

Employment Experiences of Those Living With and Being Treated For Hepatitis C: Seeking Reasonable Adjustments and the Role of Disability Legislation.

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Accounts of employment experience with Hepatitis C (HCV) are scarce, particularly within a UK context where few qualitative studies are available. This article reports on a piece of empirical work which sought to explore the experiences of living with HCV in the UK, out of which the experience of employment emerged. Two standout areas of discussion in this article are the degree to which individuals felt protected in disability legislation (i.e. the Disability Discrimination Act, 1995, 2005, now part of the Equality Act 2010) and their experiences of receiving reasonable adjustments in the workplace. This research highlights the apparent lack of acknowledgement that HCV can affect employment and indeed that the difficulties faced by those with HCV are shared by other disabled people. The findings here suggest that where workplaces facilitate or allow reasonable adjustments employees were able to take up the potential that allowed them to work in sustainable ways.

Keywords: Disability, hepatitis C, reasonable adjustments, work.

Introduction

Recent Health Protection Agency (HPA) (2012) figures suggest that, at present, there are 216,000 people in the UK living with the blood-borne virus HCV. Experience of symptoms including fatigue, cognitive impairment, joint pains, headaches, abdominal pain, depression and mood changes is possible for a number of years prior to diagnosis (Foster, 2008). When this research was undertaken the only available treatment was a combination treatment (interferon and ribavirin). The treatment side effects are variable and the impairment effects unpredictable (Harris *et al.*, 2012). Fried (2002) indicates that although severe side effects are rare (suicidal thoughts and attempts, panic attacks, onset or worsening of autoimmune and heart problems, loss of vision or hearing, strokes, acute renal failure), less severe ones, such as 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). An important point here is that for participants to maintain their long term health, HCV treatment was a form of embodied labour, with possible positive effects achieved through a gruelling process (Keane, 2011).

Focus of the existing HCV literature

Research around HCV has historically focused on clinical and medical aspects, including epidemiology (Nelson *et al.*, 2011), characteristics of the virus and its progression (Seeff, 2002), transmission routes (Jafari *et al.*, 2010), treatment options and contraindications (McHutchinson *et al.*, 2009), including the increasing momentum of clinical trials and the development of new treatments (Stedman, 2013). There is a startling lack of attention to the experience of living with HCV within the UK, and the nuances and differences in policy response and services that this entails. A specific lacuna exists in relation to the experience of working whilst living with, and being treated for, HCV.

HCV and employment in the existing literature

Studies have stated that the emotional and physical dimensions of HCV, treatment side-effects and their wide-ranging and unpredictable nature (Conrad *et al.*, 2006) can affect participation in the workplace (Blasiolo *et al.*, 2006). A recent Australian study described participants' difficulties in sustaining their careers and ambitions. Participants attributed this to HCV-related fatigue, which they stated both exacerbated other symptoms and altered their daily routines and tasks (Fry and Bates, 2012). The study found that participants reduced their hours from full to part-time, or stopped working altogether, as part of what they termed 'self-care'. It highlights that people with HCV face the dilemma between needing to work for financial and personal reasons, but not always being able to do so (Swan *et al.*, 2010).

Platt and Gifford (2003), in the only qualitative study which focuses solely on the employment experiences of people with HCV, found that in addition to the financial benefits, work was an important marker of self-worth, enabled participants to feel part of their community and provided structure to manage the effects of living with HCV. The authors found that the loss of employment had a serious impact on participant self-confidence and wellbeing. Additionally, a US study found that employment (even part-time) was associated with greater access to information and support in relation to HCV (Zucker, 2006).

However, in a comprehensive inquiry into the discrimination faced by people with HCV in New South Wales Australia in 2001, submissions to the inquiry indicated that employment was the most common site of discrimination, after healthcare, and that discrimination often followed disclosure in the workplace (Anti-Discrimination Board of New South Wales, 2001). A fear of negative consequences meant that they hid their status from employers, thus creating difficulties in explaining the need for time off for regular hospital attendance, potentially impacting on their ability to maintain appointments, and therefore affecting their health (Swan *et al.*, 2010). Hopwood *et al.*, (2010) found that very few people had disclosed their HCV status to their boss or work colleagues, 16.5 per cent (83/504) and 17.3 per cent (87/504) of participants respectively, due to concerns about their reactions, although some did describe feeling obligated to tell their colleagues. Other studies described how participants withheld their status in the workplace as they were concerned they would lose their jobs, or would not be considered for a position (Moore *et al.*, 2009). Discriminatory workplace procedures have also been described in the literature, including being subjected to invasive questions concerning the method of transmission (Conrad *et al.*, 2006), or assumptions related to participants' (perceived)

status as someone who used drugs (ADBNSW, 2001). Moore *et al.*, (2009) also found that occupational health examinations were also used as a site of discrimination, enacting HCV as highly contagious.

The exploration of employment experience

Accounts of employment experience with HCV are scarce, particularly within a UK context where few qualitative studies are available. Two stand out areas of discussion in this article are the degree to which individuals felt protected in disability legislation, i.e. the Disability Discrimination Act (DDA), 1995, 2005, now part of the Equality Act (EA) 2010 (HM Government, 2013) and their experiences of receiving reasonable adjustments in the workplace. It has been noted that in exploring disability discrimination legislation, much of the literature focuses on the perspectives of employers and not employees (Foster, 2007), thus this article makes a contribution here. It is an important time to document participant experiences, given the reported low rates of impairment disclosure in employment (EHRC, 2012), and the current instability in relation to the labour market (Patrick, 2012).

Negotiating work and treatment

Employment and making an economic contribution is understood as a key marker of citizenship (Taylor, 2004). Employment plays a key role in developing economic and social status, and exclusion from the labour market means that some groups (including disabled people) continue to be marginalised (Zucker, 2006). Paid employment has been recognised as beneficial (Roulstone and Barnes, 2005), not only financially, but in terms of an increased sense of self-worth, structure in daily life and connection to the local community (Platt and Gifford, 2003). We follow Edwards and Boxall (2010) in recognising that both impairment effects and disabling barriers affect the experience of employment and contribute to experiences and enactments of disability, and that many of the experiences documented here have commonalities with the experiences of other disabled people.

Methodology

The findings in this article formed part of a larger Ph.D. study to explore understandings, experiences and social implications of living with HCV. It focused on the support and information needs of people living with and being treated for HCV in the UK, and the accompanying social and cultural position of HCV, including experiences of stigma, discrimination and disability.

Qualitative methods aimed at generating accounts of participants' meanings, interpretations and experiences were chosen from the outset, given that the experiences of people with HCV have historically been marginalised. Twenty-one participants were interviewed between late 2009 and early 2011. 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, of which 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 MSN messenger. It is not possible to explore in depth the differences made by the different modes of interviewing (this is further explored in Mack, 2014), although it is important to note that there was no discernible difference in length or content covered, but that employment experience was discussed most extensively in the face-to-face and telephone interviews. Employment experiences were discussed less in the focus group/group interviews, perhaps owing to the breadth of topics that were discussed, rather than the depth. Interviews ranged in duration from fifty-five minutes to three and a half hours, and were typically two hours long. The authors were mindful that in asking people with HCV to talk about their experiences, this should be treated as a sensitive topic and that it may have taken considerable effort for them to come forward. With this (and possible impairment and treatment effects) in mind, participants chose the mode of interview (face-to-face, telephone, MSN or email) to make it as easy as possible for them to participate. 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. The experiences of employment were not initially included in the interview schedule, but rather emerged spontaneously during the discussion in the first few interviews. Questions regarding participant current employment and financial status were subsequently added, including whether participants were currently in employment and what difference HCV (treatment) had made to their working lives. Ethical approval for the study was granted both by the NHS Research Ethics Committee and the University Research Ethics Committee. Every effort has been made to remove details which could identify participants, and participants were invited to select pseudonyms.

Obtaining reasonable adjustments

All participants who were working while on treatment (or started treatment while working) described needing to adjust working hours and patterns of work. This depended on disclosure to employers to varying degrees. Only one participant (Freda) continued to work the hours she did before treatment, despite experiencing severe treatment effects, including debilitating fatigue and emotional instability. She described managing these effects by sleeping during her lunch hour with her office door closed. She explained that her reasons for non-disclosure related to her perceptions of her line manager whom she felt 'couldn't hold his own water, let alone a confidence'. Whilst this could be considered what Griffin-Basas (2010) refers to as self-accommodation, which allows Freda to maintain control over her personal circumstances, it also echoes Crockett and Gifford's (2004) findings that fear of negative consequences meant employees hid their status from employers and Roulstone *et al.*'s (2003) findings that reasonable adjustment negotiations depend on relationships with line managers.

For other participants, this was not an option. Shaun, who was on treatment for the second time, described taking the final weeks of his twenty-four week treatment off work:

I was doing okay for the first half . . . Then I started (laughs) – I'm laughing, it's not funny – I started picking fights with people at work, and that's when I thought it's time to back off . . . There would be days when I'd go in and I'd just be like a zombie: I'd stare at the screen, I couldn't talk to anybody . . . I was getting aggressive and snappy . . . Ordinarily I'm someone

who's very, very motivated . . . I have to be very astute; I have to talk a lot of directors. So, that felt horrid because . . . over a period of time I'd avoid people, I'd avoid meetings, I wouldn't take phone calls because I thought, I haven't got the energy to think about what you're telling me or asking me. The other thing, I'd describe it as my brain wading through treacle . . . Typically I would go into work eight, nine o'clock in the morning, but by two o'clock I was toast; I just couldn't function after that time.

Shaun's rich description of the effects of treatment on working makes visible not only the embodied experience, but the impact on wider relationships. He described raising a grievance against his employer while on treatment. While Shaun indicated that he probably would have raised this grievance in due course, he felt that treatment exacerbated this. Holi also described reducing her hours to part-time in her role as a counsellor, whilst on treatment. Ben, who was treated for HCV infection twice, reported reducing his hours on both occasions, but this was affected by his employer at the time.

Redundancy

Two participants described being made redundant whilst on treatment, possibly a marker of the time period during which these data were generated. Whilst it is unlawful to make someone redundant due to disability, it is questionable whether this occurred for Laurie. Both Keith and Laurie described taking voluntary redundancy when their respective companies needed to make savings. Keith indicated that redundancy was part of a range of options, (although the degree to which these were meaningful or suitable is debatable, as one option was to take an eighteen month unpaid sabbatical). The uncertain nature of the treatment meant that Keith took redundancy:

I decided I was going to take redundancy so they gave me a big fat cheque and I walked away and basically I have been on a holiday since. So I am not – my doctor keeps signing me off anyway so I am not due to go I have been signed off until the end of September. But I need to go back to work anyway because I quite fancy earning some money. But I don't really care what I do . . . Because I think the importance of a career is gone.

Whilst Keith spoke positively of his employer and described his changing views on the importance of a career as a good thing, he later described finding it difficult to survive on the redundancy payments given that he had parenting responsibilities. This also had knock-on effects for his housing. Keith reported that eviction procedures were started when he informed his landlord he had lost his job. This was only resolved with the involvement of his MP, his local council and his liver consultant. Here HCV treatment intra-acts with a number of areas of his life and, paradoxically, obtaining support actually required that Keith put in a great deal of 'work' whilst on treatment. The 'work' required is also likely to increase for those subject to the 'bedroom tax' or benefits cap (DWP, 2013a, b), where individuals find they can no longer afford to live in their home and have to move away from social networks and incur additional financial expenses and the stress of moving.

Laurie described a particularly difficult experience of being made 'redundant' (his use of parentheses) from his job in a legal environment:

I had to drop my working week to three and a half days, then my company made me redundant one-third way through – blessing really cos I couldn't cope at that point and my health was getting progressively worse . . . Work-wise – totally started to strip me of ability to function. Aggressive, absent-minded, short of breath – couldn't sleep – obsessive at times

When the specifics of this arrangement were later clarified with Laurie, he explained:

Going part-time for me was basically my employer allowing me a half day for the chemo shot, and a half-day recovery the following day – so part-time of one day off. The chemo laid me so low that this was problematic. Being slightly naïve, I relied on their generosity on this issue and didn't request under the Disability Act. They made me 'redundant' two months into chemo.

Laurie indicated that although his employers provided him with a generous redundancy payment, and the time off gave him the opportunity to recover from treatment, he felt their specialised legal knowledge had enabled them to make him redundant, despite this being unlawful under the DDA (1995, 2005, now under EA 2010).

Laurie indicated that he did not think to ask for reasonable adjustments under the DDA, although his employers, given their profession, might perhaps have suggested this to him. This could be interpreted as a lack of knowledge on Laurie's or his employer's part, suggesting the need for greater information, training and awareness around applications of disability discrimination and equality legislation (Foster, 2007). It might also suggest that Laurie did not necessarily identify as disabled and thus did not ask for an adjustment (Duff *et al.*, 2007). It is possible that the impact of the treatment on Laurie's cognitive ability, and the increased stress he experienced on treatment might well have influenced his willingness to pursue an adjustment. Laurie's employers may also have been unsure about his entitlement under the Act to an adjustment, given the contingent and shifting nature of the treatment effects and duration. It has been noted in the literature (Duff *et al.*, 2007) that employers recognise some impairments more than others. Further, Laurie's phrasing suggests that his employer determined how much time he needed to recover from treatment rather than asking Laurie, which proved inadequate for Laurie's needs; this echoes Roulstone's (2003) observation that power to apply the DDA rests with professionals.

Obtaining reasonable adjustments in the workplace

Some participants did describe receiving reasonable adjustments under the DDA (now under the EA 2010). The DDA requires employers to make 'reasonable adjustments' under section 6 of the Act to facilitate the employment of disabled people in the workplace, including: providing equipment (chairs, laptops, software), making adjustments to the workspace or to the structure and timetable of work (working part time, working from home, working a different routine). However, even though these rights are enshrined in legislation, adjustments may be unevenly available and the concept of 'reasonable' in reasonable adjustments remains vague (Crooks *et al.*, 2012). Griffin-Basas (2010) describes how the notion of what is reasonable has been contested in a North American context, and is often perceived to be 'asking too much' (either in terms of resources, time, or the character of adjustment).

Positive experiences

Keith described receiving a formal reasonable adjustment and a very positive response which he felt was related to the national reach of the company and the size of the organisation he was employed by:

They installed a broadband line in my house; they gave me a computer . . . so I could work from home. All I had to do was go into the office on a Friday – they insisted on that because they didn't want me to be isolated from the team – which is fair enough, they were wonderful, absolutely superb but they are a big company. They can't be seen to discriminate.

Here Keith is provided with equipment to work from home, a mechanism which, if expanded, could increase access to the labour market for many disabled people (Marsh, 2012). This experience fits with a survey by Bruyere *et al.* (2004), who found that equipment provision was the most easily accommodated adjustment.

Similarly Shaun reported a positive response, which he felt was connected to the informed and specialist nature of his role and his employer being in the public sector:

I've got a good job. I've got a good employer as well: because they're a public sector organisation they're very good about things like people with HIV and other conditions . . . they've been fine about giving me time off. During the initial part of my treatment, they said they would give me a reasonable adjustment, so I explained how I could work best and they worked around me. So, from that point of view, I can't complain. But I could well imagine there are loads of other employers who would say: what's wrong with you, well on your bike if you can't perform.

As Shaun indicates, this positive response is perhaps connected to the large nature of the organisations, and the size and specialisms of their HR and legal departments, who may be better informed and equipped than smaller organisations.

Charlie described a positive response, which he too felt was related to the nature of his employer and the type of work he did, which made adjustments relatively straightforward:

Because (my employer) is a [blood borne virus organisation] they had a fuller understanding of what I was going through. It would have been impossible in a physical type job for me to carry on . . . There was a huge amount of flexibility. I luckily had an employer who rather than restrict that actually expanded that. So things like being able to work from home was a major bonus because sometimes if I couldn't get out of bed, I could turn the computer on and just go through my emails.

Charlie makes an important point here about the forms of work that are amenable to adjustments of this type, indicating that this may have been more difficult if it involved physical work or attending somewhere every day. This raises issues regarding recent proposals to require claimants to look for jobs that entail thirty-five hours working in order to receive benefits (Citizens Advice Bureau, 2013). Those working in roles which are insecure and low paid, the current nature of much available employment (Garthwaite *et al.*, 2013), may find this is much less the case.

Similarly Daniel, who was training to be a counsellor, described his college tutor making adjustments to enable him to continue to participate, which he felt was related to his strong relationship with his tutor and the flexibility of the course and the college.

It was perhaps no coincidence that most of the participants who received a reasonable adjustment were well informed of their rights, either through working in a disability advisory role or working for an organisation which provided some advice and training on these issues (cf. Roulstone *et al.*, 2003).

Negative experiences

However, for Richard, specialised knowledge (both on his part and on the part of his employer) did not lead to a positive experience when employed by his local authority. He described disclosing both his liver transplant and the second course of HCV treatment (and the impairment effects and adjustments needed) at the interview, and was offered the job. Despite this honesty Richard reported:

[The employers were] absolutely diabolical. They tried to sack me when I became ill and eventually I won but it was like you know, unions and it dragged on for about three quarters of the year . . . exactly what I didn't need – because at that time I was going through treatment . . . if I had been slightly higher up the organisation, I guess my union might have thought it worthwhile suing them, because I would have loved to have done that but I didn't regret leaving it but its put me off my local [authority] for life . . . they just could not understand that they were dealing with someone who had a disability and they refused to accept that . . . They saw me as someone swinging the lead . . . even when Unison quoted the discrimination act at them, they still refused to be impressed by that and it got really nasty. It took over my life for some months . . . And at the end of the day, it wasn't just the shit of a line manager I had I was dealing with – I didn't speak to her for about nine months – I was dealing with their HR who should know something about this! They tried to get rid of me without even referring me to – they actually ended my contract at one point, I got a letter saying I was no longer employed by them without having gone through occupational health.

This extended extract highlights the difficulties Richard faced and the intra-action of these difficulties which materialised for him, and his impairment, in both directly and indirectly psycho-emotionally disabling ways. The extract makes visible the lack of clarity around HCV and liver disease and the coverage of the DDA. Although it is difficult to see how a person recovering from an organ transplant would not be considered disabled for the purposes of the Act, it also highlights the stressful and long-term nature of the process of challenging this using the DDA, which became even more disabling (Roulstone, 2003). Whilst Richard described resisting and challenging this, there is evidence that others do not (Edwards and Boxall, 2010). There are also serious implications given that Richard indicates that he would be deterred from seeking local authority support, potentially affecting how much he engages with regard to social work support and information in future.

As Fry and Bates (2012) have noted, responses from employers can be uneven and contingent. Ben described two very different responses. When he underwent treatment the first time, he disclosed his HIV status and eventually his HCV status to his line manager, with whom he had a positive relationship, and came to an arrangement where he went home if he felt unwell. Ben described that he felt this was a result of the size of the organisation which could temporarily absorb his work responsibility during difficult periods of treatment. However, after the company was sold to a smaller organisation,

Ben reported a less proactive response from employers, deterring him from seeking a reasonable adjustment:

Yeah, the first time round they were supportive because I suppose when you're a big HR team you know the rules and everything else. The second time around the onus was put on me to go and get the information, I thought 'well I'm not going to have the wrangle, I'm not making myself any more ill by trying to do all the homework' . . . I just thought 'I don't need any more at that point' . . . I was four months into the medication and I was tired. And of course on top of that the company had been taken over and I don't need any more stress, trying to hold onto our jobs and everything else.

Here, Ben indicates that he did not pursue reasonable adjustments under the DDA because he would have had to research and negotiate this with his employer. He described seeking advice and support from a national charity, who explained that adjustments need to be negotiated on a personal basis. Ben described not feeling well enough to do this due to the effects of treatment. Crooks *et al.* (2011), in their study of Canadian academics seeking employment adjustments, similarly found that participants did not ask for reasonable adjustments, because they expected it to be stressful and felt too ill to take on the additional work they felt it would entail. There is a parallel here with participant experiences of accessing welfare benefits, where participants reported being too impaired and disabled to pursue an appeal; paradoxically this means that those who are the most in need of support are the least likely to access it. We are reminded here of Barnes' (2003) observations that anti-discrimination legislation and support should be highly visible, its implementation adequately funded and that responsibility for enforcing it should not be left to disabled people themselves.

Further, Ben indicates that he had concerns about the stability and security of his employment if he had made his HCV status clear in his workplace. He described shredding his personal file, which disclosed his HIV status, out of concern that this may well have affected the way he was treated and his career trajectory. Similar sentiments were echoed by untenured academics in Crooks *et al.*'s (2011) study, and observed by Griffin-Basas (2010) in relation to disabled female attorneys.

Coverage under legislation

HCV was described in the context of disability legislation in Australia fifteen years ago, (Crofts *et al.*, 1997). In the UK, Mack (2007) and Paylor and Mack (2010) have suggested that those with HCV (and on treatment) should be protected under disability legislation, but there has been no exploration of the extent to which people with HCV felt they were covered. A person is covered by the DDA if they have 'a physical or mental impairment which has a substantial and long-term adverse effect on the person's ability to carry out normal day-to-day activities'. For the purposes of the EA, the wording is very similar (HM Government, 2013).

The DDA, which most people referred to in their interviews, has been criticised for being based on a medical model (Pearson and Watson, 2007). Although recent efforts have been made to cover fluctuating impairments in the EA, many participants described feeling uncertain about whether they were covered with HCV. Ben described feeling that people with HCV were covered under disability legislation, but that the difficulties he

faced in employment were a result of HCV not being *explicitly* included under legislation from the point of diagnosis in the same way HIV is; which contributed to its enactment as unimportant. Though Ben acknowledged the contingency of HCV experiences, he described how acknowledging HCV from the point of diagnosis would be validating and helpful:

And I know hep C is kind of short term, for some people it's short term, for some people it's long term, but I thought for that period of medication it would be helpful if it was classified because then it makes it easier, because my employer, they just didn't know. Even when I asked at the hospital they said it's between you and your employer, they didn't know either.

Though it is important not to reinforce the medical model by stating that those with HCV should be covered on the basis of impairment alone, the barriers described by participants in this article suggest that they should be included explicitly under the EA. This contributes to a reality where HCV is not depoliticised as an individual problem to be managed, but is the responsibility of employers and wider society.

As was explored above, significant 'work' may be required on the part of the person claiming under the DDA, and making increased reference to the DDA in wider information, campaigns and training is not intended as a panacea, especially given the findings of a recent National AIDS Trust (2009) survey which indicated that, even with legislative protection, one fifth of people with HIV questioned felt they had experienced discrimination in the workplace. However, in spite of the problems with it, the DDA has at least enacted the needs and rights of disabled people as important (Roulstone, 2004) and the EA represents a step forward regarding recognition of the cross cutting nature of oppression.

The acknowledgement of HCV

Though the DDA (2005) incorporated people with fluctuating impairments from the point of diagnosis, including HIV, MS and Cancer, there has been limited acknowledgement of the rights and entitlements of people with HCV under the DDA, and later under the EA. NHS Choices (2012) and the Hepatitis C Trust (2011) only briefly mention legislation, indicating that employers 'may have' an obligation under the DDA. Only NHS Education for Scotland (2010) explicitly and firmly acknowledges that those with HCV are disabled and are entitled to reasonable adjustments. Thus, there is a need for greater attention to employment, reasonable adjustments and coverage under the DDA.

Worklife's (2009) remit could be widened to include the experience of HCV, enabling people with HCV (and those with co-infection) to garner employment related information and to be able to signpost others. In addition, specific information could be developed for employers to explain the impact of HCV and treatment, and their obligations, such as the toolkit developed by Macmillan Cancer Support (Macmillan Cancer Support 2011).

Being self employed

The final area where there were specific issues raised around employment was the experience of self-employment. Pagan (2009) points to the value of self-employment for disabled people in enabling them to make their own accommodations. However, as

Griffin-Basas (2010) notes, this can be costly, result in a precarious employment situation and may further marginalise disabled people from mainstream employment. Both Morgan and Grace reported being self-employed and giving up their businesses due to treatment effects. For Morgan, having to give up her business was cited as the major impact of HCV treatment as she lost clients and her working premises. Grace described selling her business due to a combination of information she had read on the internet concerning difficulties while on treatment and beginning the treatment itself:

I didn't understand it or I couldn't take it in what they were telling me, because I still didn't have a clue what it was, and I'd read so much on the internet that I was struggling to take any of it in. Only the highlighted bad bits were the bits jumping out at me which I supposed would happen if you're not feeling well. It was all sort of people you know saying 'do the treatment, don't do the treatment' and now – it was just a horrible drug – I couldn't even think straight. That's why I sold my business, sold my work and I totally regret that. I feel stupid for doing that ... that was all scaremongering I got off the internet.

Here the need for clear and accurate information about the treatment, the implications for her self-employed status and the opportunity to discuss it with a business advisor or within a HCV support group (which Grace did not find until much later in her treatment) may have prevented Grace from making the decision she later regretted. Later in the interview, the complexities of being on treatment and having to survive financially after being found ineligible for welfare benefits were made visible. Grace described herself as being 'in limbo' as she did not fit the eligibility criteria for welfare benefits, but was too impaired to work. The result was that Grace used the profits from the sale of her business to survive on treatment. This raises questions regarding how easy it will be for Grace to re-enter workplace when she has to rebuild her business.

Conclusion

This article has sought to explore participants' experiences of having (had) HCV and employment, the experience of obtaining reasonable adjustments under the DDA (1995, 2005) (now part of the EA 2010), and the degree to which they felt they were covered by existing legislation are both addressed.

All participants, who were working at the time, described adjusting hours and patterns of work, some prior to beginning treatment, but most during and after. The article highlighted that the experience of obtaining reasonable adjustments in relation to HCV was variable. Where Keith, Charlie and Shaun described positive experiences of adjustments, Ben, Richard, Laurie and Freda described difficulties, and even being deterred altogether. Participants described how this depended on positive relationships with line managers and a willingness to disclose their HCV status. Indeed Duff *et al.* (2007), in their research with HR Managers in Accountancy firms, found the managers acted as gatekeepers to how disability is understood within a specific organisation. Thus, although the legislation is intended to support disabled people, the reality is that the power to apply it rests with employers. Dibben *et al.* (2001) maintain that disability policy and practice is afforded little importance by management, and that though the DDA may have affected some change, in order to make an impact this must be deeply felt and acted

upon within management and organisations. The findings in this study suggest that this has only happened within a select few.

Most participants who reported positive experiences were employed in roles or organisations which provided information and support to (other) disabled people. This is consistent with Foster (2007), who found that those employees with the greatest knowledge of entitlements under the DDA lived with impairments or worked with disabled people, and Griffin-Basas (2010), who found that those who received adjustments were working in disability rights or legal aid capacities, where there could be said to be greater understanding. Hoque and Noon (2004) found that public sector employers and larger organisations were better at understanding and implementing adjustments. However, this was not the case for all participants, as Richard found. This suggests there are still significant inconsistencies within organisations in terms of understanding and applying disability legislation and providing adjustments.

It is also worth noting that Foster (2007) found that where participants in her study described their experience of obtaining adjustments as positive this was because line managers devolved responsibility to the employees. Foster (2007) explains that this could potentially mean that employers recognise that the employee is best placed to know what adjustments they need, but this also requires knowledge of entitlements on the part of the employee. In Ben's case, placing the responsibility on him meant that he gave up on pursuing adjustments altogether.

A key finding of this article is that participants were required to undertake a good deal of 'work' (in addition to the embodied labour of treatment) in relation to their employment, from researching their entitlements under legislation and negotiating their own adjustments, to challenging oppression and unlawful treatment, to fighting for their home following redundancy. Here the legislation has fallen short for employees. It is clear that an important starting point would be the development of a formal process within organisations when negotiating adjustments (Foster and Fosh, 2010), so that employees and employers can find their way through.

There is also a potential role for trade unions here. Foster and Fosh (2010) argue that trade unions are well placed to provide employment-based support to disabled people because they can include disability as part of wider organisational concerns, rather than addressing impairment and disability as an individual issue to be managed. Indeed, there may well be an opportunity for HCV and HIV organisations to join forces with trade unions to support employees and raise the wider profile of HCV in the workplace.

The final section of the article focused on participant experiences of being self-employed. Both of these participants were self-employed prior to having HCV. Pagan (2009) points to the value of self-employment for disabled people enabling them to work in a way which suits them. Participants in this study reported a different experience. Morgan was unable to work at all due to the severity of impairment effects and the central role that feeling well in her own body played in her role as a practitioner. Grace gave up her employment due to information she had obtained online regarding the severity of treatment, later regretting this when she found she could have worked as and when she felt able. Here there was a greater need for information and guidance when working on treatment, specific written information and advice. Duff and Ferguson (2012) also note that self-employment can come as a result of being forced into it because employers are unwilling to provide support. The article ends with some recommendations.

Recommendations

- There is a need for specific written information and advice for employees around HCV (from impairment specific organisations). The fluctuating nature of impairment and contingent nature of the experience of disability means it is not just as simple as one solution being applied to all people with HCV (cf. Foster and Fosh, 2010); however there is an urgent need for the profile of HCV as affecting employment to be raised.
- Similarly, there is a need for wider discussion within HCV literature around the impact on employment and the development of guidance specific guidance.
- Support and information from union representatives around disability legislation and adjustments is needed.
- There should be a clear process for obtaining adjustments. This is not something that should be left to the individual themselves to negotiate.
- There is an urgent need for support for those who are self-employed.
- Training and information for line managers around disability in general should be provided. This is consistent with wider recommendations in the disability literature around understanding of employer obligations.

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