The inclusion of people with hepatitis C within disability studies
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ABSTRACT
This article adopts a critical position regarding the ‘illness is not disability’ debate by framing hepatitis C both as a lived, physical impairment and a socio-cultural disability/illness. This article draws on qualitative in-depth interviews with 21 people who live(d) with hepatitis C in the UK and examines the financial impact of living with hepatitis C and the process of applying and being found eligible for welfare benefits. This article contributes to the discussion around the inclusion of people with HCV within disability studies and argued that there should be greater recognition of the disabling processes and barriers they face in accessing information, support, recognition and treatment. At present, the institutional processes used to define the ability to work and determine eligibility for benefits frequently exclude and marginalize the experience of people with hepatitis C.

Introduction
A long-standing tenet of canonical disability studies scholars is that ‘illness is not disability’. This article addresses this (rather antiquated and short-sighted, but nonetheless persistent) critical position by framing hepatitis C virus (HCV) both as a lived, physical impairment and a socio-cultural one (i.e. in terms of the challenges people with HCV face in interfacing with the existing welfare system). Mirroring the findings of Harris (2010) and other chronic illness literature (Charmaz 2002; Barker 2005; Wendell 2006) we argue that the inclusion of people with HCV within disability studies represents an important contribution to a growing body of criticism within the field of disability studies that is actively working to challenge the allegedly ‘distinct’ line between ‘illness’ and ‘disability’.

Across the UK around 21,000 people (Public Health England 2016) live with chronic HCV. Spread through blood-to-blood contact, the main route of transmission in the UK is via sharing injecting drug use equipment. The negative perceptions which accompany this (Harris 2010), coupled with the ‘hidden’ nature of the impairment and the slow course of the infection, mean that HCV remains a low priority for services and policy (APPGH 2011). Estimates are that half of infections are undiagnosed (The Hepatitis C Trust 2013a, 2013b). In medical terms, HCV predominantly affects the liver but is increasingly shown to have extra hepatic manifestations (Foster 2008) including in the digestive system, lymphatic system, immune system and the brain (The Hepatitis C Trust 2014). HCV status is determined by an initial test to detect the presence of exposure antibodies in the blood. A confirmation blood test then determines whether the virus is currently present and replicating – and in what quantity (Klapper 2009). Calls have recently been made for rapid testing, particularly dried blood spot and point of care testing (Shivkumar et al. 2012) to be made available in as many
venues as possible (NICE 2012c). There is currently no vaccine for HCV, though these are currently being developed and trialled (Halliday, Klenerman, and Barnes 2011).

Medical treatment

At the time data were generated, the recommended treatment for all genotypes of HCV in the UK was a combination of Interferon (injected once per week) with twice daily oral Ribavirin (NICE 2006). Combination therapy has sustained virological response (SVR) rates of 50% and 80% depending on genotype and medical literature has pointed to the value of treatment even without SVR, as treatment can inhibit the progress of the virus (Gow and Mutimer 2001). For those with genotype 2 or 3, HCV treatment lasts for 24 weeks. For people living with genotype one, 48 weeks of treatment are recommended. Patients can be said to have ‘cleared the virus’ if they achieve a SVR rate 24 weeks following the end of treatment. In April 2012, two direct acting antivirals, Bocepravir and Telapravir, were approved by NICE (2012a, 2012b). These direct acting antiviral agents are taken in combination with Ribavirin and Interferon. At the time of writing, new direct acting antiviral drugs have the potential to make treatment shorter and easier to tolerate with reduced side effects (Public Heath England 2016).

Methodology

Qualitative methods aimed at generating accounts of participants’ meanings, interpretations and experiences were chosen from the outset, given that HCV has historically been marginalized. Twenty-one participants were interviewed – see Table 1. Eight participants were recruited from online forums, seven were recruited from support groups, four were snowballed from existing contacts, one saw an advert on an email list and one was recruited through advertising in a service. Eleven participated in face-to-face interviews: five at their home, one in the workplace, one at a residential rehabilitation centre and four at a local support meeting (three in a group interview). Eight participated in telephone interviews and two interviews were conducted via Windows Live messenger (MSN) – where typed messages are exchanged online in real time. Interviews ranged in duration from 55 minutes to three and a half hours, and were typically two hours long. The interview schedule explored the experience of HCV broadly, including the first time participants heard of it, the experience of diagnosis, access to treatment, types of support received, areas where support was required or missing, together with positive and negative aspects of living with the virus. Open questions were used throughout. Data were analysed thematically according to the framework outlined by Braun and Clarke (2006). All interviews were transcribed fully. Familiarity with the data was retained via continuous listening, reading and note-making. Initial notes and comments were made on transcripts to generate codes which were then revisited to construct themes. These themes were tested, refined and explored through drafting and redrafting during the study. There is insufficient space here to describe the effects and consequences of the different modes of interviewing on data and analysis; this is explored further in Mack (2014). Ethical approval for the study was granted both by the National Health Service (NHS) Research Ethics Committee and the University Research Ethics Committee. Participant pseudonyms are used throughout.

Meeting the eligibility criteria

A significant problem for participants was that HCV did not appear to fit the criteria for Employment and Support Allowance (ESA) and particularly, Disability Living Allowance (DLA). The ambiguous, contingent and difficult nature of HCV as a chronic illness is at odds with the processes required for gaining support or welfare benefits. Participants often experienced their impairments as variable; Boab stated it ‘depends on which day of the week you get me on’ and Grace stated that treatment effects ‘come and go’. Others described having ‘good days and bad days’ (JB) which were exacerbated.
### Table 1. Participant details.

| Participant | Age  | Gender | Interview mode | Recruited | Route of transmission | Services approached                                                                 | Employment status                                                                 | Status at the time of interview                                      |
|-------------|------|--------|----------------|-----------|------------------------|-------------------------------------------------------------------------------------|----------------------------------------------------------------------------------|-----------------------------------------------------------------------|
| Morgan      | Fifties | F     | Face-to-face   | Forum (1) | Not sure – described numerous points where this could have been contracted | GP, Consultant, Specialist Nurse, Job Centre Plus, Welfare Rights, Social Services | Self-employed. Stopped working due to effects and after effects of treatment   | Awaiting six-month test results                                      |
| Laurie      | Forties | M     | MSN            | Forum (2) | Unclear, possibly familial | National Blood Service, Consultant, Specialist Nurse, GP                             | Returned to work after treatment                                                 | Cleared the virus                                                     |
| Freda       | Fifties | F     | MSN            | Forum – was not sure where she had seen request | Transfusion | National Blood Service, Consultant, Specialist Nurse, GP, Welfare Rights            | Working full time                                                                | On treatment                                                          |
| Ken         | Sixties | M     | Telephone      | Support Group | Drug use               | GP, Specialist Nurse, Consultant, Voluntary Sector, Substance Use Services, Job Centre Plus, Criminal Justice | Retired                                                                          | Clear for five years                                                   |
| Name         | Age       | Gender | Method      | Group          | Diagnosis                      | Status                                                                 | Services                                                                 |
|--------------|-----------|--------|-------------|----------------|--------------------------------|-------------------------------------------------------------------------|--------------------------------------------------------------------------|
| Kerry        | Thirties  | F      | Face-to-Face| Forum (1)     | Drug use                      | Not working. Caring for a small daughter as well as managing numerous health issues and hepatitis C treatment | GP, Specialist Nurse, Consultant, Social Services, Mental Health Services, Criminal Justice, Voluntary Sector |
| Richard      | Fifties   | M      | Telephone   | Support Group | Drug use                      | Working status not clear.                                               | GP, Consultant, Substance Use services, Job Centre Plus, Voluntary Sector |
| Grace        | Forties   | F      | Telephone   | Support Group | Unclear – possible iatrogenic | Not working due to effects of treatment                                | GP, Specialist Nurse, Consultant, Job Centre Plus, Voluntary Sector     |
| Daniel       | Forties   | M      | Face-to-Face| Support Group | Drug use                      | Full-time education                                                   | GP, Specialist Nurse, Job Centre Plus, Substance Use Services           |
| Holli        | Forties   | F      | Telephone   | Forum (1)     | Unclear described multiple points | Working full time                                                      | GP, Consultant, Alternative Health Centre                                |
| Shaun        | Not Specified | M     | Telephone   | Snowball      | Sex                           | Not working – off sick due to treatment effects                         | GP, Consultant                                                         |

(Continued)
| Participant | Age | Gender | Interview mode | Recruited | Route of transmission | Services approached | Employment status | Status at the time of interview |
|-------------|-----|--------|----------------|-----------|----------------------|--------------------|------------------|-------------------------------|
| Charlie     | Not specified | M | Face-to-face | Flyer | Sex | Hospital, Consultant | Working full time | Attained SVR |
| Ben         | Not specified | M | Telephone  | Snowball | Sex | Consultant, Voluntary Sector, Local Network | Working full time | Attained SVR |
| Boab        | Fifties | M | Telephone  | Forum (1) | Transfusion | GP, Specialist Nurse, Consultant | Working full time | Ceased treatment due to ineffectiveness |
| Keith       | Fifties | M | Telephone  | Support Group | Unclear, described multiple points | Substance Use Services, Criminal Justice, GP, Job Centre Plus, Housing, Welfare Rights | Not working due to post-treatment effects | Attained SVR |
| Andrew      | Not specified | M | Face-to-Face | Support Group | Drug use | Specialist Nurse, Voluntary Sector | Not Working due to post-treatment effects | Attained SVR |
| Brad        | Not specified | M | Face-to-Face | Support Group | Sex (rape) | Specialist Nurse, Sexual Health Services, Voluntary Sector | Not Working due to post-treatment effects | Attained SVR |
| Carl        | Not specified | M | Face-to-Face | Support Group | Drug use | Specialist Nurse, Job Centre Plus, Substance Use Services, Voluntary Sector | Working | Attained SVR |
| Name  | Age  | Gender | Group Type | Group Details | Issue | Details |
|-------|------|--------|------------|---------------|-------|---------|
| JB    | Fifties | M      | Face-to-Face | Forum (1)       | Drug use | Not working – effects of treatment | Awaiting six-month SVR |
| Steve | Fifties | M      | Face-to-Face | Support Group   | Drug use | Not working – effects of treatment | Attained SVR |
| Pixie | Fifties | F      | Face-to-Face | Forum (1)       | Transfusion | Working | Attained SVR |
| David | Forties | M      | Face-to-Face | In service flyer | Drug use | In recovery and education | On treatment |
on treatment, or not being able to tell what was an effect of HCV treatment, or existing impairment or age. Here HCV is bound up with other aspects of their lives and experiences.

Benefits were less likely to be awarded if impairment effects were difficult to articulate under the categories on the DLA form, fluctuated or varied widely from person to person. For people with HCV, this fluidity and contingency was difficult to articulate to others and was exacerbated by brain fog and cognitive impairment. Echoing Hammond (2002), Lightman et al. (2009) point to the need to acknowledge the fluid nature of impairment and disablement, that individuals may move back and forward between being more or less impaired, disabled and able to work (consistent with being ‘in recovery’).

The restrictive and disabling assessment process

For others, the process of assessment did not fit with their experience:

Daniel: Well it was all physical it was touch your toes – do your lace up, do this and do that and it was stuff that didn’t relate to my illness – can you make a meal for yourself, can you take a shower – can you walk to the shop, can you use the telephone I was going ‘yes, yes, yes, yes’. So all ‘okay you’re fit for work’ it was nothing that related to the hep C treatment or the drugs I was on.

Though guidance states clearly that the assessment is not dependent on condition but how it affects the person (DWP 2013), Daniel explains how the work capability assessment (WCA) represents a reality where his experiences of the effects of treatment were not taken account of. Given that Daniel is referring to the WCA here, it is important to note that concerns have repeatedly been raised about it: NAT (2010) in their review of the WCA (for people with HIV, but which is also applicable to people with HCV) states that the assessment does not account for some of the major impairment effects including fatigue, fluctuating symptoms, treatment side effects, pain and mental health issues. CAB (2010) questions whether the WCA is fit for purpose given that seriously ill people are called for assessment; no account is taken of the barriers or discrimination that people face in looking for work and there are concerns about the number of people being found fit for work who then go on to successfully appeal the decision. The Harrington (2010, 2012) reviews of the WCA acknowledge these concerns and note that some health conditions are more ‘subjective and evidently more difficult to assess’ and that some of the descriptors may not fully capture the complexities of health conditions in establishing fitness for employment. At the most recent review, progress with addressing these descriptors is ongoing although, Patrick (2012) notes that in spite of these reviews, the government has not paused to implement any recommendations and further, that real change may not be seen for three years (Campbell et al. 2012). The result is that relationships between claimants, staff and the government are fragmented and characterized by mistrust (Patrick 2012).

Eligibility criteria for ESA and DLA are becoming more restrictive. Houston and Lindsay (2010) state that the eligibility criteria have been set increasingly high and one of the major concerns regarding the welfare reform is that the bar for entitlement is now set impossibly high (The Broken of Britain 2011). The move to a face-to-face assessment for Personal Independence Payment (PIP) suggests that these problems outlined in relation to the WCA will persist in relation to PIP. The assessment criteria for PIP do little to suggest that the government is aiming to move away from the culture of ‘box ticking’, which Daniel experienced during his assessment – given that it contains a range of very specific and rigid descriptors, with highest scores attributed to those with the ‘greatest need’. In reality this equates to those with the most visible, clearly understood impairment effects. There is little to suggest any shift in the way disability is understood – as called for by Roulstone over 10 years ago (2004). NAT (2011) draws attention to the lack of open questions within the assessment criteria which do not give people the opportunity to define their own needs, but force them to be defined by others (i.e. the ATOS assessor – Atos Healthcare conducts assessments on behalf of the Department for Work and Pensions for PIP). Daniel recounted his frustration at the irrelevance of the assessment to his experience of treatment, echoed by the evidence of a second-year review of

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the WCA put forward by the UKDPC (2011). Daniel was subsequently found fit for work and moved onto Job Seekers Allowance (JSA). Others referred to not fitting into the ‘disability category’. Morgan’s observation regarding ‘fitting into a box’ is particularly interesting in light of Stone’s (1986) work, which situates disability as an administrative category determined by the government, which affords particular privileges to those deemed disabled. However, it also has a severe impact on those who do not meet the category, simultaneously outlining what impairments and barriers individuals will be expected to live with unsupported. Stone (1986) maintains that the boundary is enacted in combination with the political and economic climate. In periods of high unemployment, there is a restriction on benefit eligibility and the boundaries are drawn tighter to include less people, to create a reserve army of labour (Grover and Soldatic 2013).

**Multiple HCVs**

Echoing Mol’s (2003) work it is important to note that the enactment of HCV treatment in the WCA – as not having an extensive effect on the body or ability to work – is very different from the one enacted by the hospital staff who advised Daniel to use two forms of contraception during treatment and for six months after, due to the possibility of teratogenic effects in pregnancy, which presents treatment as serious with long-term effects. The same advice is given both to women and men. Other participants found that they occupied a similarly liminal and contradictory position, where they were decreed too impaired to undergo routine surgery but not disabled enough to be awarded DLA without an appeal. Participants suggested this was likely to be connected to concerns regarding infection, despite existing policy on the use of universal precautions. In being denied surgery until treatment was over, participants experienced exacerbated impairment effects as well as increased psycho-emotional oppression (Thomas 2007).

**Psycho-emotional disablism and feeling entitled to benefits**

As well as the obvious financial implications of not fitting into the disability category, not being found eligible for welfare benefits impacted on the way participants felt about themselves. Indeed Bambra and Smith (2010, 8) indicate that being ‘sick but able to work’ is a particularly stigmatized status. Others have made reference to the negative perceptions associated with claiming benefits more generally (see Moffatt, Noble, and Exeley (2010)). Steve refers to people made to feel dishonest by claiming, or that they have morally failed. Interestingly, Steve (who was not working at the time) does not indicate that he feels ashamed, but rather than others do. Here, he is possibly participating in the interview for a political reason, raising awareness of the experiences of others beyond himself and resisting oppression by distancing himself from negative perceptions of benefit claimants. Beatty et al. (2010) found that participants were embarrassed about claiming benefits. Grover and Piggott (2007) also make reference to the perception that the majority of claimants who are impaired are somehow playing the system.

Fraser and Gordon (1994) indicate that perceptions and understandings of welfare dependency are built on and intertwined with beliefs about drug dependency. Fraser and Gordon (1994, 325) actually use the term ‘infect’ to describe the way perceptions about drug use shape perceptions of receipt of welfare benefits, pertinent in the context of HCV. Those receiving welfare support are assumed to be drug users, which enhances negative perceptions. Indeed, they indicate that dependence is perceived in solely negative terms – as an encumbrance or a drain. There are similarities here in discussions of dependency in the disability studies literature – dependence is often understood negatively to be synonymous with ‘burden’, but this ignores that everyone is (inter)dependent on others to some degree, in provision and receipt of support or services (see Thomas 2007).

Indeed, many of the participants described requiring financial support for a short time whilst on treatment, in order to save NHS funds in the longer term. Bambra (2008) indicates that the shift to ESA does not acknowledge that participants claiming it are actually sick and disabled, and may be in
recovery. She indicates that addressing health should be prioritized over return to work, as a humane and pragmatic response. Vick and Lightman (2010) similarly maintain that in regard to welfare benefits, the demand for productive bodies is prioritized over the reality of participants’ changing and unpredictable bodies. This marginalization of what participants actually need, together with the absorption of beliefs about benefit claimants as workshy, is illustrated in the extract below from Grace. She reports taking a job after being found fit for work:

I have always worked – not at the moment because I am still on treatment. Been on treatment for the last year and a half. Last time I spoke to you I had just started a new job hadn’t I? Part time – five hours a day. I lasted three days on that one – I was so physically sick I couldn’t do it after three days – so I realised I can only do so much but mentally – I am ahead of my body if you know what I mean? ... I got to the point where I was physically pulling over in the car and throwing up so I had to give it up, I was just doing too much, but I just presumed I could because I needed the money.

Despite having done a difficult treatment for 18 months (she described going ‘straight back on the treatment’ as soon as it became clear the first course of treatment had not cleared the virus), Grace is mandated to attend a Pathways to Work programme but finds that she is unable to work, even part-time. When she states ‘mentally, I am ahead of my body’ this can be taken as a sign that Grace is motivated to work (often understood as a barrier to employment), but her impairment (and the type of employment made available) prevent this. She positions herself as someone who is ‘genuinely’ ill when she says ‘I have always worked’ and ‘I did try and work’; she is aware of the ‘benefit scrounger’ rhetoric which permeates the media (Grover and Piggott 2013) and how people who receive benefits are labelled and portrayed (Garthwaite 2011).

Lastly, Grace states ‘I just presumed I could because I needed the money’. Grace indicates that a need for financial support coerced her into work though she was not fit. NAT (2010, 2011) draws attention to the processes of applying for ESA (and also potentially PIP) which forces people who are sick and/or impaired through a system which actually worsens their impairment effects, whilst simultaneously reinforcing the idea that they are not ‘ill enough’.

Grace described actively resisting the perception that she was not entitled to benefits or time off to recover during treatment, because she had paid national insurance contributions. For this reason, she described being honest in assessments, although this turned out to be counterproductive due to the fluctuating impairment and treatment effects.

Grace’s assertion that she does not ‘feel too bad’ echoes Banks and Lawrence’s (2005) findings that people had a tendency to describe their situations more positively than they actually experienced them (see also Wilson and Amir (2008)), but which lead to them being refused welfare benefits. de Wolfe (2012) indicates that in order to make a successful application, the reverse approach is necessary. This was echoed by a number of participants who stated that being honest about the impairment effects and experiences of disablism was ineffective. Participants referred to needing to ‘play the system’, including dressing in certain ways or using particular words or vocabulary on application forms, representing themselves as impaired and ‘disabled enough’ for the process – in ways that fit the category. Paradoxically this forces them to be dishonest and makes them feel as though they are stretching the truth, perpetuating the perception they are ‘not really’ entitled to benefits (Reeve and Soldatic 2012).

Applying for welfare benefits is a key site of psycho-emotionally disablism, given that claimants are forced to define themselves using a deficit model, describing what they cannot do, rather than what they can (Reeve and Soldatic 2012). The process of applying for benefits is an exercise of disciplinary power. Self-surveillance, where the individual polices themselves and their own behaviours, rather than being policed by an external body and which links to ideas around responsibility for personal health, operates to construct applicant’s bodies as ‘disabled enough’ or not. In order to access benefits such as DLA, participants are forced to become their own oppressors through turning the surveilling gaze on themselves and describing in detail the physical limitations of their own bodies in order to qualify (Shildrick 1997).
Being forced to question if you are ‘ill enough’ to qualify for support is both anxiety producing and psycho emotionally disabling; this experience can be described as ‘sapping the strength’ (Reeve 2002, 494) of disabled people beyond the presence of structural barriers.

**Enacting a hierarchy**

Not meeting the criteria presents participants as non-disabled. Grover and Piggott (2013) state that ESA claimants (like Daniel and Grace) are subject to social sorting (Lyon 2003) which leads to the development and maintenance of hierarchies of entitlement, where only severely impaired people will be entitled to benefits and others will be consigned to living in poverty. This is likely to worsen further given the recent announcements that no ESA will be paid during a period of ‘mandatory reconsideration’ (which must be gone through prior to appeal. Though claimants can ‘choose’ to claim JSA or Universal Credit during this time (Freud 2013), this presents distinct challenges for those who are not fit for work, forcing participants into a liminal space where they can neither work nor access support. This further marginalizes the needs of those with HCV, and subsequently affects the opportunities available to them, determining their life chances (Lyon 2003).

**Identifying as disabled**

Being found fit for work (like Grace was) simultaneously undermines participants’ feelings and knowledge of their own bodies, enforces a feeling of being undeserving of support and reinforces stereotypical notions of disability; for example, that impairments are static, visible and unchanging. This drives a wedge between people with HCV, (other) disabled people and the non-disabled population. Indeed, Grace later stated ‘if I was an immigrant I’d get everything’. Welfare benefit reforms encourage division rather than uniting, which weakens collective political power. Despite clearly facing structural disadvantage in terms of access and participation, experiencing psycho-emotional oppression and living with an impairment for which they undertook gruelling medical treatment (see Shakespeare, Thompson, and Wright 2010), a small but significant number of participants explicitly referred to not seeing themselves as disabled.

The concept of not being ‘ill enough’ to qualify for support is materialized in the condition-related information on HCV on the DWP’s website, which indicates that there are few symptoms prior to the onset of cirrhosis or fibrosis (which participants in this study contested). Further support is only indicated in progression of cirrhosis. Here the emphasis is on people experiencing ‘minimal’ impairment effects prior to the onset of cirrhosis (permanent liver scarring and reduced liver function). However, Thein and Dore (2009) indicate that there may be little correlation between impairment effects and degree of liver damage. Further to this, the information concerning treatment is the exact opposite to what participants in this study described, particularly around the severity of treatment effects and their persistent nature post-treatment. Whilst treatment (and post-treatment) effects are not inevitable – Pixie reported not experiencing any – this is vastly different to the reality portrayed in the DWP information. This information should be updated as a matter of urgency including links to more detailed guidance. This information presents people with HCV as not very impaired until they have cirrhosis – enforcing its own kind of hierarchy and disabling barriers.

The absorption of oppressive ideas about what it means to be being ‘genuinely ill’ or ‘really disabled’ could, in part, be explained by public perceptions around what is covered under disability legislation or what disabled people look like. For Grace, being declared as fit for work and receiving no financial support compounds the negativity she feels around having HCV. In addition, the push towards treatment and the possibility of eradicating HCV may mean not only that participants are less likely to identify as disabled people, but that living with HCV is marginalized as an experience.

This is not to say that every participant rejected a disabled identity. Ken indicated that he thought of himself as disabled, ‘I am anyway’, due to existing impairments. A significant number made specific
reference to being defined as disabled either in relation to legislation, for example, coverage under the Disability Discrimination Act (DDA), or as a result of receiving DLA. Banks and Lawrence (2005) state that receiving DLA may be considered a sign that an individual is disabled as defined under the DDA (1995), although the DLA claim form itself indicates that individuals do not have to identify as disabled in order to claim or qualify (DCS 2011). There is a need here for dedicated information which endorses people with HCV as entitled to apply for welfare benefits and which makes clear that an individual may not necessarily need to self-define as disabled. Although an engagement with wider disability issues may well encourage those with HCV to identify as disabled and thus, recognize the oppression faced by them and other disabled people.

Drug use

Cultural understandings of impairment are intimately linked to the experience of psycho-emotional disablism, and that impairment and disablism are interwoven (Reeve and Soldatic 2012). Impairment type affects how deserving benefit claimants are perceived to be in relation to the type of impairment they had (Briant, Watson, and Philo 2011) – people with physical and sensory impairments were more likely to receive sympathetic treatment by the press, whereas those with mental health conditions were mentioned far less in the ‘deserving’ stories [people with mental health issues in particular are seen as ‘fakers’ Bambra (2008)]. Individuals with impairments which were less visible, or to which society was ‘unsympathetic’ (Briant, Watson, and Philo 2011, 12), were more likely to be seen as unworthy of the benefit, with serious implications for individuals who have contracted HCV through drug use.

Here HCV intra-acts with social and cultural beliefs about drug use – it is an individual issue which must be personally managed rather than something which is connected to wider structural forces, and given that the individual is to ‘blame’, they are not entitled to support (Paylar, Measham, and Asher 2012). There are obvious parallels with HIV (Farrell and Comiskey 2014). This is often suggested as a reason for the lack of political engagement with HCV (Treloar and Rhodes 2009), or used to contextualize the provision of funding and support. For example, Copeland (2004) indicates that despite HCV affecting greater numbers of people than HIV, the profile of HIV remains much higher than HCV. While Körner and Treloar (2006) maintain that people with HIV and HCV face similar social issues – both illnesses are uncertain, both treatments require commitment and can have difficult side effects – HCV is perceived as the ‘poor relation’ of HIV, existing in its shadow. HCV was enacted as a ‘problem’ only after a high level of media coverage and public health awareness raising in the 1980s around HIV – accompanied by possible information fatigue (Slavin, Batrouney, and Murphy 2007; Treloar et al. 2011). A similar level of media interest has never existed for HCV, in part because HCV has not had the same impact, with men and women dying suddenly and visibly. Nor is there the same level of concern about HCV spreading to the general population (Pisani 2009). In addition, HCV and injecting drug use are frequently conflated (Harris 2005) which positions HCV as something that happens to ‘other’ people.

The link between HCV and drug use is particularly pertinent here. The UKDPC (2011) refer to the way in which people with drug problems are heavily stigmatized or treated differently than other claimants; they are targeted to fulfil special requirements but not afforded protection under legislation and are specifically excluded from the definition of disability under the DDA. The idea that participants were responsible for HCV permeated the narratives of many participants. This affected their sense of entitlement and, implicitly, the degree to which they felt it was their responsibility to clear the virus.

Just as Simmonds and Coomber (2009) found that drug users operated a hierarchy of comparisons depending on the method of drug administration, that is, injecting was further down the hierarchy than smoking, participants internalized (incorporated into their self-beliefs) a hierarchy in relation to the method of transmission of HCV. Carl’s status is intertwined with his (previous) heroin use. Here there is evidence of the comparison of two different forms of HCV: the kind acquired through ‘no
fault of your own’ (Andrew) – associated with the ‘innocent’ form (blood transfusion) – and the ‘guilty’ or ‘self-inflicted’ form (injecting drug use). These separate enactments of HCV have serious impacts on the material circumstances of people with HCV, particularly if they do not claim based on perceptions that they do not feel they qualify for or deserve support.

There is also evidence that this division by transmission route is being perpetuated by the provision of services which are provided based on method of transmission. In October 2011, the HCV Trust announced that it would facilitate counselling for individuals who contracted HCV via contaminated blood from the NHS (The Caxton Foundation 2011). Whilst this is an important step forward in the recognition of the needs of people affected by the NHS contaminated blood, there is an implication that those who do not contract HCV through contaminated blood do not require access to counselling. Seear, Fraser, and Lenton (2010) in their exploration of emotion and HCV maintain that emotions in this context obscure the structural factors at work – specifically the link between poverty and problem drug use which the moralizing responses of the welfare benefits system perpetuate (Grover and Paylor 2010).

The disabling process of applying for welfare benefits

Another disabling barrier (both structurally and psycho-emotionally) was the poor levels of knowledge and understanding of the experience of HCV and treatment from those making the assessments. Grace also highlights the apparent lack of knowledge and information around the impact of treatment on impairment effects. The hidden nature of HCV and the lack of information provided to staff making the assessment have serious consequences for Grace and others, especially given the information provided about HCV on the DWP website. Further to this, ‘has usual symptoms’ is particularly worrying in a treatment context, given that the symptoms can be variable. Similarly Grace feels that the ‘usual aches and pains’ does not accurately describe her embodied experience of the treatment, the shifting and contingent nature of living with HCV. By stating ‘maybe some people get it really bad’ Grace implies that her experience is not ‘bad enough’. However, at the same time she indicates that she is unable to walk without high doses of pain medication. Her health is therefore described in contradictory terms.

Richard uses the terms ‘certainly, arguably’ as though he is not entirely sure of his footing or entitlement. He indicates here that he is not ‘desperately hard up’ and he talked about giving up work and experiencing some serious post-transplant and treatment effects. Just as Richard was too ill to appeal the decision concerning his DLA application, Hammond’s (2002) participants also stated that they were too ill to attend the tribunal to appeal, or even to fill in the form. Paradoxically, the more unwell they were, the less likely they were to (be able to) make a claim.

When asserting their entitlement to benefits, other participants made reference to the disabling nature of the medical – including the exacerbation of treatment effects and worsening impairment. JB specifically highlighted the lack of knowledge and the dangers of forcing claimants with HCV to travel to assessments which, given their weakened immune system, might put them at risk of infection.

It has been well documented that the system of applying for benefits is complex and confusing and constantly changing. Morgan describes the difficulty in filling out the forms which requires a lot of effort when unwell and may worsen impairment effects. Malacrida (2010) reported how even participants who had worked in benefits advisory roles were unsure what they could claim and what they were entitled to.

Morgan’s experience of contacting the Disability Benefits Unit to stop her DLA appeal bears this out in practice. Morgan experienced severe post-treatment impairment effects which significantly impacted on her well-being and would have meant that she may have been eligible for DLA; however, a lack of professional support meant she stopped the progress of her appeal. Keith’s experience highlights the importance of professional support when he states:
I know I was surprised the length of time they gave it (to me) anyway but I mean I mentioned that to (local welfare rights organisation) and they turned around and said ‘Oh no you don’t know how long it’s going to take you to recover from your medication – I wouldn’t give it back until you know you’re going to be fine – because of how hard it is [to claim]’.

Disability benefits policies are written for an ‘ideal’ individual who is confident, literate, who has time to go over the forms and few other responsibilities or demands on their time – or indeed their health (Malacrida 2010). Concentration was highlighted as being key when completing benefits forms successfully, and completing the form in short bursts could be detrimental and lead to inconsistencies (Banks and Lawrence 2005). Thus, for individuals with HCV who experience fatigue and ‘brain fog’, the process itself is disabling. A few participants reported receiving support from friends or peers with regard to benefit applications, although Keith does later describe approaching formal services. Moffatt, Noble, and Exeley (2010) found that people with cancer also had limited knowledge of the benefits system – no one alerted them to what they could claim and they only described finding out either from specialist nurses or online forums.

**Conclusion**

HCV is a chronic illness – it is long term, fluctuating, difficult to treat, not following a conventional illness trajectory (symptoms – diagnosis – treatment – recovery) and not necessarily visible (see Lightman et al. 2009). Wendell (2001) has emphasized the need to pay greater attention to the experience of chronic illness (see also Reed-Gibson and Lindberg 2007; Price 2011) and this article adds to a body of work within disability studies which has begun to address chronic illness (see, e.g. Wendell 1996; Wendell 2006; Carrie and Chan 2008; de Wolfe 2012). Closely intertwined with this are de Wolfe’s (2002) comments on the division between illness and disability, she had previously thought of herself not as ‘disabled’ but as ‘ill’ and she did not feel that she could define herself as disabled. Whilst the disability movement has worked to emphasize that it is possible to be healthy and disabled, eliminating illness from discussions of disability shifts the boundaries of exclusion, meaning people who are chronically sick remain the sole responsibility of medicine. de Wolfe (2002) maintains that a firm division between the two cannot be maintained and similar sentiments are expressed by Harris (2010) who describes health and illness as a continuum.

In this study participants held mixed views on identifying as disabled with HCV. The hinterland of messages around impairment and disability as ‘personal tragedy’ (Thomas 2007), and largely static and physical (Grewal et al. 2002), meant that a disabled identity was endorsed as simultaneously undesirable and not applicable to people with HCV, given it is a fluctuating and hidden impairment. Additionally, the current portrayals of disabled people who claim benefits as ‘shirkers and scroungers’ (Garthwaite 2011) means that adopting a disabled identity might further present people with HCV in negative ways.

This article has made a contribution in initiating a discussion around the inclusion of people with HCV within disability studies and argued that there should be greater recognition of the disabling processes and barriers they face in accessing information, support, recognition and treatment. At present, the institutional processes used to define the ability to work (for ESA) and determine eligibility for DLA or PIP frequently exclude and marginalize the experience of people with HCV. There is little (if any) guidance around the application of legislation (e.g. Protection under The Equality Act, 2010) to people with HCV, or people undergoing treatment. The lack of acknowledgement of their needs and the absence of publicly available information and support concerning how the legislation could apply further endorses HCV as something which must be addressed and managed individually.

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References

All Party Parliamentary Group on Hepatology. 2011. “Commissioning for Better Outcomes in Hepatitis C.” http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Reports/Resources/APPHG%20Commissioning%20for%20better%20outcomes%20in%20hepatitis%20C.1%20pdf.
Bambra, C. 2008. “Incapacity Benefit Reform and the Politics of ill Health.” British Medical Journal 337: a1452–a1452.
Bambra, C., and K. E. Smith. 2010. “No Longer Deserving? Sickness Benefit Reform and the Politics of (ill) Health.” Critical Public Health 20 (1): 71–83.
Banks, P., and M. Lawrence. 2005. “Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance.” Journal of Social Work 5 (3): 299–317.
Barker, K. 2005. The Fibromyalgia Story; Medical Authority and Women’s Worlds of Pain. Philadelphia: Temple University Press.
Beatty, C., S. Fohtergill, D. Houston, and R. Powell. 2010. “Bringing Incapacity Benefit Numbers Down: To what Extent Do Women Need a Different Approach?” Policy Studies 31: 143–162.
Braun, V., and V. Clarke. 2006. “Using Thematic Analysis in Psychology.” Qualitative Research in Psychology 3: 77–101.
Briant, E., N. Watson, and G. Philo. 2011. Disability and Carers Service (DCS). 2011.
Banks, P., and M. Lawrence. 2005. “Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance.” Journal of Social Work 5 (3): 299–317.
Barker, K. 2005. The Fibromyalgia Story; Medical Authority and Women’s Worlds of Pain. Philadelphia: Temple University Press.
Beatty, C., S. Fohtergill, D. Houston, and R. Powell. 2010. “Bringing Incapacity Benefit Numbers Down: To what Extent Do Women Need a Different Approach?” Policy Studies 31: 143–162.
Braun, V., and V. Clarke. 2006. “Using Thematic Analysis in Psychology.” Qualitative Research in Psychology 3: 77–101.
Briant, E., N. Watson, and G. Philo. 2011. Disability and Carers Service (DCS). 2011.
Banks, P., and M. Lawrence. 2005. “Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance.” Journal of Social Work 5 (3): 299–317.
Barker, K. 2005. The Fibromyalgia Story; Medical Authority and Women’s Worlds of Pain. Philadelphia: Temple University Press.
Beatty, C., S. Fohtergill, D. Houston, and R. Powell. 2010. “Bringing Incapacity Benefit Numbers Down: To what Extent Do Women Need a Different Approach?” Policy Studies 31: 143–162.
Braun, V., and V. Clarke. 2006. “Using Thematic Analysis in Psychology.” Qualitative Research in Psychology 3: 77–101.
Briant, E., N. Watson, and G. Philo. 2011. Disability and Carers Service (DCS). 2011.
Banks, P., and M. Lawrence. 2005. “Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance.” Journal of Social Work 5 (3): 299–317.
Barker, K. 2005. The Fibromyalgia Story; Medical Authority and Women’s Worlds of Pain. Philadelphia: Temple University Press.
Beatty, C., S. Fohtergill, D. Houston, and R. Powell. 2010. “Bringing Incapacity Benefit Numbers Down: To what Extent Do Women Need a Different Approach?” Policy Studies 31: 143–162.
Braun, V., and V. Clarke. 2006. “Using Thematic Analysis in Psychology.” Qualitative Research in Psychology 3: 77–101.
Briant, E., N. Watson, and G. Philo. 2011. Disability and Carers Service (DCS). 2011.
Banks, P., and M. Lawrence. 2005. “Transparent or Opaque? Disabled People Living in Scotland Describe Their Experience of Applying for Disability Living Allowance.” Journal of Social Work 5 (3): 299–317.
Barker, K. 2005. The Fibromyalgia Story; Medical Authority and Women’s Worlds of Pain. Philadelphia: Temple University Press.
Grover, C., and L. Piggott. 2013. “Disability and Social (In)Security: Emotions Contradictions of Inclusion and Employment and Support Allowance.” Social Policy and Society 12 (3): 369–380.

Grover, C., and K. Solidago. 2013. "Neoliberal Restructuring Disabled People and Social (in)Security in Australia and Britain." Scandinavian Journal of Disability Research 15 (3): 216–232.

Halliday, J., P. Klenerman, and E. Barnes. 2011. “Vaccination for Hepatitis C Virus: Closing in on an Evasive Target.” http://www.ncbi.nlm.nih.gov/pubmed/21604986.

Hammond, C. 2002. “A Poorly Understood Condition: Disability Living Allowance and People with CFS/ME.” Social Policy & Administration 36 (3): 254–274.

Harrington, M. 2010. “An Independent Review of the Work Capability Assessment.” http://www.dwp.gov.uk/docs/wca-review-2010.pdf.

Harrington, M. 2012. “An Independent Review of the Work Capability Assessment.” https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/70123/wca-review-2012.pdf.

Harris, M. 2005. "Living with Hepatitis C: The Medical Encounter." New Zealand Sociology 20: 4–19.

Harris, M. 2010. “Negotiating the Pull of the Normal; Embodied Narratives of Living with Hepatitis C in New Zealand and Australia”. Unpublished PhD thesis accessed online [01/07/2012], University of New South Wales.

The Hepatitis C Trust. 2013a. "Update from the Hepatitis C Trust. Issue 15." http://www.hepctrust.org.uk/Resources/HepC%20New/Hep%20C%20Resources/The%20Hepatitis%20C%20Trust%20PDF%20Jan%202013.pdf.

The Hepatitis C Trust. 2013b. "The Uncomfortable Truth; Hepatitis C in England, the State of the Nation." http://www.hepctrust.org.uk/Resources/HepC%20New/The%20Hepatitis%20C%20Trust/The%20Uncomfortable%20Truth.pdf.

The Hepatitis C Trust. 2014. “About Hepatitis C.” http://www.hepctrust.org.uk/Hepatitis_C_Info/About+Hepatitis+C/About+Hepatitis+C.

Houston, D., and C. Lindsay. 2010. “Fit for Work? Health, Employability and Challenges for the UK Welfare Reform Agenda.” Policy Studies 31 (2): 133–142.

Klapper, P. E. 2009. “Guidelines for Laboratory Testing of Patients with Hepatitis C in Greater Manchester.” The Association of Greater Manchester Primary Care Trusts, Manchester.

Körner, H., and C. Treloar. 2006. “Representations of People with HIV and Hepatitis C in Editorials of Medical Journals: Discourses and Interdiscursive Relations.” Communication & Medicine 3: 15–25.

Lightman, E., A. Vick, D. Herd, and A. Mitchell. 2009. "Not Disabled Enough: Episodic Disabilities and the Ontario Disability Support Programme." Disability Studies Quarterly 29 (3). doi: http://dx.doi.org/10.18061/dsq.v29i3.932.

Lyon, D. 2003. “Surveillance as Social Sorting: Computer Codes and Mobile Bodies.” In Surveillance as Social Sorting: Privacy, Risk and Digital Discrimination, edited by D. Lyon, 13–30. London: Routledge.

Mack, H. 2014. “It’s all Very Blurry – Exploring the Messy Realities of Hepatitis C.” Unpublished PhD thesis, Lancaster University.

Malacrida, C. 2010. “Income Support in Canada and the UK: Different but Much the Same.” Disability and Society 25 (6): 673–686.

Moffatt, S., E. Noble, and C. Exeley. 2010. ““Done More for Me in a Fortnight Than Anybody’s Done in All My Life” How Welfare Rights Advice Can Help People with Cancer.” BMC Health Services Research 10: 259.

Mol, A. 2003. The Body Multiple: Ontology in Medical Practice. Durham: Duke University Press.

National AIDS Trust. 2010. “The Work Capability Assessment: A Call for Evidence.” http://www.nat.org.uk/Media%20Library/Files/Policy/2010/NAT_Response_WCAreview.pdf.

National AIDS Trust. 2011. “Personal Independence Payment: Draft Assessment Criteria (Response from NAT).” http://www.nat.org.uk/Media%20Library/Files/Policy/2011/PIP_assessment_NAT_response.pdf.

NICE (National Institute for Clinical Excellence). 2006. “Peginterferon Alpha with Ribavirin for the Treatment of Mild Chronic Hepatitis C.” http://www.nice.org.uk/nicemedia/live/13180/50856/50856.pdf.

NICE (National Institute for Health and Clinical Excellence). 2012a. “Telaprevir for the Treatment of Genotype 1 Chronic Hepatitis C.” http://guidance.nice.org.uk/TA252.

NICE. 2012b. “Boceprevir for the Treatment of Genotype 1 Chronic Hepatitis C.” http://guidance.nice.org.uk/TA253.

NICE. 2012c. “Hepatitis B and C: Ways to Promote and Offer Testing to People at Increased Risk of Infection.” http://publications.nice.org.uk/hepatitis-b-and-c-ways-to-promote-and-offer-testing-to-people-at-increased-risk-of-infection-ph43.

Patrick, R. 2012. “All in It Together? Disabled People, the Coalition and Welfare to Work.” Journal of Poverty and Social Justice 20 (3): 307–322.

Paylor, I., F. Measham, and H. Asher. 2012. Social Work and Drug Use. Buckinghamshire: Open University Press.

Pisani, E. 2009. The Wisdom of Whores: Bureaucrats, Brothels and the Business of AIDS. London: Granta.

Public Health England. 2016. “Hepatitis C in the UK: 2016 Report.” https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/541317/Hepatitis_C_in_the_UK_2016_report.pdf.

Price, M. 2011. Mad at School: Rhetorics of Mental Disability and Academic Life. Ann Arbor: University of Michigan Press.

Reed-Gibson, P., and A. Lindberg. 2007. “Work Accommodation for People with Multiple Chemical Sensitivity." Disability and Society 22 (7): 717–732.

Reeve, D. 2002. “Negotiating Psycho-Emotional Dimensions of Disability and Their Influence on Identity Constructions.” Disability and Society 17: 493–508.
Reeve, D., and K. Soldatic. 2012. “The Arrival of the 'Brown Envelope': The Embodied Experience of Welfare Reform in the UK.” Paper presented at 6th Biennial Disability Studies Conference, Lancaster University, 11–13 September.

Roulstone, A. 2004. “Disability, Employment and the Social Model.” In Disability Policy and Practice: Applying the Social Model, edited by C. Barnes and G. Mercer, 18–34. Leeds: The Disability Press.

Seeal, K., S. Fraser, and E. Lenton. 2010. “Guilty or Angry? The Politics of Emotion in Accounts of Hepatitis C Transmission.” Contemporary Drug Problems 37 (Winter 2010): 619–638.

Shakespeare, T., S. Thompson, and M. Wright. 2010. “No Laughing Matter: Medical and Social Experiences of Restricted Growth.” Scandinavian Journal of Disability Research 12 (1): 19–31.

Shildrick, M. 1997. Leaky Bodies and Boundaries; Feminism Postmodernism and Bioethics. London: Routledge.

Shivkumar, S., R. Peeling, Y. Jafari, L. Joseph, and N. Pant Pai. 2012. “Accuracy of Rapid and Point-of-Care Screening Tests for Hepatitis C: A Systematic Review and Meta-analysis.” Annals of Internal Medicine 157 (8): 558–566.

Simmonds, L., and R. Coomber. 2009. “Injecting Drug Users: A Stigmatised and Stigmatising Population.” International Journal of Drug Policy 20: 121–130.

Slavin, S., C. Batrouney, and D. Murphy. 2007. “Fear Appeals and Treatment Side Effects? An Effective Combination for HIV Prevention.” AIDS Care 19 (1): 130–137.

Stone, D. 1986. The Disabled State. Philadelphia, PA: Temple University Press.

The Broken of Britain. 2011. “Response to Personal Independence Payment Draft Assessment Criteria.” http://thebrokenofbritain.blogspot.com/2011/05/response-to-personal-independence.html.

Thein, H. H., and G. J. Dore. 2009. “Natural History of Hepatitis C Virus Infection.” In Hepatitis C: An Expanding Perspective, edited by G. Dore, M. Temple-Smith, and A. Lloyd, 76–89. East Hawthorn: IP Communications.

Thomas, C. 2007. Sociologies of Disability and Illness; Contested Ideas in Disability Studies and Medical Sociology. Basingstoke: Palgrave Macmillan.

Treloar, C., P. Hull, J. Bryant, M. Hopwood, J. Grebely, and Y. Lavis. 2011. “Factors Associated with Hepatitis C Knowledge among a Sample of Treatment Naive People who Inject Drugs.” Drug and Alcohol Dependence 116 (1): 52–56.

Treloar, C., and T. Rhodes. 2009. “The Lived Experience of Hepatitis C and its Treatment; a Qualitative Synthesis.” Qualitative Health Research 19 (9): 1321–1334.

UK Drug Policy Commission. 2011. “Work Capability Assessment: Issues Encountered by People with Drug Problems.” http://www.ukdpc.org.uk/resources/WCA_Y2_submission.pdf.

Vick, A., and E. Lightman. 2010. “Barriers to Employment among Women with Complex Episodic Disabilities.” Journal of Disability Policy Studies 21 (2): 70–80.

Wendell, S. 1996. The Rejected Body: Feminist Philosophical Reflections on Disability. London: Routledge.

Wendell, S. 2001. “Unhealthy Disabled: Treating Chronic Illness as Disabilities.” Hypatia 16 (4): 17–33.

Wendell, S. 2006. “Towards a Feminist Theory of Disability.” In The Disability Studies Reader, edited by L.J. Davis. 2nd ed., 243–257. Abingdon: Routledge.

Wilson, K., and Z. Amir. 2008. “Cancer and Disability Benefits: A Synthesis of Qualitative Findings on Advice and Support.” Psycho-oncology 17: 421–429.

de Wolfe, P. 2002. “Private Tragedy in Social Context? Reflections on Disability, Illness and Suffering.” Disability and Society 17 (3): 255–267.

de Wolfe, P. 2012. “Reaping the Benefits of Sickness? Long Term Illness and the Experience of Welfare Claims.” Disability and Society 27 (5): 617–630.