

Beyond the survey: Lessons from quality of life research with First Nations people living with chronic hepatitis B in the Northern Territory

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Background:

Chronic hepatitis B (CHB) disproportionately affects First Nations people in Australia's Northern Territory (NT), where prevalence is up to five times the national average. The Hep B PAST model of care has improved CHB diagnosis, monitoring, and treatment through education, remote outreach Liver One-Stop-Shop clinics, electronic hepatitis B serostatus systems, and continuous quality improvement (CQI) processes. Alongside delivery of this model, quality of life (QoL) data were collected.

Methods:

QoL data were collected from First Nations clients living with CHB attending One-Stop-Shop clinics using the EQ-5D-5L instrument alongside extraction of health record data. Due to varying English literacy levels, questionnaires were frequently read aloud and responses documented. Clinical and researcher observations arising during participant interactions were also documented. Recruitment has been completed and formal analysis is ongoing.

Results:

The questionnaire frequently acted as a prompt for broader yarning and storytelling rather than a complete representation of lived experience. While participants often reported being physically and mentally well within structured questionnaire responses, conversations commonly revealed psychosocial concerns that may influence engagement in long-term hepatitis B monitoring and treatment, including psychological distress, grief, social isolation, family pressures, uncertainty about illness, and reduced wellbeing. Several participants disclosed psychological distress requiring mental health referral. Discussions also highlighted the importance of culture, spirituality, religion, and connection to Country in shaping social and emotional wellbeing.

Conclusion:

QoL assessment within CHB programs should incorporate culturally responsive, person-centred approaches. Findings suggest that standardised Western QoL instruments alone may not fully capture First Nations perspectives of wellbeing or psychosocial factors relevant to hepatitis B care. Complementary yarning-based approaches may support more holistic clinical assessment, strengthen engagement in care, and improve long-term management within remote hepatitis programs. While the relationship between mental ill health and CHB outcomes remains an emerging area of research, these findings highlight an important area for future investigation.

Disclosure of Interest Statement:

No disclosures to declare.