



Exclusion of migrants in research and the rhetoric of social cohesion: Lessons learnt from the African Migrant Capacity Building and Performance Appraisal Initiative and the need for a cultural competence framework

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What is social cohesion

- Concept plagued with <u>contradictory, vague and difficult to</u> <u>operationalize definitions</u> (and limitations of current measurements) (See Chuang et al 2013).
- Defined as the ongoing process of developing a <u>community</u> of shared values, shared challenges and equal opportunity based on a sense of hope, trust, and reciprocity (Jeannotte, 1997)
- *The willingness of members of a society to <u>cooperate with</u> <u>each other in order to survive and prosper</u>." (Scalon Foundation, 2015)*





The 'etic' meaning: divergent meanings

Social cohesion as a process rather than an end in itself (Jenson 1998; Woolley,1998 & Forrest and Kearns 2001)

- *Social involvement*: Recognition / rejection and Belonging / isolation
- *Political involvement*: legitimacy / illegitimacy and participation / non-involvement
- *Economic involvement*: Inclusion / exclusion
- *Frequency of social interaction* & shared or common values and objectives
- *Social order, social solidarity*, social networks, sense of attachment to place and identity.





Social cohesion in Research

"the opportunity arises for communities and science to work in tandem to ensure a more balanced set of political, social, economic, and cultural priorities, which satisfy the demands of both scientific research and communities at higher risk"

(Hatch et al., 1993, p. 31).





- The "Other" category: studies have too few participants for analysis by cultural groups.
- Researchers' own attitudes: from empathy to antipathy to misgivings: Most RCTs have as inclusion criteria ability to speak and understand English. Other languages means interpreting and translation during recruitment or data collection and issues of informed consent
 - Respect and autonomy as primordial ethical factors in research: need for great sensitivity to create a sense of fairness and justice as the core value that underpins equity.





- Running and recruiting into clinical trials a costly business: the logistical challenges posed by language, cultural differences, subgroup analysis-large sample sizes, large sample sizes =more resources
 - Doing no harm as the most important pillar in research: Does the exclusion or under-representation of migrants in research increases health disparities?





- Stereotypes and prejudices: e.g. difficulties in engaging migrants populations, migrant mobility, and issues of drop out rate, understanding of research
 - Ethical issues: excluding and bypassing migrant groups
- Lack of support for research topics/methods relevant to research with migrant populations
- Institutional bias in NHMRC and ARC policies
 - Migrants have a unique set of problems that require targeted interventions and are under-represented in funding priorities





Myths vs reality

Migrants are as willing as non-migrants to participate in research, and in some instances more willing to participate if eligible and invited to participate, but less likely to be invited to participate

(Wendler et al 2006)





NHMRC & ARC Funding:2002-2011

	Initiatives	Total no. of initiative	A\$ million
Renzaho et al, 2015	NHMRC		
	All schemes	12,399	5,654.4
	Biomedical focused	11,952 (96.4%)	5,447.2
	People focused	447 (3.6%)	207.2
	Migrant related	28 (6.2%)	4.9
	Mainstream related	419 (93.8%)	202.3
	ARC		
	All schemes	15,354	5,536
	Biomedical focused	14,457 (94.2%)	5,281.6
	People focused	897 (5.8%)	254.4
	Migrant related	70 (7.8%)	21.1
	Mainstream related	827 (92.2%)	233.3





Exclusion and level of evidence: policy gaps

Level of Type of evidence evidence

- IA Evidence from systematic reviews or meta-analysis of randomized controlled trials
- IB Evidence from at least one randomized controlled trial
- IIA Evidence from at least one controlled study without randomization
- IIB Evidence from at least one other type of quasi experimental study
- III Evidence from non-experimental descriptive studies such as comparative studies, correlation studies and case-control studies
- IV Evidence from expert committee reports or opinions and/or clinical experience of respected authorities





Rethinking social cohesion: shared values & objectives

Migrants: Collectivism

- Collective =a group of individuals or a whole society
- Works for the group and not for own personal gain. Individual needs are subordinate to the collective
- Decisions are a group consensus
- Family relations are extremely important
- Conformity and compliance to social or group norms is emphasized
- Group regulates what the individual does and intend to do
- Hierarchy and respect for opinion formers

Mainstream: Individualism

- Self-reliance and work towards the fulfillment of individual needs and interests.
- Personal excellence and status is very important
- Individuals take responsibility for their own actions
- A moral, political, and social philosophy. Protection of individual rights by law
- Emphasis on self-determination, liberty, self-reliance, or personal independence
- Opposes societal authority over the will of the individual

(Triandis, 1995)





Etic meaning of social cohesion: Conclusion

Reducing the distance between members of the migrant and majority communities on certain subdimensions of social-cultural differences does not automatically lead to greater social cohesion.

Van Craen et al 2008





Emic meaning of social cohesion: methodological challenges

- Failure to bridge the cultural gaps that exist: one approach fits all model of research that fails to recognise cultural differences and their complexities
- The need to building on strengths and resources within the community: Lack of reciprocal transfer of knowledge, skills, capacity, and power: Social and political and dynamics within the community
- Issues related to distribution of power and control





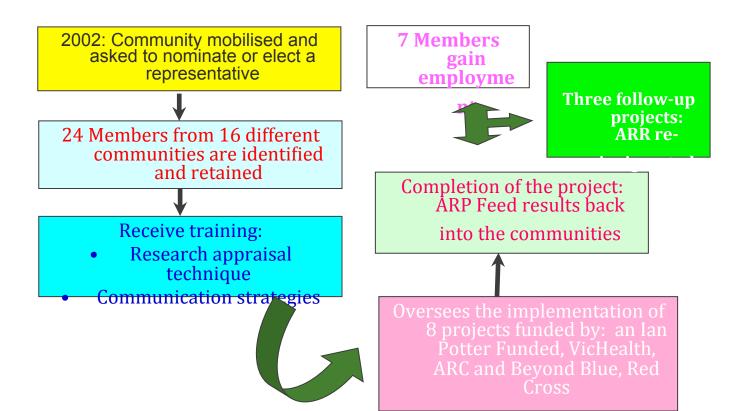
Emic meaning of social cohesion: methodological challenges

- Issues related to distribution of power and control
- How to integrate knowledge and action that benefits migrants communities especially address conflicting perspective, values and assumptions, and priorities
- Researchers' selfishness
- Hesitate to get involved due to lack of trust and respect
- Financial compensation and other incentives





Culturally competent community engagement: the ARP model

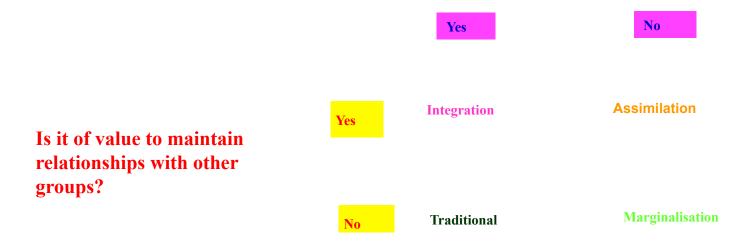






The bi-dimensional acculturation model

Is it of value to maintain cultural identity and characteristics?

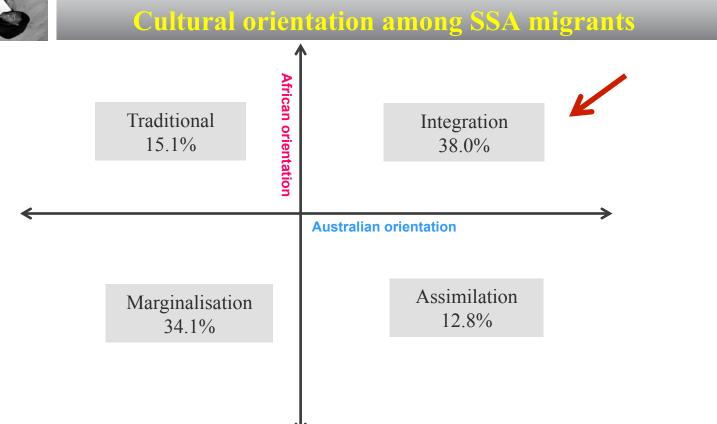


Berry 1980



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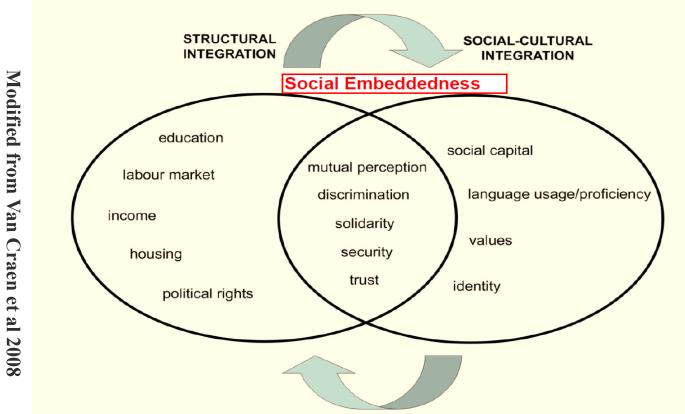




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Integration the way forward







Conclusion

- Understanding and conceptualising how different cultural process interact with the social environment and how this subsequently influences interactions, acceptance, and behaviours would assist in the development of culturally appropriate community based interventions
- Such programs need to focus on bridging the individualism-collectivism and intergeneration acculturation gaps while increasing community resilience to adopt a healthy and successful lifestyle
- Successful engagement of migrants communities can be achieved through using a community based framework that is compatible with socio-cultural values, past experiences and needs.
- Institutionalize the ARP: Guidelines for Ethical Conduct in African migrants Research (Values and Ethics)
- Moving from needs-based research to community-based interventions





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- Australian Commission on Safety and Quality in Health Care