

# Drug treatment clients' readiness for hepatitis C treatment: implications for expanding treatment services in drug and alcohol settings

Carla Treloar and Martin Holt

## Abstract

This study explores the perception of and readiness for hepatitis C treatment within a sample of 77 clients already participating in drug treatment, with a view to identifying likely barriers and incentives to hepatitis C treatment within a drug treatment population. Participants with hepatitis C did not demonstrate a consistent, indepth knowledge of the infection, lacked confidence in symptom recognition, and had little awareness of treatment options. Those without obvious symptoms or liver deterioration did not have a pressing interest in treatment, and many had heard concerning stories about the side effects of hepatitis C treatment. For those coping with anxiety or depression, the increased risk of a depressive episode under interferon treatment was a major barrier to treatment.

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THERE IS GROWING INTEREST world-wide in providing hepatitis C services, especially treatment, through drug and alcohol services, notably pharmacotherapy substitution programs such as methadone maintenance therapy.<sup>1–7</sup> There is a growing evidence base describing factors associated with successful hepatitis C treatment in these settings.<sup>8,9</sup> Drug treatment staff have been described as well placed to identify clients' special needs and advocate for client services,<sup>10</sup> includ-

## What is known about the topic?

There is growing interest in providing hepatitis C services through drug treatment services. However there is little research on the factors that may influence the uptake of hepatitis C treatment among clients of drug and alcohol services.

## What does this paper add?

This study found that the participants experienced a lack of consistency in the management and monitoring of their hepatitis C infection.

## What are the implications for practitioners?

Consumer education appears vital if more are to be convinced of the need for hepatitis C treatment, together with a concerted effort to address the complex and continuing needs of those with drug and mental health problems. Without first meeting these conditions, a public health drive towards widespread hepatitis C treatment among drug treatment populations is unlikely to succeed.

ing hepatitis C treatment. In Australia, interest in an expanded model of hepatitis C treatment is driven by projections of the future burden on health care systems as a result of hepatitis C and its sequelae. For example, it is thought that participation in hepatitis C treatment will need to increase threefold to decrease the projected burden of chronic hepatitis C, advanced liver disease and cirrhosis in Australia.<sup>11</sup>

However, there is little research on the factors that may influence the uptake of hepatitis C treatment among clients of drug and alcohol services. Surveys of drug treatment clients have shown a general willingness to consider treatment for hepatitis C.<sup>12,13</sup> However, almost a third of participants in an Australian study had declined treatment for hepatitis C after being offered it, giving reasons such as concern about adverse effects, not feeling sick enough, and having other health priorities.<sup>12</sup> Some other research has been

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done with other groups, not specifically those in drug treatment. In a sample drawn from a variety of sources, an Australian survey found that the key factors considered by those making decisions about hepatitis C treatment were concerns about treatment side effects and the effectiveness of treatments.<sup>14</sup> A qualitative study of liver clinic clients in the United States described factors influencing decisions about hepatitis C treatment uptake: assessing the risks of treatment versus its risks; conceptualisations of illness; and the recommendations of doctors.<sup>15</sup> Although no research has formally addressed this question, there is speculation that hepatitis C infection is a low priority for drug and alcohol treatment clients, who are typically faced with competing health and social issues.<sup>12,16</sup>

A potential driver to treatment could be the physical experience of hepatitis C-related symptoms, although the literature about the experience of living with hepatitis C is equivocal about the physical experience of the condition. Some people experience significant impairments they attribute to hepatitis C infection, referring to “hep C attacks”<sup>17</sup> or episodic experiences of ill health.<sup>18</sup> However, these studies also suggest many people do not experience clear symptoms they can attribute to hepatitis C infection. For those who have their liver function monitored regularly, the impact of clinical markers such as alanine aminotransferase (ALT) test results are often ambiguous and cannot be relied upon to drive individual interest in hepatitis C treatment.<sup>18</sup>

Given the increasing interest in the delivery of hepatitis C treatment in alcohol and drug settings, the aim of this qualitative paper is to explore the perception of and readiness for hepatitis C treatment within a sample of clients already participating in drug treatment, with a view to identifying likely barriers and incentives to hepatitis C treatment within a drug treatment population.

## Methods

The interview material was collected as part of an Australian qualitative study of barriers and incentives to drug treatment for people with both illicit

drug and mental health problems. Approval for the study was granted by the University of New South Wales Human Research Ethics Committee and local ethics committees in all of the jurisdictions where recruitment took place.

The method has been described in detail elsewhere.<sup>19</sup> Participants were recruited in Australia from Brisbane (Queensland), Perth (Western Australia) and Sydney and Bathurst (New South Wales). Recruitment of service users was achieved using peer recruitment, word-of-mouth, and advertising in local drug treatment centres and drug user organisations.<sup>20</sup> To be deemed eligible, participants had to be able to give or withhold consent, be aged 18 or over, report a history of illicit opiate or stimulant use, have current or recent experience of formal drug treatment (within the previous 2 years), and report a clinical diagnosis of (or treatment for) a common mood or affective disorder, such as depression or anxiety, by a qualified health professional during the previous 2 years. All diagnoses (whether for mental health status or hepatitis C status) were self-reported by participants.

Interviews were semi-structured, focusing on drug use history, experiences of drug treatment, mental health background and experiences of mental health treatment. All participants were asked to report their hepatitis C status and to discuss their experience of living with the condition, if they were currently infected. Interviews lasted up to one hour and were tape recorded. Participants received A\$20 expenses for taking part in the study. Interviews were conducted in private at community-based organisations or drug treatment services.

After being transcribed verbatim and de-identified, service user interviews were coded and entered into NVivo qualitative analysis software, version 2.0 (QSR International, Melbourne, Vic). Both authors coded the transcripts, and coding was cross-checked until consistency was achieved. Analysis proceeded by taking each main area of coding in turn and looking for patterns of consistency and points of difference, drawing on core procedures common to both discourse analysis and grounded theory.<sup>21,22</sup>

Points of connection (or contradiction) between coded areas were also identified. All quoted names are pseudonyms.

Seventy-seven consumers of drug treatment services were recruited across the four sites, with a mean age of 37 years. Participant characteristics are shown in Box 1. All participants had sought drug treatment after problems with illicit opiate or stimulant drugs, particularly heroin and amphetamines. The most commonly reported treatment was methadone maintenance treatment. Diagnosis of or treatment for depression was more common than for anxiety, and nearly all those diagnosed with anxiety also reported experiences of depression (18/22). Fifty-five participants (71%) said they had hepatitis C, with the remainder reporting their serostatus as negative, cleared or unknown. Only two participants reported previous experience of treatment for hepatitis C. The results below draw on the accounts of those who self-reported a current hepatitis C infection.

## Results

Overall, participants with hepatitis C experienced a lack of consistency in the management and monitoring of their infection. Many could not interpret results of liver monitoring, demonstrated inconsistent knowledge of hepatitis C infection, lacked confidence in symptom recognition, and had little awareness of or confidence in treatment options. Two participants had participated in earlier forms of hepatitis C treatment, with mixed results. Phillip had completed a 6-month course of treatment, during which he had experienced significant side effects:

I was injecting [interferon] three times a week I think into my stomach and yeah was basically ill for six months and I lost a lot of hair. (Phillip, 38 yrs old)

Phillip's course of treatment had not successfully eradicated his hepatitis C infection. Because he had been told that his liver had "significant scarring" Phillip was reconsidering treatment at the time of being interviewed. Alan also found that hepatitis C treatment (which was not successful) had caused a number of unpleasant side

### I Participant characteristics

Characteristic	n (% of sample)
Male	39 (51%)
Female	38 (49%)
Born in Australia	63 (82%)
Born outside Australia	14 (18%)
Aboriginal or Torres Strait Islander heritage	12 (16%)
Any experience of substitution pharmacotherapy treatment	70 (91%)
Diagnosis of or treatment for depression (lifetime rate)	73 (95%)
Diagnosis of or treatment for anxiety (lifetime rate)	22 (29%)
Welfare/social security benefits as main source of income	68 (88%)
Any experience of treatment for hepatitis C	2 (3%)

effects, including a deleterious effect on his mental health:

... the medications that they were giving me for [hepatitis C], they were causing, that's what seemed to bring it on. Especially interferon and ribavirin to the point where, now I am not an aggressive person but I was getting into fights everywhere ... I asked them to take me off it because I thought I was going to hit somebody that I loved ... they say it doesn't cause it but if you have any psych things there it will find them ... but I mean I had never had any ... real psych issues before [hepatitis C treatment]. (Alan, 42 yrs old)

For other participants, hepatitis C monitoring was inconsistent. In bigger treatment centres regular liver function tests appeared to be encouraged, although, in general, participants lacked confidence in understanding the significance of clinical markers like ALT results. For some, liver function monitoring was erratic. Roger's quote illustrates these issues and the confusion that some participants had about hepatitis C symptoms. Roger's reference to the colour of his eyes

incorrectly attributes a symptom of hepatitis A to hepatitis C infection:

My hep C levels sometimes go a bit higher than it should be, like, you're supposed to have it down near the 80s, your ALT level, and that and sometimes it goes up to being um, 200 and that's not good but not being a drinker, it helps. But apparently using [illicit drugs] doesn't affect it as much but if you're using heavily it does affect it. Like some days my eyes will be fine and other days they've got a little tinge of yellow in it that means that the hep C's acting up. But otherwise it's pretty fine. (Roger, 33 yrs old)

Many participants appeared to be confused about their hepatitis C status (the progress of their condition, what type of infection they had, and whether they might have "cleared" the virus), and this situation was aggravated by conflicting information and attitudes from health professionals.

The whole hep C diagnosis process is confusing and your standard, I mean I have even done [an educational] course on hep C and I am still confused as far as, I know about hep C positive, antibody positive, antibody negative and what and the strains, one, two, three and four are ... I acquired hep C 17, 18 years ago now. And up until 2 years that I was told, yeah I had bad hep C I've had hep A and hep B and thought that was it. (Martin, 39 yrs old)

In general, it was difficult for service users to distinguish between the symptoms of anxiety and depression, and the effects of alcohol and other drug use, substitution pharmacotherapies or hepatitis C. Without being able to isolate the effects of these overlapping issues and combined with a lack of knowledge of hepatitis C natural history and symptoms, it was difficult for service users to attribute any difficulties they were experiencing to hepatitis C infection, undermining a potential motivation for treatment.

I think once, at one stage I did have some symptoms, but that was a long time ago and that was before, that was just when I found out that I was positive and I was probably

drinking quite a bit then um and a couple of weeks I was very lethargic, very tired and I think that's what it was but other than that I've never had any. (Richard, 35 yrs old)

I don't think I've had any problems with it [hepatitis C], occasionally if I drink too much my kidneys and liver rattle around a bit but um I think that's just like anyone that drinks too much. (Charlie, 52 yrs old)

I have a much clearer head [on buprenorphine] and I can get on with things whereas before I was always tired. And I don't know if that's the hep C as well. I mean part of the problem is everything's combined so you can't really isolate anything and go "OK, that's the cause." Because there are so many things going on. I mean, you know hep C is supposed to make you tired and do all these things, as well but yeah, it's very hard as I said, to pinpoint what the cause is. (Kate, 44 yrs old)

No participants with hepatitis C were currently receiving treatment for it at the time of the study, and few were discussing treatment options with their drug treatment providers or other professionals. This may have reflected the focus of drug treatment services on stabilising drug-related issues, but it also reflected a lack of interest among the majority of service users to explore treatment options for hepatitis C. Those without obvious symptoms or liver deterioration (like Phillip, quoted earlier) did not have a pressing interest in treatment (as one participant put it, "If it's not broke why fix it?"), and many had heard concerning stories about the side effects of hepatitis C treatment.

I have queried treatment. But it seems like such a big deal and I don't, like I don't seem to have any symptoms so I don't think it's worth it. (Kate, 44 yrs old)

... the hep council [community-based organisation] and doctors ... say, it's like "Oh some people have a really bad time but a lot of people really just breeze through it" ... I've met maybe two people who have been on interferon and breezed through it.

All the rest say that it's really f....d. And my partner was on it for 6 months and she was in bed for 6 months basically, it was horrible. (Peter, 38 yrs old)

The association of interferon-based treatment and major psychiatric side effects is well documented<sup>23,24</sup> as is the high prevalence of mental health problems among drug treatment populations,<sup>25-27</sup> echoing accounts such as Alan's (quoted earlier). The threat of additional mental health problems was a source of concern for participants already coping with anxiety or depression. The increased risk of a depressive episode under interferon treatment in particular was described as a major barrier to treatment.

... well interferon just sounds too risky for me. If you're prone to depression it causes depression. So um, I would rather not. (Richard, 35 yrs old)

Another issue related to participants' positions as active consumers of hepatitis C treatment. With the knowledge of depressive and other side effects, some participants were wary of being used as "guinea pigs" for new hepatitis C drugs and had decided to wait until treatment was more efficacious.

It would have to be a different treatment, I mean I noticed that their success rates are getting better and better with like 25 percent the first time then it went to like 33 and now it's around 60 or 65 percent so I figure at this rate I will give it another few more years. (Alan, 42 yrs old)

## Discussion

These data help us understand why a sub-sample of people with hepatitis C appeared to have little interest in hepatitis C treatment. The primary reasons that our participants were not motivated to seek hepatitis C treatment were: the lack of obvious ill effects attributable to hepatitis C infection; the perception that their hepatitis C was controlled, managed or not serious; and the difficulty of knowing whether experiences of ill-health or discomfort were attributable to hepatitis

C or another aspect of their lives (such as alcohol and other drug use, pharmacotherapy treatment, anxiety or depression). Some participants suggested they would seek treatment if it was clear they had become seriously ill or were experiencing liver damage as a result of hepatitis C (as was the case with one participant), but the ambiguous experience of hepatitis C infection for most mitigated against seeking hepatitis C treatment.

For those who might seek treatment, the legacy of less effective, older forms of hepatitis C treatment was another barrier to participation. The sharing of knowledge among drug treatment clients and people with hepatitis C about the experience of hepatitis C treatment means that drug treatment clients can be suspicious of the therapies on offer, including current forms such as pegylated interferon. In particular, the high prevalence of mental health problems among drug treatment populations<sup>25-27</sup> adds to the concerns of those who might consider treatment, when there is a common perception and substantive evidence that depressive symptoms may be aggravated by interferon treatment for hepatitis C.<sup>23,24</sup>

We have attempted to portray the everyday complexity of the lived experience of hepatitis C for drug treatment users and the implications of this complexity for decisions about hepatitis C treatment. Two other "everyday" issues may be relevant to decisions about hepatitis C treatment: competing priorities and discrimination. We have elsewhere documented the complex needs of drug treatment clients (such as poverty, unemployment, criminal justice issues, unstable housing or homelessness) and the difficulties faced by this client group in accessing treatment and support for drug treatment and mental health.<sup>28</sup> These issues are likely to affect the ability of clients to consider or participate in hepatitis C treatment. Other bodies of work also point to the widespread discrimination experienced by people who inject drugs or who seek drug treatment,<sup>29-31</sup> especially in health care settings.<sup>32</sup> When discrimination forms a routine part of their everyday experience, we think it is unlikely that drug treatment clients will necessarily identify discrimination as a major barrier to their access to

hepatitis treatment. However, our findings and those of others suggest a need to examine the relative importance of each of these barriers to hepatitis C treatment highlight the need for comprehensive support services for those who decide to seek hepatitis C treatment. In particular, peer-support programs in Australia and the US have demonstrated their value in assisting clients to access, be assessed for and complete hepatitis C treatment.<sup>33</sup>

We do not claim that the results of this study are representative of all people on drug treatment: we specifically recruited those with co-occurring, high prevalence mental health problems. Our sample was limited to the areas in which we recruited and to those people who felt well enough to participate. While for some there are “endemic limitations [in] conducting research with people with co-occurring mental illness and substance use disorder”<sup>34</sup> (p. 21), we decided to focus on consumer perspectives. Ignoring client perspectives only reinforces the stigmatisation of people living with drug and mental health issues, and makes it less likely that assessments of current treatment practice will deliver outcomes of benefit to consumers.

If there is continued interest in increasing the numbers of people treated for hepatitis C, and there are moves to set up hepatitis C treatment outreach clinics in drug and alcohol centres, these data suggest a number of areas that service providers need to address before treatment uptake is improved. Drug treatment clients appear unclear about the negative health effects that hepatitis C may produce, do not see hepatitis C treatment as a priority unless they are experiencing “obvious” symptoms, and are suspicious of the iatrogenic potential of hepatitis C treatment or its aggravating effects on mental health problems. Consumer education appears vital if more are to be convinced of the need for hepatitis C treatment, together with a concerted effort to address the complex and continuing needs of those with drug and mental health problems. Without first meeting these conditions a public health drive towards widespread hepatitis C treatment among drug treatment populations is unlikely to succeed.

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## Competing interests

The authors declare that they have no competing interests.

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