Social Science & Medicine 187 (2017) 164–173

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Review article

Social and emotional wellbeing assessment instruments for use with Indigenous Australians: A critical review

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ARTICLE INFO

Article history:
Received 12 September 2016
Received in revised form
21 June 2017
Accepted 30 June 2017
Available online 1 July 2017

Keywords:
Australia
Social and emotional wellbeing
Quality of life
Conceptualisation of health
Indigenous health
Health inequalities
Cross-cultural assessment
Critical review

ABSTRACT

Rationale: There is growing recognition that in addition to universally recognised domains and indicators of wellbeing (such as population health and life expectancy), additional frameworks are required to fully explain and measure Indigenous wellbeing. In particular, Indigenous Australian wellbeing is largely determined by colonisation, historical trauma, grief, loss, and ongoing social marginalisation. Dominant mainstream indicators of wellbeing based on the biomedical model may therefore be inadequate and not entirely relevant in the Indigenous context. It is possible that "standard" wellbeing instruments fail to adequately assess indicators of health and wellbeing within societies that have a more holistic view of health.

Objective: The aim of this critical review was to identify, document, and evaluate the use of social and emotional wellbeing measures within the Australian Indigenous community.

Method: The instruments were systematically described regarding their intrinsic properties (e.g., generic v. disease-specific, domains assessed, extent of cross-cultural adaptation and psychometric characteristics) and their purpose of utilisation in studies (e.g., study setting, intervention, clinical purpose or survey). We included 33 studies, in which 22 distinct instruments were used.

Results: Three major categories of social and emotional wellbeing instruments were identified: unmodified standard instruments (10), cross-culturally adapted standard instruments (6), and Indigenous developed measures (6). Recommendations are made for researchers and practitioners who assess social and emotional wellbeing in Indigenous Australians, which may also be applicable to other minority groups where a more holistic framework of wellbeing is applied.

Conclusion: It is advised that standard instruments only be used if they have been subject to a formal cross-cultural adaptation process, and Indigenous developed measures continue to be developed, refined, and validated within a diverse range of research and clinical settings.

1. Introduction

Indigenous populations throughout the world have far poorer health outcomes and a lower life expectancy than non-Indigenous inhabitants (Anderson et al., 2016). In Australia, for example, Indigenous people live approximately 10 years less than their non-Indigenous counterparts (AIHW, 2014). The difference in life expectancy has been attributed to a failure to address the treatment gap in chronic diseases such as diabetes, renal disorders, and cardiovascular diseases (Vos et al., 2009) along with their associated psychological conditions (Cunningham and Paradies, 2012).

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http://dx.doi.org/10.1016/j.socscimed.2017.06.046
0277-9536/

Despite the establishment of a National policy response, such as the 'Close the Gap' Campaign in 2006, inequalities in health and wellbeing persist and, in many instances, are widening (Department of the Prime Minister and Cabinet, 2017). The headline aim of the campaign was to achieve health equality, as measured by life expectancy, by 2030 (Close the Gap, 2008). Notably absent from the targets is any standard measure of wellbeing, despite the stated aim of assessing improvements in the wellbeing of Indigenous Australians (Biddle, 2011).

A pertinent question, therefore, is what indicators of wellbeing should be included in closing the gap targets such as these? The International Group of Indigenous Health Measurement emphasised that it is critically important to have a detailed understanding of how health and wellness are viewed from Indigenous perspectives (Coleman et al., 2016) before instruments are applied to assess health equity. Accordingly, much has been discussed within Indigenous circles (Kite and Davy, 2015; Yap and Yu, 2016) about the need to better articulate and measure meaningful and culturally aligned indicators of health and wellbeing. Thus, the aim of this paper was to critically review how the domains pertinent to Indigenous health and wellbeing are currently conceptualised and to identify the relevant indicators and their associated instruments specifically used to assess these domains with respect to Indigenous Australians. In this review, the term 'Indigenous Australians' is predominantly used to refer to Aboriginal and Torres Strait Islander people. Where used to refer to Indigenous people of other nations, this is specifically addressed.

The United Nations Human Development Index (UNHDI) identifies three domains that could be applied universally to most populations: health and population, material wellbeing, and education (UNDP, 2016). These are also prominent domains relevant to the specific 'Closing the Gap' targets (Altman et al., 2008; Department of the Prime Minister and Cabinet, 2017). In addition, the Arctic Social Indicators group identified a further three prominent domain areas in the Arctic region to add to the UNHDI domains: fate control, cultural wellbeing and vitality, and contact with nature, thus resulting in six relevant domains for describing features of wellbeing in the Arctic region. A further task is to identify relevant indicators for each domain, as "an indicator should be the most accurate statistic for measuring both the level and extent of change in the social outcome of interest", (p.35). For example, life expectancy is an indicator of 'health and population', and relevant to the domain of cultural wellbeing, three indicators were considered important in the Arctic region: language retention, cultural autonomy, and sense of belonging.

How can health and wellbeing best be understood in the context of Indigenous Australians? In recent decades, the concept of quality of life (QOL) has been used to assess and compare subjective feelings of health and wellbeing in the general population, but how suitable is this concept in assessment of indigenous wellbeing? Even when applied in the general population, there is considerable confusion and uncertainty concerning the definition, conceptualisation, and taxonomy of the QOL construct (Barcaccia et al., 2013; Karimi and Brazier, 2016). It has been argued that QOL frameworks that result in measurement of objective social, economic, and health indicators, including health-related quality of life (HRQoL), are too narrow in scope, and may merely be a proxy for what is subjectively judged to be important indicators of QOL from the perspective of decision makers and not the population in question themselves (Costanza et al., 2007). Alternatively, other QOL frameworks are subjective and focus on perceived need in relation to social, economic, and health indicators (Costanza et al., 2007). For example, definitions of HRQoL tend to focus on factors that are considered to be closely associated with an individual's particular health status, often as it relates to the experience of a health condition or ailment (Karimi and Brazier, 2016). Typical definitions emphasise the impact of disease on perceptions of wellbeing. For example, HRQoL has been defined as 'the value assigned to duration of life as modified by the impairment, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment, or policy' (Patrick and Erickson, 1993, p. 22), and "the extent to which one's usual or expected physical, emotional and social wellbeing are affected by a medical condition or its treatment" (Patrick and Erickson, 1993, p. 73).

Subjective theorists have recognised the need to acknowledge wider and more holistic influences on wellbeing. For example, Haas (1999) defines QOL as "a multidimensional evaluation of an individual's current life circumstances in the context of the culture in which they live and the values they hold. QOL is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions" (p. 219). Indeed, there is increasing recognition that Indigenous health may be best understood within the wider historical, political, social, psychological and physical worlds in which health, and conversely illness, has been, and is currently being, constructed and experienced (Dockery, 2010). What is the evidence supporting these more holistic conceptualisations of QOL or wellbeing within populations such as Indigenous Australians?

It is argued that the health and wellbeing of Indigenous people is more heavily influenced by a range of historical factors, including colonisation, assimilation, racism, poverty, environmental adversity, intergenerational trauma and social exclusion (Atkinson and Nelson, 2014). Globally, there is increasing recognition of the impact of intergenerational legacies of colonisation, disruption of kinship networks, and social marginalisation upon Indigenous health (Kirmayer et al., 2014; Paradies, 2016; Prussing, 2014). In Canada, for example, it has been argued that the establishment of the Canadian residential school system and the creation of geographical 'reserves' discouraged traditional ways of living and systematically weakened family and cultural ties (Morton Ninomiya and Pollock, 2017). There is also evidence of healthcare inequalities derived from ongoing systemic racism in the Canadian health system (Goodman et al., 2017).

In Australia, the ongoing effects of colonisation through the impact of family separation, loss of land, social inequity, racism, and the loss of culture and identity on current Indigenous health is well recognised (Krieg, 2009; Paradies, 2016). Grief and loss brought about by colonisation and ongoing marginalisation have been identified as the central determinants of Indigenous Australian wellbeing (Swan and Raphael, 1995). For Indigenous Australians, loss can take many forms, such as the loss of land, loss of spirituality, loss of culture, loss of language, loss of freedom and bereavement (Wynne-Jones et al., 2016).

Given this background, Indigenous Australians through the landmark National Aboriginal Health Strategy (NAHS) have defined health and wellbeing (hereafter referred to as the NAHS definition) as *'not just the physical wellbeing of an individual but … to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life'* (NACCHO, 1989) (p.1). This approach highlights the understanding that social, emotional, and cultural wellbeing of the whole of community must be pursued alongside that of the physical wellbeing of individuals within that community.

Within the NAHS definition emphasis is placed on the individual within society, compared to a more Westernised mainstream biomedical model where the focus is on the "sick individual" (Neumayer, 2013) and the larger social, historical, and environmental context of the group in which the individual belongs, is