

Research Paper

Peer to peer communication about hepatitis C treatment amongst people who inject drugs: A longitudinal qualitative study



Stelliana Goutzamanis^{a,b,*}, Joseph S Doyle^{a,c}, Danielle Horyniak^{a,b,d}, Peter Higgs^{a,e,1}, Margaret Hellard^{a,b,c,1}, on behalf of the TAP study group

^a Disease Elimination Program, Burnet Institute, 85 Commercial Rd, Melbourne, VIC, SA, 3004

^b School of Public Health and Preventive Medicine, Monash University, 553 St Kilda Rd, Melbourne VIC 3004

^c Department of Infectious Diseases, The Alfred and Monash University, 85 Commercial Rd, Melbourne, Victoria, SA, 3004

^d Behaviour and Health Risks Program, Burnet Institute, 85 Commercial Rd, Melbourne, Victoria, SA, 3004

^e Department of Public Health, La Trobe University, Plenty Rd & Kingsbury Dr, Bundoora VIC 3086

ARTICLE INFO

Keywords:

Hepatitis c virus
Direct-acting antiviral treatment
Peer communication
People who inject drugs
Longitudinal qualitative research

ABSTRACT

Background: Little is known about how information on direct-acting antiviral treatment for hepatitis C circulates through peer networks of people who inject drugs. In this study we aimed to explore what and how treatment-related information is shared between people undergoing treatment and their peers.

Methods: Participants were recruited from two general practice clinics and the community-based hepatitis C Treatment and Prevention Study. Semi-structured interviews were conducted with each participant ($N = 20$) before, during and following treatment. Interviews explored hepatitis C treatment experiences, key sources of DAA information and the impact of receiving and sharing knowledge. Inductive thematic analysis was conducted. Time sequential matrices were generated to understand thematic change over time.

Results: Fifty-four interviews were conducted with 20 participants across seven field-sites in Melbourne, Australia. Key themes were: 'peers as a source treatment information', 'do it together' and 'becoming a treatment advocate'. Peers were a crucial trusted source of information. Positive treatment anecdotes were important for building confidence in and motivation to initiate treatment. Many participants adopted a 'treatment advocate' role in their close peer networks, which was described as empowering. Some participants described benefits of undertaking treatment alongside members of their close network.

Conclusion: Findings illustrate the importance of close peers in shaping treatment perceptions and engagement. This will be important in designing health promotion messaging and interventions to increase treatment uptake.

Introduction

The advent of direct-acting antiviral (DAA) therapies for hepatitis C virus has brought with it the promise of eliminating hepatitis C as a public health threat (Razavi, Sanchez Gonzalez, Yuen & Cornberg, 2020; World Health Organization, 2016). Compared to previous interferon-based treatments, DAAs are simple, short and remarkably efficacious (Millman, Nelson, & Vellozzi, 2017). In Australia, treatment is available to all people with chronic infection, including people who inject drugs, in both tertiary and primary care settings, from various prescribers and at a heavily government-subsidised price (The Pharmaceutical Benefits Scheme, 2020a; Thompson, 2016). Nevertheless, without increased testing and treatment uptake Australia will not meet the World Health Or-

ganization elimination targets (Doyle et al., 2019; Scott et al., 2019). To do so will require engaging and working with people who inject drugs to create acceptable health promotion and novel interventions to enhance treatment uptake.

The availability of DAAs has incited renewed interest in expanding and investing in initiatives driven by trained peers with a lived experience of hepatitis C and/or injecting drug use (Henderson, Madden & Kellsall, 2017). Initiatives to date have centred on peers providing emotional and logistical support (Aitken, Kerger, & Crofts, 2002; Grebely, 2010; Keats et al., 2015; Norman, 2008) or information and mentorship to people living with hepatitis C (Arain et al., 2016; Batchelder et al., 2017; Kikvidze et al., 2018; Staggs et al., 2019; Sulkowski et al., 2017). Existing evidence suggests peer-led programs are acceptable and effec-

* Corresponding author.

E-mail address: stelliana.goutzamanis@burnet.edu.au (S. Goutzamanis).

¹ These authors share senior authorship

tive (Batchelder et al., 2017; Kikvidze et al., 2018; Meyer et al., 2015; Norman, 2008; Stagg et al., 2019). Participants of peer-led programs have described formal peers as highly trusted, non-stigmatising, with the capacity to ease uncertainty, normalise experiences and offer support that clinicians are unable to (Batchelder et al., 2017; Norman, 2008). However, the relationships between formal peers and clients may be pre-determined rather than flexible and emergent (Bonnington & Harris, 2017). An individual's interactions with formally employed peers will differ from natural peer relationships.

Whilst the role of formally trained peers has been widely explored (Batchelder et al., 2017; Bonnington & Harris, 2017), health communication between peers within existing networks has received scant attention, particularly in relation to hepatitis C and treatment. Individual injecting drug use behaviours are embedded within and influenced by diverse social settings (Moore, 1993). The social context of drug use includes the immediate physical and social setting in which use occurs, but also the wider beliefs and values of social groups. These dynamic and fluid groups or networks are where people come together to interact meaningfully and create cultural understandings around drug use (Moore, 1993). Risk behaviours (Galea & Vlahov, 2002), drug overdose experience (Green et al., 2009), injecting drug use initiation (Guise, Horyniak, Melo, McNeil & Werb, 2017) and hepatitis C treatment seeking and prioritisation (Harris et al., 2018) are all in part, socially contingent. Social relationships also shape the way people who inject drugs conceptualise, communicate about and act upon hepatitis C prevention (Fraser, Treloar, Bryant & Rhodes, 2014). Hepatitis C prevention messaging and interventions often fail to consider or mobilise the membership of people who inject drugs in social groups (Fraser et al., 2014; Moore, 1993). There is a need to explore the social experience of DAA treatments, including communication within peer groups.

Health related peer to peer communication has been explored in fields of oncology (Ancker et al., 2009) and HIV (Veinot, 2010). One seminal qualitative study involved in-depth interviews with 34 people living with HIV in rural regions of Canada (Veinot, 2010). The authors reported that peer to peer information exchange was highly valued and resulted in positive emotions (Veinot, 2010). Participants shared and received disease management strategies, personal stories and importantly, experiential information. Experiential information is wisdom and knowledge developed through processed personal or collective experience (Castro, Van Regenmortel, Sermeus, & Vanhaecht, 2019, p. 318). It is possible a similar process of developing and sharing experiential information about hepatitis C and treatment occurs within peer networks of people who inject drugs.

Drawing from longitudinal qualitative data examining the experience of undertaking treatment, this article aims to explore what and how treatment-related information is received and shared between people who inject drugs undergoing hepatitis C treatment and their peers.

Methods

Study design

This study utilised a longitudinal qualitative research approach (Saldaña, 2003), as we believe that people's perceptions of health can change over time and retrospective accounts of treatment may differ from real-time representations (Grossoehme & Lipstein, 2016). We used longitudinal methods to explicitly capture important micro-social processes and personal transitions relating to the treatment experience.

Eligibility and sampling

Eligible participants were 18 years old or above, reported a history of injecting drug use, living with hepatitis C at the time of recruitment and about to begin treatment (had received a script or consultation for DAA treatment). Participants were recruited from two settings in order to recruit both research-involved and naive participants and collect data

from participants with diverse experiences of living with hepatitis C. Recruitment sources were: 1) the Treatment and Prevention (TAP) Study and 2) two large community health clinics in Melbourne, Australia. The TAP study is a nurse-led community-based hepatitis C treatment trial (Doyle et al., 2019). Eligible participants for the TAP Study had chronic hepatitis C mono-infection and had injected drugs with others in the past six months. TAP Study participants were recruited through an existing cohort study of people who inject drugs and 'snowballing'. Primary TAP participants recruited up to three members of their injecting network as secondary TAP participants and were incentivised AUD20 for doing so. TAP participants were ideal candidates to explore peer to peer communication with as they had active injecting networks, and many were undergoing treatment alongside members of their injecting network. TAP participants received DAA treatment at no cost. Community health clinic participants received treatment at a heavily subsidised cost, less than AUD7 per script for concession card holders (Hepatitis Victoria, 2016; The Pharmaceutical Benefits Scheme, 2020b). Both the community health clinics were in the same region of Melbourne, offered opioid substitution therapy (OST) prescription, and one was co-located with a needle and syringe program (NSP). Eligible participants were informed of the study opportunity by TAP research staff or a general practitioner, who worked at both clinics. Sampling was opportunistic. Participants were unknown to the interviewer prior to the first interview. Many participants were engaged with or aware of past or ongoing studies conducted by the authors' research institute.

Data collection

Data collection occurred between September 2017 and July 2019. Semi-structured interviews were conducted with each participant before, half-way through and following treatment. All interviews were conducted by the first author (SG) except for two interviews which were conducted by the first (SG) and senior author (PH) to review interviewing practice. Interviews focussed on the experience of undertaking and completing treatment. The interview guide was loosely informed by discussion amongst co-authors, existing literature on the hepatitis C treatment experience and a conceptualisation of health-related quality of life amongst people living with hepatitis C (Mhatre & Sangsiri, 2016). Topics included treatment motivations, perceptions and meanings, as well as relationships and networks, treatment knowledge and information sources and domains of quality of life (physical, psychological/emotional, social, work and cognition). Interviews were informal and flexible, largely driven by the participants' narratives and emerging concepts. All interviews began with the prompt; "So how's your week going?" to allow participants to discuss issues that were important to them, be it hepatitis C related or not. The subsequent question in the during-treatment and post-treatment interviews was; "has anything changed for you since last time we spoke?" Most topics were consistent across all interviews. For example; "what kinds of things have you told people about starting/being on/finishing treatment?" Topics relating to hepatitis C history, diagnosis experience, pathway to treatment initiation and sources of treatment information were exclusive to the first interview. Interviews lasted approximately 40 min (range: 17 min - 70 min) and were recorded with a handheld digital voice recorder. Basic demographics: age, sex, education status, employment status, country of birth, injecting status and fibrosis status (if known) were collected immediately before the first interview for participants recruited from health clinics. This information was available for participants recruited from the TAP Study as part of their TAP Study screening survey.

Interviews occurred across seven metropolitan Melbourne sites. Interviews were conducted in convenient locations for the participants, including community health centres, needle and syringe programs, parked cars, a mobile clinical trial van, the Burnet Institute meeting rooms, cafes and in quiet outdoor spaces. Interviews were generally prior to, or following health service or clinical study appointments, which was convenient for participants but at times limited interview duration. A reflexive

journal documented rationale for methodological decisions, researcher beliefs, assumptions and reflections on interviews. Reflexive dialogue between co-authors took place following interviews.

Analysis

Thematic analysis (Braun & Clarke, 2006) was performed, followed by a longitudinal trajectory analysis to explore how themes changed over time (Grosssoehme & Lipstein, 2016).

Thematic analysis was performed as per Braun & Clarke's, 2006 six phase analysis approach. Firstly, interviews were transcribed verbatim following each interview by the first author (SG) using Microsoft Word and Windows Media Player. Identifying information (names, locations and occupations) was removed. Participants were given pseudonyms. Transcripts were read and re-read, checking for accuracy and noting initial thoughts. Each participants' transcripts were revisited and read prior to their next interview so participants could be asked about specific topics they had mentioned in previous interviews. Transcripts were uploaded to NVivo (version 12, QSR International, Australia) for initial coding. Open coding began once all interviews had been conducted. Interviews were coded by time point (all pre-treatment interviews were coded before moving onto the during-treatment interviews and finally post-treatment interviews). Coding was inductive and conducted by the first author (SG). Codes were summative words or phrases (e.g. "treatment information from NSP"). The third phase of analysis involved collating similar and connected codes into broader themes representing patterns of shared meaning. Themes were then reviewed and refined by the first (SG) and senior (PH) authors, clearly named and defined and a thematic map produced. Analysis was also informed by frequent discussion between co-authors around recurrent themes, interrelation of themes and disconfirming cases. Final themes were also discussed with independent fieldworkers who regularly work with people who inject drugs in and around the study field sites.

Once all transcripts had been thematically analysed, longitudinal analysis commenced. This process of analysis was guided by Saldaña's (2003) 16 questions for longitudinal qualitative data, including "which changes interrelate through time?" Data were organised into time-ordered sequential matrices. A matrix was created for each participant and then summarised in a matrix for the entire cohort. Matrices were tables describing how the theme appeared at each time point and elements that changed or remained the same. Not all themes were longitudinal in nature. Only themes that occurred across multiple time points were subject to longitudinal analysis ('do it together' and 'becoming a treatment advocate'). Thematic descriptions in this manuscript include language and quotes from all participants.

This article explores communication between participants and their "peers" within peer-networks. Participants also refer to "associates". Based on participant narratives, tone, field notes and observations, for this manuscript we have interpreted close peers as individuals participants spend time with socially, consider a friend, have a shared history of injecting drug use with but may or may not currently be an injecting partner. A peer network was described by participants as: "a circle of close friends who use drugs and all the rest of it". "Associates" were distinguished from peers as they were not considered close friends, but rather acquaintances who were involved in a similar social scene often in the same area. However, we did not explicitly ask participants to map their close networks or provide their own definition of a peer.

Ethical considerations

Participants provided written informed consent prior to the first interview, and additional verbal consent for subsequent interviews. Participants were reimbursed AUD40 for their time following each interview. Participant contact information was securely stored separately to interview and demographic data. Ethics approval for this study was granted

by the Alfred Health (243/17) and Monash University Human Research Ethics Committees.

Results

Twenty participants were recruited (TAP Study: $n = 11$; Health clinics: $n = 9$) and 54 interviews were conducted (90% follow up rate). Fifteen participants were interviewed three times, four participants were interviewed twice and one participant only once. Contact was lost with three participants (two due to disconnected mobile phones and one due to not having a mobile phone). Two participants didn't complete all interviews as they moved to rural Victoria and were unable to commute to Melbourne for an interview. At baseline most participants were male ($n = 14$), born in Australia ($n = 14$) and had injected drugs in the past month ($n = 19$). Participant age ranged from 20 to 54 years old. Two participants were employed. Most participants had no to mild hepatic fibrosis (liver scarring) ($n = 11$), but several participants ($n = 5$) were unsure of their degree of fibrosis. Most ($n = 17$) participants were DAA and interferon treatment naïve at recruitment. Two participants had completed DAA treatment previously and become re-infected. One participant had previously completed treatment twice (pegylated interferon- α plus oral ribavirin and DAA treatment), but both treatment episodes were unsuccessful at curing infection. One participant was prescribed DAA treatment but spontaneously cleared the virus before beginning treatment.

This article reports on three themes: 'peers as a source of treatment information', 'do it together' and 'becoming a treatment advocate' (Fig. 1). The first theme is cross-sectional and related to the pre-treatment time point and the second and third are longitudinal. Only the third theme depicts a transformation throughout treatment. These themes were selected for this manuscript based on their novelty and relevance to the study aim. Themes relating to other sources of information (healthcare providers and media) were less pronounced and have been previously reported so were not included. Participants' emotional and physical experiences of treatment are described in a separate manuscript as it related to a second study aim.

Peers as a source of treatment information

This theme describes how participants received information from their peers, what information they received and their perception of their peers as a source of information. Participants mostly discussed this in the first, pre-treatment interview, in relation to decision-making about treatment.

Participants received treatment-related information from a range of sources, including health care providers, harm reduction services, media or through research involvement. Whilst a number of participants utilised multiple sources prior to treatment, the majority of participants relied most heavily or solely on their network of; peers, associates, or "other people who have hep C and have been around the block for quite some time". Participant network dynamics were complex and variable. The depth and impact of information participants received was influenced by how trusted and close the information source was.

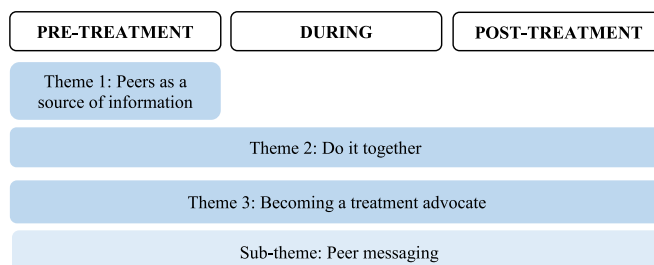


Fig. 1. Emergence of key themes and sub-themes across interviews.

The most periphery layer of participants' network was their local social injecting 'scene'. Participants described their broader injecting network as an extended community. Sharing knowledge via 'word of mouth' within this network was a social norm and so exposure to treatment information was ubiquitous and frequent. Participants did not have to intentionally seek information from peers to build their understanding of treatment. Some participants noted that treatment was brought up by others in passing which allowed them to receive information without disclosing their own hepatitis C status. However, this information was more superficial than information received from close peers. For most, it was part of day to day conversation in a social setting where injecting drug use, hepatitis C and by extension treatment were normalised.

Just from other people that use and shit...It's not uncommon for people to be like; 'oh I heard about this new medicine da da', 'oh yeah? Sounds cool'. That shit happens all the time. (Kiran, pre-treatment)

I've got a good friend that, he deals, like I sometimes hang around with him and you know you run into people you know and stuff and that's how you find out information. (Van, pre-treatment)

Three participants, all recruited from community health clinics (one who was no longer injecting and two who were attempting to stop using) felt they did not currently have a close peer injecting network. They acknowledged previously acquiring knowledge from peers but now relied mostly on harm reduction services and medical staff for treatment information.

Participant narratives highlighted the unique value of receiving information from close or distant peers. Peers were widely considered the most trusted, accessible and reliable source of information. Having a shared lived-experience and perceived social capital, with no agenda, validated peers as an information source.

Off the street, from peers and other people who have gone through treatment. That's all I've listened to; I haven't listened to anyone else. I don't believe the doctors, the doctors, all they want is to give you another prescription so they can get money... I reckon it's better to hear back from the horse's mouth rather than someone who is just promoting it and they don't care what they give you and they don't care how much they give you. So you're better off hearing it from a person that's done it, because then they know exactly. (Hans, pre-treatment)

Whilst information received from medical staff was considered technically accurate and expert by some, it was less accessible and immediate than peers or media sources.

I go to my doctor's or just off the internet or other services (pause) bits and pieces from everywhere. I think it's just the whole community in Melbourne, everyone learnt off a doctor or something like this and Chinese rumours just got better and better and better...I would rather trust a doctor but in-between the six months you ask a doctor a question and things like that you try and find out things from your friends. (Finn, pre-treatment)

Further, the "98% success rate", "one pill a day", "two to three months" messaging that almost every participant recited in their first interview was perceived as "textbook" information. This information wasn't given the same credence as when someone takes the time to explain treatment, particularly, someone who has experienced treatment.

Information shared in close-peer networks was more impactful than the in-passing information received from associates. The heightened level of trust and comfort in disclosing hepatitis C status meant participants could engage in dedicated and personal treatment discussions with close peers. Some participants even described instances of referral to care (being provided contact details of trusted general practitioners) or instances of close peers coordinating tangible assistance (being brought to a peers' treatment consultation).

A mate of mine, who, like I came with him just to get his methadone script and he must have seen [the health clinic nurse] and he comes round and she says; "do you want to do the hep C treatment?" and mate I couldn't say yes quick enough, so my mate had sort of said; "oh I've got a mate out here". So I was stocked, it just kind of fell into my lap, I didn't have to go anywhere or anything. (Simon, pre-treatment)

Overwhelmingly participants described their close peer network as a source of feedback and positive treatment anecdotes. Treatment anecdotes generally focussed on the ease of accessing and undertaking treatment, minimal side effects, effectiveness and personal treatment benefits.

People say it's just like taking antibiotics and you don't really feel a lot. (Miriam, pre-treatment)

[My friend] just said it's good, you know. It's pretty quick, it's easy to access you know. (Wesker, pre-treatment)

Hearing positive treatment stories helped participants feel comfortable, confident and motivated to initiate treatment. It was particularly important to ease uncertainty around side effects and contrast narratives of interferon treatment.

Yeah, everyone that has taken it has told me it has worked. 100% of them say. That's why I want to see. (Van, pre-treatment)

Yeah, the main thing for me was side effects and stuff. Because I had my mate with interferon, I thought; 'fuck this is going to do something crazy' and none of them said that they got any symptoms or like anything, so I just thought; 'oh mate, I want to do this'. (Simon, pre-treatment)

Watching someone in a similar position, particularly peers who were also still injecting drugs, successfully complete treatment was reassuring and built participants' confidence in their perceived treatment candidacy. Participants frequently expressed this sentiment through comparative statements such as; "he was fine so I figure I'm gonna be fine" and "if this bloke can do it, I'll be able to do it easy". Conversely, there were two accounts of negative treatment anecdotes, relating to experiencing side effects. One participant dismissed this, having received many positive anecdotes and for one participant this spurred uncertainty.

At the start, they said it made them a bit sick. So that's probably the scariest thing I reckon. (Gabriel, pre-treatment)

Interestingly, whilst in-passing information about treatment was ubiquitous in broader networks, most participants only knew of a handful of close peers who had completed treatment and who had shared anecdotes. Some participants suggested that in addition to the broad treatment-related information circulating through their social scene, people may want to see a close peer undertake treatment before initiating treatment themselves.

I suppose it's all over the drug industry, I've hung with a lot of users. Everyone's talking about the hep C program now. They talk about it and that's it, they don't go. I don't think I know anyone except my mate that's gone through with it, but everyone's talking about it and that's a start. Maybe once people see the benefits of a couple of people, they'll jump on it (pause) hopefully. (Cam, pre-treatment)

'Do it together'

This theme explores perceived benefits of undergoing treatment with peers. Several participants (six participants/three pairs) undertook treatment alongside their closest network member (siblings or intimate partners). This was partially facilitated by the 'bring your friends' TAP Study recruitment approach but was also seen amongst some participants recruited from community health clinics. This theme developed strongly during the pre-treatment and during-treatment interviews.

A few participants reported doing treatment together for emotional support, to reduce risk of transmission or because it was easier to coordinate. Doing treatment at the same time was seen as an effective way of ensuring hepatitis C is “out of our house” and for intimate partners the beginning of a new phase of their life together.

If my partner cleans up through the treatment, it would be no good me having it you know, that would be a bad thing... It's sort of umm you know very selfish. (Theo, pre-treatment)

One participant hoped undertaking treatment together would also change the social experience of drug use, where hepatitis C related worry would no longer be present.

Yeah, because then at least we get it done at the same time and everything is sweet. So start at the same time, finish at the same time and clear it, we won't have to worry about it. (Hugo, pre-treatment)

All participants doing treatment with a close peer described enhanced knowledge and awareness. Undergoing treatment concurrently was a way of pooling and sharing information to feel more prepared for and in control of treatment. It also helped validate and reassure participants about their treatment experiences.

Just so you can feed off each other's information. Like if [they are] not going through the same side effects as you, you can find out if it's wrong, like if something is adverse, you know? Like you never know, you could have an adverse allergic reaction to anything. So it's always good to have someone doing the exact same thing as you, to mirror your own experience, make sure you are going through the same, similar steps and it's not working differently for you or the other person. (Hans, pre-treatment)

Perceiving treatment as a collective effort introduced a level of accountability and control. Before treatment participants had hoped it would be a way to motivate and hold each other accountable, which was evident during treatment.

For example me and my brother do it together so if I forget about it that day he'll remember and *vice versa* and yeah it's good like that. (Alex, pre-treatment)

Oh it's good with stuff like this, where um, we usually come together to pick up the pills and stuff like that...not so much reminded me to take my pills but more like to come and get the new pills. (Alex, during treatment)

Participants who undertook treatment with a close injecting partner indicated that this had implications or expectations regarding drug use post-treatment. As close injecting partners were seen as a risk for reinfection, there seemed to be an implied expectation and trust within partnerships that following treatment they would avoid reinfection. After undertaking treatment with his brother, Van spoke of the impact of discovering that his brother's intimate and injecting partner had just been diagnosed with hepatitis C:

For example, me and my brother, being in the same circle, it's no good...because lately I'm trying to push away but he has his girlfriend as well and is in it. I don't like that...I don't use with anyone anymore, I don't trust anyone, I have my own cap, if I'm gonna do it I do it on my own, the only person I trust is my own brother and that's gotta stop too. (Van, post treatment)

Becoming a 'treatment advocate'

Throughout treatment there was a shift in participants' position within their network in relation to DAA knowledge sharing. In the pre-treatment interview participants were in a position of knowledge acquisition, but increasingly throughout and following treatment almost all participants began disseminating DAA information within their close

network, adopting a role described as a “treatment advocate”, “ambassador” or “role modelling”. This transformation is one of reciprocity, where participants receive information from their peers that help them comfortably initiate treatment, information is then integrated with their own experience during treatment and following treatment this experiential information is passed onto peers with the hope of others initiating treatment. Zara's descriptions of treatment-related conversations with her close peers prior to, compared to following treatment illustrate this evolution:

I've asked questions because I've been interested in whether it works or not (pause) I said; 'how was the treatment?', 'how did you feel?', 'did you get rid of it?' 'Do you still feel tired like you used to?', and yeah 'any side effects and that?' (Zara, pre-treatment)

I tell them the same thing; 'it's good, you'll have more energy, you know what I mean, in your daily life' ...I'd go; 'see the doctor and ask the doctor if they have that hep C treatment and get referred to the hep C specialist and then you'll do the test and then he'll see where you're at and then he'll write you out a script!' (Zara, post-treatment)

Whilst many participants began sharing information during treatment, participants more readily and confidently recommended treatment after completion and cure. This was rooted in participants' desire to provide their peers with honest and accurate “intel” and opinions on whether treatment was worthwhile.

I would just say; 'it's just a pill a day, it feels like nothing, and hopefully it works'- now, at this present moment. If I were to be successful then that's a different story. I would be more enthusiastic about it. I would say; 'get on it straight away, go to your GP, get a referral blah, you know, just get it over and done with, it works'. (Kai, during treatment)

Participants' experiences with sharing information were not universally positive. Several participants found associates and acquaintances were not interested or were dismissive of their treatment opinions. In these situations, participants perceived their associates as already having opinions and knowledge on treatment, which they did not want challenged by someone who wasn't a close peer. Participants were more comfortable being an advocate within close networks, where efforts were more effective. Seeing peers change their perceptions of or in a couple of circumstances, initiate treatment felt;

...empowering, yeah empowering to tell someone something positive and if I see him go do it that will give me more boost. (Cam, post-treatment)

Some participants shared treatment information naturally out of social norm or obligation. However, most participants were seemingly driven by a service ethic, where they felt something good had been done to them in receiving DAA treatment and wanted their friends and the broader population to benefit from this too. Participants felt they were doing a kind deed by going “that extra bit further” to help close peers understand or initiate treatment. Some participants were motivated by their own understanding of “treatment as prevention”, where one participant noted: “if one person gets rid of it and then another, then slowly it dies off” which “saves hospitals money and public money”.

Peer treatment messaging

All participants actively involved in peer injecting networks adopted varying degrees of treatment advocacy. Participants described what they had and/or would share with their close peers about treatment. Information shared by participants fell into the same categories as information previously received from peers; the ease of accessing treatment, simplicity of taking treatment, experiences of minimal side effects, effectiveness and treatment-related benefits. Additionally, some participants stressed to their peers the need for commitment to and preparedness for treatment, sharing sentiments such as; “give yourself the best chance at

like completing it” or “don’t just sort of do it half arsed”. Participants tailored treatment messaging based on their own perceptions of their peers’ treatment readiness. Finn was undergoing DAA treatment for a second time through his general practitioner. He described not feeling ready the first time he undertook treatment. Many participants seemed to hold the belief that showing commitment to avoid reinfection was a key indicator of treatment readiness. This attitude may have influenced the advice Finn intended to give a close peer:

If I was talking to him about it I reckon he’d be at least six to nine months away umm just from his habitual use at the moment and the way he’s sort of carefree about it and you can see that...There probably could be a list of things that umm that I would write down for him, like; ‘do you always use a clean spoon, do you always use a filter?’ So maybe if we wrote a checklist about how people contract the disease for their circumstances that they could keep this checklist and maybe they could go through it and [my friend], when he knows he’s covered all those and is in a good space to not reinfect himself then he might be able to prepare himself better that way (Finn, post-treatment)

Largely treatment information was received and disseminated by participants through anecdotes of reconstituted biomedical information and lived experience. Language used was indicative of a biomedical knowledge, but distinct from medical practitioner or health promotion information. Participants used non-technical language and readily likened treatment to more familiar drug and medical concepts. For example, the ease of undertaking treatment was emphasised by comparing treatment to “antibiotics” or “taking a benzo tablet” and contrasting it to “the past where you had to go get injections”. Participants reiterated the perceived ease of treatment to their peers by stating that treatment is “just a tablet”, “straight forward” and it’s “really easy to get cured”.

For me, it was just like taking a Panadol [paracetamol] and not even worrying about what was going on. It was just yeah, letting the tablet do all the work but it wasn’t affecting me in any way where I had to stop what I had to do. I still kept going and doing my daily things... Yeah I would recommend it, because it helps, it makes you feel a lot better, better in yourself too. (Miriam, post-treatment)

Do it. Do it. Best thing for ya. Do it. Straight away. Do it. It’s not hard, it’s not bad, there’s no side effects and why not? What do you have to lose? Technically, you have nothing to lose and a lot to gain. It’s a lot better for your life. (Kai, during-treatment)

Participants’ accounts of promoting treatment to their peers generally carried a tone of fervour, empowerment, confidence and at times slight surprise. Participants commonly re-enacted simply telling their peers with enthusiasm and sincerity “it works!” “It really works”.

Discussion

This study explored the content and impact of peer to peer communication about hepatitis C treatment. For participants interviewed, peers were a highly trusted source of DAA information. Information was ubiquitous within participants extended social injecting scene. Receiving positive treatment anecdotes from close peers was crucial in building confidence in treatment initiation and assessing the risk-benefit profile of DAAs. Undergoing treatment alongside a very close peer and injecting partner was another avenue for gaining knowledge and accountability. Finally, moving through treatment participants adopted a treatment advocate role within their close peer network. Patterns of communication within close peer networks were cyclical and broadly reciprocal over-time; information was received before treatment, re-interpreted based on experience and fed-back into close peer injecting networks.

Firstly, our findings highlight that sharing and receiving treatment anecdotes is highly valued, beneficial and normalised within many local close peer injecting networks. When DAA treatment had only recently

become available, peoples’ understanding of treatment was marked by uncertainty, confusion and ambiguity (Whiteley, Whittaker, Elliott, & Cunningham-Burley, 2018). This may have been as treatment was not yet commonplace or normalised within peer networks. Participants in our study described treatment-related information as ubiquitous in their broader injecting community and described themselves and their peers as having a high level of treatment-related knowledge. However, participants were generally amongst only a few of their close peers who had initiated treatment. We suggest this reflects a common curiosity or interest in treatment that has led to a widespread diffusion of basic treatment-related information within injecting networks. Nevertheless, a general understanding of treatment may not motivate everyone to initiate treatment. Witnessing a close trusted peer complete treatment and provide feedback may be more powerful in raising confidence in treatment decision-making and perceiving oneself as a suitable candidate for treatment. One key benefit of receiving treatment anecdotes was reinforcing participants’ understanding of the distinction between DAA treatment and memories of interferon treatment. Hearing treatment anecdotes also allowed participants to engage in social comparison. This was demonstrated by frequent comparative statements such as “he was fine so I figure I’m gonna be fine”. Social comparison helps individuals assess their coping abilities and can reduce uncertainty and build confidence or hope (Suls & Wheeler, 2000; Veinot, 2010). These findings illustrate how beneficial it can be for people who are early adopters of treatment within their networks to share treatment anecdotes with peers. It might also be beneficial for harm reduction and health service staff to encourage those considering treatment or newly diagnosed to reflect on their network and identify trusted peers who have completed treatment that they could also discuss treatment with.

Secondly, the micro-social responses to and experiences of DAA treatment have not been widely explored. The readily adopted treatment advocate role in our study is an example of participants engaging in socially supportive behaviour within their networks. Participants in our study were not accidentally or incidentally sharing their positive treatment experiences. Rather, as socially embedded actors they were consciously adopting a role of advocacy. By promoting treatment, participants hoped their peers and the broader population could share in the benefits of treatment. Individuals’ response to health and risk information is shaped by social context, personal security needs and perceived trustworthiness of the information source, where individuals give credibility to sources they know (Alaszewski, 2005). Interestingly, for some participants sharing treatment anecdotes in broader networks was not as successful or validating compared to sharing experiences within close networks. This further speaks to the unique trust and influence formed in a close peer relationship, which highlights why peers can be such good diffusers of information. However, as with some of our participants not everyone maintains active peer injecting networks or networks with people who have completed treatment and so perhaps formal peer-led interventions would be particularly beneficial when targeting those who may not otherwise be receiving treatment information from peers. Future research is needed to further explore the complexities of trust and influence in close peer networks. This would inform the development of peer-network based health promotion interventions.

Thirdly, information shared within participants’ peer networks utilised non-technical and familiar language. This highlights a process of meaningfully appropriation of biomedical information based on experience in order to create understanding within networks. The experience of people who inject drugs and their knowledge about hepatitis C treatment has been rendered as ‘counterpublic’, meaning dominant public health discourse is based on normative assumptions and biomedical information, instead of the local expertise of people living with hepatitis C (Bryant, Rance, Hull, Mao & Treloar, 2019). None of the treatment-related information shared by participants contradicted medical information. However, our findings demonstrate that within local peer networks, experiential information is given authority and information about treatment in part socially constructed. Acknowledging treat-

ment anecdotes as expert knowledge in broader society and integrating them into health promotion messaging may improve trustworthiness of medical information and encourage treatment initiation.

Finally, the theme of ‘do it together’ can largely be conceptualised as a method employed by participants to collectively minimise uncertainty and enhance knowledge and control. Our findings that individuals prefer to do treatment together may be seen as an extension of what prior research describes as drug-user couples “doing everything together”, a care dynamic that fosters a socially protective environment (Rhodes, Rance, Fraser, & Treloar, 2017). Participants’ decision-making around undergoing treatment concurrently and its benefits highlighted a polarity between the interferon and DAA era. These finding contrasts reports of couples in the interferon era strategically staggering treatment, to allow one member to support the other through treatment side effects (Treloar, Rance, Bryant, & Fraser, 2016). It is worth further exploring the supportive benefits of undergoing treatment together and for general practitioners to consider asking patients if they have any close peers who might also like to be tested and treated.

Whilst the longitudinal nature of this study is a unique strength, this study is not without limitations. First, opportunistic sampling may have limited the diversity of experience within this sample. This study included a highly research-engaged cohort. It is possible our sample had a greater level of knowledge and awareness of DAA treatment than the general population of people who inject drugs living with hepatitis C, which may have influenced the patterns of communication we observed. Ensuring a heterogenous sample in longitudinal research is a fine balance given if this sample is too diverse it can be difficult to depict re-occurring changes (Calman, Brunton, & Molassiotis, 2013). As such, the experience of undertaking treatment amongst people who are not well connected with other injecting drug users has not been fully captured by this research. This warrants future research into how this group receive information about treatment. Second, in the final interview most participants had completed treatment (with or without cure results), however a minority were still in the final week of medication. Whilst these were all considered the ‘post treatment’ interview, each of these situations may have distinct key contextual factors influencing the expression of themes, which were not distinguished in this study. Additionally, five participants (TAP: $n = 2$; Health clinic: $n = 3$) did not return for a post-treatment interview. Whilst attrition is expected in longitudinal qualitative research (Calman, Brunton, & Molassiotis, 2013), this may have limited the expression and development of themes at the post-treatment timepoint.

Conclusion

We have explored elements of the treatment journey that are influenced by or exist within peer networks. Participants underwent an empowering transformation from passively receiving treatment information from peers to advocating for treatment within their networks. This exemplifies that people who inject drugs are proactive agents in supporting their peers and hepatitis C elimination efforts. Information both shared and received suggests that non-technical messaging, built upon trusted treatment anecdotes resonates strongly with participants. This has implications for interventions seeking to enhance treatment uptake. Interventions should support and expand upon the self-initiated supportive behaviours that exist within peer networks and consider messaging that reflects what is shared and valued within social and injecting networks.

Declaration of Interests

SG and DH have no competing interests to declare. JD and MH have received investigator-initiated research funding to their institution from Gilead Sciences, Abbvie, Merck and Bristol Myers Squibb. JD’s institution has received funding for consultancies from Gilead Sciences, Abb-

vie, and Merck. PH has received investigator-initiated research funding to his institution from Gilead Sciences and Abbvie.

Acknowledgements

We would like to acknowledge the participants of this study for sharing their time, experience and expertise. We would also like to acknowledge the general practitioner and TAP Study team who assisted in participant recruitment.

References

- Aitken, C. K., Kerger, M., & Crofts, N. (2002). Peer-delivered hepatitis C testing and counselling: A means of improving the health of injecting drug users. *Drug Alcohol Rev*, 21(1), 33–37 <https://doi.org/10.1080/09595230220119327>.
- Alaszewski, A. (2005). Risk communication: Identifying the importance of social context. *Health Risk Soc*, 7(2), 101–105 <https://doi.org/10.1080/13698570500148905>.
- Ancker, J. S., Carpenter, K. M., Greene, P., Hoffman, R., Kukafka, R., Marlow, L. A. V., et al. (2009). Peer-to-peer communication, cancer prevention, and the internet. *J. Health Commun*, 14(sup1), 38–46 <https://doi.org/10.1080/10810730902806760>.
- Araín, A., De Sousa, J., Corten, K., Verrando, R., Thijs, H., Mathei, C., et al. (2016). Pilot study: Combining formal and peer education with FibroScan to increase HCV screening and treatment in persons who use drugs. *J. Subst. Abuse. Treat.*, 67, 44–49 <https://doi.org/10.1016/j.jsat.2016.04.001>.
- Batchelder, A. W., Cockerham-Colas, L., Peysner, D., Reynoso, S. P., Soloway, I., & Litwin, A. H. (2017). Perceived benefits of the hepatitis C peer educators: A qualitative investigation. *Harm Reduct. J.*, 14(1), 67 <https://doi.org/10.1186/s12954-017-0192-8>.
- Bonnington, O., & Harris, M. (2017). Tensions in relation: How peer support is experienced and received in a hepatitis C treatment intervention. *Int. J. Drug Policy*, 47, 221–229 <https://doi.org/10.1016/j.drugpo.2017.05.031>.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qual. Res. Psychol*, 3(2), 77–101 <https://doi.org/10.1191/1478088706qp0630a>.
- Bryant, J., Rance, J., Hull, P., Mao, L., & Treloar, C. (2019). Making sense of ‘side effects’: Counterpublic health in the era of direct-acting antivirals. *Int. J. Drug Policy* <https://doi.org/10.1016/j.drugpo.2019.06.002>.
- Calman, L., Brunton, L., & Molassiotis, A. (2013). Developing longitudinal qualitative designs: Lessons learned and recommendations for health services research. *BMC Med. Res. Methodol.*, 13(1), 14 <https://doi.org/10.1186/1471-2288-13-14>.
- Castro, E. M., Van Regenmortel, T., Sermeus, W., & Vanhaecht, K. (2019). Patients’ experiential knowledge and expertise in health care: A hybrid concept analysis. *Soc Theor*, 17(3), 307–330 <https://doi.org/10.1057/s41285-018-0081-6>.
- Doyle, J., Dietze, P., Stooze, M., Higgs, P., Desmond, P., Iser, D., et al. (2019). FRI-228-Community-based hepatitis C treatment of people who inject drugs and their injecting network is feasible and effective: Results from the TAP (Treatment And Prevention) study. *J. Hepatol.*, 70(1), e495 [https://doi.org/10.1016/S0618-8278\(19\)30973-9](https://doi.org/10.1016/S0618-8278(19)30973-9).
- Doyle, J. S., Scott, N., Sacks-Davis, R., Pedrana, A. E., Thompson, A. J., & Hellard, M. E. (2019). The Eliminate Hepatitis C Partnership. (2019). Treatment access is only the first step to hepatitis C elimination: Experience of universal anti-viral treatment access in Australia. *Aliment. Pharmacol. Ther.*, 49(9), 1223–1229 <https://doi.org/10.1111/apt.15210>.
- Fraser, S., Treloar, C., Bryant, J., & Rhodes, T. (2014). Hepatitis C prevention education needs to be grounded in social relationships. *Drugs: Education, Prevention and Policy*, 21(1), 88–92 <https://doi.org/10.3109/09687637.2013.776517>.
- Galea, S., & Vlahov, D. (2002). Social determinants and the health of drug users: Socio-economic status, homelessness, and incarceration. *Public Health Rep.*, 117(Suppl 1), S135–S145. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1913691/>.
- Grebely, J. (2010). Optimizing assessment and treatment for hepatitis C virus infection in illicit drug users: A novel model incorporating multidisciplinary care and peer support. *Eur. J. Gastroenterol. Hepatol.*, 22(3), 270–277 <https://doi.org/10.1097/MEG.0b013e32832a8c4c>.
- Green, T. C., Grau, L. E., Blinnikova, K. N., Torban, M., Krupitsky, E., Ilyuk, R., et al. (2009). Social and structural aspects of the overdose risk environment in St. Petersburg, Russia. *Int. J. Drug Policy*, 20(3), 270–276 <https://doi.org/10.1016/j.drugpo.2008.07.002>.
- Grossoehme, D., & Lipstein, E. (2016). Analyzing longitudinal qualitative data: The application of trajectory and recurrent cross-sectional approaches [journal article]. *BMC Res. Notes*, 9(1), 136 <https://doi.org/10.1186/s13104-016-1954-1>.
- Guise, A., Horyniak, D., Melo, J., McNeil, R., & Werb, D. (2017). The experience of initiating injection drug use and its social context: A qualitative systematic review and thematic synthesis. *Addiction*, 112(12), 2098–2111 <https://doi.org/10.1111/add.13957>.
- Harris, M., Bonnington, O., Harrison, G., Hickman, M., Irving, W., & team, t. H. (2018). Understanding hepatitis C intervention success—Qualitative findings from the Hep-CATT study. *J. Viral Hepat.*, 25(7), 762–770 <https://doi.org/10.1111/jvh.12869>.
- Henderson, C., Madden, A., & Kelsall, J. (2017). Beyond the willing & the waiting’ - The role of peer-based approaches in hepatitis C diagnosis & treatment. *Int. J. Drug Policy*, 50, 111–115 <https://doi.org/10.1016/j.drugpo.2017.08.004>.
- Hepatitis Victoria. (2016). *Hepatitis c treatment hepatitis victoria*. LiverWell Retrieved 07/09/2020 from <https://www.hepvic.org.au/page/17/hepatitis-c-treatment#:~:Text=The%20cost%20of%20each%20prescription,or%20where%20cirrhosis%20is%20present>.

- Keats, J., Micallef, M., Grebely, J., Hazelwood, S., Everingham, H., Shrestha, N., et al. (2015). Assessment and delivery of treatment for hepatitis C virus infection in an opioid substitution treatment clinic with integrated peer-based support in Newcastle, Australia. *Int. J. Drug Policy*, 26(10), 999–1006 <https://doi.org/10.1016/j.drugpo.2015.07.006>.
- Kikvidze, T., Luhmann, N., Avril, E., Butsashvili, M., Labartkava, K., Etienne, A., et al. (2018). Harm reduction-based and peer-supported hepatitis C treatment for people who inject drugs in Georgia. *Int. J. Drug Policy*, 52, 16–19 <https://doi.org/10.1016/j.drugpo.2017.11.014>.
- Meyer, J. P., Moghimi, Y., Marcus, R., Lim, J. K., Litwin, A. H., & Altice, F. L. (2015). Evidence-based interventions to enhance assessment, treatment, and adherence in the chronic Hepatitis C care continuum. *Int. J. Drug Policy*, 26(10), 922–935 <https://doi.org/10.1016/j.drugpo.2015.05.002>.
- Mhatre, S. K., & Sansgiry, S. S. (2016). Development of a conceptual model of health-related quality of life among hepatitis C patients: A systematic review of qualitative studies. *Hepatol. Res.*, 46(1), 29–39 <https://doi.org/10.1111/hepr.12521>.
- Millman, A. J., Nelson, N. P., & Vellozzi, C. (2017). Hepatitis C: Review of the Epidemiology, Clinical Care, and Continued Challenges in the Direct-Acting Antiviral Era. *Curr. Epidemiol. Rep.*, 4(2), 174–185 <https://doi.org/10.1007/s40471-017-0108-x>.
- Moore, D. (1993). Beyond Zinberg's "social setting": A processual view of illicit drug use. *Drug Alcohol Rev.*, 12(4), 413–421 <https://doi.org/10.1080/09595239300185511>.
- Norman, J. (2008). The acceptability and feasibility of peer worker support role in community based HCV treatment for injecting drug users. *Harm Reduct. J.*, 5(8) <https://doi.org/10.1186/1477-7517-5-8>.
- Razavi, H., Sanchez Gonzalez, Y., Yuen, C., & Cornberg, M. (2020). Global timing of hepatitis C virus elimination in high-income countries. *Liver Int.*, 40(3), 522–529 <https://doi.org/10.1111/liv.14324>.
- Rhodes, T., Rance, J., Fraser, S., & Treloar, C. (2017). The intimate relationship as a site of social protection: Partnerships between people who inject drugs. *Soc. Sci. Med.*, 180, 125–134 <https://doi.org/10.1016/j.socscimed.2017.03.012>.
- Saldaña, J. (2003). *Longitudinal qualitative research: Analyzing change through time*. AltaMira Press https://books.google.com.au/books?id=7vs_1dnjmOgC.
- Scott, N., Wilson, D. P., Thompson, A. J., Barnes, E., El-Sayed, M., & Benzaquen, A. S. (2019). The case for a universal hepatitis C vaccine to achieve hepatitis C elimination. *BMC Medicine*, 17(1), 175 <https://doi.org/10.1186/s12916-019-1411-9>.
- Stagg, H. R., Surey, J., Francis, M., MacLellan, J., Foster, G. R., Charlett, A., et al. (2019). Improving engagement with healthcare in hepatitis C: A randomised controlled trial of a peer support intervention. *BMC Med.*, 17(1), 71 <https://doi.org/10.1186/s12916-019-1300-2>.
- Sulkowski, M., Ward, K., Falade-Nwulia, O., Moon, J., Sutcliffe, C., Brinkley, S., et al. (2017). Randomized controlled trial of cash incentives or peer mentors to improve HCV linkage and treatment among HIV/HCV coinfecting persons who inject drugs: The CHAMPS Study. *J. Hepatol.*, 66(1), S719 [https://doi.org/10.1016/S0168-8278\(17\)31922-0](https://doi.org/10.1016/S0168-8278(17)31922-0).
- Suls, J., & Wheeler, L. (2000). A selective history of classic and neo-social comparison theory. In J. Suls, & L. Wheeler (Eds.), *Handbook of social comparison: Theory and research* (pp. 3–19). Springer. https://doi.org/10.1007/978-1-4615-4237-7_1.
- The Pharmaceutical Benefits Scheme. (2020a). *General statement for drugs for the treatment of hepatitis c* 01/04/2020. Australian Government Department of Health Retrieved 13/04/2020 from <http://www.pbs.gov.au/info/healthpro/explanatory-notes/general-statement-hep-c>.
- The Pharmaceutical Benefits Scheme. (2020b). Sofosbuvir. Australian Government Department of Health. Retrieved 07/09/2020 from <https://www.pbs.gov.au/medicine/item/10624e-10625f-10648k-10654r-10657x-10676x>.
- Thompson, A. J. (2016). Australian recommendations for the management of hepatitis C virus infection: A consensus statement. *Med J Aust.*, 204(7), 268–272 <https://doi.org/10.5694/mja16.00106>.
- Treloar, C., Rance, J., Bryant, J., & Fraser, S. (2016). Understanding decisions made about hepatitis C treatment by couples who inject drugs. *J. Viral Hepat.*, 23(2), 89–95 <https://doi.org/10.1111/jvh.12451>.
- Veinot, T. C. (2010). "We have a lot of information to share with each other". Understanding the value of peer-based health information exchange. *Inf. Res.*, 15(4). <http://informationr.net/ir/15-4/paper452.html>.
- Whiteley, D., Whittaker, A., Elliott, L., & Cunningham-Burley, S. (2018). Hepatitis C in a new therapeutic era: Recontextualising the lived experience. *J. Clin. Nurs.*, 27(13–14), 2729–2739 <https://doi.org/10.1111/jocn.14083>.
- World Health Organization. (2016). *Combating hepatitis b and c to reach elimination by 2030* May 2016. World Health Organization Retrieved 14/04/2020 from http://apps.who.int/iris/bitstream/10665/206453/1/WHO_HIV_2016.04_eng.pdf?ua=1.