

The consortium for Social and Policy Research on HIV, Hepatitis C and Related Research

Workshop 34 – Doubling up: influencing innovation in hepatitis C care and treatment

24<sup>th</sup> November, 2009

Attendees: Tiia Harrison and Fiona Poeder

Aims of the workshop

- To review recent and future developments in epidemiology, clinical practice and policy in relation to the care and treatment of people with hepatitis C
- To explore implication of current social research on the experience of people considering, undergoing and completing treatment
- To provide examples of innovative practice and to explore a range of new models of service delivery that aim for better care, testing and treatment for greater numbers of people
- To challenge delegates to examine how they may contribute to changed clinical practice and enhanced outcomes for people with hepatitis C.

Guest Speakers and Panel Members

Justine Doidge (JD) - volunteer with Hepatitis C Council of NSW. Recent experience of hepatitis C treatment,

Professor Greg Dore – Professor and Head, Viral Hepatitis Clinical Research Program, National Centre in HIV Epidemiology and Clinical Research (NCHECR),

Hope Everingham – NUAA peer support worker on ETHOS Project, based at Newcastle Pharmacotherapy Unit,

Dr Max Hopwood – social psychologist and research fellow at the National Centre in HIV Social Research (NCHSR),

Tracey Jones – first authorised hepatology nurse practitioner in NSW,

Stuart Loveday – Executive Officer of the Hepatitis C Council of NSW since 1994,

Susan McGuckin – Manager of Community Development Programs and Services Team at NUAA,

Janice Pritchard-Jones – Hepatitis C Coordinator in SSWAHS, and has been a Hepatitis CNC since 1994,

Dr Monica Robotin – Medical Director of Cancer Council of NSW and Senior Lecturer at the School of Public Health, University of Sydney,

Lisa Ryan – Manager, Harm Minimisation, AIDS/Infectious Diseases Branch, NSW Department of Health,

Felicity Sheaves – Harm Minimisation Coordinator for SWAHS,

Kerri Shying – currently works at NCHECR as a research assistant and as a private consultant,

Anne Taylor – currently provides education, information and access to HCV treatment in OPT dosing clinics within the Inner West for SSWAHS,

Associate Professor Carla Treloar – Head of the Hepatitis C Program at the National Centre in HIV Social Research, and Deputy Director of NCHSR and Manager of the Consortium, and

Norman Booker – Workshop Facilitator, and independent consultant working in the fields of planning and evaluation, change management, facilitation and professional learning.

## Overview

The workshop looked at clinical, social, environmental and financial factors associated with 'doubling up' the number of people receiving hepatitis C treatment.

The workshop itself was a series of discussions, speakers and interspersed with small-group activities.

Participants and delegates, though largely NSW based came from across the country and represented a number of hepatitis C related areas of expertise from treatment, to service provision to education.

Two 'peers' associated with the NSW Hepatitis C Council and NUAA shared their experience of hepatitis C treatment, with both remarkably having relatively positive experiences and clearing the virus.

The ongoing and controversial issue of side effects after treatment has ceased was also raised, and it was interesting that there appeared to be tension in relation to what constitutes 'side effects' post treatment and what might be 'underlying clinical issues' and/or 'symptoms'. Not surprisingly, this tension was between more 'socially-slanted' and more 'clinically slanted' delegates.

Obviously the issue of peer support through all stages of treatment and the resources to support such peer initiatives was another 'hot topic' of the day. There was again call to have the AIVL 'peer training and support in relation to hepatitis C treatment' proposal re-visited and funded through ETHOS.

## Presentations

*Professor Greg Dore gave an overview of what is the current position in relation to hepatitis C and liver disease and upcoming or second generation medications in relation to hepatitis treatment.*

*Interestingly, and an argument to keep in mind in relation to funding, Professor Dore stated two and half more people die of advanced liver disease in comparison to HIV/AIDS in this country. Treatment is not effective beyond a certain stage of advanced liver disease and the more advanced the liver disease the greater the reduction in chance of responding to treatment.*

*In addition, individual personal factors, such as age, general health, genotype and level of fibrosis influence treatment outcome. There are currently 3 500 individuals starting hepatitis C treatment annually – note that this figure does not give an indication of the retention on treatment, or the 'why' individuals cease treatment.*

Lisa Ryan's presentation was entitled 'Doubling the numbers on treatment – policy implications'. Lisa made a call for those in the field to consider the Lismore model and to look at ASHM's role in relation to GP prescribing.

In addition, Lisa made points in relation to looking at the people who are recruited into treatment – what is it about those people, if anything that brought them into treatment that could be utilised in recruiting others. Lisa also reminded us to look at the resource implication of ‘doubling-up’. Lisa’s call to us to be realistic in how people deal with the lived experience of hepatitis C treatment and the uncertainties of treatment itself were poignant reminders that these are real people we are discussing, not numbers or statistics.

*Fiona Lea who was engaged through NUAA was our first speaker from personal experience talked about her experience of treatment being a positive one. But for that to be so, certain key elements had to be in place from the onset; positive setting – hospitals being too sterile, positive support – knowing there was someone to talk to, and a great doctor.*

*Fiona also talked of some of the practicalities associated with treatment. Living in a share-house, Fiona found it difficult to store her Interferon in the fridge. She discussed her family and stressed that it was important to her to make the decision on who she told about treatment – family not necessarily being one of them.*

*Lastly, Fiona’s advice to others was not to smoke pot, to read as much information as possible – Users News was her nominated favourite – as it gave other people’s experiences to relate to and she felt that her experience was not “half as bad”.*

Carla Treloar’s presentation reported on a research report wherein data was still being analysed. This health literacy research looked at experiences of patients in relation to hepatitis C treatment and testing referrals, and looked largely at relationships between services and clinicians and clients – this research is likely to have a huge impact, particularly if ‘doubling-up’ means working with and increasing numbers at/through ORT clinics.

Carla’s results show that if clients have a university education they are more likely to have a positive experience, more likely to gain a referral and more likely to have long standing relationships with clinicians. However, if clients have only secondary education there is an absence of discussion with clinicians and the potential for health issues as a barrier increase.

The absence of discussion around hepatitis C signals to clients/patients that hepatitis C is not deemed important. Carla's presentation not only highlighted the importance of 'health literacy' in relation to hepatitis C, but that we have a priority to teach people to live well with hepatitis C to lessen the burden of disease.

*Justine Deidge, a volunteer with the NSW Hepatitis C Council also presented on her positive experience of hepatitis C treatment. Justine stressed the importance of positive support and the ability to ask questions, not just medically-related questions, at 'anytime'.*

*One consideration that Justine raised was that at the 'end of treatment' she felt an absence. There had been an expectation that it would be 'all over', all good etc. However, hepatitis C had become part of Justine's identity and she felt the need to re-identify herself. After a long period of intense support, Justine found herself 'free floating' and without networks.*

*Justine's recommendations to others considering hepatitis C treatment were that they should have someone to talk to as this was very important and to make sure they felt comfortable and supported.*

Max Hopwood's presentation looked at re-adjustment after treatment and ongoing side effects once treatment had ceased. Max identified that clinical services were not available after treatment and that post treatment was a low priority in the range of information on the hepatitis C spectrum. Max further identified the need for protocols post treatment to help support clients who were reluctant to access services they felt, or were led to believe were no longer available to them.

## Activities

Activities held over the course of the day identified that the often punitive nature of ORT settings could act as a barrier in the hepatitis treatment experience. Clients might feel that they were forced to go on to treatment or that their treatment was dependent on their behaviour in relation to their ORT treatment; experiences such as forced reductions and loss of take-away doses might be reflected in their hepatitis C treatment.

The final exercise for the day asked participants to look at innovative strategies to influence innovation in hepatitis C. Ideas brainstormed include:

Public awareness campaign

Addressing stigma and discrimination in health care settings

Utilising positive experiences of hepatitis C treatment in public awareness raising

Making it as simple as possible for general practitioners to prescribe

Incentives for general practitioners in rural and regional settings to provide hepatitis C treatment

Supporting and resourcing peer support in a variety of settings

Stopping the 'siloing' in relation to ORT and peer workers (ie' advocacy)