

Indigenous Health and the Reform context

The health of Aboriginal and Torres Strait Islander people continues to be poorer on many measures than the health of non-Indigenous Australians. Aboriginal and Torres Strait Islander health is the focus of the major initiative of the Council of Australian Governments (COAG) - Closing the Gap. This initiative puts in place a substantial funding package to address health, housing, employment and education for Indigenous Australians.^{1,2}

The health of Aboriginal and Torres Strait Islander people is affected by rising rates of chronic illness, with higher than community average rates of diabetes and cardiovascular disease. Their health is also affected by continuing high rates of risk behaviors such as smoking and excessive alcohol consumption.³

Most Aboriginal and Torres Strait Islander people live in urban areas, and while the needs of Indigenous Australians living in rural and remote communities have been reported in many studies, the experiences of Indigenous Australians living in urban areas are not so well recorded, nor addressed in health policy and practice. This is an emerging research area.^{4,5}

The Serious & Continuing Policy & Practice Study

The Serious and Continuing Illness Policy and Practice Study (SCIPPS) is a five-year National Health and Medical Research Council funded study which commenced in 2006 with the following aims:

- to improve the health outcomes of those suffering from chronic illness,
- to reduce unnecessary hospital admissions of this group, and
- to develop more effective preventive strategies.

Stage 1 of SCIPPS involved a qualitative study of patient (and carer) experience of living with and managing, and health professional experience of managing, chronic illness. Patients recruited to the study were aged 45 – 85 and had one or more of the following chronic conditions – chronic heart failure (CHF), diabetes, and chronic obstructive pulmonary disorder (COPD).

This research was supplemented by epidemiologic reviews of the index conditions within the Australian environment and literature reviews of the experience of people living with CHF, as well as a policy diffusion study.

Stage 2 of SCIPPS built on results of the qualitative study and included surveys of older adults living with chronic conditions, evaluations of models of chronic disease management, and a study focusing on Indigenous Australians living with chronic conditions. The findings of the study focusing on Indigenous Australians are discussed below.

SCIPPS Research and Findings

Nineteen Aboriginal and Torres Strait Islander people living in the two study areas agreed to be interviewed and to take part in the SCIPPS study. Data collection occurred during two three-month

periods between March 2007 and November 2009. They were recruited by purposive sampling through referrals from Aboriginal Medical Services (AMS) and general practices in Western Sydney in New South Wales and the Australian Capital Territory. Eligible participants included people with one or more of these three conditions aged between 30 and 85 years. The relatively low age cut-off was chosen to reflect the earlier onset of chronic illness and shorter life expectancy of Indigenous Australians.¹

Participants were people with Type 2 diabetes (n=17), chronic obstructive pulmonary disease (n=3) and/or chronic heart failure (n=11) and family carers (n=3). Participants were asked to describe their experience of having or caring for someone with chronic illness. Content and thematic analysis of in-depth semi-structured interviews was undertaken, assisted by QSR Nvivo8 software. The findings from this study are reported in a report and four articles, all of which are based on the full study sample (N=19).

The findings are discussed in the following papers drawn from the study:

- Jowsey T, Yen L, Aspin C, Ward N,J and the SCIPPS team People I can call on: Aboriginal and Torres Strait Islander experiences of chronic illness. Community report. Serious and Continuing Illness Policy and Practice Study, Menzies Centre for Health Policy 2011: Canberra http://www.menzieshealthpolicy.edu.au/research_scipps_publications.php.
- Ward N J, Jowsey T, Haora P, Aspin C, Yen L. With good intentions: complexity in unsolicited informal support for Aboriginal and Torres Strait Islander peoples. A qualitative study. *BMC Public Health* 2011; 11: 686 (doi:10.1186/1471-2458-11-686).
- Aspin C, Brown N, Jowsey T, Yen L, Leeder S. “They judge you on your looks, your dress, and then how black you are”: Confronting obstacles to health care for Aboriginal and Torres Strait Islander people with chronic illness. *(In submission)*
- Jowsey T, Yen L, Ward N J, McNab J, Aspin C, Usherwood T. *It hinges on the door*: use of time and space creates community interactions in Australian Aboriginal Community Controlled Health Services. *(In submission)*
- Jowsey T and Ward N J. Agents and identity: representations of chronic illness by urban Aboriginal and Torres Strait Islander people. *(In submission)*

Continuity of Identity as a Feature of Patient Centred Care

The physical design of health services and the temporal design of the patient pathway through them have been studied in efforts to enhance space-use, efficiency and patient experience.⁶⁻⁹ The paper by Jowsey et al, “*It hinges on the door: use of time and space* (listed above) addresses the question: How does the structuring of places and time influence Aboriginal and Torres Strait Islander patient experiences of health service spaces? The paper compares participant experiences of spaces (primarily waiting room spaces and consultation rooms) in Aboriginal Medical Services and mainstream health services.

1. **Value in spaces** - Participants report that each element of the time spent in Aboriginal Medical Services is seen as valuable and worthwhile, from social and health sharing experiences in the waiting room to high quality health care in clinical places; and that users feel they can rely on sufficient time and respectful care in their clinical consultation. In addition, this sense of being valued by both community and health professionals led to a sense of continued and sustained value and identity, where at each point in the individual's journey through the service, they were enabled to feel valued and respected. Their experiences of Aboriginal Medical Services differed from experiences in mainstream health services, where they did not feel valued in mainstream health spaces.

Confirmatory or Novel? Novel

Recommendation

Purposeful design of both physical and temporal aspects of health services to make each aspect of the experience meaningful and relevant to the whole person will be challenging, but will re-introduce opportunities for holistic health care that have been limited by the segmented 'person as illness' design features of our current mainstream system.

Family support

Understanding people's social lived experiences of chronic illness is fundamental to improving health service delivery and health outcomes, particularly in relation to self-management activity.^{10,11} In explorations of social lived experiences Ward et al in *With good intentions: complexity in unsolicited informal support for Aboriginal and Torres Strait Islander peoples* (listed above) uncovers the ways in which Aboriginal and Torres Strait Islander people with chronic illness experience informal unsolicited support from peers and family members. Participants reported receiving several forms of unsolicited support, including encouragement, practical suggestions for managing, nagging, growling, and surveillance. Additionally, participants had engaged in 'yarning', creating a yarn space, the function of which was distinguished as another important form of unsolicited support. The implications of recognising these various support forms are discussed in relation to responses to unsolicited support as well as the needs of family carers in providing effective informal support.

Recommendation

Certain locations of responsibility are anxiety producing. Family carers must be supported in appropriate education so that they can provide both solicited and unsolicited support in effective ways. Such educational support would have the added benefit of helping to reduce carer anxieties about caring roles and responsibilities. Carers will benefit from support programs that are tailored to them and do not include patients.

Recommendation

Mainstream health services would benefit from fostering environments that encourage informal interactions that facilitate learning and support in a relaxed atmosphere. That is, carers will benefit from inclusion and engagement in patient consultations with health care professionals.

Confirmatory or Novel? Confirmatory

Previous experiences of health services, by self, or by family and community members may increase access problems for Indigenous people

Aboriginal and Torres Strait Islander people with chronic illness confront multiple challenges which contribute not only to poor health outcomes but also to the current health disparities that exist in Australia.^{12,13} Participants reported a range of challenges that include poor access to culturally appropriate health services, dislocation from cultural support systems, exposure to racism, poor communication with health care professionals, as well as economic hardship.

At the same time, participants indicated that they had access to a repository of cultural and traditional knowledge, as well as insights from their own experiences which provided strategies for confronting the negative impacts of chronic illness.

The Aboriginal and Torres Strait Islander people we spoke to said that while they felt overwhelmed and confused by the burden of chronic illness, they drew strength from factors such as being part of an Aboriginal community, having regular and ongoing access to primary health care, and being well-connected to a supportive family network. As well, elders played an important role in increasing people's awareness of the impact of chronic illness on both individuals and communities.

Non-Indigenous health services are failing to meet the needs of Aboriginal and Torres Strait Islander people with chronic illness.

Recommendation

To address these complex needs, health services must recognise that patients have a wealth of cultural knowledge at their disposal. Strategies must be implemented to ensure that this knowledge is integrated into care and support programs for Aboriginal and Torres Strait Islander people with chronic illness.

Confirmatory or Novel? Confirmatory

References

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