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Treatment decisions

what makes people decide to have treatment for hepatitis C?

Hannah Wilson, Max Hopwood, Peter Hull, Yvonna Lavis, Jamee Newland, Joanne Bryant and Carla Treloar

Introduction

The physical symptoms and progression of hepatitis C virus (HCV) infection can vary widely. Some people with chronic hepatitis C infection can live somewhat unaffected by the virus, their health remaining relatively normal, while others risk progressing through varying levels of fibrosis, to cirrhosis, carcinoma and liver failure. Treatment is not effective in all cases and success depends on a number of factors, most importantly the HCV genotype. The treatment regime can last up to 11 months and is often associated with severe physical and psychiatric side effects. Therefore, although treatment can have significant health benefits for those who clear their infection, there are some important factors that may make treatment less desirable for some people.

It is estimated that approximately 211 700 people in Australia are living with chronic hepatitis C infection (National Centre in HIV Epidemiology and Clinical Research, 2009). Despite the high prevalence and the potentially serious consequences of the disease, only around 3000 people with chronic hepatitis C infection receive treatment each year. Treatment uptake has remained extremely low despite recent improvements in the efficacy and accessibility of treatment over the past few years. With the introduction of pegylated interferon in Australia in 2003, the success rate of treatment improved among those with HCV Genotypes 2 and 3 from approximately 40% to 80% of cases. In addition, treatment has become accessible to more people with hepatitis C. In 2001 the eligibility requirement that recipients could not currently be injecting drugs was removed from the PBS eligibility criteria, as was the need for a liver biopsy or a certain degree of liver damage.

It would be fair to assume that the improved success rates and accessibility should result in an increase in the number of people who initiate treatment. However, there is still a significant disparity between the number of people with hepatitis C and the number who actually undertake treatment. Therefore, there must be factors other than efficacy and accessibility that influence the decision whether

or not to begin treatment. The aim of the current study is to investigate these factors.

Many factors can lead people to commence treatment. The factors that have received the most attention from researchers to date tend to relate directly to the impact of treatment on health. A study by McNally et al. (2004) found that clinical factors were important in decision making, irrespective of the final outcome. The effectiveness of treatment and concerns about side effects were factors participants rated as important, as was the current health status of their liver. A survey by Doab, Treloar and Dore (2005) also found that two of the most common reasons for refusing treatment were concerns about side effects and current health status (in the sense of not feeling sick enough).

Despite the obvious importance of clinical factors in the decision-making process, research has also shown that social issues influence decisions. Fraenkel et al. (2005) found that many of their participants were concerned about the impact that treatment might have on family and work, and these concerns could influence their decision making in either direction. Another social issue that research has shown to be important is the level of support a person has available at the time they decide either to accept or refuse treatment. McNally et al. (2004) found that having a supportive partner, a supportive medical environment and a good relationship with a doctor or specialist were all important factors in the decision to take up treatment, while the lack of a supportive environment was often cited as an important factor in the decision to refuse treatment.

One issue that can potentially interfere with access to social support is the fear of discrimination. In order to obtain support, people with hepatitis C usually have to disclose their positive serostatus to someone. However, in many cases people with hepatitis C avoid disclosure in order to avoid discrimination (Hopwood & Treloar, 2003; Treloar & Hopwood, 2004; Hopwood, Treloar & Bryant, 2006). Fearing the consequences of disclosing hepatitis C infection to others

is potentially a barrier to deciding to commence treatment (Hopwood, Treloar & Redsull, 2006). Considering the complexity and variability of discrimination; and the limited research on the role of discrimination in making decisions about treatment, further work is needed to determine the role of disclosure and discrimination in making decisions about treatment.

In addition to clinical and social factors, personal factors also influence decision making. People's attitudes towards illness and treatment can affect the value they place on other issues relating to treatment. Fraenkel et al. (2005) found that study participants' conceptualisation of their illness influenced their decisions about treatment. If hepatitis C was seen as something that existed in the blood, without having much of an impact on life, then patients were generally not inclined to seek treatment. However, if the virus was seen as an invasion of the body, participants were more likely to seek treatment.

The level of an individual's knowledge about hepatitis C, its treatment and their eligibility for treatment is likely to have an impact on their decision making. Doab, Treloar and Dore (2005) found that only half of the participants in their study knew that current injecting drug use did not exclude them from access to treatment, and many were unaware that people who were not showing symptoms of infection were eligible for treatment. Considering that all participants in this study were currently injecting, and given that many people with hepatitis C do not show symptoms or have only mild symptoms, a lack of accurate knowledge about eligibility would appear to be a factor associated with low levels of treatment uptake. Furthermore, in a recent US study by Munoz-Plaza et al. (2008), clients at drug treatment centres were interviewed about the factors that influenced their decision to take up, defer or avoid hepatitis C treatment. Positive influences on their decision to begin treatment included knowledge of the disease and its consequences. This suggests that people's level of knowledge of the natural history of hepatitis C might be an important contributing factor in making the decision to begin treatment.

The available literature indicates that clinical factors, social factors, personal values and knowledge are all important in determining whether or not people decide to have treatment for hepatitis C. Therefore this study sought to investigate a range of factors associated with making the decision to take up treatment. Additionally, to explore how Australian clients of Opiate Substitute Treatment (OST) centres made decisions about treatment, this study interviewed a sample of OST clients and health professionals in Sydney about their perceptions of a proposed model of delivery of treatment for hepatitis C through OST clinics.

Method and sample

Data collection

This study comprised a mixed-method design; data were collected via a survey, a focus group and in-depth interviews.

Survey

The survey instrument was a comprehensive 118-item questionnaire, including four subscales from the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002): personal control, treatment control, perceived consequences, and emotional representations. Measures of concerns about disclosure and concerns with public attitudes were derived from subscales of the HIV Stigma Scale (Berger, Ferrans & Lashley, 2001) which were adapted for people with hepatitis C.

Participants were recruited from pharmacotherapy clinics, pharmacies that distributed methadone to drug-treatment clients, and from needle and syringe programs (NSPs). People attending these services were offered a survey and a \$20 gift voucher once the survey was returned. Surveys were also sent to people on the mailing lists of Hepatitis NSW and the Haemophilia Foundation of Australia.

A total of 731 people who had ever been diagnosed with hepatitis C returned surveys. Participants with bleeding disorders differed significantly on a number of demographic indicators, and data from these participants were not included in the analyses for this report. Surveys with too much missing data, inconsistent answers or duplicates were excluded from analyses, leaving a total of 633 valid questionnaires.

Two measures were developed to examine the ways in which survey participants made decisions about treatment. These included whether or not participants had considered treatment, and whether or not they had decided to have treatment. Participants who had considered treatment were defined as those who reported that they had done at least one of the following: asked a doctor for a referral to a specialist for treatment, asked a healthcare worker for information about treatment, or called an hepatitis C helpline for information about treatment. Participants who had decided to have treatment were those who reported that they had ever been on treatment, were currently on treatment or were currently on a waiting list to receive treatment.

Focus group and in-depth interviews

Clients undergoing OST who had completed the survey and had volunteered for an interview were selected to participate in the qualitative arm of the study. An additional sample of OST client participants was recruited directly from the NSW Users and AIDS Association (NUAA).

In total, 27 interviews were conducted with current OST clients. The core set of issues raised with the participating OST clients included a brief biographical snapshot (including experiences of OST and hepatitis C), knowledge and expectations about hepatitis C treatment (including concerns, advice provided by clinicians, involvement with illicit drug use and OST treatment), factors affecting decisions about hepatitis C treatment (including barriers, motivators, social supports and perceived impacts of treatment), experience of OST and interaction with hepatitis C treatment, preferences for hepatitis C treatment, experiences or fears of stigma

related to hepatitis C or its treatment, general health and well-being, and demographic information.

Delegates of the 2008 Australasian Professional Society on Alcohol and other Drugs (APSAD) Conference were also invited either to participate in a focus group held during the conference or to provide contact details for a telephone interview following the conference. A further recruitment strategy involved an email invitation to all APSAD members seeking their participation in a telephone interview. One focus group with six health professionals, and telephone interviews with 16 health professionals, were conducted.

Health professionals who participated were asked to provide a brief biographical snapshot of themselves in relation to their role in OST clinics. The core set of issues raised with clinician participants included their initial thoughts on providing hepatitis C treatment in OST clinics, influences on their decision to include treatment in their clinics (including personal, client, organisational and broader issues), and their perceptions of the primary barrier to and motivator of providing treatment in OST clinics.

Each interview used semi-structured interview guides. All OST client participants and health professionals were reimbursed with \$20 and \$60 vouchers respectively for their time and/or travel expenses.

The study was approved by the Human Research Ethics Committee of the University of New South Wales and written informed consent was obtained from all participants.

Findings of the survey

Demographic profile of survey participants

Just over half (52%, $n = 329$) of the survey participants were male, and the mean age of survey participants was 42 years (SD = 11.4 years, range = 19–84 years). The majority (82.5%, $n = 522$) had been born in Australia, with almost one in 10 participants (9.8%, $n = 62$) indicating that they were of Aboriginal or Torres Strait Islander origin. Almost one-third (33.0%, $n = 209$) reported that they were on a methadone program or other pharmacotherapy, and nearly half (44.5%, $n = 282$) of all participants reported having injected drugs in the six months prior to the survey.

Clinical factors

A participant's HCV genotype was significantly associated with their consideration of hepatitis C treatment ($\chi^2 = 67.3$, $df = 2$, $p = <.001$). Participants who did not know their HCV genotype were less likely to consider treatment than those who knew their genotype. Just under a third (30.4%) of participants who had considered treatment reported an HCV genotype of 1, 4, 6, 7, 8 or 9, while about 15% had Genotype 2 or 3. The majority (89.6%) of respondents who had not considered treatment did not know their HCV genotype (see Table 1).

Participants who reported that they had considered undertaking hepatitis C treatment scored significantly higher on the perceived consequences scale than participants who had not considered treatment (mean 21.0 versus 19.5, $p < .001$) (see Table 1). This suggests that participants who had considered treatment perceived their infection to have serious consequences. They were more likely to agree that hepatitis C was causing difficulties for those close to them, strongly affected how others saw them, or believed that their infection had serious financial consequences, compared with those who had not considered treatment.

Table 1: Clinical factors associated with having hepatitis C, and consideration of treatment

	Treatment considered		Total N (%)	χ^2 p-value
	No n (%)	Yes n (%)		
Genotype				<.001
1, 4, 6, 7, 8 or 9	12 (6.9)	123 (30.4)	135 (23.4)	
2 or 3	6 (3.5)	63 (15.6)	69 (12.0)	
don't know	155 (89.6)	218 (54.0)	373 (64.6)	
Diagnosis of mental illness				ns
yes	93 (55.0)	210 (54.3)	303 (54.5)	
no	76 (45.0)	177 (45.7)	253 (45.5)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Time since diagnosis	10.5 (6.7)	11.6 (6.4)	11.3 (6.5)	ns
Perceived consequences	19.5 (4.4)	21.0 (4.7)	20.5 (4.6)	0.001
Severity of symptoms	4.5 (5.9)	4.9 (5.7)	4.8 (5.8)	ns

ns = not significant

A participant's decision to have treatment was significantly associated with their HCV genotype ($\chi^2 = 99.6$, $df = 2$, $p = <.001$). Over half (53.9%) of the participants who decided to have treatment reported a genotype of 1, 4, 6, 7, 8 or 9, while 70% of those who decided against treatment did not know their HCV genotype.

Participants who had decided to have treatment scored significantly higher on the perceived consequences scale, having perceived their infection as having more serious consequences for their life, compared with those who decided against treatment (mean 22.3 versus 20.3, $p < .001$) (see Table 2).

As with factors associated with the consideration of treatment, genotype and perceived consequences of hepatitis C were significantly associated with a participant's decision to proceed with treatment. This suggests that these clinical factors continued to be important between the time treatment was first considered and the time the decision to undergo treatment was made.

Social factors

Participants who scored higher on a scale measuring support from family and friends were significantly more likely to consider treatment, suggesting that people who received

Table 2: Clinical factors associated with having hepatitis C, and the decision to have treatment

	Treatment decided			χ^2 p-value
	Against n (%)	For n (%)	Total N (%)	
Genotype				<.001
1, 4, 6, 7, 8 or 9	53 (19.7)	69 (53.9)	122 (30.7)	
2 or 3 don't know	26 (9.7) 190 (70.6)	37 (28.9) 22 (17.2)	63 (15.9) 212 (53.4)	
Diagnosis of mental illness				ns
yes no	140 (54.7) 116 (45.3)	66 (53.2) 58 (46.8)	206 (54.2) 174 (45.8)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Time since diagnosis	11.4 (6.5)	12.1 (6.1)	11.5 (6.4)	ns
Perceived consequences	20.3 (4.4)	22.3 (4.8)	21.0 (4.7)	<.001
Severity of symptoms	4.8 (5.6)	5.2 (5.9)	4.9 (5.7)	ns

ns = not significant

more emotional help and support from family members and who had friends with whom they could talk about their problems were more likely to consider treatment than those who had less support (mean 13.0 versus 11.9, $p = .015$; mean 13.2 versus 12.3, $p = .017$, respectively) (see Table 3).

Furthermore, participants' concerns with disclosing their hepatitis C status was significantly associated with considering treatment. Participants who were considering treatment scored higher on the disclosure concern scale, indicating a greater concern with disclosing their hepatitis C status, than those who had not considered treatment (mean 28.9 versus 27.1, $p < .002$) (see Table 3). In other words, respondents who reported that they were considering undertaking treatment saw telling someone they had hepatitis C as more risky, were more worried that people who knew they had hepatitis C would tell others and overall had a stronger tendency to non-disclose, than those who had not considered treatment.

Only two social factors, support from family and support from friends, were significantly associated with the decision to proceed with treatment (mean 13.6 versus 12.6, $p = .04$; mean 13.8 versus 12.9, $p = .03$, respectively) (see Table 4). As was the case with participants considering treatment, participants who scored higher on the family and friends support scales were more likely to decide to proceed with treatment.

Personal values

There was a significant association between participants' feelings about having hepatitis C and their consideration of treatment. Nearly two-thirds (60.3%) of participants who had considered undertaking treatment reported being constantly aware of the virus even when they were not experiencing symptoms. A similar proportion (55.8%) of participants who had *not* considered treatment reported hardly ever thinking about their hepatitis C infection, or thinking about it only when the infection was causing symptoms ($\chi^2 = 12.0$, $df = 2$, $p < .01$) (see Table 5).

Table 3: Social factors associated with having hepatitis C, and the consideration of treatment

	Treatment considered			χ^2 p-value
	No n (%)	Yes n (%)	Total N (%)	
Felt discriminated against by doctor/health care worker				ns
no yes	146 (88.0) 20 (12.0)	352 (90.5) 37 (9.5)	498 (89.7) 57 (10.3)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Support from family	11.9 (4.4)	13.0 (4.6)	12.6 (4.6)	0.015
Support from friends	12.3 (3.8)	13.2 (3.9)	12.6 (3.9)	0.017
Support from significant other	13.5 (4.0)	14.1 (4.4)	13.9 (4.3)	ns
Disclosure concern	27.1 (5.8)	28.9 (6.1)	28.3 (6.1)	0.002
Severity of public attitudes	38.0 (11.4)	37.8 (9.6)	37.9 (10.1)	ns

ns = not significant

Table 4: Social factors associated with having hepatitis C, and the decision to have treatment

	Treatment decision			χ^2 p-value
	Against n (%)	For n (%)	Total N (%)	
Felt discriminated against by doctor/health care worker				ns
no yes	288 (89.4) 27 (10.6)	117 (92.1) 10 (7.9)	345 (90.3) 37 (9.7)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Support from family	12.6 (4.6)	13.6 (4.5)	13.0 (4.6)	0.04
Support from friends	12.9 (3.8)	13.8 (3.9)	13.2 (3.9)	0.03
Support from significant other	14.1 (4.4)	14.3 (4.3)	14.1 (4.4)	ns
Disclosure concern	28.9 (5.9)	28.9 (6.4)	28.9 (6.1)	ns
Severity of public attitudes	38.3 (9.4)	36.4 (9.9)	37.8 (9.6)	ns

ns = not significant

Table 5: Personal values associated with having hepatitis C, and the consideration of treatment

	Treatment considered			χ^2 p-value
	No n (%)	Yes n (%)	Total N (%)	
Feelings about having hepatitis C				0.002
always aware of the virus	73 (44.2)	323 (60.3)	305 (55.5)	
only aware when symptomatic	42 (25.5)	71 (18.4)	113 (20.5)	
hardly ever think about hepatitis C	50 (30.3)	82 (21.3)	82 (24.0)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Emotional representation	18.5 (5.2)	19.8 (5.2)	19.4 (5.2)	0.012
Personal control	21.8 (4.2)	22.5 (3.9)	22.3 (4.0)	0.04
Treatment control	17.4 (3.2)	17.5 (3.6)	17.0 (3.5)	ns

ns = not significant



Participants who scored higher on the emotional representation scale, and therefore experienced more negative emotions about having hepatitis C, were significantly more likely to have considered treatment than those who scored lower on the scale (mean 19.8 versus 18.5, $p < .012$) (see Table 3). Those who had considered having treatment were more likely to have felt depressed, angry, anxious or afraid when thinking about their infection. Participants who had considered undertaking treatment were significantly more likely to score higher on the personal control scale than participants who had not considered treatment (mean 22.5 versus 21.8, $p = .04$) (see Table 5). Those who had considered treatment were more likely to agree there was a lot they could do to control their symptoms and believe they had the power to influence aspects of their hepatitis C infection.

However, there was no significant association between personal value measures and the decision to proceed with treatment (see Table 6).

Table 6: Personal values associated with having hepatitis C, and the decision to have treatment

	Treatment decision		Total N (%)	χ^2 p-value
	Against n (%)	For n (%)		
Feelings about having hepatitis C				ns
always aware of the virus	156 (61.2)	71 (57.3)	227 (59.9)	
only aware when symptomatic	44 (17.3)	26 (21.0)	70 (18.5)	
hardly ever think about hepatitis C	55 (21.6)	27 (21.8)	82 (21.6)	
	Mean (SD)	Mean (SD)	Mean (SD)	t-test p-value
Emotional representation	19.9 (5.0)	19.4 (5.6)	19.8 (5.2)	ns
Personal control	22.8 (4.0)	22.4 (3.7)	22.7 (3.9)	ns
Treatment control	17.3 (3.3)	17.7 (4.1)	17.4 (3.5)	ns

ns = not significant

Knowledge of hepatitis C and hepatitis C treatment

Participants who had considered undertaking treatment scored significantly higher on questions testing their knowledge of hepatitis C and its treatment, compared with those who had not considered treatment (mean 2.1 versus 1.5, $p < .001$; mean 10.7 versus 6.5, $p < .001$, respectively) (see Table 7).

Table 7: Knowledge of hepatitis C, knowledge of hepatitis C treatment and the consideration of treatment

Knowledge	Treatment considered		Total Mean (SD)	t-test p-value
	No Mean (SD)	Yes Mean (SD)		
Hepatitis C	1.5 (1.3)	2.1 (1.5)	1.9 (1.5)	<.001
Hepatitis C treatment	6.5 (5.0)	10.7 (5.7)	9.4 (5.8)	<.001

Furthermore, participants who reported that they had decided to have treatment scored significantly higher on

scales measuring knowledge of both hepatitis C and hepatitis C treatment than those who had decided against treatment (mean 2.5 versus 1.9, $p < .001$; mean 13.6 versus 9.3, $p < .001$, respectively) (see Table 8). Such results suggest that level of knowledge of both hepatitis C and its treatment affects people's consideration of treatment and the decision to proceed with it.

Table 8: Knowledge of hepatitis C, knowledge of hepatitis C treatment, and the decision to have treatment

Knowledge	Treatment decision		Total Mean (SD)	t-test p-value
	Against Mean (SD)	For Mean (SD)		
Hepatitis C	1.9 (1.4)	2.5 (1.5)	2.1 (1.5)	<.001
Hepatitis C treatment	9.3 (5.5)	13.6 (4.9)	10.1 (5.7)	<.001

Findings from in-depth interviews and focus groups

Demographic profile of interviewees and focus-group participants

In all, 26 of the participants having OST had received methadone maintenance therapy and one had received buprenorphine. The length of time they had been receiving OST ranged from 3 months to 24 years. The mean age of participants was 38.5 years (range 18–57 years). All OST participants had self-reported hepatitis C infection. The majority (89%) were unaware of their HCV genotype and had no previous experience of hepatitis C treatment.

Twenty-two health professionals participated in a focus group or individual interviews. These included medical practitioners, nurses, pharmacists and clinical managers, all of whom worked in predominantly publicly funded OST clinics. Health professionals from all states and territories, apart from the Northern Territory, were represented in the sample.

Clients receiving OST

Organisational barriers and incentives to the uptake of hepatitis C treatment

Clients of OST services reported that if treatment for hepatitis C were offered at their OST clinic they would be more likely to take up treatment as the clinic would provide a convenient 'one-stop shop':

That'd be a lot better. Then instead of going to two places to do two things you're going to one place by the time rather than going to two different places, which takes a very long time and running around here, and there ... (Man, 40)

Clients reported that their often long-standing relationships with health professionals at their OST clinic would facilitate their uptake of hepatitis C treatment because they felt that

they had a good rapport with their OST service provider and trusted them, and these health professionals understood their circumstances.

On the other hand, with regard to the one-stop-shop model, participants who were OST clients raised concerns about confidentiality. This service environment could result in people's hepatitis C status becoming public without their personal authorisation, and participants were worried about the implications of this for their lives outside treatment:

Maybe some people might have a bit of a confidentiality issue. That is why I find some people go do their methadone treatment at one place, and their hep C treatment at another, because they don't want the people [who inject] knowing they have got hep C ... (Man, 21)

Personal barriers and incentives to the uptake of hepatitis C treatment

Generally, participants who were OST clients were aware that treatment for hepatitis C infection existed. However, their understanding of what a treatment regime involved was limited. Furthermore, OST participants reported that they had not taken up treatment in the past because treatment options had not been discussed with them by a health professional:

I'm sure he would've said something to me a lot ... if I need treatment or, my liver, or whatever, my hep C was not going too good. I'm sure he would've said something ... but, no, he didn't. (Man, 38)

Participants who were OST clients identified a variety of competing priorities that presented barriers to the uptake of treatment for hepatitis C. For example, many of them had parental responsibilities:

The reason I wouldn't go on the interferon was because I've just had a baby. And there was no way I was gonna get depressed and look after a baby ... I wouldn't like to get depressed with looking after children ... The two little ones still need me. And they can't have a depressed mother. (Woman, 42)

Similarly, homelessness and unstable housing were cited as competing priorities that affected participants' ability to commence and adhere to an hepatitis C treatment regime:

It does make [hepatitis C treatment] hard because you're sleeping on the streets and you're getting up at night, and you're waking up at all hours of the night, so you're not getting much sleep. And you get a bit aggravated and you get told that you can't sleep here, you can't sleep there, you can't go here. (Man, 40)

Some participants who were OST clients questioned the efficacy of hepatitis C treatment to produce a sustained virological response. These participants alluded to the difficulties associated with tolerating the treatment drugs and the relatively high likelihood of non-response:

[I]f it [hepatitis C treatment] didn't work I'd be pretty upset. If I went through it, had done it all properly, and it didn't work, I'd be 'oh, what a fucking waste doing that was', you know what I mean. Going through all that and I've still got hepatitis, like. (Man, 27)

Finally, OST participants identified a diverse range of competing physical and psychological health priorities that presented a barrier to the uptake of hepatitis C treatment. These included having HIV, diabetes, epilepsy, hepatitis B, or depression, or having had a stroke, heart attack or serious physical injuries, and being aggressive towards others.

Health professionals

Organisational barriers and incentives to the uptake of hepatitis C treatment

Participants who were health professionals also revealed strong support for extending the provision of hepatitis C treatment and care to OST settings. The notion of a 'one-stop shop' was endorsed as a potentially efficient means of improving access to and uptake of treatment and keeping people in treatment:

I think it's ideal to provide as many treatments ... So I think that the model of marrying one or two different, you know, therapies to the one, to the one-stop-shop scenario or setting is logistically very sensible and can work very practically, very well. (Doctor, Vic)

A one-stop-shop model could build upon existing staff-client relationships, particularly where strong levels of trust and rapport have already been established. This was envisaged as a distinct strength of the integrated model:

I think it is an absolute essential for our clients, given their reluctance to go to other areas for treatment ... (Registered nurse, NSW)

Yeah, it's a really good initiative because it's on-site ... They've got, like, an allocation nurse so they've always got a contact person. It's local. It's friendly. It's in a comfortable environment. So it's enticing to want to come in and, you know ... and it's a lot more personable. (Registered nurse, Vic)

There was some disagreement among health professionals on the position of hepatitis C treatment in OST clinics. For some, the provision of treatment was arguably a duty of care, while for others there was a sense that they, or their colleagues, would consider the provision of treatment as outside their 'core business':

I think the biggest barrier for me would be possibly the organisation. I think a lot of the workers would say, 'We're too busy doing other things to do this. And that's not our core business anyway. Can't you send them to the hospital?' (Doctor, Tas)

I like the system we have. I think it's working very well at the moment. I'm not sure that I want to change anything. (Pharmacist, NSW)

Personal barriers and incentives to the uptake of hepatitis C treatment

This dichotomy of 'duty of care' versus 'non-core business' operated alongside another dichotomy of 'client interest' versus 'indifference' to hepatitis C treatment. Some health professionals reported that their clients' lack of motivation represented the primary barrier to their uptake of treatment:

In theory it sounds great but in practice the client group that we work with aren't necessarily that highly motivated or interested in the treatment. And I even find that when I'm talking to clients ... So I really would need some help around how to try to change people's level of motivation and interest in the program. (Clinical manager, WA)

On the other hand, some participants who were health professionals reported that some clients had very positive attitudes towards the uptake of treatment in OST clinics:

Well, I think one is certainly struck by the way some patients respond to knowledge about their hep C status, and are very motivated to try [treatment] and get sustained viral responses, etc. (Doctor, Qld)

Conclusion

The findings of the survey indicate that people who know and remember their HCV genotype report a level of engagement with health services and their own state of health that is conducive to learning about hepatitis C treatment. This can allow them to consider their options, including deciding to commence treatment. Similarly, if people perceive that their infection will have a range of health, social and economic consequences further down the track, then they are more likely to appreciate the potential benefits of treatment. These clinical factors are important in whether or not people with hepatitis C both consider and decide to proceed with treatment.

With regard to social factors, the previously documented beneficial supporting role of family and friends is also evident among this sample. Such support can assist people both while they are considering treatment and in making the decision to begin treatment because they know that there will be a safety net available to them if, for example, treatment side effects become difficult to tolerate. Interestingly, people who were most concerned about the risks associated with disclosing their hepatitis C status were more likely to consider treatment. It is likely that when weighing up the pros and cons of treatment, disclosure emerges as an issue which people come to realise will need to be broached.

In this study, people who thought a lot about their infection tended to be the people who had considered treatment and this was independent of whether or not they were experiencing symptoms. The finding accords with another result showing that people who considered treatment also had a sense of personal control over hepatitis C infection. On the other hand, people who became depressed, anxious, angry or afraid when thinking about hepatitis C were more likely to have considered treatment as well, perhaps because they viewed treatment as offering a way to ameliorate their concerns.

Finally, our survey results show an association between knowledge about hepatitis C and considering and having treatment. As with the findings on knowing one's genotype and the perceived consequences of hepatitis C infection, having a high level of knowledge about hepatitis C—or conversely, not knowing anything about it—affects people's resolve to either accept or reject treatment.

Therefore, factors associated with both considering and having treatment for hepatitis C infection include a range of clinical considerations, social conditions, personal values and knowledge which intersect in the lives and minds of individuals to inform their decision.

Narratives from clients of OST clinics, and the clinicians who treat them, further examined the issues related to individual decision-making within a social context and highlighted the structural as well as personal influences on the decision whether or not to undertake hepatitis C treatment. Findings from the interviews suggest that clients' concerns about confidentiality were viewed as an organisational issue requiring organisational responses. These data also show how issues on both an organisational and personal level are interrelated. Clients reported that their OST (or other) clinician did not discuss treatment with them. This absence of discussion, coupled with clients' perception that treatment would be discussed with them if their clinician perceived them to be a suitable candidate, sends a strong signal to clients that treatment is not a priority for them.

Our data also show differences of opinion among health professionals about clients' levels of interest in hepatitis C treatment, as well as differing perceptions of the legitimacy of treatment as a role for the OST clinic. If health professionals are not providing their patients with information about treatment, not recommending treatment and furthermore do not believe that treatment is a legitimate activity for OST clinics, then it is unlikely that current clients of OST

services will appreciate the benefits of treatment and viral clearance. There will continue to be the perception among health professionals that clients have a low level of interest in treatment and a resultant low level of treatment uptake. At the personal level, family and parenting obligations, homelessness and concerns about side effects and the efficacy of treatment were described in this study and have also been found in other research.

In summary, there was agreement between clients and health professionals in this study that offering hepatitis C treatment in OST clinics would be convenient for clients and would presumably lead to increases in the uptake of and

adherence to treatment. However, combining very different models and cultures of care is not without challenge. The potential to treat many more people with hepatitis C in OST settings is compelling; however, there is also the capacity to do harm or provide further marginalising care. Given the calls for resources for the urgent expansion of hepatitis C treatment in OST settings, our data highlight the importance of including the perceptions and experiences of clients and various health professionals in future research. That research must also be designed to examine this model of care from a range of positions to reflect the complexity of care and treatment for people in marginalised social circumstances.

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