Hepatitis C and Social Work

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Abstract

It is now a full decade since [Paylor and Orgel \(2004\)](#) called for social work to ‘wake up’ to hepatitis C (HCV). In that time, a small but significant body of social research has developed which has highlighted the far-reaching social consequences of living with HCV. Using this as a foundation, [Paylor and Mack \(2010\)](#) expanded arguments on the role of social work and identified specific areas where social work might become involved, arguing that the profession is uniquely placed and skilled, to respond and provide support. This article draws on qualitative in-depth interviews with twenty-one people who (had) lived with HCV in the UK, to strengthen and broaden the argument that social work and social care need to urgently take a bigger role in working with people with HCV, given the cross-cutting and wide range of issues that arise. This is the first study which uses participant data to argue for the need for social work involvement and in that it highlights a number of points in the experience where social work support is needed including pre and post diagnosis, whilst on treatment and after treatment.

Keywords: Hepatitis C, post diagnosis, pre diagnosis, social work, treatment

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This article explores some of the social implications of living with HCV ([Crockett and Gifford, 2004](#)), and argues that social work is uniquely placed to provide support. The role of social work in supporting people with HCV has been regularly, if minimally, referred to in the literature for over a decade (e.g. [Glacken *et al.*, 2001](#); [Hopwood and Treloar, 2007](#)). Both the [Department of Health’s \(2002, 2004\)](#) HCV Strategy and Action Plan for England made reference to the provision of support and information, facilitating testing and support to children and families, and even the provision

of Direct Payments to enable the provision of care, including a case study of a specialist HCV social work role. In recent years, the *Archer Inquiry* (2009) into the needs of those who acquired HCV from blood and blood products indicated that there may be a need for substantial input from social work, including support for carers, access to financial support and homecare (see supplementary data online).

This brief but regular inclusion of social work, contributes to an (academic) reality where supporting people with HCV is part of the remit for social work. However, the absence of literature which explores in depth the role of social work in supporting people with HCV has been noted (Paylor and Mack, 2010; Moulton, 2011). In spite of the clear recognition of the role of social workers, there is scant evidence that this has been meaningfully engaged with in much of the UK.

The potential reasons for social work's limited engagement are numerous. It may be explained in significant part by the increasingly constrained resource and policy environments in which social workers are expected to function and even purposeful marginalisation of the issue, given the anticipated costs, both economically and in terms of social workers' time. It may also be explained by social work's limited engagement with substance use in the UK, given that sharing injecting drug use equipment is a main route of transmission. People who use drugs require support from a range of services, including social work (Neale *et al.*, 2008). Their needs cut across the range of social work teams and may be one of a number of interlinked issues (Keene, 2001). Despite this, there is a severe lack of specialised education on undergraduate, postgraduate and post-qualifying education in social work (Galvani and Hughes, 2010). This means social workers lack knowledge and understanding about the effects of HCV and the client groups it affects. This lack of attention to substance use (and HCV) on the social work curriculum reinforces the perception of substance use (and blood-borne viruses) as health issues, and sends a message about how concerned and involved social workers are expected to be (Galvani and Hughes, 2010).

In a recent mixed-methods study (Galvani and Hughes, 2010) involving surveys and focus groups with social workers from both children's and adults services, a key finding was that those working with adults (older people and disabled people in particular) felt uncomfortable or found it difficult to ask about substance use and as a result rarely or never asked about it. This is important, as it simultaneously reduces the opportunity to have a discussion about HCV and other BBVs (blood-borne viruses). Though social workers in children's services did feel that asking about substance use was in their remit, this often only occurred when the social worker perceived it was impacting on the parent's ability to fulfil social roles or caring responsibilities, when harm may have already occurred. Thus, HCV may go unnoticed and unsupported. Galvani *et al.* (2013) point out that talking about substance use maximises the opportunity to address it and provide support. This is equally applicable to talking about HCV. The lack of guidance exploring

the role of social workers in relation to HCV (a notable exception being [Paylor, 2009, 2014](#)) may mean that social workers are unsure when to raise the possibility of a test, the kinds of support and information they can provide or how to support people through treatment and beyond (see supplementary data online).

To date, only one in-depth empirical study explicitly exploring the role of social work for those with HCV has been undertaken: [Moulton \(2011\)](#) interviewed ten of the fifteen specialist social workers attached to HCV treatment centres in New South Wales, Australia, regarding their perspectives on the support needs of people on treatment, as well as the skills, values and experiences required of the workers. [Moulton \(2011\)](#) found that client needs centred on information and support following diagnosis, identifying personal strengths and resources, support to access drug and alcohol services and to access and complete treatment. This study was from the perspectives of specialist social workers and this article explores the extent of social work support available to the participants, as well as identifying the kinds of support required and the potential barriers to social work involvement.

Living with HCV can have a serious impact on everyday life. Impairment effects include joint pain, fatigue and sleep problems, mood changes and depression, difficulty concentrating, abdominal pain and digestive problems. If left untreated, HCV can lead to fibrosis, cirrhosis and even liver cancer, but for most people the effects tend to be chronic and debilitating rather than fatal. The course of the disease can be vague and is frequently described in the literature as asymptomatic ([Glacken *et al.*, 2001](#); [Dore *et al.*, 2003](#))—an observation only very partially supported by participants in this study.

Aside from the physical impact, living with HCV is accompanied by a range of social issues, such as the actual and perceived relationship with illicit drug use, the possibility of transmission (and associated perceptions of contagion) and the realities of living with a long-term condition. [Groessl *et al.* \(2008\)](#) found that participants in their study had specific concerns about disclosing HCV diagnosis or concerns to family members and preserving relationships. This is paradoxically a time when people are most likely to require support, but may feel most isolated, having absorbed wider negative assumptions around HCV. This isolation is likely to be exacerbated by other life circumstances, including financial strain (changes to social security benefits such as Employment Support Allowance and the changes from Disability Living Allowance to Personal Independence Payment ([DWP, 2011](#)) and difficulties around employment may increase isolation from the wider community ([Campbell *et al.*, 2012](#))). Previous drug use and involvement in the prison system ([Janke *et al.*, 2008](#)) may also mean that social relationships and networks are changed. In addition, the recent introduction of the under occupancy penalty ([DWP, 2013](#)) may mean moving to different areas, resulting in uprooted social networks. For these reasons, a discussion of the role of social work support is timely.

The need for social work support

Moffatt *et al.* (2010) note that, within UK health care, it is frequently unclear who should take responsibility to support people with the social aspects of illness, given that boundaries are contingent and blurred. A key finding of this research is that social work (both in statutory and in third-sector services) may be well placed to provide this. Social workers' daily involvement with circumstances and lived experiences which are ambiguous, cumulative, contradictory and difficult (Drayton, 2013), means they have transferable skills and capabilities to manage the challenging and cross-cutting issues raised by HCV. Social workers are (and could be) ideally situated to provide a wide range of support and information ranging from harm reduction, to support through testing and treatment, as well as wider support for social issues raised by living with and beyond HCV (Paylor and Mack, 2010).

However, there continues to be a severe lack of investment in education, awareness raising and dedicated funding within social work related to HCV, likely to be exacerbated by the current constraints on funding and deep cuts to services. The development of integrated health and social care services proposed by the coalition government in the 2012 Health and Social Care Act may provide new opportunities for this, although this remains to be seen. Further to this, it has been suggested (NTA, 2012) that, as funding becomes increasingly constrained and local authorities set their own priorities for services, disinvestment in services becomes a distinct possibility.

Findings

Participant accounts highlighted a number of points where social work could play an important role. Space prohibits inclusion of all elements unearthed, but we wish to highlight in particular the issue of diagnosis, HCV treatment effects and post-treatment support, as these were three key themes which all participants referred to in their interviews. These are also areas where social work could provide specific tailored support. (See supplementary data online for methodological discussion.)

Social workers work across a range of client groups, all of whom have the potential to be affected by the issues raised in the course of HCV infection. For example, social workers may work with those seeking asylum who may have emigrated from countries of high prevalence or with people who have been involved in the prison system. In the course of their daily work, regardless of team function, social workers make contact with those who may have experimented with drug use or received blood transfusions before blood was screened. Given that it may take years for symptoms to be felt or indeed diagnosed, social workers may find themselves with

a vastly increased client group with HCV, such as among older and disabled people and indeed older drug users who may be experiencing serious HCV-related health issues (cf. Grogan and Timmins, 2010). In the USA, this has recently been addressed with the Centre for Disease Control recommending mandatory testing for 'baby boomers' born in 1945–65 (CDC 2012), although there are no similar plans to introduce this in the UK. Thus, a level of basic knowledge of HCV, testing procedure, treatment availability and effects and the kinds of support required should be rolled out across social work teams as a minimum, including those working with children and families, older people, people who use drugs, people living with HIV, the lesbian, gay bisexual and transgender community, and disabled people. Social workers should be provided with local and national contact points and services to facilitate referral and smooth communication and to provide a knowledgeable answer to any questions. A major challenge here is the patchy and inadequate HCV services available and HCV requires investment more widely, as well as that specific to social work. Given that social workers are trained to critically reflect on existing systems and to challenge marginalisation and inequality (Findlay, 2014), there is an important wider role for social workers and organisations of social workers to take a more active role in lobbying for improved HCV services and responses.

Participants in this study reported being unsure whether they could access support from social services. This may well be connected to not knowing which team to access, or concerns about being eligible for services, given that they struggled to meet the criteria for social security benefits. However, participants should still trigger local authority assessment obligations under section 47 of the 1990 NHS and Community Care Act and, at the very least, obtain signposting and information. The remainder of the article focuses on specific phases where social workers could play a key role in support.

Diagnosis

Participants in the sample were diagnosed in a number of settings, including GP practices (eight), NHS Blood Service (two), during a hospitalisation related to HIV (one), prison (one), drug services (three), sexual health services (one), HIV services (one) and during other consultations (three). One participant's place of diagnosis was not clear. The year of diagnosis ranged from 1990 to 2009. Whilst the variety of settings in which diagnosis takes place might at first glance be considered encouraging, it also highlights the multiple and far-reaching nature of HCV and the need for testing from a wide *but informed and trained* range of professionals, including social workers. Participants frequently described feeling underprepared or being diagnosed without adequate explanation, information or aftercare. Almost

half of the participants in this study reported seeking support from their GP for impairment effects, later attributed to HCV, and undergoing numerous tests and treatments prior to being diagnosed. Participants frequently described knowing 'something was wrong' (Morgan). Holli estimated that she had been feeling unwell for about twenty years and had sought support from a variety of help centres, including her GP and alternative health organisations (see also [Glacken et al., 2001](#)). Kerry described joint pain and constant fatigue.

HCV was not asymptomatic or vaguely felt, but participant experiences were frequently understood as something else. Participants suggested a range of structural barriers which inhibited their diagnosis, including GPs' limited knowledge, or awareness, or not being 'tuned in' (Morgan) to the possibility of HCV. There are some important points for reflection in relation to social work here. Clearly it is not always easy to 'spot' HCV among those who may be living with vague and unexplained symptoms. Awareness of HCV symptoms and transmission routes may be helpful in some cases, but strong working relationships between medical professionals and social work services would assist those who might be thinking about being tested or had been recently diagnosed.

For service users who disclose current or former illicit drug use or injecting practices, or through the working relationship and course of assessment describe a possible opportunity for transmission, social workers may be well placed to begin a sensitive and ongoing discussion about HCV, not only in the event that people wish to access a test, but to make discussing drug use and BBVs a part of a conversation relevant to the context of their lives. This is particularly pertinent in light of the increasing focus on gay men who inject crystal meth and mephedrone in a sexual context ([NAT, 2013](#)).

One participant Shaun, who also lived with HIV, described participating in a six week group counselling workshop which provided the opportunity to talk through his experiences with other gay men who had HCV and HIV and to explore the connections, experiences and wider structures which led to contracting the virus. However, this group had recently lost funding due to cuts, further reinforcing the silence around HCV, the impact of treatment and especially the experience of living with co-infection ([Owen, 2008](#)). Social work services may also be well placed to spend time, facilitating links to peers and advocacy services.

Social work input is important given that participants emphasised the need for strong supportive relationships when living with HCV. Participants described a lack of understanding from family, friends and professionals. Prior to diagnosis, a number of participants suggested their illness experiences were dismissed, other participants referred to a sense that they were 'malingering' (Boab) and this lack of recognition from doctors, friends and family, impacted on their self-belief and worth. Here, social workers who are involved with those diagnosed with HCV may need to work with families and carers to aid understanding of the implications of HCV diagnosis and its

treatment. People with HCV reported being deterred from playing with child relatives, being told they could not use the bathroom and being deprived of physical contact (Zickmund *et al.*, 2003), further isolating people with HCV and leading to reduced support networks (McCreaddie *et al.*, 2011). Social workers are well placed to establish and facilitate access to support groups and peer support for both service users and their families.

Following diagnosis, participants who had been unwell for a significant amount of time expressed relief at 'not having to keep fighting anymore' (Morgan). Another participant, Holi, described the diagnosis as a shock but also a relief after such a long time—bringing a sense of validation and legitimacy (Nettleton, 2006). However, for many participants, the initial optimism and relief associated with diagnosis proved to be premature, as they anticipated that the label would engender far more support, help and understanding than they subsequently got. Participants found they were expected to participate in everyday life in a way which was imbued with expectations concerning appearance. The lack of clearly visible *and recognisable* effects of HCV have had a significant impact on participants' beliefs about themselves as 'really' ill and deserving of support, as Kerry describes:

The girlfriend I talked about, she'll say 'but you look fine Kerry!' and I'll think 'yeah but I feel like shit!'

In addition, participants described expectations about ability to work and the need for support, specifically claiming social security benefits and participating in work capability assessments:

Daniel: Well it was all physical . . . 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.

Support following diagnosis

After diagnosis, participants described needing clear explanations and clear pathways of support. Daniel referred to his diagnosis in 2009 as 'clinical'. He described being clearly informed of his status and referred on to a consultant for treatment, but spoke at length concerning the lack of formal, social and emotional support in the days and weeks following diagnosis, and negotiating issues such as testing for his daughter and ex-wife, with limited help. Hopwood and Treloar (2004) indicate that, upon diagnosis, services should be aware of and refer into key agencies of support, in addition to treatment. There is a clear role for social work here in working alongside agencies which provide diagnosis, such as those delivering point-of-care testing, by acting as a point of contact for questions and information, assisting with the maintenance of stable housing, finances, family relationships and child-care arrangements.

Clearly, participants may require support to varying degrees. Laurie, Keith and Kerry pointed to the need for clear, credible information. In particular, they felt they needed printed information, specific to the UK (i.e. diagnostic processes, UK treatment guidelines, support groups and services) which could be revisited and followed up, via accessible UK-based websites, with contact details for local and national services. A key difficulty here is that services in the UK are limited in availability, funding and reach.

Participants in this study frequently described being provided with a referral to a consultant and HCV specialist nurse and little else. This reinforces the authority of medicine and treatment and marginalises the need for other forms of support and information.

For Kerry, there was a need for information which addressed wider issues and circumstances during treatment and beyond. She felt that information specifically tailored for friends and family was severely lacking and that this should be addressed urgently, particularly given that many reported receiving informal support from family members or having to answer questions. Participants wanted information about the following: the impact of HCV and treatment effects (including the invisible nature of the impairment), forms of support that may be required and advice on managing the impact on relationships.

HCV treatment effects

A major area of discussion in the literature and in participant accounts was the side effects and exacerbation of impairment effects caused by HCV treatments. The majority of participants (20/21) described experiencing some side effects which had a serious impact on their mental and physical health, working life, personal relationships and feelings about their body. The existing literature makes reference to physical and mental side effects (Korner, 2010). Fried (2002) indicates that, although severe side effects only occurred in less than 1 per cent (heart problems, loss of vision or hearing, strokes, acute renal failure), less severe ones like depression and insomnia, weight loss, anorexia, hair loss and joint pain were experienced in over 30 per cent of people, with 50 per cent experiencing headaches, fatigue and muscle aches, which contribute to discontinuation of treatment (Hopwood and Treloar, 2005). Participants in this study described: severe pain and aching joints, headaches, feeling cold, hair loss (even eyelashes and eye brows), anaemia and neutropenia (low white blood cells resulting in increased susceptibility to infections), severe weight loss, nausea and vomiting, depression, rage and aggressive behaviour, feelings of isolation, being unable to drive (or driving with dangerous consequences such as on the wrong side of the road), heightened fear and anxiety, suicidal thoughts and attempts, rashes and itching, feeling weak, fatigue, difficulty moving around (even in their home), burning scalp and skin, sensitivity to light and

noise, insomnia, feeling speedy and hyperactive, aversion to particular foods and irritable bowel syndrome. Treatment was described as ‘horrible’, ‘vile’ and ‘awful’. Carl stated ‘I can talk about it for days but I can’t say no good things about it’.

In spite of the severity of side effects and the impact of treatment on participants’ lives and well-being, participants frequently described the importance of doing it or supporting others to do treatment. Although some participants described holding information back about the experience, indicating that they would not tell others for fear of deterring them. Laurie and Charlie described the need to strike a careful balance when talking about treatment, wanting to be honest but not wanting to worry others unnecessarily. This form of emotional work (Thomas *et al.*, 2001), managing their own and others feelings and reluctance to explain just how hard the treatment is, conceals the amount of work involved in being on treatment (Persson *et al.*, 2003) and validation of participant experience is inhibited. This may in turn mean that support services remain underdeveloped (a good example of this are post-treatment support services for cancer survivors which remained underdeveloped until recently — see Abel and Subramanian, 2008; Grinyer, 2009). The key here is honest and open discussion regarding the difficulties on treatment, ensuring participants feel able to approach services and social workers for support.

Further participants made frequent reference to impairment effects and treatment as ‘individual’, which places responsibility for managing it at a personal level rather than at a wider societal and structural level. Whilst this reference to individuality might be interpreted as an act of resisting medicalisation and affirming their value as people, this sole focus at the individual level further isolates those being treated for HCV and depoliticises HCV treatment (Persson *et al.*, 2003), placing responsibility onto individuals to manage *their* illness (Race, 2001). Treatment becomes an exercise in self-management where the individual is responsible for their own outcome on treatment (Martin, 2006). Yet, vitally, the positive outcomes of treatment are reaped within wider society. People may stay in employment longer, having avoided serious health issues, pressure on health service resources and human organs is reduced and the overall prevalence of HCV decreases. In the process, the individual and their support needs are overlooked.

The difficult and unpredictable nature of HCV treatment was acknowledged by participants as problematic in developing models of support. The lack of a ‘*quick fix*’ means there is a danger that, instead of highlighting the need for *more holistic* support with social and emotional components, the needs of those with HCV become *further marginalised*; there are no consistent side effects for everyone and therefore no clear model of support to follow.

Holistic and multidisciplinary support

The importance of addressing needs holistically for people with HCV, especially those who use drugs, has been acknowledged in recent years. Treloar and Holt (2008) emphasised the need to pay attention to issues which may be inhibiting the uptake of HCV treatment and Olsen *et al.* (2013) refer to how poverty, unemployment and poor housing dominated the lives of the women who used drugs.

Similarly, participants in this study emphasised the importance of holistic support and the interconnected nature of the experience of living with the virus. Participants found it difficult to separate out what was an effect of the HCV and what was an effect of the treatment, pre-existing impairment or previous life experiences related to drug use.

Ken described not being sure whether the impairment effects he experienced (confusion) were an outcome of the treatment, past drug use, additional health problems or age. Kerry described the ‘multiple health issues’ she faced in addition to her HCV. Participants often lived with numerous impairments and life circumstances which tangled together, requiring a diverse range and form of support and information. A key finding of this research is that HCV and its treatment are not standalone experiences or issues and cannot be addressed as such, and that needs related to HCV cannot be extricated from the context of a person’s life. Whilst other recent studies have made reference to the importance of multidisciplinary support (Deacon *et al.*, 2013), the role of social work has remained largely unexplored. Findlay (2014) maintains that, in the chronic illness field, the role of social work remains marginal and argues that social workers are well placed to provide support because of their broad and holistic perspectives.

Post treatment

It is important to note that not all post-treatment effects that participants experienced were negative. A small number of participants in the sample who had finished treatment at the time (three of the sixteen) described feeling better after treatment—what Hopwood (2009) refers to as a sense of renewal. However, for many participants, attaining Sustained Virological Response (SVR) did not necessarily equate with improved health. Participants referred to ‘post-treatment effects’ and the need for greater attention to this period was raised as a specific issue. Post-treatment effects are defined for the purposes of this article as impairments which continued, or became visible, after participants finished the course of treatment. Of the participants who had finished treatment at the time of the interview (sixteen), twelve described post-treatment effects. The duration of post-treatment effects ranged from fourteen weeks to five years. It is acknowledged in

some patient information that treatment can take up to six months to recover from (Porter, 2009). However, many of the participants spoken to described being unaware that this would be the case, or did not believe that it would happen to them.

Participants described a range of impairments after the end of treatment, including fatigue, joint pain, confusion and memory problems, depression, gastrointestinal issues, rashes and feeling 'put through the wringer' (Laurie). Carl explained that, for three and a half months after treatment, he experienced both physical and psychological impairment effects.

All but two of the participants who reported post-treatment effects in this study had attained SVR. Keith had attained SVR at the time of interview, but did not feel well enough to return to work due to ongoing treatment effects. Morgan and Steve also described feeling they could not return to work due to difficulty concentrating. Morgan was self-employed as an alternative health practitioner and described how feeling physically well, and present in her own body, was a vital part of her job. Freda worked all through treatment but, in our last correspondence, having finished treatment, she was seeking support for depression. Pixie experienced the onset of rheumatoid arthritis. All participants felt these effects were connected to long-term effects of HCV and treatment.

Participants who experienced post-treatment effects described being placed in a similar position to that they inhabited prior to their diagnosis, where they knew that they still required support, but were disabled by existing structures of services (no medically authorised 'label' which validated their experience, no clear information and limited support) and subsequently found a lack of awareness and recognition. Furthermore, there was even less support available than when participants were on treatment, as they felt medical support was no longer an option.

A key finding of this research was the variation in the degree participants felt prepared for post-treatment effects and their long-term nature. Laurie described experiencing support and encouragement from the specialist nurses; the only post-treatment information he was provided with was the duration of the wait until his PCR test (to see whether the treatment had worked). Other participants reported a lack of information from their specialist team until near the end of treatment, and only knew about it 'from their own research' (Morgan).

This raises a number of pertinent issues. It mirrors Hopwood's (2009) findings that consent forms for treatment do not adequately cover the experience of post treatment and raises ethical questions about offering treatment without alerting participants to the possibility of long-term treatment effects. There are also implications for the relationship between Morgan and the consultant, and about how likely she is to return to him for support given that she did not feel this was discussed. The lack of information, advice and recognition also has very serious consequences for those participants who may be expecting (and expected) to return to work at a pace

shared by colleagues, and raises questions concerning seeking and receiving accommodation or financial support.

The failure to acknowledge post-treatment effects further undermines the experiences of those who experience them. Participants may not be aware that these are post-treatment effects when they do occur, which may cause unnecessary stress or anxiety, and may place further strain on relationships with friends and family.

It is important to note here that it may be that participants *were* informed of the possibility of post-treatment effects at various points; indeed, both Brad and Andrew reported feeling that they had been given ample information and yet still not anticipating the effects, suggesting that more than information is required. As mentioned above, this could be connected to participants believing that the post-treatment effects would not happen to them (what Hopwood and Treloar (2008) term 'unrealistic optimism'). Yet, it is also possible that the post-treatment effects were not fully absorbed or considered by participants because they were not materialised as serious in the provision of formal support services. Information indicating that post-treatment recovery may take some time is difficult to absorb if it appears that in practice no further support is required.

The lack of recognition and validation of their post-treatment experiences, coupled with the expectation of a clear division between being ill and being well (Frank, 1997), has implications for participants' sense of entitlement to peer support. Pixie and JB described forum participants feeling that they could no longer post on peer forums after attaining SVR—which led to the development of a 'post-treatment' section, explicitly acknowledging it as a specific phase of the HCV experience.

Pixie makes reference to the possibility that forum participants have internalised the idea that they are lazy or weak, rather than unwell. She further indicates that, in contact with others on the forum, she has found post-treatment effects dismissed or not taken seriously by professionals. This highlights the need for further longitudinal research into the experience of post treatment and for clear information and training produced by governmental or charitable organisations regarding the possible longer-term effects of treatment, which could be updated as more information becomes available, and which should be tailored and disseminated to GPs, DWP workers, family members and employers. The liminal status of participants' post-treatment experiences also had serious implications for participants' own sense of self and social relationships.

Pixie explained it was only when she realised the post-treatment effects were experienced by people who 'got up every day, went to work, came home, didn't have any problems' that she and JB took it seriously. Here, the post-treatment effects combine with participants' life histories, circumstances, wider cultural and societal values, and assumptions related to HCV and drug use, to enact them in persistently negative ways. The connection (or conflation; Harris, 2005) between HCV and injecting drug use

combine with wider public perceptions of people who use drugs, as weak, unproductive and deceptive. Thus, post-treatment effects are enacted (and dismissed) as an inherent personal fault rather than an iatrogenic impairment.

Other participants referred to the need for post-treatment counselling because ‘after treatment you feel in a way you feel like you should be well and no one understands’ (Morgan). Here, Morgan refers to the tentative nature of the wellness achieved through treatment. Support here would recognise the commitment involved in treatment and looks beyond the treatment as a medical response, to treatment as something which can affect a person’s life in a much wider way.

In a rare UK-based qualitative study, [Sinclair *et al.* \(2011\)](#) described feeling compelled to look beyond the current focus on the medical model, which dominates HCV support provision (two of the authors were working with the client group as psychologists), to explore support needs among co-infected gay men. They found that support focused only on treatment adherence, effectively overlooked participants’ personal needs and priorities.

Conclusion

This article has highlighted key moments where social workers (statutory and third-sector) could and should become involved in supporting those with HCV, specifically through diagnosis, post diagnosis, treatment and post treatment. Support provision could range from clear information, signposting and referral to emotional and financial support (support groups, peer support initiatives) to a more substantial and specialised role providing enabling support during and after treatment. A key issue is the availability of HCV specialist services across the UK which at present is patchy and inadequate. Funding and attention to HCV need to be rolled out across the UK and social workers, and social work organisations are well placed to highlight and emphasise the cross-cutting nature of HCV. [Findlay \(2014\)](#) points to the unique skill sets and perspectives brought by social work, in challenging oppression and the status quo, empowering service users and working innovatively in complex circumstances in a way that other professions do not. Furthermore, the varied and challenging nature of working in the HCV field means that social workers have the opportunity to forge new paths, particularly as social work in health care, substance use and chronic illness is currently minimal. The participants in this study had access to health care services—where gaps emerged, social work is uniquely placed to fill them.

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