

EXPERIENCES OF UNCERTAINTY AND STRESS FOLLOWING FIBROSIS ASSESSMENT IN PEOPLE WHO INJECT DRUGS LIVING WITH HEPATITIS C, MELBOURNE, AUSTRALIA

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Background

- People who inject drugs (PWID) are the population most at risk of hepatitis C virus infection in Australia
- The landscape of HCV care is rapidly changing; the introduction of transient elastography (TE) to measure liver stiffness and direct acting antiviral treatment will likely alter the experience of living with HCV
- We aimed to explore positive and negative influences on wellbeing among PWID living with hepatitis C

Methods

- TAP study**
 - Treatment and Prevention (TAP) study looks at feasibility of treating community-based cohort of HCV mono-infected PWID
 - N= 146
- Purposive sub sample**
 - Purposive TAP sample, stratified based on age and gender
 - n= 22
- In-depth interviews**
 - Interview questions were open-ended, focussing on the impact of health status on wellbeing, social functioning and stability
 - Participants were aware of their hepatitis C seropositive and fibrosis status (measured by TE) prior to interview
 - n= 16
- Analysis**
 - Transcripts voice recorded, transcribed verbatim and thematically analysed
 - Analysis guided by Mishel's (1988) *Theory of Uncertainty in Illness*

Results

- Participants were aged between 33 and 56 years old, most were male (n=11). Almost all participants were unemployed and had not completed high school. Close to half the sample (n=7) had high-level fibrosis
- Four participants had been hepatitis C virus (RNA) positive in the past, but had cleared infection at the time of interview

Uncertainty: a key negative impactor on stress

Uncertainty was ubiquitous in the lives of participants. It was clear participants navigated complex aspects of life with trepidation, conceding to feeling generally "lost," "stuck," "jumbled up" or "helpless."

Fibrosis related uncertainty: ambiguity and lack of information

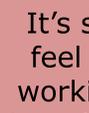
There were widespread gaps in knowledge regarding liver health and the TE scores, most of which stemmed from misunderstanding health professionals. This induced a sense of worry and confusion.



What I understood from [the liver specialist] is that a third is damaged. Well I'm like; 'can't you cut a third off?' Just get rid of that broken bit, it's simple for me! Then I don't need to live with the stress. And they're like; 'it doesn't work like that'. That doesn't make sense to me. (Male, high-level fibrosis)

Fibrosis related uncertainty: prognostic and future uncertainty

All participants demonstrated a lack of knowledge about general liver health irrespective of TE result. However, those with more severe fibrosis expressed a degree of worry and stress about how their fibrosis would progress and affect their future that those with low level fibrosis did not.



It's stressful just knowing I've damaged my liver. I feel depressed my body is so down, the liver's not working. Not knowing if I can do anything to fix it is just the worst, because it's something I didn't know I got, and now I don't know how to get rid of it. (Male, high-level fibrosis)

Finding stability through treatment

When participants described their hopes for accessing treatment, it appeared they wanted to combat feelings of uncertainty. Those no longer living with hepatitis C reported treatment reduced negative feelings associated with hepatitis C and fibrosis, and fostered confidence and an enhanced ability to navigate life's complexities.



When I knew I had this sickness there was a fog. To have the doctors say it was gone, it was unreal. It felt like butterflies and flowers, I feel alive again, with purpose again and it has motivated me to be better. (Male, high-level fibrosis)

Conclusions

- Despite advances in diagnostic tools and treatment, the HCV experience is shrouded in uncertainty, which may result in increased personal stress
- This suggests the need for simple and direct education programs and resources on liver health and TE to minimise stress
- Successful direct acting antiviral treatment appears to have a profoundly positive impact on the lives of PWID living with hepatitis C. This highlights that there are personal benefits of treatment