

Using Indigenist and Indigenous methodologies to connect to deeper understandings of Aboriginal and Torres Strait Islander peoples' quality of life

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Abstract. The lack of a common description makes measuring the concept of quality of life (QoL) a challenge. Whether QoL incorporates broader social features or is attributed to health conditions, the diverse range of descriptions applied by various disciplines has resulted in a concept that is multidimensional and vague. The variety of theoretical conceptualisations of QoL confounds and confuses even the most astute. Measuring QoL in Aboriginal and Torres Strait Islander populations is even more challenging. Instruments commonly developed and used to measure QoL are often derived from research methodologies shaped by Western cultural perspectives. Often they are simply translated for use among culturally and linguistically diverse Aboriginal and Torres Strait Islander peoples. This has implications for Aboriginal and Torres Strait Islander populations whose perceptions of health are derived from within their specific cultures, value systems and ways of knowing and being. Interconnections and relationships between themselves, their communities, their environment and the natural and spiritual worlds are complex. The way in which their QoL is currently measured indicates that very little attention is given to the diversity of Aboriginal and Torres Strait Islander peoples' beliefs or the ways in which those beliefs shape or give structure and meaning to their health and their lives. The use of Indigenist or Indigenous methodologies in defining what Aboriginal and Torres Strait Islander peoples believe gives quality to their lives is imperative. These methodologies have the potential to increase the congruency between their perceptions of QoL and instruments to measure it.

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Introduction: quality of life, a contested concept

The goal for health promotion is not only to prolong life, but also to improve a person's quality of life (QoL).¹ However, defining QoL and how it is measured is contested. Although there is growing interest in the concept of QoL, researchers often fail to agree on what it means,² how it is measured and what factors influence QoL outcomes.³ From a socioeconomic point of view, QoL relates to the gap between what a person hopes to achieve and what happens in their reality.⁴ Conversely, health and biomedical perspectives range from QoL as a purely physical phenomenon⁵ to one that incorporates aspects of mental, social and even cultural well being.⁶

The concept of QoL is particularly contested when one cultural group seeks to study QoL in another. Cultural context plays a significant role in how the needs and aspirations of individuals are shaped.⁷ The World Health Organization supports this view, suggesting that the definition of QoL is influenced by an individual's culture and value systems.⁸ Even when high-level overarching

concepts such as happiness, good health and independence could be relevant across settings, rarely do two different cultural groups experience these concepts in the same way. Therefore, QoL concepts need to be explored and understood from within contexts that relate to individuals, are relational and incorporate community and culture.⁹

Definitions of QoL range from the very prescribed, including satisfaction with life,⁷ happiness, good health and independence,¹⁰ to the more subjective, with QoL based on what the individual believes to be important.¹¹ QoL in this individual agency sense is a broad multidimensional concept¹² that is consistent with the understanding that satisfaction and well being stem from the degree to which an individual perceives he or she can meet their needs and aspirations.¹³ Others question the ability to ever define QoL, believing that it covers such a wide variety of human experience that it is almost impossible to measure.⁵ Although a globally applicable prescribed definition for QoL may be useful for

making comparisons between and even within populations,¹⁴ it is argued that only the individual concerned can determine what QoL means for them and to what extent their definition has been met.¹¹

Measuring QoL in Aboriginal and Torres Strait Islander populations

Aboriginal and Torres Strait Islander researchers are well positioned to develop instruments for measuring QoL in Aboriginal and Torres Strait Islander populations. However, this is not without challenges. It is known that QoL is a dynamic concept that is responsive to stages of life, changing circumstances or changes over time. It is also understood to be influenced by cultural and environmental factors and shaped by different 'values, expectations and aspirations'.^{13(p337)} Defining QoL in Aboriginal and Torres Strait Islander populations has the potential to overcome some of the disparities in health outcomes and life expectancy currently experienced by Aboriginal and Torres Strait Islander populations. Privileging Aboriginal and Torres Strait Islander peoples' voices and gathering culturally specific expressions, understandings and knowledge of their circumstances, including trans-generational cultural, emotional and spiritual trauma, may assist in defining the factors that enhance or diminish their QoL.

Indigenist and Indigenous methodologies

Western research methodologies currently used to define QoL that are derived from within 'industrialised and post-industrialised city-state and nation-state cultures'^{15(p255)} are fundamentally different from those of Aboriginal and Torres Strait Islander peoples, whose ontologies and epistemologies are derived from hunter-gatherer ways of knowing and being.¹⁵

Indigenous scholars¹⁶⁻¹⁹ have long been concerned with the effect of Western research and the use of Western research methodologies on Indigenous populations across the globe, believing it to be 'unrelenting research of a profoundly exploitative nature'.^{18(p44)} Such sentiments have contributed to Aboriginal and Torres Strait Islander researchers developing and using methodologies to specifically address those concerns. This involves the use of Indigenist research and Indigenous methodologies.

Indigenist research is a process informed by three fundamental principles that are interrelated and are an integral part of the 'Indigenous liberation struggle';^{16(p116)} they include: (1) notions of resistance as part of Indigenous peoples' struggle for self-determination; (2) responsibility of Indigenous researchers to assist their communities to achieve self-determination; and (3) ensuring political integrity and privileging voices of Indigenous peoples by focusing on their 'lived, historical experiences, ideas, traditions, dreams, interests, aspirations and struggle'.^{16(p117)} Indigenist research uses existing research methodologies to achieve this. Indigenous methodologies are founded within an Indigenous paradigm. Indigenous researchers are both insiders and outsiders

in the research processes and seek to incorporate Indigenist research by drawing on their own Indigeneity and using methods that representative of their ways of knowing and being.^{17,18} This aligns well with the notion that research should be reflective of the 'socio-cultural and political context within which their research is framed'.¹⁷ Adding to this is the role of language and how it affects the research. Applying culturally appropriate language 'is a central component of Indigenous epistemologies and must be considered within Indigenous research frameworks'.^{20(p60)} Indigenous researchers are more likely to use culturally specific language to craft their research stories and gain additional benefit by disrupting the current 'methodological homogeneity in research'.²⁰ The benefit is in sharing the same world views as those of research participants.

Indigenist and Indigenous methodologies facilitate the articulation of the social and emotional perspective of Aboriginal and Torres Strait Islander peoples' lived experiences in accordance with their understandings. Aboriginal and Torres Strait Islander researchers are more likely to convey information in a manner that is both culturally acceptable and specific to those participating in the research and benefiting end users of the information.²⁰ The advantage of using Indigenist and Indigenous methodologies is that they are more likely to provide congruency between Aboriginal and Torres Strait Islander peoples' understandings of QoL and the development of instruments designed to measure it.

Research activities that are derived from and driven by Western research methodologies led by non-Indigenous researchers are less likely to achieve the same outcomes¹⁷ and have been criticised for having unintended consequences for Indigenous people, including unethical practices, the production of questionable data and subjugation of Indigenous knowledge through the silencing of Indigenous voices.²¹

Defining indicators of Aboriginal and Torres Strait Islander peoples' QoL

Using Indigenist and Indigenous methodologies in the development of QoL instruments to measure the indicators of Aboriginal and Torres Strait Islander peoples' QoL rarely occurs. Effectively measuring Aboriginal and Torres Strait Islander peoples' QoL requires more than cross-cultural adaptation of existing QoL instruments. It requires insight into what defines quality in Aboriginal and Torres Strait Islander peoples' lives and the circumstances in which they live. Whether they reside in cities or in rural and remote locations and communities across Australia, wherever they are, Aboriginal and Torres Strait Islander people continue to experience the effects of colonisation. Yet, they remain intrinsically connected to their ancestral country, their land and sea, the natural landscape and their cultural beliefs.^{22,23} There are similarities in their views of the world and in their ways of knowing and being.²⁴ The contemporary nature of their lives does not negate their Aboriginality or Indigeneity, nor their cultures. It is known that '[c]ultural identities are historical, fluid and dependent on context',^{15(p257)} although

many continue to be pressured to justify who they are or where they belong in contemporary Australian society. They endure and suffer the consequences of racism and discrimination, even being considered by some as 'too contemporary to be traditional, and too Indigenous to be modern'.^{15(p258)}

Whether they reside in cities, towns or regional and remote Aboriginal communities, Aboriginal and Torres Strait Islander people share health beliefs that not only pervade the social and cultural context in which many live, but also their ways of being.²⁵ The foundations of their health are defined in complex interactions between themselves and their natural and spiritual worlds, the interconnections between their community structures and their environment²⁶ and evidenced of their creative expressions.²⁷ Their creation beliefs²⁸ are a tapestry of spirituality, values, attitudes, concepts, language and relationships interwoven into their physical and material worlds. The struggle to maintain the balance between their spiritual, physical and emotional health and well being and the world around them,^{23,29} and their beliefs in the materialisation of supernatural intervention and sorcery,^{30,31} is complex. It is from within this paradigm that Aboriginal and Torres Strait Islander peoples' QoL is defined and the notion of how to measure it³² is to be drawn.

To develop instruments that effectively measure the QoL in Aboriginal and Torres Strait Islander peoples it is imperative that they are involved throughout the process. They must participate in designing instruments that reflect and articulate their understandings, experiences and realities.³³ Their inclusion in this process mirrors the Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (Values and Ethics), in particular the need for inclusion of Aboriginal and Torres Strait Islander people in research regarding their health and the notion of fairness, respect and ethics.^{34(p10)}

Designing QoL instruments: generality versus specificity

Instruments designed to measure QoL in one Aboriginal and Torres Strait Islander community or population may not necessarily translate for use in all Aboriginal and Torres Strait Islander populations, even with modifications.³⁵ Although some Aboriginal and Torres Strait Islander people share similar beliefs, they are diverse.³⁶ Their diversity is characterised by distinct ceremonial traditions and practices, languages and creation stories, and is bound to the country to which they belong. Aboriginal and Torres Strait Islander people identify themselves in accordance with names that define their respective language groups, clans, kinship groups and their social organisation and control.³³ As distinct groups they are responsible for maintaining and caring for country in accordance with their spiritual beliefs. This intrinsic relationship with their world and the connectedness within is evident in their kinship structures and relationships with each other and the connections to others outside their group.³⁶ It is also demonstrated in multiplicity of their cultural histories, creation

stories, cultural practices and belief systems and the ways in which these are maintained and continued through ceremonies.³⁶

Conclusion

The definition of QoL and how it is measured continues to be discussed. Researchers and clinicians continue to use different descriptions and are unable to agree on a common definition. Although the needs and aspirations of individuals shape their QoL, they do so in a cultural context. This has implications for Aboriginal and Torres Strait Islander people, whose QoL is founded within their ways of knowing and being, including their connections to country, cultural beliefs and practices.

Although there may be similarities in and between various language groups, Aboriginal and Torres Strait Islander people are heterogeneous and their communities remain culturally and linguistically diverse internally as well as externally. Modifications to standard instruments do not improve their suitability for measuring QoL across culturally diverse groups. Using Aboriginal and Torres Strait Islander people to assist in designing instruments to measure their QoL has benefits.

Aboriginal and Torres Strait Islander people are best able to articulate what is required based on their understandings. This is best achieved using Indigenist and Indigenous methodologies to extricate Aboriginal and Torres Strait Islander peoples' perceptions of QoL and to develop instruments that are cognisant and congruent with their terms of reference.

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