

Theoretical Reflections: Can realist evaluation and the PEN-3 model elucidate Aboriginal Australians' cancer narratives?



WARDLIPARINGGA
Aboriginal Research



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Realist Approaches: a Synopsis (Pawson et al, 2005)



...a research synthesis for complex social interventions or programs
what works for whom, in what circumstances, in what respects and how.

Step one:

Make explicit the program theory, the underlying assumptions about:

- **how an intervention is meant to work**
- **what impacts it is expected to have.**

Step two:

- **Look for empirical evidence to populate this program theory**

Which supports, contradicts or suggests modifying the program theory

The review combines theoretical understanding and empirical evidence with a focus on explaining the relationship between

- **the context [C] in which the intervention is applied,**
- **the mechanisms [M] by which it works and**
- **the outcomes [O] which are produced.**

The Aboriginal Cancer Pathway



Programme theory (or theories) -- underlying assumptions:

Cancer Council Australia: Optimal cancer care pathways are designed to promote a full understanding of the patient journey in order to foster quality cancer care from the point of diagnosis.

Does a focus on explaining the relationship between

- the context [C] in which 'optimal care pathways' are applied,
- the mechanisms [M] by which they work (or not) for Aboriginal people
- the outcomes [O] of quality cancer care which are (or not) produced.

...help us understand Aboriginal peoples' patient journey within the health system from the point of diagnosis?

<http://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways.html>

Senior Cultural Advisor on: Thinking about the notion of 'Mechanism'



'Mechanism':

In what ways would Aboriginal people in South Australia yarn about their behaviour or thoughts in relation to their experiences of cancer and cancer services?

- Influenced by 'cancer as a death sentence'...
- The 'shame' of cancer
- We don't talk about cancer...
- Cancer is family business...
- My cultural needs are not understood...
- I feel alienated from 'White' mainstream healthcare
- Language impinges on communication, e.g. medical terms
- Reflective listening helps communication
- Mainstream needs to acknowledge traditional medicine use
- Strong motivation to 'survive'...a will to get through it...

The PEN-3 Principles*



- Culture plays a vital role in determining the level of health of the individual, the family and the community
- The three domains of the PEN-3 Model incorporate specific constructs:
 - relationships and expectations
 - cultural empowerment
 - cultural identity

Using the three domains, personal actions are examined as functions of broader social, cultural contexts.

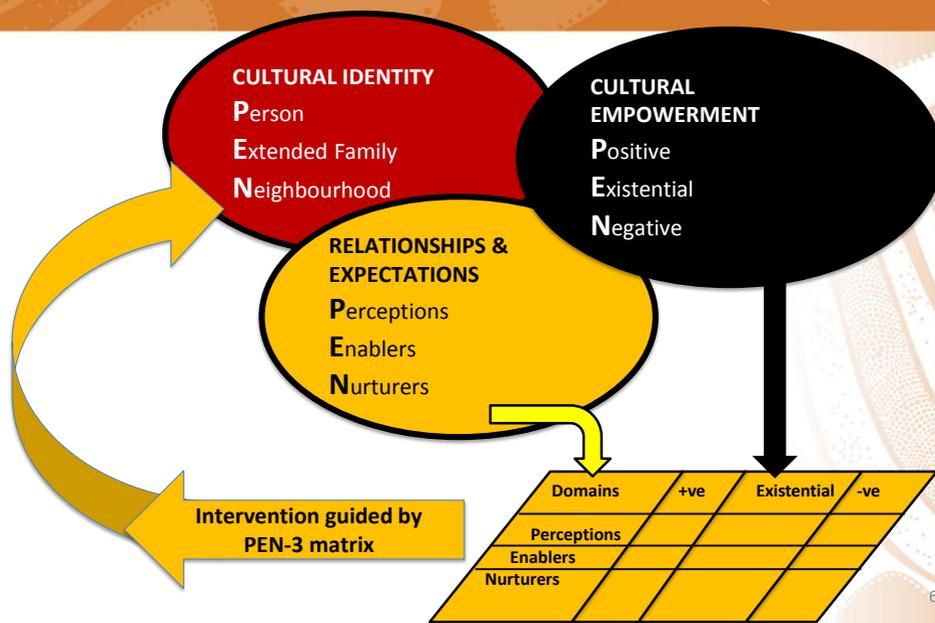
PEN-3 is about *changing interventions, not cultures* (Erwin et al 2010**)

*AIRHIHENUWA, C. O. & WEBSTER, J. D. 2004. Culture and African contexts of HIV/AIDS prevention, care and support. *SAHARA J*, 1, 4-13

**ERWIN, D. O., TREVINO, M., SAAD-HARFOUCHE, F. G., RODRIGUEZ, E. M., GAGE, E. & JANDORF, L. 2010. Contextualizing diversity and culture within cancer control interventions for Latinas: changing interventions, not cultures. *Soc Sci Med*, 71, 693-701.

The PEN-3 Theoretical Framework

Collins Airhihenbuwa 1989



Domains:	Positive	Existential	Negative
Perceptions	Importance of community and Family	Men's Business	Stigma of Cancer
Enablers	Aboriginal Cancer Care Co-ordinators Aboriginal Liaison Officers Patient-centred care		Access to specialists
Nurturers	Community Family Men's Support Groups	Aboriginal Support Groups	Stigma of cancer Men's Groups (Reticence)

Senior Cultural Advisor on: Conditions for using PEN-3



- Recognition/acknowledgement of language used by Aboriginal participant on a day-to-day basis
- Structure and language content of interviewer questions
- Establishment of cultural, family and Community values and context
- Recognition of the diversity of such values and contexts
- Interpretation and expectations are framed by such values and contexts
- Response of participant determined by their 'cultural lens'
- Gender issues are key cultural parameters:
Women's business and Men's business
- Status of participant in family group acknowledged as influencing responses, e.g. marital status
- Knowledge and understanding of these cultural parameters can determine responses received – Cultural Safety

Concluding thoughts:



Realist Approaches and/or **PEN-3** as explanatory frameworks used independently or in conjunction:

- Little written about use in Australian Aboriginal Community-based participatory action research
- Worth consideration with cultural caveats in place
- Diversity of cultural contexts points to using frameworks which recognise that healthcare policies or programs are founded on:
 - *what works for whom, in what circumstances, in what respects and how*
 - *...changing interventions, not cultures*

Why not give them a try...Thank You