



Cancer Control and Screening
Research Group
Wellington

“This strange world that is cancer”: Experiences of cancer patients in the Aotearoa/New Zealand health system

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Background



- There are persistent inequities in cancer survival between Māori and non-Māori patients
- Evidence that the health system services Māori patients less well than non-Māori
- This study was part of a larger three phase study which aimed to explore inequities in health care between Māori & non-Māori New Zealanders with cancer.

Aim

- To identify factors that enhanced and hindered cancer patients' experiences & how they contribute to health inequities between Māori and non-Māori New Zealanders with cancer
- To identify appropriate interventions



Methods



- Māori-centered research: Māori researchers, tikanga, te reo, generating gains for Māori, strengths-based approach
- Semi-structured interviews were conducted with 34 participants, 19 Māori & 15 non-Māori
- Eligibility 18y + & completed initial treatment for cancer in the previous 2 years



Results

Overall satisfaction



- Overall participants largely reported being satisfied with care provided through the public health system & other health providers.
- People appeared reluctant to complain about their care.
- Particularly unpleasant experiences were isolated, relating to the actions of one particular staff member each.

Complex medical terminology

The importance of being well informed in language they could understand was a strong theme in the interviews with both Māori and non-Māori.



- I'd been sort of told that you'd be going in to see the oncology unit. I mean I didn't even know what oncology was then. And the first question I got was, "What's your NHI number?" I said, "What the hell's an NHI number?" Then I kind of got the sense that the people that I was talking to knew about **this strange world which is cancer** (IV33)
- I said to him, "**You have to speak to me in simple English...because I am not a doctor, I am not a nurse. And I really want to know, for myself.** You know you can use those high-faluting words, but then you have to explain them to me, because I'm not a doctor" (IV1)

Support people



The strange world of cancer, with its own language, its various specialties and complex drug and treatment regimes can be overwhelming. 9 Māori and 7 non-Māori talked of taking family or friends to appointments.

- **there's so much** that... you need another pair of ears. A support person, because **it just so much goes over you** (IV12)

Lack of culturally appropriate support services



Providing culturally appropriate health services is particularly important for people facing the stresses associated with a long-term and often frightening illness.

- It would have been nice, **to korero** [talk] **to a Māori**, what do they call them? advocates, or specialists, at the Cancer Society (IV6)
- When I went to park at the Cancer Society, they pointed out the different services that I could access, like counselling, and massage. But the environment there was...they were friendly enough, but I don't think it's suitable for Māori. If you walked into Kokiri [Māori health provider] you've got, "Haere mai, haere mai". **I felt like a fish out of water** (IV28)



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- Overall people largely reported being **satisfied** with their care
- Māori and non-Māori participants reported **similar** experiences
 - cancer is an unwelcome and foreign world
 - with complex medical terminology &
 - the need for support people
- However, Māori need **culturally appropriate health services**
- As colonised peoples **Māori experience inequities** in nearly all determinants of health
- As a result the complex world of cancer may be **even more difficult to navigate for Māori**



- This research demonstrates the value of a
 - **culturally appropriate research** process – Māori centered
 - research collaboration between a Māori provider and a university
- There is an urgent need to **close the gaps** for Māori in cancer survival
- We need interventions that
 - **make the world of cancer less foreign**
 - ensure health professionals use clear & understandable **lay language**
 - enable **support people** to fill their role
 - invest in culturally appropriate services for Māori e.g. **cultural competence** across the health sector, a **Māori 'navigator'** to assist patients to navigate the system.
 - **address the determinants of inequities** for Māori.

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