Title:
Beyond a 'post-cure' world: Sketches for a new futurology of hepatitis C
Authors:
Kate Seear*
Australian Research Centre in Sex, Health & Society
La Trobe University, Australia
k.seear@latrobe.edu.au
Currente France
Suzanne Fraser
Australian Research Centre in Sex, Health & Society
La Trobe University, Australia
Adrian Farrugia
Australian Research Centre in Sex, Health & Society
La Trobe University, Australia
National Drug Research Institute
Curtin University, Australia
kylie valentine

Social Policy Research Centre

UNSW Sydney, Australia

* = corresponding author

Abstract:

Australia's recent investment in, and optimism about, direct-acting antivirals to treat

hepatitis C brings with it the promise of new drug futures, including the possibility of a post-hepatitis C world and a revolution in the lives of people affected by the disease. But is the situation more complicated than we might assume? What expectations are being produced about post-cure lives? And what is being overlooked along the way? We argue that hepatitis C policy, practice and research can instantiate a problematic orientation towards medicine and 'the future' and explore ways of moving beyond these orientations. The essay then proceeds into two main stages. First, combining critiques from existing research with preliminary insights from a new study on hepatitis C 'post-cure' lives, we outline some of the key logics regarding cure and post-cure, and explain why such logics are problematic. We argue against the assumption that the availability of a medical cure will alone reverse the entrenched social, political and structural dynamics that drive infections and limit service access. To do so, we note, is to overlook the net of meanings and power relations that co-constitute hepatitis C and injecting drug use and render those associated with them marginalised and disenfranchised. Such optimism erases the legacy of laws and policies devised in a pre-cure world, and their role in generating and limiting new ways of being. Second, we introduce new ideas to the field and articulate a vision for what we call a 'futurology' of hepatitis C, designed to counter these assumptions and take us beyond problematic temporal logics. Our futurology is inspired by the work of Marco Cuevas-Hewitt (2011) on the 'futurology of the present'. Cuevas-Hewitt's approach discards linear temporalities, expectations of revolution and reform, and instead pays attention to multiplicities of becoming in the perpetual present. Taking up ideas from Cuevas-Hewitt, we introduce our own sketches for a 'futurology of hepatitis C'. This is a set of practices for thinking, researching, writing about and otherwise engaging with hepatitis C, characterised by attention not to what an imagined, singular future might look like, or to assumptions about treatment as revolutionary, but to what Cuevas-Hewitt (2011) calls the multiple 'perpetual presents' already with us, and aims to foment hope for change.

Introduction

Hepatitis C was first named in 1989, having previously been known as 'non-A, non-B hepatitis'. Fraser and Seear (2011: 1) have observed that since its naming, the 'form, meaning and implications of hepatitis C have been subject to continual debate'. Its meaning and implications continue to be, in Jacalyn Duffin's (2005: 83) terms, very much 'under construction'. This has continued in recent years, as a new generation of hepatitis C treatments based on direct-acting antivirals has emerged. These treatments were almost immediately lauded as groundbreaking. In Australia's Fifth National Hepatitis C Strategy: 2018-2022, they are described as offering an 'unprecedented opportunity to change the course of the epidemic' (Australian Department of Health 2018: 5). Compared to previous treatments, they have higher rates of cure (around 90% for some genotypes as opposed to 40% for the most common, now with even newer medications, for all genotypes), bringing a promise that the virus might actually be eliminated altogether (Franco et al. 2018). Indeed, the World Health Organization has announced an ambitious goal to eliminate hepatitis C by 2030. Australia, where the research to which this essay refers is being conducted, is one of the few countries in the world to adopt this ambitious goal (Australian Department of Health 2018; World Health Organization 2016). Many have met the possibility of elimination with great enthusiasm. It has been heralded as a 'revolutionary' moment (Martinello et al. 2018; de Graaf et al. 2018; Asselah et al. 2016; Gane 2014) and a 'gamechanger' (Scott et al. 2017: 107) as well as the 'dawning' of a 'new era' (Bragg, Crowl and Manlove 2017; Elbaz, El-Kassas and Esmat 2015) which has the potential to radically transform the health and social lives of people with hepatitis C. Importantly, in accounts of these new generation treatments, medicine is often understood to be an agent of transformation. For instance, Kish, Aziz and Sorio (2017: 329) argue that: 'The progress achieved in the 30 years between the discovery of this disease and the development of targeted medications represents the amazing potential of medicine'.

Importantly, these glowing accounts of medicine's 'revolutionary' potential and a 'postcure future' contain a series of assumptions regarding time, medicine, change and progress that warrant careful critique. They assume, for instance, that a medical cure will radically transform the lives of those treated. This appears overly optimistic, given the many, deeply entrenched social, political and structural dynamics that have shaped and limited the lives of people with hepatitis C to this point. These include the practical and symbolic associations between hepatitis C and the heavily stigmatised practice of injecting drug use. As Fraser and Seear (2011: 2) have previously explained, hepatitis C's

association with injecting drug use creates a powerful net of meanings that help shape understandings of the disease and of prevention and treatment options. Further, the illicit status of injecting drug use both reflects and contributes to stigmatisation, as well as contributing to the scale and shape of the epidemic.

Will these associations be simply resolved or somehow magically lose their force by virtue of cure? Optimism about medicine's revolutionary power overlooks these issues, as well as the various structural forces that generate and limit new ways of being for those who have been treated for hepatitis C. This includes, most notably, the ongoing criminalisation of drugs, but also the legacy of other laws and policies that were devised in a pre-cure world, but which continue to shape the lives of people with hepatitis C (discussed in more detail in the next section). Optimistic accounts of cure may also assume that treatment journeys unfold as sequential and progressive rather than emerging as complicated, multiple and digressive. All of these issues raise important questions about post-cure worlds. What promises are being made about these treatments and the new, post-cure world that accompanies them? Will it indeed be 'new'? What might a focus on the post-cure revolution do, and what might it overlook, along the way?

In this essay, we argue that there is a need to think through these questions. We argue that hepatitis C policy, practice and research can sometimes instantiate a problematic orientation towards medicine and 'the future'. Our purpose is to articulate some of these problems and to explore ways of moving beyond them. We do this using an approach that unfolds in two stages. First, combining critiques from existing research with preliminary

insights from a new study on hepatitis C 'post-cure' lives, we outline some of the key logics regarding cure and post-cure, before further elaborating on why such logics are problematic. Second, we introduce new ideas to the field and articulate a vision for what we call a 'futurology' of hepatitis C. This futurology is inspired by the work of Marco Cuevas-Hewitt (2011) on the 'futurology of the present'. Cuevas-Hewitt's approach challenges conventional revolutionary logic, discards linear temporalities, expectations of revolution and reform, and instead pays attention to multiplicities of becoming in the perpetual present. Following Cuevas-Hewitt (2011), we call for researchers to proceed cautiously about claims of a post-cure 'revolution', to think more critically about linear and compartmentalised approaches to time (regarding drugs, hepatitis C, and 'addiction') and to confront the related logics of progress and inevitability that are often embedded within them. As we will explain, a 'futurology' of hepatitis C also recognises that modes of research, writing and practice are constitutive of realities. If we reproduce problematic temporalities and temporal logics, we increase the likelihood that people who have already been cured will remain stigmatised and discriminated against. The possibility of ongoing suffering for people who use drugs or have/had hepatitis C will be, put simply, selffulfilling. Practices of research and writing can also increase the risk of people becoming reinfected, especially if people continue to be discriminated against and socially excluded in the putatively 'new' post-cure world. We need to consider the legitimacy and effects of claims that cure will open up access to a revolutionary 'new', 'future' life, where people who once had hepatitis C/people who use drugs are no longer subjects of stigma, discrimination and denigration. Our futurology seeks to outline an agenda for a new kind of scholarship that is more sensitised to these issues. Our essay culminates in sketches for a futurology of hepatitis C, which we define as a (non-exhaustive) set of practices characterised by attention not to what an imagined, singular future might look like, but to what Cuevas-Hewitt (2011) calls the multiple 'perpetual presents' already with us, and aims to foment hope for change. In the next section, we provide a brief introduction to work on drugs, addiction, hepatitis C, time and the future, before moving onto the key elements of our approach.

Drugs, hepatitis C and the problem of time

Temporality features centrally in discourses of 'addiction' and drug use. Writers such as Gerda Reith (1999) and David Lenson (1995) have written about the importance of time in drug use, 'addiction' and the controversial concept of 'recovery'. In this work, distinctions are often drawn between pre and post 'drug time', and between temporality as experienced before, during and after periods of 'addiction'. In Reith's work, for instance, addiction was described as a 'period of "lost time" characterized by an inability to envisage the future', where recovery from addiction was positioned as a 'reawakening' and 'reanimation' of the future. Such accounts have been the subject of critique. For instance, Suzanne Fraser and kylie valentine (2008) have argued that distinctions between pre and post 'drug time', and drug-using temporalities play an important role in the constitution of 'addicted' subjectivities, insofar as they are underpinned by a binary logic of normal/abnormal time, natural/unnatural consciousness and subject/abject. They argue that we should pay special attention to the way that logics regarding time circulate in drug discourse and practice, since such logics have the capacity to produce, reproduce or exacerbate stigma and discrimination. Related arguments were developed in Fraser, Moore and Keane's (2014) work on 'addicting', which introduced Steve Woolgar's work on 'gerunding' and futuring' (2011) to social research on drug use and related issues (see also Dilkes-Frayne, 2014; Fraser 2006; Michael and Rosengarten, 2012; Race and Wakeford, 2000).

Within the context of hepatitis C, there have been very few detailed considerations of temporality. An early example was Fraser and Seear's book (2011) on hepatitis C, which explicitly engaged with ideas of change and transformation over time, including, in particular, the assumption that medicine was heroic and transformative. They developed a 'quasispecies epistemology', defined as 'a set of observations about the constitution of phenomena drawn figuratively from hepatitis C's own genetic multiplicity' (2011: 143). This epistemology emphasised repetition, error, constant motion, non-linearity, multidirectionality and contingency as features of hepatitis C medicine. Following the work of Annemarie Mol (2002, 1999) a key theme of the book was the ontological

multiplicity of hepatitis C objects and subjects and the constantly moving, mutually constitutive relationship between medicine and its subjects. Building on ideas from Mol and collaborator John Law (2002) in order to examine the treatment available at the time, (pegylated interferon and ribavirin combination therapy), Fraser and Seear (2011: 115) noted that medical narratives regarding treatment (including those that take the form of standard, linear, progressive 'overviews' purporting to document how and under what conditions treatments work) performed hierarchies in which hepatitis C medicine 'figures as both "heroic" and "transformative" and as an agent of mastery' (see also Rose 2007a, 2007b, 1999). Observing that new treatments would likely emerge in future, they called for work tracing developments in hepatitis C medicine and its effects. As we have already explained, it did not take long before such treatments became available. Further work on hepatitis C and time has been published recently by Lancaster, Rhodes and collaborators who have also raised the issue of temporality in a series of papers examining hepatitis C futures. This includes work that revisits Woolgar's idea of 'futuring' (Lancaster and Rhodes 2020; Fraser, Moore and Keane, 2014), but with a focus on the significance of visual depictions of a possible hepatitis C-free future; work on numbers and modelling as performative and political (Rhodes and Lancaster, 2020); and work on the universalising and dehumanising effects of the global elimination agenda (Lancaster, Rhodes and Rance 2020; see also Fraser and Moore, 2011, for related concerns about the treatment as prevention debate).

Unexamined issues regarding post-cure worlds

Despite the aforementioned work, a series of issues relating to time, medicine and the future that have yet to be comprehensively addressed in hepatitis C research, practice and policy. Indeed, simplistic 'post-cure' logics can be located in all of these places. In this section, we outline some of these issues, based on previous research and on observations from the preliminary findings of a major new study we are embarking on, investigating post-cure lives. Our purpose here is to document a range of challenges that have emerged in the context of new generation hepatitis C treatments, and to give expression to a core set

of concerns that unite them, but which remain largely unexamined by researchers. We also argue that these challenges require a new, more holistic and systematic approach to claims being made about hepatitis C and the 'post-cure world'. The first issue is one we noted earlier: the significance of claims that current treatments will usher in a revolutionary 'new', 'future'. Little consideration has been given to that which lies 'beyond' cure, beyond optimistic claims about a brave new world. In recent years, a small body of research has emerged documenting post-cure experiences. Largely quantitative, biomedical and scientific, this research has focused on a limited set of issues, such as whether treatment results in improved health-related quality of life (Smith-Palmer, Cerri and Valentine 2015), and how to improve awareness of new treatment options, access 'hard to reach populations' and encourage people to take up treatment (Bajis et al. 2017). A (much smaller) body of qualitative social science literature has examined personal experiences after cure. For instance, one study (Harris 2017) found that people anticipated a range of benefits from new treatments, including social benefits in the form of improved social connections. The research found 'social suffering' persisted, and argued that managing expectations about life after cure was important (Harris 2017). A research team in Scotland also examined some of these issues (Whiteley et al. 2018; Whiteley et al. 2016). They found that hepatitis Crelated discrimination and stigma remained a major challenge even after successful treatment. They argued that the biomedical response 'decontextualised [hepatitis C] from people's lives, and, to date, has failed to concurrently address its wider socio-cultural impact' (Whiteley et al. 2018: 2736-2737). They further noted that discrimination and stigma might undermine the 'full potential' (Whiteley et al. 2018: 2737) of new treatments. Their proposed solutions were also biomedical, however: more care in treatment delivery was called for, with nurses asked to take more time to explain how new treatments differ from old ones (Whiteley et al. 2018; Whiteley et al. 2016). An Australian study also examined experiences of new treatments (Madden et al. 2018), similarly finding that expectations of a better life after cure were not fulfilled, and that patients felt let down by the 'hype' of direct-acting antivirals. Among those cured, multiple challenges remained. The authors suggested taking care not to over-state the benefits of direct-acting antivirals, and cautioned against implying that cure will profoundly transform people's lives (Madden

et al. 2018; see also Rhodes, Lancaster, Harris and Treloar, 2019). These issues appear to be reflected in challenges emerging in global access to treatment and cure. As approaches to treatment access differ between countries, debate has arisen about how and for whom treatment should be prioritised. As Magdalena Harris (2017: 162) points out, this has resulted in a 'discursive shift in the [hepatitis C] treatment landscape', characterised by an apparent need to manage expense and expectations 'nested within a broader aspirational discourse of biomedical innovation and promise'. These complexities are important because they suggest that enthusiasm for direct-acting antivirals, while widespread, might differ between countries, shaped by local considerations, such as huge variations in the cost of treatment around the world (Kirby 2019; Henry 2018; Kollewe 2018). These differences may also have implications for claims of a single, revolutionary future for all, since futures are being imagined – and performed – differently, and elimination is a global issue, rather than one comfortably bounded by nation states. These findings suggest a need to reflect more critically on the way we are approaching treatment and post-cure lives, and how we think about, study and describe post-cure worlds.

Preliminary data collection for a new study we are commencing on hepatitis C post-cure in Australia has also identified a series of structural challenges within the post-cure context that require examination. Our particular focus is on laws and policies that shape the imagined, post-cure future and have implications for claims to lives revolutionised. These laws and policies include medical records that continue to hold personal information on past hepatitis C sero-status and drug use history, and various policies (e.g. insurance, employment). To illustrate the point, we outline three examples of relevance to post-cure worlds:

• *Identifiable notifications:* as with HIV and some sexually transmitted diseases (e.g. syphilis, chlamydia) at least three Australian states (NSW, QLD, Victoria) have laws requiring medical practitioners to notify government departments when a person is diagnosed with hepatitis C (such as the *Public Health and Wellbeing Act 2008* [Vic]). This is done via a prescribed form, and this information is then

entered into health record systems. In the case of HIV or STI diagnosis, information identifying the affected individual is not collected. With hepatitis C, however, the individual must be identified by name, and the likely transmission route (e.g. 'injecting drug use') must be recorded. The notion of a post-cure world therefore raises questions about how these records will be managed, and whether the law should be amended or a mechanism developed by which affected people can apply have their health records changed. The existence of these records in parts of Australia's current health system raise the possibility that no 'post-cure world' or 'post-cure subject position' is fully possible. The possibility of 'post'-hepatitis C subjecthood is further complicated by the fact that even after cure, antibodies persist in the body, indicating that the virus was once active. Although such antibodies may eventually decline and disappear for some individuals (European Association for the Study of the Liver 2020; Mazzarella, et al. 2019), these material factors problematise the notion that new 'post-cure' identities are achievable;

• *Insurance policies:* Under Australian law, people applying for insurance cover — such as health or life insurance — are required to disclose all relevant matters. For health and life insurance this usually includes existing medical conditions or other 'risk' factors such as a history of injecting drug use. Research suggests insurance providers routinely refuse insurance to people with hepatitis C or increase insurance premiums to account for the perceived risk of future ill health or premature death (Australian Human Rights Commission 2016; NSW Anti-Discrimination Board, 2001). The law in this area is complex, but in some instances it is unlawful to refuse insurance or charge high premiums, especially where this is based on out-of-date information (Australian Human Rights Commission 2016). The Australian Human Rights Commission last provided advice to the public and insurers on these issues in 2016 — just as the new treatments were being rolled out. The obligations of people who have received

-

¹ Insurance Contracts Act 1984 (Commonwealth), section 21.

direct-acting antiviral treatment are now less clear. Is disclosure of a past diagnosis obligatory if that person is deemed cured? Can a person who is deemed cured ask for a new insurance policy and a reduced premium? Is the insurer permitted to retain information about a person's prior diagnosis? If retained, what use, if any, can insurers make of the fact of previous diagnosis? The insured futures of formerly hepatitis C positive people are by no means clear. Here, we see a potential overlap between electronic records of the kind described above, and antibodies in the system, all of which 'mark' subjects as having once had hepatitis C and/or injecting drugs. These factors once again call into question the promise of post-cure worlds;

• *Blood donation:* The Australian Red Cross Blood Service guidelines prohibit people who have ever had hepatitis C from donating blood (Madden et al. 2018). They also prohibit donation by people who have had sexual activity with a hepatitis C positive person in the last 12 months (Broady et al. 2018). Whether or not these policies are necessary to protect the health of the recipients of blood products, they act to stigmatise current and former hepatitis C positive people, potentially impacting on intimate relationships and undermining self-worth, among other things. They also complicate the imagined post-cure world, indicating that in some ways, or at least for many decades to come, no simple post-cure world is possible.

As these three examples suggest, cure raises a series of challenges not currently being addressed. Most importantly, they complicate simplistic imaginaries of the transformative power of cure, and of a singular post-cure world. The legacy of laws and policies devised in a pre-cure world appear instead to be capable of generating and limiting new ways of being. These becomings include subjects who are simultaneously (medically) 'cured' and 'marked' as perpetual hepatitis C subjects, as is occurring in those jurisdictions that retain identifying sero-status data despite cure. How might we think of these subjects? And what else is being brought into being by legal and policy frameworks not in step with a post-cure

world? Might these frameworks continue to enact those medically cured as 'Other', through barriers to rights and privileges we often associate with social cohesion and citizenship (being able to donate blood), or infrastructure that supports financial independence and stability (insurance)? As we noted, such becomings undermine visions of a singular, predictable and progressive future in which those who once lived with hepatitis C are no longer abjected. Importantly, because the specifics of relevant laws, practices and policies will differ between and within countries, post-cure lives are likely to be ontologically multiple (following Mol 2002).

Finally, we note that the logic of a revolutionary post-cure world is also forged by absences. For instance, Australia's Fifth National Hepatitis C Strategy: 2018-2022 (Australian Department of Health 2018), identifies several priority areas for action. These are principally concerned with testing, diagnosis, treatment, prevention and elimination. Although stigma and discrimination are also priorities, the focus appears to be on alleviating stigma and discrimination for those who are living with hepatitis C, and for the purposes of encouraging people into treatment. There is no recognition that stigma and discrimination may pose challenges for those who have been through treatment, or that there may be other issues in a post-cure world worth addressing. This logic is also reflected in and reproduced by the key public health figure of the 'cascade of care'. Central to the goal of eliminating hepatitis C, it first emerged as a model for understanding HIV treatment engagement (Mugavero et al. 2013). In the context of hepatitis C, it envisages care as a systematic sequence, beginning with diagnosis and moving to treatment, and then to sustained virological response (or SVR), the accepted definition of cure (Kirby Institute 2018; see also Iversen et al. 2017). Under this system, diagnosis, treatment and cure are prioritised (Kirby Institute 2018). The cascade is also a method to epidemiologically 'map' the movement of people at 'key points' in the journey from diagnosis to cure (Henderson, Madden and Kelsall 2017) and to identify why some people may not complete the passage from one point (e.g. diagnosis) to another (e.g. treatment). This model is central to how we imagine the journey towards a post-hepatitis C future. It envisages care as a systematic, unidirectional sequence, from diagnosis to treatment, and then to cure. Importantly, it is

also sometimes described as demonstrating 'the *entire* continuum of care' (Kirby Institute 2018: 94; emphasis added). While compelling and seemingly self-evidently logical, the construct also raises questions worth exploring in considering how elimination futures are composed, and the kinds of problems they entail (for critiques, see, for example: Scott et al. 2017; Paparini and Rhodes 2016; Yehia et al. 2014). Its vision of a linear trajectory towards a transformative post-cure future, while compelling in many respects, assumes that such trajectories and transformations occur in a neutral environment and can therefore proceed frictionlessly in a predictable direction. Most important for the purposes of the argument we make in this essay, the cascade ends at the point of cure. Given that hepatitis C policies and strategies do not simply document or represent treatment journeys, but actively *shape* them (Fraser and Seear 2011), this absence of attention to post-cure worlds is significant. It valorises cure by signalling that what lies beyond cure is less important or even unremarkable; that the need for care, support or other action is finished. The cascade of care construct has also been criticised by Crawford (2018), who argues that it oversimplifies consumer experiences of hepatitis C treatment. Crawford points to stigma, discrimination, legal barriers and treatment refusal, among other things, as complicating the linear upward journey assumed in the construct. There is a need to think beyond the cascade, Crawford argues, to implement structural reforms and additional supports, including after treatment. Others have made similar calls (e.g. Henderson, Madden and Kelsall 2017). Given the issues discussed thus far, we argue that new approaches are needed for studying the 'post-cure world'. Our approach moves beyond the cascade of care and singular imaginaries of the future, sensitises us to the material and structural forces that shape lives, challenges thinking on revolution and change, and prompts new perspectives on hepatitis C cure-related expectations and temporalities. In the next section, we introduce Marco Cuevas-Hewitt's (2011) work on 'futurology' to develop a novel guide for a futurology of hepatitis C. This functions as a set of ideas to inform our own program of research, but we also hope that it might be of use to others working on these issues.

The futurology of the present

In a 2011 essay, anthropologist Marco Cuevas-Hewitt (2011: 1) reflects on the 'art of writing', including the relationship between processes of writing and social movements. First introduced to us through Karen Barad's work (2015: 388) on the 'mutual indeterminacies of being and time', Cuevas-Hewitt's essay focuses on a specific kind of revolution in the form of revolutionary politics. In doing so, it engages with several questions of direct relevance to post-cure worlds, including questions on how we should think, talk, research and write about revolution and change, and larger ontological questions about the nature and meaning of time. Central to Cuevas-Hewitt's analysis is the question of how change is conceptualised and represented, and what different approaches to documenting change do. His central argument is that writers – especially those concerned with social movements and revolutions – tend to adopt a specific orientation towards time, one he considers problematic. 'Generations of activists', he argues, have adopted Hegelian logic (accessed via Marx) uncritically, viewing time as unidirectionally linear. According to Cuevas-Hewitt (2011), work of this kind 'compartmentalises' time, assuming it 'moves in a straight line from an identifiable origin toward an ultimate endpoint'. Here, 'progressions from past to present and from present to future are cast as somehow natural and inevitable'. One problem with this, he argues, is that it leads writers to reify 'that which they claim to oppose': the very notion of inevitability. Cuevas-Hewitt cites Marx's detailed account of capital as one such example, noting that it positions capitalism as creative and dynamic, with an inherent, almost irresistible, force. In other words, 'even as Marxists angrily denounce capitalism, they ironically naturalise the social injustices that it produces as necessary by-products of the inexorable forward impetus of time' (2011: 4). This naturalisation of both phenomena and injustice is a critical concern of ours, too, relevant to hepatitis C treatment in ways that might not be immediately apparent. Whereas Cuevas-Hewitt's concern is with the tendency of key figures (activists and writers) to naturalise capitalism and injustice, ours is with the tendency of other key figures (policymakers and researchers) to naturalise the epidemic and its associated injustices, such as stigma. Take, for instance, Australia's Fifth National Hepatitis C Strategy: 2018-2022, which, as we noted earlier, described new treatments as offering an 'unprecedented

opportunity to change the course of the epidemic' (Australian Department of Health 2018: 5). Mobilising common epidemiological terminology, here, hepatitis C is described as having 'a course', a curious phrase that implies epidemics are the product of a 'natural', linear progression, rather than an assemblage of material-discursive practices (Fraser and Seear 2011).

For Cuevas-Hewitt, accounts of injustice and their negation have a tendency to produce a sense of helplessness and hopelessness about the future, and about change, or position change as happening only in one way (e.g. the complete overthrow of capitalist systems). Such accounts also tend to imagine both 'the present' and 'the future' as singular entities. There is, in other words, one likely future (under capitalism) and only one alternative (forged via revolution). Present forms of injustice under capitalism, that is, can only give way when we reach the imagined, alternative future. Taking a different view of time and of how it should be approached, Cuevas-Hewitt draws on the work of Michel Foucault and Felix Guattari to challenge singularising notions of present and future. Instead he poses present and future as part of a 'common, indivisible flow' (2011: 2; see also Guattari 1995). Here, both inhere in a kind of 'perpetual present', such that there 'is no Future with a capital 'F'; only the delta, opening out into the infinite expanse of the ocean'. (2011: 2). These ideas resonate with our own observations about hepatitis C futures. As we have already explained, the notion of a singular, revolutionary post-hepatitis C world is limiting and overly optimistic. It also assumes that cure will erase injustice and transform lives. This both risks complacency and implies inevitability, postponing justice in the perpetual present. Importantly, temporal logics that reproduce a demarcation between the present and the future also overlook unique elements of the hepatitis C experience, including the possibility that people remain perpetually 'marked' as hepatitis C subjects, by virtue of antibodies, legal or policy processes, and medical records, after treatment. They also overlook the phenomenon of 'spontaneous clearing', in which some people simply 'clear' the virus without undergoing any treatment at all.

The value of Cuevas-Hewitt's work is in combining these insights on temporality and revolution with a new mode of articulation. In particular, he argues that how one approaches the task of studying and writing about time, revolution and/or social change of any kind is inherently constitutive, and therefore political and ethical. The way we write about these phenomena helps shape them, and the broader world that writing purports to merely document, a point made by several alcohol and other drug scholars in recent years (e.g. Fraser 2020; Seear 2020; Seear 2014; Fraser and Seear 2011; Mol and Law 2002; Law 2002; Mol 2002). Cuevas-Hewitt's approach shares these concerns but extends them further, by inviting reflection specifically on processes of change and revolution. In a bid to do things differently, Cuevas-Hewitt calls for a new 'writerly practice' – one he calls the 'futurology of the present'. As he explains it, the futurology of the present is a method of studying and writing about social change that actively resists the trappings of compartmentalised and linear time, as well as assumptions about a singular possible future. It is a practice in which 'the writer treats the present and future not as two separate things, but as conjoined in an indivisible flow within which means and ends are consonant' (2011). According to Cuevas-Hewitt (2011),

The futurology of the present [...] aims not to be merely descriptive or prescriptive, but rather, *demonstrative*. By this I mean that its concern is with fostering inspiration and hope through the demonstration of alternatives. So many contemporary writers and scholar-activists dedicate their lives, as Marx did, to writing about what is wrong with the world, but far fewer have cared to write about what people are already doing to change the world or to bring to light the many living, breathing examples all around us of how things can always be otherwise. (2011: 3; original emphasis)

Central to this style of thinking and writing is a need to attend to the work of activists and other grassroots actors, especially those creatively navigating and remaking worlds in the perpetual present. As Cuevas-Hewitt puts it:

The futurology of the present, then, might fruitfully be characterised as a *practice of hope*. It is not simply about the transfer of knowledge, but more significantly of 'affect'. It is animated by revolutionary desire, while at the same time acting as a relay for this desire to spread. It does not speak *about* movements, but *with* them. It thinks with them, moves with them, and tries to inspire movement in turn. (2011; original emphasis)

By way of illustration, Cuevas-Hewitt (2011) shares the example of a North American anarchist initiative called 'CrimethInc Collective'. In 2011, they initiated an 'alternative commons-based society' through an article distributed in print and online. Rather than simply documenting an imagined future, the piece sought to foment action on the part of others, and soon enough, similar initiatives began to pop up all over the globe. Importantly, however, the form these new becomings took was variable. The process of working with those affected involves starting 'not with capitalism (or any other kind of domination), but with the ideas and practices of those challenging it' (Cuevas-Hewitt 2011). A futurology of hepatitis C would be one that similarly traces local efforts to live differently, seeking to instigate movement and change, and noting that things can always be otherwise. Importantly, our project will be guided by the experiences, views and needs of those most directly affected: people who have undergone hepatitis C treatment, as well as those who have not. Our project will centre their experiences through interviews with them about their post-cure lives, attending to their ideas and practices including other modes of being and becoming in a post-cure world. In the next section, we synthesise these thoughts into sketches for a futurology of hepatitis C.

Sketches for a new futurology of hepatitis C

Drawing these ideas together, we now outline our sketches for a new futurology of hepatitis C. This futurology is non-exhaustive, and represents a way of thinking, talking, writing, researching and practising post-hepatitis C worlds. It also inspired by Suzanne Fraser's work on ontopolitically-oriented research (2020), which synthesised ideas from

earlier work by Mol and Law (2002) and articulated a vision for how to constitute alcohol and other drug realities differently through research and writing, informed by several empirical projects on these issues. This futurology:

Avoids stabilising, totalising, singular or simplistic accounts of post-cure life, and instead attends to complexity, multiplicity, heterogeneity and contingency of experiences. As a set of practices, a futurology invites those who encounter hepatitis C (whether as researchers, policymakers or others) to take account of the full range of post-cure experiences, including the possibility of multiplicities of becoming through medicine, non-linear journeys, transformations and digressions, and new subject-identities emerging through treatment processes as well as outside of them;

Pays special attention to what happens beyond the point of cure, or, to refer back to that key public health construct, beyond the 'cascade of care'. It recognises the indivisible flow of the perpetual present, the deltaic formations and modes of becoming as posed by Guattari (1995) already brought into being by new treatment modes, and the possibility that these modes of being and becoming are not as transformative as we might hope. It also attends, crucially, to the forces (including laws and policies) that help shape the lives of people living with or cured of hepatitis C, and traces how these forces relate to the simplistic ideal of a revolutionary singular future in which stigma and discrimination are magically neutralised;

Acknowledges that research and writing constitutes realities and intervenes in the worlds it often purports to merely document (see also Fraser 2020; Fraser and Seear 2011). This has implications for both how we conduct research and how we write about it. Most notably, a futurology demands a new set of writerly and other modes of expression. These modes should not perform treatment as revolutionary, or treatment journeys as presumptively sequential and progressive, when they may be more complicated, multiple and digressive. For instance, when conducting research, researchers might avoid reproducing assumptions about cure and change, and avoid enacting an expectation of revolution by, for example,

asking people who have been treated to straightforwardly perform change/growth/development or transformation through their accounts of treatment 'journeys', since this assumes that this is how treatment always works. In a related sense, researchers might invite those who have gone through treatment to articulate how they feel and how they understand themselves through formats that both avoid non-linearity (or allow for its disruption) and that work for them;

Consciously cultivates non-linear and otherwise less conventional ways of presenting data, including formats that disrupt temporality, linear narratives, structures of progress or other forms of order and progression (for similar work, see Fraser 2020). The cascade of care construct is one example of a problematic construct, as it instantiates a logic of progress and inevitability. We have indicated here the importance of critical perspectives on these invocations of linear progression. A futurology of hepatitis C approaches the cascade of care and other related constructs sceptically, does not reproduce them uncritically, and searches for new ways of visualising or performing the multiplicity of becomings (e.g. deltaic formations) likely characteristic of post-cure worlds. Thus, a futurology considers collecting and presenting data in ways that allow for other modes of expression and experimentation with time, as feminist scholarship (e.g. Irigaray, 1985) has long done. This includes presenting data through poetry, dance, song, art or other performance, longer form storytelling (podcasting) and other modes that may perform multiple modes of becoming (for examples, see recent edited collections, Hickey-Moody and Page, 2016; Taylor and Bayley, 2019) (for examples in alcohol and other drug research see, Dennis, 2019a, 2019b; Fraser, 2020). Researchers might take inspiration from film, literature or other forms of expression that can afford non-linear narratives and foster open-endedness, uncertainty and multidirectionality;

Goes beyond merely documenting problematic practices and experiences regarding 'postcure' and works to instigate change. As well as resisting the assumption that new forms of treatment always already transform lives, it seeks to intervene in the self-fulfilling temporal logic of the claim that transformation must be inevitably postponed until people undergo treatment. One way this might be achieved is through working collaboratively with peer-based drug use advocacy organisations, those who have undergone treatment and those who have not, to cultivate less stigmatising and more just modes of living now, modes that can also be further cultivated in the (perpetual) present;

Encourages the formulation of new languages for hepatitis C experiences, acknowledging the constitutive power of language. This may include abandoning the concept of 'post-cure life' (given that it implies singularity and permanent change), or even terms such as 'post-cure lives' or 'post-cure worlds', since terms like these risk reproducing unhelpful temporal logics and binaries (i.e. pre/post) of the kind that Fraser and valentine (2008) and others have demonstrated work against the achievement of more accepting and equitable approaches. Instead, and inspired by Fraser's (2020) work on ontopolitically-oriented research, we encourage new writerly practices that disrupt the tendency to perform the post-cure world as a wholly new world distinct from the pre-cure one, and to search for language that helps instantiate different temporal flows.

Conclusion

In recent years, direct-acting antivirals have been developed to treat hepatitis C, bringing with them the promise of new drug futures, including the possibility of a post-hepatitis C world and a revolution in the lives of people affected by the disease. In this essay, we have highlighted several problems with this imaginary, including the persistence of stigma and discrimination and the importance of laws and policies that complicate the imagined transformative post-hepatitis C future. The tendency to imagine a post-cure future in which lives are wholly transformed by and through medical intervention carries several risks. First, such tendencies may naturalise existing forms of suffering or injustice by positioning them as inevitable, normal, necessary or unavoidable preconditions to a transformative future. Second, they may distract attention from these forms of suffering and injustice, including stigma and discrimination, by directing all efforts and attention towards medical cure. While medical cure is, of course, important, it is not, we argue, the only thing that matters.

Third, the focus on a medical solution to suffering risks obscuring the various forces that shape suffering in the present, including the many that exceed or lie beyond medicine. Fourth, these processes risk overlooking the work of others (including drug user organisations and peers) who may already be finding new ways of being and becoming in the present, including ways of being not dependent on cure.

In this essay, we have argued that these various forces and dynamics require a new way of thinking about hepatitis C and the concepts attached to cure, including notions of time and the future, change and transformation, revolution and progress. This essay has introduced a new approach for thinking through these issues, based on the work of Marcos Cuevas-Hewitt (2011). Following Cuevas-Hewitt, we call this a 'futurology' of hepatitis C. A founding premise of this futurology is that post-cure lives will not be transformed by medicine alone. Instead, laws, practices and policies devised in a pre-cure world may be shaping lives. These include stigmatising approaches to people who use drugs, potentially discriminatory laws and practices and legal and policy frameworks unable to accommodate the many thousands now deemed medically cured. Moreover, the persistence of hepatitis C antibodies and the lingering effects of a lifetime of exclusion and marginalisation may continue to circulate, continuing, in turn, to shape lives purportedly transformed. Collectively, these phenomena counter the vision for a singular and revolutionary post-cure future in which the lives of subjects are profoundly revolutionised. The emerging research on post-cure lives already demonstrates the unevenness of personal experiences, but a need to better understand these forces and address them remains. In order to begin to better understand and address these issues, we established sketches for a hepatitis C futurology. These sketches establish a series of principles that might shape hepatitis C practice, policy and research. A futurology of post-hepatitis C worlds is one that both identifies and attends to these challenges. It is a mode of thinking, researching, writing and working with those affected by issues of the kind we have described above. This new critical orientation to hepatitis C futures acknowledges the interconnectedness of law, policy and practice with individual lives and calls for a move beyond the assumption that cure transforms all lives. It is a mode of practice that eschews uncritically optimistic views of the future as well as

fatalistic resignation to the present. It recognises that modes of writing, researching and practice are themselves constitutive of realities, and that some ways of thinking about hepatitis C undermine optimism about access to a revolutionary 'new' life. They also perpetuate the possibility that the likelihood that people who have already been cured will remain subjects of stigma and discrimination, excluded from social worlds. Our futurology aims to articulate a new vision for working with and addressing these challenges, through modes of thinking, researching and writing that, as Cuevas-Hewitt urges, demonstrate how things can always be otherwise.

Acknowledgments

The research reported in this essay is funded by the Australian Research Council (Discovery Project DP200100941). The authors also thank Emily Lenton for research assistance with aspects of this article.

REFERENCES

Asselah, T., Boyer, N., Saadoun, D., Martinot-Peignoux, M. and Marcellin, P. (2016). Direct-acting antivirals for the treatment of hepatitis C virus infection: Optimizing current IFN-free treatment and future perspectives. *Liver International*, *36*(suppl. 1), 47–57.

Australian Department of Health. (2018). *Fifth national hepatitis C strategy 2018-2022*. Canberra: Department of Health.

Australian Human Rights Commission (2016). Guidelines for providers of insurance and superannuation under the *Disability Discrimination Act 1992* (Cth).

Bakhtin, M. (1981). Forms of Time and of the Chronotope in the Novel: Notes toward a Historical Poetics

Barad, K. (2015). Transmaterialities: Trans*/Matter/Realities and Queer Political Imaginings. *GLQ: A journal of lesbian and gay studies*, 21:2-3, 387-422.

Bragg, D., Crowl, A. and Manlove, E. (2017). Hepatitis C: A new era. *Primary Care*, 44(4), 631–642.

Broady, T., Cama, E., Brener, L., Hopwood, M., de Wit, J. and Treloar, C. (2018). Responding to a national policy need: development of a stigma indicator for bloodborne viruses and sexually transmissible infections. *Australian and New Zealand Journal of Public Health*, 42(6), 513–15.

Crawford, S. (2018). Who and what is missing from the hepatitis C treatment cascade of care? Paper presented at the 11th Australasian Society of hepatitis medicine Viral hepatitis conference, Adelaide, Australia, 14 August.

Cuevas-Hewitt, M. (2011). Towards a futurology of the present: Notes on writing, movement, and time. *The Journal of Aesthetics and Protest, 8.* Online, available: http://www.joaap.org/issue8/futurology.htm (Accessed 7 April 2020).

de Graaff, B., Yee, K.C., Clarke, P. *et al.* (2018). Uptake of and Expenditure on Direct-Acting Antiviral Agents for Hepatitis C Treatment in Australia. *Applied Health Economics and Health Policy*, *16*, 495–502.

Degenhardt, L., Peacock, A., Colledge, S. *et al* (2017). Global prevalence of injecting drug use and sociodemographic characteristics of prevalence of HIV, HBV, and HCV in people who inject drugs: A multistage systematic review. *Lancet Global Health*, *5*, e1192-1207.

Dennis, F. (2019a). *Injecting bodies in more-than-human worlds: Ediating drug-body-world relations*. Abingdon: Routledge.

Dennis, F. (2019b). Making problems: The inventive potential of the arts for alcohol and other drug research. *Contemporary Drug Problems*, 46:2, 127-138.

Dilkes-Frayne, E. (2014). Tracing the 'event' of drug use: 'Context' and the coproduction of a night out on MDMA. *Contemporary Drug Problems*, *41*(3), 445–479.

Duffin, J. (2005). *Lovers and livers: Disease concepts in history.* Toronto: University of Toronto Press.

Elbaz, T., El-Kassas, M. and Esmat, G. (2015). New era for management of chronic hepatitis C virus using direct antiviral agents: A review. *Journal of Advanced Research*. *6*(3), 301–310.

European Association for the Study of the Liver (2020). EASL recommendations on treatment of hepatitis C: Final update of the series. *Journal of Hepatology*. Early online: https://doi.org/10.1016/j.jhep.2020.08.018

Franco, R., Gelbraith, J., Overton, E. and Saag, M. (2018). Direct-acting antivirals and chronic hepatitis C: Towards elimination. *Hepatoma Research*, *4*(74).

Fraser, S. (2020). Doing ontopolitically-oriented research: Synthesising concepts from the ontological turn for alcohol and other drug research and other social sciences.

International Journal of Drug Policy, 82.

Fraser, S. (2011). 'Beyond the "potsherd": The role of injecting drug use-related stigma in shaping hepatitis C'. In: Fraser, S., and Moore, D. (Eds.). *The Drug Effect: Health Crime and Society.* Melbourne: Cambridge University Press, 91–105.

Fraser, S. (2006). The chronotope of the queue: Methadone maintenance treatment and the production of time, space and subjects. *International Journal of Drug Policy*, 17(3), 192–202.

Fraser, S. and Moore, D. (2011). Harm reduction and hepatitis C: On the ethics and politics of prevention and treatment. *Addiction Research and Theory*, *19*(4), 375–379.

Fraser, S., Moore, D. & Keane, H. (2014). *Habits: Remaking addiction.* London: Palgrave Macmillan.

Fraser, S. and Seear, K. (2011). *Making disease, making citizens: The politics of hepatitis C.* Aldershot: Ashgate.

Guattari, F. (1995). *Chaosmosis: An Ethico-Aesthetic Paradigm*. Bloomington: Indiana University Press.

Henderson, C., Madden, A. and Kelsall, J. (2017). 'Beyond the willing and the waiting'—
The role of peer-based approaches in hepatitis C diagnosis and treatment. *International Journal of Drug Policy*, *50*, 111–115.

Henry, B. (2018). Drug pricing and challenges to hepatitis C treatment access. *Journal of Health and Biomedical Law*, *14*, 265–283.

Hepatitis Australia (2018). Submission to: The Senate Community Affairs Reference Committee on the *My Health Records Amendment (Strengthening Privacy) Bill 2018.*

Hickey-Moody, A. and Page, T. (2016). *Arts, pedagogy and cultural resistance: New materialisms.* London: Rowman and Littlefield International.

Hopwood, M. and Treloar, C. (2007). Pretreatment preparation and management of

interferon-based therapy for hepatitis C virus infection. *Journal of Advanced Nursing*, *59*(3), 248–254.

Insurance Contracts Act 1984 (Commonwealth), section 21.

Irigaray, L. (1985). *The sex which is not one.* Ithaca and New York: Cornell University Press.

Iversen, J., Grebely, ZB., Catlett, B., Cunninghan, P., Dore, G. and Maher, L. (2017). Estimating the cascade of hepatitis C testing, care and treatment among people who inject drugs in Australia. *International Journal of Drug Policy*, 47, 77-85.

Kirby, M. (2019). Access to health care as a global human right. Presented at: *Drug use and human rights: The missing piece of the hep C elimination puzzle?* University of New South Wales: Sydney, 29 July.

Kirby Institute. (2018). *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual surveillance report 2018.* Sydney: Kirby Institute, UNSW.

Kish, T., Aziz, A. and Sorio, M. (2017). Hepatitis C in a new era: A review of current therapies. *Pharmacy and Therapeutics*, *42*(5), 316–329.

Kollewe, J. (2018, April 12). Non-profit's \$300 hepatitis C cure as effective as \$84,000 alternative. *The Guardian*, Retrieved:

https://www.theguardian.com/science/2018/apr/12/non-profits-300-hepatitis-c-cure-as-effective-as-84000-alternative.

Lancaster, K. and Rhodes, T. (2020). Futuring a world without disease: visualising the elimination of hepatitis C. *Critical Public Health*. Early online:

https://doi.org/10.1080/09581596.2020.1787347

Lancaster, K., Rhodes, T. and Rance, J. (2020). 'Towards eliminating viral hepatitis': Examining the productive capacity and constitutive effects of global policy on hepatitis C elimination. *International Journal of Drug Policy*, 80.

Law, J. (2002). *Aircraft stories: Decentering the object in technoscience*. Durham and London: Duke University Press.

Lupton, D. (2017) Digital Health: Critical Perspectives. London: Routledge.

Madden, A., Hopwood, M., Neale, J. and Treloar, C. (2018). Beyond cure: Patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduction Journal*, *15*(42), 1–8.

Mazzarella, C., Rocco, C., Vallefuoco, L., Sorrentino, R., Braschi, U., Lauritano, G., Di Blasé, A., Misso, S. and Portella, G. (2019). Differential reactivity of anti-hepatitis C virus screening assays in patients with waning antibodies. *Future Virology*, *14*(*5*), 303-309.

Michael, M. and Rosengarten, M. (2012). HIV, Globalization and Topology: Of Prepositions and Propositions. *Theory, Culture & Society, 29*(4-5), 93–115.

Mol A. (2002). *The Body Multiple: Ontology in Medical Practice.* Durham: Duke University Press.

Mol, A. (1999). Ontological politics. A word and some questions. In J. Law & J. Hassard (Eds.), *Actor Network Theory and After* (pp. 74-89). Oxford: Blackwell Publishers.

Mol, A. and Law, J. (2002). *Complexities: Social studies of knowledge practices.* Durham and London: Duke University Press.

NSW Anti-Discrimination Board (2001). *C-Change: Report of the Enquiry into Hepatitis C-Related Discrimination*. Sydney: Anti-Discrimination Board.

Paparini, S. and Rhodes, T. (2016) The biopolitics of engagement and the HIV cascade of care: a synthesis of the literature on patient citizenship and antiretroviral therapy. *Critical Public Health*, *26*(5), 501–517.

Race, K. and Wakeford, E. (2000), Dosing on Time: Developing Adherent Practice with Highly Active Anti-Retroviral Therapy. *Culture, Health & Sexuality, 2*(2), 213–228.

Rhodes, T. and Lancaster, K. (2020). How to think with models and targets: Hepatitis C elimination as a numbering performance. *International Journal of Drug Policy*. Early online: https://doi.org/10.1016/j.drugpo.2020.102694.

Rhodes, T. and Lancaster, K. (2019). Evidence-making interventions in health: A conceptual framing. *Social Science and Medicine*, 238, 112488.

Rhodes, T., Lancaster, K., Harris, M. and Treloar, C. (2019). Evidence-making controversies: the case of hepatitis C treatment and the promise of viral elimination. *Critical Public Health*, *29*, 260-273.

Rose, N. (2007a). *The politics of life itself.* Princeton: Princeton University Press.

Rose, N. (2007b). Beyond medicalisation. *Lancet*. 369(9562), 700-702.

Rose, N. (1999). *Powers of Freedom: Reframing political thought.* Cambridge: Cambridge University Press.

Scott, N., Doyle, J., Wilson, D., Wade, A. et al. (2017). Reaching hepatitis C virus

elimination targets requires health system interventions to enhance the care cascade. *International Journal of Drug Policy*, *47*, 107–116.

Seear, K. (2020). Law, drugs and the making of addiction: Just habits. London: Routledge.

Seear, K. (2014). *The Makings of a Modern Epidemic: Endometriosis, Gender and Politics.* Aldershot: Ashgate.

Taylor, C. and Bayley, A. (2019). *Posthumanism and higher education: Reimagining pedagogy, practice and research.* New York: Palgrave Macmillan.

Valverde, M. (2015). *Chronotopes of Law: Jurisdiction, scale and governance.* Routledge: Milton Park.

Woolgar, S. (2011). Where did all the provocation go? – reflections on the fate of Laboratory Life. STS Workshop at the European University of St Petersburg, Russia, 19th November 2011. Available at: https://www.youtube.com/watch?v=gPDNptLkiyk (accessed 25th September, 2020).

Yehia, B. R., Schranz, A. J., Umscheid, C. A., & Re, V. L. III (2014). The treatment cascade for chronic hepatitis C virus infection in the United States: A systematic review and meta-analysis. *PLoS One*, *9*(7), e101554.