

Assessing cultural appropriateness of Patient-Reported Outcome Measures for Aboriginal people with diabetes

BACKGROUND

Monitoring quality of life is an important component of equitable health service delivery in chronic diseases like diabetes. Patient Reported Outcome Measures (PROMs) provide healthcare consumers with a platform to report on health services and interventions. Aboriginal people experience disproportionality high rates of diabetes, so PROMs should meet their cultural, spiritual and medical needs. However, the author isn't aware of any validated Australian Aboriginal population-specific diabetes PROMs reported in the literature. The aim of this study was to explore the perceptions of Aboriginal people about the cultural appropriateness of two diabetes management-related PROMs [Patient-Reported Outcomes Measurement Information System-29 (PROMIS 29), Problem Areas In Diabetes (PAID) Scale].

METHODS

Thirty Aboriginal people living with diabetes in the Shoalhaven discussed two PROMs in one of four focus groups or an individual interview. Preliminary data coding was conducted by clinician researchers, with thematic analysis overseen by Aboriginal co-researchers. Subsequent individual interviews with participants were undertaken to refine feedback and articulate what culturally-specific content was needed to be captured when evaluating Aboriginal people's self-reported quality of life and diabetes management.

RESULTS

The PROMs assessed did not capture accurate cultural information or knowledge about the healthcare of Aboriginal people with diabetes, with considerable content considered irrelevant (i.e. *"I think there are too many irrelevant questions about irrelevant stuff"*). Participants' recommendations included adapting culturally appropriate materials and improving alignment of measures with day-to-day activities. This study also describes a genuinely collaborative, Aboriginal community-guided approach to assessment of diabetes management tools.

CONCLUSION

Cultural appropriateness of evaluation tools in government-initiated evaluation of health outcomes is paramount. The learnings from this study will contribute to the development of tools that capture culturally tailored outcome measures and highlight the importance of collaboration when initiating Aboriginal Community work. This study is of interest to those researching or developing Patient Reported Measures, particularly in relation to the practicality of tools for First Nations peoples and those involved with Aboriginal-focused research and project implementation.

KEYWORDS

Diabetes Mellitus; Aboriginal; Patient Reported Outcome Measure; cultural appropriateness; Indigenous methodology



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