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Quality of Life among Indigenous Australians with Cancer

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Co-authors

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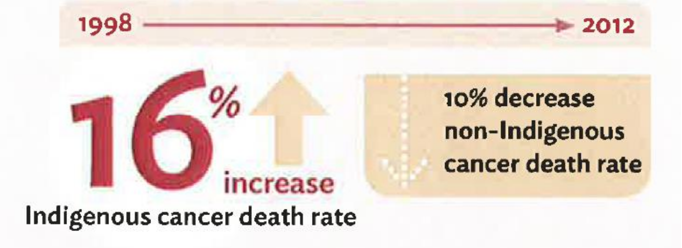
Cancer disparities

Significant cancer disparities in cancer outcomes between Indigenous Australians and non-Indigenous Australians



Reference: AIHW, Cancer in Australian Aboriginal and Torres Strait Islander people, 2013
Cancer Australia National Aboriginal and Torres Strait Islander Framework 2016

A cancer diagnosis and treatment may have a considerable impact on patients' lives which can lead to difficulties in fulfilling family roles, the ability to work, or participating in social activities[75,76]

Increasingly, clinicians have recognised that while traditional endpoints such as morbidity and mortality are important factors for cancer patients, overall health-related quality of life (HRQoL) is fundamental to a patient's care.[77,78]

Health Related Quality of Life (HRQoL)

- HRQoL refers to the **effects of disease and treatment** as **perceived** and **reported** by the **people affected by disease or disability** themselves
- HRQOL is **influenced a persons lived experience** of illness across a broad range of dimensions
- QoL instruments are used to capture the **participant perspective** regarding **the impact of health on quality of life**

Reference: PoCoG quality of life office

Why assess HRQoL??

Assessing HRQoL and the associated factors is essential as a means of ***identifying and improving the length and quality of cancer survivorship***, especially in groups that have significantly poorer cancer outcomes, such as Indigenous Australians

No published studies among Indigenous Australians [23].

Study aim

To report the level of HRQoL and factors associated with HRQoL among Indigenous cancer patients in Queensland using an existing questionnaire (AQoL-4D)

Note: This study is part of a larger longitudinal study conducted to assess the unmet supportive care needs of Indigenous Australian cancer patients

Methods

Study participants:

-Indigenous adults with a cancer diagnosis (newly diagnosed/recurrent);

-Hospital inpatient /outpatient clinic for their cancer;

-Received treatment or were about to receive treatment for their cancer;

-able to understand English; and were

-well enough and capable of participating

Setting: 4x major public hospitals

Study period: Sept 2010 – June 2012

Procedure

- Patients were interviewed at three time points:
  - recruitment (face-to-face), 3 and 6 months (face-to-face or via telephone)
- Initially approached by hospital staff (cancer care staff or ALOs)
- Those who agreed - contacted by a trained interviewer
- Informed consent was obtained and then interview

Data collection

Demographic information: age, Indigenous group (Aboriginal, Torres Strait Islander, or both), sex, marital status, employment status, educational level, postcode of residence, and main language spoken at home; and degree of contact with other Indigenous Australians;

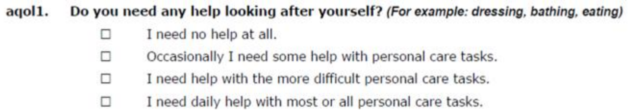
Clinical information: cancer type, cancer stage, and comorbidities, was abstracted from medical records by trained abstractors using a standardised data extraction form;

Tools: Assessment of Quality of Life (AQoL-4D)

Assessment of Quality of Life (AQoL-4D) **Questionnaire**

- 4 dimensions each with 3 items and four response levels
- Dimensions/items include:
  - Independent Living - self-care, household tasks and mobility;
  - Relationships - friendships, isolation and family role;
  - Mental Health- sleeping, worrying and pain;
  - Senses - seeing, hearing and communication.

Example: Independent Living



aqol1. Do you need any help looking after yourself? ***(For example: dressing, bathing, eating)***

☐ I need no help at all.
☐ Occasionally I need some help with personal care tasks.
☐ I need help with the more difficult personal care tasks.
☐ I need daily help with most or all personal care tasks.

Ethics approvals

- Charles Darwin University, Northern Territory Department of Health;
- Menzies School of Health Research;
- QIMR Berghofer Medical Research Institute;
- Four participating Queensland Health hospital ethics committees; and the
- Relevant Aboriginal and Torres Strait Islander sub-committees.

Results

- **Data analysis**: Standard scoring algorithms were used to derive a HRQoL score; bivariate and logistic regression analysis
- **155 participants** at approx. 6 months after their cancer dx (248 in the larger longitudinal study) (mean 182.7 days; 4–9 mths) after their cancer diagnosis
- **Demographics and clinical characteristics**
  - average age of 51.6 years (range 20–78)
  - most were female (60 %), unemployed (72 %), recruited from outpatient clinics (64 %)
  - about 1 in 7 participants (13 %) spoke a language other than English as their main language at home
  - most common primary cancer diagnosis was breast cancer (27 %),

Results HRQoL

- **Overall mean HRQoL** score was 0.57
- **Median HRQoL** was **significantly higher**:
  - Torres Strait Islanders than Aboriginal patients (p = 0.01)
  - those whose main contacts were Indigenous people (p = 0.05)
  - those who spoke a language other than English at home (p<0.01)
  - remote area residents (p = 0.04), and
  - those with **one** compared with no or 2+ **comorbidities** (p<0.01)
- **Cancer stage** were **not significantly associated** with the overall **HRQoL** score in our study

Excellent HRQoL

- **13.5 %** had excellent HRQoL (utility score 0.90 or above)
- Unadjusted/adjusted* odds of **excellent HRQoL** were **significantly higher** for:
  - **Torres Strait Islanders**' than Aboriginal patients (OR 3.21, 95 % CI 1.18–8.78); and
  - for those who **did not speak English** as their main language at home than those who did speak English (OR 3.40, 95 % CI 1.14–10.18), and
  - for those residing in **regional** (OR 4.33, 95 % CI 1.17–16.01) and **remote areas** (OR 3.82, 95 % CI 0.84–17.29) than those in major cities.

* Adjusted for categorical age, patient admission status, and treatment

Discussion

- The **mean HRQoL** utility score in our study is **lower than** that reported **in other Australian studies** [11, 14, 29, 30];
- several socio-demographic/clinical characteristics are associated with median HRQoL, and the relative odds of having excellent HRQoL;
- Aspects of culture, values, and spirituality are also key aspects of Indigenous people's quality of life that add to the complexity of its measurement. These concepts and issues are reflected to some extent in our results.
  - ➢ participants who spoke an Indigenous language at home, who maintained contact with other Indigenous people, and who lived outside of major cities were more likely to have higher HRQoL than the relevant comparison groups.

Limitations

Our sample included a broad range of cancer groups, with a maximum of 41 patients for any individual site.

A larger sample size may have resulted in greater power to detect small differences in quality of life and may have allowed analysis within individual tumour sites.

Most participants were recruited through cancer outpatient clinics and were well enough to participate in the study, and this may have influenced the results in a positive direction.

The suitability of the AQoL-4D and its properties including its sensitivity for Indigenous patients is not clear, but it has been shown to be robust across a range of different population groups and chronic diseases [11, 29, 30, 36, 37].

Conclusion

- HRQoL is increasingly being considered as a **critical endpoint in oncology** that can provide useful information for both the patient and the cancer care team
- Despite the burden of cancer for Indigenous Australians, this study is to our knowledge the **first published assessment of HRQoL in Indigenous Australian cancer patients**
- **Internationally only 1 published study** comparing HRQoL among Indigenous /non-Indigenous cancer survivors (Burhansstipanov, 2012);

Conclusion

HRQoL assessment can provide valuable information for improving patients cancer care and their patient experience and, in some settings, **lead to improvements** in their health and wellbeing.

However, to do so, it is vital that the **tools used capture and accurately measure** the components of **HRQoL** that are **valued by** the study population, in our case **Indigenous Australians**.

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