Lessons from research: Aboriginal peoples’ experiences of cancer care

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Aboriginal Cancer in Australia

- Increasing trend of some cancers
- Higher rates of smoking-related cancers
- Lower participation in screening services
- Diagnosed later/advanced stage
- High mortality
- Non-compliant/incomplete treatment
- Poor treatment outcomes:
  - Individual/Community level reasons
  - Health Care System level reasons
Cancer Matters: Aboriginal beliefs about cancer and views of cancer treatment services

- Initiated following a research consultancy undertaken for TCCWA to look at how they could improve their services for and engagement with Aboriginal people around cancer
- PhD project [Rural-urban differences in Aboriginal Australian Perspectives on Cancer]

- Identify and explore the variations in understanding, beliefs and views of cancer, related services and treatment among rural and urban Aboriginal people in WA
- Explore the diversity in experiences and barriers of rural and urban Aboriginal people in WA with respect to cancer services and relevant treatment
Methodology and Ethics

Cancer Council Grant 2007, $60,000
- Data collection in Perth, Geraldton, Roeburn, Carnarvon
- Mainly used one-on-one in-depth interviews
- Over 50 interviews with Aboriginal people affected by cancer and service providers

Data Analysis
- Literature summary and critical analysis
- An ecological, holistic approach
- Results analysed thematically
- NVivo software used to manage data
Methodology and ethics continued…

- Approval from the Human Research Ethics Committee, Curtin University, Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC) and from the hospitals in Perth
- Aboriginal Reference Group was formed and is constantly involved in the research process
- Efforts were made to build trust and relationship prior to conduct the actual interviews
- Informed consent was given by all participants
- Interviews taped and transcribed verbatim
Research findings

Aboriginal Experiences of Cancer Care

- Cold, indifferent, intolerant, scary
  “I think you are treated as a number”
  “When these fellows come from wherever they are from to a place like a hospital, …you know, they are scared [Strong emphasis]. They are terrified, and they want to know what’s going on”

- Lack of understanding of the service providers about Aboriginal peoples’ social and cultural preferences and the impact of colonisation on their health and behaviour
  - Holistic perspectives on health
  - Space for the family members, especially children
  - ‘Dying at home’/importance of land
  - Language
  - Food
  - Impact of colonisation and life-circumstances
  “…her cervical doctor from King Edward came in to see her — we had some questions for him. He was like… he didn’t even want us in the ward with her.”
Communication difficulties

- Use of medical terminology
- Issues of privacy
- Transparency and openness
- Sensitivity and compassion
- Lack of understanding about patients concerns

“you wake up all you see all these doctors there, *all these white coats* watching over you. I found that a bit embarrassing, and a bit annoying.”

“What has put me off, too, *all the initial consultations was with the Ear and Nose doctor that I needed to see, but he comes with all these student doctors from different unis.*”

Logistical and infrastructural issues for Aboriginal people
Rural disadvantages

- Transportation
- Accommodation in Perth
- Expense of medication and treatment
- Problems in negotiating with PATS
- Lack of coordination between local GPs, specialists and metropolitan hospitals

“They don’t know which end of Perth [city] is left, right or centre…like when people come to Perth they just say ‘Just go to the hospital. How do people know where the hospital is… especially some people have never left their home town?”

“Because a lot of people when they get here and have got nowhere to room, they like to wait until the next morning and go back. They don’t even know about people like in the social worker side because nobody told them.”
- Insufficient information and support system
- Aboriginal Australian’s negative experiences and perceptions of racism and discrimination within the health system impact on their willingness to access services
  
  “There were instances when Aboriginal people had to wait on the veranda, sit on the veranda outside the surgery while all the white people were seen to. We would sit there for a whole day, the Aboriginal people, and wait….Even if it was freezing cold…”

- Lack of appreciation about traditional healing and bush medicine
Positive Experiences and Support during Cancer Journey

- Support from the PATS which paid the airfare or fuel costs and accommodation costs
- Some rural and remote participants praised palliative care and nursing services that came to their homes to look after patients
- Other supports included local Aboriginal Medical Services, morale-boosting wigs from the Cancer Council and Disability Services installing amenities to assist patients disabled by their treatment or illness
- Some talked about the extensive support from the Social Work division within the regional and metropolitan hospitals in the form of arranging accommodation, maintaining links with their family during treatment, receiving discounted food supplies and returning home
Key Suggestions from the Research

• Employment of more Aboriginal staff
• Need to increase logistical, psychological and emotional support services
• Warmth, caring about the person, good communication
  “don’t be afraid to talk about death. Because it is also part of the journey of living”
• Need to ensure the use of clear, sensitive, plain language communication
  “the doctors need to be more aware, too. They need to sit down with the patients and say to them, ‘This is what your medication is for’, because you do, you get scared…”
• Architectural sensitivity and planning
• Enable contact and support with extended family
• Greater Aboriginal outreach
• Aboriginal survivors telling of positive experiences
• Establishment of Aboriginal cancer support systems
• Acknowledge the past injustices and the impact it has on the current health status
• Recognise the cultural and geographical diversity within Aboriginal populations

“you’ve got saltwater Aboriginal people like myself now. We are from like they call saltwater people, because we were brought up on the ocean, and you’ve got Aboriginal people that are inland. So it’s two different things….”

• Appreciate and promote the use of holistic and traditional healing approaches as an alternative therapy
• Develop culturally appropriate resources and service-based programme

“I don’t think they really understand, and I suppose it’s difficult for the hospital system to cater for cultural barriers and stuff. I don’t know, but there should be something a bit more done about that….”
Conclusion

- Accept cultural differences/cultural acceptance
- Communication – verbal and body language
- Partnerships – GPs, specialists, IHWs, AMS
- Aboriginal involvement – at all levels
Thank You!!!