"My spirit wants to live…"

Using narrative data for continuous quality improvement of cancer care for Aboriginal and Torres Strait Islander people in SA

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World Indigenous Cancer Conference, Brisbane, April 2016

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

Responding to the News

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To my surprise I immediately responded with my brother-in-law will heal me. He is an Aboriginal healer Ngangkari. This is when I realised that I reached out for my spiritual and cultural healing. I had never experienced this before. When your back is against the wall you can call on your ancestors to hear you.

Ngangkari Healing

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The specialist from the hospital rang and said I should come in straight away to start the chemo treatment. I told him I was waiting for my brother-in-law, Ngangkari to come and see me and heal me before I start the chemo treatment.

I closed my eyes and soaked up all the healing. His wife was there to assist him.

After a while he said, "you are right now sis."

The next day I rang the hospital and the doctor said we will start the chemo.

Medical Treatment

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I felt the liquid go into my body I felt this green horrible stuff flow through me. I felt like I was drowning on the inside I felt scared because I am not a very good swimmer.
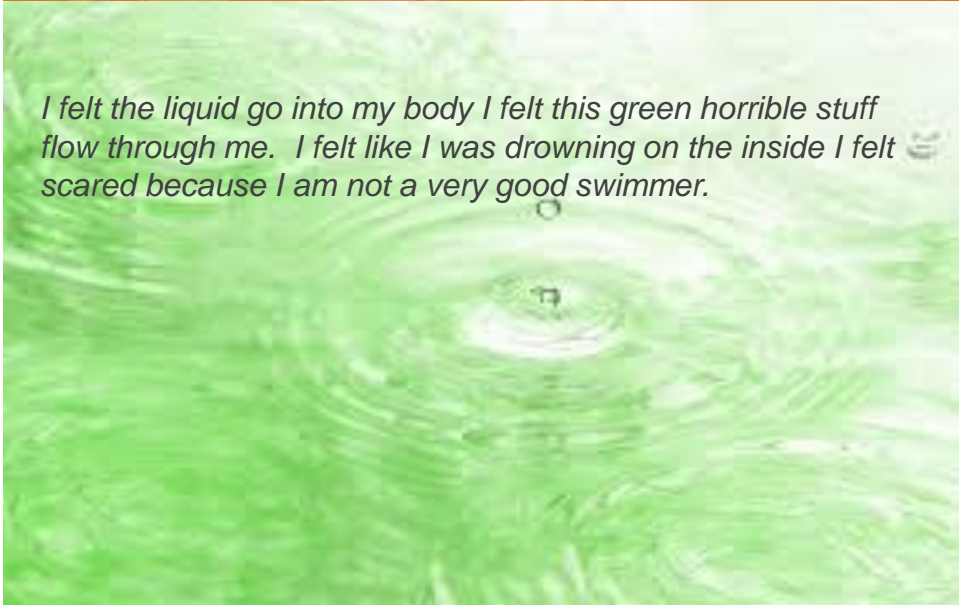
Drawing Strength from my culture

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I felt was a blessing for me to connect with my cultural background. These visits strengthened me more than I realised at the time

By October of that year I had finished my job and also my chemo. I could rest for now.

Getting on with life, then…..

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I wanted to throw myself in front of a truck.

I resigned from my job.

My body was not coping.

Cancer Data and Aboriginal Disparities (CanDAD): ACoRG

CanDAD's Aim

CanDAD aims to develop an Advanced Cancer Data System for ongoing, systemic and culturally appropriate tracking of Aboriginal peoples' experiences of cancer and cancer services for continuous quality improvement

Epidemiological data

Experiences of Cancer Care

Aboriginal Cancer Experiences

Semi-structured interviews with:

27 patients / survivors

[aged 19-75, 52% Male. Primary sites: Lung (5), lymphonma (4), breast (4), leukemia (3), head & neck (2), colorectal (1), multiple (1)]

eg. "When you have been unwell with cancer, have people looked after you properly?"

14 Carers / family members
[aged 20 – 67, 71% female (10)]

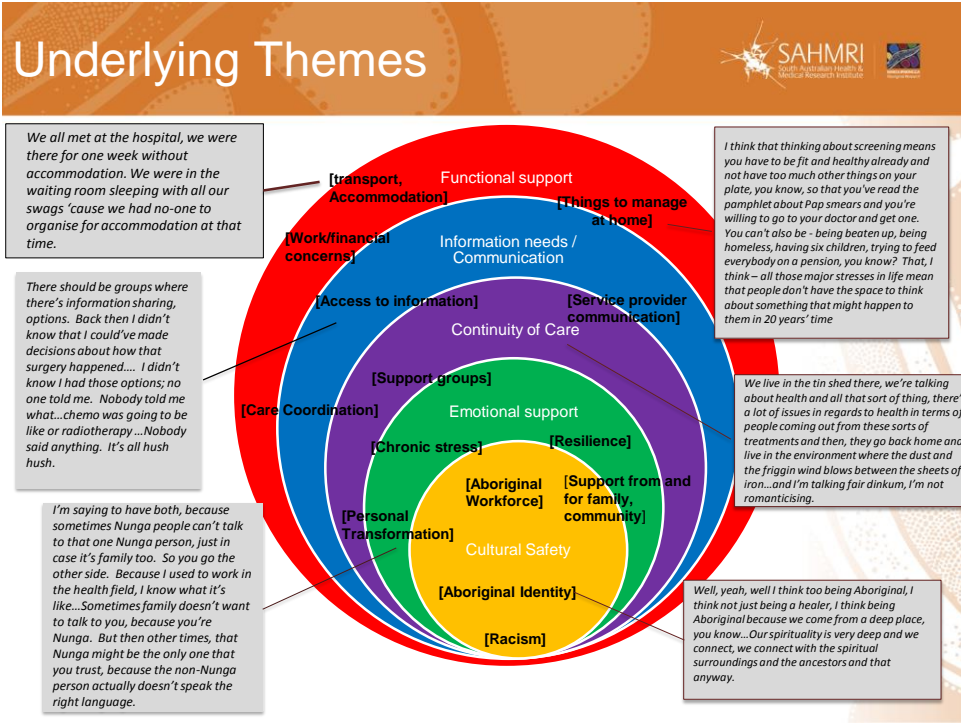eg. "How could things be better for you and your family to get the care you need when they are unwell?"
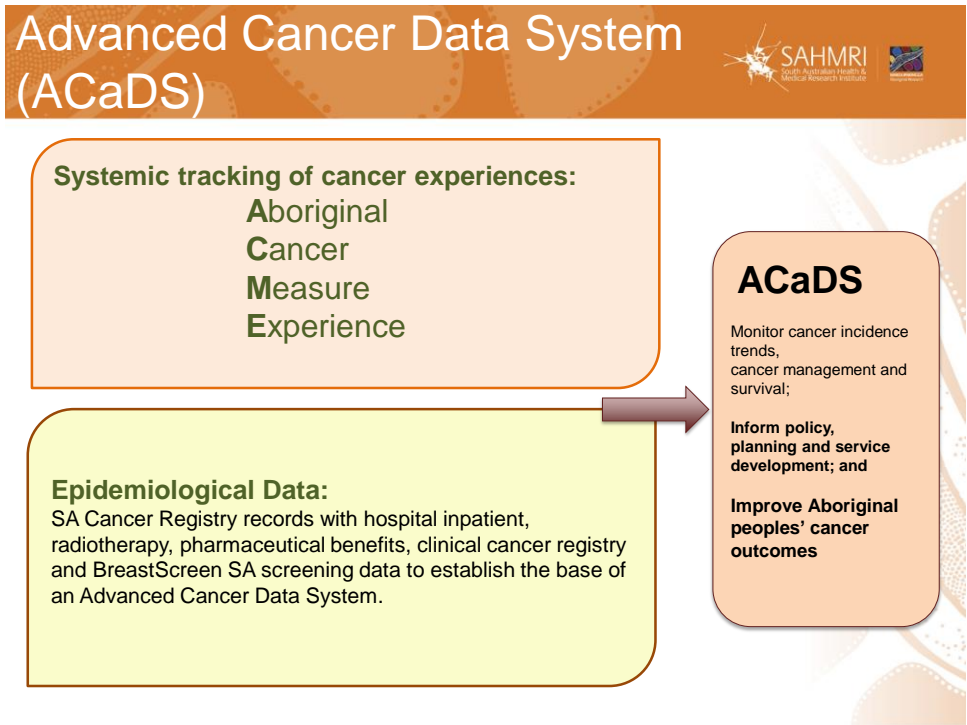
22 Service Providers
[80% women (16); 13 Aboriginal; 7 non-Aboriginal]

eg. "Do you feel you are able to practice 'caring well' for your Aboriginal patients with cancer in this health service? Why/why not?"

Cancer pathway mapping tool

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	Cancer awareness and risk factors	Symptom recognition and screening	Diagnosis and referral	Getting to specialist/ Pre-treatment	Treatment as an inpatient	Treatment as an outpatient	Discharge and transfer	Follow-up, ongoing support or palliation	Traditional or complementary healing/therapies
Health service priorities									
Patient experience									
Patient priorities, concerns and commitments									
Family/carer experience									
Family/carer priorities, concerns and commitments									
Barriers to health service provision									
Enablers to health service provision									
Service gaps									
Responses to service gaps									
Health service implications									

Underlying Themes

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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.

There should be groups where there's information sharing, options. Back then I didn't know that I could've made decisions about how that surgery happened…. I didn't know I had those options; no one told me. Nobody told me what…chemo was going to be like or radiotherapy …Nobody said anything. It's all hush hush.

I'm saying to have both, because sometimes Nunga people can't talk to that one Nunga person, just in case it's family too. So you go the other side. Because I used to work in the health field, I know what it's like…Sometimes family doesn't want to talk to you, because you're Nunga. But then other times, that Nunga might be the only one that you trust, because the non-Nunga person actually doesn't speak the right language.

Functional support
[transport, Accommodation]
[Work/financial concerns]
Information needs / Communication
[Things to manage at home]
[Access to information]
[Service provider communication]
Continuity of Care
[Support groups]
[Care Coordination]
Emotional support
[Chronic stress]
[Resilience]
[Aboriginal Workforce]
[Support from and for family, community]
[Personal Transformation]
Cultural Safety
[Aboriginal Identity]
[Racism]

I think that thinking about screening means you have to be fit and healthy already and not have too much other things on your plate, you know, so that you've read the pamphlet about Pap smears and you're willing to go to your doctor and get one. You can't also be - being beaten up, being homeless, having six children, trying to feed everybody on a pension, you know? That, I think – all those major stresses in life mean that people don't have the space to think about something that might happen to them in 20 years' time

We live in the tin shed there, we're talking about health and all that sort of thing, there's a lot of issues in regards to health in terms of people coming out from these sorts of treatments and then, they go back home and live in the environment where the dust and the friggin wind blows between the sheets of iron…and I'm talking fair dinkum, I'm not romanticising.

Well, yeah, well I think too being Aboriginal, I think not just being a healer, I think being Aboriginal because we come from a deep place, you know…Our spirituality is very deep and we connect, we connect with the spiritual surroundings and the ancestors and that anyway.

Advanced Cancer Data System (ACaDS)

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Systemic tracking of cancer experiences:
Aboriginal
Cancer
Measure
Experience

ACaDS

Monitor cancer incidence trends,
cancer management and survival;

Inform policy, planning and service development; and

Improve Aboriginal peoples' cancer outcomes

Epidemiological Data:
SA Cancer Registry records with hospital inpatient, radiotherapy, pharmaceutical benefits, clinical cancer registry and BreastScreen SA screening data to establish the base of an Advanced Cancer Data System.

Palya.
Nukkin ya.