“YOU KNOW IN THE COMMUNITY WHEN THEY HEARD OF SOMETHING AND THEN YOU CAN'T EVEN BE WITH THEM”: LIVED EXPERIENCES OF CHRONIC HEPATITIS B AMONG SOUTH SUDANESE IN AUSTRALIA

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Background: Chronic hepatitis B (CHB) is a leading cause of liver cancer and liver related problems worldwide. In Australia, only 13% of the 220,000 people with CHB receive clinical care and only 5% are taking antiviral treatment. While the challenges of managing CHB in clinical settings are known, there is a lack of understanding of daily experiences of people with CHB from culturally and linguistically diverse (CALD) populations. This study reports on experiences of South Sudanese people with CHB in Australia.

Method: The study employed a qualitative inquiry using semi-structured interviews with 15 South Sudanese people living with CHB in Australia. Following a verbatim transcription of data, a thematic analysis with theme identification and coding to several relevant categories was performed using NVivo 11.

Results: In addition to the clinical sequelae including medication side effects, disease progression, fear of developing liver cancer, and infecting others, concerns about psychosocial and socioeconomic implications of CHB were expressed. The fear of disclosure which could lead to discrimination and stigma was pervasive and was associated with negative implications on individuals and their families. Socioeconomic disadvantages including employment and educational disruption, financial uncertainty and vulnerability due to uncertain course of their illness progression were recurrent views.

Conclusion: CHB presents both psychosocial and clinical challenges to affected individuals. This study shows that in addition to clinical challenges, psychosocial and economic challenges of living with CHB among the South Sudanese are an important part of their CHB experience. There is a need to provide services that support affected people cope with their psychosocial experiences of the infection.

Disclosure of Interest: None