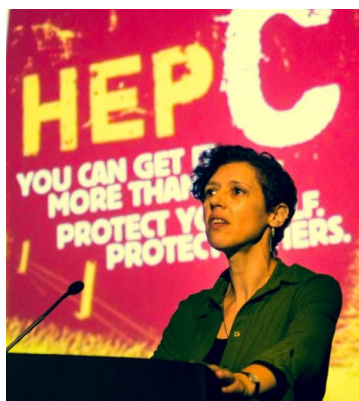


From hepatitis C researcher to peer: an academic and personal perspective



Magdalena Harris, Associate Professor, London School of Hygiene & Tropical Medicine.

Introduction

This article is based on an invited presentation for the recent Amsterdam Hepatitis C Community summit (<http://hepatitiscommunitysummit.eu/>), where I was asked to draw on my journey as a person living with hepatitis C and as researcher - and how I have experienced and worked to bridge the researcher-peer divide in my own practice.

I frame my talk around the cycle of care, encompassing prevention, testing, treatment and broader social structural supports. I use this phrase rather than 'cascade of care' – as cascade implies a linear process, focused on biomedical compliance and with treated hepatitis C being the successful end-point. Here I want to talk about the cycle of care as relational – as a social and environmental engagement as much as a biomedical one. And, through drawing on my research over the past 15 years, provide illustrations of the importance of peers in all aspects of this cycle.

The personal

So, how does the personal come into this? For a decade I was a daily injector – primarily of heroin, but also anything I could get my hands on. During this time, I was diagnosed with hepatitis C. I put the diagnosis to the back of my mind and continued with my life – using drugs, working at a peer led needle exchange and doing what I had to keep my habit going. Indeed, the gravity of living with hepatitis C only hit me when I ceased injecting in my early 30's. For the first time, I was living with so called 'normal' people; I didn't disclose my status as I didn't want to be perceived as infectious. I was noticing the impact of hepatitis C more than ever before – experiencing intense fatigue and, with ALTs in the 400s, I was encouraged to start interferon treatment by my GP. This seemed an impossibility – how could I keep interferon in our shared fridge and go through possibly debilitating side effects without telling my flatmates what was going on? The side effects also filled me with fear – particularly the possibility of being triggered, by these and the interferon syringe, to recommence injecting.

These dilemmas were the impetus for my first research project 15 years ago – on the lived experience of hepatitis C in New Zealand. I have kept a similar research focus since then. My history also informed my research practice – very familiar with hepatitis C stigma and dilemmas around disclosure I took care to alleviate that fear in others, by disclosing – where appropriate – my past. This was also a political strategy. By being open in disclosure, in my research practice as well as presentations and publications (for example: Harris 2012; 2015), I take a small step against the silence around hepatitis C; in recognition of the silence = death activism mantra of the early HIV movement.

Disclosure

How was this disclosure managed? At times I explicitly out myself; the recruitment notice for my PhD study states that I also live with hepatitis C. I am also outed by my body. Jack, noting my track mark scars, remarked approvingly “*a lot of heroin must have gone in those arms!*” At other times, it could be uncomfortable. Frank, for example, was an older professional man with medically acquired hepatitis C, so when he asked “how did you get hepatitis C?” it was with apprehension I gave my answer. And sometimes the right to disclose is something I have had to fight for. This ethics committee feedback is a case example:

“It is not appropriate for the researcher to include in the study that she has had hepatitis in past. ... The Committee agreed that the study appears to have preconceived ideas and could possibly have potential for bias and personal interests involved.” (REC 12 LO 0294 Unfavourable opinion)

My reply was not to deny the influence of my history or argue against possibilities for ‘bias’ but to argue instead that all research is inherently biased; important is transparency about your position as a researcher in this process (it was this point that provoked an unexpected round of applause from the Community Summit audience!).

Aiding engagement

So, disclosure was not always comfortable or straightforward – but something I have fought for and maintained – as important to my research practice. Why is it important for my practice? One reason, apart from the political and personal reasons mentioned earlier, is that it appears to aid engagement, trust and the development of rapport. For example, I had no recruitment money to offer anyone in my PhD study, but ended up having to turn potential participants away – many of whom said they had never talked with another person with hepatitis C before. For Claire, this was the primary reason she signed up for the study:

You know what I’ve been going through and I know what you’ve gone through, even though we have different, totally different lives. We’re still connected by, by that virus.

Kyle, in a later study about HCV prevention, stated:

The good thing about it [interview] is because you’re an ex-user so you know how it feels. Like if you had been a normal person it would have been harder for me to break out and tell you how I felt.

This is not to say I am better at engaging participants than other researchers or that I can get closer to the ‘truth’ of a story, whatever that may be – but just that, at times, I can access a different kind of story, a different mode of accounting. For example, Abby in her first two interviews with my experienced, warm and empathic colleague said she never shared needles or syringes. To me she spoke of extensive sharing. When I mentioned this, she replied vehemently:

These ‘textbook junkies’ I call them, they just know what they read in a book. Have they ever felt a rattle? Have they ever felt them shivers and them cramps? No ... I knew he wasn’t a drug user and I thought ‘no, he’s not judging me for something I’ve done, no.

Prevention: broadening the conversation

Abby felt safe to disclose extensive sharing practices as she knew she would not be judged. In this way, community and peer providers are an important access point for prevention initiatives. They can aid engagement but also act as a conduit for alternative stories to be told – stories important for inspiring, developing and sustaining community acceptable interventions.

As mentioned earlier, there was often a strong embodied connection between myself and participants in the interview situation, with mutual attention to injecting traces and sites. As Max exclaimed: “Oh look: you’ve got a massive vein there! Bloody hell!” This influenced the sorts of questions I was interested in and the kinds of stories that I was told.

An interesting finding, for example, of our prevention study (Harris & Rhodes, 2012) was that hepatitis C avoidance did not appear to be a strong motivation for the adoption of protective practices. Much more important were the pleasures and pragmatics, the vital stuff of everyday life that mattered most to people. Among participants who had been injecting for the long term and were hepatitis C free, vein care – being able to maintain venous access, get a quick hit and ideally avoid injecting relating scars – was drawn on as a central reason for the use of sterile injecting equipment. Here new works were not important because they were sterile but because they were sharp. As Jeff says: If you always use fresh needles you minimise any vein damage ... [I do it] to look after my veins to try and get more usage out of them. And similarly, Giles a service user rep said:

People would rather use clean works because they’re sharp for a start so, you know, they’re not going to be blunt. But does the message get through? Because hep C, you know: “yeah hep C, so what. I’m not going to drop down dead tomorrow”.

Here, Giles explicitly references how hepatitis C messaging can fail to resonate with people faced with many competing demands. These accounts were interesting, and somewhat remarkable, given the responsibilising emphasis on blood-borne virus prevention in harm reduction materials. Paying attention to these stories enables different conversations to take place in services, with perhaps different results. After hearing of these findings, a service provider told me that she started asking her clients if it hurts when they inject; this has opened the space for a completely different sort of conversation and level of engagement.

Testing: removing barriers & overcoming fear

From prevention to testing – what enabled me to get tested for hepatitis C? Primarily, the availability of testing in the peer-led needle exchange where I worked by a compassionate non-judgemental doctor, aptly named Dr Friend. I wouldn't have gone anywhere else, not for any tests at all, given the state of my arms and how I felt I would be treated.

But for some, community provision of testing is not enough. Max's story (Harris et al., 2014) highlights the important role of peers in the care continuum. When I met Max he had been injecting regularly for over 20 years and never had a hepatitis C test. He had been at his drug treatment service – where testing was available – for 10 years, yet never had a test. When I asked why he said:

I've never had a test. I don't want a test ... I don't feel I'd be strong enough in my mind if I did have it to handle it and it could make me spiral worse out of control. That would be my reason."

I interviewed Max three times, disclosed my own past as a drug user and someone who had had hep C and been successfully treated for it. This disclosure elicited questions from Max such as: "So if I did have it, if I did, what would happen? What would happen then when you've got it. Where do you go from there?" Eventually, he said: "As long as I know it's curable then I can face it." Even with this new willingness Max still found it hard to get a test, and it wasn't until we arranged for another peer to go with him and be there during the process that he went through with it (diagnosis: negative!).

Treatment: power of the personal

For many, hepatitis C treatment is also replete with fear – and this fear, associated with interferon treatment, can still cause a barrier to engagement with the less toxic DAA treatments. For me, fear of treatment side effects held me off for many years, and it was only really through engagement with peers – those in my research project – that I decided to give it a go. As I wrote at the time:

She [participant] was interested and encouraged me to do treatment and after talking to her and hearing her positive experiences I feel more inclined to think about the possibility of doing it. (Field notes, 04/05/06)

I – like many other users – had a profound distrust of medical professionals and needed to access personal experiences before being willing to try treatment. This was reflected in my recent, hepatitis C treatment study, where my treatment history was of great interest to participants. Many – such as Ibrahim – questioned me extensively about my experience: "So you said you were on exactly the same treatment ... and then when you find out that you are absolutely clear? ... So what things did you actually personally do on treatment? ... What exactly your routine was? ... How did exactly you find it after the injection?"

This interest can be read as reflecting a lack of, and need for, meaningful peer engagement in services providing HCV treatment. As Alec says: "It would be really good to have someone sit down with you and talk to you, you know, just in a peer mentoring way, that would be great for anyone ... it could be someone like, whose been through the treatment themselves, who can connect on a different level".

Broader supports / unexpected stories

But what I want to emphasise in this talk, is that hepatitis C is a situated concern – one that, for many, may fade into insignificance against a backdrop of historical and ongoing traumas. This became increasingly apparent through the unexpected stories told in the interview encounter – stories of rape; childhood abuse; kidnapping; domestic violence; loss of child custody; structural violence & stigma. How to cope with and what sense to make of these unsolicited narratives of trauma? Rather than to be discarded, as irrelevant digressions from the research focus of hepatitis C, I believe they tell us something important about the relative priority of hepatitis C in people's lives. Services that can attend foremost to these issues might be more successful in engaging clients with hepatitis C prevention and care.

In thinking about the cycle of hepatitis C care we need to move beyond a focus on the biomedical; particularly pertinent in this era of great treatment advance and enthusiasm. As Vinh-Kim Nguyen and colleagues (2011) remind us: *“Treatment is not a substitute to the removal of the vulnerabilities that place people at risk of infection in the first place”*.

To give an example. Noting the under-representation of women in hepatitis C treatment and drug services I asked one user why. She said: *“They [women] suffer in silence, they just buy it [methadone] on the street ... do what they can to survive. And then there's the fear if they've got kids. That's one of the big issues, it's their kids.”* (Abby)

Parents who use drugs face huge barriers to accessing services, particularly women. For parents who experience the trauma of child removal, this is often a time of intense devolution and risky practices. Many feel they no longer have anything left to live for. Hepatitis C is not a priority. There is a need therefore, to think broadly regarding engagement in care. Community based projects, such as developed by Counterfit in Canada can be valuable in empowering PWID to address pressing issues such as the trauma of having children removed:

“The Grief and Loss Education and Action Project engages women who are past or current drug users and who have had children apprehended by [social services] in the sharing of lived experiences, coping strategies, art-making, and action planning to work toward creating a transformed child welfare system”. (<https://www.srchc.ca/program/common-ground-program>)

Not only can this improve overall mental and physical wellbeing, but it holds the potential to spill over in to other areas such as hepatitis C treatment access interest and activism.

In closing

The Amsterdam hepatitis C Community Summit is concerned with bridging the gaps – gaps between international guidance and national policy, between national policy and practice on the ground and – most importantly – the gaps between the needs and concerns of the affected community and those of the clinicians and researchers who work for and with them. Scrutinising and working to ameliorate these gaps is particularly crucial at a time of great treatment advance.

I was asked to talk about how I bridged the gaps between the worlds of peer and researcher. I never fully feel like I belonged to either world – but was in some nebulous in-between state, akin to academic ‘imposter syndrome’. By being ‘in-between’, however, I have the ability to act as a ‘translator’ between researcher/clinician and peer community/organisations. At this time of biomedical advance we need to foster peers as translators: vital for the development of innovative community-acceptable interventions. Although developments in DAAs are hugely welcome they can also work to focus the ‘solution’ to hepatitis C on the biomedical and emphasise the role of the clinician and, in doing so, diminish attention to other aspects of the cycle of care and the need for community involvement in this process.

References

- Harris, M. (2012). Harm reduction and me. <http://www.youtube.com/watch?v=0H51Nk-l7PA>
- Harris, M. (2015). Three in the room: Disclosure, embodiment and vulnerability in qualitative research. *Qualitative Health Research*, 25(12):1689-1699. <https://www.ncbi.nlm.nih.gov/pubmed/25576481>
- Harris, M., McDonald, B. Rhodes, T. (2014). Hepatitis C testing for people who inject drugs in the United Kingdom: Why is uptake so low? *Drugs: Education, Prevention and Policy*. 21:4, 333-342. <http://www.tandfonline.com/doi/abs/10.3109/09687637.2014.899988>
- Harris, M. & Rhodes, T. (2012). Venous access and care: Harnessing pragmatics in harm reduction for people who inject drugs. *Addiction*, 107, 1090–1096. <https://www.ncbi.nlm.nih.gov/pubmed/22151433>
- Nguyen, V.-K., Bajos, N., Dubois-Arber, F., O’Malley, J., & Pirkle, C. M. (2011). Remedicalizing an epidemic: From HIV treatment as prevention to HIV treatment is prevention. *AIDS*, 25(3), 291–293. <https://www.ncbi.nlm.nih.gov/pubmed/20962615>