

Understanding decisions made about hepatitis C treatment by couples who inject drugs

C. Treloar,¹ J. Rance,¹ J. Bryant¹ and S. Fraser² ¹Centre for Social Research, UNSW Australia, Sydney, NSW, Australia; and ²National Drug Research Institute, Curtin University, Melbourne, Vic., Australia

Received March 2015; accepted for publication July 2015

SUMMARY. Efforts to increase the number of people having hepatitis C virus (HCV) treatment require understanding how to best deliver services to meet consumers' needs. The general health literature has examined the role that partners can play in supporting health outcomes. This study examines the experiences of couples who inject drugs in relation to knowledge of, decisions about and management of HCV treatment. This is a qualitative interview study of people who inject drugs in couples. Participants were recruited from harm reduction services in two major Australian cities. Couples were interviewed separately. Data were examined using the couple as the unit of analysis and to identify patterns of experience related to the HCV serostatus of couples. Knowledge of HCV and HCV treatment was low and variable but showed some relationship

to serostatus. Decisions about HCV treatment were deeply informed by concerns regarding treatment side effects. Positive concordant couples considered 'staging' treatment to ensure that each partner could (in turn) care for the other. People with HCV in serodiscordant relationships may need specific support regarding HCV treatment information. Within positive concordant partnerships, our data indicated the need to support the HCV-positive 'carer' during their partner's treatment. Changing treatment regimens, and their anticipated lower side effect profiles, will need to be actively promoted to ensure that couples understand how these changes affect their treatment options.

Keywords: couples, hepatitis C treatment, injecting drug use, qualitative research, relationships.

INTRODUCTION

Continuing efforts to increase the rates of hepatitis C virus (HCV) treatment in Australia and other countries necessitate the examination of various models of care to identify how these can be best delivered or tailored to people living with HCV to meet their needs [1]. Some attention has been paid in the HIV field to tailoring interventions to couples both in terms of prevention of transmission [2–4] and in relation to strategies to support adherence to treatment [5,6]. This article's focus on couples draws on the wider literature acknowledging the importance of social relationships as mediators of health and healthcare seeking [7,8] and calls for greater attention to be paid to families or couples in efforts to better the management of chronic disease [9].

Services for people at risk of or living with chronic health conditions benefit from including partners/spouses within their models of care [10]. However, research in this area has paid little attention to people experiencing high

levels of social exclusion, such as people who inject drugs [11], the group that represents the majority of HCV infections [12]. The literature has tended to portray relationships between couples who inject drugs as inauthentic, unhealthy and dominated by the presence of a third potent force, that is the drug [13–16]. Hence, couples are either ignored [17], with injecting drug use portrayed as a lone activity [18], or cast as detrimental: as a cause of relapse or further harm [19]. The negative aspects of some relationships on health and well-being cannot be overlooked. However, we risk missing important understandings of decision-making about HCV treatment if we dismiss partnerships or ignore the unique issues that emerge for people living in partnerships.

Research on couples who inject drugs has focused primarily on risk of transmission of blood-borne viruses, including HCV [3, 20–25]. Specifically, sharing of injecting equipment by couples has been described as imbued with meanings of intimacy and trust and as equivalent in perceived risk to unprotected sex [13, 26]. There has been only very limited research focusing on the experience of living with HCV among couples who inject drugs and the impact of the relationship on decisions about treatment for HCV [27]. Additional gaps in the literature include questions regarding the ways in which couples who inject

Abbreviation: HCV, hepatitis C virus.

Correspondence: Carla Treloar, Centre for Social Research, UNSW Australia, Sydney, NSW 2052, Australia.
E-mail: c.treloar@unsw.edu.au

drugs negotiate decisions about HCV treatment and how these decisions may be influenced by other relationship dynamics such as whether the couple is new or well established, whether both partners have HCV or are serodiscordant, whether HCV was acquired by one partner during the life of the relationship or infection occurred prior to the relationship.

This study examines the accounts of individuals who inject drugs in couples (CWID) in relation to their knowledge of, decisions about and management of HCV treatment. This study is novel in the emphasis given to the moderating effect of the relationship on these factors and how this then produces insights different from those already described in the literature focusing only on individuals. Knowledge, decisions and HCV treatment management are also examined in relation to various patterns of HCV serostatus within these relationships (i.e. HCV concordant and discordant couples).

METHODS

Purposive sampling was used to recruit heterosexual couples in which both partners identified as people who inject drugs. Participants were recruited from inner city, harm reduction services such as needle and syringe programs and primary care services for people who inject drugs. Staff directed clients to fliers advertising the study and, with individual's consent, facilitated contact with the researchers. While no specific eligibility criteria were required regarding participants' drug use (such as current or previous injecting), all participants indicated current drug use.

Couples were included in the study on the condition that both partners agreed to be interviewed. Partners were interviewed separately by the same researcher. The importance of anonymity and confidentiality was reiterated to all participants, including reassurances that in this context the researcher would not disclose any information to the participant's partner.

Recruitment focused on generating a sample with a balance of HCV serostatus (negative concordant, positive concordant and discordant) and a range of ages. To facilitate recruitment of younger CWID, 'single' participants under 30 years of age were included where they reported current or previous relationships where injecting drug use had occurred.

Semi-structured interview schedules were organized around the core themes of injecting drug use, HCV and romantic partnership. Participants were asked to describe the nature of their current relationship (including other sexual partners), their knowledge of HCV and its relevance to the relationship, their experiences injecting with partner (s) and with friends, their experience accessing harm reduction services and their knowledge of and decisions about HCV treatment. Interviews took between 30 and

60 min. In accordance with convention, each participant was reimbursed \$30 for their time and travel expenses.

Digitally recorded interviews were transcribed verbatim and de-identified to ensure participants' anonymity. A coding frame was developed and informed by our previous couples-related pilot study [13] and by the existing literature. The transcripts were then entered into a qualitative data management program, NVivo 9 (QSR International, Doncaster, Victoria, Australia). Summaries of coded data were produced by one of the authors (JR) and then reviewed by other authors to assist in identifying concepts and support emerging hypotheses. The analysis process necessitated a shift in the unit of analysis from the individual to the couple [28]. In practice, all transcripts were organized, labelled and analysed in a way that identified both the participant and their partner. Each transcript was assigned a unique pseudonym, an interview number (shared by both partners) and a code that identified the recruitment site, age and HCV stats of the participant and their partner. Coded data relevant to HCV treatment were included for analysis, data from partners were examined together, and then, themes across couples were explored in three categories: HCV-negative seroconcordant, discordant and HCV-positive concordant. Three main areas emerged as important to couples' experiences: knowledge of, decisions about and management of HCV treatment.

The study was approved by the Human Research Ethics Committee of The University of New South Wales and from the relevant human research ethics committees at each site. Written, informed consent was obtained from all participants.

RESULTS

A total of 80 semi-structured interviews were conducted. This sample comprised 34 couples and 12 'single' participants. The data set included 75 accounts of people who were injecting drugs with a partner at the time of the interview (involving accounts from 41 current couples: 34 where both members of the partnership were interviewed and seven where only one partner participated) along with a further five accounts from sole participants (either single or in a relationship with someone who did not inject drugs at the time of the interview) who reflected on prior experiences of partnerships where injecting drug use had occurred. Men and women were equally represented ($n = 40$) and participants ranged in age from 19 to 61 years. Nine participants were in part- or full-time employment, with nearly all receiving some form of social welfare ($n = 71$). Nearly a quarter of participants identified as Aboriginal or Torres Strait Islander ($n = 17$). Serostatus was determined by self-report only, and in several cases, couples offered conflicting accounts. There were also cases where participants reported that their serostatus had

changed during the course of the relationship – through treatment, spontaneous clearance or seroconversion. Hence, we have classified participants by serostatus as reported at the time of interview. Where participants' changing serostatus is important to the interpretation of accounts, these details will be provided. HCV serostatus was almost equally shared among participants, with 35 reporting to be HCV negative and 45 HCV positive. Of the sample's 41 couples, 24 were HCV concordant (11 HCV negative and 13 HCV positive) and 17 HCV discordant (10 HCV-positive men and 7 HCV-positive women). Data collection did not yield sufficient detail regarding participants' attendance for HCV screening or assessment to include this information in analysis.

Creating knowledge together

To examine attitudes towards and decisions about treatment, we first examined participants' knowledge of HCV natural history and treatment. Typically, participants were aware that a treatment existed which was potentially curative and that this treatment produced significant and difficult side effects. Participants were also typically aware that better treatments (particularly in relation to side effects and efficacy) would be available in the future. Some participants, typically those with HCV and those in positive concordant relationships, demonstrated detailed knowledge of HCV natural history and treatment. However, discussion of detailed knowledge regarding genotype and its impact on treatment was limited. Participants' understandings of genotype were usually connected with the length of treatment: 'depends on the strain you have too, though because some strains can't be treated with that and some require 6 months, some require 12 months ... so we have the one which is 6 months treatment' (Shelley, 34 years, HCV positive; Steve, 33 years, HCV negative following treatment).

Examples of incorrect knowledge included Sandra's statement that her partner did not have a 'high dose' of HCV as he had 'only shared [injecting equipment] once' (Sandra, 40 years, HCV positive; Sean, 41 years, HCV positive). Although Tanya reported that she was 'not eligible' for HCV treatment as her other health conditions were not 'stable enough', she also incorrectly indicated that she had 'the strain that can't be fixed' (Tanya, 23 years, HCV positive; Tim, 39 years, HCV negative).

Participants with HCV and in positive concordant relationships did not always demonstrate high levels of knowledge regarding HCV treatment. Mandy (45 years, HCV positive) described her sister's experience of HCV treatment, saying that it was 'really hard' and 'made her go a bit crazy or something', but was not aware of what treatment entailed. Her partner Mike was similarly unaware of the details of HCV treatment except for some aspects of side effects.

Some treatment where they cleanse your body of, something like that. I can't remember what the name is. All I know is that it's sort of, towards the end it's like the flu. You get sick, you get drained, feel crappy. That's what I know about, I've seen people have the treatment and they hate it. But they do it to make themselves better. (Mike, 37 years, HCV positive).

The experiences of Sandra and Sean and Mike and Mandy demonstrate that incorrect knowledge, or misinterpretation of information, is not in general corrected within couples, even when both partners are living with HCV. This may be because talking about HCV and HCV treatment was difficult for some couples. One older positive concordant couple, Cliff (58 years) and Clare (46 years), explained that HCV was not discussed very often or in very much detail. Cliff noted that Clare had undertaken a transient elastography liver scan ('fibrosan') and that he had not. He added that he found HCV a 'touchy subject' as he had witnessed friends who had 'suffered' on treatment. Angie (36 years, HCV negative) attended a service for PWID and brought home HCV information material regularly for her HCV-positive partner Andy (38 years) but was not able to engage him in more than 'very quick' discussions about HCV and treatment. Indeed, one of her motivations for participating in the research project was to engage Andy in more detailed discussion.

I've talked about [Andy] behind his back to people. ... he reads the magazines, I can see he's very interested but he won't talk to me about it. When we do talk about it, it's a very quick conversation. So I was hoping that this [research interview] would make him come home this afternoon and chat to me about it. This is what I was hoping to get out of it. ... I want him to start talking about it because it's now been years and years. And he needs to think about when he gets that treatment. And the older he gets, the harder it will be. I just want to have the conversation, we might not have it unless we did this [research interview] (Angie).

Andy was relatively knowledgeable about HCV treatments, noted that he and Angie discussed HCV 'sometimes' and acknowledged the information Angie passed along and her interest in the results of his HCV-monitoring tests. He did not, however, acknowledge Angie's heightened level of concern for his health, instead forecasting his treatment decisions over a possible 5-year time frame.

She gets the [HCV information magazine] for me every month you know and we might discuss an article in there, "oh there's a new treatment coming out, they're doing a trial" ... Treatments and triple combo, that's out now and it's meant to be a lot better. So yeah we do talk about that. I need to get a fibrosan. We've talked about that a few times and I get blood tests now and again to check my PCR levels and she's always

interested about that. I need the fibroscan to see if I can delay the treatment, I'm hoping to delay it because I've got the genotype 1 which is very hard to beat. There's a lot of new treatments coming out in another 5 years.

Couples coming to decisions about HCV treatment

Concern about the side effects of treatment was a primary theme across all groups, one about which there was general consensus between partners. Participants had witnessed friends or family members undertake treatment or had heard of side effects from health workers. Concern about side effects was the primary barrier to treatment, especially when participants did not feel unwell. Within couples, these concerns may have a feedback effect, reinforcing each partner's view on HCV treatment. If so, this may require approaches that provide new information for couples and actively address the concerns of each partner.

I think treatment scares me, you know what I mean, like I think it scares me, just like knowing that it's so intense on the side effects, that's what scares me the most. (Samantha, 39 years, HCV positive; Simon, 42 HCV positive).

Nah, interferon, no thanks ... I'd rather live me, like, I've had it for like, God, what is it, 20 years, now, and I don't really feel the effects of it (Simon, 42, HCV positive; Samantha, 39 years, HCV positive).

Mental health concerns were emphasized in discussions regarding the side effects of HCV treatment. Some participants did not consider treatment due to previous experiences of mental illness. Mental health issues were also a factor in participants' concerns for their partners' well-being. In one case, a seronegative participant actively dissuaded his partner from undertaking treatment, despite her own high levels of motivation to rid herself of a condition that carried negative social and personal meanings.

Like I would do it tomorrow, I don't want to have [HCV]. And it makes me feel dirty that I have got it. ... [Terry] just worries ... like I wanted to get [HCV treatment] straight away. But at the time, I was in a bad way, like very depressed and down and that. And he was like "no, you're not doing it yet, no way". Because I am weak minded in a way, I probably would have suicide ... But I want to get rid of [HCV] too, so if there's other treatment that didn't have that side effect, I would do it tomorrow. (Tegan, 38 years, HCV positive; Terry, 37 years, HCV negative).

[HCV treatment] makes you depressed. My mate was real suicidal, he was real depressed on it. So why would you do it? (Terry, 37 years, HCV negative; Tegan, 38 years, HCV positive).

There were other elements of incongruence between couples' decisions about HCV treatment. In two couples, the female partner said that *both* members would 'love' (Fran) or were 'really keen' (Rachel) to start HCV treatment. Their partners were, however, much more equivocal. While motivated, Fred described agreeing to have treatment only if his health markedly deteriorated. Robert was concerned about the side effects of treatment ('getting crook' or being very unwell) and had decided to undertake this research interview instead of attending an appointment about HCV treatment.

Yeah, if it was something I had to do and it would benefit me and I could get rid of it, yeah ... because nobody wants hepatitis at the end of the day. Yeah, if I was in a situation where that was something I had to do, yeah for sure. (Fred, 34, HCV positive; Fran, 31, HCV positive).

The only thing we really have discussed was about doing the Interferon ... We've done everything, all we have to do is go get our liver fibroscan ... to see where we are at and then there is a decision whether we are going to go ahead and do it or not ... We don't talk a lot about it with each other ... I wasn't really sure about doing it to start with because I heard about people getting crook on it, rah rah rah, and yeah, I just didn't go ahead with it. (Robert 42, HCV positive; Rachel, 41, HCV positive).

Managing treatment together

A small number of participants had experienced treatment themselves or witnessed their partner go through it, and this had influenced their decisions about treatment. Mac began HCV treatment soon after he and Mindy began their relationship. Directly witnessing Mac's experience of treatment had deterred Mindy even though she reported being extremely upset about being diagnosed with HCV while pregnant (during a previous relationship). Mac was very grateful for the support Mindy provided, saying that this was instrumental to his completion of treatment.

To be honest if it wasn't for her I don't think I would've got through it ... She put up with me fucking out, you know, going off me head some. Not at her but just myself, just the frustration was going through me head ... Like there was times I felt like jumping off the balcony and, you know? Cause deadset like, if you've ever been through heroin withdrawals, it's like that. Maybe not so intense but the same sort of feeling constantly. (Mac, 35 years, awaiting results of treatment; Mindy 39 years, HCV positive).

Other couples described ways in which they had considered managing if they were to undertake HCV treatment.

These plans centred on ensuring that they could care for each other through what was anticipated to be a demanding period. Staging treatment, where partners undergo treatment consecutively rather than concurrently, provided couples with a means to take it in turns to support each other while coping with treatment side effects – that is while feeling ‘crook’ or very unwell. Understandings of genotype figured in only a limited way in these plans.

We know we’ve got it and we just kind of talked about it me and Fred, and said, “look we’d both love to do treatment, but we’ve heard it’s very full on” ... and he was like “what about one of us do it and the other one looks after that one” ... so we look after each other (Fran, 31, HCV positive; Fred, 34, HCV positive).

I don’t know if we’ll do it together because they were saying you get sick. So I want to be there if he gets sick and then he can be there if I get sick (Rachel, 41, HCV positive; Robert 42, HCV positive).

But it wasn’t so much “right I’m doing it, you’re doing it”, it was decisions ... if [my partner] wants to do it by all means, go for it, I’ll support you. If I want to do it too with her, well we’ll both support each other, because I wasn’t too sure about the sickness. You do get crook from it ... and if it was bad, I would hate to have two of us bang crook at the same time, so yeah. It would’ve had to be something we talked about more I suppose. She sounds more determined of doing it. Her hep C apparently is a bit worse than mine. She’s got A1 strain and mine was whatever something four, so yeah. Hers needed a bit more treatment than what mine did, so we were told. (Robert 42, HCV positive; Rachel, 41, HCV positive).

DISCUSSION

A recent meta-analysis concluded that couples-oriented interventions for chronic illness hold promise for improving health outcomes [10]. However, the experience of HCV in couples has received scant attention in the clinical or associated literatures. The data presented here show some of the ways in which HCV knowledge, decisions and treatment experiences can be produced and shaped within couples.

Knowledge of HCV natural history and treatment was highly variable in this sample, which supports results from HCV knowledge surveys [29,30]. Participants’ level of HCV knowledge was somewhat associated with serostatus: people in HCV-negative seroconcordant partnerships showed lowest knowledge, followed by people in HCV serodiscordant partnerships, while people in HCV-positive seroconcordant partnerships demonstrated the most complete knowledge. While this pattern was not neat or linear, it does suggest that people in HCV discordant rela-

tionships may require specific targeting to support their knowledge of HCV treatment. This follows our finding that many positive concordant couples reported sharing what they had learnt (or information sources that they had acquired). Awareness of and emphasis on HCV genotype, a key factor in determining treatment options, was low across the sample.

Anticipation of side effects was a major concern for participants and shaped decisions about whether to have treatment and how treatment could be staged within a couple to maximize available support. Interferon-based HCV treatments can place additional burdens on the caregiver. For people living with HCV, the effort of caring for a partner struggling with interferon-related side effects may strain or undermine the positive and supportive elements of this relationship. This cyclical effect is especially concerning given the demonstrated association between relationship quality and health status [31,32]. If treatment is ‘staged’ within a positive seroconcordant couple, then providing the carer with additional support may also positively impact on the outcomes of the partner undergoing treatment.

The staging of treatment by couples is also relevant when considering HCV treatment-as-prevention trials [33] which aim to simultaneously treat large numbers of people in order to substantially lower prevalence and hence prevent future infections. Although these trials may employ interferon-free regimens with fewer side effects [34], concern about side effects so profoundly shapes understandings of HCV treatment that couples may be reticent to embark on HCV treatment *at the same time* until the claims of diminished side effects are validated by ‘on the ground’ experience. Augmenting clinical services with HCV education programmes conducted by peer workers may be necessary and more effective in changing normative understandings of HCV treatment [35–39].

The data presented here also reflect the well-documented stigma associated with HCV [40–42]. Wanting to rid oneself of a stigmatized identity marker may contribute to decisions about treatment. As these data showed, this drive may be moderated within a couple in relation to concerns about management of side effects or may be felt differently by each partner. Gender differences in the use of health care are well established [43], with women reporting higher healthcare seeking across a range of conditions. Our data also demonstrated higher interest in HCV treatment among women than their male partners. How differing levels of interest in HCV treatment is negotiated within couples remains a fertile area for future research.

This paper draws upon qualitative interviews with a sample of 80 people living in Sydney and Melbourne, Australia. These data may not be applicable to people living in nonmetropolitan areas or where access to services is more limited. These interviews could not scope the entire

range of possible concerns or decisions about HCV treatment. However, our method of interviewing both partners of a couple and keeping their data connected during analysis is a key methodological strength and innovation in this area.

This paper adds to the small but growing literature on the need for couples-oriented approaches to talking about or providing HCV treatment but, as has been called for previously, such interventions require clear articulation of the conceptual framework on which they are based [10,44]. Interventions targeting couples who live with HCV and who have a history of injecting drug use should account for the stigma and discrimination that can be a potent force in everyday life and in health decision-making [45] while also generating concomitant distrust in health services [46].

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ACKNOWLEDGEMENTS

This work was supported by a grant from the National Health and Medical Research Council (1023437). The Centre for Social Research in Health is supported by a grant from the Australian Government Department of Health. We thank the services which assisted recruitment for this study and the participants who so generously participated. The National Drug Research Institute at Curtin University is supported by funding from the Australian Government under the Substance Misuse Prevention and Service Improvement Grants Fund. The last author (SF) is supported by an Australian Research Council Future Fellowship (FT120100215).

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