

Experiences of diagnosis, stigma, culpability, and disclosure in male patients with hepatitis C virus: an interpretative phenomenological analysis

Krzeczkowska, Anna; Flowers, Paul; Chouliara, Zoe; Hayes, Peter; Dickson, Adele

Published in:
Health

DOI:
[10.1177/1363459319846939](https://doi.org/10.1177/1363459319846939)

Publication date:
2021

Document Version
Author accepted manuscript

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):

Krzeczkowska, A, Flowers, P, Chouliara, Z, Hayes, P & Dickson, A 2021, 'Experiences of diagnosis, stigma, culpability, and disclosure in male patients with hepatitis C virus: an interpretative phenomenological analysis', *Health*, vol. 25, no. 1, pp. 69-85. <https://doi.org/10.1177/1363459319846939>

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please view our takedown policy at <https://edshare.gcu.ac.uk/id/eprint/5179> for details of how to contact us.

Article

Corresponding author: Anna Krzeczowska, University of Strathclyde, 40 George Street,
Glasgow, G1 1QE, UK

E-mail: anna.krzeczowska@strath.ac.uk

Experiences of diagnosis, stigma, culpability, and disclosure in male patients with Hepatitis C Virus: An Interpretative Phenomenological Analysis.

Anna Krzeczowska¹, Paul Flowers², Zoe Chouliara³, Peter Hayes⁴
and Adele Dickson⁵

¹ University of Strathclyde, UK;

² Glasgow Caledonian University, UK;

³ Edinburgh Napier University, UK;

⁴ University of Edinburgh, UK;

⁵ Glasgow Caledonian University, UK

Experiences of diagnosis, stigma, culpability, and disclosure in male patients with Hepatitis C Virus: An Interpretative Phenomenological Analysis.

Abstract

The current study aimed to explore the lived experience of patients with HCV infection. Semi-structured interviews were conducted with seven male participants living with HCV and were analysed using Interpretative Phenomenological Analysis (IPA). Two master themes were identified: (1) Diagnosis and the search for meaning, and (2) Impact of stigma on disclosure. Participants reported fears of contaminating others, feelings of stigma and concerns of disclosing the condition to others. Response to diagnosis, stigma and disclosure amongst the participants appeared to be interrelated and directly related to locus of blame for virus contraction. More specifically, HCV transmission via medical routes led to an externalisation of culpability and an openness to disclosure. Transmission of HCV as a direct result of intravenous drug use led to internalised blame and a fear of disclosure. The inter- and intra-personal consequences of HCV explored in the current study have potential implications for tailoring future psychological therapy and psychoeducation to the specific needs of the HCV population.

Keywords

Hepatitis C Virus (HCV), stigma, disclosure, Interpretative Phenomenological Analysis (IPA).

Introduction

Hepatitis C Virus (HCV) is a blood-borne infection of the liver that affects approximately 170 million people worldwide (Blach et al., 2017); of which 214,000 cases reside in the UK (Public Health England, 2014). Prevalence and incidence of the virus has reduced since 1990, when blood screening programmes were introduced following a series of contaminated blood-transfusions (Sy and Mazen Jamal, 2006). Currently transmission of HCV occurs primarily through intravenous drug use (Poynard, 2005). According to the most recent report by Public Health England (2017) over 90% of new infections each year are identified amongst people who inject illicit drugs.

For some individuals, acute HCV infection is a short-term disease that can be spontaneously cleared within a matter of weeks following exposure to the virus (Poynard, 2005). However, the acute form of the virus can, if more severe and untreated, often develop into chronic infection. The disease is typically asymptomatic for many years after the acute episode, when progression to severe end stage liver failure can occur. Orthotropic liver transplantation (OLT) is a life-prolonging option for many patients with Hepatitis C infection. However, postoperative recurrence of infection occurs invariably in all HCV-infected liver transplant patients and constitutes a great burden on patients' quality of life. Of those 're-diagnosed' with HCV, only 10-30% of patients progress to liver cirrhosis, developing graft failure. However, once HCV cirrhosis recurs, patients only survive up to five years after transplant (Berenguer et al., 2000). To increase survival rates of post-transplant patients antiviral therapy is used. More recently, HCV treatment has chartered new territory with the introduction of direct-acting antivirals (DAAs) that have shown efficacy of 81-100% in post-transplant patients (Pungpapong et al., 2015).

Despite increased availability and promising results of such treatments, many patients report experiences of HCV-related stigma and discrimination (Brener et al., 2015, Harris, 2009; Zickmund et al., 2003). The aetiology of such stigma is multifaceted but includes fear of infectiousness (Fraser and Treloar, 2006), social aversion to illness (Maynard, 2006), and an association with illicit drug injecting (Cama et al. 2016; Paterson et al, 2006). Research has shown that individuals who acquire HCV via medical transmission

are considered as morally, socially and politically exculpated, whereas those associated with non-medical transmission (injecting drugs) are considered as morally questionable and culpable (Duffin, 2005). Compensation claims emphasize the ‘innocent’ status of people with HCV acquired through iatrogenic means, while a blame culture exists for those who are or have been an injecting drug user (Duffin, 2005; Fraser, 2004). Duffin (2005) described this dichotomy as ‘two diseases’ that directly reflect assumptions regarding illness-related guilt, innocence and responsibility identified in previous HCV research (Fraser and Treloar, 2006).

Discriminatory reactions can also affect self-perception in those living with HCV and the way in which they internalize these reactions. Scambler (2004) described this as ‘felt stigma’ that refers to the fear of being labelled by others (‘enacted stigma’) or to the shame of having a disabling condition. Many studies reveal infectiousness, shame, guilt and ostracism as major components of HCV felt-stigma (Conrad et al., 2006; Crocket and Gifford, 2004; Lekas, Siegel and Leider, 2011). Participants often refer to themselves as infectious or as a ‘potential contaminant’; ‘a leper’ who should be avoided (Harris, 2009). Moreover, their self-perception and the embodiment of stigma are facilitated by a lack of knowledge about the disease, modes of transmission and risks of HCV in various settings (Lekas et al., 2011; Crofts et al., 1997; Paterson et al., 2006). Therefore, raising awareness of HCV is not only important in enhancing people’s ability to cope with the illness, but it can also determine a willingness to disclose their HCV status to others (Suarez, 2010).

Fear of stigma may inhibit disclosure of HCV status to others. Given the predominantly asymptomatic nature of the illness, HCV can be easily concealed- many individuals living with the condition, will, therefore, make a decision to not make ‘visible the amorphous nature of the condition’ (Harris, 2009: 44). Disclosure to family, partners and medical staff is common (Hopwood & Treloar, 2003), amid fears of transmission within families, particularly to partners and children (Lowe and Cotton, 1999).

Considering that the virus is mainly contracted parenterally by injecting drug use (90% of cases worldwide) (Wasley et al., 2008; Hepatitis C Virus Protections Working

Group, 2006), patients' fear of transmission may seem irrational. Fear can be to some extent justified by the fact that HCV is more transmissible than most of the other viruses, as it can be carried by any blood products and spread via indirect sources (e.g., used razors), but epidemiological significance of intrafamilial transmission remains very low (Centers of Disease Control and Prevention, 2017). The real reason, however, for the extreme fear that causes patients' social alienation appears to be stigma (both enacted and felt) experienced in health services and in people's own homes. This relates to the lack of understanding of the disease (Crocket & Gifford, 2004). In this way discrimination from poorly informed health professionals or significant others can erode patients' self-worth and lead to exaggerated fear of virus transmission (Butt et al., 2008).

The current article contributes to the HCV literature by exploring experiences of diagnosis, culpability, stigmatisation and disclosure across a heterogeneous sample of patients with HCV. To date, no qualitative studies have specifically addressed the inter-connection between such experiences nor how they impact the lives of patients (and their families) living with the condition. It is important to understand the interconnections as they can help predict and understand differences of responsiveness to diagnosis, stigma, and disclosure amongst patients. If they are indeed related to locus of blame for virus contraction, different psychological interventions should be tailored to meet the individual needs of patients with HCV.

Misconceptions surrounding HCV diagnosis can create not only negative public attitudes but also patients' negative attitudes towards disclosure. Exploring experiences of HCV diagnosis may help professionals to facilitate patients' positive attitudes to disclosure and their access to support. Therefore, we aimed to reveal a complex journey through the experience of the illness that might have different trajectories for different groups of patients with HCV. This study also gives 'voice' to a particular group of participants (five participants in the current study) that seldom feature within the HCV literature- patients who contracted the virus between 1970s-1980s through contaminated blood transfusion.

Method

Participants

Seven patients with HCV infection were recruited via a hospital outpatient clinic in Scotland. Participants were male and aged between 53 and 68 years (M=57.3yrs). Participants were recruited from various geographical locations in Scotland. Participants contracted HCV via contaminated blood transfusions (n=5; Gus, Harry, Jimmy, Eric, Chris) or injected drug use (n=2; Ted, Steve). Participants reported difficulty in ascertaining when they had contracted the virus and in remembering when they were diagnosed with it. However, it is noteworthy that participants who contracted HCV through blood transfusion, had undergone medical procedures before 1990- the point at which HCV blood screening was introduced in Scotland.

Procedure and interview

Ethical approval for the study was sought and obtained from Edinburgh Napier University (where the first author was based at that time) and the appropriate regional NHS ethics committee.

Recruitment packs comprising information about the study were either sent directly to patients via post (n=18) by a senior research nurse or were distributed by the transplant co-ordinators during routine appointments at an out-patient clinic (n=10). The first and last authors' details were provided in order for potential participants to contact the research team and indicate their willingness to partake. Participation in this study did not include any remuneration.

Inclusion criteria were that participants should be adults over 18 years of age who had diagnosis of HCV and were fluent in the English language. Patients excluded from this study were individuals who: (a) had not been seen routinely at the hospital; (b) had been currently receiving methadone treatment; (c) had been currently imprisoned; and (e)

had been deemed by the lead Hepatologist as being too emotionally fragile or possessing a current psychosis or other mental health condition.

The interviews were conducted by the first author and took place at either a hospital (n=5) or in participants' own homes (n=2). Interviews lasted between 32 and 68 minutes (M=50.6) and were recorded on a digital voice recorder. Written consent was obtained from the participants prior to the commencement of their interviews.

A semi-structured interview schedule was prepared prior to the interview and included open-ended questions such as 'Tell me about your experience of HCV diagnosis' and 'What impact (if at all) has the diagnosis had on your life?' The topic areas that were prepared for the semi-structured interview schedule included: experience of diagnosis, instances of stigmatization and approaches to disclosure. The interview schedule was not followed in a rigid way, and instead a process of reflecting (e.g., 'you said there that...') and probing (e.g., 'tell me more about that') was adopted. This allowed the participants to direct the content of the interview and prioritise issues which they felt were central to the topic under investigation. Interviews were then transcribed verbatim and were analysed using interpretative phenomenological analysis (IPA).

Analysis

Interpretative Phenomenological Analysis (IPA) has been predominantly applied in health psychology contexts due to its early concerns with health and illness (Brocki & Wearden, 2006). This methodology was chosen for this study as it was concerned with the interpretation of meaning and the detailed exploration of lived experiences that were reflecting authors' exploratory orientation. IPA foregrounds the experience of the individual, and hence provides a 'voice' for the lived experiences of a given clinical population. This study was also carried out in accordance with principles for validity of qualitative research defined by Yardley (2000). Thus, sensitivity to context was demonstrated by taking into account existing theoretical and empirical literature and by choosing a methodology that was most appropriate to capture the meaning of the phenomenon under investigation. Rigour and commitment were demonstrated by the author's personal engagement in the process of recruitment and data collection, and by

recording data objectively and comprehensively (i.e. voice recording). Authors were focused on idiographic engagement in data analysis, illustrating particularities of individual cases by using appropriate quotes, but they did also emphasize the importance of shared experiences in formulating the major themes.

The first author conducted the analysis and the last author independently analysed a sample of transcripts. All coding was validated by the second and last author who carried out credibility checks on both coding and interpretation. The process of analysis involved several key stages as suggested by Smith et al. (2009). These included: 1) reading and re-reading the transcript, 2) making initial descriptive notes, 3) transforming initial comments into emergent themes, 4) looking for connections between the identified themes and defining master themes, 5) moving to the next interview and repeating all the steps of the analysis, and 6) looking for connections between the cases and developing master themes for the whole sample. The extracts presented herein have been selected as they represent the most powerful or insightful quotes and capture the very essence of each theme.

Results

This article presents two inter-related master themes: (1) Diagnosis and the search for meaning; (2) Impact of stigma on disclosure (see Table 1). It is noteworthy that in the extracts which follow, (...) represents missing text. Pseudonyms are incorporated throughout to ensure participant anonymity and confidentiality. The mode of transmission will be indicated against participant pseudonyms, so the reader can better orientate context when reading quotes. In efforts to not further stigmatise those who contracted HCV through injecting drug use, no acronym will be added to their quotes while 'BT' (blood transfusion) will be noted against those who contracted HCV in this way.

Table 1. Master themes and Subthemes.

Master themes	Subthemes
1. Diagnosis and the search for meaning	Processing diagnosis Internalised and externalised blame
2. Impact of stigma on disclosure	Risk of contagion Facets of exposure

Diagnosis and the search for meaning

Processing diagnosis. For participants, the lived experience of HCV began at the point of diagnosis. For some (Eric, Jimmy, Gus) diagnosis was a highly distressing, life changing experience. Others, however (Steve, Ted, Harry), appeared unconcerned or even indifferent. The nature of the response varied depending on the medical context of examination and diagnosis. All participants of this study were diagnosed when the disease was vaguely described and understood, which in a way determined obscure and unclear circumstances of medical testing and speculations regarding life expectancy and treatment:

I was in hospital, getting a blood sample taken for something else and I don't even really know why they wanted the blood sample. It had nothing to do with what I was in for. Then, about maybe a week or two weeks later, I got a call and I think it was a letter, saying that there is an abnormality in my liver (...). I was a bit concerned about it, you know, just because it was just suddenly out of the blue. And eh... another appointment was made for me. I had a chat and I was told

something like, “you maybe have got 15 years to live” (laughter). At that time, you know, they didn't really know a lot of this. So, it was a bit disconcerting...(Gus)

Another participant reported being completely unaware of attending a HCV clinic (Jimmy) while awaiting his blood test results:

When they took me in, and when they told me [diagnosis] (...) I had no idea how, or where I'd got this. (...) They're looking at it could've been lying dormant for years and not – they've never actually checked the blood for it and then when I was taken unwell, then they kind of looked at me and thought, here, there's something not right. They checked the blood and the Hep C showed up. (Jimmy, BT)

Following the investigation of Jimmy's symptoms, HCV was perceived to have 'shown up', stirring from its dormancy like an uninvited, unanticipated stowaway. Its undetected existence prior to diagnosis further reinforces the participants' shock and disbelief at the point of diagnosis. Jimmy's diagnosis reflected a deep sense of shock and disbelief; the news appears inconceivable and he instantly is concerned with its aetiology. For other participants, uncertainty surrounding their illness evoked a sense of helplessness, uncertainty and loss of control:

When I got told I had the virus there was nothing I could do because I'd had it for years and years, and I didn't even know I had it. But once I got the liver transplant, I says, “I've got that and I've still got this virus.” And that probably preyed on my mind a bit, but there's nothing I could have done about that. [] There's nothing you can do, you know. (Steve)

Thus, at the time, participants found themselves in a position of ‘limbo’- with no information around HCV, its progression, prognosis or outcome. A profound loss of control ensued, resulting in feelings of helplessness and powerlessness. Many of the participants reported being shocked by their diagnosis. There was a troubling sense of uncertainty about the ‘dormant’ and unknown nature of HCV. Consequently, in an attempt to understand their situation, the participants often sought to identify the source of their HCV.

Internalised and externalised blame. Many participants identified clear circumstances which they believed led to them acquiring HCV. Two participants (Steve, Ted) reported potential exposure events relating to injecting drug use:

When I was 21 I was at a party and there was heroin went around, and I was totally naive, I never had taken drugs in my life, and I was 21. I’d taken a pint, a drink, but not much, and it was coming, I never even touched it and I injected it. I was 21 years of age, but that was it, I never knew until I was about 51. So, you’re talking about 30 years I never knew I had that. (Steve)

Like Steve’s account, Ted echoed feelings of naivety reporting his drug use as ‘just one of those stupid things you have done when you’re a kid’. Irrespective of the frequency or duration of injecting drug use, both participants expressed some sense of responsibility for contracting the virus. There is also a sense of guilt, shame, and genuine regret in Steve’s account when he confessed later that injecting drugs was ‘the worst thing’ that he has ever done in his life.

Ted seemed to distance himself from his early life experiences of taking drugs, when talking about prioritizing access to treatment. For Ted, a complex combination of inferred agency, diverse transmission routes, the ability to overcome drug addiction and the stigma associated with drug use *per se* all result in an apparent hierarchy of those ‘deserving’ priority access to treatment:

People who've caught hepatitis through no fault of their own, should they get treated before drug addicts? Well, my opinion is, it depends how far they are into drugs. I wasn't into drugs for a long time. It wasn't like years I had drugs. These people, they're taking drugs for years and years, they don't want to help themselves. (...) But if somebody catches it through blood transfusion, I think they should get it before drug addicts, because they've done it. Drug addicts have given it themselves, so no, I think people who've caught it accidental, through blood transfer or whatever, I do think they should get it before drug addicts, aye, because drug addicts have applied it for themselves, self-inflicted. (Ted)

Whilst locating himself within this hierarchy of access to treatment, it is interesting to note how Ted accomplishes 'othering' work through demarcating the 'deserving' from the 'undeserving'. However, he still does not locate himself within a group of 'no guilt of their own', which seems to reveal a sense of internalised blame for contracting the virus. Stigma is associated with drug use, duration of drug use and inability to overcome addiction. It is also interesting to note how the attribution of agency connects the person to the HCV virus; amongst people who inject drugs, it is inferred that they have knowingly given themselves the virus when in fact they have only knowingly given themselves drugs. Perhaps the confusion lies within the agency relating to the needles which have introduced the virus into all the participants respective bodies. For those people who had contracted the virus through blood transfusion there was relatively little stigma. Five participants (Jimmy, Eric, Gus, Harry, Chris) identified undergoing blood transfusion as the likely cause of their HCV. These participants reported a sense of anger and injustice at their diagnosis:

I contracted Hep C through contaminated blood given to me for treatment for my haemophilia. (...) "You've got it." (...) Somebody gave it to me. I didn't go out there and stick a needle in me... (Eric, BT)

Echoing the earlier points relating to social importance of the attribution of responsibility for the movement of the virus from one body to another, Eric's extract serves to deflect

any sense of personal culpability. Although not explicit, there is a sense of how he distances himself from drug users, denying any role within the moment of transmission and the process of injection. In fact, injection is transformed and constructed into a pejorative new behaviour ‘sticking needles’:

(...) it shouldn't have happened, that is basically it. (...) All these thousands of people that have been affected by the Hep C they shouldn't have happened and that's why we are fighting at the moment.” (...) we try to get answers because nobody is saying, “It was me that did it.” All we want is somebody to say, “It was the national health's problem, the government did it and then let's do something about it. (Eric, BT)

Eric's account is not an individual testimony but an expression of the shared experience of injustice. By using 'we', he seems to unite with all of those who acquired HCV through blood transfusion in univocal protest against public silence and dismissal. The repetitive use of the personal pronoun ('we') might also reinforce the conviction of mutual benefits in identifying external sources of blame and responsibility.

In summary, this section has focused on the participants' collective and personal approaches to diagnosis. The socio-political context of medically acquired HCV appeared to influence the external attribution of blame and responsibility, as well as levels of distress and uncertainty in response to diagnosis. Conversely, where transmission occurred through self-administering drugs, attribution of culpability seemed to be internal and there appeared to be less distress associated with the diagnosis itself.

Impact of stigma on disclosure

Risk of contagion. An awareness of the infectious nature of HCV led all participants to avoid interactions with others. An implicit fear of potentially harming other people, was reinforced with stigmatising attitudes which eventually led to a reluctance to disclosing their condition to others. Intrusive thoughts of being under surveillance preyed on some participants' minds:

I don't drink now, but I can go and sit in a pub with them [other people], see if I've got a glass of juice. I think they're looking at me as if, what he is doing with a glass, he shouldn't have one. You know, "he's sitting there with Hep C, I hope they're going to put that glass in the bin when he's finished with it sort of thing." You think, is that what's going through their head, you know. Aye, as if, you know, they're sitting watching you. And you see other people about the pub and you think, do they know, what're they staring at me for? Or what're they looking over here for, you know? It's a weird, weird feeling, you know. (Jimmy, BT)

This excerpt reflects Jimmy's own fears and highlights a sense of paranoia. He projects his anxieties about being exposed and of being a potential threat to others. The account is peppered by a Jimmy's sense of feeling 'contaminated'. Similarly, Chris highlights how he interprets his increasing social isolation:

(...) it has changed a lot I don't see people as much, and I never get invited to their house and they seem to think that they'll catch something of me, but I've told them you cannot catch it. (Chris, BT)

Stigma, therefore, appears to be embedded in preconceptions of HCV as highly contagious despite the participant's best efforts to educate otherwise. Consequently, the expectation and eventual experience of social ostracism and rejection created deep emotional turmoil for participants. Chris expressed his wish that all those who discriminated against him, could 'look inside to how my body felt at being excluded'. This was particularly important within the family context:

There was a couple of times where my niece was there (...) and wanted something for the kids and it was in my mum's house and I said to her, "Oh I'm going to the kitchen I'll get you it." And her mother, who is a nurse herself,

jumped up and shouted, “No, you’ll not bother, I’ll get it.” I thought, that’s a big one, she’s a nurse, she should know. (Jimmy, BT)

Here, there is a sense that the imagined contagion fueling stigma in those closest to participants, was an even greater blow- ‘a big one’. This extract reveals lack of understanding of the disease even amongst the health providers who should not hold these kind of misconceptions or irrational fears.

While for some participants, disrupted and limited interactions with family and friends were considered as unwanted consequences of their ‘infectious status’ and a distinct signifier of their exclusion, for others the social separation was their own conscious choice and a way of dealing with the situation. Harry and his wife isolated themselves from their closest social circle. Harry’s precaution against onwards transmission was manifested in his decision to ‘protect’ his relatives and friends from contracting the infection by avoiding them:

So, I told them not to come to our house, not to bring their kids to our house... Even my friends stopped coming (...) the first three months I completely ignored all people. (Harry, BT)

Facets of exposure. From participant accounts, there was a sense of the moral dimensions of disclosure. At times, the participants understood isolating themselves from others as a means for protecting other people. There is also another aspect of exposing the ill-self that might be anxiety-evoking and result in social withdrawal. There is no failure to disclose, if no social interactions take place. In this sense, Jimmy, who disclosed to all his family members and friends, prevented himself from dating:

After I was diagnosed I was scared to go into a relationship (...) something I don’t think I will, ever have another one, because I don’t think I can turn around and say to a female, I’m sorry but I’ve got Hep C, or I’ve had Hep C. Because I think they’d just about turnabout and walk out the door on you. So, it’s kind of,

it's sad in a way knowing that – I don't think I could get into a relationship knowing that, to have to tell somebody that and then knowing they might just walk through the door, reject you, and just walk out the door altogether. (Jimmy, BT)

Here, the extent of the negative impact of living with HCV is evident. For others, the avoidance of revealing the transmission route brought embarrassment and regret. For example, Steve's decision not to disclose his HCV, even to his loved ones, appeared to reflect his shame relating to the single injecting incident from his past. The asymptomatic nature of his HCV helped him to disguise his status from his family who were only made aware of liver cirrhosis as an official justification for his liver transplantation:

None of my family knows. When I found out about the cancer they didn't know from where it was. (Steve)

In contrast, an extremely open approach to disclosure was evident in participants with medically acquired HCV that voided any personal responsibility for their illness:

I know a lot of people have a stigma about Hep C but I've got no – I'll tell everybody that I've got it because it wasn't my fault. (Eric, BT)

Identifying themselves as 'innocent victims', most participants shared their status with 'anybody that wanted to know', especially with those who showed interest and support. The position of being an 'innocent' recipient of contaminated blood seemed to moderate the impact of stigma. Participants who felt that they had nothing to regret or disguise in terms of their past, therefore, they were not afraid to disclose their status. Eric seemed to contrast himself with those who have a stigma by entering the position of a victim and by the act of disclosure. He attempted to do away with HCV stigma by enacting anti-stigma.

In sum, the act of disclosure appeared as either a means of accessing support or as a means of avoiding it. In this sense, some participants tended to disclose their HCV status to their family and friends to obtain help they needed, whereas others concealed their seropositive status even from their loved ones to protect themselves from rejection and judgment.

Discussion

This study offers a rich, insightful, experiential account of living with HCV. Semi-structured interviews afforded participants freedom to respond in their own way and to explore anticipated and unanticipated areas of their lived experiences of HCV. The current article also contributes to previous HCV literature by exploring diagnosis, culpability, stigmatization, and approaches to disclosure across a heterogeneous sample of people with HCV. The sample included patients who contracted the virus via recreational drug use and those who received it through contaminated blood products. Finally, this study raises awareness of the psychosocial challenges that reflect HCV patients' everyday lives. These should be central to future interventions with this population.

Distinct patterns of responsiveness to diagnosis, stigma and approach to disclosure were apparent in relation to HCV transmission routes. Participants who acquired HCV through non-medical injecting seemed to report relatively little biographical disruption caused by symptomatology or diagnosis. They experienced shame when reflecting on how they acquired the virus, but they also seemed to silence remorse by adopting an unconcerned view of HCV. In some sense across time, their awareness of the risks of HCV associated with sharing injecting equipment consequence became incorporated in their identity as former drug users (Olsen et al., 2013). There were continuous agentic behaviours that linked their non-medical use of injecting equipment with HCV transmission, diagnosis and treatment. Their relatively 'unconcerned' attitude could also result from the asymptomatic nature of the illness. According to Bury (1982), there is a causal relationship between changes in the body and an alteration of the person's identity. Thus, those who experienced no visible or life-

interfering symptoms were able to abnegate the significance of diagnosis and perceive treatment as more disruptive than diagnosis itself.

Conversely, participants with medically acquired HCV revealed a different response to diagnosis that reflected autobiographic uncertainty (Bury, 1982). Feelings of fear, shock, anger and helplessness were identified in their excerpts. Strong negative reactions to diagnosis were reported and are also reflected within the wider literature (Hepworth and Krug, 1999; Tompkins et al., 2005; Suarez, 2010). These feelings are often explained in relation to redefining previous identities shaped over years through relationships with others (Hepworth & Krug, 1999) or a response to lack of knowledge provision (Suarez, 2010). A negative experience of receiving insufficient information and help from medical staff over years affected individuals' sense of control over HCV (Hill et al., 2015).

The history of injecting drugs was found to be associated with rather 'unconcerned' responses to diagnosis and internalised blame for viral transmission. Conversely, for patients who contracted the virus through blood transfusion or other medical procedures, diagnosis was a life-disrupting news that affected both their self-perception and social identity. However, unlike the two participants with the history of intravenous drug use, these individuals felt no shame or guilt regarding their condition. For participants who acquired the virus through IDU, a sense of responsibility and regret accompanied their reactions to diagnosis. Young age and associated naivety seemed to offer a justification for their risky behaviour from the past, but they seemed to be aware that they were to be blamed for contracting the virus.

A synergy of the lack of knowledge and irrational fear developed in some participants into 'felt' and 'enacted stigma', distinct forms of negative attribution recognized in previous literature (Lekas et al., 2011; Tompkins et al., 2005; Scambler, 2004). The experience of 'enacted' and 'felt stigma' applied less to populations with medically acquired HCV. Unlike participants who contracted the virus through non-medical injecting, they responded to stigma with directing their strong feelings of blame and anger towards external parties. These kinds of responses have the power to preserve

positive self-identity (Stuenkel and Wong, 2009). They seemed to represent an ‘enacted anti-stigma’

Although, according to Zickmund et al. (2003), stigma affects all diagnosed individuals, the current research highlighted that the experience of it can greatly differ depending on perceived transmission route, information provision and the source of contraction. Combined, these factors appeared to merge and created a foundation of various patterns of psycho-social responsiveness to the illness. Two of the patients (Eric, Gus) who acquired HCV through blood transfusion and were actively seeking information about the disease and treatment, seemed not to be affected by either the felt or enacted stigma. They perceived themselves as ‘innocent victims’, not responsible for what happened to them, and as such contrasted themselves with the stigmatised population with HCV. Openly revealing their health status and actively seeking professional support and information, they seemed to demonstrate their anti-stigma approach and cope with illness-related uncertainty. Thus, this study has demonstrated how a framework of uncertainty, that is related to the diagnosis of a chronic illness (Bury, 1982), can suddenly shift towards a framework of possibilities and certainty when a sense of healthy identity is regained through successful battle against stigma and culpability.

Conversely, all other participants, regardless of the mode of virus transmission, described various stigmatizing encounters. Such experiences were intensified by either their own or the public’s lack of HCV knowledge. An irrational fear of contagion and eroded sense of self in some of the participants stemmed from the lack of understanding of the disease observed amongst family members or even health care providers (Crocket and Gifford, 2004). Some of the participants, in response to discriminatory episodes that were encountered or anticipated, perceived their situation as highly distressing. Fear of social alienation led one of the participants to hide his status even from his own family, and another one to limit the disclosure only to particularly significant others. This is a common reaction towards stigmatisation in HCV and AIDS/HIV populations (Schafer et al., 2005; Audet et al., 2013).

The context, attitudes and beliefs surrounding diagnosis determined participants approach to disclosure. A predominant association of HCV with intravenous injecting and fear of social discrimination, made the participants with the history of injecting drug use either to disclose exclusively to relatives and friends or prevented the disclosure at all. In contrast, the participants with medically acquired HCV tended to readily disclose their status, emphasizing their role as ‘innocent victims’. Their desire for exposure is unrelated to the moral obligation imposed on them by society, as previously recognized by Hepworth and Krug (1999), but instead, serves as a means to communicate their own moral imperatives despite the experience of injustice and negligence.

There are a number of limitations of the current research that should be recognized. Regarding recruitment, this study had limited accessibility to participants (confined to one hospital-based out-patient clinic). Moreover, data herein is exclusive to the HCV population in Scotland and required rigid inclusion criteria. This may also have limited the pool of potential volunteers. Moreover, the sample of this study consisted of male participants only, therefore, it would be important to extend the considerations of the experience of HCV diagnosis, stigma and disclosure to the female patients’ point of view. Considering that women are mainly identified as caregivers and are associated with this role in society in general, it may be of interest to explore their experience in the opposite role. Dunne and Quayle (2001) who explored female patients with HCV showed that women might feel guilty and perceive their role within the household as greatly affected by their debilitating condition. Thus, the impact of HCV on patients’ quality of life might differ between male and female participants. Moreover, five of the participants interviewed in this study received the virus through contaminated blood transfusion in the 70s and 80s, when HCV diagnostics and treatment were unavailable. The socio-political aspect of their reflections might not match experiences of patients diagnosed and treated most recently.

Despite these limitations, there are a number of clear, important messages from the current study. The sense of uncertainty in relation to current and past social interactions dominates in participant’s narratives, indicating that there is a definite need for developing and delivering new patient-focused approaches in clinical guidance.

Problem-solving interventions could provide training to people diagnosed with HCV on how to respond to diagnosis regardless of the mode of contraction and how to approach various disease-related issues. These interventions should be carefully tailored to the different needs of various groups of patients with HCV and be focused on the ambivalences that characterise their cases rather than offer a generalised advice.

In the new era of direct-acting antivirals (DAAs) that is currently available, patients should be thoroughly informed about its efficacy and outcomes for different patient groups (i.e. with different HCV genotype or impacted by comorbidities). These information sessions regarding new treatment may buffer the impact of diagnosis, giving hopes for recovering, or at least minimise HCV-related speculations and uncertainties.

HCV-focused psychoeducation about HCV-related stigma and transmission risks is also needed. It may have a format of interaction among healthcare professionals, patients and primary caregivers that would allow all participants to reflect on negative attitudes in relation to HCV and bridge the disconnect between patients and health care (Treloar and Hopwood, 2004; Treloar and Rhodes, 2009). Patients' ability to cope may be enhanced by raising awareness of their condition amongst the nearest social and support network. Poor knowledge was found to fuel stigma against infected individuals (Butt et al., 2008) and stigmatization, in turn, was associated with feelings of social isolation (Hill et al., 2014). Thus, the actual infectiousness of HCV needs to be demystified by sharing information and establishing regular interpersonal communication.

Difficulties in accepting the diagnosis by patients with HCV may be alleviated by improved access to treatment and by establishing various support groups carefully tailored for this heterogeneous group of patients. Furthermore, cognitive-behavioural therapy (CBT) can reduce stigma, a sense of self-blame and associated shame. Assigned support services may promote assertive approach of patients with HCV in seeking psychological help and establishing social networks. However, it is crucial to make sure that the different psychosocial approaches to HCV patients aim to meet the individual

patient's needs and do not facilitate the 'guilty-innocent' distinction based on the HCV transmission routes (Fraser and Treloar, 2006).

Given fearfulness to disclose positive serostatus to others, optional individual or family/couple counselling services should be offered to all those recently diagnosed with HCV. Physical or emotional symptoms and fear of transmission can be the major factors contributing to deteriorating relationships and weakening a circle of support, thus, psychological interventions have potential to: 1) resolve communication issues within families at the point of diagnosis; 2) strengthen family relationships; and consequently 3) improve the support provided.

Finally, healthcare services should develop a new HCV programme within a broader framework of chronic illness which is not only focused on prevention and access to health service, but also addresses various aspects of living with chronic conditions, such as HCV. Hence, longitudinal findings from future data collection among people living with HCV at various points in time is required in order to develop care practices that are tailored to the changing needs of HCV patients and to improve their overall quality of life.

Acknowledgments

The authors express their gratitude to all the research participants and all the transplant co-ordinators for their time and co-operation.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest to the research, authorship, and publication of this article.

Funding

This work was conducted as part of a postgraduate research degree, funded by Edinburgh Napier University.

References

- Audet CM, McGowan CC, Wallston KA and Kipp AM (2013) Relationship between HIV Stigma and Self-Isolation among People Living with HIV in Tennessee. *PLoS ONE* 8(8): e69564.
- Berenguer M, Prieto M and Rayon JM (2000) Natural history of clinically compensated hepatitis C virus-related graft cirrhosis after liver transplantation. *Hepatology* 32: 852–858.
- Blach S, Zeuzem S, Manns M, Altraif I, Duberg AS, Muljono DH, Waked I, Alavian SM, Lee MH, Negro F and Abaalkhail F (2015) Global prevalence and genotype distribution of hepatitis C virus infection in 2015: a modelling study. *The Lancet Gastroenterology & Hepatology* 2(3):161-76.
- Brocki JM and Wearden AJ (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health* 21: 87–108.
- Bury M (1982) Chronic illness as biographical disruption. *Sociology of Health and Illness* 4(2): 167-182.
- Butt G, Paterson B and McGuinness LK (2008) Living with the stigma of hepatitis C. *Western Journal of Nursing Research* 30(2): 204-221.
- Centers of Disease Control and Prevention (2017) *Viral Hepatitis*. Available at www.cdc.gov/hepatitis/hcv/hcvfaq.htm. (accessed on 04 February 2018)
- Conrad S, Garrett LF, Cooksley WGE, Dunne MP and MacDonald GA (2006) Living with chronic hepatitis C means ‘you just haven’t got a normal life any more’. *Chronic Illness* 2(2): 121–131.

- Crockett B and Gifford SM (2004) 'Eyes wide shut': Narratives of women living with hepatitis C in Australia. *Women and Health* 39(4): 117–137.
- Crofts N, Louie R and Loff B (1997) Stigmatization and discrimination related to hepatitis C virus infection in Australia. *Health and Human Rights* 2(2): 86–97.
- Cama, E., et al. (2016). Internalized Stigma Among People Who Inject Drugs. *Substance Use & Misuse* 51(12): 1664-1668.
- Dudley T, Chaplin D, Clifford C and Mutimer DJ (2007) Quality of life after liver transplantation for hepatitis C infection. *Quality of Life Research* 16(8): 1299-1308.
- Duffin J (2005) *Lovers and Livers: Disease Concepts in History*. Toronto: Toronto Press Incorporated.
- Dunne EA and Quayle E (2001) The impact of iatrogenically acquired hepatitis C infection on the well-being and relationships of a group of Irish women. *Journal of Health Psychology*, 6(6): 679–692.
- Forsberg A, Backman L and Moller A (2000) Experiencing liver transplantation: A phenomenological approach. *Journal of Advanced Nursing* 32(2): 327–334.
- Fraser S (2004) 'It's your life!': injecting drug users, individual responsibility and hepatitis C prevention, *Health* 8(2): 199–221.
- Fraser S and Treloar C (2006) 'Spoiled identity' in hepatitis C infection: the binary logic of despair. *Critical Public Health* 16: 99–110.
- Gane EJ, Naoumov NV, Qian KP, Mondelli MU, Maertens G, Portmann BC, Lau JY and Williams R (1996) A longitudinal analysis of hepatitis C virus replication following liver transplantation. *Gastroenterology* 110(1):167-77.
- Gonzalez SA (2010) Management of Recurrent Hepatitis C Following Liver Transplantation. *Gastroenterology & Hepatology* 6(10): 637–645.

- Hajiani E, Masjedizadeh R, Hashemi J, Azmi M and Rajabi T (2006) Hepatitis C virus transmission and its risk factors within families of patients infected with hepatitis C virus in southern Iran: Khuzestan. *World Journal of Gastroenterology: WJG* 12(43): 7025–7028.
- Harris M (2009) Injecting, Infection, Illness: Abjection and Hepatitis C Stigma. *Body & Society* 15: 33–52.
- Hepatitis C, Virus Projections Working Group, (2006) Estimates and projections of the hepatitis C virus epidemic in Australia 2006, Canberra Hepatitis C Sub-Committee, Ministerial Advisory Committee on AIDS Sexual Health and Hepatitis. Available at: [http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/HCVPWG2006/\\$file/HCVPWGRepAug06.pdf](http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/HCVPWG2006/$file/HCVPWGRepAug06.pdf). (accessed 22 June 2013).
- Hepworth J and Krug GJ (1999) A socio-cultural perspective on the effects of a new virus on a community's health. *Journal of Health Psychology* 4: 237–246.
- Hill R, Pfeil M, Moore J, and Richardson B (2015) Living with hepatitis C: a phenomenological study. *Journal of Clinical Nursing* 24(3-4): 428-38.
- Hopwood M and Treloar C (2003) *The 3D Project: Diagnosis, Disclosure, Discrimination and Living with hepatitis C*. Sydney: National Centre in HIV Social Research.
- Kumada H, daCosta DiBonaventura M, Yuan Y, Kalsekar A, Kopenhafer L, Tang A, Victor TW, L'Italien G, Chayama K and Toyota J (2014) The Patient-Related Burden of Pegylated-Interferon- α Therapy and Adverse Events among Patients with Viral Hepatitis C in Japan. *Value in Health Regional Issues* 3: 50-58.
- Lekas H, Siegel K and Leider J (2011) Felt and Enacted Stigma among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering. *Qualitative Health Research* 21: 1205-1219.

- Lowe D and Cotton R (1999) *Hepatitis C: A review of Australia's response*. Canberra: Department of Health and Aged Care.
- Maynard R (2006) Controlling Death—Compromising Life: Chronic Disease, Prognostication, and the New Biotechnologies. *Medical Anthropology Quarterly* 20(2): 212–34.
- Olsen A, Banwell C and Dance P (2013) Reinforced biographies among women living with Hepatitis C. *Qualitative Health Research* 23(4): 531-40.
- Paterson BL, Butt G, McGuinness L and Moffat B (2006) The construction of hepatitis C as a chronic illness. *Clinical Nursing Research* 15(3): 209-224.
- Paterson DL, Gayowski T, Wannstedt CF, Wagener MM, Marino IR, Vargas T, Laskus T, Rakela J and Singh N (2000) Quality of life in long-term survivors after liver transplantation: Impact of recurrent viral hepatitis C virus hepatitis. *Clinical Transplantation* 14: 48–54.
- Poynard T (2005) *Hepatitis C and B: Management and Treatment* (2nd Edition). London and New York: Taylor and Francis.
- Public Health England (2014) *Hepatitis C in the UK, 2014 report*. Available at: www.gov.uk/government/uploads/system/uploads/attachment_data/file/337115/HCV_in_the_UK_2014_24_July.pdf (accessed 17 August 2014).
- Public Health England (2017). Shooting up: Infections among people who inject drugs in the UK, 2016. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/663003/Shooting_Up_2017_report.pdf (accessed 23 December 2017).
- Pungpapong S, Aqel B, Leise M, Werner KT, Murphy JL, Henry TM, Ryland K, Chervenak AE, Watt KD, Vargas HE, Keaveny AP (2015) Multicenter experience

using simeprevir and sofosbuvir with or without ribavirin to treat hepatitis C genotype 1 after liver transplant. *Hepatology* 61(6):1880-6.

Rodger AJ, Jolley D, Thompson SC, Lanigan A and Crofts N (1999) The Impact of Diagnosis of Hepatitis C Virus on Quality of Life. *Hepatology* 30(5): 1299-1301.

Scambler G (2004) Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory and Health* 2: 29–46.

Schafer A, Scheurlen M, Felten M and Kraus M (2005) Physician patient relationship and disclosure behaviour in chronic hepatitis C in a group of German outpatients. *European Journal of Gastroenterology and Hepatology* 17: 1387–1394.

Singh N, Gayowski T, Wagener MM and Marino IR (1999) Quality of life, functional status, and depression in male liver transplant recipients with recurrent viral hepatitis C. *Transplantation* 67(1): 69–72.

Smith JA, Flowers P and Larkin M (2009) *Interpretative Phenomenological Analysis: Theory, Method, Research*. London: Sage.

Stuenkel D and Wong V (2009) Stigma. In: Larsen P and Lubkin I (eds) *Chronic illness: impact and intervention*. USA: Jones and Bartlett Publishers.

Suarez AE (2010) Racial Disparities in Knowledge of Hepatitis C Virus (HCV). In: Kronenfeld JJ (ed) *The Impact of Demographics on Health and Health Care: Race, Ethnicity and Social Factors*. Bingley: Emerald Group Publishing, pp.21-46.

Sy T and Mazen Jamal M (2006) Epidemiology of Hepatitis C Virus (HCV) Infection. *International Journal of Medical Sciences* 3(2): 41–46.

Treloar C and Hopwood M (2004) Infection control in the context of hepatitis C disclosure: Implications for education of health professionals. *Education for Health* 17:183-191.

- Treloar C and Rhodes T (2009) The Lived Experience of Hepatitis C and its Treatment Among Injecting Drug Users: Qualitative Synthesis. *Qualitative Health Research* 19(9): 1321-1334.
- Tompkins CNE, Wright NMJ and Jones L (2005) Impact of a positive hepatitis C diagnosis on homeless injecting drug users: a qualitative study. *British Journal of General Practice* 55(513): 263-268.
- Thuluvath PJ (2016) Overview: Disease Recurrence After Liver Transplantation. In: *Thuluvath PJ (ed) Disease Recurrence After Liver Transplantation. Natural History, Treatment and Survival*. New York: Springer, pp.1-12.
- Wasley A, Gallagher KM and Grytdal S (2008) Surveillance for acute viral hepatitis, United States, 2006.
- World Health Organization (2017) *Global hepatitis report, 2017*. World Health Organization.
- Yardley L (2000) Dilemmas in qualitative health research. *Psychology and Health* 15: 215–228.
- Zickmund S, Ho EY, Masuda M, Ippolito L and LaBrecque DR (2003) “They treated me like a leper.” Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine* 18(10): 835-844.