Addressing inequities in cancer care for Indigenous people in Australia and New Zealand

Indigenous Patient Navigator: an intervention aimed at addressing unmet supportive care needs of Indigenous cancer patients in Australia

Chairs: Patricia Valery and Gail Garvey

Speaker: Patricia Valery
Aboriginal and Torres Strait Islander Peoples

- Not ‘one group’
- 3% of Australian population
  - 90% Aboriginal people
  - 6% Torres Strait Islander
  - 4% both
- Over-represented in rural Australia
- Younger than the non-Indigenous population
- More likely to be of low socio economic status
- Higher burden of chronic disease

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Compared to non-Indigenous Australians, Aboriginal and Torres Strait Islander people have

Higher overall cancer incidence
Higher overall cancer mortality
Poorer overall cancer survival
Less likely to receive cancer treatment
High and specific unmet supportive care needs

All cancers
Factors impacting on poorer outcomes of Indigenous cancer patients

Patients
- Financial problems
- Transportation
- Attitudes towards service providers
- Out of town / country
- Previous experiences
- Access to supportive care services
- Appropriateness of service / service providers
- Lack of confidence in system, staff & treatments
- Communication (misunderstanding)
- Patients’ views and understanding of cancer & cancer treatment
- Shame and fear of disease
- Housing
- Remoteness
- Literacy
- Patient disability
- Co-morbidities
- Family & community commitments

Health Care System
- Late diagnosis (stage at diagnosis)
- Medical Practitioner (gender, technical and communication skills)
- Short consultation time
- Attitudes of staff (language, body language, tone of voice, how questions are asked)
- Access to supportive care services
- Reduced uptake of treatment
- High unmet support needs
- No holistic treatment
- un- or under-insured (high co-pays)
- One system to fit all (no valuing of diversity)
- Waiting times for appointments when there

Socio-Cultural
- Disempowerment
- Language (interpreter)
- Historical implications
- Lack of respect
- Experience of others
- Discrimination
- Traditional healers
- Mistrust
- Cultural & Spiritual beliefs
- Collective society
- Support person (the right person)

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Patient Navigation

- Patient Navigation (PN) was introduced in 1990, by Dr Harold Freeman
- Intervention to reduce cancer disparities by assisting patients from minorities and low-income populations to improve access to cancer care
- PN is patient-centered, with the goal of facilitating timely access for all to quality standard care in a culturally sensitive manner
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- Access to supportive care services
- Late diagnosis (stage at diagnosis)
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- Short consultation time
- Attitudes of staff (language, body language, tone of voice, how questions are asked)
- Un- or under-insured (high co-pays)
- One system to fit all (no valuing of diversity)
- Waiting times for appointments when there
- Location of health facilities
- Historical implications
- Experience of others
- Discrimination

**High unmet support needs**
- Mistrust
- Cultural & Spiritual beliefs
- Historical implications
- Experience of others
- Discrimination

**Accessibility**
- Language (interpreter)
- Traditional healers
- Support person (the right person)
- Mistrust
- Cultural & Spiritual beliefs
- Historical implications
- Experience of others
- Discrimination
Objectives

1. Protocol development

2. Patient Navigator Training

3. Refine and pilot the intervention with a small number of Indigenous cancer patients
1- Protocol Development

**Partnership:** Princess Alexandra Hospital; Menzies School of Health Research and Cancer Australia

**Consultation:** Aboriginal Health Workers, Aboriginal Liaison Officers, Cancer Care Coordinators (Nurses), Social Workers, Indigenous cancer survivors and an Indigenous reference group

**Products:**
- Training protocol (e.g. role description, training content, procedures)
- Information resources
- Study forms (assessment tool, action tool, evaluation)

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2- Patient Navigator Training

Delivery

- one-to-one sessions
- case scenarios

These were used to introduce the study forms, the patients’ needs assessment procedure, ‘action plan’ to assist patients using available resources and support services

Training content

- Module 1 – Fundamentals of Patient Navigation: Communication
- Module 2 – Understanding your illness
- Module 3 – Physical and emotional needs in the patient care and their families
- Module 4 – Daily living and practical support
3- Pilot the intervention

- July 2013 – March 2014
- 46 Indigenous cancer patients were identified through patient lists from hospitals and through the hospital’s IHLOs
  - 26 (56.5%) invited to participate
    - 8 (31%) refused participation
    - 18 (69%) recruited
Flyer used to recruit patients

Have you met our new Indigenous Patient Navigator?

Meet Phillipa!
Phillipa Cole is our new Indigenous Patient Navigator. Phillipa will be offering a culture-sensitive cancer care service to Aboriginal and Torres Strait Islander growing or former patients of the Princess Alexandra Hospital.

Phillipa will assess your needs, provide information and link you with services when needed.

Why do we have an Indigenous Patient Navigator?
Aboriginal and Torres Strait Islander people have higher incidence and mortality than other Australians. Their experience more aggressive cancer and are less likely to receive adequate cancer treatment. This is an important part of our study to help cancer patients in their journey.

If you would like Phillipa to help you please contact her through the Indigenous Patient Liaison Officers, Baptist Health Group through the below details.

Phone: 1300 321 777
Email: indigenous@cancer.org.au
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Needs Assessment
Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)

Score 2 – little more help

Score 3 – Some more help ‘Moderate Need’

Score 4 – A lot more help ‘High Need’

Observe, explore
Results

18 patients assessed

- 94% Aboriginal, 56% female
- aged 55 years old
- most frequent cancer type:
  - 28% gastrointestinal
  - 17% lung
  - 17% breast
- 66% receiving treatment (surgery/chemo/radio)
- 66% at least one comorbidity (diabetes most common)
‘What is the most significant challenge or problem for you now that you have cancer?’ (open ended question)

- cost of travel *
- understanding medical terminology *
- household cleaning
- special dietary planning
- returning to work
- difficulties with comorbidities
- challenges with personal care
- telling family members about their cancer

‘Moderate or high needs’ (SCNAT-IP)

- 28% ‘worrying about the illness spreading’
- 22% ‘concerns about the worries of those close to you’
- 17% ‘feeling down or sad’
- 17% ‘anxiety’
- 17% ‘work around home’
Actions taken by the Patient Navigator

Initially.....

• Education and information (resources, community and allied health services, support groups, lifestyle/hospice programs)
• Patients encouraged to have a more active involvement in seeking support for their cancer

As study progressed.....

• Patient Navigator accrued experience with screening for unmet needs and with the provision of support and education
• Provided additional, more targeted, support for patients who had ‘moderate to high needs’ with specific items (as per SCNAT-IP)
Evaluation

‘Patient satisfaction’ survey
Most patients were “extremely satisfied” with the Indigenous Patient Navigator’s:

- communication
- responsiveness to requests for support and advice
- information provided (cancer pamphlets)
- assistance given in making appointments at clinics/supportive services
- assistance given in writing down some questions to be used at their next doctors’ appointment

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Six patients indicated that the greatest contribution of their experience with the Patient Navigator was having someone to talk to and show compassion.

Comments made by the patients included:

“Have someone show compassion on that day. Taking the time for me. Made me feel better about myself.”

“In my case it was more about having someone talking to me than helping with things. I’m satisfied with the support I have, I just want to talk and have a cuppa.”

“Somebody to talk to who knows about it and who you don’t know.”

“Company during treatment and having someone who understands.”
Challenges and difficulties

- Ascertainment and recruitment of patients
- Linkage with services
- Physical space for the screening and referrals
- Transition between clinical service vs. research setting (how to change ‘hats’)
- Follow a structured questionnaire (systematic assessment)
Lessons learned

• It is feasible and practical to have an Indigenous Patient Navigator working in the current health service system

• Participants were highly satisfied with the education and information provided to them and their families

• Patients appreciated having an Indigenous person to share their experience with cancer, even patients who did not report moderate/high unmet needs

• The information about cancer and support services given by the Patient Navigator was readily accepted by patients
Indigenous Patient Navigator
Lessons learned from a pilot study in Queensland, Australia

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E-poster
Advocacy & Awareness - Control Systems/Palliative Care
Friday 1:15 pm
Acknowledgments

Other investigators - Gail Garvey, Euan Walpole, Jennifer Martin
Project co-ordinator – Christina M Bernardes
Patient Navigator - Phillipa Cole
Princess Alexandra Hospital staff - Gary Cowburn and Tanya Kitchener (Indigenous Liaison Officers); Vivienne Lloyd (assisted with patients’ lists)

We thank the members of the Indigenous Reference Group established to inform the study investigators about cultural matters and translation of results to the community.

Most importantly, I would like to thank the Aboriginal and Torres Strait Islander people who took part in the study.

Funding
The Indigenous community ‘champion’ project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government.

Patricia Valery was supported by an Australian Research Council Future Fellowship (grant 100100511).

Christina M Bernardes was supported by NHMRC grant 1044433 and a DISCOVER-TT Centre of Research Excellence Research Fellowship (No. 1041111).

G Garvey was supported by the Lowitja Institute, incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health.

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