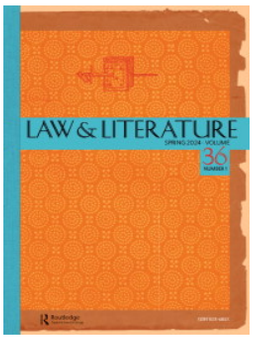

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Performing Hepatitis C, Problematising "Cure": The Construction of Hepatitis C (Cure) in Social Security and Migration Law

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Abstract, Direct-acting antiviral (DAA) treatment for the blood-borne virus hepatitis C has shifted conceptions of the disease from a chronic infection – and, in some legal contexts, a "disability" – towards a non-permanent impairment capable of "cure". The shift in treatment has also led to a shift in law. This paper explores the shift in Australian social security and migration judgments by drawing from performance studies research on disability and recovery. It examines legal performances before and after the introduction of DAA treatment to track the way in which "disability" is performed in earlier cases and to problematise "cure" in later cases.

Keywords, hepatitis C, disability, cure, law, performance

INTRODUCTION

Hepatitis C is a blood-borne virus associated with a range of serious health problems if left untreated, including cirrhosis of the liver and liver cancer.[1] These health problems may become a thing of the past with the advent of a new generation of hepatitis C treatment known as direct-acting-antivirals or "DAAs,"[2] which became available through Australia's Pharmaceutical Benefits Scheme or "PBS" from March 2016.[3] Lauded as "revolutionary,"[4] DAAs have the potential to cure hepatitis C in most cases, and to potentially eliminate the virus. This has

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resulted in considerable optimism about the medication and its potential to radically transform people's lives.[5] However, the focus on a biomedical solution to the problems associated with hepatitis C may overlook the deep-seated discrimination and stigma associated with the virus. This discrimination and stigma cannot be reduced by treatment alone and is often shaped by legal frameworks that may undermine the public health ambition to achieve elimination. As Australia works towards an ambitious target of reducing hepatitis C stigma as part of a broader agenda to eliminate hepatitis C by 2030,[6] it is important to investigate and understand the laws that affect people who have – and have been treated for – hepatitis C, and how they might generate, perpetuate, and exacerbate stigma and discrimination against people who have – or have had – hepatitis C.

This paper investigates constructions of hepatitis C in Australian law. It stems from a major Australian Research Council-funded project on hepatitis C and post-cure lives. A key early stage of this project involved the collection of legal statutes and legal judgments relevant to hepatitis C through online searches of a comprehensive legal database. In this paper, we analyse the findings from this search to explore how hepatitis C figures in Australian law, how it is performed in legal cases both before and after the advent of DAAs, and the effects of these legal performances of hepatitis C and its cure. This exploration of hepatitis C-related law, both pre- and post-DAAs, can help us better understand the status of hepatitis C before the law, including whether legal approaches to hepatitis C are changing since the advent DAAs, in what ways, and with what effects. This includes a consideration of how hepatitis C-related stigma and discrimination play out through law – that is, how they are sustained, exacerbated, magnified, reduced, or even potentially eliminated through law. If Australia's ambitious goal to reduce hepatitis C-related stigma and eventually eliminate the virus is to succeed, we need to attend to the way these meanings are made and remade through law.

In our analysis, we apply performance theory to enhance the understanding of hepatitis C stigma and discrimination as it plays out in Australian case law. Our interest lies in how hepatitis C is performed in legal proceedings and how the introduction of DAAs has (re-)shaped conceptualisations of hepatitis C from something that is a "disability" to something that is readily "curable." We argue that attending to the performative effects of legal rhetoric around "disability" and "cure" is important as legal discourses and practices can shape how hepatitis C and life with the disease is both conceptualised and experienced.

BACKGROUND

Prior to the advent of DAAs, the main treatment for hepatitis C was a six- to twelve-month process involving regular oral administration of ribavirin and injections of interferon.[7] The treatment was known to be gruelling, marked by serious

side effects, and difficult to manage with other treatments and co-morbidities, which limited its use.[8] Whilst these treatments could "cure" hepatitis C, they were efficacious for only 40% of patients.[9] Because of the treatment's limited cure rates, hepatitis C was still seen as a chronic disease. DAAs, on the other hand, are much quicker to act, much less severe in their side effects, and much more effective, so much so that they have come to be heralded as a pathway to the elimination of hepatitis C.[10] The excitement around these drugs and the concomitant shift in public health rhetoric from one of treatment and management to cure and elimination has also caused a commensurate legal shift in the consideration of hepatitis C as a "disability." For example, under the *Social Security (Tables for the Assessment of Work-Related Impairment for Disability Support Pension) Determination 2011* (Cth), there is a requirement that a person's condition be "permanent" and that it "impair" the person, which may no longer be the case for many of those who have been treated for hepatitis C (although some may experience ongoing impairment such as damage to the liver). Whilst it is not possible to get data on how many people with hepatitis C previously qualified for the disability support pension in Australia, a study of Swedes undertaken prior to the advent of new treatments suggested that 30% of those with chronic hepatitis C received a disability pension.[11] In the context of social security law, the advent of new treatments has transformed hepatitis C into something that is now transitory, capable of being cured and thus no longer a disability (though the case is less clear for discrimination law, in part due to different definitions of "disability" under federal, state and territory discrimination law). Because the focus of recent efforts in hepatitis C research has largely been on strengthened and more efficient pathways to elimination of the virus, less is known about the impact of these and other legal changes on the lived experience of people treated with DAAs.

There have been calls for more qualitative research that focuses on life after treatment.[12] In one example from the small pool of emerging qualitative research on the topic, Goodyear et al. conducted in-depth interviews with people in Canada following their completion of DAAs.[13] Almost all participants identified stigma-reduction as a key personal motivator for seeking or initiating treatment and expressed hope that being cured of hepatitis C could reduce the overt stigmas they faced in various other contexts. However, participants reported that "experiences of enacted stigma had continued to occur in their post-treatment lives."[14] Goodyear et al. use the term "enacted stigma" to refer to stigma enacted by others in contradistinction to "internalised stigma."[15] Other research has found that some people with a history of hepatitis C express internalised stigma about having or being treated for an infection and can also experience what has been understood as a "loss of identity" with the advent of cure.[16] As Australian research by Madden et al. concluded:

> Given the stigma associated with HCV (and by associated, drug use), it may be surprising that some participants expressed concern that they would experience a loss of identity in being "hep C free." To identify as a person with HCV who injects drugs is a political act, due to the socio-legal sanctions ascribed to the social practice of injecting drug use and the perceived threat to community represented by infectious disease. Historically, people with identities and practices that are perceived as threatening, and which are subsequently marginalised by institutions such as healthcare, have at times effectively organised political action and extended support to fellow "travellers," creating movements and moments where a sense of solidarity through common purpose and shared hope for the future prevail … It is not entirely surprising then that in some ways, for some people, HCV infection comes to represent a struggle for visibility, legitimacy, and equality in a hostile world, and that being cured of the infection removes positive aspects of "otherness" that affected people highly value.

Madden et al.'s framing of hepatitis C status as an identity is striking, as it suggests that hepatitis C, as with HIV and various other conditions, is not just a medical condition but also an identity – an identity, we would argue, that is shaped by forces outside the self, including the reception of others. The research suggests that identifying as a person with hepatitis C is a political act; we argue that it is also a performative act, noting that politics is inherently performative.[17] What this means is that individuals perform their hepatitis C identities in a variety of ways, and audiences engage with those performances differently. Regarding identity as a performative act, we are particularly interested in how hepatitis C is *performed* in legal cases concerning people with hepatitis C, and what impact this may have. Focussing on legal performances can contribute to an understanding of how legal ideas of hepatitis C have shifted since the advent of DAAs, and how people with hepatitis C are both treated and perceived in a post-cure era. To explore this, we draw from theatre and performance studies, and related social research on performance.

THEORY

The "performative turn" has been apparent in social sciences and humanities since midway through the last century.[18] However, as performance theorist Richard Schechner cautions, defining performance is a subjective process determined by the thinking of the day.[19] Schechner points to two theorists who have

considered the connections between performance and law. In *How to Do Things with Words*, legal philosopher John Austin introduced the notion of "performative utterances," which are words that are capable of transforming a situation; for example, the sentencing of a judge – "I sentence you to…" – or the oath to tell the truth – "I solemnly swear to tell the whole truth."[20] As per the title of his book, Austin suggests that performative utterances are "doing something with words." His notion of the performative dimension of legal speech in part inspired the field of performance studies, and as Cheryl Lubin observes, "ignited the entire discourse" of performance studies "by expanding the ontological contours of drama to include not just the stage but actions committed in legal and non-legal exchanges in the course of life."[21]

In later work, Judith Butler applied theories of performativity to the law, arguing that the judicial decision or judgment is a performance of law.[22] In doing so, both were influenced by Jacques Derrida's work on the performative force of law.[23] Judges have the power to affect the world through their performative utterances. Judges are performing a political action as they make their decisions that go on to bind future matters through the principle of *stare decisis*, to stand by that which has been decided. Whilst Butler is critical of the system of precedent and *stare decisis* in that it can derail a quest for transformative shifts within the law, the fundamental point is that law is created and recreated through performance and is performative. Our interest in legal performance is tied to the recent growth in scholarship on law and/as theatre/-performance. As Marett Leiboff writes, legal scholarship often "draws on themes and concepts analogous to the theatrical, and theatre has produced an extraordinary set of insights into law in return."[24] In line with this approach, we both utilise theatrical analogies and draw insights from performance studies research to understand and describe the way that hepatitis C is performed in legal proceedings.

To date, consideration of performance in studies of hepatitis C is relatively rare. Suzanne Fraser and Kate Seear argue that disease is made through language and practice, in that "conventions and values and social practices such as health policy and stigma make the disease as much as microbes do."[25] This is particularly the case in the context of treatments for hepatitis C, where "there is an expectation that [one] perform a particular version of subjectivity (responsible, stable, orderly) as a precondition to starting treatment."[26] Fraser and Seear were writing before the advent of new treatment, so it is opportune to reconsider this since the introduction of more accessible treatment. More recently, Tim Rhodes and Kari Lancaster have pointed to the performance of hepatitis C *via* the elimination agenda, arguing that models and targets for hepatitis C elimination – as well as DAAs themselves – are "performative actors" that contribute to "performing the worlds of health and viral elimination in particular ways."[27]

We extend analyses such as these to consider how hepatitis C is performed in law as a performance of both "disability" and of "cure," with particular attention to changes in rhetoric in legal judgments since the advent of DAAs. Given their authoritative effect, legal judgments can impact the ways hepatitis C is conceptualised in a post-cure world, and legal actors have a role in shaping that conceptualisation. In this regard, we argue that stigma and discrimination is perpetuated through legal language and practices, including in cases concerning recovery or cure from hepatitis C.

METHOD AND APPROACH

For this project, we mapped legal frameworks that may impact people with (a history of) hepatitis C. This involved a thorough search of Australian legal databases for all case law that might be relevant to people affected by hepatitis C. Data were gathered by a search for the phrase "hepatitis C" in Australian case law databases through the open access Australian Legal Information Institute ("AustLII") collection. As of January 2021, we identified 1102 mentions of "hepatitis C" in case law. The search results were then screened for relevance. We found 232 cases with a substantive discussion of hepatitis C. Cases where hepatitis C had no bearing on the outcome or were mentioned only fleetingly were excluded. Of those cases with a substantive discussion of hepatitis C, 177 cases occurred before DAA treatments became available on the PBS in 2016 and 55 occurred post-2016. Cases from both time periods were analysed on the basis that historic case law can offer insights into how things might have changed since the advent of new treatments.

Relevant laws that affect people living with hepatitis C or who have been cured of it include social security laws, which raise questions about whether hepatitis C can be classified as an "impairment" or a "wartime injury" for the purposes of accessing the disability support pension or the veterans' pension,[28] and whether it affects a person's capacity to work. Within the case law, there is an emerging expectation that people undergo treatment now that more tolerable treatments are available, even if there are conditions that militate against treatment, such as mental health issues, advanced liver disease or other conditions.[29] Hepatitis C also figures in migration and refugee laws. Difficulties accessing treatment for hepatitis C in a home country may be considered in decisions about visa cancellation and refoulement. For example, a tribunal may refuse to refoul a migrant or asylum seeker with hepatitis C if there is limited access to treatment in their home country.[30] However, asylum seekers with hepatitis C have not been held to be a particular social group for the purpose of refugee claims.[31] In some cases, asylum seekers with hepatitis C have been given advice about avoiding stigma, being told that they will not face

discrimination if returned to their home country so long as they keep their hepatitis C status private.[32]

As many of these cases occurred before the availability of DAAs, a key question for us is whether there has been any change in rhetoric or approach in the era of cure; in particular, whether legal approaches, expectations and rights have changed since the advent of DAAs and whether these are changing in ways that might not always work to the benefit of people with hepatitis C. One possibility may be that the law lags, that it has not been updated to account for the ready availability of cure, and that legislators need to address the issue of cure and its impact in a post-cure world. It may be that the advent of cure has raised problems with laws created in a pre-cure world that are interpreted and applied to a post-cure world. This necessitates a more careful examination of the legal discourse both pre- and post-DAAs.

In this paper, our focus is on administrative law judgments, with our analysis of the criminal law published elsewhere.[33] We explore judgments of the Administrative Appeals Tribunal, an Australian tribunal that provides a forum for independent merits review of administrative decisions. The Tribunal's decision-makers consist of a President and other members who may be appointed as Deputy Presidents, Senior Members or Members. We focus on cases within the Administrative Appeals Tribunal because the bulk of the cases we identified were heard there (84 in total). These cases dealt with two broad areas of administrative decision-making: social security claims and refugee or migration matters. Given that a significant proportion of cases fall into these two areas, and the vast majority of the Tribunal's caseload are in these two areas,[34] we have limited our focus in this paper to these two areas of law. These are also two areas of law, as discussed above, in which the availability of new treatments is reshaping approaches towards hepatitis C.

In the first part of the next section, we investigate social security cases in the Tribunal decided prior to the advent of DAAs and, in the second part, we investigate migration or refugee cases decided around the time of or after the advent of DAAs. This enables an exploration of how accounts of hepatitis C have changed over time and the potential significance of these changes for people living with hepatitis C. Upon examination of the cases, we witness a shift in rhetoric over time that parallels the shift in medical responses around hepatitis C – from "disability" to "cure." We then discuss how expectations of "disability" and "cure" in the administrative law cases under study have changed over time. To help explain this, we propose thinking of hepatitis C as constituted through performance – a performance of "disability" and "cure" that plays out through legal discourse. In conclusion, we reflect on how these legal performances affect conceptualisations of hepatitis C in the post-cure era.

Performing Disability

We start by considering the relationship between disability and performance and how the disabled body is re-framed in legal performance. In their foundational work on the constitution of hepatitis C, Fraser and Seear argue that pathways into treatment of the virus can "perform its subjects as chaotic, disordered and unstable."[35] As Fraser and Seear put it, medicine demands that people affected by hepatitis C "perform a particular version of subjectivity (responsible, stable, orderly) as a precondition to starting treatment."[36] As we will explain here, a similar process is underway to obtain certain legal outcomes. When coupled with legal proceedings concerning hepatitis C, the push for treatment both performs hepatitis C and its subjects and *demands specific kinds of legal performances* on the part of those affected by hepatitis C. As with Fraser and Seear's thesis that the person with hepatitis C must perform "through reference to an imagined sense of what order might look like,"[37] here the person with hepatitis C performs according to the law's imposition of order.

In "Performing Disability, Problematising Cure" (whose title inspires the name of this article), Johnson Cheu explores the performance of the disabled body in theatre. Cheu argues that disability operates as both a corporeal impairment and a cultural identity that is projected or assigned by the able-bodied viewer onto the disabled body. The perspective of the able-bodied spectator is paramount, such that the disability "lies not with how [the person with disability …] sees himself [*sic*], but how others see him [*sic*] and his [*sic*] body."[38] These processes constitute both performer and spectator, as well as disability. Petra Kuppers argues that "all bodies are limited, disabled by language" and that discourse assigns disability to the body through a process of "othering" by which the disabled person is cast as different or other than the (predominantly) able-bodied spectator.[39] As Kuppers and Marcus explain in other work, "many disabled people, if their differences are visible or not, have to perform their disability, perform their stories, are asked to explain 'what happened to you'."[40] The disabled person can challenge or re-stage this through tactical performance, though this is rare.

Turning to legal performance, the primary audience in court proceedings is the judge. The judge is, of course, not just passively observing proceedings but actively participating in them, so constitutes a very specific kind of audience. Throughout the performance, "the judge may interrupt the proceedings … manipulate them … or stop them for a designated break or other official adjournments."[41] Judges are in a unique position to co-constitute subjects and objects given their mediating role and legal powers. In his ethnographic study of the courtroom, Alexander Kozin argues that "the judge forms a special kind of intermediary audience, *audience-inside-the-proceedings*." And, in her analysis

of court trials, Leora Bilsky argues that what is occurring in the role of the judge is "a reciprocal movement between the perspective of actors and spectators" in the way the judge exercises both reflexive and determinative judgment.[42] Here, Bilsky – unintentionally, it seems – gestures to what theatre-maker Augusto Boal refers to as "spect-actors": that is, "those who observe … in order then to act."[43] We argue that the judge-as-spectactor plays an active role in legal proceedings. In combination with other practices in law, including testimonials given by plaintiffs on affidavit, or expert opinions given by physicians furnishing written reports, judges constitute those affected by hepatitis C, as well as the nature of hepatitis C itself, through their written judgments of the performance.

In judgments that occurred prior to DAAs becoming available on the PBS, hepatitis C is described as something that "probably does exclude" a person from employment in certain industries.[44] It is described as "that unfortunate illness,"[45] a "deadly virus,"[46] something fatal,[47] and incurable.[48] Furthermore, through the requirement to give oral testimony, submit affidavits and provide evidence (including health and job capacity assessment reports, medical certificates and testing results) to account for the effects of hepatitis C, the person with hepatitis C is compelled to perform their disability, making the invisible visible and the private public on the legal stage. There is no real choice in this. They are obliged to articulate their illness and its effects in detail and ultimately cast by the judge-as-spectactor as unfortunate, incapable of work and, in many instances, likely to die. Below, we consider the operation of these processes in two migration cases in the Administrative Appeals Tribunal from the pre-cure era. These have been selected because they are indicative of migration cases concerning applicants with hepatitis C prior to DAAs more broadly. In the section that follows, our attention will turn to cases that occurred after the advent of DAAs in Australia.

In *Marsh v Minister for Immigration and Multicultural Affairs*, the Minister ordered the deportation of the applicant, a long-term resident of Australia, to New Zealand on the basis that he was convicted of several crimes, including drug offences.[49] The applicant sought a review of that decision, in part on the grounds that returning to New Zealand would pose a hardship because "his condition of hepatitis C could degenerate into liver disease quickly and he would not have the family support that would be available here in Australia."[50] The matter was heard before Deputy President Desmond Breen of the Administrative Appeals Tribunal. Deputy President Breen assessed the applicant's medical condition as follows:

> The applicant has been diagnosed as suffering from Hepatitis C positive [*sic*]. Dr G Marinos, a Gastroenterologist, gave evidence to the effect that Hepatitis C can be fatal. It progresses over a

> period of decades. It is the commonest cause of liver transplants and is fatal if there is no liver transplant. He went on to say that if liver disease erupts, which can be rapid or slowly developing, then the patient would not be able to cope with normal functioning and it is then that family support becomes very important.[51]

In this passage, we can see the construction of hepatitis C as a present dominated by suffering, and a bleak future, commonly requiring major medical treatment (transplanting an organ) and even fatality. The movement between the present and the future "can be rapid or slowly developing" and, throughout this indefinite period, liver disease has the potential to "erupt" and halt "normal functioning," leaving the person with hepatitis C reliant on the support of others – namely, the applicant's family – to function. Deputy President Breen goes on to discuss the available treatment at the time, combination interferon and ribavirin:

> Patients who have the treatment report feelings of tiredness, lethargy and loss of ability to cope. Patients suffer from psychological stress, mood swings and depression so there is a need for family assistance.[52]

If hepatitis C is staged as something that causes "suffering," so does the treatment for it; it renders the person with hepatitis C reliant on the support and assistance of family to "cope." The person with hepatitis C is cast as unable to act by themselves. This is all staged through the evidence of a gastroenterologist, rather than the applicant. How the applicant sees himself and his hepatitis C status is not mentioned in the judgment, and the Tribunal's rhetoric shifts from considering the applicant himself to "patients" more generally. The use of the term "patient" (as opposed to person) with its particularly medical resonance suggests that hepatitis C is something that must be treated, and that the sufferer must be cared for. Furthermore, the person's identity becomes entirely one of "patient" – a medical status. This affirms Cheu's point that the performance of disability is not articulated by the person themselves, but by the audience that observes them – in this case, a medical audience.

Despite all this consideration of disease and treatment, Deputy President Breen concluded that he, "on the available evidence, cannot see that it affords a basis upon which to change a decision" to deport the applicant, in part because of evidence from the gastroenterologist "that the degeneration of the condition into life-threatening disease takes decades" and that there is "no reason why treatment for the condition of Hepatitis C available in New Zealand would be any

different from that available in Australia."[53] Therefore, according to medical evidence, the bleak future described can yet be averted by treatment in the present. The Deputy President also noted evidence from the applicant "that returning to New Zealand would be a 'fresh start'."[54] Though ostensibly in response to his history of criminal offending, the fresh start can also be read to include treatment for hepatitis C, suggesting that treatment alters a person's life and reshapes their identity. In this moment, we also see the Deputy President taking on the role of the spect-actor; watching and reviewing the medical evidence and then acting in judgment. Again, it is noticeable that there is very little, if any, attention paid to the performance of the person with hepatitis C themselves, meaning that they are only seen through a medicalised lens.

In *Gray v Minister for Immigration and Multicultural Affairs*, the Minister ordered the deportation of the applicant to Scotland on the basis that he was convicted of a crime.[55] The applicant sought a review of the decision in part on grounds of hardship. After the initial review was set aside on appeal, the matter was remitted for a further hearing before Deputy President Stephanie Forgie of the Administrative Appeals Tribunal. In her judgment, Deputy President Forgie considered the applicant's medical condition through the prism of medical evidence from Dr Wendell Rosevear, the applicant's medical practitioner. Deputy President Forgie surmised:

> In Australia, HCV is usually spread by intravenous drug use. The condition manifests itself as a chronic infection that is often unrecognised for years. In Mr Gray's case, the clinical features suggested that he had first contracted the infection either during his adolescent years or in his twenties. Active HCV can produce symptoms of lethargy and fatigue. As Mr Gray has a lower grade chronic form of HCV, these symptoms tend to be highly intermittent. The treatment for Mr Gray's symptoms is one of maintenance rather than of cure.[56]

In this passage, hepatitis C or "HCV" is staged as something that "manifests itself" in a long-lasting but potentially unrecognisable condition that can itself produce negative states such as lethargy. It can hide itself "for years." The possibility of cure seems to be dismissed. Later, Deputy President Forgie cites the report of Dr Frank Varghese, a consultant psychiatrist who had read the court documents, affidavits and reports as well as the applicant's clinical records. In that report, an excerpt from which was included in the judgment, Dr Varghese concluded that:

> There is the issue of complications of hepatitis, which could include liver failure and cancer. Thus there is an urgent need for

> him to turn his life around and for him to have appropriate assistance.[57]

Here, hepatitis C is linked to complications in the form of negative and severe conditions (organ failure and cancer). Hepatitis C is seen as entailing the possibility of severe health conditions, but the person with hepatitis C is constituted as agentive, with the capacity to turn things around. He is enjoined here to reverse his direction in life and seek support. He can only do so, however, with assistance from others. This way of describing the agency of people with hepatitis C resonates with earlier findings from Fraser and Seear,[58] who argued that patients were constituted as responsible for their own illness and treatment and enacted as "failed" and "transgressive" when treatment did not work.

In this judgment, hepatitis C is also strongly linked to injecting drug use, which has its own stigmatising connotations. Drawing from clinical evidence presented at the hearing, Deputy President Forgie describes the history of the applicant after leaving a methadone programme:

> After he jumped off the programme, he again started using heroin. He used it at that time on an intermittent basis. It was not a habit at that stage. Heroin provided some relief at the time. He was in a very sorry state from benzodiazepines at the time he went to HADS [the Hospital Alcohol and Drug Service]. His hepatitis C was affecting him very badly, he had lost some 29 kilogrammes in weight, had phlebitis, had lost a vein in his right arm which was swollen and could not reach the bathroom to vomit or relieve himself. He was, he said, in a very bad way.[59]

In this excerpt, the applicant's state is constituted as pitiful, perhaps informing the medical practitioners' discourse around the need for assistance. But it is also noticeable that, against the reliance on medical voices in other parts of the judgment, here the applicant's voice is brought in to make a series of points about how he sees himself, how others might see him, and how his present condition and trajectory is a consequence of his own action and inaction. In this passage, each condition – weight loss, phlebitis, immobility, nausea – compounds the other, creating a cumulative effect or crescendo of loss (from his weight to his vein) that leads to the conclusion that he is "in a very bad way." Finally, he is rendered immobile in the way that he is unable to move even from one room to another, underpinning the conclusion that the only way for him to move forward is for he himself to "turn his life around." This notion of (path-)ways is reflected in Deputy President Fergie's conclusion:

> Mr Gray has used his best endeavours to discourage others from following his path. He is to be praised for that. Even taking account of that and of the hardship which his family and he will suffer, I have concluded that the hardship which they will face is outweighed by the damage which would be caused to the Australian community should he re-offend as there is a real risk that he may do so.[60]

In this passage, the applicant is praised for discouraging others from following his apparent medical path – from injecting drugs, to acquiring hepatitis C, to negative health conditions – but also his criminal path that conflated drug use (sometimes to provide relief from the hepatitis C) and offending. His hepatitis C journey is thus cast as an example and warning to others. He is made, in Kuppers' terms, to perform his disability before the watching legal audience as a kind of cautionary tale to others. Then, when judgment comes, the language performs his disability as a cumulative impact of conditions that leads him down the wrong path. We also see in this moment the kind of reflexive versus deterministic performance of judgment that Bilsky describes. The Deputy President reflects on the applicant's conditions whilst determining his deportation.

In both these cases, the applicant's story of hepatitis C is performed before the tribunal member who assesses the credibility and authenticity of their performance, amongst other things. In so doing, the tribunal member constitutes the person with hepatitis C in particular ways, including as both disabled and agentive. However, it is the voice and views of others that are most privileged in these judgments, and the voices of the applicants themselves are largely absent. It is as if applicants are invisible actors in all this; that is, they play a central but largely invisible role in the judgments.[61] We cannot speak for the proceedings themselves, reliant as we are on the judgments – the written records of the case and decision. However, in these two cases, the material effects of this performative process could hardly be more pronounced: both were deported. Whilst this was not the case for all applicants, with some applicants with hepatitis C not being deported,[62] these cases are emblematic of the way that migration decision-makers treat hepatitis C.

In the next section we will turn again to the case law, including cases that occurred near or after the advent of DAAs, to understand how hepatitis C is performed over time and whether there has been a change since the advent of DAAs. We examine social security cases concerning treatment-as-cure that are, we argue, emblematic of the wider whole of social security cases concerning people with hepatitis C near or after the advent of DAAs.

Problematising Cure

In exploring the performativity of legal language and practice in cases around or after the advent of DAAs, we note that a similar discursive construction or constitutive rhetoric applies to cure as it does to disability. Here we draw from research on narratives and performances of "recovery" from "addiction." In so doing, we suggest that cure is linked to ideas of recovery and that recovery is an emplotment with identifiable strictures and desired audience effects.[63] Noe Montez argues that performances of recovery are designed to satisfy multiple constituencies, especially the spectators to these performances, through dramatising rehabilitation.[64] Montez argues that the audience has expectations of how rehabilitation is to be performed. There is a voyeuristic – even exploitative – dimension to this spectating: the audience wants to see authentic-seeming emotional performances of difficulty; they want to understand what it feels like. But it is not just about the audience. Stephanie Kewley argues that performances of recovery constitute performer identities themselves.[65] The possibility of recovery is, however, predicated on "recovery capital" – availability of and access to resources that support the recovery process – including physical health, social and familial relations, cultural and community factors, as well as socio-economic status. Recovery is socially contingent, and cure does not erase the history of disease.[66]

As much as the hepatitis C identity is constituted by the judge-as-spect-actor, so too is "cure" a performance that is constituted before and by the judge-as-spect-actor. As Cheu describes, "medical cure, the possibility of a 'normal' body, is a *perspective* that is assigned by the able-bodied viewer to the disabled body … The perspective of the able-bodied spectator drives the ideas of normalcy and cure in disability performance."[67] In legal contexts, the person with hepatitis C is compelled to perform their cure, which often involves sharing intimate information with the judge-as-spectator. This often creates a sense of distance, disconnection, or "othering," although this is not so in every instance and is largely dependent on how the person acquired hepatitis C. For example, the person who acquires hepatitis C through the sharing of injecting equipment is almost always perpetrating a crime, owing to the criminalisation of injecting drug use. The person who injects drugs and acquires hepatitis C is cast as "other" in part because of their criminality, whereas the person who acquires hepatitis C as a victim of crime (including crimes involving the use of syringes) is cast as "vulnerable" and in need of protection.[68] The "other" with hepatitis C must satisfy the judge-as-spect-actor's expectations of witnessing rehabilitation on the legal stage. Recovery is performed – often very viscerally, through acute descriptions of lives pre- and post-treatment – to satisfy the expectations of the judge-as-spect-actor, as we will explore further. Recovery produces cure, which is the aspirational light

at the end of the tunnel in disability performance. It is an aspiration very difficult to resist, in part because it closes the loop from disability to recovery to cure.

In more recent cases, hepatitis C is described as something that can be beaten, to use the terminology of a party with a history of hepatitis C,[69] is not permanent,[70] and is temporary.[71] Once treated and cured, it is cast as something that no longer affects the life of a person. This shift means that a person with hepatitis C is now even more likely to face visa cancellation and refoulement on the basis that treatment for hepatitis C is more readily available in migrants and asylum seekers' home countries (not that hepatitis C has much impact on migration decision-makers, as discussed above). There are other implications for administrative decision-making, however.

The shift towards cure also means that people with hepatitis C are less likely to be able to access the Disability Support Pension (a government payment to people who have a permanent medical condition that stops them from working). In this section, we will explore cases concerning entitlement to the Disability Support Pension amongst people with – or with a history of – hepatitis C. Questions as to entitlement frequently come before the Administrative Appeals Tribunal because the Disability Support Pension provides higher income support compared to the alternative Jobseeker Payment, with fewer activity tests or mutual obligations on which eligibility depends.

The first case of *Dean v Secretary, Department of Social Services* occurred at a time when there was an anticipation of curative drugs being soon available.[72] In this case, the departmental Secretary cancelled the applicant's Disability Support Pension following a review process that found that, though he had hepatitis C, he did not have legally sufficient impairment. The applicant sought a review of the decision. After the initial review affirmed the original decision, the applicant sought a second review before Member Sandra Taglieri of the Administrative Appeals Tribunal. It was common ground between the parties that the applicant had hepatitis C at the time the Disability Support Pension was cancelled. However, though his hepatitis C had been diagnosed, there was a dispute as to whether it had been fully treated and stabilised. This was important because the law requires that any condition be fully diagnosed, treated, and stabilised before it can be regarded as being a "permanent impairment." Member Taglieri considered the applicant's hepatitis C as follows:

> He had been to the Launceston General Hospital in February 2010 and it had been diagnosed at that time… He was still suffering from Hepatitis C at the time his pension was cancelled. Although it was diagnosed in February 2010 it was not 'followed through' at the time but he was on a waiting list to receive treatment at the Launceston General Hospital but that had not

> yet begun. There was a suggestion that there may be some oral treatment available in the future. The Applicant claimed that Hepatitis C caused him to become very tired, lose his appetite and his liver function was compromised. The Applicant stated that he felt very tired on account of this condition and did very little because of it … Although the condition is fully diagnosed, the Tribunal is not satisfied that is [*sic*] has been fully treated and stabilised. Under cross-examination the Applicant gave evidence that there was no treatment for the condition of Hepatitis C, but this is at odds with the evidence that he gave in chief namely that he was on a waiting list at the Launceston General Hospital and waiting for treatment there to begin. There would be no purpose to being on a waiting list at the hospital for this condition unless some form of investigation and/or treatment of it were proposed. I note indeed that there is evidence in the report of Dr Bush in section L on page 5 of her report indicating that 'he has not had further investigation of his Hep C to determine if treatment is needed.' This statement was made some two years ago and has not yet occurred. At the relevant time when the DSP was cancelled, the requirements for concluding permanency for Hepatitis C were not met.[73]

In this passage, hepatitis C is constituted as a form of "suffering" that causes various conditions ranging in severity from feelings of tiredness to compromised organ function. The tiredness, however, meant that the applicant "did very little" and was in some form of stasis. The applicant was on a "waiting list" for treatment and "waiting for treatment … to begin" (though he disputes this), but he has not "followed through" with further investigations. His life is cast in limbo – between diagnosis and treatment. It is as if he cannot move forward. This is very much a performance of disability of the kind that Kuppers describes. We also see the Member as spect-actor, who watches and describes this performance and then acts in judgment.

There is a suggestion of oral treatment, but that is cast as "in the future" while the applicant is stuck in the present state of "suffering." The cure hangs elusively in the distance. Nevertheless, this present state is not accepted as permanent. The expectation is that the applicant will move from diagnosis to treatment, and then forward.[74] There is no consideration in the judgment of how ineffective existing treatments at the time were, and that many people were advised by doctors to delay treatment until new oral treatments became available. Instead, the prospect of oral treatment or DAA hangs elusively in the future as an expectation about a future state of health into which he should be moving,

or to which he should be aspiring; the present is a transient state and change is readily achievable through existing treatments, if only he would take advantage of them. What this means is that hepatitis C, if left untreated, is unable to meet the requirement under social security law for permanency of impairment; the disability can be treated, and thus the person with hepatitis C is unable to access social support until they have undergone treatment. When brought together, a state of limbo is produced between the transient present marked by impairment and the aspirational future characterised by treatment.

In *Rossi v Secretary, Department of Social Services*, we have arrived in at the point where DAAs are now widely and freely available. In this case, the Secretary rejected the applicant's claim for the Disability Support Pension on the basis that he did not have sufficient impairment.[75] The applicant sought a review of the decision. After the initial review affirmed the original decision, the applicant sought a second review before Senior Member Theodore Tavoularis of the Administrative Appeals Tribunal. In his original application, the applicant listed his medical conditions as including hepatitis C. His application for the Disability Support Pension was rejected, in part, on the basis that although his hepatitis C had been diagnosed it had not been fully treated and stabilised. This is because, as noted earlier, the law requires that any condition be fully diagnosed, treated, and stabilised before it can be regarded as meeting the legal criteria of "impairment." However, by the time of the hearing a year later, the applicant himself regarded hepatitis C as no impairment, as Senior Member Tavoularis wrote in judgment:

> During the hearing Mr. Rossi, the Applicant, very helpfully and in quite a forthcoming and honest way, told the hearing that the specific issues of alcohol dependency, Hepatitis C, liver cancer and depression were effectively in his past and that he did not want them considered or taken into account for the purposes of this matter. He said that in all respects those four conditions caused him no functional impact on his capacity to get on with his life on a day-to-day basis.[76]

In this passage, the applicant performs hepatitis C as something "in the past" and incapable of impacting his progress. On this basis, he argues for hepatitis C not to be considered or accounted for in the present, along with a range of other issues. He can "get on with his life" and move forward. He is described as speaking towards the present and the future (in a "forthcoming" way). His telling of intimate details of his past also renders him "honest," as though to come forth about one's past condition is to make oneself honest. We see here the way in which performances of recovery – in this case, speaking at the Tribunal hearing

– constitute the performer-applicant's identity by casting the disability as in the past. This performance is done very deliberately for "the hearing," and we see the effect of this in the way that SM Tavoularis also emulates the way the applicant himself describes his experience of hepatitis C:

> At the hearing the Applicant told me he has been told by his medical advisers that the Hepatitis C is clear and that he is no longer affected by it. To use his words, he has beaten that condition.[77]

In this passage, SM Tavoularis does not rely on medical advice but, rather, what the applicant *says* he was told by medical advisors. The applicant says he has "beaten that condition" – that way of being with hepatitis C – to such a degree that it is "clear" and incapable of affecting his life moving forward. It has been reconceptualised from a "condition" or *existing* state to a *past* that "no longer" has any affect in the present. Moreover, it is something that "*he* has beaten," suggesting that the applicant himself is responsible for clearing the condition and is the agent of his own recovery. There is something further important to note here. Against the theory that cure is assigned by the able-bodied viewer to the disabled body, it is the applicant who asserts the cure themselves, leading SM Tavoularis to conclude that:

> Obviously, he is clear of the hepatitis C and it is not a factor in his life anymore, and nor is there any other evidence to suggest that he has in the past refused to comply with treatment due to some sort of medical or other compelling reason. There is no need to go into those factors … because as he has told us hepatitis C is no longer affecting his life and he has been told that he is otherwise clear of it.[78]

SM Tavoularis accepts the applicant's performance of his experience of hepatitis C and concludes that hepatitis C no longer contributes to the applicant's life. What this suggests is that, as much as cure is assigned by the viewer to the disabled body, people with a disability may also invest in a cure narrative themselves. It is important to also reflect, as Montez reminds us, on who this performance of cure is being done for: the applicant performs their cure through their testimony at the hearing before SM Tavoularis to satisfy the judge-as-spect-actor that they have rehabilitated. The performance also asserts the applicant's own agency over his rehabilitation: he has beaten a condition that debilitated him such that he can now get on with his life. Therefore, the performance is also a way for him to erase the history of his past conditions.

SM Tavroularis also relies on the absence of contradictory medical evidence to buttress the applicant's assertion of cure. Though he does note, almost in passing, that the applicant "has a small benign liver cyst,"[79] a mark that suggests the applicant has health issues, though it is unclear if the cyst was linked to the hepatitis C or the applicant's liver cancer or alcohol dependency or a combination thereof. The applicant's assertions that these issues were in the past and should not be considered now could be because he is trying to present as deserving of social support. Though we can only speculate on this point, it is nevertheless clear that he is collaborating in the cure narrative, performing himself as transformed, and disavowing any effect of hepatitis C in his present life.

In *Secretary, Department of Social Services v Scott*, again, the Secretary rejected the respondent's claim for the Disability Support Pension on the basis that he did not have sufficient impairment.[80] He was diagnosed with hepatitis C, "but the condition is considered temporary as it can be eradicated with antiviral medication therapy."[81] The respondent sought a review of the decision. After the initial review set aside the original decision, the Secretary sought a second review before Member Dominque Grigg of the Administrative Appeals Tribunal. Member Grigg noted that as regards hepatitis C, "this condition is temporary and is not relied upon by Mr Scott for the purpose of this application."[82] It is considered temporary because it has the potential to be "eradicated." He is still, however, "waiting treatment,"[83] and his general practitioner confirmed that he was unable to work due to "his need to treat his hepatitis C."[84] This passage suggests both his ownership over hepatitis C and its treatment – it is "*his* hepatitis C" and "*his* need to treat" – and his stagnation, which appears to be his responsibility. The waiting time is only "temporary," even though the inability to work may have a severe impact on his livelihood. In some respects, this is a failed performance of recovery. Though the possibility of normality – constituted as the ability to work – is the light at the end of the tunnel, the applicant is not there yet because they have not performed the necessary steps to recovery in the form of treatment. As such, the possibility of cure is assigned to the applicant by the judge-as-spect-actor and drives the way in which the applicant's argument is performed. Notably, Member Grigg argues that one of the objects of treatment "is to assist persons with disabilities … to work towards full participation as members of the community" including through "paid employment."[85] Although his hepatitis C affects his ability to work, even the respondent himself does not rely upon it in pressing his claim (instead relying on other conditions including spinal impairment, drug dependency, asthma, and a mental health condition). In doing so, the applicant is perhaps recognising the double bind in which hepatitis C will only be regarded as an impairment if it is treated but, once it is treated, it is no longer an impairment. They also perhaps understand that success is contingent on a performance of recovery that can satisfy the judge-as-spect-actor.

In the earlier cases, the possibility of cure hangs tantalisingly in the future. In the migration cases of the 1990s, cure is not even described as *possible*, even though it was (speaking, perhaps, to a lack of knowledge on the part of judicial officers); but by the mid-2010s, cure is suggested as a possible future, before becoming accepted as a reality by the latter half of that decade. When it does become available, a person with hepatitis C is effectively compelled to undertake DAA treatment before being able to apply for the Disability Support Pension. However, they are then placed in a double bind: hepatitis C will only be regarded as an impairment for the purposes of the Disability Support Pension if it is treated but, once it is treated, it is no longer an impairment. In these cases, the applicant is making a claim for Disability Support Pension to gain an income because of their claimed inability to work. In *Scott*, for example, the applicant claimed that he was unable to work because of the need to treat his hepatitis C, a claim supported by his general practitioner, despite the new DAA treatment having no effect on the capacity to work. Despite the curiosity of this claim, he was caught in a state of limbo where his income was suspended until he could access treatment. Without the capital – financial or otherwise – necessary to access treatment, the hepatitis C identity and its associated stigma persist.

In these cases, treatment is positioned as the pathway to a future in which hepatitis C is no longer a factor in life. Once cured, the person with hepatitis C must fashion a new identity. But this takes time and is predicated on access to recovery capital, including the ability to work and sustain an income. Two things may be said about this. First, treatment may be elusive for those who cannot more readily access treatment;[86] for those who can access treatment, whilst they may be able to work while waiting for treatment, their ability to access social security benefits from the Disability Support Pension is placed into an effective limbo until treatment is accessed. Second, treatment will cure the impairment but simultaneously remove a person's entitlement to some social security. Thus, those people living post-cure who were previously reliant on social security must not only fashion a new identity but also find new ways to access security, both of income and residency, which can be particularly hard given the difficulties that being out of the workforce for a long period of time poses for a person seeking to enter the workforce, sometimes for the first time. Without income, residency or other forms of capital, the stigma that attached to hepatitis C may persist post-cure. Further research as part of this project has investigated how people who have undergone treatment for hepatitis C understand and articulate their relationship to hepatitis C post-cure.[87]

In these cases, the person with hepatitis C is compelled to share intimate information about their condition: health and job capacity assessment reports, medical certificates, and test results. Law and performance scholar Nicole Rogers explores the "depersonalising process by which courtrooms turn people's stories,

their lives, into legal narratives."[88] She argues that judgments are often dry and depersonalised and operate on such a high level of abstraction that distinctive private or subjective features – such as materiality, affect, and emotions – are diminished. In the judgments, there is a remarkable lack of empathy towards the lived experiences of people with hepatitis C and a distancing from any emotional response to those whose stories the tribunal members are re-telling. Rogers calls for "the infusion of other stories, other perspectives, other ways of 'seeing' than the strictly legalistic."[89] Building on this, we suggest that there needs to be attention to the rhetorical construction of hepatitis C by judges and tribunal members in their judgments, as well as by experts in their evidence, and the impact that this might have on people affected by hepatitis C. Of course, we cannot know what occurred in the courtroom, but the judgments serve as a distillation of the proceedings and the ultimate record of the case. As such, the judgments have the potential to highlight different narratives that attend to the lived experiences of people living with hepatitis C and challenge dominant narratives around "disability" and "cure."

CONCLUSION

This paper has considered the performance of disability and cure in legal cases involving hepatitis C. Through careful attention to the discourse in these cases we can see a shift in rhetoric surrounding hepatitis C from a permanent, impairing disability to a temporary, curable illness. What is also discernible is the temporal location of disability in the present and cure in the future. In Australian cases heard and decided since the advent and widespread availability of more tolerable and effective treatments, and once the possibility of cure became apparent, people with hepatitis C were no longer conceptualised as disabled for the purposes of social security law. This means that whilst hepatitis C – and associated symptoms such as fatigue – was regarded as an impairment,[90] it is no longer. People with hepatitis C were enjoined to undertake treatment on the basis that it would move them into a utopian future in which the virus has negligible impact on their life – or at the very least, productive citizenship that is primarily characterised (in the social security case law) by the ability to work.

We must caution that this mapping of law is somewhat speculative. It draws in part from our personal knowledge supplemented with searches of statutes and judgments. Given the various ways in which hepatitis C might operate in legal contexts, including in ways that are unexpected or novel, and given that the emergence or disappearance of hepatitis C in different areas of law can shift over time, this mapping does not comprehensively capture every relevant materialisation of hepatitis C in law, including in otherwise unrecorded practices of law.

New renderings are possible in the future, including ones we have not yet anticipated. Indeed, as other stages of this project evolve, we are continuously identifying new areas of law that might impact on people who have – or who have previously had – hepatitis C, even if the law does not explicitly mention hepatitis C.

Why pay attention to the performative dimensions of hepatitis C pre- and post-cure? Through such noticing, we can better understand the performative effects of the object under study. As Marett Leiboff puts it, in the context of jurisprudence, to notice is "to pay attention and *to become aware*."[91] Through noticing the performative effects of legal rhetoric around "disability" and "cure," we can become aware of the affect that legal discourse has on materialising hepatitis C and life with the disease. This act of noticing does not simply encourage a momentary pause and reflection, it compels us – as Leiboff puts it – "to respond and react … to acquire something of that imagination and experience needed to notice when law goes wrong."[92] We should also notice the visceral response we have to the legal rhetoric surrounding hepatitis C, pick up where it goes wrong and resolve to correct this. Despite the quite significant changes in the legal performance of hepatitis C, one thing that has persisted is the requirement for the person with (or cured of) hepatitis C to tell the story of their status, to "confess" their illness to the court.[93] Given this constant retelling, it is unclear whether the stigma connected with that status can, like the virus, be overcome. While hepatitis C is recast in post-cure cases as temporary, the stigma associated with it – and perhaps exacerbated through the telling and retelling before a court of law – may be more lasting.

Changes in rhetoric indicate the way in which the law shapes "disability" and "cure." This matters because legal performance and rhetoric has an authoritative effect on the constitution of hepatitis C even post-cure. The decisions made in legal judgments and rendered in legal statutes have ongoing effects on access to residency, social security and other social benefits, and the rhetoric used is particularly important in framing to whom and how access to social benefits is accorded. The later legal rhetoric frames cure as a means of escaping hepatitis C and the stigma surrounding the virus. This might seem a positive rendering, especially when it picks up on the rhetoric that people who have undergone treatment often use to describe themselves. However, it also has the effect of endorsing "cure" as transformative, conveying an impression that hepatitis C has negligible ongoing effect on the life of a person post-treatment. It offers an understanding of hepatitis C in quite stark terms: it is there, and once treated, it is gone. More careful attention to the people with hepatitis C in these cases instead suggests that the mark of hepatitis C is still present even post-treatment, at the very least in the legal documents in which the lives of people affected by the virus are recorded.

DISCLOSURE STATEMENT

The authors report that there are no competing interests to declare.

NOTES

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