



Full length article

“Don’t think I’m going to leave you over it”: Accounts of changing hepatitis C status among couples who inject drugs



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ABSTRACT

Background: While the health-related benefits of intimate partnership are well documented, little attention has been paid to couples exposed to high levels of social stigma and exclusion. In this project we investigated an important site of stigma for partnerships by collecting accounts of changing hepatitis C (HCV) status (“sero-change”) among couples that inject drugs. We explored what these accounts reveal about the meaning of HCV for these couples, and how this understanding contributes to our collective efforts at prevention and care.

Methods: Drawing from a large dataset of qualitative interviews with couples, we focussed on those containing reports of sero-change. By adopting a methodology that positioned partnerships rather than individuals as the primary unit of analysis, we addressed the commonplace tendency to either overlook or discount as dysfunctional, the sexual relationships of people who inject drugs.

Results: While some couples sought greater biomedical understanding as a means of coming to terms with sero-change, others drew on alternative logics or “rationalities” that sat firmly outside conventional biomedical discourse (privileging notions of kinship, for example). Regardless of which explanatory framework they drew on, participants ultimately prioritised the security of their relationship over the dangers of viral infection.

Conclusions: Effectively engaging couples in HCV prevention and care requires acknowledging and working with the competing priorities and complex realities of such partnerships beyond simply the identification of viral risk. The “new era” of direct acting antiviral treatments will provide ongoing opportunities to learn to integrate biomedical information within more socially sophisticated, relationally aware approaches.

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1. Introduction

While the health-related benefits of intimate partnership are well documented (Kiecolt-Glaser and Newton, 2001; Lewis et al., 2006), little attention has been paid to couples experiencing high levels of social stigma and exclusion, such as those who inject drugs and are affected by the hepatitis C virus (HCV) (Treloar et al., 2015). In Australia, approximately 90% of newly-acquired HCV infections are due to the sharing of contaminated injecting equipment (The Kirby Institute, 2015). Australia’s primary public health response to HCV is focused on the distribution of sterile equipment (along

with safer injecting advice) via government-funded needle syringe programmes (Treloar and Fraser, 2007).

Integral to the prevention response has been the long-held understanding that avoiding transmission is a matter of individual responsibility (Dwyer et al., 2011; Fraser, 2004; Fraser et al., 2014). This is reflected and reinforced not only through the prevention education and health promotion materials produced for people who inject drugs (PWID) (Dwyer et al., 2011; Fraser, 2013), but the practical measures designed to enable the fulfilment of this responsibility, such as the ways in which sterile injecting equipment is distributed (Fraser et al., 2014). Despite epidemiological and surveillance data consistently showing that the majority of equipment sharing occurs between sexual partners, this onus on individual responsibility has effectively elided the importance of the intimate partnership as a key site of hepatitis C prevention and transmission (El-Bassel et al., 2014a,b;

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Fraser, 2013; Rhodes and Quirk, 1998; Seear et al., 2012; Simmons and Singer, 2006). Recent survey data, for example, indicate that over 50% of participants who reported sharing injecting equipment did so with their regular sexual partner (Iversen and Maher, 2015), with similar patterns found in earlier studies (Roux et al., 2014; Bryant et al., 2010; Cao and Treloar, 2006).

This “individualising tendency” (Fraser et al., 2015) has important implications for efforts to understand and prevent the transmission of hepatitis C, particularly within couples where arguably the risk is greatest. In this article we address this tendency by adopting a methodology that positions partnerships rather than individuals as the primary unit of analysis (Eisikovits and Koren, 2010; Simmons and Singer, 2006). Drawing on qualitative interviews with couples who inject drugs, we focus on those couples that reported changes in HCV-status (or “sero-change”). We explore how these participants responded to sero-changes within the lived contexts of their intimate partnerships and how such changes affected their perceptions of transmission risk.

Framing participants’ partnerships as the primary unit of analysis represents a novel and instructive way of thinking about HCV transmission and prevention. Rarely have the intimate partnerships of PWID been conceptualised as units of analysis in their own right, tending to be either overlooked or discounted as dysfunctional and drug-driven (Fraser, 2013; Keane, 2004; Seear et al., 2012; Simmons and Singer, 2006). Recently there has been an emergence of HIV-related research focussing on the “micro-social contexts” of heterosexual couples who inject drugs (El-Bassel et al., 2014a,b; Montgomery et al., 2012). This work emphasises the need to move beyond individual-level, cognitive-based models of health behaviour, underscoring instead the importance of a conceptual, motivational and “ideological shift from focusing on the individual to the dyad” (Jiwatram-Negron and El-Bassel, 2014, p. 1885) – from an orientation of “self-care” and “independence” to one prioritising “relationship”, “interdependence” and “communal coping” (Montgomery et al., 2012). In this article we build on these broad conceptual concerns via new empirical territory: an exploration of the particularities of acquiring and living with HCV among couples who inject drugs. Here a qualitative approach is not only well suited to capturing the richness and subtleties of contextualised, interpersonal dynamics, it is also particularly effective when exploring new and under-developed areas of research such as people’s accounts of sero-change (Patton, 2002).

2. Materials and methods

2.1. Recruitment and data collection

This project used purposive sampling to recruit heterosexual couples in which both partners identified as PWID. Recruitment took place across four harm-reduction, inner-city services within two Australian states, New South Wales and Victoria. Couples were included on the basis that both partners agreed to be interviewed. Each partner was interviewed separately by the same researcher, with assurances of confidentiality emphasised. Interviewing partners separately, it was felt, would best facilitate the emergence of sensitive intra-relationship talk (Eisikovits and Koren, 2010): the attribution of responsibility (or “blame”) for HCV transmission within couples, for example. Semi-structured interview schedules were organised around the core themes of injecting drug use, HCV, and intimate partnership. Interviews took between 30 and 60 min. Each participant was reimbursed \$30 to cover time and travel expenses.

2.2. Data management

The total dataset comprised 80 qualitative, in-depth interviews.¹ All interviews were digitally recorded, transcribed verbatim, de-identified and anonymised with the use of pseudonyms. A coding frame was developed collaboratively by the authors, drawing on the data itself, the interview schedule, and our knowledge of the literature. Consistent with positioning “the partnership” as the basic unit of analysis, transcripts were entered as couples within a qualitative data management program, NVivo 9. Consequently, any narrative detail extracted for analysis was readily identifiable as part of a broader story of partnership rather than simply an individual account. Individual theme files or ‘nodes’ were reviewed by all authors to assist with identifying and consolidating key themes and concepts. The data analysed in this article comprised 28 of the total 80 interviews, collected from the 14 couples that reported changes in HCV status during the course of their relationship. Our focus was on the node that collated all data concerned with couples’ accounts of sero-change.

2.3. Analysis

Our analysis was conducted using a mix of inductive (data-driven) and deductive (analyst-driven) approaches (Braun and Clarke, 2006). Induction enabled key themes to be identified in the relevant node and subsequently corroborated against the original transcripts. These emergent themes plus indicative quotes were discussed among all authors. During this stage, summary accounts of each couples’ sero-change story were also mapped out (see Table 1). Accounts from some participants included recollections of confusion or “misinformation” regarding their status; others described being uncertain, even perplexed, regarding the circumstances of transmission. Within couples, too, partners sometimes made contradictory statements about the other’s status. A deductive analytical approach enabled us to begin to make sense of this apparent confusion or “mess”. The extant literature, including our own earlier analyses of the dataset (see for example, Rance et al., 2016; Treloar et al., 2015), provided an analytical framework through which to interpret couples’ often complex accounts of sero-change. Our final analysis, including the three themes under which our results are organised, reflect these elements of grounded analysis (Glaser and Strauss, 1967) coupled with analyst-driven deduction. Throughout the writing process, each subsequent iteration incorporated suggestions from all authors, with differences negotiated until agreement was reached.

The study was approved by the Human Research Ethics Committee of The University of New South Wales (reference HC12430). Written, informed consent was obtained from all participants. All extracts cited here are identified by the participant’s pseudonym, age and self-reported HCV status² (at time of interview), followed by their partner’s corresponding details, and the duration of their relationship.

¹ The 80 respondents comprised 34 couples, plus 12 “sole” participants included on the basis of having had relationship experience (prior or current) involving injecting drug use.

² Our use of terms in this paper refers to HCV-status as it relates to the potential for transmission. “HCV-positive” refers to chronic infection (antibody-positive and RNA-positive); such a person is infectious to others. “HCV-negative” refers to people without chronic infection (that is, antibody-negative and RNA-negative, or antibody-positive and RNA-negative); such a person is not infectious to others. “Exposure” refers to an exposure to HCV which did not result in chronic infection (antibody-positive and RNA-negative). “Seroconversion” refers to exposure to HCV which did result in HCV chronic infection (antibody-positive and RNA-positive). We use the term “sero-change” as a catchall to describe any change in HCV-status reported by participants.

Table 1
Participant accounts of sero-change.

^a Seth34pos/Suzie46pos (2 yrs.) 1 seroconversion	Initially positive seroconcordant (i.e. at relationship outset). Seth reported subsequently contracting an additional genotype (1a) via Suzie.
Janine48neg/Jim61pos (15 yrs.) 1 seroconversion + post-pregnancy clearance	Initially serodiscordant. Janine reported subsequent seroconversion following accidentally sharing a needle-syringe with Jim. She reported clearing the virus following the birth of their child three years later.
Fran29pos/Fred29pos (8 yrs.) 1 seroconversion or “clinical mistake” 1 seroconversion	Initially negative seroconcordant. Fred reported a previous HCV-positive diagnosis but a “negative” result at the start of the relationship. Believed his HCV had subsequently either “come back” or that the clinician had been mistaken regarding his earlier “negative” result. Fran reported contracting HCV after the relationship commenced, via Fred.
Debbie33pos/Dan33pos (14 yrs.) 1 seroconversion	Initially serodiscordant. Debbie reported subsequently contracting HCV via Dan and remaining HCV-positive. Dan agreed he “gave it” to Debbie but believed she had subsequently cleared her infection.
Keith40pos/Karen32neg (8 yrs.) 2 exposures + spontaneous clearance 1 seroconversion	Initially positive seroconcordant. Both claimed to have been HCV-positive twice. Karen: “I had hep C and then it went away and come back and now it’s gone”; Keith: “I’ve got rid of it and got it again . . . I feel stupid”. Although unclear, it seems Keith’s latest infection was acquired during his relationship with Karen but not via her. Karen reported she had been exposed to the virus twice during the relationship (at least once via Keith) but is now HCV-negative. Keith, however, believes they are <i>both</i> still HCV-positive. Accounts suggest Karen began injecting drug use after the relationship began.
Terry37neg/Tegan38pos (6 yrs.) 1 seroconversion	Initially negative seroconcordant. Tegan reported subsequently contracting HCV via Terry <i>except</i> he reports always being HCV-negative.
Jenn31pos/Jimmy32pos (6 yrs.) 1 seroconversion or “clinical mistake” 1 seroconversion	Initially negative seroconcordant. Both reported being diagnosed HCV-positive after beginning relationship: Jenn for the first time; Jimmy for the second. Jimmy reported receiving a “positive” diagnosis years earlier before later being told by a clinician that he had cleared the infection. Suggested he then “got it again” after he started injecting with Jenn. Jenn, however, believed Jimmy’s doctor had made a mistake and that Jimmy had not cleared his initial infection. Jenn reported contracting HCV since meeting Jimmy but was unclear about source of transmission.
Ava33neg/Alan48pos (1 yr.) 1 exposure + spontaneous clearance	Initially serodiscordant. Ava reported acute HCV symptoms after relationship began but subsequently cleared infection. She recalled sharing spoons/filters with Alan but suspected transmission had been via “this couple I used to share it with . . . a lot of times”. Alan reported he had been HCV-positive for 20 years; believed Ava was <i>still</i> HCV-positive.
Les55pos/Libby26neg (1 yr.) 1 seroconversion	Initially negative seroconcordant. Les reported commencing injecting drug use two years previously; shocked by HCV-positive diagnosis.
Charlie34neg/Crissy30neg (10 yrs.) 1 exposure + spontaneous clearance	Initially negative seroconcordant. Crissy reported subsequently contracting HCV before spontaneously clearing; perplexed by circumstances of exposure.
Tanya23pos/Tim39neg (9 yrs.) 1 seroconversion 2 exposures + spontaneous clearance	Initially negative seroconcordant. Tanya reported subsequently contracting HCV while pregnant via a non-drug related blood exposure. Tim reported two HCV exposures and spontaneous clearance; vague about timeframes and details for both but did not link either directly to Tanya.
Shelly34pos/Steve33neg (8 yrs.) 2 seroconversions 1 clearance following treatment	Initially negative seroconcordant. Shelley introduced Steve to injecting drug use. Both reported HCV-negative results following tests at start of the relationship. Shelley refused to show Steve her results but insisted it was “negative”. Both reported subsequently seroconverting; speculation from about transmission source included: contaminated “street deal” and ex-partners. Steve later successfully completed treatment.
Mindy39pos/Mac35neg (10mths) 1 clearance following treatment	Initially positive seroconcordant. Mac reported successfully completing treatment during the relationship.
Cameron39neg/Camila39neg (9 yrs.) 1 spontaneous clearance	Initially serodiscordant. Camila diagnosed HCV-positive prior to relationship. Although later tests indicated Camila had cleared it, both she and Cameron believed her to be “positive” (i.e. infectious) at the start of the relationship.

^a Couples identified by participant pseudonym; age; HCV status (by self-report at time of interview); and length of relationship.

3. Results

The 28 participants ranged in age from 23 to 61 years; their relationships varied in duration from 10 months to 15 years. Twelve participants identified as ‘Anglo-Australian’ or ‘Anglo-New Zealander’, nine as Aboriginal and Torres Strait Islander, and the remainder as Australian-Armenian ($n=2$), Greek-Italian ($n=2$), Hungarian ($n=1$), Scandinavian ($n=1$) and Indian ($n=1$). Three quarters of participants ($n=21$) received some form of social welfare, five worked full-time ($n=3$) or part-time ($n=2$), one was dependent on his partner’s income and one declined to answer. Based on self-reported status at the time of interview, two couples identified themselves as HCV-negative, four couples as HCV-positive, and the remaining eight as serodiscordant. The

couples reported a total of thirteen seroconversions (including two instances alternatively described as “clinical mistakes”), eight exposures-plus-spontaneous-clearances and two successful treatment outcomes.

This section explores participants’ accounts of sero-change via three themes identified in the data: negotiating new diagnoses and accommodating chronic infections; status confusion; and the prioritisation of partnership.

3.1. Sero-change: new diagnoses and chronic infections

While participants’ accounts of negotiating a new diagnosis within the context of intimate partnership varied markedly according to the relational, social and viral specificities of their situation –

including stated beliefs regarding the source of transmission – they invariably shared an overarching concern for the effect it might have on their relationship.

“It’s almost like having to tell your partner you’re pregnant or something, it’s really fucking scary . . . it tests your relationship, it really does.”

“I hate it, I was so ashamed, and I didn’t tell [partner Dan] that I had caught it off him for, say, like 13 months . . .”

“I didn’t contract genotype 3 until a lot later in life. I was only diagnosed with that in the last 18 months . . . It’s most probable that I got it from [Suzie] . . . I’m very happy and lucky in the sense that I’m glad that she hasn’t got my genotype 1, which seems to be a bit more problematic at times for people.”

Crissy recalled feeling bewildered by her diagnosis, stating she had “never shared or used someone else’s needles.” Nonetheless, these feelings were ultimately secondary to her fear of transmitting the virus to her partner in the period before her spontaneous clearance was identified: “the guilt would just kill me.” For Debbie, her reluctance to tell her partner Dan was bound up with feelings of shame but also her desire to protect him from similarly uncomfortable emotions: “I didn’t want him to blame himself and feel bad, because it wasn’t his fault that he got it either.” However, for Seth (already living with genotype 1), “It was kinda just like acceptance. I was more concerned when the results were coming back that ‘please don’t let [Suzie] get what I’ve got.’”

Participants reported a range of emotional, discursive, and practical concerns and accommodations to living with long-term sero-change within their partnerships. Beyond a shared expression of concern among parenting participants about preventing household transmission to children, these accounts were diverse. For Fran, who reported seroconverting via her partner Fred and initially feeling “devastated”, living with HCV “actually hasn’t been like a big thing.” Fred reported that his one concern was “that I don’t want her to feel angry if she feels I gave it to her.” Partners Debbie and Dan adopted a strategy of relative “sero-silence” (Persson, 2008) in what appeared to be a mutual (if unspoken) effort to normalise their relationship in the face of internalised stigma and shame. For Jenn and Jimmy, who both reported seroconverting whilst together but expressed uncertainty about the source of transmission, their confusion emerged from time to time in moments of tension within their relationship.

“It’s a hard thing to talk about . . . you try and keep it as low as possible. We’ve had a few talks about it, but not as much as we should.”

“A little bit of ‘who gave it to who?’ . . . The occasional ‘well you gave me hep C!’ And it can be used against you, and when you don’t know where it comes from that doesn’t help either, because you don’t want either party to have it.”

3.2. Status confusion

Also commonplace (and evidenced in participants’ excerpts above) was uncertainty and confusion regarding HCV-status and/or the circumstances of transmission. Both Camila and Crissy, for example, were perplexed by their diagnoses. For Crissy and her partner Charlie, the distress caused by both the diagnosis itself, and the uncertainty of the circumstances surrounding transmission, seemed to be unnecessarily compounded by a delay Crissy experienced in receiving a follow-up PCR³ test.

“They said it was a blood-borne thing, but I was so careful . . . like I never used anybody’s [injecting equipment], so how did their blood connect to my blood?”

“It’s something that I’ve really thought about because, like I said, I’ve never shared a needle . . . Charlie hasn’t got it and I haven’t used his needles. So, it was a real mystery to me . . . Something I really, really ponder and pondered with Charlie as well . . . My doctor was more of a sports doctor . . . I hassled him and hassled him and hassled him for a year and a half to do the PCR test. Turned out I cleared it myself, so for a year and a half . . . That was a really horrible part of my life.”

A number of participants reported that clinical “mistakes” or “misunderstandings” were the source of their confusion about status. For others, understanding the circumstances of transmission, or simply their current status, was complicated by a complex chronology of events: of previous relationships ending and new ones beginning, HCV testing window periods and so on.

“At the start [of our relationship] I went and got blood tests, and the doctor did a mistake: he told me I was clean and then I went back a couple of months later and said, ‘are you sure?’ And when he checked I had hep C . . .”

“When I met him [partner Jimmy], he thought he didn’t have it . . . The doctor actually made a mistake . . . I think he did actually have it [and] the doctor got it mixed up.”

“I don’t know if [HCV] was from my old partner . . . I had a test done [at the beginning of current relationship] and it was clear, but then sometimes they say it can take up to 6 months to show up in the test.”

In addition to HCV-related confusion and uncertainty among participants, there were several sets of partners whose respective accounts of status appeared to be in clear contradiction. Debbie believed she was still living with a chronic infection, while her partner Dan expressed the conviction that she had cleared it. Karen and Keith both reported seroconverting twice, yet Karen also reported clearing her infections on *both* occasions; Keith, however, believed that she, like himself, was still HCV-positive. Tegan and Terry’s accounts provided another permutation: while Tegan was adamant she had contracted HCV via Terry, Terry himself reported *never* having been HCV-positive. While Tegan agreed that Terry was no longer HCV-positive, she argued that he had either “secretly” undergone treatment in prison or had spontaneously cleared it.

3.3. Prioritising partnership

Accompanying participants’ diverse, sometimes contradictory, accounts of negotiating HCV within their relationships was an important series of statements in which the centrality of the partnership, and its priority over HCV-related concerns, was articulated. Libby’s response to her partner’s diagnosis (from an unknown source) captures the essence of this commitment: “Well, I just said to him, ‘don’t think I’m going to leave you over it or anything like that’, because I didn’t want him to worry” (Libby26neg.; Les55pos., 1 year). Similarly, Debbie reported insisting to her partner that, despite his responsibility for her contracting HCV, “I’m always going to be with you, so don’t worry!” For Janine, the “good responsibility” her partner Jim had consistently demonstrated around the management of his HCV helped consolidate their relationship, making her feel cared for and “valued” (Janine48neg. following spontaneous

³ A PCR test can detect infectious agents *directly*, as opposed to antibodies which are produced in *response* to infection (Dore, 2009). Approximately 25% of people

exposed to HCV do not go on to develop chronic infections but will nonetheless remain “antibody-positive”. A PCR test should therefore be included as part of a complete virological assessment in order to avoid confusion.

clearance; Jim61 pos., 15 years). Her suggestion that HCV-positive partners can demonstrate their love and support by making sure that they “deal with it” was reiterated by a number of participants. As Libby (cited above) went on to explain: while she did not want Les to worry, “I wanted him to learn about [HCV].” This complex interplay of intimacy, partnership and status is insightfully captured by Janine in an observation about sero-discordant relationships: “Sometimes you [the ‘negative partner’] can show your love by showing them that it’s not important, but they [the ‘positive partner’] show their love by saying that it is important.”

In addition to these observations, a number of participants framed their experiences of sero-change within broader narratives of personal and relational transformation: HCV came to mean something different to them over time. For Jimmy, attending to his and his partner’s HCV had become a priority:

“Once we’ve lost [HCV], I would not do it again to a person and I would not like to get it back. Because it was clumsiness from the addiction – you don’t care about it – but now we’re down this stage of the track, it is the first thing on the mind.”

While for Suzie, her relationship with Seth catalysed a change in her knowledge and attitude towards HCV:

“[Seth] actually educated me on it . . . About the genotypes and the interferon and everything. He’s very knowledgeable in that area; more so than me . . . Now I’ve got to do 6 months of interferon to correct my carelessness in the past.”

While some participants acquired or sought greater biomedical understanding as a means of coming to terms with sero-change, others employed explanatory frameworks that sat firmly outside conventional biomedical discourse. Drawing on a number of alternative logics or “rationalities”, these participants were primarily concerned with limiting the potential *social* and *relational* damage associated with contracting HCV. The virus itself *meant* something different when transmitted within the partnership rather than outside it. Jenn, for example, explained the difference between Jimmy’s experience of contracting HCV via a friend’s “betrayal” and, years later, their experience together when she seroconverted. Fred too, accommodated (“rationalised”) Fran’s seroconversion within a narrative of romantic intimacy.

“He’s just never gotten over it, of course not . . . Whereas what happened with us [seroconversion] was an accident . . . It’s very different from a friendship to a relationship . . . in a relationship, you love each other, you don’t want to harm each other. That’s the way I look at it.”

“Most likely I gave [HCV] to [Fran], because we share utensils but . . . it’s only with one partner, it’s not like I share it with everyone. And because we’re soul mates for life, it doesn’t really matter . . .”

Tim and Karen similarly articulated socially and relationally situated rationalities, constructing a hierarchy of equipment sharing based on a logic of *social* rather than *sero* status. While Tim, like Jenn and Fred, referenced Western tropes of romantic love in order to differentiate between sharing equipment with a friend and a partner, Karen drew on notions of kinship to extend the intimacy, and thus the acceptability, of sharing to include family members.

“I usually let her [inject] first, even though she’s the one who’s got hep C . . . To me she’s still my lady and she goes first no matter what . . . We’ve both got each other’s best interests at heart. Now my mate, we could be mates for years [but] the main thing in his head though is not going to be ‘Oh fuck, I hope he doesn’t get sick or anything’, you see where I’m going? So there’s that

emotional connection with [a partner] as well as just the fact we’re friends or we use together.”

“I don’t really use [injecting equipment] after anyone. Only like my partner or my sister or my real close cousin. Because they’re family. Like with my sister, we got the same blood.”

4. Discussion

In this article we have focussed on participants’ accounts of changing HCV-status within the context of their intimate partnerships. While some couples sought greater biomedical understanding as a means of coming to terms with sero-change, others drew on alternative rationalities that sat firmly outside conventional biomedical discourse. Regardless of which explanatory framework they drew on, participants ultimately prioritised the security of their relationship over the dangers of viral infection. The intimate partnerships of PWID may function as forms of social care and protection in relation to typically hostile social environments and structural vulnerability (Seear et al., 2012). As Rhodes and Cusick (2000) suggest, “efforts to protect intimacy and relationships from risk may be particularly important in lives perceived to be particularly insecure or continually under threat” (p.4). Among people who are socially excluded, including many who inject drugs, meaningful intimate relationships may provide one of the few forms of social capital available to them (Stevenson and Neale, 2012). We need to recognise then, that within such partnerships the negotiation of risk is as much an enactment of emotional intimacy as of reasoned action: that ensuring the ongoing maintenance of the relationship is itself a form of risk management (Rhodes and Quirk, 1998). As our findings suggest, participants frequently prioritised the security – the ‘emotional refuge’ (Syvertsen et al., 2013) – of intimate partnership over competing concerns, including those of viral safety.

Enacting effective prevention and care, we argue, requires moving beyond the employment of narrowly-defined, individual-level psychological models of behaviour – beyond simple injunctions to take “individual responsibility” (Fraser, 2004) – to acknowledge the often complex interpersonal, social and structural imperatives governing intimate (and other) relationships among PWID. We need to better acknowledge and work with the competing priorities and complex realities of such partnerships beyond simply the identification of viral risk. We need to recognise that, as Hepworth and Krug (1999) argue, “While medical and psychological knowledge are necessary and relevant in the case of HCV, they are not the sole basis, nor necessarily the primary basis, on which individuals act” (p. 245).

We recognise that this study was designed in ways that could affect the findings. We have drawn on couples that reported changes in HCV-status whilst remaining together. Consequently there was less likelihood of attracting accounts from couples for whom the pressure of status change contributed to the end of their relationship. More broadly, recruitment required self-selection and participation from both partners. This too may have shaped the dataset and the kinds of partnerships studied; it could have, for example, reduced the likelihood of making contact with couples affected by inter-partner violence and abuse. While we noted a general absence of gendered inequity within our dataset (only two female participants provided explicit accounts of diminished power and agency within their relationship) we cannot be sure that such experiences were not more widespread.

Participants were adept at accommodating changes to status within the lived contexts of their private lives and relationships. For our participants, the meaning of risk and safety was multiple, socially and relationally situated, rather than singular, fixed and pre-determined. Even serodiscordance itself was perceived

in diverse and unexpected ways, encompassing a range of meanings and practices among participants (Persson, 2013). This is perhaps not surprising, given that, as others have argued (Fraser and Seear, 2011; Hepworth and Krug, 1999), the meanings of diagnosis and living HCV are “embedded” within the social and cultural dimensions of everyday life and relationships. Participant accounts of status confusion and contradiction, of doctor’s mistakes and lay (mis)understandings, need to be balanced against the limitations of conventional biomedical approaches to HCV education and care. Social researchers have consistently described the disconnection reported between people’s lived experience of HCV and biomedical concerns focussed solely on the physical body (Harris, 2005; Krug, 1995; Sutton and Treloar, 2007). As Rhodes and Treloar (2008) argue, biomedical responses can be “at extreme odds with the situated and competing priorities of people who inject drugs” (p. 1330). Nonetheless, our results do suggest the need to continually engage those who inject drugs, in both HCV testing and in improving the systems by which these tests and resultant information are provided. With the “new era” of direct acting antiviral treatments promising to profoundly change what it means to acquire and live with HCV, opportunities will arise to learn to integrate biomedical information within more socially sophisticated, relationally aware approaches.

Conflict of interest

None declared.

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Contributors

Jake Rance conducted the interviews in Sydney, while Suzanne Fraser and research assistant Caroline Hart conducted those in Melbourne. Jake Rance and Carla Treloar developed the coding frame. Jake Rance reviewed and coded the transcribed interviews. Jake Rance wrote the manuscript and all co-authors provided substantive feedback and final approval.

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