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# A diagnosis of hepatitis C

## Insights from a study on patients' experiences

### Background

Previous research has documented patient experiences of hepatitis C virus (HCV) diagnosis to be without sufficient pretest and post-test discussions – health professionals have expressed a need for training in this area.

### Objective

This study aimed to examine the diagnosis experiences of 24 people diagnosed with HCV in the preceding 2 years.

### Method

Face-to-face interviews of 24 participants (recruited through advertising) were conducted.

### Results

Overall, the HCV diagnosis experience of participants was poor. Participant narratives of HCV diagnosis were characterised by confusion in relation to tests that were performed and the implications of test results. Post-test discussions were inadequate – there was a reported lack of information, support and referral provided to participants.

### Discussion

Most clinicians do not receive specialised training in hepatitis C but may be involved in diagnoses in their careers. The impact of negative diagnosis experiences for patients can be serious and long term. These findings highlight areas of suboptimal diagnosis experience and suggest training and support needs of health professionals.

**Keywords:** communicable/infectious diseases; research; qualitative research; patient centred care



Although 10 000 new hepatitis C virus (HCV) infections and 400–500 notifications of new cases are estimated to occur each year in Australia,<sup>1</sup> few medical practitioners, especially at the primary care level, have specialised HCV knowledge and skills. Further, there has been little research on the HCV diagnosis experience with a view to examining the support and training needs of diagnosing doctors.<sup>2</sup>

The National Hepatitis C Testing Policy<sup>3</sup> (*Table 1*) provides guidance on management of the diagnosis experience (ie. states which tests should be used, that pretest and post-test discussions are fundamental to the diagnosis experience, and outlines the issues that should be covered in each discussion and the manner in which these discussions should be conducted). Although two-thirds of the Australian general practitioners surveyed in Gupta, Shah and Ward<sup>4</sup> felt more confident in managing people with HCV than was reported 5 years ago, substantial proportions identified ongoing training needs. Pretest and post-test counselling was indicated as a topic for future skills development by 32% of the sample and was the third most frequently endorsed topic following drug therapy and interactions (45%) and interpretation of tests.<sup>4</sup> The diagnosis experience can determine patients' engagement with care and support for any illness, including hepatitis C.

Serious institutionalised patterns of HCV related discrimination within healthcare have been previously documented.<sup>5,6</sup> Subsequent social research has identified overwhelmingly poor experiences of diagnosis: diagnoses were frequently provided without the provision of additional information or referral to specialists, and were frequently delivered in a judgmental

manner.<sup>7,8</sup> Further, suboptimal diagnoses were significantly more common among people who inject drugs (PWID).<sup>9–12</sup>

The current study explored the diagnosis experience of people who had recently acquired (within the preceding 2 years) HCV infection. We assessed the adequacy of the diagnosis using the recommendations of the National Hepatitis C Testing Policy<sup>3</sup> with the aim of identifying training and support needs of diagnosing doctors.

### Method

Participants were recruited from advertisements placed in community magazines produced by a New South Wales (NSW) drug user organisation – NSW Users and AIDS Association (NUAA), and the Hepatitis C Council of NSW (HNSW) and via referral from the Hepatitis Incidence and Transmission Study – community (HITS-c), a longitudinal study of PWID. The HITS-c participants who met the eligibility criteria were provided with the recruitment flyer and asked to contact the researchers. A screening interview was conducted with people who responded to recruitment to identify people who reported evidence of recent HCV infection. Twenty-four participants were recruited and interviewed. Two interviews were conducted by telephone and the remainder were face-to-face. Participants were reimbursed \$30.

The interview used a semistructured interview schedule that explored the participants' understanding of:

- HCV
- the HCV seroconversion event
- timing and reason for HCV testing
- tests undertaken and understanding of HCV tests
- explanation at diagnosis and referrals made
- attitudes

- awareness
- readiness and willingness to undertake HCV treatment
- changes in risk practices.

Interviews were between 25–140 minutes in duration. Face-to-face interviews were conducted in a private meeting room at either the NUAA or HNSW.

Interviews were audiorecorded and recordings were transcribed verbatim. Transcripts were checked against the recordings for accuracy. Identifying information was removed from the transcripts and pseudonyms applied. The diagnosis experience was assessed by identifying, coding and analysing participants' responses against the principles of testing and key components of the post-test discussion as outlined in the National Hepatitis C Testing Policy.<sup>3</sup>

Ethics approval for this study was obtained from the University of New South Wales Human Research Ethics Committee. All participants provided informed consent.

## Results

By self report, all participants had received a diagnosis of HCV between 2006 and 2009 (median time since diagnosis, 15 months). Twenty-two participants were recruited from the Sydney metropolitan area and two resided in regional NSW. The mean age of participants was 35 years (range, 21–49 years). Further demographic information is reported in *Table 2*. The site of diagnosis is reported in *Table 3*. Only four participants received their diagnosis in general practice or hospital settings.

### Types of tests performed

Nine participants indicated that HCV antibody and liver function tests only had been performed; two identified that they had received an HCV ribonucleic acid (RNA) test; four participants identified their genotype, indicating RNA viral genotype testing; and one participant reported that their doctor had told them their genotype was the 'good one'. (Dylan, 37) The remaining participants were unaware of RNA testing or did not mention this.

### Diagnosis experience

Participants identified instances in which post-test discussions met some of the components

of the national testing policy. At least three participants identified that they were given written information following their positive HCV diagnosis. Two participants identified that they were provided with emotional and psychological support following diagnosis. However, in neither case was this provided by the diagnosing doctor: one identified peer support from clients of a residential drug rehabilitation service, the other from a nurse in the service who happened to see

the participant's distress and provided emotional support and referral to a community based service.

For the majority of the study participants their diagnosis experience did not meet some, or any, of the components of the national testing policy. These experiences are characterised by results provided at an inappropriate time, with little or no information; a lack of post-test discussion regarding risk, treatment and management; or no effort to address emotional and psychological issues.

**Table 1. Elements of the National Hepatitis C Testing Policy**

#### Guidance on tests to confirm exposure to and chronic hepatitis C infection

- Exposure to HCV is determined by testing for HCV antibodies (anti-HCV) in serum or plasma
- Current HCV infection is usually determined by qualitative testing for HCV RNA
- Qualitative HCV RNA testing should be a standard component of the diagnostic work up of all anti-HCV positive individuals

#### Guiding principles of the National Hepatitis C Testing Policy

- Confidential, voluntary testing with informed consent and pretest and post-test discussion is fundamental to Australia's response to HCV
- Testing is of the highest possible standard
- Testing is of benefit to the person being tested
- Testing is accessible to all those at risk of HCV infection
- Testing is critical to understanding the epidemiology of HCV infection in the community
- Testing can be critical to interruption of transmission and can support harm minimisation
- Testing to monitor people with HCV before, during and after treatment is an integral part of their care

#### Guidance on post-test discussions

- Deliver the test result in person and in a manner that is:
  - confidential
  - sensitive
  - appropriate to gender of patient
  - appropriate to cultural beliefs and practices of patient
  - appropriate to behaviour of patient
  - appropriate to ongoing risk for patient
  - appropriate to patient level of understanding of hepatitis C
  - appropriate to language and literacy level of patient
- Reassess support mechanisms and requirements of the person and making immediate referral to a support agency to be accessed at the patient's discretion

#### Guidance if test result is positive

Post-test discussion should include at an appropriate time, issues such as immediate needs and support, including written referral information about:

- safer behaviours
- education
- information and support including needle and syringe programs if appropriate
- legal requirements for disclosure and how to disclose to family and friends
- managing or understanding strong emotions, feelings, reactions and changes
- options in drug treatments and medical management
- ongoing counselling or therapy if required
- complementary/alternative management options
- ways to deal with loss and grief, depression, anger and anxiety
- strategies for managing hepatitis C which are flexible and appropriate to the patient's needs
- legislative requirements (notification, contact tracing, storage and coding)

'Oh the doctor didn't say anything just that, except that I have hep C. And they didn't explain to me anything about it or anything really. I didn't get given anything. I asked, "Do I need to change my diet or anything?" and I was told, "No, nothing I could do."' (Andrew, 38)

'They didn't really give me any information. All they showed me was my blood tests. And I said to her, I said, "It's positive isn't it?" She said, "Yeah. You've got hep C."' (Cathy, 21)

The following case highlights the impact of inappropriate timing of diagnosis. As a result of the experience, this participant did not access the service for more than 2 years despite it previously having been his primary source of sterile injecting equipment.

'I came in 5 minutes before they closed and they sat me in the room, and they said, "Oh wow, you're positive." And I said, "What? For what?" They said, "Hep C." I said, "You've gotta be fucking joking," I was, actually was devastated you know. The fact that I had a blood borne, communicable disease... and they're like, "But we can't give you any counselling at the moment... because we're about to close." And I'm like, "Why the fuck did you tell me now when you could have told me

when I came in the next time," which was only 2 days... after that – when I had an appointment... and I was actually really devastated. I was left to leave with this information, go back to work [to undertake sex work]... thinking, "Fuck, am I gonna infect people [via sex]?" I didn't know. I didn't know transmission ways. I didn't know if it was like blood borne, semen borne. Is it in my hair? Is it in my saliva? I didn't know. And here they are just letting me just walk out the door.' (Wilson, 37)

### Peer and community based support

For five participants, the lack of information and emotional and psychological support provided by their diagnosing doctor was somewhat alleviated by support from peers and community based organisations. These responses highlight the importance and need to integrate peer support into HCV pretest and post-test discussions.<sup>13–15</sup>

'I mean I cry sometimes and sometimes I get angry with myself, and ... that's when these guys and the Hep C Council, and Lifeline... Because I mean I can't pinpoint when I'm gonna get depressed. And just say it is one o'clock in the morning... I'm not alone... I've been told a thousand times: "You're not alone"... Because I mean I get depressed sometimes about it... Because I feel sometimes that, you know, I'm this diseased person and like I just feel different now.' (Narelle, 31)

'I have support. I have friends and people who have hep C, and I can talk to them, and people who are in rehab were really supportive. So I found that it helped, actually. Because a lot of the girls had been through similar situations.' (Karen, 34)

### Referral to HCV treatment

Seven participants identified that they had been, or thought they had been, referred to a liver specialist. Further, two participants had asked their diagnosing health professional about the possibility of HCV treatment but were refused access to treatment. One participant was told

that she needed to have HCV for 1 year before undertaking treatment. The other was told that he needed to be abstinent from drug use for 12 months before treatment – despite current injecting drug use being removed as an exclusion criteria for HCV treatment in 2001.

One participant identified that he was surprised that no health professional had made him aware of HCV treatment, or referred him to HCV treatment as he had been told he had the 'good genotype'.

'No options for treatment were given to me or anything like that, which I thought was a bit strange... Even the [rehabilitation] clinic are very... not even talking to me about options of treatment I've been seeing lots of different people. But... there's, none of them have really pointed me in the direction of the person to speak to about treatment.' (Andrew, 38)

### Discussion

The results of this study suggest that significant training and support needs exist for at least some doctors providing HCV diagnosis. Typically, HCV diagnoses described by participants were poorly delivered according to the national policy, particularly with regard to appropriate testing procedures and almost all elements of the post-test discussion, including sensitive and appropriate delivery.

These results are relevant for three reasons. First, the use of inadequate tests (ie. antibody and liver function) can result in false positives. Up to 25% of people exposed to HCV will clear infection.<sup>16</sup> In this sample where nine people reported no RNA tests, two or three participants may have been incorrectly diagnosed. Besides the emotional toll of a positive diagnosis, false positives are a major concern, as post-test discussions with appropriate RNA test information could encourage safer injecting practices among those who clear the initial HCV exposure to avoid future exposures and the risk of chronic infection.

Second, poor diagnosis experiences have potential to further disengage people living with HCV from healthcare and self management strategies.<sup>7,10</sup>

Third, lack of effective referral to treatment at diagnosis is especially relevant given recent studies indicating better treatment outcomes for people treated early.<sup>17</sup>

**Table 2. Participant demographics**

	N	%
<b>Gender</b>		
Male	14	58
Female	9	38
Transgender	1	4
<b>Aboriginal or Torres Strait Islander</b>		
Yes	7	29
<b>Main language spoken</b>		
English	24	100
<b>Main source of income</b>		
Pension/unemployment	19	79
<b>Ever been in prison</b>		
Yes	12	50
<b>Imprisoned in past 2 years</b>		
Yes	7	29

**Table 3. Location of hepatitis C diagnosis**

Site	Number	Percentage of total participants
Clinic and health service*	10	42%
Drug rehabilitation	5	21%
Hospital or general practice	4	17%
Research participation	3	13%
Prison	2	8%

\* Participants identified sexual health clinic, 'clinic' and health service as location

## Study limitations

This is a qualitative study of 24 participants self reporting their experience of a diagnosis of HCV in the previous 2 years – drawn mainly from metropolitan Sydney. We acknowledge that recall bias may influence responses as some diagnoses were made up to 24 months before interview. We provided reimbursement of \$30 to participants, which is standard practice in research with people who inject drugs,<sup>18</sup> and is used to motivate participation beyond those who may participate for altruistic reasons alone. However, this payment, along with the self selected nature of the sample, and reliance on community organisations to advertise the study, may have resulted in disproportionate representation of people who felt aggrieved by the diagnosis experience. Therefore, care must be taken in drawing conclusions and generalisations from these findings. However, results are consistent with previous studies<sup>19</sup> and specific attention was paid to examining participant's accounts for both positive and negative diagnosis experiences. Further, the consistency between these results and previous results demonstrates that, at least for some people, receiving hepatitis C diagnosis has improved very little in almost a decade.

## Conclusion

Of the 24 participants in this study, four indicated that their HCV diagnosis was conducted in a general practice or hospital setting. The majority were conducted in other settings, including primary health services, drug rehabilitation facility, through the HITS-c study, and prison – the authors were not able to determine the training or professional background of the diagnosing health professionals. The study results identify the need for greater support for diagnosing clinicians, which will include GPs, who may deliver a HCV diagnoses in their career. It is not possible or practical that all GPs have up-to-date knowledge regarding treatment options in a rapidly changing field. However, diagnosing clinicians should be able to provide adequate pretest and post-test discussions as per the national policy, provide these within a nonjudgmental context, and provide sufficiently supported referral to specialists for treatment review and to community based organisations, such as hepatitis councils and drug user organisations. Three recommendations to support diagnosing doctors are apparent:

- campaigns to increase awareness of National Hepatitis C Testing Policy key principles among doctors working in sexual health clinics and drug and alcohol services, and GPs
- provision of programs for mentoring at time of diagnosis, as are currently run for low (or no) case load GPs providing HIV diagnoses (ie. via laboratory notification to a brokering agency, low case load doctors are offered a telephone consultation with doctors experienced in HCV diagnosis, care and treatment)
- provision of a resource sheet to accompany pathology reports which includes key information to be provided to the patient, including referral to community based organisations.

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