

A qualitative study exploring perceptions to the human T cell leukaemia virus type 1 in Central Australia: Barriers to preventing transmission in a remote Aboriginal population

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Background:

Central Australia has the highest recorded prevalence of the human T cell leukaemia virus type 1 (HTLV-1). Each of the clinical diseases associated with HTLV-1 have been reported in this region, including deaths due to adult T cell leukaemia. Nevertheless, there has been no public health response to reduce transmission among the affected population. In the first study to explore the perceptions of healthcare professionals along with those of Aboriginal people, we sought to understand the barriers to preventing transmission in this remote area.

Methods:

Semi and un-structured interviews were conducted with 30 Australian Aboriginal people, 26 non-Aboriginal healthcare professionals and 3 non-Aboriginal community workers. Interviews explored perceptions towards HTLV-1 with a focus on sexual and reproductive rights. Deductive and inductive analyses were applied to data within a decolonizing theoretical framework.

Results:

A major finding was the contrast between the perceptions of Aboriginal participants and healthcare professionals regarding the provision of knowledge to those affected. Aboriginal participants consistently articulated that they and their communities should be informed of, and can hold, knowledges pertaining to HTLV-1. This finding controverted the perceptions of healthcare professionals that the complexities of HTLV-1 would not be well understood by Aboriginal patients. Further analyses revealed a spectrum of understanding and clinical practice, while also delineating signs of an imagined public health response.

Conclusion:

We demonstrate that differences in the perspectives of stakeholders present a significant barrier to the development of culturally safe prevention programs that foster a shared knowledge of HTLV-1. A successful public health response will likely require a dual approach of clinical care and community-driven health promotion. Aspects of this approach, which would raise awareness and potentially reduce transmission and lower HTLV-1 prevalence in Central Australia, may be applicable to endemic settings with similar conditions of social disadvantage, geographic remoteness, resource limitations and cross-cultural challenges.

Disclosure of Interest Statement:

None