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Participatory action research in indigenous health

Background
Participatory action research engenders change not just through research outcomes but through the research process itself. Collaboration between researchers and those being researched is intrinsic to the model.

Objective
This article discusses the 'Sadness and Heart Disease' research project undertaken by an Aboriginal community controlled health service in Darwin (Northern Territory) in 2005 and 2006 using a participatory action framework.

Discussion
A systematic approach, flexibility and a willingness to engage are necessary for researchers to successfully undertake a project using the participatory action framework. The benefits of participatory action research extend to both the community and the researchers.

Research is a dirty word for many Indigenous Australians, particularly when research is disengaged from the needs of the community and makes only a small contribution. Part of the indigenous community, however, sees research as an important tool for equalising some of the disparity between indigenous and nonindigenous health. This positive perspective is reflected in the work of organisations such as the Cooperative Research Centre for Aboriginal Health, and in burgeoning indigenous research networks.

The disadvantages faced by Indigenous Australians demand a collaborative effort to achieve understanding and change. Participatory action research provides a framework for such collaboration by 'removing barriers and promoting environments within which communities can increase their capacity to identify and solve their own problems'.[1]

Beginning as a movement for social justice,[2] participatory research encompasses a collection of research methodologies. It focuses on the benefits to the community not just of research outcomes but of the research process itself.

Intrinsic to participatory action research is a respect for community knowledge; indeed the two way transfer of knowledge between the research team and the community is imperative. Rather than researchers putting forward an unwavering plan, the research process is instead structured as a reflective cycle interspersed with action.[3]

The project

The 'Sadness and Heart Disease' project was conducted by Danila Dilba Health Service in 2005 and 2006, and examined the suitability of a depression screening tool for use with Aboriginal and Torres Strait Islanders with ischaemic heart disease (IHD). The project was was initiate by the recognition that depression is a significant risk factor for IHD, the well documented prevalence of IHD among the indigenous population, and suggestions of high depression rates in a similar population.[4–6]

Phase one of the project involved focus group discussions among Danila Dilba staff and patients to assess the acceptability of the nine item depression scale of the Patient Health Questionnaire (PHQ-9). The scale was then modified to improve the acceptability of administering a psychological assessment tool in this population.[3]

Phase two compared the answers to the modified PHQ-9 with the gold standard of a psychiatric interview in a subset of IHD patients.

The research findings, which have been discussed elsewhere,[7] are beyond the scope of this article. Rather, the project serves as a case study to demonstrate practical ways of employing the participatory method.

Four aspects of the model incorporated within this project were participation, the two way transfer of knowledge, capacity building and ownership.

Participation

Service managers were involved in the design of the project from the outset, and the steering committee included staff and patients. The project also had the support of Danila Dilba's Cooperative Research Centre for Aboriginal Health (CRCAH) research fellow, placing it in a wider context of indigenous participatory research. Most importantly, the participation of staff and patient focus groups led to modifications to the depression screening tool. Finally, a group of patients with IHD engaged in psychiatric interviews to validate the tool.

A two way transfer of knowledge

The community communicated its specific needs concerning the screening tool via the steering committee. Focus group members and psychiatric interview participants also communicated information through their participation, which was important for tool modification and validation. In addition, staff and patients shared their personal experiences of both depression and IHD informally – a process that was facilitated by an open relationship between researchers and the Danila Dilba community.

Researchers were able to contribute to an improved awareness of depression as a risk factor for IHD and to provide information regarding the use of psychological assessment tools, information on research methodologies and finally – via feedback to management and participants – the research findings themselves.

Capacity building

Danila Dilba was named as the principal institution on a National Health and Medical Research Council Capacity Building in Primary Health Care grant. This improves capacity for future research projects.

An Aboriginal health worker employed as a research assistant on the project developed research skills, participated in indigenous research networks and presented at indigenous research workshops. The project also raised the research profile of Danila Dilba and improved its clinical capacity in terms of recognition and treatment of IHD patients with depression.

Table 1. Useful strategies for facilitating a participatory action process

- Consultation with community leaders regarding their research needs
- Ownership of the project by the community
- Consultation with the community throughout the project design, data collection and data interpretation stages of the study (eg. through steering committees)
- Incorporation of qualitative methodology
- Inclusion of community members on the research team
- Providing feedback of final results to the community
- Enabling a reflective research cycle

Ownership

Danila Dilba retains intellectual property rights from the project. Input from other organisations notwithstanding, the 'Sadness and Heart Disease' is identified as a Danila Dilba project.

Discussion

Participatory action models provide an important framework for strengthening disadvantaged communities. *Table 1* describes useful strategies for facilitating a participatory action process.

A participatory action approach has benefited both researchers and the Danila Dilba community. The research is sustainable, and the process results in improved capacity for the transfer of research findings into policy and practice and the strengthening of concurrent organisational projects.

Some researchers are not comfortable having control transferred away from them, and there is potential for researchers to be come involved in organisational politics.[8] It is however, a method which enables socially minded researchers to offer a contribution independent of final project results.

Four rationales for participation in Aboriginal and Torres Strait Islander health research have been proposed.[9] The pragmatic rationale suggests that indigenous participation is practically important for ensuring project success. Although this was the experience of the research team, other rationales underpinned the project and ultimately ensured its success. These were:

- the moral rationale that indigenous communities actively control the research process in response to historical wrongs
- the interventionist rationale that research participation leads to empowerment and subsequent health improvement
- the epistemological rationale that indigenous people possess a greater understanding of indigenous health than outsiders.

Ultimately the epistemological rationale that indigenous people best understand the indigenous experience of depression drove the project.

Conclusion

A participatory action framework allows researchers to engage with

communities in the quest for change. Primary health care researchers are strongly urged to use a participatory action model in their work. Transfer of the locus of control to the community and respect for community knowledge is essential to the success of such projects.

Conflict of interest: none declared.

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