



Experiences of DAA treatment and hepatitis C cure:

Treatment knowledge, interactions with health professionals and questions after cure

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

This broadsheet is the third in a series of four that summarise key project findings.

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Broadsheet No. 3

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

Experiences of DAA treatment and hepatitis C cure:

Treatment knowledge, interactions with health professionals and questions after cure

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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](#).



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Recommendations

This broadsheet is the third 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 treatment 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). Along with significant differences between old and new treatments in prescribing and availability, the new medications have transformed the clinical management of hepatitis C (Bajis et al., 2017; Richmond et al., 2018).

Optimism surrounds the relative ease and simplicity of the new medications, the 'miracle' of cure and a much longed-for future without hepatitis C (Rhodes et al., 2019). Qualitative research suggests that patients find the new DAA treatment comparatively easy and it leads to improvements across physical, emotional and mental health (Goutzamanis et al., 2021). However, a range of social issues continue to shape and often impede uptake.

In Australia, Madden et al. (2018) identify barriers to treatment such as gaps in continuity of care, stigma, poor vein health, and the challenge of finding supportive and non-judgemental care. Commenting recently on Australia, 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-related barriers for undertaking treatment. They also identify enablers at the personal level such as the support of social networks, at the provider level such as trusting and respectful GPs, and at the system level such as fully subsidised costs and simple treatment pathways.

While DAAs have vastly fewer side effects than interferon-based treatments, concerns about side effects are also thought to continue to shape treatment access and experiences (Bryant et al., 2019; Wright et al., 2019). In this respect and others, some contend that efforts to increase uptake would benefit from fully engaging with the meanings given to treatment that circulate within affected communities (Bryant et al., 2019).

While improvements in physical health, such as an increase in energy levels, are significant (Goutzamanis et al., 2021);

Mora et al., 2020), experiences of cure are also imbued with deeper meanings. Some research indicates that people affected by hepatitis C primarily value the broader effects of cure such as the relief of not having a looming chronic illness (Mora et al., 2020) and, consequently, treatment benefits need to be understood beyond clinical outcomes alone (Goutzamanis et al., 2021). In this sense, hepatitis C cure is not solely defined by sustained virological response (or SVR), the accepted definition of cure (Kirby Institute, 2018), or by improved physical health, but is invested with meanings beyond the virus and its effects. Multiple articles argue, for example, that hepatitis C cure offers a symbolic break from a past life and stigmatised subjectivity linked to a history of injecting drug consumption (e.g. Harris, 2018; Madden et al., 2018; Pourmarzi et al. 2020; Richmond et al., 2018; Vega et al. 2021; Williams et al., 2019). Reflecting the complexity of treatment experiences, some research emphasises that individuals accessing treatment often hope for outcomes beyond cure, such as new social connections and strategies to manage health and wellbeing (Madden et al., 2018).

Our research contributes to this literature by exploring the way that participants described their qualitative experience of treatment. We show that participants had concerns about DAA treatment when they were not given sufficient information about what treatment involved or post-treatment life.

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 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.

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 third 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 we interviewed for this project described positive experiences of DAA treatment. The ease and simplicity of DAA treatment, along with the high success rates, were highly valued by participants and central to their treatment experiences. While many participants recounted positive interactions with health professionals, some described wanting more information about hepatitis C itself, treatments and potential health issues that might occur in the future after cure. Overall, descriptions of being cured indicate that treatment was

generally a positive experience, connected to improved health and wellbeing and feelings of optimism about the future.

In the following sections, this broadsheet covers participants' perspectives on and experiences of DAA treatment, their reflections on the role of health professionals in treatment experiences, their need for further information, and experiences of cure.

The new treatment: Simple and easy

Participants with experience of DAA treatment generally described it as 'simple' or 'easy' to take. Comments were almost wholly positive, and often focussed on the treatment's minimal side effects or how easy it was to include it in daily routines.

Dave (male, 65, experience with both DAA and interferon-based treatment) said that DAA treatment was 'quite easy' to incorporate into everyday life, and he encouraged others to have it too.

It was just a bottle of tablets that was sitting next to my vitamins, which I had every morning. I took them at seven [pm], every night I took them at seven, so quite easy [...] I have friends who still have hepatitis C and I try and encourage them to get treatment [...] Good hep C treatment [should be] available to everybody whether they are using drugs or not [...] It should be freely available to everybody.

Sam (male, 35, experience with DAA treatment) offered a similar assessment when he said treatment could not have been 'any easier'.

I don't think that you could get anything better than taking one tablet a day. You couldn't get it any easier than that [...] For people having treatment down the road in the future, like, yeah, as long as they can stay on top of it, I don't think you could make it any easier than one tablet a day.

For some participants, treatment was so uncomplicated, there was not much to say about the experience.

Robbie (male, 54, experience with both DAA and interferon-based treatment) had DAA treatment at the same time as his friend.

[My friend and I] heard about this new program, the tablets, and then the friend I'm staying with, we both got

on it and both got rid of it within a month [...] We heard about it] from the doctor [...] who said] that there was a new treatment out and it worked for others pretty good, and if you want to try, give it a go, yeah. So we did and it worked [...] Yeah, it went for three months and, yeah, I stayed on the program for the whole three months, even though [the hep C] was gone within the first month.

Because the interferon-based treatment was known for significant negative side effects that diminished quality of life, many of the people who had DAA treatment expressed that they were relieved by and happy with their experiences with DAAs. Harriet (trans woman, 30, experience with both DAA and interferon-based treatment), for example, reported that it was 'the best thing [she] ever did for [her]self [...] because there are no side effects or anything'. Similarly, Terence (male, 34, experience with DAA treatment) said that for him there were 'no side effects whatsoever', and Regina (female, 69, experience with DAA treatment) explained simply that for her there were 'no side effects, and it worked and it was fantastic'.

Commenting on the absence of side effects for him, Tristan (male, 49, repeat diagnoses, experience with both DAA and interferon-based treatment) compared DAA treatment favourably to taking headache medication.

I was expecting there to be some sort of side effects, but no. Just like taking an aspirin once a day and that was it [...] No side effects, nothing at all. Whereas with the interferon, you'd get to the end of the week, you'd start feeling good because all the drugs are wearing off, and you'd have to stick [inject] yourself in the belly again and an hour later, you feel like dog shit for the next five days. And then it starts wearing off and you become good, and then you stick [inject]

yourself again. But the new one [treatment], that is unbelievable.

While Chris (male, 60, experience with DAA treatment) did not speak about side effects directly, he described DAA treatment as 'gentle'.

I didn't [know] what to expect, but it was so gentle and unassuming and unnoticeable. I just had this pill every day and that was it, and 12 weeks later it was done [...] It was like the beginning of the disease [hep C] where you know you've got it, but it doesn't bother you [with any symptoms, so you] think it doesn't matter. The treatment was kind of the same, it was really benign and gentle.

Participants described DAA treatment in very positive terms: 'gentle', 'fantastic', 'unbelievable' and 'the best', but, as discussed below, some suggested they would have liked more information about what to expect during and following treatment. Because the interferon-based treatment was known for significant negative side effects, participants were often surprised by their absence. In contrast, DAA treatment was generally without side effects and simple to take.



Reflections on DAA treatment and being cured

Need for more information about DAA treatment

Overall, DAA treatment was widely considered to be much better than the old interferon-based treatment, but some participants indicated they would have liked more information while having treatment. Key points included uncertainty about the effects of hepatitis C and about treatment policies and procedures, and in some cases, there was a desire for more information about treatment before starting it.

Steve (male, 49, experience with DAA treatment) said he was given minimal information about DAA treatment.

No, no, I wasn't told hardly anything. I was just handed a bottle and said, 'Here, take this once a day.' [...] I instantly linked it to giving me an extra few years of quality life, you know [...] I was sort of expecting to maybe feel a bit off, like, after I started taking it, but no, I didn't even notice it really.

Alexander (male, 45, experience with DAA treatment) also described being given little information about hepatitis C and the tests he had.

I was on the treatment a few months ago, this new medication that they've got for hepatitis, and they did some sort of check then, but my liver exam is normally generally pretty good, even when I've been [taking] drugs [... Even after the check-ups] I've [still] got no idea [what my genotype is].

Paulie (male, 45, experience with DAA treatment) explained that while his GP advised him to have treatment, he was not informed that he could have treatment again if he was cured but acquired the disease again in the future.

If I got it [again], I'd like to do [treatment] again, but I don't know. Are you allowed to do it again? If I had hep C and I'd done the treatment and [been cured of] it and then I've caught it again, can you reapply and get the treatment done again, or [do] they ban you or something after you've done it once and you get it again or something? I don't know.

Sam (male, 35, experience with DAA treatment) described his GP's approach as comforting but not informative enough.

I thought [being diagnosed with hepatitis C] was a life sentence, and I went and saw my GP and got tested and, yeah, like, he was pretty blasé about it, you know what I mean. He said, 'It's so easy to get cured from it, there's no reason to be getting upset.' It sort of made me feel a lot more comfortable with it, in all honesty, but in saying that, I still really didn't understand it and I didn't ask the questions... like, I didn't get the answers from him that I should have been getting. In saying that, I didn't ask questions to him to fully understand what I was dealing with [...] I would have liked to have known] just how it affects the body, you know, what am I going to be going through as opposed to someone who didn't have hep C. You know, how it's really going to affect my day-to-day life.

These findings indicate that while treatment is straightforward, more detailed information about hepatitis C is often desired, including whether it can return, and what to do in the case of reinfection.



Reflections on DAA treatment and being cured

Interactions with health professionals

Many people we interviewed recounted their experiences with the health professionals who managed their hepatitis C treatment. Health professionals were instrumental in guiding people into treatment and had an important part to play in their treatment experiences overall. Many of the people we interviewed said that health professionals described DAA treatment as simple and easy, and encouraged them to consider it.

Rod (male, 41, repeat diagnoses, experience with DAA treatment) talked about how a doctor encouraged him to begin treatment.

I had the nurses explaining to me, like, how easy it was [... to have] treatment

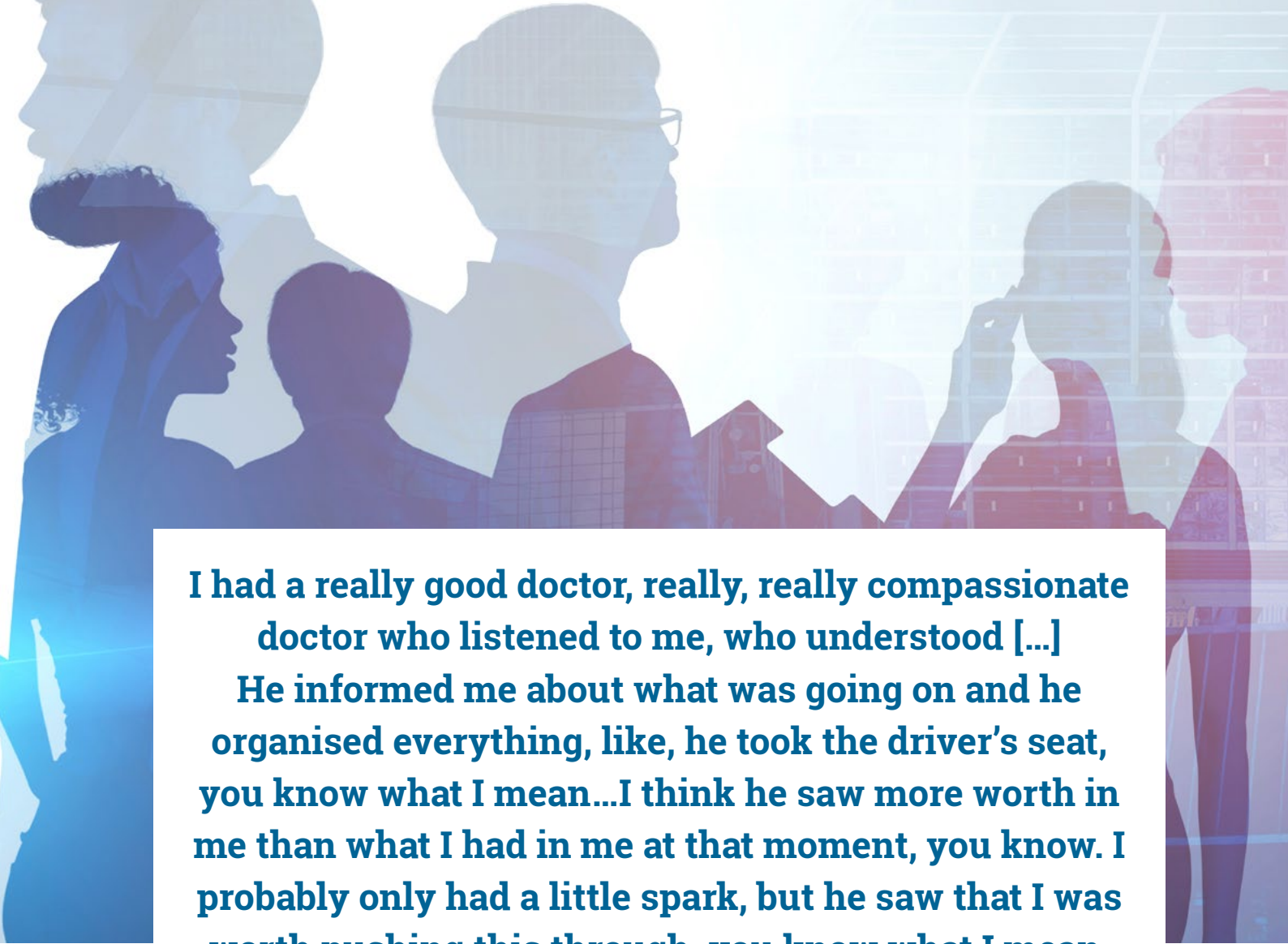
and I went to the [hospital liver clinic] and there was a doctor... can't think of her last name, really nice lady [...]
Yeah, she explained everything to me and said it was a good time for me to do it now and, yeah, [I] just stuck with her and got that done.

Many of the interviews considered what good healthcare looks like for hepatitis C treatment. A common response was to highlight the value of knowledgeable and thorough healthcare professionals who take an active role in treatment and provide care and support.

As Gretchen (female, 68, no treatment experience, experience with spontaneous clearance) explained, she chose her current GP because he was

'knowledgeable' and did not have a negative reaction to her experience with hepatitis C.

I'm very sceptical of doctors. Because I've worked in the health system, I know they're not all good. So, when I changed from [my current doctor to] where I live now, about 10 years ago, I needed a good GP. I think it's good to have rapport with your doctor, not just any port in a storm. You've got to get to know each other [...] Yes, and that's why I chose him, because he didn't flinch, he asked me about it [hepatitis C], he asked me stuff and he's... I'm 68, he could be about my age ... He wears boots and jeans, you know, and I thought, 'He's an old hippie', but he's very good. He's very



**I had a really good doctor, really, really compassionate doctor who listened to me, who understood [...]
He informed me about what was going on and he organised everything, like, he took the driver's seat, you know what I mean...I think he saw more worth in me than what I had in me at that moment, you know. I probably only had a little spark, but he saw that I was worth pushing this through, you know what I mean, and he chased it up, chased it up and chased it up.**

COLIN (MALE, 44, EXPERIENCE WITH BOTH DAA AND INTERFERON-BASED TREATMENT)

knowledgeable and very thorough, and there was no discrimination.

Colin (male, 44, experience with both DAA and interferon-based treatment) described the way his doctor took charge of his treatment and demonstrated he was invested in his future and wellbeing.

I had a really good doctor, really, really compassionate doctor who listened to me, who understood [...]. He informed me about what was going on and he organised everything, like, he took the driver's seat, you know what I mean, and [he] really did, you know what I mean. It was more than just bedside manner, like, he showed a vested interest, like, in me getting better, you know what I mean. I think he saw more worth in me than what I had in me at that moment, you know.

I probably only had a little spark, but he saw that I was worth pushing this through, you know what I mean, and he chased it up, chased it up and chased it up.

Sana (female, 71, experience with DAA treatment) said that the health professionals managing her treatment were 'fantastic' and very respectful. She explained further that she experienced some skin-related side effects during treatment, and the doctor was very helpful.

Every person during the treatment was fantastic [...]. Even the nurses [...] the ones that work under a specialist, they are so helpful. [...] They were very helpful and [...] they speak nicely. When they know that I can't understand English, they

speak, like, [a] little bit slowly and just on the targeted words and with a smile, facial expressions, and they give [me...] full respect [...]. I got a lot of itchiness on [my] whole body during the treatment, when [I] was having that medication. So [...] I just keep applying a lot of Vaseline and, you know, high petroleum jellies and things like that. [I] asked the doctor, like, 'I'm having [itchiness]', but the doctor said, 'Yeah, it normally happens during that treatment'.

Importantly, the information and support provided by trusted health professionals can encourage people to access treatment. Participants explained that informative, trustworthy and caring health professionals were important to their overall experience of treatment and wellbeing.



Reflections on DAA treatment and being cured

Experiences of cure

The people interviewed for this website offered a range of different perspectives on what being cured means and how it affected their everyday lives. Some explained that it led to improvements in health, vitality and wellbeing, while others expressed concerns about hepatitis C returning in the future. Overall, participants' descriptions of being cured indicate that, while it was generally a positive experience, its effects were not uniform and were shaped by personal circumstances.

Kylie (female, 46, experience with DAA treatment) said that completing treatment got rid of the frequent headaches she had previously experienced, and it also improved her mental health.

I shout it from the rooftops [...] Yeah, it's just made me happier [...] Well, [being cured] made me feel better, because I don't suffer from the headaches that I used to suffer

from all the time, and I don't feel as depressed as what I did when I knew that I had hepatitis. So yeah, it's made me feel happier within myself.

Many of the people we interviewed described feeling great emotion after being told they were cured of hepatitis C. Feelings such as relief, happiness, joy and optimism were common.

According to Lou (female, 40, experience with DAA treatment), although she was not comfortable speaking with many people about her experience of hepatitis C, her treatment experience and cure led her to reflect on what was meaningful in her life and now informs her practice as a social worker.

I think [my cure's] probably, you know, added to the richness of what's meaningful in my life, and I think it's probably made me a better social worker. It's certainly helped me

maybe, yeah, reflect on some of my own assumptions and vices that I didn't realise that I had. I think I have always thought that maybe one day I would like to be able to talk a bit more about it publicly. Perhaps that day will come, perhaps it won't, but yeah [...] And [...] maybe it's added to my thinking that you just don't know what's coming around the corner, so just make the most of it. It sounds a bit like a platitude, but really, just to make the most of what's in front of you right now.

According to some of the participants, being cured also meant feeling free of worry about passing on hepatitis C to other people, and feeling more optimistic about the future.

Miguel (48, male, experience with DAA treatment) started having treatment during a period in which he was making other positive changes in his life. He



Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't dying, but of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something [...] I think I've got cirrhosis, if I remember [correctly], a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink, not that I was a big drinker, but I've not had a drink of alcohol since.

FOR REGINA (FEMALE, 69, EXPERIENCE WITH DAA TREATMENT)

described being cured as offering him renewed optimism and vitality.

As soon as the treatment started, I started feeling not much difference, but [then I started to feel [...] a fresh new start kind of feeling, you know [...]] At that time [...] I found some work, and also [other] things were falling into place, and I [wasn't taking drugs any more]. On top of that, [I was also thinking...] that soon enough I would get rid of hep C and then I [wouldn't] have to think of it ever again. [I wouldn't have to ask,] 'If I cut myself, who's around?' [... This] stuff weighs on you, and feeling like you are less than others because you've got this disease. So yeah, I reckon [...] I felt relieved and stronger and just able to look at the world with a new set of eyes. I felt I had an influence on the people around me too, because I was like, 'Okay, things are finally working out': rehab, this [new] work and now a clean bill of

health. Yeah [...] it worked so fast as well. The treatment was [...] about three months and the doctor [...] said, 'Yes it's definitely cleared up', whereas for years, we didn't have a clue [what] we were going to do. There was no cure or hope in sight, and then all of a sudden, there it is, you know what I mean?

Some people explained that they had a different response, one not totally free of worry about their health and future, as they considered the longer-term health effects of having had hepatitis C or the potential for it to come back (see Broadsheet No. 4, *Life after hepatitis C treatment: Health, wellbeing and the future*).

For Regina (female, 69, experience with DAA treatment), being cured of hepatitis C was a 'relief', but she worried about developing liver cancer in the future.

Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't

dying, but of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something. There's always that slight worry, but I try not to worry [...] I think I've got cirrhosis, if I remember [correctly], a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink, not that I was a big drinker, but I've not had a drink of alcohol since.

While many participants experienced cure as a joyful event that signified positive changes in health and wellbeing, and was connected to renewed optimism and energy, some continued to be concerned about the future, especially the possibility of developing hepatitis C-related health issues, including liver cancer.

Conclusion and recommendations

Most of the people interviewed for this project had overwhelmingly positive experiences of DAA treatment. Treatment was described as simple and easy, and most people experienced few side effects.

While most of the people we interviewed described positive experiences of DAA treatment, some mentioned needing further information about treatment and more support following treatment. They were left with questions about what to expect during treatment and after cure, including questions about ongoing health effects and reinfection.

Positive interactions with health professionals were found to be crucial to positive experiences of treatment. Participants described health professionals encouraging them to begin treatment and guiding them through this process. Respectful and trustworthy healthcare was highly valued by participants.

Finally, while the meanings given to cure varied, they were often connected to improved health and wellbeing, feeling positive about the future and increased vitality more generally.

Key recommendations based on these findings

- 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.

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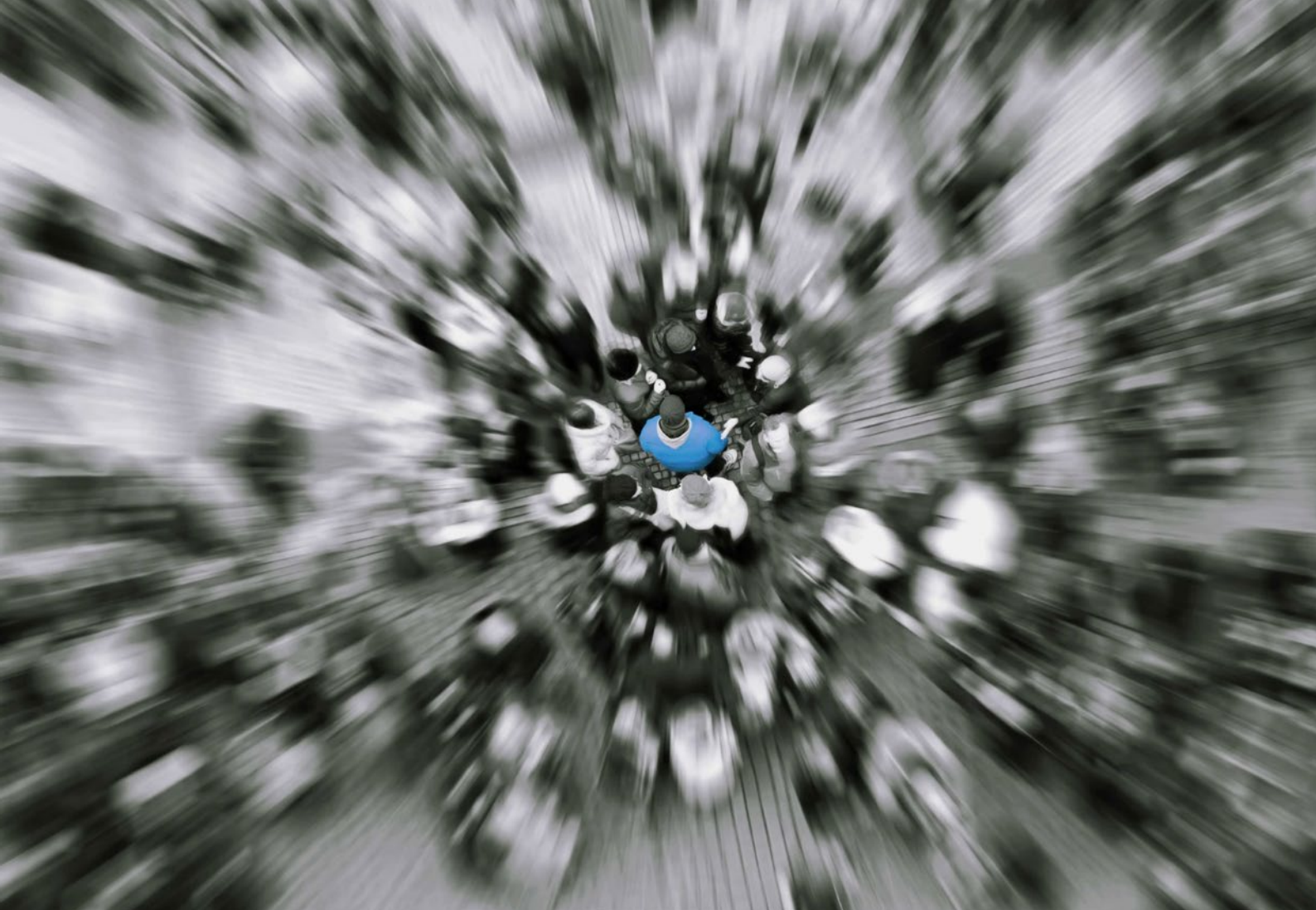
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Appendix 1: Participants

| Participant information | Number |
|--|--------|
| Gender | |
| Men | 27 |
| Women | 21 |
| Trans women | 1 |
| Non-binary | 1 |
| State | |
| Victoria | 31 |
| New South Wales | 29 |
| 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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