



Hepatitis C treatment uptake:

Understanding treatment incentives and obstacles

Broadsheet No. 2

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit [*Vital voices: Personal stories of treatment for hepatitis C.*](#)



Acknowledgments

The authors gratefully acknowledge the contributions of all interview participants in this project.

We also wish to acknowledge the contributions and guidance of our advisory panel:

Dr Susan Carruthers, Evaluation and Community Development Officer, Peer Based Harm Reduction WA; Dr Nico Clark, Medical Director, North Richmond Community Health Medically Supervised Injecting Room; Sione Crawford, Chief Executive Officer, Harm Reduction Victoria; Steven Drew, Chief Executive Officer, Hepatitis NSW; Kay Dufty, Health Promotion Project Officer, LiverWELL/ Hepatitis Victoria; Melanie Eagle, Chief Executive Officer, LiverWELL/Hepatitis Victoria; Carrie Fowlie, Chief Executive Officer, Hepatitis Australia; Dr Marianne Martinello, Infectious Diseases Physician at the Prince of Wales Hospital and St Vincent's Correctional Health and Postdoctoral Research Fellow in the Viral Hepatitis Clinical Research Program, Kirby Institute; Piergiorgio Moro, Programs and Projects Coordinator, Multicultural Health and Support Service, Centre for Culture,

Ethnicity & Health; Sonam Paljor, Senior Media and Digital Communications Officer, Multicultural HIV and Hepatitis Service; Bianca Prain, Manager, Hepatitis Programs, Centre for Population Health, NSW Government; Kerry Walker, Aboriginal Project Officer, Education and Development, Hepatitis NSW

Thanks also go to the many people and organisations that assisted with participant recruitment, including colleagues and friends:

Access Health; ACON; Australian Federation of AIDS Organisations (AFAO); Australian GLBTIQ Multicultural Council; Australia India Society of Victoria; Australian Research Centre in Sex, Health and Society (ARCSHS); Australian Vietnamese Women's Association; Blood Borne Virus Sector Development Program; Carrington Health; Central and Eastern Sydney PHN; Centre for Culture, Ethnicity & Health; Clinic 36; cohealth; David O'Keeffe; Dean Murphy; Gastroenterological Society of Australia; Greg Dore; Dr Gurdip Aurora; Haemophilia Foundation Australia; Harm Reduction Victoria; Hepatitis Australia; Hepatitis NSW; Hepatitis Victoria; Indian Link; Jane Dicka; Judy Gold; Kathleen Desmyth; Kerry Walker; Kobi Clinic; Living Positive Victoria; Matthew Talbot Hostel; Medically Supervised Injecting Room (MSIR); Multicultural Centre for Women's Health; Murray PHN; North Western Melbourne PHN; Northern Region Indian Seniors Association (Vic.) Inc.; Northern Sydney PHN; Peter Higgs; Peter Waples-Crowe;

Positive Life NSW; Prahran Clinic; Rankin Court; Self Help Addiction Resource Centre (SHARC); Sione Crawford; Taylor Square Private Clinic; The Migrant Information Centre (Eastern Melbourne); VACRO; Veterans 360 Australia Facebook group; Youth Projects; Zoe Belle Gender Collective; 3ZZZ radio

Funding: This work was supported by an Australian Research Council Discovery Project grant (DP200100075).



Recommendations

This broadsheet is the second in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

Broadsheet No. 1: Experiences of hepatitis C diagnosis: Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.
- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

Broadsheet No. 2: Hepatitis C treatment uptake: Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.
- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.
- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should

provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.

- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

Broadsheet No. 4: Life after hepatitis C treatment: Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme.

This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA medication offers much shorter treatment durations

(approximately eight to 12 weeks), far fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004).

Research on hepatitis C treatment access before and after the availability of DAA treatments has identified a series of social issues shaping and often impeding uptake. For example, Harris and Rhodes' (2013) review of literature on access to interferon-based treatments explored 'individual' and 'social' level impediments. Individual level impediments include mental health issues, co-morbidities, the possibility of reinfection and concerns about side effects. Social level impediments include stigma, housing availability, geography, gender and cultural background, and criminalisation of people who consume drugs.

More recent research, conducted after the advent of DAAs, indicates that many of the same issues continue to impede access to treatment (Bryant et al., 2019; Gunn et al., 2021; Harris et al., 2021; Madden et al., 2018; Wright et al., 2019). Heard et al. (2021) argue that barriers at the 'personal' level include mental and physical health conditions, at the 'provider' level include stigma in healthcare settings, and at the 'system' level include complex treatment pathways and cost. They also identify enablers at the personal level such as the support of social networks, at the provider level such as trusting and respectful general practitioners, and at the system level such as fully subsidised costs and simple treatment pathways. While DAAs have far fewer side effects than interferon-based treatments, concerns about side effects also continue to shape treatment access and experiences (Bryant et al., 2019; Wright et al., 2019).

While barriers to treatment are well documented in the literature, less has been written about how people living with hepatitis C make decisions about treatment. Several studies indicate the social and relational nature of treatment decisions. Regarding the interferon-based treatment, Treloar et al. (2016) found

that those in couples make decisions together. In relation to DAA treatment, Goutzamanis et al. (2021) find that local and peer-based advocacy are key to sharing information about treatment. People undergoing treatment may also be an important source of information and referral (Reygosa et al., 2021). Mattingly et al. (2019) discuss the role of altruism in treatment decisions, with fear of harming others forming part of the decision-making process. They also note that people considering treatment want to have confidence that treatment will be effective (Mattingly et al., 2019).

This broadsheet builds on and contributes to this growing literature by exploring how participants describe making decisions about treatment and the issues and social relations that complicate completing treatment.

Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was entitled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

The project used a purposive data collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded

informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A\$50 cash or an A\$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts

were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment. Interview material from selected codes was carefully analysed by members of the research team to develop website content for this online resource. Topic sections for the website were developed

in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed four broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the second of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience; for example, 'Dave (male, 65, experience with both DAA and interferon-based treatment)' said that the DAA treatment was "quite easy" to incorporate into everyday life. For more details about participants, see the demographics table in Appendix 1.

Summary of findings

The people interviewed for this project described a range of issues that influenced decision-making about treatment. Many explained that the health and wellbeing of family and friends was important when deciding whether to commence hepatitis C treatment. Supportive and encouraging social relationships could motivate people to have treatment.

While the DAA treatment was widely considered straightforward and easy to complete, some issues continued to impede treatment uptake for participants. These issues included limited knowledge of DAA treatment, the impact of other

health concerns on treatment, and broader social obstacles connected to criminalisation and stigma.

This broadsheet explores participants' discussions of making decisions about treatment, beginning with discussion of how relationships bear on decision-making. The later sections cover social and political impediments to treatment, including issues within the healthcare system, homelessness and insecure housing, stigma, mental illness and criminalisation and custodial settings. This broadsheet concludes with recommendations to support the uptake of DAA treatment.

Family, friends and intimate relationships

Participants described different ways relationships influenced their decisions about hepatitis C treatment. Many focussed on the importance of family, partners and friends in their lives. For many, supportive relationships and caring for the health and wellbeing of others were significant considerations when thinking about treatment.

As Miguel (male, 48, experience with DAA treatment) explained, his mother's success with DAA treatment influenced his decision to have it too.

[I had hep C for] 10 years or maybe a decade or more [...] until [...] Mum one day rings me and says, 'There's a treatment [available, my] doctor reckons', and then a couple of weeks later she's on the tablets, and within three or four months she [has been cured of] it, and we were like, 'Oh wow [...] we've got a cure', and I thought, 'It's too good to be true', and yeah, I did it too. So [...] my mum found out about her treatment and then obviously it worked, and I found out through my doctor that I too could do that, and after we checked up the liver count, this whole thing, yeah, I got the drugs. So as soon as the treatment started, I started kind [of] feeling not much difference, but positively and, you know, like a fresh new start kind of feeling.

Explaining how her family shaped her treatment experience, Carol (female, 58, repeat diagnoses, experience with DAA treatment) said that her sister helped her understand test results and that her grandchildren were part of her motivation for treatment.

I think the biggest [reason I had treatment] would have been when my grandson... when my eldest son and his wife got pregnant with their child. You know what I mean, so, like, I didn't want to take any chances [...] so I spoke to [...] the Hepatitis line. Well,

the thing is that, like, my niece, she had hep C too [...] and just talking to my sister about the antibodies and stuff like that, I worked it all out. I did copies of my blood tests now and my liver scans, so that I can compare them or have a look at the different results.

Wanting to have children in the future was one of the key reasons Kylie (female, 46, experience with DAA treatment) decided to have treatment.

Well, I wanted to have children down the track, so [...] I wanted to make sure that... I really didn't think you could have children if you had hepatitis [C]. Of course, you can [have children], but I always thought the child would be born with it [...] My child still had to get blood-tested... as soon as he was born, they took him away and blood-tested him and then let me know that he didn't have [hep C], thank God.

Parenting responsibilities and concerns about children were especially significant to many of the interview participants. Concerns about the welfare of children were an important aspect of decision-making about treatment for these participants. In some cases, children were described as a reason to have treatment.

Several participants explained that their intimate relationships were an important part of their hepatitis C treatment decisions. While partners were often described as an important source of support, for some they were discouraging and unhelpful. Overall, worries about the impact of hepatitis C on intimate relationships were common among the people we interviewed. Several participants, for example, expressed concern that having hepatitis C meant that they could not have intimate relationships or that potential partners might be put off. Paulie (male, 45, experience with DAA treatment) said that treatment relieved him of the need

to disclose his hepatitis C to potential intimate partners.

Yeah, [treatment] made me happy and content, so that way I don't have to go around, yeah, always getting in contact with some people, you know, new people or in a relationship or having sexual affairs, I don't have to say, 'Excuse me, you know, I've got hep C, just so you know.' Like, I just don't have to say it [any more] because I'm [cured], so it takes away that agitation [... When I found out I was cured,] yeah, I was very overwhelmed, I was happy, I was vibrant. I was just happy that I don't have to disclose to people who I get in contact with and, yeah, because there's no need to because I've [... been cured of] the virus or disease.

For many, much of the significance of treatment was about being able to have intimate relationships (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*). Seeking support from intimate partners and friends was important for many, but experiences varied. Some described receiving support and help and others described unhelpful and unsupportive relationships.

Many of the participants said they often spoke with friends about hepatitis C treatment. While friends were generally described as a vital source of support, participants said they were careful about who they spoke to about hepatitis C. On speaking to close friends about her hepatitis C, Regina (female, 69, experience with DAA treatment) found out some of them had also had it. She said that even though she did not usually tell other people 'everything', it was 'nice' to find out that they also knew about hepatitis C.

Well, the only people I have told have been close friends, and the interesting thing was, one of the close friends



Well, I wanted to have children down the track, so [...] I wanted to make sure that...I really didn't think you could have children if you had hepatitis [C]. Of course, you can [have children], but I always thought the child would be born with it [...] My child still had to get blood-tested...as soon as he was born, they took him away and blood-tested him and then let me know that he didn't have [hep C], thank God.

KYLIE (FEMALE, 46, EXPERIENCE WITH DAA TREATMENT)

[...] it turns out, he also had hep C, but he got [...] cured] a long, long time ago with interferon. I told another friend whose husband also has it, but [...] I don't know his story at all [...] I think it [...] came up in conversation or something along those lines. It wasn't an 'Oh, I'm going to disclose this to someone' [type of moment]. It would have come up in conversation, I think [...] They were people my age who lived through the same era, you know, who lived through the same time, so it was the same thing [...] It was] actually quite good. It's nice to know that other people know [about it], but it doesn't really matter to me. You know, I'm not one of these people who's big on, you know, telling people everything.

Some participants also detailed how friends helped them overcome challenges that emerged while they were having treatment. In explaining the reasons they spoke to others about hepatitis C, some of our participants said that they wanted other people to consider getting tested or having treatment.

Given his disappointing experience with interferon-based treatment, Robbie (male, 54, experience with both DAA and interferon-based treatment) said that he recommends the DAA treatment to other people living with hepatitis C.

Yeah, I was spewing [disappointed] that [the interferon] didn't work. The doctor didn't really explain a great deal, just that it didn't work and, yeah, that I have to follow it up [again in the future]. So then I heard of this new treatment many years later, just the tablets, and went to the doctor and saw him about it, and he put me on the program [...] I tell others about the program, if I hear they have hep C or anything like that, to do the program and see how they go, because it, yeah, worked for me [...] I tell them that] all this is a matter of taking a tablet.

As Terence (male, 34, experience with DAA treatment) explained, while friends could be supportive, some people were not enthusiastic about the prospect of also having hepatitis C tests and treatment.

I told friends of mine [about my hepatitis C and treatment...] Yeah, my friend was really supportive, and I spoke to someone who I used to inject drugs with and sort of said that 'I tested positive for hepatitis C and, you know, I'm not able to definitively pinpoint the origin of it, but I think it's a good idea [for you] to get tested [too].' Yeah, they sort of weren't too keen on the idea.

Participant interviews show the importance of family relationships in influencing how people make decisions about treatment. They also suggest that people affected by hepatitis C often encounter a range of responses when speaking with friends about the virus or treatment. While intimate partners and friends could shape decisions to seek treatment and be a source of support during treatment, some friends were less encouraging.



Experiences of making decisions about hepatitis C treatment

Issues in the healthcare system

Several people said they had difficulty finding out about and starting hepatitis C treatment because of issues in the healthcare system. They felt that treatment was not promoted very widely, and they described several other barriers to hepatitis C testing and treatment. Additionally, some indicated that even though they had heard of DAA treatment, they were not sure of the details, including how to start it. As Laura (female, 30, no treatment experience) said, 'I didn't even know there was a new treatment until you mentioned it [...] Yeah, it's all confusing'.

Dana (female, 53, no treatment experience) explained that between 2012 and 2016 she had regular blood tests for hepatitis C and other tests for STIs. She did not remember receiving much information about hepatitis C during this period.

Being an IV drug user [who had] shared equipment in the past and [who was] also a working girl for a little while there too in [sex work...], I just needed to get checked and make sure I didn't have it [...] Yeah, I think we had to go once a month [...] or maybe three months for blood [tests] and one month for STD thing[s], I think [...] The only thing I think I ever received is a little brochure once, and it was about hepatitis, and then it had a few numbers or letters under it, like, I think it was A, B, C or something, I don't know. And all it said was that it can be transmitted [...] through] sharing of [injecting] instruments and sexual[ly], and to be aware.

Also speaking about the issue of awareness about treatment, Mikey (male, 40, no treatment experience) said that social and community organisations

need to provide more information about hepatitis C to their clients.

All through the Salvation Army crisis housing and stuff, you never hear anything about hep C ever, and I feel like it's something that, yeah, people should be aware of [...] hep C [...] like, I wouldn't be surprised [if I acquired it in the future], and I probably would go and read about the current treatments, because my information is outdated, I think [...] I didn't even realise that there was a new treatment, actually. I had no idea [...] I haven't noticed] anything that would advertise this new treatment, [and] I would have noticed.

In a few cases, participants described difficulty starting treatment due to vein damage. Hepatitis C testing in preparation for treatment may be hard to carry out due to difficulty accessing veins and may require special expertise and equipment that is not readily available.

Mem (female, 41, experience with DAA treatment) said that because an ultrasound is needed to guide her blood tests and collect blood, it took nearly 12 months to start treatment.

I believe I probably went for treatment [and] it took me nearly 12 months to be able to get bloods out [...] I have an issue with bloods, getting them out of my body, so I need an ultrasound guided [test], with a machine, to get bloods out. So [...] there was] a year or so in between knowing [I] had the hep C and getting treatment, because when I've gone to go up to either the hospital or the doctor to get bloods out, if they didn't have an ultrasound machine, I

[was] knocked back. So then it's just perpetuated the problem.

Carol (female, 58, experience with DAA treatment) tried to access DAA treatment relatively early (in 2016) and said that living regionally and having difficulty accessing suitable appointment times could result in missing out on treatment.

I had an appointment that didn't suit, so I had to change it, and if you do that more than twice, you are off the list, more or less [...] Yeah, but I suppose they've got a lot of people to deal with, you know what I mean. You've got to respect that as well [...] You can't be messing them about.

In addition to a lack of information about hepatitis C treatment within healthcare and other services, and limitations in services in regional areas, follow-up support and access to the appropriate diagnostic and testing equipment were also identified as impacting on treatment decisions.



Experiences of making decisions about hepatitis C treatment

Insecure housing, stigma and mental illness

Several participants spoke about the ways broader issues such as insecure housing, stigma and mental illness could act as barriers to hepatitis C treatment. While treatment was generally described as easy to take (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*), these broader social issues can contribute to difficulty beginning and completing it.

Alexander (male, 45, experience with DAA treatment) said being homeless made it difficult to complete his treatment.

I still currently have hep C. I was on treatment for a while. I got halfway through but circumstances [around] where I was, like, staying at the time changed and it was really hard for me to keep up with the medications [...] I was taking the medication every morning because I was actually staying at [a supported short-term crisis accommodation], but then when my time was up there and I left, it was hard for me to keep up with the medication, because I was homeless again. So, although it's a very simple task, my memory is not the best and it was a bit hard for me to keep up with it [...] Just being transient, like, I was never in the same place, I'd never wake up in the same place every day. So, it was hard for me to, sort of, remember to take the tablets, because I had other things on my mind.

Referring to stigma, Lou (female, 40, experience with DAA treatment) said she worried about privacy at the local

pharmacy during treatment, as she was known in the local community.

It was all pretty easy, really [...] By that stage, I had started to notice there was lots of posters coming up in waiting rooms and around the hospital about, you know, 'hep C treatment: this clinic now treats hepatitis C'. It had come onto the Pharmaceutical Benefits Scheme, people were quite excited by that. So, the way it worked is that I had to go to Melbourne to get the prescription [...] and then there was a few barriers, like again, the local community. I didn't want to come down to this pharmacy and get it, because, you know, I'm in here all the time. You are standing around talking to your neighbours and friends while you are waiting for your prescription to be filled, all of that silly stuff, which probably wouldn't bother me any more, but did back then.

Some participants were living with mental health conditions that made it difficult to have hepatitis C treatment. The most common conditions spoken about by our participants were depression and anxiety, with several describing how managing these can make it hard to get and complete treatment.

Rose (female, 36, no treatment experience) explained how depression and anxiety reduced her motivation to have hepatitis C treatment.

Yeah. I've tried so hard to start the treatment. How many years... a lot of years on and off where I didn't give

two shifts. I couldn't wait to die, you know what I mean? So I was like, 'I don't care, I'm not going to do nothing' [...] Why? Because [my] depression and anxiety and all that [make this] a big uphill... an up[hill] and downhill process for me, and every day it changes, like, I can't catch a break. I'm happy, down, happy, not happy.

Evan (male, 45, no treatment experience) explained that while he was unsure whether he agreed with his mental health diagnoses, his mental health was the focus of his meetings with his doctor. That meant that, for him, hepatitis C was only one of a number of health issues needing attention.

Yeah, mental health [...] Yeah, it was always severe depression and personality disorder, but I think I would argue that one and just say, we all have up and some downs. But let's say, it's usually been about that [...] I remember when I was 23 or 24 [...] it seemed to be mostly what we were dealing with every time I'd go see him – apart from doing my prescribing when it needed to be done.

The interviews show that those seeking and completing treatment for hepatitis C are affected by a range of issues, including many beyond individual control. Broader issues such as insecure housing, stigma and mental illness can act as barriers to hepatitis C treatment and need to be addressed in efforts to improve treatment uptake.



Experiences of making decisions about hepatitis C treatment

Minimal symptoms and confusion about treatment side effects

Several people described delaying treatment because they had not experienced any significant hepatitis C symptoms. Some participants who were diagnosed when interferon-based therapy was the only treatment option also described waiting until DAA treatment was available. Other participants described confusion about the differences between the old and new treatments.

Marty (male, 65, experience with both DAA and interferon-based treatment) said he delayed having treatment because he did not experience any hepatitis C symptoms.

I served probably 18 years in jail. That's not one sentence, that's just altogether. Now, in jail, I also knew I had hepatitis C [...] because they did blood tests and my ALTs¹ and ASTs² were pretty high, but all they could do was tell me that I had the virus. There was nothing they could do. But again, it didn't feel or seem serious

because I didn't, at that stage, have any ill effects. So, that's all I sort of knew, you know. Your ALTs are high, your ASTs are high, all that sort of stuff. Anyway, fast-forward, and still no ill effects in jail. Even though I was becoming aware of it because there was an old-timers' wing, like unit, that they had turned into a hepatitis treatment sort of section (and it was interferon), but the amount of thought I gave it was minimal [...] I wasn't serious then, because there was no ill effects.

Laura (female, 30, no treatment experience) recounted concerns about side effects associated with the interferon-based treatment and explained that they are one of the reasons she had not had treatment yet.

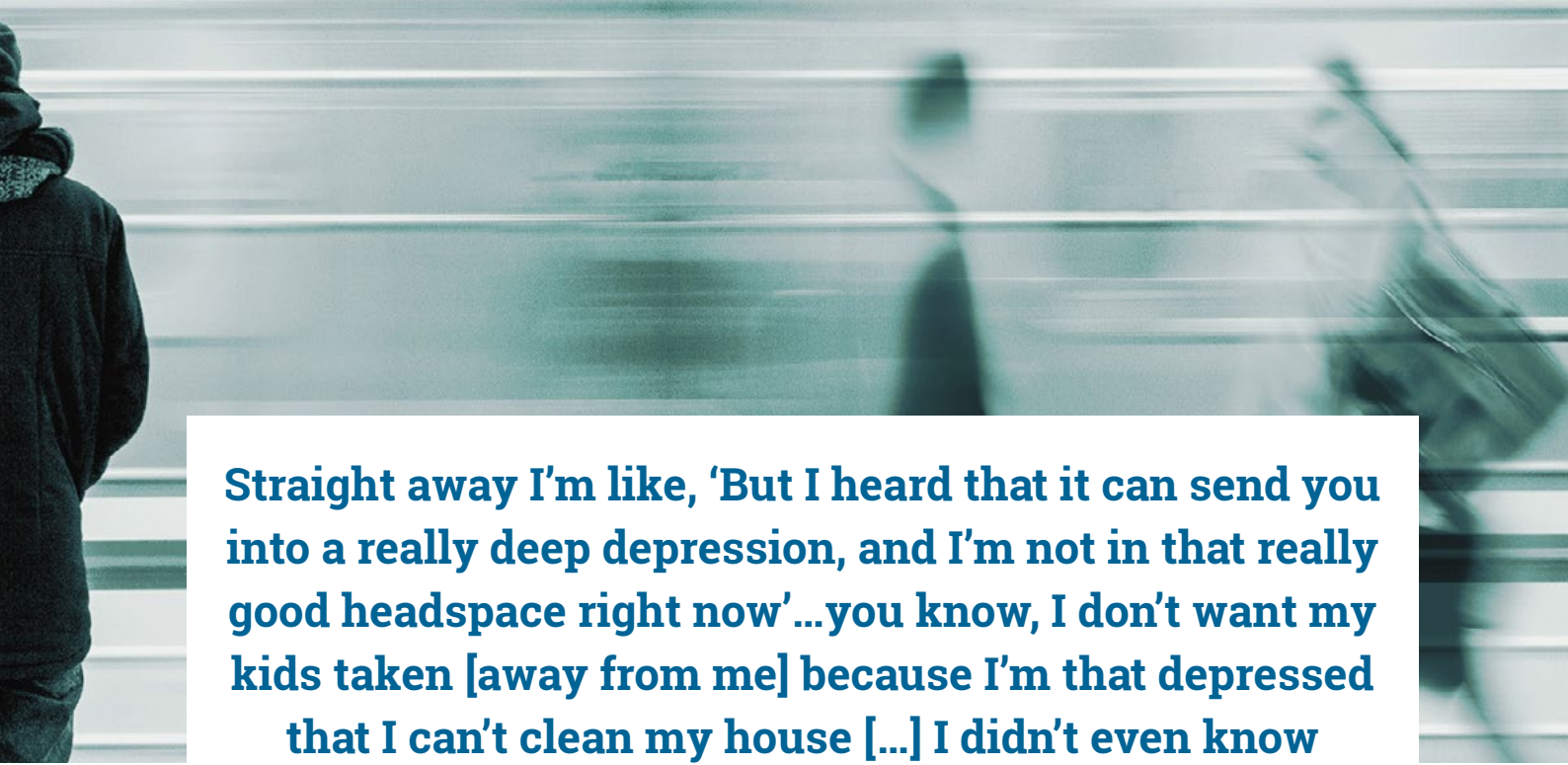
Straight away I'm like, 'But I heard that it can send you into a really deep depression, and I'm not in that really good headspace right now' [...]

Exactly the first thought that came into my head was that [...] Like, at one point, [treatment is] going to help me heal, but at the same point, I don't want to, you know, put my kids through that and I don't want to... you know, I don't want my kids taken [away from me] because I'm that depressed that I can't clean my house [...] I didn't even know there was a new treatment until you [the interviewer] mentioned it [...] Yeah, it's all confusing.

While DAAs are not associated with significant side effects, these findings show that the negative reputation of past treatments may linger and continue to discourage people from seeking treatment. Also, people may delay treatment because of an absence of symptoms.

¹ Alanine transaminase, or ALT, is an enzyme found in the liver that helps turn proteins into energy for the liver cells. When the liver is damaged – for example, by hepatitis C – ALT is released into the bloodstream and levels of it in the body increase.

² Aspartate transaminase, or AST, is an enzyme that helps the body process amino acids. When the liver is damaged – for example, by hepatitis C – AST is released into the bloodstream and levels of it in the body increase.



Straight away I'm like, 'But I heard that it can send you into a really deep depression, and I'm not in that really good headspace right now' ...you know, I don't want my kids taken [away from me] because I'm that depressed that I can't clean my house [...] I didn't even know there was a new treatment until you [the interviewer] mentioned it [...] Yeah, it's all confusing.

LAURA (FEMALE, 30, NO TREATMENT EXPERIENCE)

Experiences of making decisions about hepatitis C treatment

Criminalisation and custodial settings

While there are several ways to get DAA treatment in Australia, some obstacles remain even for those who wish to have it. For several people interviewed for the project on which this broadsheet is based, criminalisation and imprisonment made accessing and completing treatment difficult.

Cal (male, 50, no treatment experience) described how he wanted to have treatment to 'make the best' of his time in prison but found it hard to complete treatment because of cycles of imprisonment and bail (conditional release).

Yeah, [I wanted to start treatment while I was in prison in] 2014 [...] I thought, 'I am going to make the best of this and start treatment' because I could have been in there for a while. Then I ended up being bailed. But I

wanted to continue on [the treatment after I left prison but...] I ran into a few hurdles [...] I was staying at [...] the homeless place where I was bailed to and, yeah, [...] they were making life hard for me. I don't know whether it was over the charge that I was on from the court or, you know, but right from the start, I was copping hassles with them, and [...] they kicked me out [...] This made me breach my bail and so I ended up just going, 'What's the point?', you know, and I didn't chase it up [any] more.

Referring to the conditions inside prison, Dominic (male, 36, experience with DAA treatment) explained that while he had hoped to have treatment during his sentence, medical care was scarce.

I actually did want to do it [treatment] when I was locked up,

but it would be a miracle if you get to see a doctor when you're inside, a miracle [...] The medical system inside is a nightmare [...] It's just hard to even get them to take you to see a doctor. It's hard to get a Panadol if you've got a migraine [...] I put [hep C treatment] on the medical form and requested it and it went nowhere [...] But it would have been good to do it while I was inside, because you are just locked in your cell all day and it's a perfect place to do it.

Several participants described the criminal justice system as disrupting their efforts to look after their health and wellbeing in general, and to have treatment for hepatitis C in particular.

Conclusion and recommendations

Participants described a variety of social and political issues that shape decision-making around treatment and the ability to access or complete treatment. Friends, family and intimate partners are central to deciding to have treatment.

Many of the people we interviewed said they were motivated to start treatment out of consideration for partners or concern about transmitting hepatitis C to friends and family. Others wished to avoid having to disclose a positive hepatitis C status to potential partners.

People may also have treatment in order to care for the wellbeing of family members, particularly when parenting and children are concerns. Wanting to have children in the future, or managing existing parenting responsibilities, were also considerations, especially among the women we interviewed. People also described relying on family and friends for support and guidance during this period; however, many were careful about who they disclosed to.

Difficulty finding and starting hepatitis C treatment was also a key issue. Obstacles identified in the healthcare system include barriers to testing, being removed from waiting lists due to missed appointments and limitations in the quality of healthcare. This research project also found that limited information about the availability of DAA treatment and confusion about side effects contributed to treatment non-uptake. Some participants who were aware of DAA treatment did not know how to access it.

Other significant issues such as insecure housing, stigma and mental illness continue to make accessing and completing treatment difficult and sometimes impossible. Importantly, criminalisation and obstacles arising from custodial settings also make it difficult for people to access healthcare and address health concerns.

Key recommendations based on these findings

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.
- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.
- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

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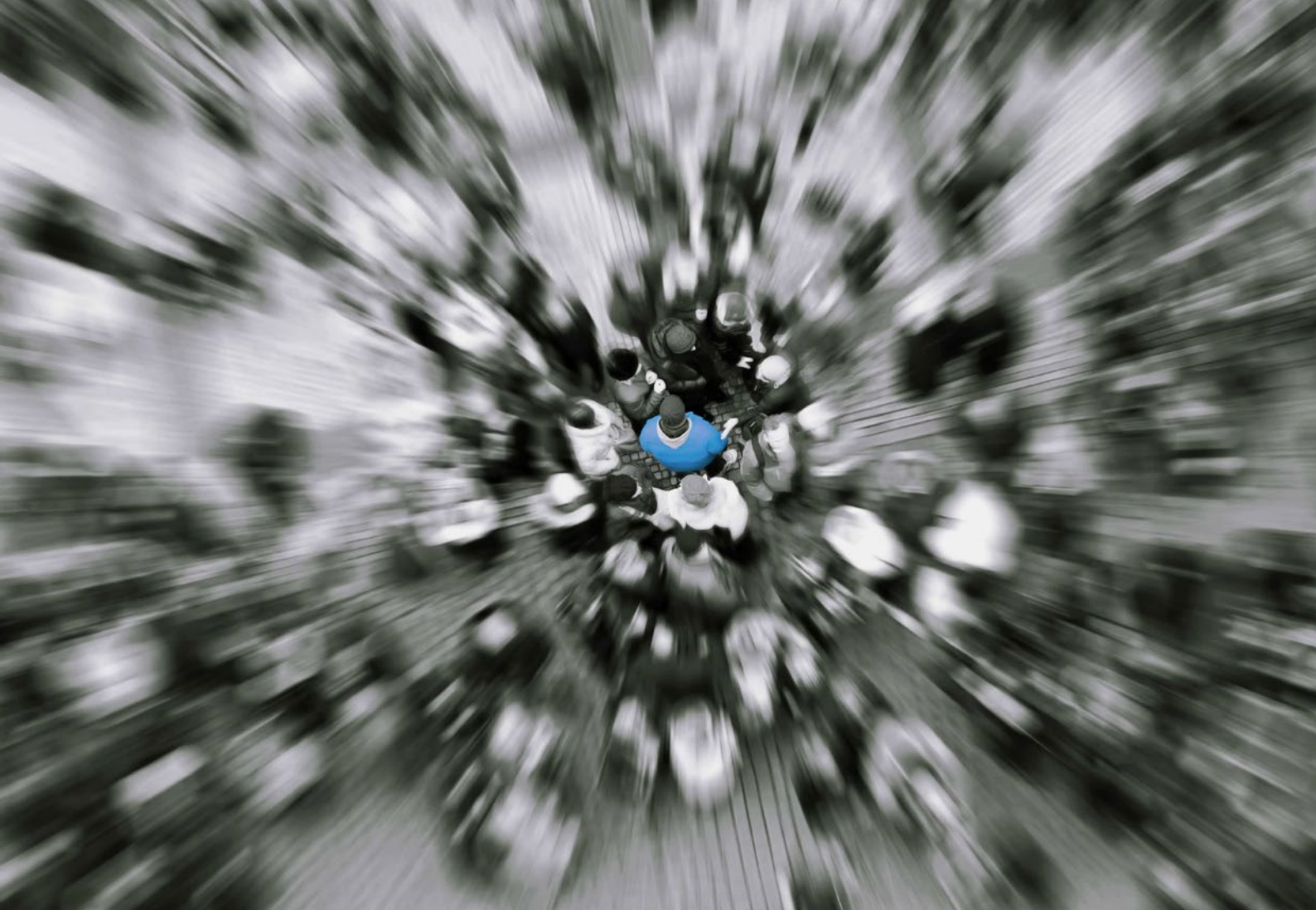
Appendix 1:

Participants

| Participant information | Number |
|--|--------|
| Gender | |
| Men | 27 |
| Women | 21 |
| Trans women | 1 |
| Non-binary | 1 |
| State | |
| Victoria | 27 |
| New South Wales | 23 |
| Age | |
| 30-39 | 10 |
| 40-49 | 21 |
| 50-59 | 9 |
| 60-69 | 8 |
| 70-79 | 2 |
| Type of treatment | |
| DAA treatment | 19 |
| Interferon-based treatment | 9 |
| Both DAA and interferon-based treatments | 9 |
| No treatment experience | 13 |
| Employment status | |
| Working or studying | 15 |
| Not working or studying | 31 |
| Retired | 4 |

| Participant information | Number |
|--|--------|
| Education level | |
| Incomplete secondary | 22 |
| Complete secondary | 12 |
| Post-secondary | 6 |
| Tertiary | 10 |
| Cultural and ethnic background* | |
| Australian | 32 |
| Aboriginal Australian | 5 |
| New Zealander | 2 |
| North African and Middle Eastern | 1 |
| North American | 1 |
| North-West European | 2 |
| Southern and Eastern European | 6 |
| Southern and Central Asian | 1 |
| Sexuality | |
| Heterosexual | 41 |
| LGBQ+ | 9 |

* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.



Appendix 2:

Articles in press and under review

Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness*. <https://doi.org/10.1111/1467-9566.13467>

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments

to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment

decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug

consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.



La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world's largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to 'gamagoen yarrbat' – to soar.

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