

Living with Hepatitis C : a psychosocial exploration of hepatitis C infection and its treatment

Citation for published version (APA):

Hopwood, M. N. (2007). *Living with Hepatitis C : a psychosocial exploration of hepatitis C infection and its treatment*. Maastricht University.

Document status and date:

Published: 01/01/2007

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

SUMMARY

Chapter 1 presents an overview of the work contained within this thesis. This chapter contextualises the thesis within Green and Kreuter's (1999) educational and ecological approach to health promotion planning. It provides a summary of the latest epidemiological estimates and projections of the hepatitis C epidemic in Australia and contains background information on living with hepatitis C. The chapter then outlines the theoretical frameworks and methods used throughout the thesis including a discussion of the thesis aims and research questions. Finally, an overview of the main findings of the thesis is provided and recent hepatitis C-related psychosocial literature is integrated and added to that which appeared in the author's sociological review of literature published in 2003.

Chapter 2 reviews international and Australian literature related to living with hepatitis C infection. At present, scholarly research into this worldwide epidemic focuses on medical and scientific understandings of the virus and its effects on people's health-related quality of life. Exploration of the socio-cultural impact of hepatitis C infection is for the most part absent from this literature. However a nascent academic inquiry into living with hepatitis C infection points to a complex range of concerns regarding diagnosis, disclosure, stigmatisation and discrimination against people with hepatitis C. The increasing association of hepatitis C infection with injecting drug use and the medicalisation of those affected by the virus is discussed. This chapter argues for an expanded socio-cultural understanding of hepatitis C to account for the material effects of medicalisation, stigmatisation and discrimination, and the socio-cultural impact of treatment on the lives of people with hepatitis C infection. It concludes with suggestions for future directions in social research to address the silence surrounding living with hepatitis C infection.

Chapter 3 reports on a study of people's experiences of receiving a positive hepatitis C diagnosis. To address a paucity of academic literature that described people's experiences of receiving a positive diagnosis, including doctors' explanation of the infection and referral to support services, a cross-sectional study was conducted of people with hepatitis C infection living in New South Wales (n=504) during 2001 and 2002. People diagnosed with non-A non-B hepatitis prior to 1989 when the hepatitis C virus was identified were excluded from analysis as it was assumed that these people were subjected to different social dynamics to those diagnosed after 1989, by which time epidemiology had established that hepatitis C infection was commonly associated with injecting drug use. Among participants diagnosed with hepatitis C infection after 1989 (n=417), just under a third (29.5%, n=123) reported that they had received 'no explanation' about their infection from their doctor at diagnosis. Women and those diagnosed from 1989 to 1996 – the year before the Australian Hepatitis Council was established and commenced publishing informational pamphlets – were significantly more likely to report receiving no explanation than men and those diagnosed after 1996 (35.4% vs 23.7% and 37.5% vs 23.0% respectively). Similarly, current injecting drug users and those diagnosed from 1989 to 1996 were

significantly more likely to report receiving no post-test counselling than those who were not currently injecting and those diagnosed later (42.9% vs 30.2% and 37.6% vs 25.9% respectively). Participants diagnosed from 1997 to 2001 were significantly more likely to report receiving pamphlets about hepatitis C infection (39.2% vs 23.7%), information about treatments (24.5% vs 16.2%) and advice regarding natural therapies (9.1% vs 3.8%) than those diagnosed earlier. These data provide evidence of an increase in the dissemination of hepatitis C information by doctors at diagnosis, during the latter stages of the 1990s. However continued effort is needed to improve doctors' provision of information and referral to specialists and support agencies for people newly diagnosed with hepatitis C.

Chapter 4 presents data regarding hepatitis C-related discrimination. The chapter reports findings from a cross-sectional study of people with self-reported hepatitis C virus infection (n=504) conducted in New South Wales (NSW), Australia throughout 2001 and 2002. Participants completed a self-administered questionnaire enquiring into their experience of living with hepatitis C infection. Over a half of all participants (57.5%, n=290) reported that they had acquired their infection from injecting drug use. Discrimination was reported by 64.7% (n=326) of participants and healthcare was the most commonly reported site where discrimination occurred. A logistic regression identified the predictors of any discrimination as: knowing many other people with hepatitis C infection (i.e., six or more people); feeling 'very tired' due to hepatitis C symptoms; and being younger (i.e., less than 51 years). Predictors of higher levels of discrimination were: knowing many other people with hepatitis C infection (i.e., six or more people); being limited (i.e., either 'some of the time' or 'a lot of the time') in the time spent with family, friends, neighbours and groups due to hepatitis C; and feeling pessimistic about hepatitis C treatment and the future because of hepatitis C-related ill health. Although discrimination occurred in a range of social domains, effort is needed to improve healthcare workers' service delivery to people with hepatitis C infection. Continued discrimination may inhibit people from seeking a range of health services and impede efforts to contain the epidemic.

Chapter 5 presents one of the first published qualitative studies of the experience of receiving treatment for hepatitis C infection. Clinical trials of interferon-based treatments for hepatitis C infection show decrements in patients' health-related quality of life due to side effects of therapy. The impact of side effects on patients' overall quality of life remains unclear. To explore this issue, people living in New South Wales, Australia who had undergone treatment for hepatitis C were interviewed. This chapter reports participants' experiences of treatment side effects and the impact of the therapeutic regimen. This information is important because a new interferon-based regimen has been adopted as the mainstay of hepatitis C treatment and it is predicted that many more people will seek treatment in Australia. The author argues for further qualitative research to enhance knowledge of the impact of this therapy on quality of life.

Chapter 6 reports on the experience of preparing and managing people throughout six or twelve month courses of interferon-based treatment for hepatitis C infection. From the clinical literature a high proportion of patients receiving hepatitis C treatment has dose reductions or discontinues treatment because of adverse events arising from the therapeutic drugs. Currently there is no published literature which explores how health professionals prepare patients for hepatitis C treatment and there is a paucity of literature regarding how treatment-related adverse events are managed. Data is presented from the author's exploratory qualitative study which used semi-structured in-depth interviews with a sample of health professionals with experience in managing hepatitis C treatment regimens. The study was conducted in Sydney Australia throughout 2004 and 2005. The study aimed to report health professionals' perspectives regarding hepatitis C treatment preparation, and to identify and describe the hepatitis C treatment management strategy used by health professionals in this study. Participants reported that pre-treatment preparation focused on information provision regarding adverse events and the medical strategies that could ameliorate their impact. Patients' vulnerabilities and supports were assessed prior to treatment and health professionals sought to address patients' problems as they arose during treatment. Participants discussed patients' resilient coping style and the beneficial impact this had on treatment management. These findings indicate that among this sample of health professionals a deficits-based approach was taken to hepatitis C treatment management. While some attempts were made to assess patients' strengths, this was limited to identifying those in family, work and social networks who could lend support to patients when problems occurred. Exploring patients' past experiences of adversity and making a detailed evaluation of a range of patients' strengths (i.e. strengths-based assessment) might assist clinicians in managing hepatitis C treatment regimens.

Chapter 7 explores the phenomena of people using illicit drugs while receiving hepatitis C treatment from the perspective of one group of health professionals. Exploration of patients' illicit drug use during treatment for hepatitis C virus infection is largely absent from the clinical literature. Data are presented from a qualitative study of health professionals responsible for managing hepatitis C treatment regimens at three major metropolitan hospitals across Sydney, Australia. During semi-structured in-depth interviews participants discussed patients' use of injected and non-injected illicit drugs while coping with a demanding therapeutic regimen. Health professionals highlighted the socially conservative environment of healthcare and its negative perceptions of illicit drug users. Also discussed are the management of people who inject during treatment and the efficacy of cannabis to reduce side effects. The findings of this study indicate that while the health professionals adopted a harm reduction approach to patients' illicit drug use during HCV treatment, information regarding the risks and benefits of illicit drug use is silenced in this context. While ever prohibition remains Australia's illicit drug policy this situation appears unlikely to change. Research which investigates the extent of illicit drug use during hepatitis C treatment, the risks and benefits associated with their use in this context and the harms of perpetuating a duplicitous healthcare system is required.

Chapter 8 explores a paradoxical association between social marginalisation and positive health outcomes among people receiving treatment for hepatitis C infection. In this chapter, participants who were living in socially disadvantaged circumstances reported applying adaptive approaches which they had learned from past experiences of drug dependence, living with symptoms of chronic illness, coping with depression and childhood sexual abuse to enable them to cope with severe treatment-related side effects. This finding has implications for the clinical management of hepatitis C treatment; the factors and processes that facilitate adaptive coping to adversity associated with social marginalisation can be assessed for their clinical contribution to coping with an arduous regimen.