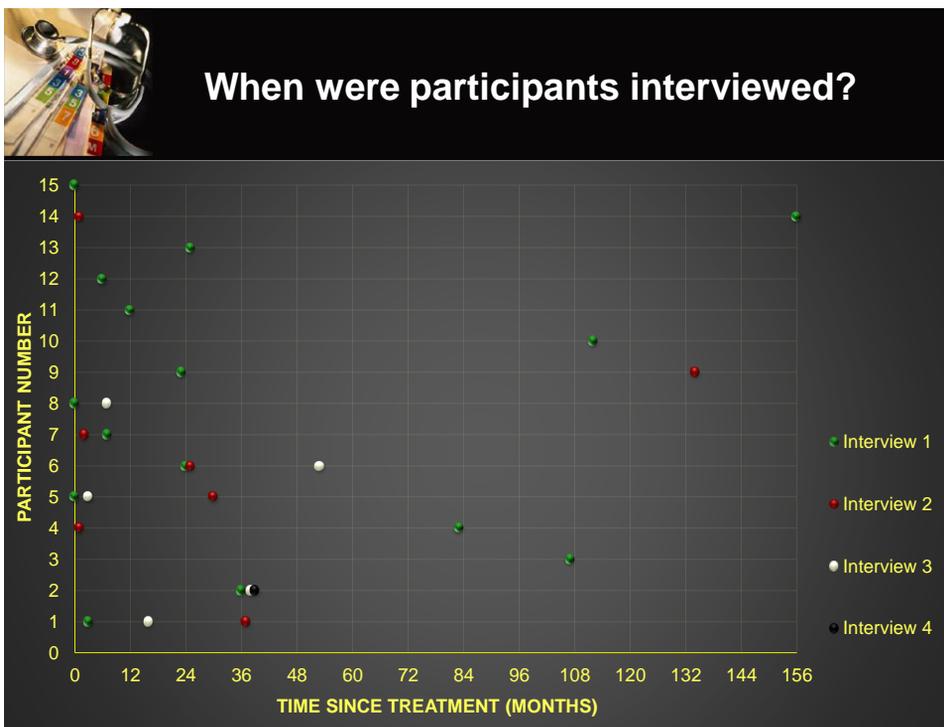
Cohort population:
Aboriginal patients diagnosed with HNC at the RAH between 1997 and 2011

Aboriginal patients diagnosed with HNC	South Australia	Central Australia	Total
Total	31	41	72
Confirmed deceased	18	27	45
Potential participants	13	14	27
Consenting participants	9	6	15
Non-participants	4	8	12



Participants' tumour sites



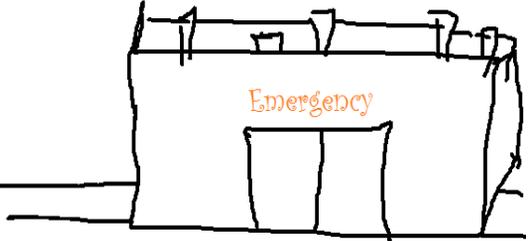


Physical and functional well being

Symptoms of illness and side effects of treatment can alter:

saliva	speech
swallowing	voice
chewing	hearing
taste	appearance
pain	energy
breathing	sleep
body mass	shoulder movement
mood	appetite etc.

TERTIARY HOSPITAL



PRIMARY HEALTH CARE



HOME

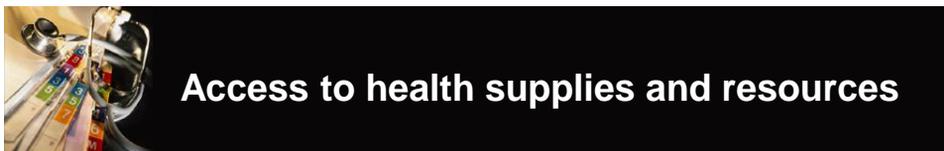
Access to treatment, follow up and support

Primary Health Care (Aboriginal Community Controlled Health Services, General Practitioners, visiting locums, Regional Hospitals, public vs. private systems etc.)

Tertiary Hospitals (Radiologists, Pathologists, Nurses, Specialist Physicians, ENT Surgeons, Oral & Maxillofacial Surgeons, Plastic Surgeons, Radiation Oncologists, Medical Oncologists, Specialist Dentists, Speech Pathologists, Dieticians, Social Workers, Clinical Psychologists, Palliative Care etc.)

Co-ordination of services (Communication, interpreters, escorts, transport, accommodation, prescriptions, welfare, etc.)



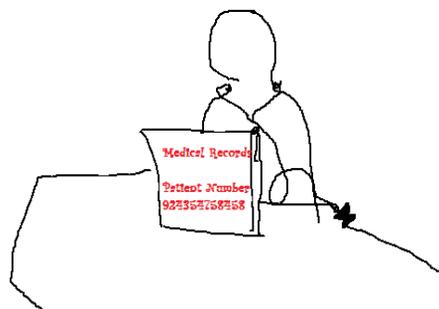
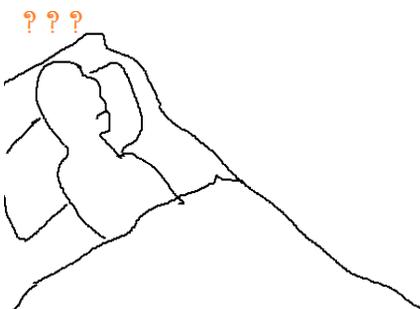


- Surgical wound care
- Tracheostomy
(Temporary or permanent breathing hole)
- NET
(Temporary feeding tube through nose)
- PEG/PEJ
(Semi permanent or permanent feeding tubes through stomach)
- Special needs dentistry



Access to information about illness & treatment

When at first they had to put me in that thing I was scared. Lie still, don't move. They want to press everything. Those one - two male that scan me – I think they gonna kill me in there. First time I been seen it, put me. I thought that they were gonna lock the door or something, lock me in. I think to myself that they might kill me inside here. But now I got a use of it. I don't worry now...It was funny the first time when I went in, I was scared. But now, no worries now – I know.



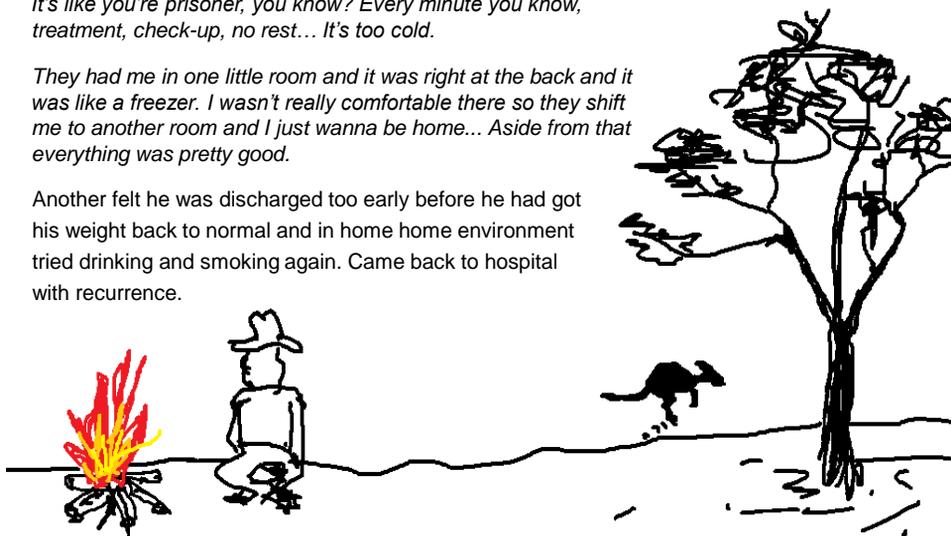
Environmental well being

*When I was on medication but I could have been at home doing that –
That really bothers me. Drive me up the wall, They wouldn't let me come home...*

*It's like you're prisoner, you know? Every minute you know,
treatment, check-up, no rest... It's too cold.*

*They had me in one little room and it was right at the back and it
was like a freezer. I wasn't really comfortable there so they shift
me to another room and I just wanna be home... Aside from that
everything was pretty good.*

Another felt he was discharged too early before he had got
his weight back to normal and in home home environment
tried drinking and smoking again. Came back to hospital
with recurrence.



Financial well-being

*Being down here is causing me (money problems) 'cause I'm not working so
there's no money coming in.*

*I no friends and I got no money, you know? I did money problems.
I did read. I get bored. It's really boring and no friends there and you can't get
books, you know? When I got my book and a TV up there I'm OK.
All I want are magazines, you know? I love reading.*

*When he's here he's doing nothing much, just watching TV and sometimes he
goes out shopping and sometimes his son come and picks him up and takes him
home for a day. He does some enjoyable things like going out for a walk or
shopping. But his son's got a broken car – he can't. That mean he can't go out.*

Tobacco, alcohol and other substances

Enjoyment:

Yeah I drink. I love my beer. Well, everyone does a bit now and then.

Coping with side effects:

My saliva's the worst bloody thing. When I get on the piss it just goes out the window. I'm alright and I got all the fluids I want... the only thing I can taste full time is beer. Do you realise that?

When he starts coughing he has a smoke to stop the itch in his throat.

Coping with emotions:

Yes drinking... Was feeling down. Not now.

From a survivor:

I tell them "Don't smoke, you might get cancer too."



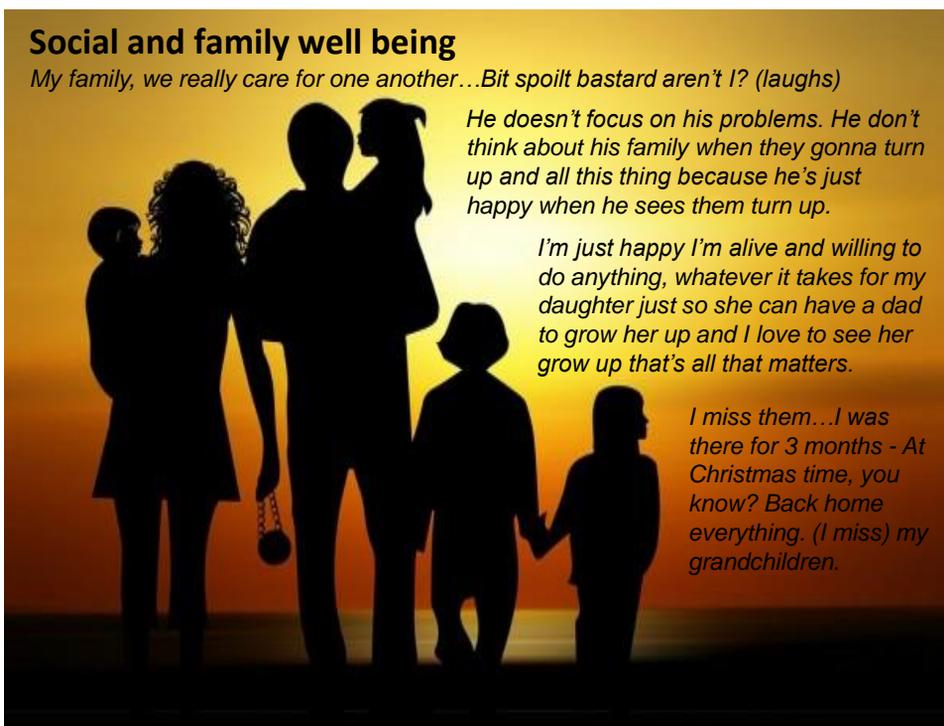
Social and family well being

My family, we really care for one another...Bit spoilt bastard aren't I? (laughs)

He doesn't focus on his problems. He don't think about his family when they gonna turn up and all this thing because he's just happy when he sees them turn up.

I'm just happy I'm alive and willing to do anything, whatever it takes for my daughter just so she can have a dad to grow her up and I love to see her grow up that's all that matters.

I miss them...I was there for 3 months - At Christmas time, you know? Back home everything. (I miss) my grandchildren.



Emotional and mental well being

*I seen too many people go down...I've been through the laps.
I seen my (parent) go through it.*

Survivors as peer support:

I can give him encouragement to go, a bit like me. "Go and fight it out, don't worry. Think about the next day, don't worry about it. Don't be scared, just go and do it. Don't be scared, you can fight like me. You can fight." I give him courage.



