

Stigma's impact on treatment – a bilingual community health worker's experience

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Background: Hepatitis is little known by the African community including the South Sudanese community. However, chronic hepatitis B (CHB) can severely affect people living with CHB from an African background at a young age. It is recommended that people from African backgrounds living with CHB over 20 years old need hepatocellular carcinoma surveillance every six months, but other groups are only required when aged over 40 or 50.

Hepatitis is a highly stigmatised health issue in the South Sudanese community as it is usually associated with immoral behaviours. People with hepatitis are fearful of being judged and usually do not seek help including required care and treatment.

Analysis: A case about single mother in her thirties with hepatitis B and C co-infection will be presented and analysed to demonstrate how stigma and other barriers had impacted her care, and how the support she received helped her to extend her life enabling her to spend more time with her three young children.

Outcome: Stigma and lack of understanding caused the single mother to stop treatment for hepatitis B and she also drank alcohol heavily due to depression. After receiving our support, she stopped drinking and started treatment again. Despite this, it was too late to save her life due to hepatocellular carcinoma, but she lived nearly two years longer than her doctor expected. Her quality of life also improved in her last two years of life.

Conclusions: Stigma along with other barriers has profound impacts on people living with chronic hepatitis in the South Sudanese community. Appropriate support is very important, but stigma also needs to be addressed through not only individual education but also family and community-wide education. Otherwise, it will be difficult to achieve better outcomes of care in the community if not targeting stigma at all levels.

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