

Psychosocial Factors Influencing Successful Hepatitis C Treatment Outcomes

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Adherence and outcomes

Hepatitis C (HCV) can be cured if the patient is adherent and completes treatment

- › Low adherence and treatment discontinuation rates are high
 - › ~ 50% cannot maintain "80/80/80" adherence
 - › 4-27% do not complete treatment

Why don't patients stay adherent and finish their treatment?

- Severe physical and psychiatric side effects from Interferon and ribavirin
- Complicated dosing schedule
- Psychosocial issues



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Treatment adherence & completion

What we do know

- The influence of medical predictors of treatment outcomes such as HCV genotype and the IL28B polymorphism

› What we don't completely understand

- The impact of psychosocial factors on adherence and completion
 - Social support
 - Coping strategies and resilience
 - Stigma and discrimination
 - Unstable housing
 - Employment
 - Limitations of the public health system



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Key Aims

Aims of this research

› Key AIMS:

1. To explore the psychological, practical and social issues faced by patients living with Hepatitis C on treatment adherence and completion
2. To identify ways that healthcare professionals and services might better support patients with Hepatitis C to improve their treatment outcomes.



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Methods

Qualitative interviews

- Semi-structured interviews conducted from August to November 2012
- 20 patients in all stages of treatment
- Liver clinics in Western Sydney



- › Framework analysis¹
- › A systematic process of coding, charting and organising data into key issues and themes

¹Ritchie J, Spencer L, O'Connor W. Carrying out qualitative analysis. In: Ritchie J, Lewis J, editors. Qualitative research practice: A guide for social science students and researchers. London: Sage Publications; 2003. p. 219-62.

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THE UNIVERSITY OF SYDNEY Results

Four overarching themes

1. Patients' motivations for Hepatitis C treatment
2. The influential role of provider communication throughout the treatment cycle
3. Facilitators of treatment adherence and completion
4. Barriers to treatment adherence and completion



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THE UNIVERSITY OF SYDNEY Theme 1: Motivations for treatment

Patients' motivations for Hepatitis C treatment

› Fear

I thought I was going to die.... I had Hepatitis, I thought I was gone. ...I don't have any choice. If I didn't get treated it's not going to go away... there's no decision to be made, you have to do it. (Male, 49, treatment in progress)

› Stigma and shame

...a lot of people have got Hep C that didn't get it from using IV needles – or I don't even know if that's how I got it, I could have got it through tattoos in jail, or, I don't know, but it's definitely got a stigma attached to it, which is gone now. (Male, 50, treatment completed)

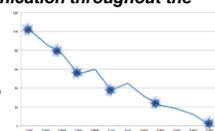
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THE UNIVERSITY OF SYDNEY Theme 2: Communication

The influential role of provider communication throughout the treatment cycle

› Clinical feedback

When I started the program... the viral load was about 1.6. ...Then a month after that it came to about 465,000 and another month after that it came to about 165,000. So I could see that it is dropping, so that also gave me hope. (Male, 43, treatment in progress)



I feel better since the very beginning when I was told that after the first six weeks of the treatment, and I had my blood test that there was no virus detected. As long as I am told how I am progressing, and progressing good, bad, or indifferent, yeah, that's good enough for me. (Male, 54, treatment completed)

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THE UNIVERSITY OF SYDNEY Theme 2: Communication

The influential role of provider communication throughout the treatment cycle

› Information overload

I think they're good [informational materials on Hepatitis C], as long as you don't get an overload of umpteen sheets and you can get a little bogged down, flicking through them, you think, God, I'm not going to get through this and understand it all...

(Male, 62, treatment in progress)



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THE UNIVERSITY OF SYDNEY Theme 2: Communication

The influential role of provider communication throughout the treatment cycle

› One-size-fits-all approach to providing information

The information [I get only focuses on] medication and the treatment... [but] something...outside [of that] for example, I usually play sport, right, with the treatment, can I still play... That kind of information I don't have. (Male, 49, treatment in progress)



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THE UNIVERSITY OF SYDNEY Theme 3: Facilitators

Facilitators of treatment adherence and completion

› Social and emotional support

I said to my wife, I said, 'I can't deal with this,' but she talked me back around to it and brought me grandkids over and said ... 'You've got to do it'... A very good support system. You need something like that. ...I just wanted to throw it all away, but everybody supported me. (Male, 57, treatment in progress)

You've got to have people around you. You can't do it by yourself. (Male, 47, treatment in progress)



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Theme 3: Facilitators

Facilitators of treatment adherence and completion

› Coping strategies

Active I used to walk every morning and every afternoon just for about half an hour and that took my mind off – yeah, well, depression kicks in. They wanted to put me on depression tablets, but I said no... **the walking helped a lot** because just peaceful time, just walking laps around the oval, and just thinking about other things, you know, where the itch didn't really matter anymore... (Male, 57, treatment in progress)

Disengagement through drugs Okay. **This is how I cope [takes out Panadeine Forte] it numbs me out.** ...I've never told the doctor but they never say anything about it. Yet, if I take stuff over the counter... then it starts showing up. I'm actually better off taking those [because they don't show up in blood test results]. (Female, 52, treatment in progress)

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Theme 3: Facilitators

Facilitators of treatment adherence and completion

› Coping strategies

Resilience

Well, I had such a bad childhood and such a shocking adolescence, that I actually survived it and I didn't become insane is enough for me. **I just think back on that. I got through all of that crap and I survived it.** (Female, 52, treatment in progress)

Reflecting on harder times and comparing them to treatment

And even the worst days of the sickness of interferon side-effects, **they're just still nowhere near as bad as withdrawals of opiates.** (Male, 50, treatment completed)

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Theme 3: Facilitators

Facilitators of treatment adherence and completion

› Unemployment

As a facilitator

Being on the treatment and working at the same time **that is the hardest thing.** That is why I put the work on hold at the moment. (Male, 43, treatment in progress)

I have no problems with the issues [caused by] the treatment, but it's just more so, for me, is **getting the time from work.** (Male, 49, treatment in progress)



As a barrier

Well, it's upsetting...it was very emotional for me because I – **I had to give up too many things, like my job and people that I was happy around and that's what got to me more than anything.** (Female, 69, treatment in progress)

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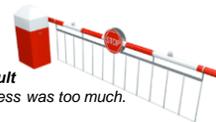


Theme 4: Barriers

Barriers to treatment adherence and completion

› Treatment side effects

Initially I experienced dizziness, tightness, vomiting. Fatigue. ...**That's why currently I'm not working because ...I find it difficult because of the fatigue.** Initially, the dizziness was too much. (Male, 43, treatment in progress)



› Complicated treatment regimen

The difficult part?... Just watching your times of your meds... Because everything's got to be refrigerated and if I've got to go out in the middle of the day I take the little freezer brick and I wrap the meds up in that but then I've got to remember to take ... that's a little pitfall. I can take the stuff with me and forget to use them anyway. (Male, 62, treatment in progress)

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Theme 4: Barriers

Barriers to treatment adherence and completion

› Limitations of the medical system

Poor coordination of services

Just waiting, but it's a hospital. You know that's going to happen. ...it's sort of **badly timed for me** ... because I give blood in the morning and then I have to wait to do the afternoon, and I have to come in early enough for the bloods to get [processed]. (Male, 51, treatment in progress)

Long wait times

That's a pain, I mean, **you wait around for hours.** I mean, all I wanted today was a result on my blood test, and I've been here for three hours. A couple of hours is a bit much. So I don't know. Write a letter to the health system, I guess. It's not the doctors' fault. It's a funding issue, isn't it? (Male, 55, treatment completed)

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Summary & Clinical Implications

To improve clinical outcomes for patients, we need to:

- › Deliver patient-centred healthcare tailored to the individual needs of the patient
- › Improve communication between healthcare providers and patients
- › Decrease clinic congestion and pressure on physicians
- › Improve treatment accessibility



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Conclusion

To positively impact adherence and completion rates

- › Recognise and address psychological and social factors that impact patients' treatment adherence and completion
- › Ensure patients have:
 - adequate social and emotional support
 - adaptive coping strategies before treatment initiation
- › Provide practical support, advice, and clinical feedback tailored to individual patient needs

1¹⁹

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Question time

Thank you for your attention

Questions?

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Notes

- › Health literacy
- › Communication training for physicians

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