

## Viral hepatitis keynote 2016

Dr Kate Seear

### **'Hepatitis transmission and prevention: Exploring the role that the law plays in shaping blood borne virus epidemics'**

I would like to begin by acknowledging the traditional owners of the land on which we meet today, to acknowledge elders past and present, and to extend that respect to other Aboriginal and Torres Strait Islander peoples. I would also like to thank the organisers of the conference for the invitation to speak: I am grateful that they trusted a lawyer to speak to you all.

Today I want to talk to you about the various ways that BBVs intersect with the law, how the law shapes the very size and scale of BBV epidemics, and some of the opportunities for advocacy and reform that remain unrealised in Australia. To set the scene, let me begin by sharing two quick stories about what happens when the law and hepatitis C come into contact.

The first story was revealed in a 2013 piece for the *International Journal of Drug Policy*. kylie valentine and Carla Treloar explored what they called the 'child protection mess', focussing, in particular, on how child protection workers conceptualise AOD risks when making the very significant decision to remove a child from their parent's care. They shared the story of a colleague who related to them the removal of a child from her family. They wrote:

The child was removed from their parents' care over concerns regarding one parent's possible hepatitis C status (the parent does not in fact have hepatitis C). [...] Access to the case documents revealed, among other things, that the child had been 'vaccinated' for hepatitis C. This is, of course, not possible as no vaccine exists for hepatitis C. In this case it appears that case workers who primarily deal with parents presenting with drug and alcohol issues were unaware of basic information about hepatitis C and that the court readily accepted this incorrect evidence.

This first story tells us a few things: about how the law and key decision-makers in the law understand – or perhaps do not understand – hepatitis C, and about the symbolic meanings that attach to it. The story also raises a few questions: How do key decision-makers understand risk when it comes to hepatitis C? Does a parent thought to be living with hepatitis C pose a risk to their children? What kind of a risk, on what basis and why? If they are also a person with a history of injecting drug use, does the law trust them to mitigate those risks? If not, why not?

The second story tells us a little bit more about the ways concepts of risk can intersect with the law. Recently, I was at an event exploring the use of legally mandated involuntary treatments for people experiencing AOD problems. A debate was unfolding about the ethics of coercing people who use illicit drugs into drug treatment. At a certain point, someone suggested that coerced treatment might be justified because of the risk of acquiring hepatitis C through injecting drug use. The argument, so it went, was that if a person injected drugs, then acquired hepatitis and that hepatitis then developed into liver cancer, their life might be at risk. Drug use is thus a fundamentally risky situation, and as such, in order to save their life, it might be justified to override that person's autonomy and try and get them off drugs. As with the first example, there's a central flaw in the logic here: injecting drug use is assumed to *cause* hepatitis C. Indeed, as Magdalene Harris (2005) has argued, hepatitis C is mainly seen as a 'result' of injecting drug use in the West, where injection and infection are 'virtually conflated'. But if a person injects drugs, it doesn't automatically follow that they will acquire hepatitis C. A complex range of

forces are at play in BBV transmission, including whether clean needles and syringes are readily available for those who need them.

In much recent work, BBV transmission is increasingly conceptualised as a complex phenomenon shaped by a multitude of forces. As Suzanne Fraser and David Moore (2010) have argued, for instance, diseases are not purely biomedical phenomena, but ‘socially constituted’ objects. In other words, the hepatitis C virus and its epidemics are directly shaped by an array of factors, including policy and practice, the availability of some programs and the lack of others. In my own book on hepatitis C with Suzanne Fraser (*Making disease, making citizens: The politics of hepatitis C*), we argued that particular BBVs and the shape and scale of BBV epidemics are not simply ‘natural’ phenomena that exist prior to policy or practical interventions. The importance of this insight is that it changes up how we think about causality: loosening the way we understand the processes of virus transmission and prevention, responsibility and blame. If BBV transmission and prevention isn’t a purely biomedical phenomenon, but one shaped by a multitude of factors including policy and practice, then changing policies and practices is essential if we are to change the very shape of epidemics.

I suspect that many of these ideas are well understood; they form the basis for much outstanding advocacy – a good deal of which is undertaken by people in this room. Today, though, I want to shift our attention to the way that another institution impacts on BBV epidemics in this country. I want to focus on the law and legal processes, because the law, like policy and practice, plays a powerful and oft overlooked role in shaping BBV epidemics. I want to explore these issues today by focussing on three things.

First: I want to talk a little about some of the best-known factors that undoubtedly shape BBVs in Australia. Because they’re well known, I’ll go over them very quickly. Then, I want to examine some of the lesser-known factors associated with BBV epidemics and consider some of the obstacles to progress. Thirdly, I want to explore the options for reform. I will look at what’s happening elsewhere in the world to harness the law’s potential to positively intervene in the size and scale of BBV epidemics, and consider whether there are lessons we can take away from elsewhere and put into practice here, in Australia, in our own work.

The UNODC, WHO and UNAIDS argue that a package of supports should be made available to PWID. As we know, however, not all of these have been realised. Despite the fact that prison NSPs have been in place in some parts of the world since 1992, and there are now more than 60 in place worldwide, Australia still doesn’t have a PNSP. Just a couple of weeks ago, ACT prison staff voted down a proposal for a PNSP at Alexander Maconochie Centre, thwarting longstanding hopes of a breakthrough, and causing advocates and harm reductionists to consider their next move. Recently, Rubenstein et al. (2016) for a special series in *The Lancet* argued that the absence of PNSPs represents a significant human rights violation. There can be no doubt that numerous international human rights principles and instruments support this. More than this though, I think the continuing legal prohibition on such a vital harm reduction measure likely contributes to the shape and scale of BBV epidemics in Australia, by inhibiting people’s capacity to access clean needles and syringes in prison.

There are other examples. Despite recent reforms in Tasmania and the ACT, Australia continues to have laws that prohibit peer distribution within the community. There is also a continued risk of manslaughter prosecution, if a person unlawfully aids and abets self-administration and that person suffers fatal overdose, as occurred in NSW in the late 1990s, in the case of *R v Cao*. By discouraging harm reductionist measures, legal barriers such as the prohibitions on peer distribution and the threat of prosecution work to produce harm, and in so doing, play a role in shaping the nature, size and scale of BBV epidemics in Australia.

Of course, as I am sure you all know, there have been countless calls for reform in areas such as these. In spite of all of this, change remains painfully – even glacially – slow. Why such inertia? And could lawyers do more to push for change? If so, how and where would this work be done? Unfortunately, there are structural factors that inhibit the capacity of lawyers to engage in advocacy for reform. UNAIDS (2016: 8) has called for an assurance that ‘the human rights of people who use drugs are not violated, by providing access to justice (including through legal services)’. Each year in Australia there is a significant unmet legal need, however. People living with BBVs and PWUD encounter legal issues in many different spheres – in employment, access to health care and services, family law, child protection, criminal law and more. A very large number of these people rely on government-funded services such as legal aid and community legal services for support. But in recent years, funding to legal aid has been significantly reduced, with a flow-on affect for the capacity of community lawyers to take on cases. Because their resources are limited, most community legal centres have strict guidelines that govern who they can help and in what kinds of cases, so that there is consistency and transparency in their approach. Typically, these guidelines exclude community lawyers from participating in whole areas of law, meaning that lawyers don’t always have the capacity to provide legal advice and representation. Recently I have been conducting a series of in-depth interviews with lawyers in Australia and Canada about how AOD issues come up in their work. As one of my interviewees said, legal centres:

‘are a dumping ground for what no one else wants, although we are limited in the areas of law we handle, but a lot of lawyers will refer people to our office for help in areas of law that we don’t handle, simply because they don’t want to deal with these people’.

Lacking expertise and resources, many clients are simply turned away, leaving those clients to either fend for themselves, seek help from another legal service, or accept whatever their legal fate may be, leaving the status quo undisturbed. As well, government funding has been made conditional in recent years: community lawyers are prohibited from undertaking certain forms of strategic advocacy, hampering our capacity to pursue novel cases and adventurous arguments about areas of law that we know impact upon our clients.

Beyond this, lawyers’ own assumptions, stereotypes and lack of knowledge shape the way that legal approaches to BBVs play out. In very general terms, my research suggests that although many lawyers are passionate about social justice and the rights and interests of their clients, their advocacy is often hampered by simplistic assumptions and stereotypes about drug use, BBVs, ‘addiction’ and other drug-related harms. Lawyers regularly make assumptions about BBVs, ‘addiction’, drugs, risks and harms – including the kinds of assumptions that featured in the two stories that I opened with. Lawyers also use stigmatising language and concepts in their work, and often have simplistic understandings of the nature of causality and risk. Indeed, as one of the lawyers I interviewed for my research suggested, dealing with lawyers is ‘no different than dealing with the general public [...] in terms of the perception and stigmatisation’.

There are good reasons for this, I think. At university, law students study broad areas of law such as criminal, family and constitutional law, learning fundamental legal principles. There’s no BBV or AOD specialism in law though. When law students go onto legal practice, they’ll know the fundamental doctrines of an area of law – like the family law principle that says the best interests of a child are paramount when decisions about that child’s welfare are at stake, but they don’t learn about how the fact of a parent’s injecting drug use or hepatitis B status relates, for instance, to a child’s welfare. These issues are not touched upon in conventional legal education, and yet having a basic understanding of them is central to a lawyer’s capacity to advocate for their client. Lawyers must typically fill in the gaps through self-education or through extra-curricula study undertaken on their own initiative. Sometimes, they fill in the gaps through recourse to stereotypes and common-sense assumptions. If we are to talk, then, about tangible opportunities

for systemic reform in ways that can support the needs of people living with BBVs, PWID and others, let us start with legal education, which can and should be reformed to improve lawyers' understanding of the complexities of the issues they deal with in their work. This can only lead to more progressive thinking and more courageous advocacy. There's certainly precedent for this elsewhere. In recent years, for example, lawyers and advocates have worked hard to force a radical shake-up of conventional thinking and practice pertaining to family violence. We have moved from the status quo, where family violence was understood as a private, natural and lawful practice, to one in which family violence has been repositioned as a grave social and criminal wrong. Advocates have also pushed for – and achieved – an expansion in the definition of family violence, so that we now understand family violence to include patterns of behaviour that exceed physical abuse, and that incorporate emotional and financial abuse. We might wonder: where are the important conceptual shifts that need to happen when it comes to AOD, BBVs and the law? Do we need a radical reconceptualisation of concepts of harm, and of risk? If we were to try and reshape thinking, where would we begin?

One country that is active in this space is Canada. Canada is an interesting place to turn to for a few reasons. First, there's something very different about its legal system. Unlike Australia, they have a Charter of human rights and freedoms – a law that embeds some fundamental rights in Canada and allows people to bring legal challenges against the government when people's human rights have been breached. I'll say more on how this works in a minute, but the key point of interest is that strategic human rights litigation has exploded in Canada in recent years (Voell 2012). Canada is arguably leading the way in litigation of this kind, especially for people living with BBVs, sex workers, PWUD and PWID. Some of you might be aware of major cases unfolding there in the last few years. These include:

1. The much-heralded *Insite* decision: In 2011, a strategic human rights case in Canada's Supreme Court was responsible for saving Vancouver's supervised injecting facility, Insite, after attempts by the Federal government to shut it down;
2. In 2013, in the case of *Bedford*, certain laws associated with sex work – including bans on brothels and bans on street soliciting – were deemed unconstitutional;
3. And soon, a major case called *Simons* will go before the Canadian Supreme Court arguing that the government's failure to provide NSPs in prisons is a breach of prisoner's human rights. This will be one to watch, but many lawyers and scholars, including me, think this has a good chance of succeeding.

These cases are complex, but in a nutshell, they revolve around a couple of key ideas. Simply put, the Canadian Charter includes a section that says:

Section 7. Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.

In the *Insite* case, the claimants argued that closing down Insite threatened their right to life because it increased their risk of death. The claimants argued that the attempt to close down Insite:

'created an impermissible barrier between persons afflicted with the serious and debilitating illness of drug addiction and their access to the professional health care and services offered by Insite which would reduce, if not eliminate, the risk of death from overdose and reduce, if not eliminate, other serious and life threatening diseases' (see Voell 2012: 14)

Including, most likely, BBVs. The prison NSP case makes a similar argument about the way corrections policy infringes the right to life by increasing the risk of death, and will be one to watch. You can follow developments in that case through the ‘prison health now’ website.

But change can happen, of course, without recourse to litigation. For example, my colleague Suzanne Fraser has looked at supervised injecting facilities in her work comparing addiction policy and practice in Australia and Canada. One large charitable organisation in Vancouver had been informally running a supervised injecting facility for some time. When finally challenged by the authorities to dismantle it, lawyers and nurses worked together to assess whether the site was legal. They found that (to quote one of the key players in the process): ‘It is within the scope of registered nursing practice to supervise injections for the purposes of preventing illness and promoting health and furthermore, in the nursing practice standards, an employer is responsible for ensuring a nurse has the support to practice according to their standards in the workplace’. Making facilities available to allow nurses to supervise self-injections was in this way argued to be an employer responsibility under nursing regulatory requirements. Here, then, is another creative example of the way that lawyers and healthcare workers engaged in a dialogue about their respective duties, legal risks and harms, and developed a creative solution for the benefit of the local community.

But back to the Charter. As I mentioned earlier, Australian doesn’t have a Charter like Canada’s. Lawyers don’t have the option to build strategic human rights cases quite like the ones that Canadian lawyers have crafted in cases such as *Insite* and *Bedford*. But, as you may know, both Victoria and the ACT do have human rights charters of some sort. Although they don’t have the same legal status as the Canadian charter, they do allow human rights arguments to be made, particularly where it can be argued that public authorities – like government departments, police, public prisons and so on – might be breaching people’s human rights. And, crucially, a bit like the Canadian Charter, both Victoria and the ACT charters include a right to life provision.

In Victoria: “every person has the right to life and has the right not to be arbitrarily deprived of life”.

In the ACT: “everyone has the right to life. In particular, no-one may be arbitrarily deprived of life”.

Is there a missed opportunity here? I think so. I think that lawyers in both jurisdictions have at their disposal a potentially powerful tool for advocating for the rights of PWUD, PWID, prisoners, sex workers and people living with or at risk of acquiring BBVs. This is an opportunity that remains, in my view, unrealised.

These charters, like most laws, are complex, and it is beyond the scope of my presentation today to explore all of those complexities and limitations in depth. Here’s a few things that we do know, however. These charters apply to ‘public authorities’: like government departments. The charters require those departments to take people’s human rights into account when they make decisions. We know that charter arguments are often made before people go to court – with hospitals, for example, when restrictive or problematic policies about treatment are made, and that hospitals have on occasion overhauled their policies on service delivery when charter arguments have brought to their attention problems with the way they treat particular groups. We also know that charter arguments are sometimes made strategically – to encourage local councils, police departments and other authorities to think more carefully about human rights in the work they do. Sometimes, without ever having to go to court, agreements are reached for changes in policy and practice. Lawyers and other key stakeholders can and should work together

to identify key problem areas; they should also look to what's happening in Canada for inspiration and consider making arguments based on the charter more often.

These arguments are not without their problems, though. As you will perhaps have noticed, these cases tend to rely upon problematic ideas about drugs and drug 'addiction' in order to succeed. In the *Insite* case, for example, lawyers argued that PWID are 'addicts' suffering from a disease in the form of addiction and that the drug consumption facility was thus a vital, life-saving health care facility. The notion that PWID are addicts, suffering from an illness in the form of a disease does not, of course, sit well with everybody. The victory in *Insite* relied upon stigmatising language and concepts. Strategic human rights litigation of this kind can generate benefits, to be sure, but also costs.

Lawyers I have interviewed in Canada are aware of these complexities and challenges. There are no easy answers, but as with the development of these strategic law suits in the first place, dialogue between key stakeholders and lawyers is crucial. Lawyers and key stakeholders in Canada work closely together to establish which key problems, policies or laws are worthy of challenge. They also discuss what language, concepts and frameworks to use in the development of a strategic human rights case – this includes a consideration of how potential plaintiffs want to be portrayed, how to frame complex phenomena such as BBV transmission and prevention, and how to argue for basic health care rights and services. What I admire about this work is that lawyers and consumer groups are working together to try and harness the potential of the law to positively impact upon the nature and scale of BBV epidemics and to reduce other harms.

So where to from here? What do we need in order to change?

As I have argued today, I think there are a number of hitherto unrealised opportunities for advocacy and potential reform. There is a need for better and more comprehensive legal education including a specific focus on peer-led education on BBVs and AOD, greater support for community lawyers, and for strategic advocacy. In two jurisdictions in this country, we have human rights charters that might be strategically utilised to advocate for the rights of people living with BBV, at risk of BBV and/or for PWUD. There are a number of possible places to start. This might include advocating against discriminatory health care practices and policies, or for vital harm reduction programs such as PNSPs. This work cannot, crucially, be done alone. There is enormous scope for lawyers and healthcare workers to work together on these issues. One of my interview participants, Tania, summed this up when she said that we need to move towards a model of 'lawyering as ally [...] not to be judgmental, and also to be curious, and that (lawyer's must realise) there's often much we don't know. And to try to kind of shift away from really dichotomous thinking'.

Although they might not always view it as part of their job, I argue that lawyers have ethical and professional obligations to consider the potential for their work to shape, reinforce and entrench stigma, to produce harms and to shape BBV epidemics. I argue in favour of a 'dialogue' model of practice, through the development of stronger integrated networks of practice, where lawyers engage more fully with clients, healthcare workers and others *as peers* in the identification of key areas requiring reform, and in the development of legal strategies pertaining to AOD use. Much can be learned through such dialogue, along with knowledge sharing with human rights experts, and with peers and colleagues from other countries who are already leading the way in this space.

Acknowledgments: The organisers for this invitation; My interview participants in Australia and Canada; My research is supported by an Australian Research Council DECRA Fellowship (DE160100134); The pilot was funded by the National Drug Research Institute (NDRI) in the Faculty of Health Sciences at Curtin University. NDRI is supported by funding from the

Australian Government under the Substance Misuse Prevention and Service Improvement Grants Fund; Some of the preliminary pilot work was undertaken in conjunction with Professor Suzanne Fraser. Prof Fraser is supported by an Australian Research Council Future Fellowship (FT120100215) My Project Advisory Board.

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