

Stigma's Impact on Treatment – South Sudanese Bilingual Community Health Worker's Experiences

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Background

- Chronic HBV (CHB) is not well understood in the South Sudanese Community
- CHB can severely affect younger people from an African background
- Hepatitis B related stigma is associated with immoral behaviours
- Misinformation is prevalent in the South Sudanese Community

1. The case

- A single mother of three young children diagnosed with chronic hepatitis B & C
- Illiterate in own language and English
- Drank alcohol excessively due to depression
- Stopped hepatitis B medications without informing her doctor
- Developed liver cancer and expected to live six months

2. Analysis

Failed treatment due to:

- Poor understanding of communication with her care: didn't know the treatment could control hepatitis B & alcohol could damage liver
- Lack of knowledge and understanding of CHB: e.g hepatitis B was only transmitted by sex
- Stigma – increased isolation and felt shame to seek information and help
- Depression – fear of death due to worries about her young children

5. Conclusion

- Appropriate education considering language and culture was the key
- Need to address stigma along with other barriers such as language, culture and different health beliefs
- Prepare to provide support anytime, not only during working hours

3. Approach

- Informal education in home language: to ensure full understanding of CHB
- Support to reduce alcohol consumption
- Be available on phone or in person including weekends and afterhours: discussing any concerns and issues, answering questions
- Encouragement of treatment
- Linked to social groups

4. Outcome

- Stopped drinking
- Resumed treatment
- Lived longer (two more years) than doctor predicted
- Was positive and happy in the last two years of life as she could spend more quality time with her young children including a toddler

