Exploring Health Literacy and Navigation Needs of NZ Refugees and Migrants with Cancer

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Multicultural NZ
Ethnic Disparities in Cancer Outcomes - International

- Minorities tended to:
  - lower screening rates
  - less likely to undergo surveillance
  - diagnosed with more advanced disease
  - receive inferior cancer care (or perceived)
  - experience greater morbidity and mortality
  - higher psychological distress and poorer QoL

Butow PN et al. (2015). Supportive Care Cancer, 21, 2509-2520.
Ethnic Disparities in Cancer Outcomes - NZ

Cancer Trends
Trends in cancer survival by ethnic and socioeconomic group
New Zealand 1991–2004


Survival disparities in Indigenous and non-Indigenous New Zealanders with colon cancer: the role of patient comorbidity, treatment and health service factors

Indigenous inequalities in the presentation and management of stomach cancer in New Zealand: a country with universal health care coverage

Indigenous inequalities in cancer: what role for health care?
No Refuge for the Ailing? – NZ Grey Lit

Refugee faces death after cancer undetected

Health
– Tumours as small as one millimeter
– Imaging scans
– Healthy lifestyle support
– Innovative today
– Cost effective to treat

Preventive and fighting cancers
– Nutritional changes for healthy lifestyles
– Early cancer detection

Health needs assessment of Asian people living in the Auckland region

Asian Health Chart Book
2006

Public Health Intelligence Monitoring Report No. 4

Refugee Health Care:
A handbook for health professionals

Health needs assessment of Middle Eastern, Latin American and African people living in the Auckland region
Differences between Migrants and Refugees

<table>
<thead>
<tr>
<th>Migrants</th>
<th>Refugees</th>
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<tbody>
<tr>
<td>Choose to leave their homeland and settle in a new country</td>
<td>Do not choose to leave; flee in response to crisis and have little choice about where to go and by what means they travel.</td>
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<tr>
<td>- Arrange the most suitable methods of travel and pack the possessions they wish to take</td>
<td>- Almost everything is left behind.</td>
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<td>Have time to prepare emotionally for their departure and farewell friends and family</td>
<td>Unprepared emotionally for leaving and may not have time to farewell loved ones</td>
</tr>
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<td>Take with them their travel documents, passports and other documentation</td>
<td>Flee without any documentation</td>
</tr>
<tr>
<td>Usually emigrate with families</td>
<td>Often leave family members behind</td>
</tr>
<tr>
<td>Depart for their new country knowing that they can return to their homeland for visits or permanently</td>
<td>Unlikely to happen</td>
</tr>
<tr>
<td>Usually well-prepared and well-motivated to settle in a new country</td>
<td>Arrive in new country ill-prepared and often traumatised; have little possessions and financial resources</td>
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</tbody>
</table>

What are the potential RISK FACTORS for poor minority cancer outcomes?
Underlying Mechanisms

Mediator?
- Health Literacy
- Language
- Knowledge about the health system
- Communication
- Culture

Moderator?
- Health Literacy
- Language
- Knowledge about the health system
- Communication
- Culture

Immigration Status → Poor Cancer Outcomes

Immigration Status → Poor Cancer Outcomes
Health Literacy and Health Navigation

How Complex are the Cancer Pathways?

Prevention
- Public Health
- Cancer Awareness Campaign/Program
  - Lifestyle risks
  - Screening

Initial Investigations
- Positive Screening Tests
- Symptoms
  - Emergency Admission: Acute Symptoms
- GP + tests

Specialist Investigations
- Diagnostic Tests
  - Specialised blood test
  - Faecal occult blood
  - Ultrasound
  - Biopsy
  - CT scan
  - MRI
  - Endoscopy
  - Explorative surgery etc.
- GP

Dx confirmed
- MDT review
- Family meeting
- Genetic counselling

Tx Plan
- Chemotherapy
- Radiotherapy
- Surgery
- Adjuvant therapies
- Palliative/ Symptom Management

F/up; 2nd/3rd line treatment
- GP
- Chemotherapy
- Radiotherapy
- Adjuvant therapies
- Palliative

Cancer Society Support Groups

Alternative/Complementary Therapies

Interpreting services

Counselling/ Psychosocial support
Not everyone follows the action
Stakeholder “Sandpit” Consultation

1. What are the unmet needs of refugees and migrants with cancer in NZ?

2. “Wish List” – How would best practice look like?

3. What is in place to improve practice for refugees and migrants with cancer in NZ?

4. What are the gaps? How do we measure outcomes?

1. Where do we go from here?
Diversity: Stakeholders

- GP
- Clinical Manager/Manager
- Psychologist/Mental Health Clinician
- Palliative Care
- Nurse
- Palliative Care
- Public Health Researcher
- Interpreting Service
- Academic/Researcher
- Refugee Services
- Health Literacy Service
- Coordinator
- Family Support Coordinator
• To find out what health literacy and health navigation issues are encountered by English-speaking NZers
• Recruited cancer outpatients from MidCentral, Otago-Southland and Capital Coast DHBs
• Used selected, validated online HL survey tools
• Took wi-fi enabled i-pad into their homes, or sent the web link to participants.
Results- participants

- 18 potential participants referred, 3 declined.
- 11 of the 15 completed the survey,
- Age range 29-73, 27% male
- All but one NZ-born, one Australian-born
- Breast cancer (5), lung cancer (3), colon, ovarian, brain cancer (1 each)
Results re treatment comprehension

• All knew the treatments received
• All stated treatment aim eg palliation, cancer burden reduction, but 45% were expecting a cure: realistic?
• Health Literacy Questionnaire results showed 70-80% understanding of most items
Results: care coordination

• Cancer patient participants rated the coordination of their care as very good (mean=8.64, range 7 to 10/10).
• Significant correlation between health literacy and cancer care coordination: higher health literacy levels related to better care coordination (r=.66, p=.03).
• Three health literacy factors significantly correlated with patient experience of cancer care coordination: Having sufficient information to manage my health, r=.75, p=.008; Ability to engage with healthcare providers, r=.83, p=.002; Navigating the health system, r=.75, p=.008.
Results: anxiety and depression

• Using HADS score cut-off*, for cancer patients in acute care,
• All our patients meet the clinical cut-off for anxiety and depression,
• Psychosocial screening in cancer patients is key to offer timely support.

Results - what they said

‘the lack of communication from (the specialist DHB) until the last minute’
regional patient transferred to specialist centre at another DHB for treatment

• ‘departments become desensitised to the fact that patients have families and workplaces who are also impacted’
more participant words of wisdom

• ‘though we are encouraged to take a support person to help us pick up the information... they can end up feeling most uncomfortable’

• Patient struggled with the interpretation of some questions... wanted to explain her experiences at each step.. then asked researcher which answer to give.
but not all bad..

• ‘..once in the system, everything worked well.

• ‘All HPs very positive and helpful and inspired confidence’.

• Health Professionals’ instructions ‘generally easy to understand’ but she does sometimes forget and have to phone someone to check.
Current HL Initiatives

- CALD Resources
  - Waitemata DHB
  - Professor Butow & PoCoG
  - Professor Merryn Gott (Culturally Appropriate Palliative & End-of-Life Care)
  - Dr. Ben Gray (How to Use Interpreters in GP Practice)
  - Refugee Telehealth Clinic (Melbourne)
  - Advocate Services: Changemakers Refugee Forum
  - Interpreting Services

- University of Otago – Sydney collaboration
Current HL Initiatives – Cont.

- Health Literacy and Health Navigation

  ✔ Health Navigator NZ
  ✔ Workbase NZ
  ✔ Dr. Jacquie Kidd (Palliative Care)
  ✔ U.S. CDC: Health Literacy for Public Health Professionals
  ✔ Ten Attributes of Health Literacy Health Care Organisations
  ✔ Health Literacy Universal Precautions Toolkit
So... where to next?

• Clearly even English-speaking NZers have HL & HN problems
• Research work with University of Sydney collaboration progresses, BUT
• We need to focus on improvements for everyone, not just for refugees and migrants.
Acnowledgements

- University of Otago Human Health Ethics committee and the three DHB ethics committees
- All the specialists who approached their patients
- All the patients who showed interest
- All those who completed the e-survey
- All the ‘sandpit’ participants
- And YOU for being an appreciative audience
Me mahi tahi tatou mo te oranga o te katoa
We must work together for the wellbeing of all
Any Questions?