



LA TROBE UNIVERSITY

Non-uptake of treatment for hepatitis C in the anti-viral era: A qualitative analysis

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Acknowledgement of country

We acknowledge the traditional owners of the lands on which our research was conducted and recognise their continuing connection to land, waters and culture. We pay our respects to their Elders past and present.

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Project overview

Background

- Hepatitis C is a blood-borne virus that harms the liver. In Australia it is mostly transmitted via injecting drug use.
- Treatment has improved enormously in recent years with the introduction of interferon-free direct-acting antiviral (DAA) medications.
- With the advent of these new treatments, the Australian Government adopted the World Health Organization's ambitious goal of eliminating hepatitis C by 2030.
- Not enough is known about experiences of hepatitis C and its treatment, and reasons for not having treatment, in this new phase in which elimination seems possible.

This presentation

- People who do not take up treatment are of increasing concern to researchers, health professionals and policymakers.
- The presentation draws on 50 interviews conducted for a research project on treatment uptake.
- It will focus on one case study to illuminate broad issues needing attention in the quest for elimination, but the article on which it's based has three different case studies.
- The analysis is informed by Lauren Berlant's work on 'slow death' and the 'wearing out of populations' under late capitalist neo-liberal systems.
- It explores key issues of agency and sovereignty to explain the dynamics at work in such apparently inexplicable and individually disadvantageous outcomes.

Background

- About 130,000 people in Australia have hepatitis C.
- In 2016 the Australian government subsidised the new treatment under its Pharmaceutical Benefits Scheme, so treatment is free.
- Cure is largely conceptualised as now 'easy'. In this context, questions arise about those who, despite having a diagnosis of hepatitis C, don't take up treatment.

Literature

- Treatment uptake is identified in the literature as an effect of social dynamics as well as availability.
- Little research considers the question of agency within disadvantageous structural contexts to understand treatment decisions.

Approach

- How should we understand conduct that seems to run counter to personal benefit and the accrual of resources and social standing?
- Dilemma (Moore and Fraser 2006): should drug consumers be considered self-managing autonomous agents, capable and rational actors in making decisions about harm reduction, or should their unique disadvantages authorise offering them special treatment but in doing so define them as limited, because their capacity to make rational decisions is presumed to be compromised?
- Berlant raises similar questions, proposing a new language or the complexities of agency in 'conditions of attrition': 'slow death', 'exhausted practical sovereignty' and 'lateral agency'.

Approach

Berlant's key term in the article is 'slow death', which is defined as:

the physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence. (Berlant, 2007, p.754)

Berlant's aim is to better account for what the piece describes as experience that is:

simultaneously at an extreme and in a zone of ordinariness, where life building and the attrition of human life are indistinguishable, and where it is hard to distinguish modes of incoherence, distractedness, and habituation from deliberate and deliberative activity, as they are all involved in the reproduction of predictable life. (Berlant, 2007, p.754)

Berlant offers useful ways of understanding 'inconvenient human activity' that retain ideas of sovereignty and agency, but reframe them to shed necessary light on the systemic impediments and forces of attrition to which individuals, especially those living in conditions of deprivation or disadvantage, are subject.

Method

- 50 in-depth qualitative interviews with people affected by hepatitis C (27 in Victoria and 23 in New South Wales)

The 50 interview participants have the following characteristics:

- Experiences of DAA treatment only: (n=10)
- Experiences of interferon-based treatments only: (n=8)
- Experiences of both treatments: (n=6)
- Experience of hepatitis C without any treatment experience: (n=8)
- Experiences of reinfection after cure: (n=6)
- Uncertainty about hepatitis C status (e.g., they may see themselves at risk of hepatitis C): (n=6)
- Key populations for elimination goals (e.g., participants not connected to AOD services or participants who acquired hepatitis C overseas): (n=6)

Case study: Cal

- Cal: male, aged 50, homeless, history of incarceration
- Diagnosed with 'non-A, non-B hepatitis' in the early 1990s, at age 17.
- Told his life expectancy could be curtailed by the disease, felt frightened and hopeless.
- Diagnosed when little was known about the disease, and before the internet made information readily available.
- Blames himself for not starting treatment yet conditions extremely disadvantageous.

Case study: Cal

Cal explains that taking up treatment was not easy, even once DAAs became available:

... my drugs kept getting in the way. I knew in myself I wouldn't have finished them courses [of treatment] if I started them, because I was just too unreliable for anything [...] I did attempt to try to start, but it just seemed to be too much [...] like I couldn't have turned up daily to take things, you know, so, yeah, I sort of sabotaged a lot of the things that I maybe could have done.

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Case study: Cal

- During most of Cal's adult life, treatments were onerous, with low success rates, and his circumstances were marked by homelessness and incarceration. Drug consumption a form of lateral agency – as about 'making a less bad experience' (Berlant) of life.
- Cal's attempts to begin treatment are stymied by random incarceration and bail events and an unanticipated hepatitis B diagnosis.

It just seemed like I'm always getting stoppers, like it's... I lift my spirits up or someone gees me up to give it a go and then there's ... [...] it was just like, 'Man!' I couldn't start [treatment] even then, you know, so it's sort of been put on the back burner again.

- Cal's experience of hepatitis C within a prohibitionist legal context, shaped by unpredictable events in the criminal justice system, can be understood via the notion of 'slow death' (Berlant).

Case study: Cal

- Cal's health is composed via demands and circumstances that frame experience through notions of individual agency and responsibility but are simultaneously antithetical to the advancement of individualised projects of self-care.
- Despite many structural obstacles, Cal invests in very strong sense of, potentially counterproductive, individual responsibility and agency.
- Cal: strong fear of letting others down through an inability to sustain treatment.

I have panic attacks real easy and, yeah, if I start going into one, I pretty much can be lost in that [...] Like, if I go into a panic attack, then it can totally scare me away from even starting something, you know?

Conclusions

- This presentation aims to illuminate an area epidemiologists, policy makers and health professionals might consider 'inconvenient human activity': the non-uptake of treatment among people with hepatitis C.
- Aim to expand understanding of sovereignty and agency such that neither are simplistically individualised nor discarded altogether, and 'modes of incoherence, distractedness, and habituation' – as in Cal's struggles to engage treatment and his returns to consumption of illicit drugs – are understood to co-exist alongside 'deliberate and deliberative activity [...] in the reproduction of predictable life' (Berlant, 2007).

Conclusions

As Berlant might say, these are ‘the burdens of compelled will that exhaust people’ (2007).

These burdens are made by conditions of privation and exhausted practical sovereignty and addressed via lateral agency in a criminalising, pathologising, capitalist carceral context of attrition that produces and wears out lives even as it also fetishises individual autonomy, responsibility and choice.

The full article covers more examples such as Cal’s and spells out the theoretical approach in more detail, including some of its limitations.

Key references

Berlant, L. (2007). Slow death (sovereignty, obesity, lateral agency). *Critical inquiry*, 33(4), 754-780.

Moore, D., & Fraser, S. (2006). Putting at risk what we know: Reflecting on the drug-using subject in harm reduction and its political implications. *Social science & medicine*, 62(12), 3035-3047.

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PERSONAL STORIES OF HEPATITIS C, TREATMENT AND CURE

Welcome to *Vital voices: Personal stories of treatment for hepatitis C*. This website has two aims. First, it aims to **support people living with hepatitis C in thinking about and/or having treatment**. Second, it aims to **inform the public about hepatitis C and what can be done about it**.

Why this website now? Public discussion of blood-borne viruses rarely looks further than the statistics, but it's important to remember health issues such as hepatitis C are experienced by many people in Australia and around the world, and that those people have complex lives, stories and experiences. After the advent of the **highly effective direct-acting antiviral hepatitis C treatments (DAAs)**, the **World Health Organization** developed a strategy to eliminate the virus as a public health problem by 2030. Australia is one of several countries that committed to the goal of eliminating hepatitis C by 2030, and this has led to a range of measures including listing the medications on the Pharmaceutical Benefits Scheme and initiatives promoting treatment.

This website allows you to explore vitally important personal stories of hepatitis C and treatment at a time when elimination of the disease across communities seems possible. *Vital voices* also aims to showcase the lives of people affected by hepatitis C, emphasising their significance, complexity and vitality.

Vital voices aims to inform public discussions of hepatitis C, to counter stigmatising misconceptions, and to promote understanding of living with the virus and its treatment.

WHAT IS HEPATITIS C?

Hepatitis C (often called 'hep C') is a disease caused by a virus that affects the liver. Most people living with hepatitis C have what's often referred to as 'chronic hepatitis C'. This can cause liver damage over time and can seriously affect the body if left untreated. A minority of people acquire and clear the virus without treatment. There are six different genotypes ('strains') of hepatitis C. These are labelled one to six, with subtypes organised using letters (such as 1a or 1b). Treatment is available for all genotypes and subtypes of hepatitis C.

HOW IS HEPATITIS C ACQUIRED?

Hepatitis C is a blood-borne virus. This means it is acquired through blood-to-blood contact. A common way to acquire hepatitis C is by sharing injecting equipment such as needles, syringes, or other items used for injecting, with someone who has hepatitis C. Hepatitis C can also be acquired by sharing personal items such as toothbrushes and razors, or through other forms of skin penetration – such as tattooing, body piercing or acupuncture – if unsterilised equipment has been used. It can also be acquired through healthcare procedures where sterilised medical equipment hasn't been used, or where hepatitis C is in the medical blood supply. In Australia, blood is screened for hepatitis C, and medical facilities are expected to use sterile medical equipment. **Find out more about the experiences of people who acquired hepatitis C sexually or through medical procedures.**

Hepatitis C is **not** acquired through:

- Hugging or kissing
- Sharing food or utensils
- Eating food made by someone who has hepatitis C

PREVIEW PERSONAL STORIES





Thank you

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