The Cancer Data and Aboriginal Disparities (CanDAD) Project:

Analysing Aboriginal illness narratives in a complex socio-cultural environment and health system using a realist analytic framework

NHMRC Partnership Project: Aboriginal Health Council of SA; SA Health; Cancer Council SA; SA Cancer Services; SA-NT DataLink; Wardliparingga Aboriginal Research Unit, SAHMRI

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² School of Population Health, University of South Australia
³ University of Manchester Business School and University of Adelaide
⁴ Aboriginal Health Council of South Australia
South Australia
Figure 3.1: Age distribution of deaths, by age, sex and Indigenous status, NSW, Qld, WA, SA and NT combined, 2008–2012

Source: AIHW, 2014.
A widening gap in cancer mortality

Figure 5.7: Age-standardised mortality rates for cancer, by sex and Indigenous status, NSW, Qld, WA, SA and NT combined, 2001 to 2012 (deaths per 100,000 population)

Source: AIHW, 2014
Barriers to Care

- Transport
- Accommodation
- Hospital Environment
- Lack of Aboriginal support and liaison
- Transfer of care


CanDAD Objectives

STAGE 1
TO CONSTRUCT FROM NARRATIVES AN ABORIGINAL PATHWAY OF THE EXPERIENCE OF CANCER AND CANCER SERVICES

STAGE 2
Concept Mapping to identify targets for intervention / systems change

STAGE 3
Short-form patient recorded outcome measure for CQI and data linkage

Methodological Challenges

Bringing Aboriginal world-views to the centre

Accounting for diversity

Respecting diverse ways of story-telling

There is no established Aboriginal patient-centred pathway

1. Dudgeon et al., 2014
2. Horten, 1994
3. Moore et al., 2010
The PEN-3 Theoretical Framework
Collins Airhihenbuwa 1989

CULTURAL IDENTITY
Person
Extended Family
Neighbourhood

RELATIONSHIPS & EXPECTATIONS
Perceptions
Enablers
Nurturers

CULTURAL EMPOWERMENT
Positive
Existential
Negative

Intervention guided by PEN-3 matrix
Categorisation of CMOs from Patient/Provider Narratives

Level 1 CMO Interpretation

Conjectured Pathway 1

Level 2 Conjectured CMO Configurations [CCMOC]

Patient-Experience-Narrative Provider-Experience-Narrative
Conjectured Pathway 2

Positive

Existential

Negative

Perception Enablers Nurturers

PEN-3 from Narratives

Level 2 Conjectured CMO Configurations [CCMOC]

Level 1 CMO Interpretation

Patient-Experience-Narrative

Conjectured Pathway 1

PEN-3 from Literature
Method

Participants: Men and women with cancer recruited via the Aboriginal Cancer Care Coordinators at Royal Adelaide Hospital
- N ≈ 50, urban, rural and remote, all cancer types

Choice of interviewer
- Male, female, Aboriginal, non-Aboriginal, range of ages, professional backgrounds

Recorded and transcribed, sent back to participant and checked by an Aboriginal team member

Approved by Aboriginal Health Research Ethics committee and relevant university HRECs
The analysis adopts a realist perspective to identify:

(C) The context of episode in *individual participant’s* stories;

(M) The hidden cognitive or behavioural mechanisms employed by individual participants

(O) The outcome of each episode
I really was shame [about the procedure]… the information’s out there…and I thought well, it’s either get it, before it gets me. So I said no, I’m going in for it. And when I actually got into the hospital for my appointment, for the procedure, I got pretty settled, because there was other people there for the same stuff, so I thought, I’m not the only one in the world, there’s other people that’s got this. That was comforting to know that you’re not the only one with an issue, so that was good, that settled me, a bit. [74-82]

<table>
<thead>
<tr>
<th>C</th>
<th>M</th>
<th>O</th>
<th>Implication for healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>11</strong></td>
<td>Hospital appointment-potential ‘shame,’ other people there for same procedure</td>
<td>Felt ‘settled’. Comforted by knowing not the only one. Normalising of treatment within hospital setting-</td>
<td>carried through with procedure with reduced discomfort</td>
</tr>
</tbody>
</table>

[74-82]
Funny thing, **my brother**…he’s very worried about his health all the time and he lives in Darwin, and **he tells me he bought a mob of medical books**…one of the books was on cancer and polyps and piles and haemorrhoid’s and all that, and I got reading, and came up with that scenario that polyps, they can bleed and you want to get it seen to… and that’s the line of action I took from reading that book. After that, I went into the Alice, and one of the doctor’s there, reckons it could be, just a tear or might be a haemorrhoid, and I thought, **oh well, it will be too late ‘cause I’ve already committed myself to following it right through. So, that’s how I came to really know it, by reading.** [85-99]

<table>
<thead>
<tr>
<th>C</th>
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<th>O</th>
<th>Implication for healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for info on symptoms within cultural setting. This patient literate.</td>
<td>Cultural imperative to seek information from kin.</td>
<td>Followed through with procedure based on information gained.</td>
<td>Understanding how traditional cultural communication operates</td>
</tr>
</tbody>
</table>
### Level 2 Categorisation

<table>
<thead>
<tr>
<th>TAM No.: Level 1</th>
<th>Context Category: Level 2</th>
<th>Mechanism Category: Level 2</th>
<th>Outcome Category: Level 2</th>
<th>Health System Implications</th>
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</thead>
<tbody>
<tr>
<td>12</td>
<td>Treatment info</td>
<td>Self-determined-Info seeking</td>
<td>Referral-Clinical</td>
<td>Communication-Diagnosis information</td>
</tr>
<tr>
<td>51</td>
<td>Treatment-record</td>
<td>Coping-Info seeking</td>
<td>Referral-Cultural</td>
<td>Communication-Health system</td>
</tr>
<tr>
<td>14</td>
<td>Symptom recognition</td>
<td>Acceptance</td>
<td>Independence-Physical</td>
<td>Communication-Side effects</td>
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<tr>
<td>4</td>
<td>Service provider-CCC</td>
<td>SP-noted</td>
<td>Referral-Cultural</td>
<td>Support-Aboriginal/Mainstream Services</td>
</tr>
<tr>
<td>44</td>
<td>Support-Finance</td>
<td>Self-determined-Agency</td>
<td>Independence-Financial</td>
<td>Support-Aboriginal/Mainstream Services</td>
</tr>
<tr>
<td>50</td>
<td>Service provider-ALO</td>
<td>Coping-Cultural focus</td>
<td>Need for resources</td>
<td>Support-Aboriginal/Mainstream Services</td>
</tr>
<tr>
<td>52</td>
<td>Service provider-ALO</td>
<td>Coping-Cultural focus</td>
<td>Need for resources</td>
<td>Support-Aboriginal/Mainstream Services</td>
</tr>
<tr>
<td>30</td>
<td>Support-Family</td>
<td>Self-determined-Managing expectations</td>
<td>Referral-Clinical</td>
<td>Support-Clinical staff</td>
</tr>
<tr>
<td>31</td>
<td>Support-Hospital</td>
<td>Self-determined-Managing expectations</td>
<td>Referral-Clinical</td>
<td>Support-Clinical staff</td>
</tr>
<tr>
<td>20</td>
<td>Male Connectedness</td>
<td>Coping-Cultural focus</td>
<td>Support group-Agency</td>
<td>Support-Cultural advocacy</td>
</tr>
<tr>
<td>23</td>
<td>Male Connectedness</td>
<td>Coping-Cultural focus</td>
<td>Referral-Cultural</td>
<td>Support-Cultural advocacy</td>
</tr>
<tr>
<td>24</td>
<td>Support-Group</td>
<td>Coping-Cultural focus</td>
<td>Referral-Cultural</td>
<td>Support-Cultural advocacy</td>
</tr>
<tr>
<td>43</td>
<td>Support-Work</td>
<td>Coping-Cultural focus</td>
<td>Referral-Cultural</td>
<td>Support-Cultural advocacy</td>
</tr>
<tr>
<td>5</td>
<td>Service provider-Personal</td>
<td>SP-Personal role change</td>
<td>Support group-Agency</td>
<td>Support-Groups</td>
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<tr>
<td>14a</td>
<td>Support-Group</td>
<td>Self-determined-Agency</td>
<td>Support group-Psychological</td>
<td>Support-Groups</td>
</tr>
</tbody>
</table>

**Legend**
- **Triad**
- **CM Dyad**
- **MO Dyad**
- **CO Dyad**
Support groups for men’s health: [5, 14a, 20, 23, 24, 43]

Psychological needs: [33, 35]
<table>
<thead>
<tr>
<th>Domains:</th>
<th>Positive</th>
<th>Existential</th>
<th>Negative</th>
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</thead>
<tbody>
<tr>
<td><strong>Perceptions</strong></td>
<td>Importance of community and Family</td>
<td>Men’s Business</td>
<td>Institutional racism</td>
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<tr>
<td></td>
<td></td>
<td>Women’s Business</td>
<td>“Cancer is Death Sentence”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ngangkari</td>
<td>Colonisation</td>
</tr>
<tr>
<td><strong>Enablers</strong></td>
<td>Aboriginal Cancer Care Co-ordinators</td>
<td>Ngangkari</td>
<td>Remote access</td>
</tr>
<tr>
<td></td>
<td>Aboriginal Liaison Officers</td>
<td>Aboriginal Support Groups</td>
<td>Access to specialists</td>
</tr>
<tr>
<td><strong>Nurturers</strong></td>
<td>Community Family Men’s Support Groups</td>
<td>Balancing traditional and Western frameworks</td>
<td>Stigma</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Men’s Groups (Reticence)</td>
</tr>
</tbody>
</table>
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STAGE 2
Concept Mapping to identify targets for intervention / systems change

STAGE 3
Short-form patient recorded outcome measure for CQI and data linkage

Thank you

WARDLIPARINGGA