Finding the undiagnosed: a qualitative exploration of hepatitis C diagnosis delay in the United Kingdom

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SUMMARY. Hepatitis C virus (HCV)-related morbidity and mortality will continue to rise unless HCV testing and treatment uptake increases. In the European region, an estimated nine million people live with HCV, yet only 10–40% are diagnosed. Over 100 000 undiagnosed people live with HCV in the United Kingdom (UK). For some, a late diagnosis can come too late. The aim of this qualitative study was to explore the context of a diagnosis delay among people living with HCV in the UK. Participants were recruited through two London Hospitals and The Hepatitis C Trust. Eligible participants identified a recent (<3 years) HCV diagnosis and a historical HCV transmission risk period (>15 years). The primary method of data collection was in-depth interviews (12 participants) and focus groups (16 participants). Analysis was informed by grounded theory principles. The sample, 17 men and 11 women, reported an average gap of 28 years between their HCV-risk period and first HCV test. Forty per cent had cirrhosis at HCV diagnosis. Diagnosis delay was attributed to limited HCV relevance, felt wellness, stigma, compartmentalization of former injecting practices, unexplained symptoms and general practitioner inaction. Diagnosis context involved a change of health care providers or a chance medical encounter. Trust in providers was impacted by a delayed diagnosis, with implications for future engagement in care. These data indicate that risk awareness does not necessarily result in action. A multipronged approach is needed to increase HCV case finding in the UK, particularly among ‘hidden populations’ such as former injectors and transfusion recipients.

Keywords: blood transfusion, former PWID, hepatitis C, testing, trust, undiagnosed.

INTRODUCTION

The licensing of highly effective and tolerable direct acting antiviral (DAA) treatments for the hepatitis C virus (HCV) has brought considerable enthusiasm to the sector. For the first time, it is possible to contemplate the ‘end of hepatitis C’ [1]. This enthusiasm must, however, be tempered in the light of suboptimal diagnosis rates, particularly in the European region. Here, an estimated nine million people live with HCV, yet only 10–40% have been diagnosed [2]. In the United Kingdom (UK), diagnosis rates of 40% translate to over 100 000 people unaware of their condition [3]. In order for new treatment developments to have any significant impact on HCV mortality and population prevalence, it is crucial that case finding and screening initiatives are improved.

In the UK, targeted case finding of risk groups is evidenced as more effective and cost-effective than opportunistic testing [4–6]. At-risk groups include people who inject drugs (PWID), prisoners, immigrants from HCV endemic countries, people who received blood products or transfusions in the UK before September 1991 and people who formerly injected drugs. Of these, the latter two groups can be the hardest to identify. Not all people remember, or were told about, receiving a blood transfusion, particularly in the context of surgery or childbirth. Transfusion history is not routinely asked for or recorded by general practitioners (GPs) and historical records can be difficult to obtain [7]. Former injecting practices are also not necessarily documented. Many former injectors will no longer be in touch with drug treatment services – or will have never been, particularly if their drug use was experimental, opportunistic or recreational and occurred some decades in the past. The primary point of care for many former injectors is a general practice, with the targeting of ‘older’ (>40 years) former injectors recommended as a high priority for case finding in these settings [6,8].

Primary care HCV case-finding studies in the UK have identified a number of barriers to testing uptake among
PWID and other risk groups in general practice settings. Many of these pertain to current or recent injectors, such as limited venous access, unstable lifestyles, competing priorities, GP reluctance to test based on re-infection concerns; reliance on drug treatment services (DTS) to address HCV and lack of shared data systems with DTS [9–11]. Barriers to the identification of former injectors include GPs’ reticence to ask about risk practices, low HCV prioritization and knowledge among many GPs, complex GP administration systems and inconsistency of coding for injecting practices [9–11]. These insights into testing and case-finding barriers are, in the main, informed by GP perspectives, with a dearth of qualitative research exploring the context of late presentation, or delayed diagnosis, from the patients’ perspective.

This article reports findings from a study that aimed to assess the context of a self-reported HCV testing delay and late diagnosis from the patients’ perspective. Unlike HIV, there is currently no consensus definition of late presentation for HCV. Here, we use the term ‘delayed diagnosis’ as— unlike ‘late presentation’—this does not place an onus on the individual’s engagement (or lack thereof) with healthcare services. For the purposes of this study, we define ‘delayed diagnosis’ as a diagnosis occurring >15 years after a self-reported transmission period. This has limitations in that it precludes all individuals for whom risk practices are ongoing and period of transmission ill-defined, but has the advantage of being able to capture a distinct and under-researched population: people who formerly injected drugs, often for a defined period many decades ago; migrants from endemic countries; and recipients of blood products and transfusions prior to 1991. A primary study objective was to identify the barriers that impact on this heterogeneous population to improve case finding and diagnosis initiatives outside of DTS. This need is particularly acute, as many in these populations have lived undiagnosed with HCV for several decades, increasing the risk of advanced liver disease. Few will be in touch with drug treatment or custodial services and therefore are less visible as part of an ‘at-risk’ population.

MATERIAL AND METHODS

The study reports findings from a qualitative longitudinal study exploring experiences of the HCV treatment journey from patient and provider perspectives. Data were collected between 2012 and 2015 and comprised 108 depth interviews (1–5 interviews with 28 people living with HCV, single interviews with 10 providers and eight stakeholders), demographic and symptom data, and 100 h of HCV clinic observations. Self-reported HCV testing and diagnosis delay was a recurring theme in interview and observation data analysis. To investigate this issue further, three focus groups were conducted in collaboration with The Hepatitis C Trust in 2014. A delayed diagnosis survey instrument was developed and tested in conjunction with the focus groups and is piloted on The Hepatitis C Trust website. The sample selected for this study comprises 28 participants (interviews: 12, focus groups: 16) sampled for a recent HCV diagnosis (<3 years) and self-reported historical risk factor period (>15 years). Diagnosis in the past 3 years was chosen to reduce recall bias and ensure identified testing barriers were of contemporary relevance.

Interviews

Of the 28 ‘HCV treatment journey’ interview participants, 11 are included in this analysis—all recruited through two London hospitals. Thirteen participants reported a HCV transmission window period over 15 years before their first HCV test, with eleven recently diagnosed. In-depth interviews, averaging 100 min in duration, were audio-recorded and conducted in private rooms at the participating services or in participants’ homes. An additional interview was conducted with an eligible participant who was unable to attend a focus group.

Focus groups

Three targeted focus groups were conducted in collaboration with The Hepatitis C Trust. Participants were recruited through two London hospitals and through The Hepatitis C Trust newsletter and website. Participants were theoretically sampled for those with a recent HCV diagnosis (<3 years) and a historical transmission period (>15 years before diagnosis). Sixteen eligible participants attended three focus groups. The audio-recorded groups were held in a Hepatitis C Trust meeting room, facilitated by the lead author and were of 4 h duration.

Analysis

Audio files were transcribed verbatim; analysis was assisted by NVivo10 qualitative software. Interview data were coded as collected to inform the direction of subsequent interviews, coding and case selection. Following a grounded theory approach, open and in vivo codes informed the development of a provisional coding frame which was modified with the inductive analysis of each interview transcript [12]. Data from the focus groups were analysed alongside the 12 relevant interviews with attention to delayed diagnosis and testing context.

Ethical approval

The Hepatitis C Treatment Journey study and additional focus groups received ethical approvals from NRES London-Chelsea (12/LO/0652) and London School of Hygiene & Tropical Medicine Research Ethics Committee (6115). All participants provided signed consent prior to data...
collection and are assigned pseudonyms. Interview participants received £20 for their time and expenses, and focus group participants, £40.

RESULTS

Participants identified a number of interrelated factors contributing to their HCV testing and diagnosis delay. We report these under the following grouped categories: relevance and felt wellness, stigma and the compartmentalized self, unexplained symptoms and GP inaction. Trust was impacted by a delayed diagnosis. We touch on this, before overviewing the context of participants’ HCV diagnosis.

Sample characteristics

The total sample (n = 28) comprised 17 men and 11 women, with an average age of 54 years (range 30–70). Participants’ identified transmission period ranged from 1970 – 1990, with an average delay of 28 years to diagnosis (range 18–42). Identified risk practices comprised: drug injecting (n = 11), blood transfusion (n = 7), medical practices in country of origin (n = 3) and selling blood (n = 1). Six participants were unsure (or unwilling to disclose) how they acquired HCV, but believed transmission occurred >15 years prior to diagnosis. Forty per cent of the sample (n = 11) had liver cirrhosis at the time of HCV diagnosis, and only one participant had ever been on opioid substitution therapy (OST) or in touch with DTS. Participants resided in a variety of UK locations: London, Southampton, Oxford, Northumberland, Somerset, Wales and Worcestershire.

Diagnosis delay

Relevance and felt wellness

The majority of participants had either not heard of HCV prior to their diagnosis, or did not perceive it as personally relevant. Limited demarcation between the different viral hepatitides could result in erroneous perceptions of prior testing and immunity:

I thought hepatitis was a generic illness and I remember saying to him [GP], ‘But I can’t have that I’ve been vaccinated against it’, from having travelled, I assume I’d had a hep vaccine. I had to come off the phone and Google it, I didn’t know what it was. (Helen)

Helen had heard of HCV prior to her diagnosis, but did not connect with the information provided: ‘I’d heard of Anita Roddick . . . there was no connection and I was so well . . . I was totally disinterested, I just didn’t think I was ill’.

Sam, despite frequent contact with others with HCV, spoke of his limited knowledge and, like Helen, contextualized this in terms of felt wellness:

I’ve spent the last 30 years of my life full of people with hep C and addiction problems. But I was fit and well . . . The idea that if you have no symptoms you can’t be ill is quite a powerful notion. And I didn’t know anything about hep C really and I didn’t know that it could sit dormant for decades. (Sam)

Sam and Helen, both middle-aged professionals, had injected drugs for a short duration in the 1980s. They had never sought help from DTS, been on OST or felt any reason to disclose their past injecting history to their GP. This lack of visibility or identification as a former drug user, combined with their apparent good health, meant that for many years they were neither offered – nor sought – a HCV test.

Stigma and the compartmentalized self

Bella, like Sam and Helen, did not readily identify with her past injecting practices. She had injected drugs briefly in her late teens, with no other risk practices reported until she was diagnosed with both HCV and cirrhosis in her late 50s. Bella was one of the few participants asked screening questions prior to diagnosis. She chose not to disclose her injecting history due to a fear of judgement and confidentiality concerns: ‘they [GP] know your family . . . it was a small village and everybody knows everybody’. Matt, who injected in the early 1970s, experienced a decade of ongoing health problems for which he tried to find answers:

I had as many tests as they deemed necessary to try and find out what it was, and it went on and on but obviously I didn’t get the hep C test then. No GP has ever said ‘Have you used drugs?’ Because there was a huge stigma and there still is a huge stigma.

Matt was one of the few participants to ask for a HCV test. This request was, however, made two decades after he first heard of HCV and a decade after he began seeking diagnostic help. Matt conceptualizes this delay in terms of a disconnection from former risk practices:

It does [involve a disconnect] for me. I mean I have used some other softer, recreational drugs over the years, on and off, but I’ve never been involved in any injecting since that period so long ago and I didn’t really want to think about it.

While Matt believes there is a considerable need for awareness materials about HCV, he is not sure if they would have prompted him to action, saying: ‘I still wouldn’t really have connected myself with [injecting]’.

Jane, like Matt and Bella, injected for a short period – she describes ‘going off the rails’ as a teenager before ‘turning my life around’. Despite working in a hospital, including some contact with people with HCV, Jane did not seek a test during a lengthy period of illness. She does not
believe increased HCV awareness would have helped, stating:

I don’t know whether I’d want to know. The shame of it… I think what I’d put my family through… maybe… I didn’t want to go back to it being so long ago, it was 30 years ago… I think it’s just if they’d screened me and then I have to face it, which is what I’ve done.

Notable here is the desire for a routine HCV test to be instigated, taking the responsibility for action and the concomitant connection with prior risk behaviours away from the individual. For Moira, this was also the case. She felt that her role as a nurse prohibited her from disclosing any prior risk practices and notably refers to herself in this period as ‘that other person’: ‘I was ashamed of it, I didn’t want people to know. Plus being a nurse I couldn’t admit to being that other person that I had been for the decade before’.

Unexplained symptoms and GP inaction

While felt wellness constituted a barrier to HCV testing for some, others – such as Matt – spoke of years of ongoing ill health, for which they had sought medical help to little avail. Experienced ill health could be severe, with repercussions for work and family life:

I left work before I was diagnosed because I just didn’t feel safe, my memory and the fatigue and just lots of niggles, and I didn’t feel safe anymore working in an ICU unit. (Jane)

Jane injected briefly in her teens, approximately thirty years before her HCV diagnosis in 2013. She spoke of years of help-seeking for persistent unexplained symptoms, culminating in a hysterectomy. Sarah also described ‘losing my job through illness’ and of having her symptoms attributed to ‘women’s problems’:

I asked my doctor when I was feeling ill, for about four or five years, and firstly, ‘Oh you’ve got an infection’, or, ‘There’s something wrong with down below’, being a woman, a lot of doctors do say it’s down below, it’s the answer for everything, ‘It’s your hormones’ but I said, ‘Well can’t you just…’ ‘Oh no no, we wouldn’t want to run loads of tests because there might be a little marker or something and it would scare you, like cancer or something, so we don’t do lots of tests’.

GP’s were variably described as attributing high liver function test (LFT) results to alcohol use, lacking HCV knowledge and being reluctant to test:

They do the first test and if that’s slightly high ALT, like the doctor says ‘Well I really don’t think you’ve got this [HCV] because you drink a reasonable amount’. So if I hadn’t insisted I wouldn’t have got the second test, he said it was like £5 for the test but I don’t know if that was the first test or the second test because the second test is a lot more expensive, I know it’s a bit like PCR and that is a lot more expensive. It’s about £300 isn’t it? (Anton)

Anton’s quote, while indicating some confusion about the testing process, highlights a recurrent theme in the data – perceived testing expense. As Nikki says: ‘It’s really frustrating that you go to your GP and the blood test is too expensive to do as a routine’. And Helen: ‘[My GP] said it was really expensive’.

Trust

Experiences of delayed diagnosis, combined with perceived testing and treatment expense, were often spoken of with bitterness. This was particularly the case when identified transmission was due to a blood transfusion:

And it’s like they’re not looking for people, as far as I can tell, it would be too expensive to find people that were infected through blood transfusions, the sooner you die quietly, the better for them [the NHS]. (Cheryl)

Cheryl’s comment speaks to a generalized mistrust and cynicism in relation to the UK health system. While this mistrust was not shared by all, it reflects a perception among the majority that HCV, and people living with it, is of low priority to the NHS. A lack of visible information about HCV and the medical ignorance that some encountered affirmed this belief.

Diminished trust was particularly compounded among those diagnosed with cirrhosis in conjunction with HCV. This is a clear indicator of diagnosis delay and was experienced as devastating for some. Bobby had been receiving OST for thirty years, prescribed by the same GP for the past eighteen years. He expressed considerable anger that he had not been offered a HCV test during this time, impacting on his perception of his GP and her competency to treat other conditions:

It’s been going on for over a year now, the weeing… I keep telling her [GP], she ain’t done nothing, the stupid cow… I’m going to put my foot down, I want tests done and I want them done straightaway. (Bobby)

Bobby was found to have cirrhosis at the time of HCV diagnosis. A subsequent treatment attempt was unsuccessful. The full course of interferon-based treatment possibly precipitated a chest infection, leaving Bobby dependent on long-term oxygen treatment.

Justine, like Bobby, already had cirrhosis when she found out she had HCV. Like many of the other participants, she had injected briefly in her teens with her first HCV test thirty years later. Justine could not recall hearing of HCV prior to diagnosis and attributed her lack of knowledge, in part, to its low visibility:
There’s nothing about hep C in the doctor’s surgery, there’s nothing even about hep C in the hepatology clinic, you’d think that it’s about liver health, there’s nothing about hep C. You’d think there’d be a poster wouldn’t you? At least! But there isn’t.

Justine’s vehemence speaks to the way that awareness materials can not only educate but affirm. The absence of HCV resources, in medical and other spaces, was experienced not only as a barrier to awareness but also as acting to compound HCV stigma – by rendering the experiences of those living with the virus unimportant, irrelevant and invalid. This, in turn, had implications for the participants trust in, and engagement with, their healthcare practitioners.

**Testing context**

For the majority of participants, their eventual HCV test and diagnosis were occasioned by a change of GP or a chance encounter with another medical professional. Bobby’s diagnosis resulted from an unrelated hospital procedure: it was the nurse who sussed it. When I had my shirt open, she looked at my chest and she said ‘I think you’ve got hepatitis’. Similarly, Andy was diagnosed due to a chance hospital-based encounter:

> Going into hospital many times and having liver function tests because of having jaundice, EDS and stuff like that, they had plenty of opportunity to come and find me … And not once, until I got this lovely lady who said, ‘I’m very concerned you’ve never been tested’, and that took one lady, I wish I’d found her years ago. (Andy)

A number of participants had visited their GP for years with unresolved health issues. It was only when seen by a different GP that they received their first HCV test and diagnosis. Tim spoke of his ‘new doctor’ who immediately diagnosed him:

> The phrase ‘it came up’ in the quote above is telling. Sam did not request a test, even when becoming unwell. He was aware of prior risk but hoped he had ‘dodged that bullet’ and did ‘not really want to know’. In this context, it appeared that in order for HCV to come off ‘the back burner’ it was necessary for the test to be instigated by a GP – thus removing the responsibility for, and connection with, past identity necessary to request a test.

**DISCUSSION**

If the promise of HCV elimination – or even HCV-related mortality reduction – is to be realized, strategies to enhance HCV case finding and diagnosis must improve. The majority of interventions and research in the UK context focus on the most easily identifiable at-risk populations – people who are currently injecting and/or who are in touch with criminal justice or drug treatment services. Barriers to testing uptake for current PWID in the UK have been identified and include the following: concerns regarding discrimination and confidentiality breaches; fear of a positive test result and its implications; poor venous access and lack of alternative testing mechanisms (oral swabs, dried blood spot, jugular/femoral venous access); lack of colocated services; poor data sharing systems and limited HCV knowledge among PWID and providers – including about HCV treatment eligibility [9,11,13,14]. The introduction of dried blood spot testing in custodial and drug treatment services can help to ameliorate some of these barriers [15] as can the provision of community-based HCV testing and treatment, particularly when provided in a context of trust with flexible appointment systems. Meaningful peer involvement and minimal restrictions on treatment eligibility [16–19].

Less is known about the barriers to diagnosis facing other populations affected by HCV, many of whom are arguably less easy to identify. We report findings from a sample of 28 people who identify a recent HCV diagnosis (<3 years) and a historical transmission risk period (>15 years). The majority described a discrete injecting period in the late 1970s–early 1990s (39%) or a blood transfusion prior to 1991 (25%). The average self-reported
delay between transmission risk period and first HCV test was 28 years, with 40% of the sample cirrhotic at HCV diagnosis. Only one individual had been on OST or in contact with a DTS. The reliance on self-report to establish diagnosis delay is a study limitation; however, the high incidence of cirrhosis in the sample at diagnosis indicates self-report validity. Twenty-one per cent of the sample reported being unsure of transmission route, posing a limitation in terms of ascertaining transmission period. It is probable that many of these individuals chose not to disclose historical injecting practices, particularly as the majority (67%) participated in focus groups where confidentiality concerns can be more acute. An initial report of these findings was circulated to focus group participants who provided respondent validation [20]. We make no claims for generalizability, given the sample size, but believe that the study provides important insights into HCV testing barriers for never and former injectors.

The HCV testing needs and barriers impacting the study sample differ from those reported for PWID. Although lack of HCV awareness is a testing barrier common to many study populations [13,21,22], barriers posed by GP inaction, limited HCV relevance and a compartmentalizing of former injecting were unique to this study sample. Not in touch with DTSs, GPs were the primary point of contact for the majority. Participants described not being asked screening questions; not being offered a HCV test in the context of high LFTs and/or ongoing unexplained symptoms; and GP reticence to test in relation to the ‘expense’ of HCV tests. Few participants actively sought a HCV test, even when risk aware. Evident was a preference for GPs to instigate testing, thus reducing the onus of individual responsibility and de-emphasizing the role of potentially stigmatizing risk practices. This finding has implications for the success of targeted case-finding initiatives in the UK, which rely on patient record searches for noted risk factors. In the context of limited cost-effectiveness evidence for widespread screening initiatives in the UK [23], there is a need to incorporate other markers of potential risk than injecting alone. Surrogate markers such as incarceration and OST history are unlikely to identify former injectors who have not come in touch with services. The addition of raised ALTs to screening algorithms, although associated with a number of other conditions, might be necessary to aid identification of HCV among hidden populations.

While our findings indicate that risk awareness does not necessarily result in action, this does not mean that HCV awareness initiatives should be deprioritized. The majority of participants spoke of seeing very little information about HCV, so it is difficult to tell what impact increased HCV visibility would have on seemingly intractable barriers to testing. Participants indicated that the limited visibility of HCV as a public health issue acted to perpetuate stigma, also influencing their perception that HCV was of limited priority to the NHS. An experience of diagnosis delay, especially when attributed to GP inaction, impacted on participants’ trust in their healthcare providers and attitude towards future care. It is notable that the majority of participants received their first HCV test in the context of changing doctors, with the diagnosing doctor often spoken of as younger and ‘clued up’. While there is an evident need for enhanced GP training and awareness in regard to HCV, these findings also indicate that recent GP training initiatives [24] might be having a positive impact.

In England, an estimated 89 000 people living with HCV are former PWID [25]. Recent data indicate that 83% of the 27 434 undiagnosed in Scotland belong to this category [26]. This is an ageing population, with many commencing injecting during the surge in injecting drug use in the UK in the 1980s. Also ageing, are the population who contracted HCV through an NHS medical intervention prior to 1991. For both, the chance of HCV-related morbidity and mortality is high. The number of people estimated to have contracted HCV through a blood transfusion from 1981 to 1991 in England is comparatively low: 14 000, with many now deceased [27]. This is, however, an important constituency. The recently released Penrose Inquiry, reporting 7 years of data collection, contains only one recommendation in its 1811 pages: ‘That the Scottish Government takes all reasonable steps to offer an HCV test to everyone in Scotland who had a blood transfusion before September 1991 and who has not been tested for HCV’ [28]. No recommendations are provided for finding this population or what the ‘reasonable steps’ might entail.

This study illustrates the need for a multipronged approach in the UK to increase HCV case finding among hidden populations, such as blood transfusion recipients and former PWID. While increased visibility and awareness of HCV can enhance testing uptake, stigma and confidentiality concerns will still preclude access for some. Here, take-home pharmacy-purchased rapid diagnostic tests [29] can aid access. For participants who reported compartmentalization of previous injecting, this strategy is unlikely to work. Most expressed a strong preference for GPs to instigate routine HCV testing, with little desire to adopt the ‘expert patient’ role promoted by the NHS. A broadening of screening criteria is therefore recommended, dependent on acceptability and cost-effectiveness. This could include screening people with persistent high ALTs, particularly in the 40–60 age cohort, and/or integrating HCV testing with extant screening programmes, such as for diabetes or cardiovascular disease. Screening should never preclude consent. The majority of participants were not asked screening questions – illustrating that recommendations for this practice in GP services [5] have not been widely implemented. Although many will not necessarily disclose an injecting history, it is imperative that all identifying receipts of blood products or transfusions prior to 1991 are offered a HCV test.

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CONCLUSION

Our findings illustrate that, even in a context of heightened awareness, HCV testing will not necessarily be instigated by the affected individual. This is due to the barriers posed by felt wellness; lack of perceived relevance; injecting-related stigma; and a compartmentalization of past drug use. A strong reluctance to revisit or identify with past drug injecting made it difficult for some participants to connect with injecting risk-related messages, or to ask for a HCV test. A diagnosis delay can impact on transmission potentials, disease progression, treatment success, quality of life and trust in healthcare services. There is a need for a multipronged approach in the UK to increase HCV case finding and diagnosis among hidden populations. Potential components include the following: broadened screening criteria, pharmacy take-home tests, GP and public awareness initiatives, as well as peer-based and community testing initiatives.

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