

## The chicken or the egg: medical markers and the social experiences of hepatitis C

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### Hepatitis C: a chronic illness

...an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life.

Chronic Illness alliance

chronic illness care involves the recognition that people with chronic illness develop an authoritative knowledge that may contradict the advice of practitioners

Paterson et al. (2006) Hepatitis C as a Chronic Illness, *Clinical Nurse Research*, Vol. 13 (209)

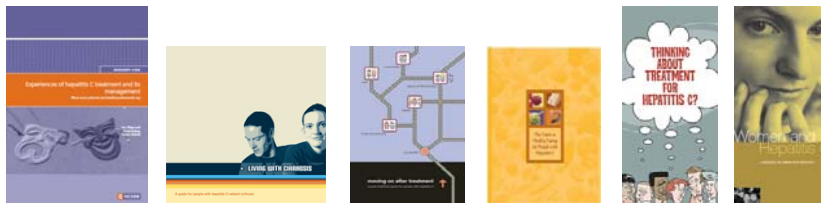
## Hepatitis C: the medical model

*Practitioners have largely embraced a biological reductionist construction of Hep C centred on the virus and the progression of liver disease. This has caused them to provide care within an acute care model. In contrast, people with Hep C view their illness within the context of their everyday experience and life goals*

Paterson et al. (2006) *Hepatitis C as a Chronic Illness*, *Clinical Nurse Research*, Vol. 13 (209)

## Hepatitis C: the social experience

*there is a need for information that goes beyond observation of clinical markers to explore patient's narratives in order to address the physical, emotional and social side effects of hepatitis C treatment*



National Centre in HIV and Social Research (2006) *Experiences of hepatitis C treatment and its management: what some patients and health professionals say*

## Hepatitis C: the chicken and the egg

... what started off me being wary about treatment is my own experiences. Cleaning up after using drugs and suddenly thinking, "Fuck I've got Hep-C. What am I gonna do?" **Getting really high liver counts and the doctors, specialists going, "You've gotta go on Interferon, you've gotta go on Interferon." Not asking me about my social situation, my support.** Not asking me... "What about the side effects? What about depression? What about anaemia?" Also since I already had a bit of depression and anaemia ... "And they completely sort of just wave it all under the table and like, "Oh it's not a big deal," ... And I don't think that that's okay. I think that there needs to be a bit more honesty and a bit more like this is a hard treatment. It might not work but you know; you can do it if you want to do it.

*Harris, Magdalena. Experiences of individuals living with hepatitis C in Auckland and Sydney. Qualitative Doctoral Research Project, National Centre in HIV Social Research, UNSW.*

## Hepatitis C: a way forward...

- Explore individual experiences of living with a stigmatised illness: integrating a positive diagnosis, grief and loss processes, coping strategies, misconceptions and belief systems (ie: having children)
- Avoid discounting symptoms, especially fatigue, the impact of hepatitis C on relationships and ability to manage themselves day to day
- If there is no clinical markers of liver damage, explore perceptions of their healthcare and support needs
- Explore treatment preparedness, coping strategies, support networks, quality of life etc
- Shared care models

