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Making sense of 'side effects': Counterpublic health in the era of direct-acting antivirals

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ABSTRACT

Direct-Acting Antiviral (DAA) treatments for hepatitis C have been widely promoted by health promotion professionals and medical clinicians as being 'side-effect free'. In this paper, we draw on data that troubles this approach. We used a mixed method design to collect data from people who inject drugs, and who were DAA treatment naïve, in New South Wales, Australia. We describe knowledge about and perceptions of DAA treatment. We found that concerns about side effects were commonplace – for example, one-third (37%) of participants who had not taken up treatment worried "a lot" about 'side effects' – and that these concerns were underpinned by a general distrust and suspicion of medical institutions and their technologies, including widespread negative associations linked to interferon treatment. In trying to make sense of this, we draw on the concept of *counterpublic health* and its recognition that the everyday health needs, knowledges and aspirations of subordinated citizens frequently contradict the normative frameworks governing public health interventions. We suggest that failing to engage with concerns about 'side effects' could hinder elimination efforts. Our analysis suggests that addressing the issue of 'side effects' within the 'public' discourse of DAAs will not dampen or damage elimination efforts, as some might fear, but rather it will legitimate the concerns of people who inject, decrease their suspicion of medical interventions, and better support the uptake of DAA treatments.

Introduction

New, highly-effective, direct-acting antiviral (DAA) medications have 'revolutionised' the hepatitis C virus (HCV) treatment landscape (Banerjee & Reddy, 2016), inaugurating ambitious public health plans to eliminate HCV (World Health Organisation., 2016), with people who inject drugs a key population in high income countries (Dore & Hajarizadeh, 2018). This optimism has been particularly salient in Australia where, since March 2016, DAAs have been universally available through the country's national Medicare system. Uptake rates since this time have been unprecedented, with 58,280 people, or an estimated 26% of people living with hepatitis C in Australia, having thus far been treated (The Kirby Institute, 2018).

The announcement of universal availability, and a determination to achieve elimination, has galvanised an array of social marketing and health promotion activities in Australia focused on enhancing the assessment and uptake of DAA treatment. Promotional activities have included broad-based, public health campaigns (such as those seen on bus shelters, billboards and so forth), and initiatives that have focussed particularly on people who inject drugs attending needle and syringe programs (NSP) and/or opioid substitution therapy (OST) clinics. In this promotional activity, the messaging has been enthusiastic and optimistic, consisting of messages that 'cure is easy' and that treatments have 'few or no side effects', claims that are premised on clinical research that has found DAA therapies to be safe, highly tolerable and efficacious (Falade-Nwulia, Suarez-Cuervo, Nelson, Fried, & Segal, 2017).

Much of the existing research has focussed on treatment efficacy (Dore, Altice, Litwin, Dalgard, & Gane, 2016; Grebely, Dore, Zeuzem, Aspinal, & Fox, 2016; Grebely, Mauss, Brown, Bronowicki, & Puoti, 2016; Falade-Nwulia et al., 2017) and studies of treatment models such as those within community-based settings and/or that are peer-led (Morris, Smirnov, Kvassay, Leslie, & Kavanaugh, 2017; Read, Lothian, Chronister, Gilliver, & Kearly, 2017). Such research is important for providing reassurances about the safety of medications and for attempting to provide optimal care for people once they have elected treatment, but less helpful when attempting to understand the range of complex social factors that support getting people *into* care in the first place - what people think about DAAs, including their motivations and preferences for treatment, what acts as facilitators or barriers to their

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decision-making, and their experiences of treatment itself. There is a small but growing body of social research addressing these issues, which shows that treatment is understood by people who inject as not simply an opportunity to improve their physical health, but also as a means to enact a symbolic break from their past, to unburden themselves from the constant need to negotiate stigma (Richmond, Ellard, Wallace, Thorpe, & Higgs, 2018), to create new identities as 'normal' and 'worthy' (Madden, Hopwood, Neale, & Treloar, 2018), and to permit social reconnection and belonging (Harris & Rhodes, 2018; Harris, 2017; Richmond et al., 2018). Structural factors are also at play here, with the latest research identifying that DAA treatments may not be considered 'core-business' by OST providers and that people considering treatment often need to manage multiple health and social priorities that interfere with medical appointments (Madden, Hopwood, Neale, & Treloar, 2018). This emerging research reminds us of the social dimensions of biomedical treatment: that 'taking medicines involves more than the physical ingestion of pharmaceuticals for remedial purposes' (Persson, 2004: 46): it also incorporates a means to achieve positive changes in relationships to self and other.

In this rapidly evolving post-interferon era, such findings about the knowledge, motivations, and experiences of people who inject are crucial. A compelling criticism of public health interventions targeted at socially marginalised and stigmatised groups is that they often fail to adequately appreciate the ways in which such communities understand and respond to matters of their own health. This has been articulated in various ways through research focussing on 'illness narratives' (Kleinman, 1988) and 'lay epidemiology' (Allmark & Tod, 2006) that analyse how people's understandings about 'health risks' are formulated through a 'web of meanings that make sense only in the context of particular lives' (Kaplan-Myrth, 2007), which can inhibit the reach and 'believability' of public health messages. The concepts of 'publics' and 'counterpublics', which we are employing in this paper, also provide a valuable means by which to understand this phenomenon, but pays more attention to the way power is imbued in systems of knowledge production. First coined by Fraser (1990) to describe the alternative spheres or 'publics' of subordinated social groups, the term was subsequently adapted in Warner's (2002) influential, post-structuralist work. Critical health and drugs scholars (Race, 2009; Bell & Aggleton, 2012; Duff & Moore, 2015; Farrugia & Fraser, 2017) have since developed the concept as a valuable means by which to understand health in the context of social disadvantage. These authors describe how public discourses, including those related to health, are constructed in relation to an imagined 'public' – as an idealised collective of listeners, readers, and recipients of public address. Rather than responding to the needs of an existing population, public health discourse effectively imagines or enacts a public based on normative assumptions about its citizenry, thus failing to apprehend the local knowledges and care practices that exist among people living in conditions of social disadvantage. The notion of *counterpublic health* acknowledges, rather than disregards or stigmatises, the everyday health needs and aspirations of socially marginalised people whose own norms of embodied practice (such as injecting drug use) and knowledge contradict the normative principles underpinning public health frameworks (Bell & Aggleton, 2012).

In this paper, we argue that engaging with these alternative systems of knowledge and practice can permit innovation in health education, promotion and care (see also Race, 2009; Duff & Moore, 2015). We propose that our collective aspirations towards viral elimination could be substantially enhanced if we fully engage with the meanings and effects of DAAs as they circulate among the communities of those affected. A counterpublic approach, we argue, reminds us to pay attention to the challenges of practicing health in a context of material constraint (Duff & Moore, 2015), enabling us to better appreciate the socially situated nature of the alternative epistemological frameworks or 'rationalities' that exist among communities of people who inject drugs. This paper presents data that explores the knowledge about and perceptions of DAA treatment among people who are treatment naïve. As we will discuss, one of the most compelling themes to emerge from the findings centred on participants' concerns about the potential 'side effects' of DAA medications. We use the concept of 'counterpublics' to explore this theme and to consider what this means in relation to popularly promoted messages that DAAs are 'side effect free' and to elimination efforts more broadly. We conclude by arguing for a different sort of health promotion, informed by a counterpublic health sensibility.

Method

Research design

Quantitative and qualitative data were collected as part of a study assessing the barriers and facilitators of DAA uptake among people who currently inject drugs in New South Wales, Australia. Quantitative survey methods were used to map knowledge about DAA treatment and perceptions about the advantages and disadvantages of treatments; and in-depth interview methods were used to explore and characterise the perceptions about and reasoning behind concerns about DAA. The study was approved by the South Eastern Sydney Local health District Human Research Ethics Committee and the Aboriginal Health and Medical Research Council of NSW Ethics Committee. Survey participants indicated consent by ticking an approval box on the first page of the computer-assisted survey. Interview participants provided verbal recorded consent.

Data collection

Survey data were collected from five of the highest turnover needle and syringe programs in NSW: three in metropolitan Sydney and two in regional centres in NSW. Researchers visited each site for a period of 2–3 days in which every person who entered the NSP during opening hours, and who was aged 18 years or older, was invited to participate. The data were collected between September 2017–April 2018, approximately 18–24 months after the introduction of universally accessible DAA in Australia.

Participants were asked to complete a survey using touch screen tablet devices. Surveys used a mixture of previously validated measures and questions developed specifically for the current study. Information was collected about mental and physical health (using the Kessler 6 and WHO-8 measures); current substance use (from Australian Institute of Health & Welfare, 2017); knowledge about and perceptions of DAA treatments (adapted from Doab, Treloar, & Dore, 2005; Treloar, Hull, Bryant, Lavis, & Grebely, 2011; Adam et al., 2011); experiences of stigma and discrimination and peer-support (adapted from Berger, Ferrans, & Lashley, 2001) ; links to health services; and, if a participant had taken up treatment, questions about their pathways through the care system. The survey also asked a series of questions about participants hepatitis C status (current status and if they had ever had hepatitis C in the past) and whether they had ever had any treatment for their hepatitis C (including Interferon or DAA and approximately when this treatment was undertaken). We used this self-report data about hepatitis C and treatment status to extract data about the group of interest for this paper: people who inject drugs who report as having hepatitis C but have not yet taken up DAA treatment.

Interview participants were a sub-sample of the survey sample described above. They were selected to complete an interview if they had indicated in their survey that they had not been treated. We contacted them six months after completion of the survey to find out whether they had taken up treatment since their survey and to ask them about the reasons why they had or had not taken up treatment. Additional interviews were conducted, at the request of the project funder, with people with hepatitis C who lived outside of urban or regional centres, in order to capture their experiences of accessing treatment in more

rural and remote parts of the state. Interviews were conducted in person or by phone and took 20–30 min to complete. Participants were asked whether they had been treated, or assessed for treatment, and if so, what this experience had been like; and they were asked about the reasons why they had or had not taken up treatment, and their views about what others with hepatitis C think about treatment. Interviews were audio-recorded and transcribed by a professional transcriber.

In line with what we have outlined above in relation to the survey sample, for the purposes of this paper we use the interview data of those people who had not yet taken up DAA treatment. This follows the reasoning that elimination efforts should focus on those 'beyond the willing and waiting' (Henderson, Madden, & Kelsall, 2017); that is, those that have not been treated and the view that they have qualitatively different views and experiences to those that have been treated.

All participants were compensated for their participation: $20AU was provided for survey participation and $25AU for interview participation.

Data analysis

For this paper survey data are presented using descriptive statistics (e.g., proportions, rates). Interview data were analysed using an iterative thematic approach whereby transcripts were read independently for themes by three researchers. These themes were then synthesised and further developed using series of brief analytic documents in order to outline and organise themes (following the approach outlined in Grbich, 2002). All qualitative data have been de-identified and participants ascribed pseudonyms to ensure anonymity and confidentiality.

Results

The survey recruited a total of 293 participants. Of these, n = 155 or 53%, were ineligible for DAA treatment (because they were hepatitis C negative, did not know their status, or had cleared the virus previously with interferon treatments). Of the remaining n = 138 who were eligible to take up treatment n = 82 had done so (60%) and an additional n = 56 had not (Table 1). It is this n = 56 that are the focus of this paper. Participants were aged, on average 44 years, and were predominantly men (68%). The main drug last injected was heroin (by 39%) and about half (52%) reported injecting daily or more frequently.

Twenty-eight in-depth interviews were conducted for the study, including 14 with people who reported they were hepatitis C positive but had not had treatment. These 14 transcripts are drawn on for this paper. Of these, eight were men and six were women. They ranged in age from 29 to 55 years, with one participant in her 20 s, six in their 30 s, and the remaining seven being in their 40 s and 50 s. Three participants identified as Aboriginal.

Perceptions of DAA treatments and knowledge about eligibility: 'most of it's good'

Together the survey and interview data reveal several important and consistent themes in relation to knowledge and perceptions of DAA treatments: that everyone knew about the existence of DAA treatments; that the new treatments were thought to be more successful and have fewer 'side effects' than the previous interferon treatments; and that uptake was widespread. Indeed, there was a general enthusiasm for DAA treatments and the promise they offered, with survey data showing that an impressive proportion of eligible participants had already taken up treatment (60%, Table 1) at the time of our survey, and interview participants describing the general positivity around treatment among their peers. For example, when we asked Anthony (35 years) what he had heard about treatment, he responded that 'most of it's good'; while Steve (50 years) described the sense of enthusiasm treatment had generated among his peers:

> I hear a lot of people talking about it and a lot of them are amazed. And I see the smile on their face when they come back and go 'I've got rid of my Hepatitis; my Hep C is gone' you know? And people with smile on their faces. And I'm like, good on you, keep it up.

DAA treatment was seen by interview participants as a welcome opportunity for regaining physical well-being, unburdening themselves from the stigma of living with hepatitis C and a general opportunity for self-renewal, as described by Grant (53 years) who was thinking about starting treatment soon:

> The thought that I could lift myself back to feeling that I'm a better person and hoping that clearing this virus from my system will give me back a bit of energy and a bit of self-motivation and I won't be as doom and gloomy, if you know what I mean?

Survey data show that participants had good knowledge about their eligibility for DAAs (Table 2). Most knew that poor liver function did not exclude them from treatment, nor did concomitant treatments or conditions such as being on OST or having depression. Significantly, however, a quarter of participants (25%) believed that their current injecting made them ineligible for DAAs (Table 2). All interview participants said that they knew about DAA treatments, and some mentioned the near impossibility of *not* knowing about new treatments:

> It's always there when you have to sit there and wait for the doctor. It's all there you know, all the information on it, so it's like staring you in the face when you are sitting there waiting to see the methadone doctor. (Michelle, 40 years)

Some participants also mentioned that DAAs were a topic of discussion within their peer and family networks. The messages that circulated were largely reassuring: 'that there are less side effects and it's more successful' (Cathy, 45 years). Watching others undergo treatment was reported to be helpful; Ellie (29 years), for example, said she 'knew heaps of people… they've been quite happy with it.' In some networks, however, talk about treatments was limited as people were reluctant to reveal that they had hepatitis C:

> People just don't like to discuss the treatment. They see it as it's dirty. It's like a nasty disease kind of thing and it's like if you admit to having it, then it's like you are admitting to not being clean, because I think that's the stereotype around it. Like you get it because you've been dirty. So, no one wants to talk about the treatment. (Michelle, 40 years)

Participants were broadly positive and enthusiastic about DAAs even though they themselves had not started treatment. All knew about

Table 1
Recruitment overview.

	n	%	
Total recruited	**293**		
Not tested, unknown status	13	4.4	53% (n = 155) ineligible for DAA treatment
hepatitis C negative, never had hepatitis C	109	37.2	
hepatitis C in the past, treated with Interferon, currently hepatitis C negative	33	11.3	
hepatitis C in the past, treated with DAA since 2016	82	28.0	47% (n = 138) eligible for DAA treatment. Of these, 60% have been treated.
currently hepatitis C positive	56	19.1	

Table 2
Knowledge about treatment eligibility among people who had not taken up treatment (n = 56).

	n	%
Believed that the following makes a person ineligible for treatment		
Current injecting	14	25
Currently on OST	4	7
Liver cirrhosis	2	4
Liver failure	3	5
Heavy alcohol intake	9	16
Absence of symptoms for hep C	5	9
Normal liver function test results	4	7
History of depression	2	4
Pregnancy	9	16
Having been on treatment in the past and been cured	6	11
Table presents valid percent (i.e. missing values removed)		

DAAs and their knowledge about treatment ineligibility was generally very good. Participants also told us that they talked about treatment with their peers and, while this word of mouth was mostly reassuring, it also revealed some fears. Indeed, as Anthony (35 years) noted above, 'most' of the word of mouth about DAAs was good, but some fears and concerns were present, a topic that we will turn to now.

Concerns about DAA: Trust, suspicion and concern about side effects

In both the survey and interview components of our study we asked participants about the factors informing their decisions about treatment, and their reasons for not taking up treatment. Two main sources of concern were evident: firstly, confidentiality and privacy; secondly and most predominantly, potential side effects. Table 3 shows that 25% of treatment naïve participants reported that they worried 'a lot' about confidentiality and the prospect of treatment staff giving out information about them, and 17% worried 'a lot' about the negative attitudes of treatment staff. However, of greatest concern to participants was the potential side effects of DAA medication, with a substantial minority (37%) reporting that they worried 'a lot' about this (Table 3). Beliefs about side effects were that DAAs caused tiredness or fatigue (reported by 43%), lack of energy (36%) and irritability (38%) (Table 3).

Regarding interview participants specifically, a range of reasons for not having started treatment were given. Some of these related to being 'too busy' to fit in medical visits (Jermaine, 35 years) or not 'feeling sick right now' so not feeling a pressing need for treatment (Brent, 38 years). Other reasons resonated more closely with survey data, with interviewees voicing concerns about confidentiality in relation to health care providers and being worried about side effects. Health care providers were talked about in a range of ways - participants worried that they wouldn't be able to find a sufficiently skilled phlebotomist (Cathy, 45 years), or that they didn't have health care providers with whom they felt 'safe' (Michelle, 40 years) and who they trusted would respect their privacy. For example, Campbell (36 years) noted that 'nurses all talk'. These concerns about privacy and confidentiality relate to a deeper mistrust of health professions that was identified by other participants such as Steve (50 years):

> I was sceptical of everything and sometimes I think that I am a guinea pig, do you know what I mean? Do they really have something that's really going to work? Because I don't know, it just seems to me that, well, ok you've got drug addicts, they are already down. They virtually do whatever you want for $50. They would sell their soul to the devil if they could.

Steve was not the only participant who drew on the metaphor of 'guinea pig' (also expressed by Campbell, 36 years) to communicate their suspicion of the medical institution and its technologies. Others, like Rhonda (33 years), similarly described how they were sceptical about the promise of DAAs. Through their scepticism participants were objecting to and resisting views of themselves and other drugs users as less deserving of quality medical intervention, a stigmatising attitude commonplace among staff in healthcare settings towards people who inject drugs (e.g. Brener & Von Hippel, 2007)

This scepticism also played out in interview participants concerns about side effects. Most narratives about side effects reflected a shared belief that the side effects of DAA were minimal and much less severe than those associated with interferon treatments, but participants did not agree with the view that there were 'no side effects'. Many participants reported knowing others who had experienced some symptoms while on treatment – tiredness, constipation, or nausea, for example. Some participants acknowledged that these symptoms might not be directly pharmacologically related to DAA medications - for example, Anthony (35 years) noted that many of his friends 'couldn't tell whether they have symptoms or not because many of them had fluey symptoms which had been going around'. In any case, symptoms were understood to be minor in comparison to the symptoms associated with interferon treatments:

> Now it's totally different than the old treatment. It takes a shorter period, you don't get as sick. (Jewel, 40 years)
> The side effects are a lot better and it seems to work. (Campbell, 36 years)
> You don't get as sick. You're not 'in bed' sick like you was with the interferon. (Ellie, 29 years)

In these narratives, participants do not agree that DAA are 'side effect free', as suggested in widespread promotional campaigns. Instead, the view is that the side effects are 'better' and that people do not get 'as sick'. Interferon treatments are the clear comparison point for participants' understandings of DAAs and the spectre of interferon remains strong. All participants had heard about, or witnessed first-hand, the side effects of interferon treatments and many described how they were 'not pleasant' (Vinnie, 52 years) and how they had been 'scared off' interferon treatment (Campbell, 36 years). The meanings that circulate about interferon among participants are highly relevant to understanding current beliefs about DAA: the side effects of interferon were often touted as acceptable by the medical institution, but this was not the experience of our participants, and this is the context in which participants reconcile their opinions about DAAs. For many, the interferon experience produced mistrust and suspicion about DAAs, a view that is evident in Steve's excerpt above about 'guinea pigs': that

Table 3
Perceived advantages and disadvantages of DAA and beliefs about side effects among people who had not taken up treatment (n = 56).

	n	%
Believed the following are side effects of DAA…		
Depression or mood swings	19	34
Irritability	21	38
Cognitive impairments	12	21
Tiredness or fatigue	24	43
Flu-like symptoms	16	29
Insomnia	13	23
Lack of energy	20	36
Headaches	19	34
Loss of appetite	19	34
Weight gain	12	21
Proportion who reported that they would worry A LOT about the following when considering DAA treatment		
Talking with a doctor about my injecting drug use	9	17
The medications involved in treatment	9	17
The potential side effect of the medications	19	37
The reaction of people close to me	4	8
The reaction of others	5	10
Negative attitudes of staff in treatment services	9	17
Treatment staff talking about or giving out information about me	13	25

Table presents valid percent (i.e. missing values removed).

the medical establishment believes it acceptable to offer substandard and even potentially harmful 'treatments' to drug users.

In this way, participants' concerns about side effects were not always based on beliefs that DAA medications directly produce symptoms; rather their fears related to distrust and suspicion of the veracity of medical claims that DAAs are 'side effect free'. Participants acknowledged that the side effects that they had heard about or witnessed were minor, and that these side effects could have been related to things other than the DAA medications (such as 'the flu'). Instead, in explaining their worries about side effects they often referred to negative past experiences of interferon treatment. As we will now go on to explore, this 'system of knowledge' revealed in our data is crucial to understanding how people who inject make decisions about DAA treatments, and to best supporting the development of relevant and innovative health education, promotion and care.

Discussion: DAA knowledge as counterpublic knowledge

Thinking about the knowledge systems that we have described above as 'counterpublic knowledges' is helpful for understanding the study findings and their possible implications. Participants' knowledge about DAAs can be thought about as knowledge that is setting specific, produced through the contexts and histories of social disadvantage and stigmatisation that define counterpublics (Bell & Aggleton, 2012; Warner, 2002). Many participants talked about their own vulnerability, and that of their peers, as instrumental in the making of their beliefs concerning DAA: for example, in Campbell's fear of the negative way that nurses might talk about him, or through Steve's beliefs that drug users are seen to be less worthy, and as acceptable subjects of medical experimentation. Participants also made reference to the historically located nature of their knowledge and how their beliefs about DAAs were made in relation to past negative experiences with the medical institution and in particular with interferon. Our data also demonstrate how participants' counterpublic knowledges are produced in relation to 'expert information' (Farrugia & Fraser, 2017: 598). Many participants believed in the conventional public health discourse about treatment being 'easy', as demonstrated by the impressive number of survey participants who had already taken up treatment and as evident in interview participants' widespread positivity and enthusiasm for treatment. In this sense, participants' counterpublic knowledge should not be understood as being counter 'public health' *per se* (Race, 2009), but rather recognises the socially situated nature of their knowledge formation – a way of knowing that may not align neatly with the 'expert' discourse of public health education and promotion.

As we will now go on to discuss, our analysis of the data as a form of counterpublic knowledge permits us to interrogate assumptions and consider implications for viral elimination, including: 1) recognition that what counts as a 'side effect' is diverse and imbued with power whereby certain kinds of knowledge is valorised to the exclusion of others; 2) that this power-knowledge nexus supports assumptions that the group that requires education and 'correction' are always and necessarily people who inject drugs; and 3) if people's alternate understandings of 'side effects' are not valued and addressed, then this may be seen by people who inject as yet another reason to be suspicious of the medical institution, and its messages, interventions and treatments.

What counts as a 'side effect'?

Participants understanding of 'side effects' did not wholly align with scientific and other public accounts of DAAs. Clinical discourse about DAAs and their safety among people who inject drugs tends to be concerned with 'adverse events' which can include a range of symptoms including fatigue, headache, nausea and other more serious symptoms. Among people taking part in clinical trials these events happen commonly; however, only a small number are seen to result from the pharmacological effects of DAA medications (Asselah, Kowdley, Zadeikis, Wang, & Hassanein, 2018; Feld, Jacobson, Hezode, Asselah, & Ruane, 2015; Zeuzem, Dusheiko, Salupere, Mangia, & Flisiak, 2014). A placebo-randomised trial among people on OST found that symptoms like fatigue and headache occurred commonly (70–80%), regardless of whether participants were on DAA therapies or not (Dore et al., 2016). This suggests that in actuality many 'adverse events' stem from the health and social conditions frequently experienced by people who inject drugs, including the symptoms of living with chronic HCV, the effects of prescribed medications and/or illicit drug use, and other morbidities associated with social marginalisation.

This is somewhat different to how 'side effects' were understood by participants in our study. A substantial minority of our survey participants reported that they believed things like fatigue, irritability, headaches and loss of appetite were caused by DAAs. For the most part, this view was shared by our interview participants, although some mentioned that it was sometimes difficult to directly attribute such symptoms to DAA medications or whether, instead, these symptoms were due to 'things that had been going around' such as 'the flu' (see Anthony, 35 years). What matters is that when participants referred to 'side effects' they were referring to something qualitatively different than what is understood to be a 'side effect' in medical discourse. While medical discourse allows only a very small range of permissible 'effects', participants viewed side effects to include a much broader range of symptoms.

What counts as 'evidence' amidst these competing claims — as to the *true* nature of 'side effects' — is invariably resolved by recourse to the public authority of scientific modes of understanding, leaving participants' alternative framings marginalised, discounted or simply overlooked. Here scientific discourse evokes what Persson (2004, 49) describes as 'the metaphysical principles that underpin biomedicine: [of] truth, logic, reason'. The hegemony of scientific method is thus central to the making of DAA 'publics' in which treatment is seen to be largely 'side effect free' and any understanding to the contrary needs to be corrected.

Yet, as other counterpublic analyses imply (e.g. Farrugia & Fraser, 2017), the failure to adequately address popularly-held fears of 'side effects' does not simply risk causing the intended audience of people who inject drugs to ignore the promotion of treatment, but actively (re) constitutes them as deficient counterpublics. What becomes clear is that simply insisting on science-as-truth overlooks the tensions between public and counterpublic understandings of the nature of evidence, including the latter's distrust of institutional authority, particularly medical authority. Any educational or promotional work involving DAAs directed at communities of people who inject drugs should not take for granted that its target audiences have faith in scientific claims, a point that is well-evidenced in our data by Steve's guinea pig metaphor, and a topic that we will return to in the final section of this paper.

Who is in need of correction and education?

The positioning of DAAs as 'side-effect free' within the DAA 'public' means that the 'counterpublic' understanding of our participants are inevitably viewed as somehow erroneous or deficient: a problem to be solved (see also Farrugia & Fraser, 2017). This is evident in calls to 'better educate' people who inject and to improve their knowledge about DAA side effects; in other words, to bring their knowledge into line with dominant, scientifically-established views. This attribution of 'deficiency' is not lost on participants in our study, many of whom identified how they and other drug users were seen to be less worthy of, and to lack the capacity to demand, quality treatment. However, our counterpublic analysis suggests a range of other, more innovative ways forward with DAA education and promotional interventions, including calling into question who is actually in need of correction and education. As a starting point, our counterpublic analysis suggests we need to build educational messages about DAA side effects that are seen as relevant and trustworthy by people who inject drugs. In the first

instance, this means recognising the limited potential of clinical 'expert' perspectives in influencing people's beliefs and choices, especially given the widespread scepticism evident in our interview data.

Following Farrugia and Fraser (2017, 599), a counterpublic analysis permits recognition that local knowledges are simultaneously bound up in local identities, and that if one is ignored or devalued, both are. Consequently, we need to take better account of the values and concerns of the treatment counterpublic. Our findings, and other emerging qualitative research on DAAs, gives some insight into what such education might look like: that it should include elements of what people who inject say they desire from DAAs – regaining physical well-being, unburdening themselves from the stigma of living with hepatitis C, and offering the opportunity for self-renewal (Harris & Rhodes, 2018; Harris, 2017; Madden et al., 2018a; Richmond et al., 2018)— rather than focussing on being 'side effect free' as is often currently promoted. Our findings also suggest that innovative messaging should reference interferon-based treatment and the persistent belief that DAA side effects are similarly onerous. Interferon treatments were the clear comparison point for participants understandings of DAAs and the lingering distrust produced from that era must be addressed for while the DAA treatment 'revolution' was presaged on the absence of interferon, its promise remains open to scepticism as long as interferon remains a constitutive feature of the counterpublic imaginary.

As alluded to above, a counterpublic analysis permits us to interrogate our assumptions about whose knowledge needs to be corrected and who needs to be educated. Such an analysis reveals not only the tensions that exist between competing forms of knowledge but the nexus that inevitably exists between power, knowledge and identity. Here counterpublic knowledge is readily conflated with the stigmatised, discredited identity of the 'injector', and public knowledge with that of the '(scientific) professional'. Within the domain of public health, power is entrenched within a particular epistemological framework that works to silence or marginalise lay knowledges, and by extension, their associated identities. Here public health promotion is envisaged as primarily an exercise in unilinear, expert-knowledge 'translation'; a model that, as Bourgois (2002, 267) puts it, adheres to a 'psychological-reductionist model of individual rational choice decision-making.' Yet, the most innovative educational activities in relation to HCV elimination should not only be directed at people who inject, but could also equally be aimed at health professionals and clinicians working towards elimination. Educating these professionals might improve their resources for promoting and negotiating treatment uptake among people who inject, but would require the same careful considerations described above. Messages would need to be seen by professionals as relevant and worthy in order to best facilitate changes in *their* choices and practices around promoting DAA. Effective educational activities directed at health professionals might improve their capacity to communicate with prospective patients in ways that feel relevant to those patients, minimising the suspicion felt by many people who inject, and in turn potentially optimising their uptake of DAA treatments.

Suspicion and the trouble with claims that DAA are 'side-effect free'

Participant fears about 'side effects' have emerged from personal and shared histories of social marginalisation and disadvantage: their concerns about being 'safe' in medical settings, worries about staff talking about them, and fears of being subject to medical experimentation are constituted by histories of subjection to dominant discourses (of drug-taking as deviant and deserving of contempt) and rooted in prior individual and collective experiences (of discrimination, shame and substandard treatment by social and health services) (Harris & McElrath, 2012; Treloar & Rance, 2014; Rance & Newland et al., 2012). Such histories produce embodied subjectivities as 'in deficit' and justify (if only implicitly) the provision of substandard healthcare (Treloar & Holt, 2006; Karasaki, Fraser, Moore, & Dietze, 2013), and affect the choices and actions that people who inject make about health services and treatment. As other research shows (Bryant, 2018; Foster & Spencer, 2011), marginalised people engage in calculated 'choice-making', cost-benefit decision-making regarding their use of health services, typically making the 'least-worst' choice based on the limited options that their marginalised conditions afford; a counterpublic logic. In this sense, marginalised people come to embody a sort of historically produced and ontologically-located *suspicion* of medical (and other) institutions: their understanding of their place in the world (their 'worldview') is made through this history of poor treatment and lens of suspicion. This is playing out here in relation to their views of 'side effects' and public efforts to eliminate hepatitis C.

Our participants were recruited from the highest turnover NSPs in NSW which have run intense HCV treatment uptake campaigns since the introduction of universal access in March 2016. They had multiple and ongoing exposure to the health promotion messages about DAA being 'easy' and 'side effect free', indeed, as Michelle identified, they are 'staring you in the face'. Thus, the persistence of their beliefs about DAA side-effects is not accidental nor a result of 'missing the message'. Rather, as the counterpublic framing allows us to see, beliefs about side effects are rooted in suspicion of the veracity of the messaging. Appeals from medical authorities that DAAs are 'side effect free' simply fails to register with the counterpublic sensibility of some people who inject. Indeed, as Steve's guinea pig metaphor highlights, such appeals can even be interpreted as another opportunity to be suspicious of the medical establishment, its messages, and the treatments it offers.

Limitations

Our survey sampling method was not randomised and, while we attempted to capture every person who entered the study sites, we do not know how many people were missed or whether they were different from those we captured. This means our survey sample is not generalisable to other people who inject. However, an obvious strength of the research design is the mixed method approach which permitted us to measure the prevalence of concerns about DAA, and explore the reasons why these concerns were so common.

Conclusion: maximising elimination by engaging with the counterpublic

Much of the research evidence, including our own, demonstrates that people who inject drugs believe in the value, efficacy and opportunity DAAs afford. People are taking up treatments in impressive proportions and are generally enthusiastic about DAA despite the often-challenging material circumstances in which they live. Maximising future elimination efforts will necessarily need to focus on building relationships with the so-called 'hard-to-engage' and/or 'hard-to-reach', including the participants who have been the focus of this paper. As we have argued, this effort would be best supported by using a different sort of health promotion; one informed by a counterpublic health sensibility that does not operate from a presumption of deficit or deficiency. We suggest that rather than dismissing such counterpublic constituents as irrational, lacking objectivity or ill-informed, we develop more nuanced messages and practices that acknowledge the genuine concerns of people who have not yet taken up treatment. Indeed, the concept of 'the counterpublic' helps us to realise that acknowledging 'side effects' within the 'public' discourse of DAA will not dampen or damage elimination efforts, as some might fear, but rather it will legitimate the concerns of people who inject, decrease their suspicion of the medical institution, and promote their uptake of DAA treatments.

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