

## **Hepatitis C in a new therapeutic era: recontextualising the lived experience**

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## **TITLE**

Hepatitis C in a new therapeutic era: Recontextualising the lived experience

## **ABSTRACT**

*Aims and Objectives:* To explore the experience of adults living with hepatitis C in a new era of interferon-free treatment.

*Background:* Hepatitis C is a leading cause of morbidity and mortality worldwide, posing a significant challenge to global public health. Historically, the treatment of hepatitis C was poorly efficacious and highly demanding, however, more effective and tolerable therapies have become available in high-income nations in recent years. This is the first study to explore how these significant developments in the treatment of hepatitis C may have influenced the experience of those living with the virus, and their understanding of the disease.

*Design:* A qualitative study underpinned by social phenomenological theory.

*Methods:* Data were generated through semi-structured interviews with a purposive sample of 20 hepatitis C positive adults living in a large city in Scotland.

*Results:* Thematic analysis identified three over-riding themes. 'Positioning hepatitis C' illustrated how the disease was understood within wider sociocultural, medical and politico-economic contexts. 'Beyond a physical burden' emphasised the emotional aspect of infection, and 'a new uncertainty' revealed participants' cautious response to the advances in hepatitis C therapy.

*Conclusions:* Inter-thematic discourse portrayed the new era of hepatitis C treatment as holding little sway over constructions of the illness, as narratives resonated with previous studies. Such unmoving 'lay' understandings of hepatitis C may pose potential barriers to the new therapeutic era from reaching its full potential.

*Relevance to clinical practice:* How people living with the virus perceive and understand hepatitis C can have an adverse impact on their engagement with care and treatment. Whilst global medical

discourse eulogises the arrival of a new era of therapy, there remain significant challenges for nurses engaging those with hepatitis C in therapeutic pathways.

## **SUMMARY BOX**

### ***What does this paper contribute to the wider global community?***

- This paper provides the first exploration of how individuals living with hepatitis C are experiencing an interferon-free era of therapy.
- The arrival of interferon-free treatments in clinical practice has yet to challenge societal constructions and understandings of hepatitis C.
- The emergence of treatment rationing provides fresh challenges for engaging disenfranchised hepatitis C populations in care.

## **KEYWORDS**

Direct-acting antivirals, Hepatitis C, interferon-free treatment, lived experience, social phenomenology, thematic analysis, treatment rationing

## **INTRODUCTION**

The hepatitis C virus (HCV) is a leading cause of mortality and morbidity worldwide, posing a major challenge to global public health (World Health Assembly, 2016). The virus is acquired through exposure to infected blood, and whilst the spontaneous resolution of acute infection is possible, long-term infection occurs in approximately 60-85% of cases. Chronic HCV is characterised by slowly progressing liver fibrosis, which leads to the development of cirrhosis in approximately 10-20% of patients (Westbrook and Dusheiko, 2014). Injecting drug use is the cause of a substantial proportion of the global burden of HCV disease, with injecting drug use-attributable HCV highest

in high-income nations (Degenhardt et al., 2016). Within the UK, the most recent national estimates suggest around 214,000 individuals are infected, of which approximately 37,000 reside in Scotland (Public Health England, 2015).

## **BACKGROUND**

For over 15 years, recurrent qualitative investigation has illuminated how HCV is experienced, understood and constructed by those living with the virus. Studies commonly portray a disruptive and distressing phenomenon manifest in social, emotional and physical spheres of illness, with specific facets of experience such as diagnosis (Glacken et al., 2001), fatigue (Glacken et al., 2003; Zalai et al., 2016) and stigma (Butt et al., 2008; Fraser and Treloar, 2006) often emphasised. This body of work provides insight into how HCV is conceptualised by those it affects, exposing common expectations of chronic morbidity and altered life trajectories (Conrad et al., 2006; Paterson et al., 2006; Sutton and Treloar, 2007). In contrast, the normalisation of HCV has also been reported from studies focused on people who inject drugs (PWID), revealing constructions of HCV infection as inevitable, unavoidable and ultimately part of the PWID identity (Harris, 2009; Roy et al., 2007; Wozniak et al., 2007). Importantly, these insights into lived experience are situated within their sociocultural and temporal contexts, and have been repeatedly entwined with societal understandings of the challenging treatment available for HCV at the time, and an associated expectation of not being cured (Fraenkel et al., 2005; Groessl et al., 2008; Hill et al., 2015; North et al., 2014; Swan et al., 2010).

Historically, the treatment of HCV was stubbornly reliant on the notoriously unpleasant immunomodulating agent interferon- $\alpha$ . This drug, when combined with the nucleoside analogue ribavirin, comprised the dual therapy standard of care for HCV which endured throughout the 2000s and into the early part of this decade. These drugs needed to be taken for up to 48 weeks,

demonstrated limited efficacy, and came with an extensive catalogue of both physical and neuropsychiatric side-effects (Manns et al., 2006). Multiple studies exploring the experience of taking interferon-based regimens have repeatedly emphasised the severity of the treatment and the apprehension and fear it could produce (Hopwood and Treloar, 2005; Kinder, 2009; Sheppard and Hubbert, 2006). The arduous and protracted nature of HCV treatment contributed towards the low rates of uptake recurrently reported (Grebely et al., 2009; Lazarus et al., 2014; Midgard et al., 2016), although multiple patient, provider and social factors have been identified as barriers to individuals accessing and completing a period of interferon-based therapy (Harris and Rhodes, 2013; McGowan and Fried, 2012). These barriers included poor adherence (and provider concerns of poor adherence), comorbidities (most notably psychiatric disorders), perceived and actual risks of reinfection and societal stigma (Grebely et al., 2013; McGowan and Fried, 2012), and were most acutely felt among groups of PWID. The bulk of literature focused on the lived experience of HCV is predominantly situated within the context of this demanding, traumatic and inadequate treatment.

Whilst the use of interferon-based dual therapy persists in many regions of the world, recent pharmacological advances have given some individuals, in mostly high-income nations, the potential to access new drugs that offer a highly effective and well-tolerated cure. These interferon-free Direct Acting Antiviral (DAA) regimens offer substantially shorter treatment durations, improved side-effect profiles and have demonstrated sustained virological response rates of over 90% (Asselah et al., 2016). The dawn of this new era of HCV therapy has been heralded as a medical triumph (Chung and Baumert, 2014), although the global use of interferon-free DAAs has been hampered by their considerable costs. How such remarkable and rapid advances in the HCV treatment landscape may be influencing the experience of being HCV positive has so far received little attention. To date, only three articles focused on the lived experience of

HCV have utilised qualitative data collected during the interferon-free DAA era. One of these articles focused exclusively on the Aboriginal community in Australia (Treloar et al., 2016), one on the experience of taking interferon-free treatment (Whiteley et al., 2016), and the other was limited to an examination of HCV-related fatigue (Zalai et al., 2016). A broader contemporary understanding of how HCV is being experienced and perceived is therefore currently absent.

In Scotland, during the timeframe of this study, a number of interferon-free DAA regimens were granted approval for use in clinical practice. Access to these medications was restricted due to budgetary constraints, resulting in guidelines recommending concurrent provision of both interferon-free (typically a twelve week course of treatment) and interferon-based (up to 48 weeks of treatment) therapies to those accessing care (Healthcare Improvement Scotland and NHS National Services Scotland, 2015). Treatment rationing was dependent on a number of factors, including HCV genotype and the degree of liver disease. Participants in the study recruited from specialist HCV care had been made aware of the treatments available and associated restrictions as part of routine care by their regular healthcare providers. This study aims to recontextualise the lived experience of HCV within the context of this new therapeutic era. In doing so, it seeks to consider the influence of an advancing therapeutic landscape on constructions of the illness.

## **METHODS**

### **Design**

A social phenomenological perspective underpins the study. This sociological approach rotates phenomenology outwards, and postulates that the way humans construct their perspective on the outside world is not a purely individual process. It emphasises the importance of the social world in establishing the meaning of phenomena, asserting the inter-subjective world as the foundation

for human knowledge and experience (Shaw and Connelly, 2012). Social phenomenological research explores the shared features of subjective experience that define a phenomenon's meaning, focusing on the commonalities found in the life-worlds of more than one actor (Ajiboye, 2012).

The qualitative study design comprised of face-to-face, semi-structured interviews. In total, 20 participants with HCV were purposefully sampled from two locations; a hospital-based infectious diseases outpatient clinic, and a primary care doctors' surgery, both situated within a large Scottish city. The use of two recruitment sites aimed to select participants who had both engaged, and not engaged, with HCV specialist care. Further characteristics of the purposive sample were identified in order to recruit a diverse group of participants, theorising that patterns emerging from great variation are of particular interest in capturing the shared dimensions of a phenomenon (Patton, 2015). These characteristics were date of diagnosis, mode of acquisition, HCV treatment history and degree of liver disease, in addition to various sociodemographic factors. The identification of these characteristics was based on a literature review conducted in the process of developing the study, and reflection by the research team on what may constitute 'common-sense' categories (Mason, 2002). The sample size of 20 was deemed sufficient to capture this range of diverse characteristics, but not so large that detailed and nuanced analysis of the data would be compromised (Mason, 2002).

Inclusion criteria consisted of being diagnosed with HCV for more than six months, aged 16 years or over and able to converse in English. The requirements of the maximum variation sample were also taken into account as recruitment progressed. Individuals who fulfilled the criteria were approached by their healthcare provider, and consent obtained for their details to be passed to the researcher (DW) if interest was shown in participating. Records were not kept of how many

individuals were approached but declined to participate. A meeting was then arranged with the researcher, where the purpose of the study was explained, any questions answered, and written informed consent obtained.

### **Data collection**

Interviews were conducted between June and December 2015, either within a suitable room at the outpatient clinic or doctors' surgery, or at the participant's home. Interviews lasted between 19 and 67 minutes, with a mean duration of 39 minutes. An interview schedule was used to guide the conversation, which detailed four broad topic areas for discussion: the experience of diagnosis; the illness experience in everyday life; treatment knowledge and perception; and future outlook. Within these topic areas, brief open-ended questions were used to initiate conversation e.g. "tell me about your life since diagnosis", "what's it like for you having hepatitis C?", however, the interviews were conducted with a fluidity and responsiveness that allowed participants to talk about their experiences as they wished. All interviews were conducted by DW, a registered nurse who had worked as a HCV nurse specialist between 2009 and 2013. The interviews were audio-recorded using an encrypted recording device, and transcribed verbatim by DW, during which any information that may identify the participant was obscured from the narrative. Following each interview a reflective account was written and added to field notes in a research diary. Each participant was offered a £15 supermarket voucher in line with national guidelines, although three participants declined payment for their involvement in the study.

### **Analysis**

Six phases of thematic analysis were used to guide the analytical process (Braun and Clarke, 2006). Each transcript was read repeatedly by two researchers (DW and AW) in order to ensure subsequent coding and theme development remained grounded in the participants' narratives.



Inductive coding was then conducted by DW using *NVivo v.10* software to help manage the data. Whilst depicted as a linear process, the interviewing, transcribing and coding of the narratives occurred in parallel, with each activity informing the others. This analytical process began following the initial interview, and as this iterative process continued, groups of codes were gradually combined, resulting in the formation of a number of sub-themes. This cycle of analysis aided the identification of data saturation; coding of the final three transcripts aligned with the provisional sub-themes already developed. These sub-themes were then combined into candidate themes, which were examined in relation to the corpus of data and the research diary. During the analytical process, all four authors met regularly to probe and interrogate the evolving analysis, and to contest any preconceptions DW may have brought to the study due to his work history and association with the topic, consistent with the concept of bracketing. Within social phenomenological research, bracketing demands that belief in the existence of the world as we know it is suspended, and encourages doubt that the world could be anything other than it appears (Schütz, 1967). This ongoing peer review of the analysis aided rigour, and ensured the resulting themes were founded in the subjective life-worlds of the participants.

### **Ethical approval**

The study was considered and approved by the South East Scotland NHS Research Ethics Committee 01 (15/SS/0010) and by Edinburgh Napier University Research Integrity Committee.

## **RESULTS**

### **Participants' characteristics**

The characteristics of the sample are shown in table 1. The participants were approximately equal by gender, predominantly white and ranged in age from 27 to 70. The majority were unemployed and identified injecting drug use as their mode of HCV acquisition. Few had previous experience

of HCV treatment, with most reporting mild to moderate degrees of liver disease. Despite recruitment attempts, only two participants were not currently engaged with specialist HCV services. Analysis of the data resulted in three predominant themes: positioning hepatitis C; beyond a physical burden; and a new uncertainty.

### **Positioning hepatitis C**

The first theme illustrates how hepatitis C was understood within wider sociocultural, medical and politico-economic contexts. Participants described reactions to their medical diagnosis of HCV that positioned it within the context of their lives at the time. For example, for those who situated their diagnosis within a period of drug use, familiar reactions of shock, fear and anguish appeared mitigated by a perception that they had put themselves at risk:

*...but aye, it was, it was pretty devastating, but the same time I sort a' had that attitude well ken what, you knew what you were doing at the time, you knew the risks you were taking, things we do a' get stoned eh?*

(Female, diagnosed 2013, degree of liver disease unknown)

Similarly, for participants who reported a pre-existing HIV infection, diagnosis of a further blood borne virus was portrayed as holding little significance, often negating such emotional reactions entirely:

*I was actually, no' numb or anything, jus' indifferent, because of my HIV status, I jus' thought oh that's another disease I've got (...) 'cause, I always assumed that HIV was gonna kill me anyway.*

(Male, diagnosed 2004, non-cirrhotic)

Whilst the participants' sociocultural and biographical circumstances shaped their reactions, the timing of the diagnosis within the context of HCV treatment evolution appeared to have little influence. Approximately equal numbers of participants were diagnosed before and after the start of the DAA era in 2011, yet narratives around response to diagnosis did not reflect any recognition of these pharmacological developments. A discourse which comprised socially contextualised distress, disbelief and depression remained critical to the participants' experiences of HCV diagnosis in the era of DAAs. Indeed, some of the most vivid and striking accounts of intense reactions to diagnosis came from participants who received the news most recently:

*I remember going to the nurse, and err, my mum was with me, an' I remember they read out the hep B, hep A blah blah blah, AIDS an' all that, an' [pauses] an' they said hep C – positive [pauses] an' [pauses] I was, I jus' [blows out air] God, blanked out, I, I, I went into shock, 'cause all I remember hearing was, my mum going "oh my God" and they ended up having to go an' get the doctor because I had went into shock...*

(Female, diagnosed 2014, non-cirrhotic)

This brief discussion of diagnosis provides insight into how participants initially positioned and contextualised the disease within their testimonies. However, such reactions were often modified and revised as they lived with the disease and came to understand it from a new perspective. Post-diagnosis, participants often framed their experience of living with HCV in terms of how they were faring in relation to others who were HCV positive, whether personally known to them or

not. The majority of participants recounted a perception that HCV was having less impact on their life than it was for other individuals, and a broad perception pervaded that 'others have it worse':

*M: Hmm, I think, compared to a lot of people with hep C, I have been really, really lucky.*

*I: Why?*

*M: It's not really had that much of an impact on my life day-to-day, you know what I mean? Compared to people with this an' that, I can see, no it hasn't. I'm very, very lucky.*

(Female, diagnosed 1997, non-cirrhotic)

*...I think I've been a little bit lightweight here because, you know, there's a lot of people out there that are, really in much worse chance with hep C than I have, so I'm, you know, considering myself to be quite fortunate...*

(Male, diagnosed 2012, non-cirrhotic)

A major contributing factor to this perception was often the relative health of their liver compared to others, which began to fracture their understanding of HCV as a single disease. For those who engaged with HCV services post-diagnosis, the results of blood tests and scans fostered a

recognition that the diagnostic HCV label disguised a range of illness trajectories and outcomes.

Hepatitis C could be both a malignant killer and a benign inconvenience:

*...and I have [the ultrasound scan] done today, and according to the person who did it, everything seems to be normal, no damage at all, which I feel like I won the lottery! I know many people die of hepatitis C in the past, and it's not that easy to cure, or some people have more complication than other, but to be honest with you, I feel relief knowing that there is no damage in the liver.*

(Male, diagnosed 2015, non-cirrhotic)

Examples of feeling fortunate were also present amongst the narratives of those with more advanced liver disease, although these tended to be positioned in relation to their own mortality, rather than other people. Despite being cirrhotic, a diagnosis of HCV had given one participant the impetus to stop drinking alcohol, and his understanding of HCV therefore included protective and beneficial elements:

*...over three years now I've been sober, d'y'know, an' my liver's knackered [laughs] an' it kind a' makes you feel wow – what would I have been like if [pauses] - I'd be dead. I would've been dead. Wow. Y'know, it's like there's no way I'd have survived that, nah, err, so you're thinking well I'm very, very lucky...*

(Male, diagnosed 2005, cirrhotic)

By engaging in social comparison, the participants fractured HCV into degrees, producing a continuum of illness, rather than a uniform disease. There were those who 'had it worse' or who were 'more in need'. This understanding was further enforced as participants confronted the inequality of access to new HCV treatments, and came to understand that their position on the illness continuum had direct consequences for their entitlement to new medications. Whilst a healthier liver conferred a positive prognosis, it could also mean denial to the most effective treatments and could therefore be recognised as a double-edged sword:

*...an' then today I've been told that I dunnae fit the criteria, because my liver's quite healthy which is, a bit of a' shock but hey, wait a minute, you want me a' go to start using [drugs]? Or you want me to, y'know, make mysel' worse so I could, get an easier [treatment]?*

(Male, diagnosed 2000, non-cirrhotic)

Although this reaction was echoed by a small number of other participants, the denial of access to new HCV drugs was more commonly embraced as a positive endorsement of liver health. New treatments were associated with a greater degree of liver damage, therefore *not* being prioritised further affirmed and corroborated the reassuring test results previously received:

*...after doing the test [mimes fibroscan®], I felt a bit relieved in the sense that err, even though I've had hepatitis for a long time, and err, with all the alcohol I've been drinking, the damage was not that bad that I should be put on the priority [treatment]. So it was a bit comforting for me.*

(Female, diagnosed 2005, non-cirrhotic)

Treatment rationing was accepted by the majority of participants as an undisputed clinical necessity, with distributive justice discussed in terms of merit, as well as need. These narratives positioned people as less deserving of treatment if they were perceived as likely to waste resources due to ongoing drug and/or alcohol use:

*I do believe that if they're still drinking an' that they shouldn'ae be getting the treatment.*

*It's no' because I dunnae want them a' get better, it's jus' 'cause they're wasting resources an' money. It's stupid, when you're getting a drug that costs so much, an' really, if you're jus' gonna keep taking, drinking, ken, fucking up...*

(Male, diagnosed 2005, non-cirrhotic)

Concurrent narratives of distributive justice by need and merit could sit side-by-side within a single participant's account, with little sense of conflict. A complex social understanding of HCV treatment allocation became evident, with individuals balancing need, merit and other idiosyncratic factors against a perception of their own position on the HCV illness continuum. For the most part, such narratives were underscored by an unquestioning tolerance and acceptance of treatment rationing and inequality.

### **Beyond a physical burden**

The second theme reveals how the participants firmly located the emotional burden of a somatic disease as their predominant concern. The physical aspect of HCV infection was absent from

almost half of the participants' testimonies, and where it did occur, the discourse of physical disruption was rarely emphasised as particularly significant. Reduced energy and general fatigue were mentioned anecdotally, and framed by most as a manageable and slight inconvenience, rather than a life-changing condition:

*I jus' feel [pauses] a little bit drained, but not sick, sick. My body's jus' went through like a, a big deal, y'know, but I don't feel like - oh my God, y'know, I'm dying, I'm dying...*

(Female, diagnosed 2014, non-cirrhotic)

*I dunnae focus much on it [HCV], an' then when I do think about it, I think well, it's no' like it changes my lifestyle or, y'know there's things that I cannae do, I can still live a normal life...*

(Female, diagnosed 2008, non-cirrhotic)

Whilst the physical burden of HCV formed a weak and insubstantial pattern within the data, the impact on participants' emotional wellbeing was richly constructed and comprised multiple strands. Hepatitis C was framed as an illness that caused a persistent disquiet and underlying worry, which participants' attempted not to dwell upon or brood over:

*I try not to obsess about it, you know, it's kind of running away in the back of your mind the whole time but I try not to, you know, let it affect me too much...*

(Male, diagnosed 2012, non-cirrhotic)

The lack of physical impact from HCV could contribute towards this enduring worry. Whilst some participants used the lack of symptoms to try and block HCV from their thoughts, others found



being unable to monitor the effect HCV may be having on their body unsettling. The fear of transmitting the virus to others was also framed as a significant source of anxiety, with specific fears over transmitting HCV to children and partners commonplace within the narratives:

*I struggle wi' it, I struggle wi' jus' being around people an', an' jus' knowing that I could put them at risk, it's jus' a worry, I worry, a day a' day worry...*

(Female, diagnosed 2013, degree of liver disease unknown)

*Since I got divorced, I jus' thought, nah, I can't. Y'know, an' that's been over, I don't know, seven year? I jus' thought well you cannae have sex again, 'cause you'll end up likes, giving it to somebody else.*

(Male, diagnosed 2005, cirrhotic)

Whilst onward transmission and fears of insidious disease contributed to the emotional burden of HCV, this thematic strand was most evident within the discourse surrounding stigma. Words such as 'dirty', 'branded' and 'leper' were persistently employed by participants to describe how HCV made them feel, with one individual's account describing the physical manifestation of such intense emotions:

*Once, a couple a' months ago, thinking about it, I start scratching, I start – oh, I'm no' bothered brushing my teeth today, I dunnae need to do it, what's the point when I've got this?*

(Male, diagnosed 2015, cirrhotic)

The narratives drew frequent associations between such internalised stigma, and predominant societal attitudes towards drug use and PWID. The participant went on to describe how his physical reaction had been related to his association of HCV with this socially vilified group:

*I think most people jus' treat hep C as just a dirty, dirty, disgusting virus, an' I think most people jus' think you're a bloody drug user. That's the way most people think.*

(Male, diagnosed 2015, cirrhotic)

Most participants sought to manage the stigma associated with HCV by strategically and cautiously selecting their confidantes. However, a small number tackled the issue of disclosure head-on by announcing their HCV status widely. It was better to be open and honest with everyone than contend with the complexities of selective disclosure. Participants justified this uncompromising approach by emphasising the personal gain to be achieved (*"I tell people right up front 'cause I dinnae wanna waste time wi' somebody who's gonna be my fair-weather pal"* [Male, diagnosed 2004, non-cirrhotic]), and by citing altruistic intentions. One woman positioned herself as a cautionary tale:

*I'm straight up with people, y'know, because if I can sort a' make someone think y'know, hey, I'm no' away a' do that, then, yeah, I'll, I'll, I tell people.*

(Female, diagnosed 2014, non-cirrhotic)

Whilst the participants constructed narratives rich in anxiety concerning anticipated stigma, and replete with accounts of internalised shame, discussion of first-hand experiences of stigma were often hard to pin down. Sporadic reports detailing explicit and overt acts of stigmatising behaviour were the exception, rather than the rule:

*...these friends, they always used to give you a cuddle cheerio an' now they don't do that y'know, an' I don't think they realise how much that hurts, y'know to think that that's what they could catch.*

(Female, diagnosed 1991, cirrhotic)

Whilst this may imply that the stigma felt by participants was disproportionate to the level of stigma found within society, the narratives also alluded to the passive and covert nature of much stigmatising practice. For example, one participant related how a chance encounter with an acquaintance revealed a concealed act of discrimination that may otherwise have gone undetected:

*...there's a woman used a' go a' the [community centre], now she's got a cup in the [community centre] – now I never told her I'd hepatitis C, 'cause I, I dunnae use or that wi' her - she's standing at the bus stop - "aye, fuckin' I'm gonna get my cup 'cause, what if they've got hepatitis C"...*

(Female, diagnosed 2013, degree of liver disease unknown)

The emphasis on the emotional burden of HCV within the narratives produced a discourse that also highlighted the importance participants placed on support. Whilst family and friends were commonly positioned as central to preserving emotional welfare, speaking to someone 'outside the family', who had personal experience of living with HCV was particularly valued:

*...but the groups an' everything that I went to, oh, they were amazing. Other people talking about what they go through, erm, an' you're no' sort a' looked at as being different fae anybody else...*

(Female, diagnosed 2009, non-cirrhotic)

### **A new uncertainty**

The final theme explores how uncertainty was etched throughout the collected narratives, and the prominence of uncertainty and scepticism in understandings of new HCV therapies. The concept of uncertainty was often established during discussion of how HCV was understood at the time of diagnosis:

*...and [my GP] was like, can you sit down, an' I'm like I'm just in a' get my prescription, an' she was like no I need a' speak to you, an' I didn't even know what hepatitis C was, I was like, is this like HIV, is this gonna kill me?*

(Female, diagnosed 2012, non-cirrhotic)

Uncertainty was not limited to retrospective reflections on diagnosis, but pervaded across the illness trajectory. For example, those with no history of injecting drug use repeatedly expressed

uncertainty as to how HCV had been acquired, and nearly all participants voiced concerns and confusion surrounding the silent advance of liver disease:

*...you don't know how it could progress, is it changing? How fast is it progressing? Even though the appointments are six months apart what's happening in-between? You think well, things could change an', oh, will I know about it?*

(Female, diagnosed 1997, non-cirrhotic)

In addition to these familiar refrains, uncertainty was also prominent in the participants' discourse surrounding HCV therapies. Understandings of new treatment options were vague and ambiguous, with participants expressing confusion regarding the plethora of new treatment regimens becoming available:

*...there's jus' a lot a' misinformation about what treatment drugs people were on, whether it be first, the first treatment that came out, or the second one, or the newer one, because they're coming out so fast...*

(Male, diagnosed 2013, non-cirrhotic)

Such confusion contributed to the cautious reception that often greeted these new HCV therapies. A perception that individuals would respond differently to the drugs based on unspecified innate factors was also repeatedly voiced, and a discourse emerged that emphasised scepticism and the importance of experience over blind faith:

*... 'cause everything affects everybody differently, everyone's different, every drug affects everybody differently as you know, err, it, it might be, I might be jus' one of these people err, these awkward, err buggers, it doesn't agree with.*

(Male, diagnosed 1997, cirrhotic)

For those co-infected with HIV, HCV treatment uncertainties were rooted in their experience of failed HIV regimens and unforeseen side-effects. Despite the reassuring and optimistic rhetoric espoused by healthcare professionals, new HCV therapies were unknowns, which needed to be closely monitored:

*I think [HCV treatment] would be a matter of me being in [the hospital] for a few days, to see that it's settling down ok, then let me out and come back an', y'know, just keep a good eye on me.*

(Female, diagnosed 1991, non-cirrhotic)

The provision of written information by healthcare staff on the practicalities of taking the drugs did little to challenge the treatment uncertainty. Although one participant was given literature on how to take his drugs, he still felt he knew little about them:

*I, I know nothing about this stuff, all I know is err, I've been err, described on, how to take it, err, an' how many times to take it, y'know, dosage, erm, frequency of dosage an' all that, all that bumf.*

(Male, diagnosed 1997, cirrhotic)

During the study, the hospital-based recruitment site hosted two phase III randomised controlled trials (RCTs) for new HCV drugs, and an awareness of clinical trials was therefore common among the participants. However, the perception of HCV treatments as 'trial drugs' was not limited to RCTs, but more commonly applied in blanket fashion to *all* DAAs which were available in clinic. A couple of participants who were not considering RCTs still referred to themselves as "*guinea pigs*", emphasising the novelty and nascent nature of the regimens. A perception persisted that despite being licensed, these drugs were still largely unknowns:

*I ken they've obviously done clinical tests an' that, but, that's in a sort a' controlled environment, but when you're talking about people who're, normal people who're suffering from depression an' drug problems an' all a' that, y'know what I mean, that kind a' goes oot the window, that clinical test...*

(Male, diagnosed 2004, non-cirrhotic)

The uncertainty around access to new therapies, and contemporaneous use of interferon-based regimens alongside interferon-free options created a sense of conflict for participants. Decisions about HCV treatment were often framed as a trade-off: live with the virus and wait indefinitely for access to improved therapies, or take an interferon-based option now:

*...if [the doctor] says there's a chance we could gi' you this new treatment, but you'll have to wait two year or three year, then I would wait y'know, but if they says no that's no' gonna happen, then I would jus' have to deal wi' it an' get on wi' [the interferon]...*

(Female, diagnosed 2008, non-cirrhotic)

Whilst some participants eschewed the interferon option, in favour of an uncertain wait, others embraced whatever treatment regimen was offered. This latter approach was underpinned by the protracted and challenging journeys to treatment that many participants described, and which created a sense that they had already waited long enough. A prevailing sense of wanting to be free of HCV at any cost developed for a few participants, with a willingness to accept the ordeal and disruption of interferon-based regimens:

*I mean, the end game is, erm, I want a' go through the treatment, if, if it has to be a six month one that'll have to be, I mean I'll, have to grin an' bear it eh?*

(Male, diagnosed 2000, non-cirrhotic)

## **DISCUSSION**

A qualitative focus on HCV has long provided valuable insight into the experience of those living with the virus, and their understanding of the illness (e.g. Miller et al., 2012; Treloar and Rhodes, 2009). However, the wealth of research in this area must be viewed within its historical context, as the majority of studies were conducted during the era of arduous, and poorly efficacious, interferon-based therapy. Over the last five years, rapid pharmacological advances have transformed the prospects of those undergoing HCV treatment in Scotland, and whilst access to new interferon-free DAA regimens has been restricted, significantly improved therapeutic options for HCV now exist (Chung and Baumert, 2014). This study has sought to contextualise the lived



experience of HCV within this modern era of therapy, and in doing so allow exploration of whether constructions of HCV have been disturbed by the arrival of a fast, effective and tolerable cure.

The complex emotional burden of HCV was writ large throughout these contemporary narratives within familiar refrains that have dominated previous research. For example, reactions at diagnosis and the tenacity of stigma resonate with studies conducted during the interferon era (e.g. Butt et al., 2008; Conrad et al., 2006; Fraser and Treloar, 2006; Hill et al., 2015; Rhodes and Treloar, 2008) and speak to the lack of influence a rapidly improving cure has yet to exert on emotional spheres of illness. Biomedical attention on treating and curing the somatic disease has decontextualized HCV from peoples' lives, and, to date, has failed to concurrently address its wider sociocultural impact. The persistence of societal stigma continues to incite anxiety, shame and fear in those infected, perpetuating the spoiled and discreditable label of HCV (Treloar et al., 2013), resulting in an unyielding and obstinate emotional burden of illness.

Beliefs about the illness course and duration also appeared little altered from previous studies as a discourse of chronicity wove throughout the themes. 'Positioning HCV' was underpinned by an assumption that participants' were at a particular point on an illness continuum, and that HCV presented an advancing threat with degrees of severity and diverse trajectories. Of course, understandings of HCV as a *potentially* progressive disease do not automatically equate with an expectation that long-term effects would be directly experienced. Indeed, participants positioning their experience in relation to others may simply be viewed as a discursive strategy, used protectively to assess their own situation in a better light. The uncertainty with which DAA regimens were framed, however, supports a notion that voicing concerns of illness chronicity was not solely a strategic device. These effective, well-tolerated drugs, feted and lionised within medical discourse (Chung and Baumert, 2014; Pawlotsky et al., 2015) were not met with the same

chorus of adoration by the participants. Rather, narratives of caution, confusion and uncertainty emerged, emphasising a vague and ambiguous grasp of HCV treatment evolution. The participants' understandings and belief in this new era of therapy were too untried and untested to challenge the well-founded cultural memory of HCV as a chronic condition (Paterson et al., 2006; Sutton and Treloar, 2007), echoing reports of a cultural lag described by Whiteley et al. (2016).

A cautious framing of the effectiveness of these new medications, and beliefs surrounding the likelihood of gaining access to the drugs, also constructed an understanding that participants lacked control over their illness trajectory. An implicit acceptance of the health inequality status quo underpinned the participants' discourse, as they constructed narratives around the assumption that HCV treatment rationing was an absolute, and adapted their understanding to accommodate that assumption, rather than challenge it. This instinctive tolerance of health injustice speaks to theoretical arguments that suggest an individuals' capability to be healthy can be constrained by their physical and social environments, as well as the political, economic, cultural and legal determinants of those environments (Venkatapuram, 2011). It resonates with the lack of entitlement and therapeutic citizenship reported within HCV communities over the years (Rhodes et al., 2013; Wolfe et al., 2015), and reinforces perceptions that control over the illness lies in political and economic domains, rather than in the hands of healthcare providers or the individuals themselves.

This study has a number of limitations. The participants were a small group from one city in Scotland, and their experience was located within a particular social, cultural and political context. However, the insights gained speak to wider populations of HCV positive individuals within high-income nations with restricted access to interferon-free DAAs. Despite recruitment attempts, the

sample was also mainly composed of individuals who were already accessing specialist HCV care, who may have been more conversant with developments in HCV treatment than those who do not engage with services. The scarcity of individuals recruited from without the hospital site also contributed to the relative dearth of those who identified as current PWID.

## **CONCLUSION**

This exploration of the contemporary lived experience of HCV has emphasised how a rapidly improving treatment has so far failed to successfully challenge inter-subjective perceptions of the illness. How long this situation may endure is unknown. Within high-income nations, the social perception of HCV may naturally evolve as the costs of interferon-free DAAs reduce, and their use proliferates. However, in the short- to medium-term, understandings of HCV as a long-term, life altering and emotionally draining illness continue to impact how individuals respond to and make sense of the infection. The new therapeutic era of HCV may be constrained by inter-subjective perceptions of the illness as a chronic, emotionally scarring condition over which there is little control.

## **RELEVANCE TO CLINICAL PRACTICE**

Whilst the advent of interferon-free DAA treatments has been widely eulogised, this study exposes how their arrival has yet to effectively challenge societal constructions of HCV. The perception and understanding of HCV has previously been demonstrated to adversely impact on the prevention of transmission, testing and diagnosis, engagement with care and access to treatment (Harris et al., 2016; Miller et al., 2012; North et al., 2014; Sublette et al., 2014; Treloar et al., 2013), and as these long-held and deeply-rooted perceptions endure, interferon-free DAA regimens are unlikely to realise their full potential. For nurses working within the field of HCV, this poses challenges to engaging HCV positive individuals in appropriate care and treatment

pathways. Effective drugs are only part of the solution to addressing the HCV global health epidemic; nurses must also acknowledge and challenge perceptions of the disease.

## **DECLARATION OF COMPETING INTERESTS**

There are no conflicts of interest.

## **REFERENCES**

Ajiboye O. (2012) Social phenomenology of Alfred Schütz and the development of African sociology. *British Journal of Arts and Social Sciences*. 4(1): 12-25.

Asselah T., Boyer N., Saadoun D., Martinot-Peignoux M. & Marcellin P. (2016) Direct-acting antivirals for the treatment of hepatitis C virus infection: optimizing current IFN-free treatment and future perspectives. *Liver International*. 36(suppl. 1): 47-57. doi: 10.1111/liv.13027.

Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2): 77-101. doi: 10.1191/1478088706qp063oa

Butt G., Paterson B.L. & McGuinness L.K. (2008) Living with the stigma of hepatitis C. *Western Journal of Nursing Research*. 30(2): 204-221. doi: 10.1177/0193945907302771

Chung R. & Baumert T. (2014) Curing chronic hepatitis C – The arc of a medical triumph. *New England Journal of Medicine*. 370(17): 1576-1578. doi: 10.1056/NEJMp1400986

Conrad S., Garrett L.E., Cooksley W.G., Dunne M.P. & MacDonald G.A. (2006) Living with chronic hepatitis C means 'you just haven't got a normal life anymore'. *Chronic Illness*. 2(2): 121-131. doi: 10.1177/17423953060020020701

Degenhardt L., Charlson F., Stanaway J., ... Vos, T. (2016) Estimating the burden of disease attributable to injecting drug use as a risk factor for HIV, hepatitis C, and hepatitis B: findings from

the Global Burden of Disease Study 2013. *Lancet Infectious Diseases*. 16: 1385-1398. doi: 10.1016/s1473-3099(16)30325-5

Fraenkel L., McGraw S., Wongcharatrawee S. & Garcia-Tsao G. (2005) What do patients consider when making decisions about treatment for hepatitis C? *The American Journal of Medicine*. 118(12): 1387-1391. doi: 10.1016/j.amjmed.2005.05.029

Fraser S. & Treloar C. (2006) 'Spoiled identity' in hepatitis C infection: the binary logic of despair. *Critical Public Health*. 16(2): 99-110. doi: 10.1080/09581590600828683

Glacken M., Kernohan G. & Coates V. (2001) Diagnosed with hepatitis C: a descriptive exploratory study. *International Journal of Nursing Studies*. 38(1): 107-116. doi: 10.1016/S0020-7489(00)00046-8

Glacken M., Coates V., Kernohan G. & Hegarty J. (2003) The experience of fatigue for people living with hepatitis C. *Journal of Clinical Nursing*. 12(2): 244-252. doi: 10.1046/j.1365-2702.2003.00709.x

Grebely J., Raffa J.D., Lai C., Krajdén M., Kerr T., Fischer B. & Tyndall M.W. (2009) Low uptake of treatment for hepatitis C virus infection in a large community-based study of inner city residents. *Journal of Viral Hepatitis*. 16(5): 352-358. doi: 10.1111/j.1365-2893.2009.01080.x

Grebely J., Oser M., Taylor L.E. & Dore G.J. (2013) Breaking down the barriers to hepatitis C virus (HCV) treatment among individuals with HCV/HIV coinfection: Action required at the system, provider, and patient levels. *Journal of Infectious Diseases*. 207(suppl 1): S19-S25. doi: 10.1093/infdis/jis928

Groessl E.J., Weingart K.R., Kaplan R.M., Clark J.A., Gifford A.L. & Ho S.B. (2008) Living with hepatitis C: qualitative interviews with hepatitis C-infected veterans. *Journal of General Internal Medicine*. 23(12): 1959-1965. doi: 10.1007/s11606-008-0790-y.

- Harris M. (2009) Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis. *Sociology of Health and Illness*. 31(7): 1028-1042. doi: 10.1111/j.1467-9566.2009.01172.x
- Harris M. & Rhodes T. (2013) Hepatitis C treatment access and uptake for people who inject drugs: a review mapping the role of social factors. *Harm Reduction Journal*. 10:7. doi: 10.1186/1477-7517-10-7
- Harris M., Ward E. & Gore C. (2016) Finding the undiagnosed: a qualitative exploration of hepatitis C diagnosis delay in the United Kingdom. *Journal of Viral Hepatitis*. 23(6): 479-486. doi: 10.1111/jvh.12513
- Healthcare Improvement Scotland and NHS National Services Scotland (2015) National Clinical Guidelines for the treatment of HCV in adults: version 2.0. December 2015. Available at: <http://www.documents.hps.scot.nhs.uk/bbvsti/hepatitis-c/guidance/national-clinical-guidelines-treatment-hepatitis-c-in-adults-2015.pdf> (Accessed 15 May 2017)
- Hill R., Pfeil M., Moore J. & Richardson B. (2015) Living with hepatitis C: A phenomenological study. *Journal of Clinical Nursing*. 24(3-4): 428-438. doi: 10.1111/jocn.12620
- Hopwood M. & Treloar C. (2005) The experience of interferon-based treatments for hepatitis C infection. *Qualitative Health Research*. 15(5): 635-646. doi: 10.1177/1049732304273932
- Kinder M. (2009) The lived experience of treatment for hepatitis C. *Gastroenterology Nursing*. 32(6): 401-408. doi: 10.1097/SGA.0b013e3181c1497f
- Lazarus J.V., Sperle I., Maticic M. & Wiessing L. (2014) A systematic review of hepatitis C virus treatment uptake among people who inject drugs in the European region. *BMC Infectious Diseases*. 14(suppl. 6): S16. doi: 10.1186/1471-2334-14-S6-S16
- Manns M., Wedemeyer H. & Cornberg M. (2006) Treating viral hepatitis C: efficacy, side effects, and complications. *Gut*. 55(9): 1350-1359. doi: 10.1136/gut.2005.076646

Mason J. (2002) *Qualitative Researching*. (2<sup>nd</sup> ed.) London: Sage Publications Ltd

McGowan C.E. & Fried M.W. (2012) Barriers to hepatitis C treatment. *Liver International*. 32(0 1): 151-156. doi: 10.1111/j.1478-3231.2011.02706.x

Midgard H., Bramness J.G., Skurtveit S., Haukeland J.W. & Dalgard O. (2016) Hepatitis C treatment uptake among patients who have received opioid substitution treatment: A population-based study. *PLoS One*. 11(11): e0166451. doi: 10.1371/journal.pone.0166451

Miller E.R., McNally S., Wallace J. & Schlichthorst M. (2012) The ongoing impacts of hepatitis C – a systematic narrative review of the literature. *BMC Public Health*. 12: 672. doi:10.1186/1471-2458-12-672

North C.S., Devereaux R., Pollio D.E., Hong B.A. & Jain M.K. (2014) Patient perspectives on hepatitis C and its treatment. *European Journal of Gastroenterology & Hepatology*., 26(1): 74-81. doi: 10.1097/MEG.0b013e32836382b5

Paterson B., Butt G., McGuinness L. & Moffat B. (2006) The construction of hepatitis C as a chronic illness. *Clinical Nursing Research*. 15(3): 209-224. doi: 10.1177/1054773806288569

Patton M. (2015) *Qualitative research and evaluation methods: Integrating theory and practice*. (4<sup>th</sup> ed.) London: Sage Publications

Pawlotsky J-M., Feld J.J., Zeuzem S. & Hoofnagle J.H. (2015) From non-A, non-B hepatitis to hepatitis C virus cure. *Journal of Hepatology*. 62(1 suppl.): S87-S99. doi: 10.1016/j.jhep.2015.02.006.

Public Health England (2015) Hepatitis C in the UK: 2015 report. Available at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/448710/NEW\\_FINAL\\_HCV\\_2015\\_IN\\_THE\\_UK\\_REPORT\\_28072015\\_v2.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/448710/NEW_FINAL_HCV_2015_IN_THE_UK_REPORT_28072015_v2.pdf) (Accessed 10 May 2017)

Rhodes T., Harris M. & Martin A. (2013) Negotiating access to medical treatment and the making of patient citizenship: the case of hepatitis C treatment. *Sociology of Health and Illness*. 35(7): 1023-1044. doi: 10.1111/1467-9566.12018

Rhodes T. & Treloar C. (2008) The social production of hepatitis C risk among injecting drug users: a qualitative synthesis. *Addiction*. 103(10): 1593-1603. doi: 10.1111/j.1360-0443.2008.02306.x

Roy É., Nonn É., Haley N. & Cox J. (2007) Hepatitis C meanings and preventive strategies among street-involved young injection drug users in Montréal. *International Journal of Drug Policy*. 18(5): 397-405. doi: 10.1016/j.drugpo.2007.02.005

Schütz A. (1967) *The Phenomenology of the Social World* (G. Walsh & F. Lehnert, Translators). London: Heinemann Educational Books

Shaw J. & Connelly D. (2012) Phenomenology and physiotherapy: meaning in research and practice. *Physical Therapy Reviews*. 17(6): 398-408.

Sheppard K. & Hubbert A. (2006) The patient experience of treatment for hepatitis C. *Gastroenterology Nursing*. 29(4): 309-315.

Sublette V.A., Smith S.K., George J., McCaffery K. & Douglas M.W. (2015) The hepatitis C treatment experience. Patients' perceptions of the facilitators and barriers to uptake, adherence and completion. *Psychology & Health*. 30(8): 987-1004. doi: 10.1080/08870446.2015.1012195

Sutton R. & Treloar C. (2007) Chronic illness experiences, clinical markers and living with hepatitis C. *Journal of Health Psychology*. 12(2): 330-340. doi: 10.1177/1359105307074278

Swan D., Long J., Carr O., ... Cullen W. (2010) Barriers to and facilitators of hepatitis C testing, management, and treatment among current and former injecting drug users: a qualitative exploration. *AIDS Patient Care and STDs*. 24(12): 753-762. doi: 10.1089/apc.2010.0142



- Treloar C., Rance J. & Backmund M. (2013) Understanding barriers to hepatitis C virus care and stigmatization from a social perspective. *Clinical Infectious Diseases*. 57(suppl. 2): S51-S55. doi: 10.1093/cid/cit263
- Treloar C. & 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. doi: 10.1177/1049732309341656
- Treloar C., Jackson L.C., Gray R., ... Brener L. (2016) Multiple stigmas, shame and historical trauma compound the experience of Aboriginal Australians living with hepatitis C. *Health Sociology Review*. 25(1): 18-32. doi: 10.1080/14461242.2015.1126187
- Venkatapuram S. (2011) *Health justice: An argument from the capabilities approach*. Cambridge: Polity Press.
- Westbrook R.H. & Dusheiko G. (2014) Natural history of hepatitis C. *Journal of Hepatology*. 61(1 suppl.): S58-S68. doi: 10.1016/j.jhep.2014.07.012
- Whiteley D., Whittaker A., Elliott L. & Cunningham-Burley S. (2016) The lived experience of interferon-free treatments for hepatitis C: A thematic analysis. *International Journal of Drug Policy*, 38: 21-28. doi: 10.1016/j.drugpo.2016.10.013
- Wolfe D., Luhmann N., Harris M., Momenghalibaf A., Albers E., Byrne J. & Swan T. (2015) Human rights and access to hepatitis C treatment for people who inject drugs. *International Journal of Drug Policy*. 26(11): 1072-1080. doi: 10.1016/j.drugpo.2015.05.007
- World Health Assembly (2016) Sixty-ninth World Health Assembly A69/32 provisional agenda Item 15.1, 22 April 2016. Available at: [http://apps.who.int/gb/ebwha/pdf\\_files/WHA69/A69\\_32-en.pdf?ua=1](http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_32-en.pdf?ua=1) (Accessed 29 April 2017)
- Wozniak L., Prakash M., Taylor M. & Wild T.C. (2007) Everybody's got it, but...: situational and strategic participation in normalized HCV discourse among injection drug users in Edmonton, Canada. *International Journal of Drug Policy*. 18(5): 388-396. doi: 10.1016/j.drugpo.2007.02.006

Zalai D., Carney C., Sherman M., Shapiro C. & McShane K. (2016) Fatigue in chronic hepatitis C infection: Understanding patients' experience from a cognitive-behavioural perspective. *British Journal of Health Psychology*. 21(1): 157-172. doi: 10.1111/bjhp.12155

Table 1: Demographic information for the 20 participants. All information was self-reported during their interview.

Engagement with specialist HCV care	Engaged	18
	Not engaged	2
Date of diagnosis	Pre-2011	12
	2011 and after	8
Mode of acquisition	Injecting drug use	13
	Other	7
HCV treatment history	Previous treatment	3
	No previous treatment	17
Gender	Male	11
	Female	9
Ethnicity	White British	18
	Other	2
Age	≤39	5
	40-49	4
	50-59	9
	≥60	2
Degree of liver disease	Pre-cirrhotic	13
	Cirrhotic	5
	Unknown	2
HIV coinfection	HIV positive	5
	HIV negative/unknown	15
Employment status	Paid employment	6
	Unemployed	13
	Retired	1
Living arrangements	Lives alone	8
	Lives with family	12