

Impact of a positive hepatitis C diagnosis on homeless injecting drug users: a qualitative study

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ABSTRACT

Background

Increasing numbers of injecting drug users are presenting to primary care and a growing number of general practices are specifically providing care for homeless people. Injecting drug users are at the greatest risk of hepatitis C infection and homeless drug misusers, because of their drug-taking behaviour and patterns, have been identified as being at greater risk of harm of blood-borne diseases than the general population. However, little work has been conducted with injecting drug users or homeless people who have hepatitis C and little is known about how the virus may affect them.

Aim

To explore the impact of a positive hepatitis C diagnosis on homeless injecting drug users.

Design of study

This study employed qualitative research. In-depth interviews allowed the exploration of the impact of a potentially life-threatening diagnosis within the context of a person's expressed hierarchy of needs.

Setting

A primary care centre for homeless people in the north of England.

Method

In-depth interviews about the impact of a positive hepatitis C diagnosis on their lives were conducted with 17 homeless injecting drug users who had received a positive hepatitis C diagnosis. The interviews were audiotaped, transcribed, and analysed using the framework approach.

Results

Receiving a positive diagnosis for hepatitis C resulted in feelings of shock, devastation, disbelief, anger, and questioning. A positive diagnosis had lasting social, emotional, psychological, behavioural, and physical effects on homeless injecting drug users, even years after the initial diagnosis. Most responders were diagnosed by a doctor in primary care or by hospital staff; however, not all had sought testing and a number were tested while inpatients and were unaware that blood had been taken for hepatitis C virus serology.

Conclusions

The implications for clinical policy and primary care practice are discussed, including the issues of patient choice, confidentiality, and pre- and post-test discussions. Post-test discussions should be followed up with additional social, psychological, and medical support and counselling.

Keywords

hepatitis C; homeless persons; intravenous drug abuse; primary care; qualitative research.

INTRODUCTION

Intravenous drug use is the main mode of transmission of the hepatitis C virus^{1,2} and an estimated 50–80% of injecting drug users in the UK are infected.³ In the UK, homelessness remains a common social problem⁴ and general practice has become more engaged with working with this marginalised client group. This is due to GPs developing a special clinical interest in substance misuse.⁵ Also, there has been a steady increase in the number of general practices working specifically with homeless people as a result of personal medical services (PMS) schemes.⁶

Homeless people and drug misusers have been identified as being at greater risk of infection with blood-borne viruses than the general population.⁷ Although injecting drug use is the main expressed health need of UK homeless populations,^{6,8,9} few studies have explored the psychosocial effects of a laboratory-confirmed positive hepatitis C virus diagnosis. Although some qualitative work has been conducted with people with a positive hepatitis C diagnosis, the study population^{10–13} was not specific to homeless people or injecting drug users. Therefore, it is questionable how transferable the findings are to this homeless/drug-injecting population,¹⁴ who are not thought to prioritise their health needs.^{10–13} Our study explored the impact of a

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How this fits in

Injecting drugs is the main mode of transmission of the hepatitis C virus and an estimated 50–80% of injecting drug users in the UK are infected. Little work however, has explored what a positive diagnosis of hepatitis C means to them and how it might affect them. This qualitative research identified strong emotional responses to being diagnosed with hepatitis C. A positive diagnosis has potentially devastating and lasting social, emotional, and psychological effects on homeless injecting drug users. Improved pre-and post-test discussions in the primary care consultation for homeless drug misusers diagnosed as positive for hepatitis C are needed.

diagnosis of a chronic illness with high morbidity and mortality among a population who prioritise financial, addiction, and housing needs above health issues. The originality of our research comes, therefore, from using qualitative methods to focus on this group to examine their responses to receiving a potentially life-threatening diagnosis within the context of a person's expressed hierarchy of needs.

METHOD

This study was conducted at a UK inner-city primary care centre for homeless people. The multidisciplinary team carries out over 10 000 consultations a year, with most consultations being related to illicit drug use. A search of computerised records identified 71 registered patients (56 men and 15 women) who had received a positive antibody test for hepatitis C. Letters explaining the study and inviting participation were distributed at clinic or outreach appointments. These included a pre-interview request for current accommodation and contact details and information on the length of time injecting drugs. Posters in the health centre also advertised the research. The sample was then purposively selected to ensure diversity across primary variables, including current accommodation, time since diagnosis, and injecting drug use history. Age and sex were monitored as secondary variables. Interested patients were introduced to the researcher and a convenient interview time was arranged.

A topic guide was used in in-depth interviews, which explored homeless injecting drug users' attitudes to, and experiences of, hepatitis C. The key themes included injecting drug use, receiving the positive diagnosis, and its impact on behaviour and lifestyle. After seeking ethical approval, confidentiality and the right to withdraw without affecting their care was explained and written consent was obtained from each participant. A non-clinical researcher interviewed 17 homeless injecting drug users with a hepatitis C-positive status.

The interviews lasted from 30 to 90 minutes and were audiotaped and transcribed. A £10

supermarket voucher was given to each participant on completion of the interview. The interviews took place over a 12-month period and were conducted in private at the health centre, in a custodial institution, and on a hospital ward.

The transcripts were analysed using the categories that emerged from the interviews. The primary researcher analysed the interview data manually. The other authors also independently identified key themes from the transcripts and the team had fortnightly discussions to facilitate the analysis and interpretation. A framework approach provided a structure to allow detailed analysis of the emerging themes and concepts.¹⁵ This involved coding each transcript to identify important categories. These categories were revised and condensed and then formed a framework chart for individual responders. All interview responses were entered on the chart. This chart provided a framework for analysis of peoples' accounts, which included the range and diversity of responses. The quotations presented in the results reflect the diversity of responses from participants. In order to protect anonymity, the responders were each given a unique number, which is presented at the end of their quoted speech in place of their names.

RESULTS

Fifteen homeless men and two homeless women were interviewed. All were Caucasian and from the UK, except for one southern European. Although this reflected the ethnicity profile of single homeless people attending the health centre, women were slightly under-represented among responders. The study participants ranged in age from 22 to 49 years with injecting drug histories ranging from 6 months to 20 years. A few had histories of chronic repeated homelessness, although they were currently sustaining their own tenancies; most, however, were either living in hostels, or bed and breakfast accommodation, staying with friends, or sleeping rough. Two responders were staying in institutions with no planned accommodation upon release/discharge. All had received a positive antibody test for hepatitis C virus, and five of them had had a polymerase chain reaction (PCR) confirmation at the time of interview. Three patients had had a liver biopsy; two were awaiting biopsy appointments. The time since diagnosis (which we took to be the first antibody test) ranged from 1 week to over 10 years.

Testing, diagnosis, and response

Tests for hepatitis C took place in primary care or in hospital. Although some responders sought testing, others were unaware that blood had been taken for hepatitis C virus serology while they were in hospital.

This was a recurrent theme and raised important issues about pre-test discussions and patient choice. Most received the diagnosis from a doctor in primary care or by staff in hospital, but one received it from an ambulance worker and another from a family member via a doctor. The way in which the diagnosis was given concerned some participants, as this hostel resident expressed:

'The doctor came in and he said, "Oh I've got your results here and I'm sorry to say that you've got hepatitis C" and left.' (Responder 2.)

A 48-year-old, who did not seek hepatitis C testing, commented:

'I was just stunned, I thought, you are telling me I've got hepatitis C and you just say it like you were saying hello to me and he just walked away.' (Responder 3.)

Receiving a diagnosis of hepatitis C led participants to question how they had contracted the infection. Participants believed that injecting drug use, particularly the sharing of injecting paraphernalia items such as spoons (rather than needles and syringes) was responsible for hepatitis C positivity. Knowing the occasion and from whom it was contracted was not unusual as, despite disclosing risk behaviours, responders described something different about that particular injecting incident from their normal practices.

'I got the hepatitis C injecting amphetamine and I know how, I even know the person you know, everything, because it's so starkly stuck in my head because it was once.' (Responder 1.)

Others believed their hepatitis C was either contracted through unprotected sex, sharing a personal toiletry item, or being tattooed in prison with a needle that had been commonly used for injecting. Even those who could not specify how they contracted the virus felt the need to do so as it appeared to 'make sense' of the diagnosis.

Receiving the positive diagnosis had a significant emotional impact on all of the study participants. Initial responses included feelings of disorientation, shock, devastation, disbelief, and anger, as illustrated by this man:

'I couldn't believe it, you know my head was in a jumble and for about a week after. I didn't talk to the nurses or that. I didn't want any visitors or anything. I was just sat in the corner of my room.' (Responder 2.)

Using drugs at the time of diagnosis meant some reactions were muted, but not for all current users. Blame was a common reaction, either directed at themselves or towards those they felt to be responsible. Some responses involved anger and violent outbursts towards people or property. The hepatitis C diagnosis also led to responders' fear of premature death, from imminent death, to ideas that they had 5 or 15 years left to live. Strong language expressed these feelings and the diagnosis was occasionally likened to receiving a 'death sentence/warrant' or a 'curse.' One responder described this:

'I thought I was a goner, I thought I was going to die, you know what I mean? I thought this disease was going to get a grip of me and make me die an awful death.' (Responder 7.)

These beliefs had different responses. Some felt that they would make the most of the time they had left, while others were more fatalistic — one participant contemplated suicide. Other negative feelings raised by the diagnosis were directed against themselves, including self-disgust, shame, regret, and annoyance. This meant that many didn't want to talk about it. Others, however, described feelings of acceptance and re-adjustment:

'At first I was devastated but to be honest with you I think I've just come to terms with it, you know what I mean? We've all got to die anyway.' (Responder 4.)

A current injector said:

'I don't have no emotions to it anymore, it doesn't upset me, I don't get wound up about it or anything like that, what's done is done, I can't change it now, can I?' (Responder 7.)

Other responders remained anxious about having hepatitis C, particularly during times of minor illness:

'I've got a bad stomach ache and I'm going to the toilet all the time and I'm thinking, "well is this the hep C starting you know, to kick in, so to speak" and then you end up better the next couple of days so you put it down that it isn't.' (Responder 4.)

Psychosocial impact and knowledge

There was a psychological impact associated with having a positive hepatitis C status, even for those responders who said that they were 'not bothered' about having it. People described how much they thought about it, with one participant (responder 9)

commenting that, 'There's not a minute that goes by that I don't think about it and regret it'.

There was overlap between the psychological and social impact of the diagnosis. People described being more concerned for others, especially for their children and partners, than for themselves. One man stated:

'It don't bother me so much, it bothers me about my girlfriend'. (Responder 12.)

Disclosure also evoked mixed responses. Many participants thought it was 'morally right' or they felt 'obliged' to tell others about their diagnosis. This included family, friends, partners, other injectors, hostel workers, dentists, support groups, and housemates. However, participants were often anxious about telling others, as reactions were unpredictable. Some negative reactions included disbelief, being upset and denial from families or from other injectors, which made some responders hide their diagnosis. Fears about others' reactions and whether their family or friends would still associate with them resulted in some concealing their hepatitis C status. A 26-year-old expressed this fear:

'I'm having to lie to people all the time, you know what I mean and stuff like that. Even me own family, I can't tell them.' (Responder 9.)

Another responder described telling people about the diagnosis:

'I thought it was only right they should know but I only did that about twice and then it got around town.' (Responder 17.)

Others' ignorance about hepatitis C was given as a reason for not disclosing or talking about it. This ignorance accounted for the stigma associated with having hepatitis C and people described how other injectors likened it to HIV or AIDS:

'A lot of people think it's like AIDS or something like that. They think it's really bad, keep away from thing, you know, yeah a lot of people, just because people don't know about it, they treat it like AIDS or something.' (Responder 3.)

Another negative effect was the impact on social life as highlighted by this responder:

'Before I found out I caught it I used to have a laugh with people and that, you know what I mean? But now, I just don't and like I spend most of me time on me own. I don't go out socialising, I've stopped socialising with people.' (Responder 16.)

There was also an impact on relationships. Where people had told their partners, it appeared that they acted supportively. However, those not in relationships raised doubts about telling future partners. Male participants felt that hepatitis C reduced or stopped their chances of having heterosexual relationships, as expressed by this man:

'It stops me going out and getting a girlfriend and stuff like that. It bothers me in ways like that, having hepatitis C.' (Responder 5.)

There were also real fears about having children for some male participants:

'If they wanted to have kids or stuff, I'd be stuffed won't I cos I mean, how am I going to talk my way out of that one?' (Responder 9.)

'It depresses me now. It sort of puts the lid on having a family now and that's the bad, the bad depressive side of it, I can't sort of make my own family now.' (Responder 16.)

People mentioned encountering negative experiences from other injectors and the wider community as a result of having hepatitis C. Many professionals, including hospital staff, dentists, and the police treated them negatively. One responder described how their computerised police file flashed a warning when accessed and that officers wore rubber gloves around them. Others described how people thought they should use separate eating utensils and showers. Such responses, especially from professionals, resulted in participants feeling angry and 'contagious'. One responder described their hospital experience:

'They [hospital staff] said use the commode, they didn't say why and then I said, "is it cos I've got hep C?" and they said yeah.' (Responder 17.)

A 46-year-old spoke of their experience at the dentist:

'He [dentist] claimed to not have the sterilising equipment that would be required in order to treat me and that he'd have to refer me to a specialist.' (Responder 11.)

Participants believed that such stigma resulted from the association of the hepatitis C virus with injecting drug use. The same 46-year-old (responder 11) stated:

'He [the dentist] automatically expects you to have had a needle stuck in your arm.'

Although a range of possible symptoms were described, there was no uniform experience of symptoms attributed to hepatitis C. Differing levels of hepatitis C-related knowledge were identified. Even those who had been diagnosed a number of years before had important gaps in their knowledge:

'It can affect your kidneys, erm, am I right in saying that? Actually I'm not even sure now. It can either affect your kidneys or your liver.' (Responder 3.)

In general however, a positive hepatitis C diagnosis led to improved knowledge.

People showed better knowledge about the transmission risks, but were confused about whether hepatitis C could be sexually transmitted. Additionally, although some had heard about treatment, others were uncertain if hepatitis C could be prevented or treated:

'I don't know if there's a cure for it. I don't know if there's a drug to prevent you getting it like there is with hepatitis B.' (Responder 7.)

Current epidemiological evidence that some can clear the hepatitis C virus may not have been fully explained to some participants and was also a source of confusion:

'I was so much under the impression that I got it, I had it and I kept it and I know a lot of people are like that.' (Responder 1.)

In general, participants welcomed more information to help overcome their confusion.

DISCUSSION

Summary of the main findings

Homeless injecting drug users had strong emotional responses to testing positive for hepatitis C. These responses were akin to bereavement reactions and to receiving positive HIV test results.¹⁶ The way that a positive hepatitis C diagnosis impacted on homeless injecting drug users is an important finding, especially for primary care. In particular, the effect of the diagnosis on homeless injecting drug users challenges many negative assumptions regarding the value that these patients place on their health.

Long-term psychosocial effects of the diagnosis included depression and anxiety about sexual relationships and having children. Many felt stigmatised by the diagnosis and were, therefore,

often reluctant to disclose it. This threatens the potential for hepatitis C-related support. Our research identified that some homeless injecting drug users were tested for hepatitis C without giving informed consent or without any pre-test discussion. This was worrying, especially considering the importance of obtaining patient consent and conducting pre-test discussions.¹⁷⁻¹⁸ Although knowledge generally improved after the diagnosis, some still had limited knowledge about the virus.

Strengths and limitations of the study

As one of the first qualitative studies based solely on homeless injecting drug users with hepatitis C, we accessed a marginalised and hard-to-reach sub-population of injectors. We identified that homeless drug users with hepatitis C have concerns about the virus. This may challenge a number of commonly held stereotypes about homeless drug users and their perceived hierarchy of needs. In particular, it is often assumed that homeless people place a low value on their health. However, homeless injecting drug users expressed real concerns in relation to their quality of life and their future health status as a direct result of the positive hepatitis C diagnosis. Although it could be argued that such responses were given to please the interviewer, this is unlikely as the same participants described engaging in high-risk injection practices and also acknowledged sharing items of injecting paraphernalia. Gaining trust, assuring confidentiality and talking in an open and non-judgmental manner was instrumental at putting participants at ease and allowed them to talk freely.

The limitations of the study were that female injecting drug users with hepatitis C and homeless drug users from ethnic minorities were under-represented. This could be addressed in future by sampling from multiple centres.

Implications for clinical practice and future research

Our research raised implications for future practice. It highlighted the importance of training generic hospital staff in pre-test discussions and informed consent prior to offering serological testing for hepatitis C virus. This may avoid some of the strong emotional responses to the positive diagnosis.

For those made aware of their diagnosis in hospital without any pre- or post-test discussion, there is a counselling role for primary care practitioners. There is also a need for improved post-test discussions, and sensitive testing could minimise some of the potentially devastating affects of the diagnosis among homeless injecting drug users. This research has also highlighted a need for ongoing support and counselling beyond initial post-test discussion. It is

appropriate that much of this takes place in primary care consultations.

Setting up local and national support groups for injecting drug users with hepatitis C also warrants further investigation. Information, support, and counselling should also be more readily available for close friends, family members, and other injecting drug users as their increased understanding may lessen discriminatory attitudes, reduce feelings of alienation, and increase support for those who have been positively diagnosed.

The findings also raise implications for future research. In particular, there is a need for improved understanding about the effectiveness of current health promotion interventions aimed at reducing the

prevalence of hepatitis C. Where interventions have had limited effectiveness, new interventions should be evaluated. In particular, the possibility of training schemes for patients of GPs to assume roles of peer educators merits further research activity.

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Ethics committee

The Leeds Teaching Hospitals Local Research Ethics Committee approved the study. Reference 02/155

Competing interests

None

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