Person-centred care as caring for country: an indigenous australian experience

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Abstract
There is an emerging interest and a developing evidence base about the significance of dementia within Aboriginal and Torres Strait Islander communities across Australia. Poor Indigenous health status remains a fundamental issue, particularly when compared to New Zealand and North America where in the past ten years health inequities have begun to be successfully redressed. As the life expectancy of Indigenous Australians has started to increase beyond 45 years, the issue of dementia is becoming a priority health issue to address. As there is currently, on average, a 17 year gap in life years between Indigenous and non-Indigenous people, there is a need to better understand both dementia and ageing within the Indigenous context in order to provide meaningful services and care. Within a historical context, colonization has had, and continues to have, a significant impact on the health of Indigenous people. In 1997, the Human Rights and Equal Opportunity Commission released its report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families, more commonly known as the Bringing Them Home report (Australian Human Rights Commission, 1997). The report examined evidence from members of the ‘stolen generations’, a term which refers to those Indigenous children forcibly removed from their families and communities as part of past government policies. The legacies of past policies continue to impact upon Indigenous Australians, many of whom continue to experience multiple disadvantages including diminished mental and physical health as they age.

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Person Centred Care as Caring for Country: An Indigenous Australian experience

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There is an emerging interest and evidence base about the importance of dementia within Aboriginal and Torres Strait Islander communities* with an initial focus on understanding prevalence in remote areas now moving to urban regions. As the life expectancy of Indigenous Australians has started to increase beyond 45 years the issue of dementia is becoming a priority health issue to explore. However, it needs to be remembered that on average there still exists a 17 year gap in life years between Indigenous and non-Indigenous people. Thus, there is a need to better understand dementia within the Indigenous context and also provide meaningful services and care. Within a historical context, colonisation has had, and continues to have, a significant impact on the health of Indigenous people. In 1997, the Human Rights and Equal Opportunity Commission released its report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families, otherwise more commonly known as The “Bringing Them Home” Report (1997). The Report (1997) examined evidence from members of the ‘stolen generations’, a term which refers to those Indigenous children forcibly removed from their families and communities as part of past government policies. The legacies of past policies continue to impact upon Indigenous Australians many of whom continue to experience disadvantage and diminished mental and physical health. It can be seen that poor Indigenous health status remains a fundamental issue, particularly, when compared to New Zealand and North America where in the past ten years health inequities have begun to be successfully re-dressed.

The writers of this editorial aim to raise awareness about some of the assumptions and, ultimately, the appropriateness of person centre care approaches (such as those advocated by Kitwood 1997, McCormack and McCance 2006; 2010 in press and Nolan et al. 2004) in the context of Indigenous peoples. We also suggest that advocates of person centred care can learn from Indigenous Knowledge to enhance their models. As editors, we believe that the concept of person-centredness is universal. However, person-centredness and personhood may have very different meanings in Indigenous cultures. Further, existing specific theories, models and frameworks may not be easily transferable to Indigenous cultures and communities. For example, Westernised approaches to person centred care tend to privilege the individuality of the person with dementia and family members. In sharp contrast, the notion of personhood in Australian Indigenous communities is not defined by individuality but by a deep connection to the notion of ‘Country’.

"Country is multi-dimensional and consists of people, animals, plants, Dreaming, under ground, earth, soils, minerals and waters, surface water, and air. Country has origins and a future: it exists both in and through time."

Rose (2004 p. 153)

This means that people belong to Country (rather people owning land: a Western notion). It also means that in order to maintain good health and well-being the connection to the Land must be strong and vibrant. There are important concepts which are relevant to consider when we try to understand the experience of dementia within Aboriginal and Torres Strait Islander communities more clearly. First, community for many Indigenous Australians is largely defined
as connection to ‘Country’, a shared history, mutual responsibility, the role of kin and family as the basis of social organisation as well as social and emotional well-being (Pearson 2000, cited in Eckermann et al. 2006, p. 56). This definition will probably resonate for all, regardless of culture, but is distinct in many Aboriginal and Torres Strait Islander communities especially in rural areas. In the city, Indigenous communities are increasingly likely to live in and between two worlds: the white person’s world with its built environment and ‘man’ made structures and the Indigenous notion of belonging to Country. This cultural duality and having to constantly navigate between two worlds is demanding for even the most cognitive able people. Another significant consequence of connection to Country and the sense of community can be illustrated by understanding the meaning of agency. Unlike modern westernised notions of agency lying within the individual, agency for Indigenous people is with the community. Individuals have choices, but without the community as the vehicle, choices cannot be realised. Time is also a concept relevant for understanding the experience of dementia and it is useful to explore the cultural role of time. For Indigenous peoples there is no discrepancy between the past and present. Thus it is common to find that linear time lines do not exist nor do they take priority. This specific concepts which are relevant for understanding dementia within Aboriginal and Torres Strait Islander communities is illustrated below (Figure 1).

Figure 1: Indigenous model of person-centred care

It is important that Westernised person centred care approaches do not repeat the fundamental errors of the Western biomedical approach to dementia care by: (i) assuming universality of models and frameworks; (ii) assuming theirs is the only or dominant discourse; (iii) valuing individuality over collectivism and (iv) imposing these frameworks on Indigenous communities. These reflections have highlighted to those of us who prescribe the person centred care model of dementia care that ‘we’ (Western people) must not assume that in other cultures our model is seen as non-traditional or exclusively non bio-medical. It is likely that, despite intentions to be inclusive and flexible, our approaches are not nearly sufficiently holistic for the successful application within Aboriginal and Torres Strait Islander communities. Person centred care frameworks need to be more transparent about who the models and frameworks are intended for or minimise assumptions about their universality if they are to be meaningful within care practices within Indigenous communities. Further, it demonstrates the need to question the appropriateness of the person centred care approaches and how
they are introduced. Person centred care approaches can benefit from understanding more about how Indigenous communities maintain their health and well-being. Wellness within Indigenous communities is focused on maintaining connectedness to space, place (that is, Country and community) and time. Ageing in place, familiarity and connectedness are all well known ideas in the gerontological literature but here is a culture that truly values and asserts these values through community Lore and explicit use of mutual responsibilities for social organisation. We need to engage more closely with Indigenous peoples and seek connectedness to be shown what Knowledge is held within the community about living with dementia and how to maintain and promote well-being through connectedness to Country, kinship and community.

NOTE: *Aboriginal and Torres Strait Islander people are referred to as Indigenous Australians and by mentioning this term the authors acknowledge the rich diversity of Aboriginal and Torres Strait Islander people.

References


