

Troubling biographical disruption: narratives of unconcern about hepatitis C diagnosis

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Abstract This paper explores the impact of hepatitis C diagnosis among participants of a recent qualitative study based in New Zealand and Australia. The findings of this research were unique with regard to the small amount of existing literature on the topic. Whilst most social research indicates that diagnosis with hepatitis C is a disruptive or distressing experience, study participants were almost evenly divided between those who reported being distressed by diagnosis and those who described contracting hepatitis C as 'no big deal'. The varied nature of participants' narratives about their hepatitis C diagnosis indicates that the experience of biographical disruption is contextual: dependent upon previous experiences of illness, marginalisation or hardship, and the extent to which hepatitis C is an unknown entity or normalised within community networks. This paper draws on the theoretical frameworks of biographical disruption, normalisation and dys-appearance to illuminate these and other contextual issues informing participants' narratives of unconcern about hepatitis C diagnosis.

Keywords: hepatitis C, diagnosis, biographical disruption, narrative, meaning

Introduction

This paper explores the diagnosis meaning-making processes of 40 research participants living with chronic hepatitis C in New Zealand and Australia. Most social research which addresses hepatitis C diagnosis finds it to be a distressing or disruptive occurrence. However, the responses of study participants were almost evenly divided between those who described diagnosis as distressing and those who reported being unconcerned. Due to a focus in the literature on diagnosis as disruptive, both in regard to hepatitis C (Krug 1995, Burrows and Bassett 1996, Hepworth and Krug 1999, Glacken *et al.* 2001, Gill *et al.* 2005) and chronic illness more generally (Bury 1982, Mathieson and Stam 1995, Wilson 2007), this paper will focus on the experiences of the 21 participants who described their experience of diagnosis as of 'no big deal'. It is important to note, however, that these reactions pertain only to participants' recollections of finding out that they had hepatitis C. The paper will also include references to experiences of living with the virus to illustrate how reactions to health and illness are shifting and contextual, and how for some participants their understandings of living with hepatitis C changed over time.

Hepatitis C is a blood-borne virus which, in industrialised countries, is largely confined to people who have injected illicit drugs. Another, much smaller, group of people with

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hepatitis C are those who received blood transfusions or blood products before the onset of blood screening in the early 1990s. Hepatitis C progresses to chronic illness in 75 per cent of infected individuals and, of those, 20 per cent may experience the long-term consequences of liver cirrhosis or carcinoma (Dore 2001). The association of hepatitis C with injecting drug use, infectiousness and chronicity means that it is a highly stigmatised disease. Despite over 170 million people worldwide estimated to live with chronic hepatitis C (World Health Organisation 2002), political action and public awareness regarding the disease is scarce. Hepatitis C has been called 'the silent epidemic' because of its long latency period (Steedman and Zobair 2000), a name which is also appropriate, considering the lack of political or public discourse about the disease. In Australia and New Zealand where this study was conducted, approximately one per cent of the population live with chronic hepatitis C (NZ Ministry of Health 2002, National Centre in HIV Epidemiology and Clinical Research 2008).

Qualitative studies addressing hepatitis C diagnosis report that a majority of respondents found diagnosis to be stressful and distressing. Reactions included feeling 'shocked', 'devastated', 'unclean' and 'contaminated', with the word 'leper' a frequent descriptor (Krug 1995, Burrows and Bassett 1996, Hepworth and Krug 1999, Glacken 2001, Harris 2005, Gill *et al.* 2005). Gill *et al.* refer to hepatitis C diagnosis as 'more stressful than divorce, loss of source of income and a move to another city' (2005: 1741). Diagnosis with hepatitis C has been described as a transition (Hepworth and Krug 1999), a break in the structure of individuals' lives (Krug 1995), and a 'biographical disruption' (Glacken 2001). These findings accord with Bury's (1982) theory of biographical disruption, which has been influential in the field of medical sociology and has occasioned significant debate in *Sociology of Health and Illness* (Bury 1982, Carricaburu and Pierret 1995, Pound *et al.* 1998, Williams 2000, Sanders *et al.* 2002, Faircloth *et al.* 2004). → Bury

This paper utilises, and troubles, Bury's theory of biographical disruption along with the theoretical frameworks of normalisation (Emerson 1992, Wozniak *et al.* 2007) and disappearance (Leder 1990) to explore the contextual issues informing participants' narratives of unconcern about diagnosis. These issues include: the injecting status of participants, the year of diagnosis and type of information available, participants' community identification, the extent to which hepatitis C is known or 'normalised' within that community, and previous familiarity with experiences of bodily and social disruption. Also important is the interview context and the co-constructed nature of resulting data. In exploring these contextual issues this paper does not provide a tidy set of ingredients accounting for a particular response, but instead seeks to illustrate how understandings of hepatitis C diagnosis can arise from an amalgam of embodied experiences, cultural messages, structural constraints, and intersubjective negotiations. → CHRONIC INCLUSION ?

Method

Study aims and objectives

This paper draws from a qualitative research study of the experiences of 40 people living with chronic hepatitis C: 20 living in Auckland, New Zealand and 20 in Sydney, Australia. The aims of the study were to explore the ways in which participants' discursive, intersubjective and embodied experiences interacted to inform their practices around, and understandings of, living with the virus. Analysis was conducted upon various themes that arose from the data. The aim of this paper is to shed light on participants' reactions to, and meaning-making process around, hepatitis C diagnosis. OBSTACLES TO OBJECTIVE RESEARCH

Ethical considerations

COMITATO ETICO

Approval for this research was obtained from the University of Auckland Human Research Ethics Committee and the University of NSW Human Research Ethics Committee in 2004 and 2006 respectively. The interviews commenced after participants read a study information statement and provided written consent. Confidentiality and anonymity were assured.

Recruitment and participant characteristics

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Participants were recruited through research notices placed in the New Zealand Hepatitis C Resource Centre's newsletter *The Chronicle* and the Hepatitis C Council of New South Wales magazine *Hep C Review*. Notices were also distributed at Narcotics Anonymous meetings in central Auckland and central Sydney. A posting was made on the peer support website *Hep C Australasia* informing members of the research project and inviting interested people to participate. The research notice comprised the header 'If you have hepatitis C, I would like to hear your story' and introduced the researcher as someone who was also living with hepatitis C. This disclosure was made to facilitate an interactive 'reflexive dyadic' interview process (Ellis and Berger 2001), in which the researcher is open to questions and the sharing of personal experience on the topic at hand. One question occasionally asked of the interviewer was how she contracted hepatitis C. If asked, she disclosed that she had contracted the virus through drug injecting practices.

For recruitment the only criteria was that each participant was to have, or have once had, hepatitis C. No financial incentive or remuneration was offered to partake in interviews. Approximately 50 individuals responded to the advertisements in Sydney and Auckland with a sample of 20 decided upon for each site. This was due to time constraints and project manageability. In selecting the sample a gender balance and wide age range were aimed for. The research study recruited 22 women and 18 men with an age range of 25 to 63 with a median age of 47. Participants were diagnosed between 1989 and 2006, with 21 stating that they had lived with the virus for over 20 years. Whilst 34 participants identified having injected drugs in the past, none reported that they were currently injecting.

Data collection and analysis

Semi-structured in-depth interviews were conducted with participants in Auckland in 2004 and in Sydney in 2006. Interviews lasted from 60 to 120 minutes and were conducted at a place of the participant's choosing. An opening question for each interview was 'tell me about how you first found out you had hepatitis C' with following questions addressing areas such as experiences of disclosure, stigma, relationships, medical encounters, as well as views on, and experiences of, hepatitis C treatment. Within this format there was space for new topics to emerge and for the participant to take the lead, bringing up issues that were of importance to them. Interviews were transcribed verbatim and analysed with attention to individual narrative form and structure as well as thematic commonalities and differences. One theme that arose from the interview data was the impact of hepatitis C diagnosis, with two broad reactions evident, that of hepatitis C diagnosis as 'devastating' or conversely, as 'no big deal'.

ANALISI LONGITUDINALE Findings
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ANALISI TRASVERSALE

Of the 40 participants in this study, 19 described being either 'devastated', 'shocked' or 'scared' when diagnosed. Conversely, 21 participants described the diagnosis of hepatitis C as 'no big deal', 'a minor detail' or 'expected'. What is interesting about these reactions is

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that the participants who were devastated upon diagnosis reported either having ceased injecting drug use, being in transition from using (in a drug rehabilitation or detoxification centre), or never having injected illicit drugs. However, the majority of the participants who described hepatitis C diagnosis as 'no big deal' reported regular injecting at the time of diagnosis. This is not to say that people who inject drugs do not care about their health. This paper will attempt to resist that easy assumption, by shedding light on the contextual issues that inform a response of unconcern to hepatitis C diagnosis.

The majority of the 21 participants who described diagnosis as 'no big deal' were not only using illicit drugs at the time of diagnosis but tended to have been diagnosed considerably earlier than participants who were 'devastated'. Diagnosis for the less concerned group ranged from 1981 to 2003 with 1991 as the median year. Five of these participants were diagnosed with non-A, non-B hepatitis before 1989. The 19 participants who reported distress at diagnosis were diagnosed from 1990 to 2006 with 1997 as the median year. None of these participants were diagnosed with non-A, non-B hepatitis. The relationship between reaction to diagnosis and the period when diagnosed is noteworthy and can help to elaborate some of the disparities in participants' attitudes towards finding out that they had hepatitis C.

Information provision and naming of the virus

Prior to the naming of hepatitis C in 1989 very little was known about the virus with its designation as non-A, non-B hepatitis reflecting this absence of information. The majority of participants who reported being unconcerned at diagnosis describe receiving little information about hepatitis C, with those diagnosed before 1989 often given the impression that they had an acute infection that would disappear in time. Isobel received her diagnosis in 1983:

I went to the GP and said I thought my eyes looked a bit yellow. And he took some blood and I went back and he said, 'You've got non-A, non-B hepatitis'...I remember getting very little information about it...at that point he was treating it like an acute, he thought it was going to be like hep B (Isobel, 43).

The diagnosing doctor's prognosis of an acute attack was supported by Isobel's embodied experience of yellow eyes and temporary nausea and fatigue. After a couple of months she started to feel better and assumed that the acute infection had passed.

The designations non-A, non-B hepatitis and hepatitis C, whilst generally signifying the same virus, appear to have different implications for participants. For Connor, the imprecise nature of the name non-A, non-B hepatitis meant that the diagnosis lacked credibility:

...for about a year I just didn't feel right, I lost a whole lot of weight, and was exhausted all the time. I had tests done though one of the hospitals, and they said you have antibodies for A which means you have had hepatitis A recently. And that you've got non-A, non-B, but that's powerless because I didn't click that I had anything other than A. And then I went to the doctor in '91 and he said you've got what is now known as hepatitis C (Connor, 46).

The reference to non-A, non-B hepatitis as 'powerless' is illuminating, in that it expresses the absence of meaning reflected in its name. Non-A, non-B hepatitis specifies what it is not, and for Connor the reference to non-A was also connected in his mind with his hepatitis A diagnosis, thus rendering it 'powerless' as a separate issue of concern.

The absence expressed in the name non-A, non-B, means that the recipient of this diagnosis is in a liminal zone, neither ill with a legitimate knowable disease, nor in full possession of disease-free health. Matthew received a diagnosis of chronic persistent hepatitis in 1983 and expressed frustration with the lack of information available at the time. Of his hepatitis C diagnosis in 1990 he said:

I was excited in one area, because at least they knew something about it, but I was discouraged in the other area because I went in for a minor operation and all these doctors came standing around my bed like I was a guinea pig or something. The senior doctors plus interns and they were saying this guy has non-A, non-B, and then they were saying chronic persistent hepatitis and hepatitis C, and they were having all this big intellectual discussion, and I thought what the heck is going on here. And it's like they didn't know much (Matthew, 49).

Matthew described the information he received from the medical profession, first regarding 'chronic persistent hepatitis' and then hepatitis C, as negligible. He went on to explain that he was initially excited about the designation of a new name to non-A, non-B hepatitis, hoping that with this name would come information, leading to some certainty and validation of his symptomatic illness. What he found, however, was that the diagnosis of hepatitis C left him in an equally liminal zone. While non-A, non-B hepatitis was defined by what it was not, hepatitis C, for Matthew, consisted of prognostic and symptomatic uncertainty. As Duffin (2005) writes, hepatitis C is a 'disease still under construction' (2005: 83) and many, especially early, diagnoses are characterised by a lack of information which can result in the sense that the disease is 'powerless' or transient.

HCV as 'normalised'

A lack of knowledge by the medical profession as regards early diagnoses helps to explain why current injectors who received a diagnosis in the 1980s and early 1990s reported being unconcerned. Often their diagnosing doctor had minimal information and presented the illness as an acute infection that would resolve. As time progressed and more people who injected drugs were diagnosed with hepatitis C, information became available regarding the chronic nature of the virus and long-term outcomes. However, the prevalence and largely asymptomatic nature of the virus in the injecting populations encouraged a 'normalisation' of the virus as reported in Davis *et al.* (2004) and Wozniak *et al.*'s (2007) studies. By the time Isobel realised that her infection was chronic it had become the unspoken norm within her social circle:

And nobody talked about hep C really. I mean you know, in passing, it was just so assumed everybody had it. And nobody saw it as a big deal. No-one was thinking about it. Nobody thought it was anything other than just a complete minor detail that had no bearing on life at all (Isobel, 43).

Isobel became more concerned about her hepatitis C in 1991 when she distanced herself from her drug using community. Her health 'hit the wall' and she discovered that her chronic fatigue could be attributable to the virus. In ceasing injecting and moving away from other users, Isobel was exposed to an understanding of hepatitis C that had never affected her before. She describes the beginnings of a relationship with a non-drug-using man and her realisation:

...for the first time in my life what it meant to have this virus in the mainstream world. Because I'd never been part of the mainstream world. It was absolutely devastating to realise that I could be rejected as an entire human being because of this thing (Isobel, 43).

Isobel's experience illustrates how meaning-making around health and illness is a fluid and changing process, influenced by, amongst other things, community involvement and personal relationships.

As well as potentiating rejection in 'mainstream' society, hepatitis C was perceived by some participants as a marker of community. As Zac said:

It is so widespread in our community, the Auckland drug-using community, oh yeah, part of the hep C club. You just sort of accept it, you gonna use long enough, you're gonna have it, and I think it would be a bit different if you were the odd one out, you are the odd one out if you don't have it (Zac, 36).

Like Isobel, Zac did not experience a diagnosis of hepatitis C as biographically disruptive when he was using drugs, as most of his fellow injectors also had the virus. Unlike Isobel, when Zac ceased injecting, his meaning-making processes around hepatitis C did not dramatically change. Five years prior to the interview Zac had become a member of Narcotics Anonymous or NA. Many NA members have hepatitis C and it is rarely stigmatised within the fellowship. Thus, for Zac, attending NA meetings may have buffered the impact of ceasing drug use and entering the 'mainstream world' where hepatitis C is often stigmatised. Zac's statement 'you are the odd one out if you don't have it' is in the present tense indicating that his understandings of hepatitis C as a 'norm' and marker of belonging amongst people who inject drugs continues to be relevant within a community of ex-injectors such as Narcotics Anonymous. Hence, hepatitis C for Zac did not occasion a sense of disruption, neither at diagnosis nor in the years since.

Hepatitis C in relation to HIV

An additional reason why hepatitis C may be perceived as of minimal concern by people who inject drugs is its status in relation to HIV/AIDS in drug-injecting communities. Needle and syringe exchanges were first introduced to Australia and New Zealand in 1986 and 1988 respectively (Kemp 2003), in response to the growing occurrence of HIV amongst people who inject drugs in the USA. The focus of initial harm-reduction messages for drug injectors centred on HIV prevention, with hepatitis C appearing within this framework as an additional concern (Davis and Rhodes 2004). The juxtaposition of hepatitis C with HIV in early harm-reduction messages meant that many people who injected came to view hepatitis C as the lesser evil:

I think that I was really irresponsible, and that yeah it was my fault that I got it, I wasn't very careful, and I'm also kind of glad that that is all I got, I could have easily had AIDS, and I haven't. As much as I resent my hepatitis C sometimes, I feel grateful that that is all I have got (Kate, 41).

Kate referred to hepatitis C as 'my fault' reflecting a neoliberal emphasis on personal responsibility for health which is also evident in hepatitis C harm-reduction campaigns (Fraser 2004). Her narrative is one of an 'irresponsible' past from a perspective of having moved on and changed her life. The relational context in which Kate framed hepatitis C

and HIV can also be seen as a tactic for coping with her hepatitis C diagnosis and mitigating guilt for 'irresponsible' past practices.

The relational context of HIV and hepatitis C is reinforced by a common practice of testing for hepatitis C and HIV together so that the results for both are given at the same time. Zac received both results together and his prominent emotion upon diagnosis was one of relief at being HIV negative:

I was stoked that I was HIV negative...I didn't really care [about hepatitis C]. I cared more about HIV. When I was in Sydney I was a lot safer, but when I was [in NZ], if I had to share to get on, I shared. I thought well it won't kill me. That's what I thought about hepatitis C that it's not really life threatening. I still have that feeling really, because I don't see people die from it. You hear that it fucks your liver and kills you eventually, but I just think well I can get on the interferon and get rid of it (Zac, 36).

The national status of HIV and hepatitis C framed Zac's injecting practice, with minimal care taken in Auckland where he perceived HIV to be less prevalent within the drug injecting population. Zac did not share Kate's sense of guilt over 'irresponsible' past practices. Instead his drug use was framed as strategic; the decision to share or not dependent on his perceived risk of contracting HIV. Whilst strategic sharing is far from harm-reduction recommendations, Zac obtained his desired aim; he was free from HIV and five years since ceasing drug use remained as pragmatic about his hepatitis C infection as he was at the time of diagnosis.

Zac's pragmatic reaction to his hepatitis C diagnosis can be seen as arising from his understanding of hepatitis C in relation to HIV, his biomedical knowledge of interferon treatment, his experience of others successfully living with the virus, and the acceptance of hepatitis C within his community. In viewing hepatitis C as familiar, knowable and curable, Zac calculated his injecting practice in terms of exposure to HIV. Thus, when he received diagnosis of hepatitis C, it was perceived in relation to HIV and, as such, was of minimal concern. In the calculation and weighing up of bodily and social risk Zac fulfils the neoliberal role of the enterprising individual. As Rose (1996) states:

The enterprising self is both an active self and a calculating self, a self that calculates about itself and that acts upon itself in order to better itself (1996: 154).

Conceptions of what it is to 'better' the self are relational. While hepatitis C is rarely regarded as possessing an intrinsic good it is seen by many injectors as the 'better' of two evils, a calculable risk in the maintenance of a lifestyle. Illness understandings are contextual and relational, community acceptance and biomedical understandings as well as embodied experiences may co-constitute disease hierarchies and meanings. This is illustrated by the meanings that the diagnoses of HIV and hepatitis C had for the two co-infected study participants.

Marcus is a heterosexual ex-injector receiving methadone-maintenance treatment. He was diagnosed with HIV and hepatitis C in 1991. Marcus believed that he contracted hepatitis C in the 1970s before the virus was identified and before needle and syringe exchanges were established:

We had glass syringes in those days. You just put your arm under the toilet door and use [the syringe] he had, you know? But I never thought I, I'd get anything like that. I mean I was even selling dope to guys who had HIV and again I thought it was mostly

just a gay thing, you know. So it didn't bother me. And then when I went back over my lifestyle, I thought well hello! You're a fucking walking time bomb. And yeah, so hep C came to me at the same time [as HIV] (Marcus, 51).

Although Marcus started talking about how he believed he contracted hepatitis C, the narrative immediately swung back to HIV: 'I never thought I, I'd get anything like that'. HIV is the shock diagnosis, a disease which he initially framed as a 'gay thing' therefore posing little threat. Marcus references hepatitis C at the end of his narrative, almost as an afterthought, and the placement of this virus as peripheral continued throughout the interview. For Marcus, the stigmatising and debilitating nature of living with HIV, coupled with his desire to free himself from the restrictions of the methadone programme, dominated his narrative. It is indicative that, in the 15 years since his diagnosis, Marcus had only disclosed his HIV status to medical professionals, one long-term female friend and within the context of this interview. He was, however, more open about his hepatitis C status, seeing this as less stigmatising than HIV.

In contrast to Marcus, Luke was more concerned about living with hepatitis C than HIV. Luke identified as a homosexual occasional injector. He was diagnosed with HIV in 1996 and hepatitis C in 2002. While he was 'shocked' at his hepatitis C diagnosis, HIV was framed in more positive terms:

The HIV thing actually is quite weird. I suppose being gay and having that lifestyle, it's almost a bit of a relief in a sick sort of way...I never found a stigma with HIV...it's never been a problem for me. It's never bothered me having it. I know too many people with it that are fine. And I really do believe that it is now just a chronic manageable disease (Luke, 39).

Luke's understanding of HIV as a chronic manageable disease, affirmed by his and his friends' ability to live with the illness, echoes Zac's reference to the manageability of hepatitis C. While the narratives of ex-injectors, including Marcus, frame HIV as the 'other' disease, one that is invariably more problematic, Luke describes hepatitis C as 'the worst', due to its perceived biomedical uncertainty, the potential it has to interact with HIV and its stigmatising nature. While Luke is open about having HIV, he rarely discloses his hepatitis C status because of its association with injecting drug use, an activity he feels to be stigmatised in the gay community. For Zac however, it is the association between hepatitis C and injecting which provides connection and community.

Dys-appearance / biographical disruption

The concept of biographical disruption posits that diagnosis and symptoms of chronic illness create an upheaval in individuals' lives, causing them to rethink their circumstances and eventually mobilise resources in response to this disruption (Bury 1982). This conception of illness causing disruption rests on an understanding of ongoing bodily dys-appearance as a non-normative experience. Dys-appearance is a term conceived by Leder (1990) to express the way the body demands attention, or comes to awareness, in times of pain, illness and dysfunction. He contrasts this kind of awareness with the everyday experience of the body which, when all is functioning as it should, 'moves off to the side' or is absent from attention. The body may also be brought to awareness through the stigmatising or objectifying gaze of another person, which Leder refers to as social dys-appearance.

Bodily dys-appearance is common to individuals dependent on illicit drugs, particularly heroin or other opiates. The body clamours for attention when experiencing drug withdrawals; this 'hanging out' often subsuming all other illnesses or bodily disturbances, including that of hepatitis C. As Caleb said of the virus:

I didn't notice any adverse effects. I just got up in the morning feeling like shit. It was because I was hanging out (Caleb, 50).

Dependent injectors can also feel marked or singled out by their bodies. Track marks and other visible markers such as 'pinned' pupils, poor skin condition or low body weight may inadvertently signify their injecting status, and as such become a source of stigmatisation. When the body is regularly experienced as a site of stigmatising assumptions as well as a site of intense pain and pleasure (through the experience and alleviation of drug withdrawals), a diagnosis of hepatitis C can be experienced as congruent, yet another occasion of bodily dys-appearance or alienation.

Grace did not remember her diagnosis of hepatitis C, describing it as 'just something that turned up'. When looking back at her history punctuated by emotional despair, material deprivation, drug dependency and multiple heart operations, Grace described her present experience:

I lead my little life, and I step out the front door, and I look at the trees, and I go, 'Thank you God'. [Starts crying] Sorry. I get really emotional about it because it's kind of like I still get such a thrill that I'm fucking alive. And more than just surviving, I'm living...So in terms of hep C, it's a bit low on my barometer. But it's one of those things that I have, it's one of those things in my magic bucket that's a real jewel to take out and to take care of. And you're really taking care of yourself if you're gonna address that. But I haven't done it yet...I've always thought, like chess, I'll learn hepatitis C one day and keep it for when I'm older (Grace, 47).

For Grace, hepatitis C did not constitute a biographical disruption, her diagnosis was instead lost in a sea of multiple disruptions. All too aware of pain, suffering and the possibility of death, at the time of diagnosis Grace felt that she was not living but 'just surviving'. Over the past seven years her life had changed. At the time of the interview she was enjoying 'living'. In this context it is evident that, for Grace, the experience of hepatitis C diagnosis was not one of disruption or bodily dys-appearance but instead the virus had become a life-affirming symbol of potential self-care.

Kleinman (1998), in addressing the creation of meaning in illness, believes the fundamental questions are those of bafflement (why me?) and those of order and control (what can be done?) (1988: 29). Research participants who contracted hepatitis C through means other than injecting drug use, commonly did ask 'why me?' This was often with a degree of anger and frustration, especially for those who received contaminated blood products. One exception to this was Nathan who contracted hepatitis C during a heart transplant in 1992. Nathan was familiar with bodily dys-appearance due to his experience of cardiomyopathy or heart muscle disease. When he became suddenly ill and lost a great deal of weight his GP sent him to an HIV specialist. For Nathan and his wife, his body suddenly became the site of readings and assumptions never experienced before.

Nathan was a married man in his 60s, who had for 28 years worked for an international airline. While Nathan described being too sick to care about the implications of an HIV referral, his wife Sophie was affronted by what she saw as the GP's assumption of Nathan's

infidelity on his frequent overseas trips. Nathan's weakened body, coupled with his occupation, created a dys-appearance not only caused by his illness but by the assumptions that accompanied it. When Nathan was correctly diagnosed with cardiomyopathy he received a heart transplant, and the fear that accompanied this far outweighed the latter diagnosis of hepatitis C. As Nathan said of his hepatitis C diagnosis:

I was quite philosophical about it, I just accept these things. After being so close [to death] I am just lucky to be here anyways (Nathan, 63).

This sense of acceptance, predicated on a prior biographical disruption, echoes that of the participants who, like Grace, were injecting at the time of diagnosis. For these participants the experience of prior disruption and familiarity with bodily dys-appearance mitigated the impact of hepatitis C diagnosis.

Discussion

Bury's (1982) theory of biographical disruption posits that a diagnosis of chronic illness precipitates a radical disruption, necessitating a reformulation of the individual's life. However, this causative relation of chronic illness to biographical disruption does not allow for the experience of individuals who are familiar with bodily or social dys-appearance, either in the form of prior illnesses, trauma, deprivation or experiences of stigma. According to Bury, chronic illness 'involves a recognition of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others' (1982: 169). Many of the participants who previously injected drugs were familiar with pain, suffering and the possibility of death long before being diagnosed with hepatitis C. A diagnosis of hepatitis C was variously experienced by these participants as a liminal uncertain state, a marker of community, less serious than HIV, and/or as a continuation of prior bodily and social difficulties.

The contextual nature of biographical disruption is acknowledged by Williams (2000) who asks if a focus on the biographically disruptive nature of chronic illness may mask as much as it reveals. Such potentially masked circumstances include those in which conditions of material deprivation or other disruptions precede or precipitate the onset of chronic illness. As Williams points out, 'the biographically disruptive nature of illness is perhaps most keenly felt among the privileged rather than disadvantaged segments of society' (2000: 50). Hepatitis C was experienced as biographically congruent by the majority of participants who were diagnosed whilst injecting. While many of these participants were living in circumstances of material hardship at the time, also relevant is the high prevalence of hepatitis C within injecting populations. This can result in the virus becoming 'normalised' in communities of injectors and regarded as an expected consequence of the injecting lifestyle.

Wozniak *et al.* (2007) use the concept of normalisation to describe how people who inject drugs in Canada position themselves in relation to hepatitis C. The authors affirm Davis *et al.*'s (2004) London findings that many people who inject drugs view hepatitis C as a ubiquitous consequence of injecting. Wozniak and colleagues draw from disability studies to define the 'normalisation thesis' as incorporating 'processes whereby stigmatised individuals, groups and behaviours are accommodated into everyday social life' (2007: 389). However, while the authors reference the social activist origins of the term (Emerson 1992), their use of normalisation refers not to the de-stigmatisation of people living with hepatitis

C in the wider, non-affected, population, but to the acceptance of the *virus* within the population most affected, those who regularly inject illicit drugs. While the narratives of the Sydney and Auckland research participants reinforce Wozniak *et al.*'s concept of community normalisation of the virus, other factors also need to be taken into account, including the year of hepatitis C diagnosis, the amount of information available and the attitude of the diagnosing physician, to fully appreciate participants' reactions.

It is well documented that a large proportion of people living with hepatitis C receive minimal or inaccurate information from their doctor upon diagnosis (Burrows and Bassett 1996, Gifford *et al.* 2003, Hopwood and Treloar 2003, 2004). This dearth of information was noted by participants who identified as current injectors at the time of diagnosis. Whilst the generally early dates of these diagnoses may explain why accurate information was not forthcoming, research indicates that people who inject drugs are more likely to receive minimal information, no pre- or post-test counselling or referrals to support services (Hopwood and Treloar 2003, 2004). This differential treatment may indicate an attitude amongst physicians where a diagnosis of hepatitis C is perceived as unremarkable in patients who inject drugs. A lack of concern by the diagnosing physician, accompanied by minimal information, can reinforce an attitude of unconcern towards hepatitis C among injecting populations. The normalisation and minimisation of hepatitis C by diagnosing physicians was not explored in Wozniak *et al.*'s (2007) study, yet this may be a contributing factor to normalisation of the virus in injecting communities.

The narratives of participants such as Zac, Marcus, Isobel and Kate illuminate how community normalisation of a virus can impact on diagnosis experience. For these participants hepatitis C was congruent with their drug using identity as many of their injecting peers were already living with the virus. Kate and Zac spoke of hepatitis C as an expected consequence of injecting drug use that was not as serious as HIV. For Isobel, the extent to which hepatitis C had been normalised within her injecting community was brought into sharp relief when she encountered the stigmatising attitudes of the 'mainstream' world. Luke's reaction to diagnosis was also influenced by his community identification. While a diagnosis of HIV reinforced his sense of gay identity, his hepatitis C diagnosis was incongruent with gay community norms and thus was highly disruptive. Thus, for many participants, their understandings of hepatitis C were enmeshed with a sense of community; in particular, the degree to which the virus was normalised or stigmatised within their particular community networks.

The link between community identification and illness meaning-making is noted by Carricaburu and Pierret (1995) who, in their study of 24 gay and 20 haemophilic HIV positive men, found that for both groups HIV could occasion a sense of biographical reinforcement, albeit in different ways. For the men living with haemophilia HIV was reinforcing in that it could be incorporated into a life already framed by illness. For the gay men, an HIV diagnosis was found to reinforce a sense of homosexual identity. Biographical reinforcement, however, did not exclude the experience of biographical disruption, with all interviewees being 'deeply disturbed by their HIV-infection' (Carricaburu and Pierret 1995: 71). Sanders *et al.* (2002), in their study involving 27 people living with osteoarthritis, similarly found that illness symptoms were perceived by many participants as both a normal part of ageing and as disruptive in the context of their daily lives. Thus, for the participants of these two studies, notions of biographical reinforcement and disruption were coextensive. This was less evident in the narratives of participants explored in this paper. One reason for this may be that these recollections focused on the experience of diagnosis. However, when examining the trajectory of participants' illness narratives, it appeared that accounts of disruption and continuity were more likely to occur at different times in the

illness than to co-exist. Isobel's experience is indicative. She described her experience of hepatitis C diagnosis as biographically continuous. After a number of years and a change in circumstances, however, she found living with hepatitis C to be highly disruptive.

Sanders *et al.* (2002), Pound *et al.* (1998) and Faircloth *et al.* (2004) utilise the concepts of biographical disruption and continuity with reference to illnesses commonly associated with ageing: osteoarthritis (Sanders *et al.* 2002) and stroke (Pound *et al.* 1998, Faircloth *et al.* 2004). These studies found that a narrative correlation was created between ageing and illness, positioning stroke or osteoarthritis as just one part of the lifecycle. All three studies also mention the mitigating impact of prior illness or lifestyle disruption, in that participants who experienced previous illnesses or other lifestyle upheavals were more likely to frame their current illness as continuous with biography. This finding is analogous to the experiences of Grace and Nathan who referred to the dys-appearance occasioned by hepatitis C as continuous with, or minimal compared to, their prior experiences of stigma and illness. Thus, for those who have already lived with bodily and/or social dys-appearance, the onset of a chronic illness may not necessarily be disruptive but can be a form of biographical continuity or identity reinforcement.

This is not a unique finding. Indeed, as discussed above, the contextual nature and limited applicability of the concept of biographical disruption have been referred to in a number of studies (Carricaburu and Pierret 1995, Pound *et al.* 1998, Williams 2000, Sanders *et al.* 2002, Faircloth *et al.* 2004). This paper is distinctive, however, in that it combines the concepts of normalisation, dys-appearance and biographical disruption to address the experiences of people living with hepatitis C. Despite the high global prevalence of hepatitis C the amount of literature on people's experiences of living with the illness or receiving a diagnosis is minimal. Existing literature addressing the experiences of people living with hepatitis C has focused on the experience of diagnosis as disruptive. This paper reports a novel finding, that 21 of 40 participants described hepatitis C diagnosis as of little concern. The central difference between these participants and the 19 who described being 'devastated' was their injecting status at the time.

This study also utilises a unique factor in building trust with marginalised individuals (Grow and Christopher 2008), the researcher's willingness to disclose her personal experiences of living with hepatitis C. Common to the research situation is an unequal power dynamic between interviewer and interviewee. This, accompanied by a researcher's stance of professional distance, may lead the interviewee to provide socially acceptable responses or the story they feel most comfortable telling in their interactions with professionals. An interactive interview where both interviewer and interviewee are members of the same marginalised group is likely to provide a different dynamic. While neither less or more valuable or 'truthful' than data obtained with other research methods, this interactive approach may provide access to stories less often heard in the research literature (Green *et al.* 2005). Indeed, the unique position of the researcher in this study may have facilitated the telling of less socially desirable diagnosis narratives. It is possible that people living with hepatitis C may feel a social pressure to have experienced diagnosis as disruptive. The danger of declaring oneself 'unconcerned' is that this can be interpreted as a lack of self-care, potentially reinforcing a stereotype that people who inject drugs are irresponsible and have little concern for their health (Elliot and Chapman 2000).

The issues informing a reaction of unconcern to hepatitis C diagnosis are important, in that awareness of these can help to inform current diagnosis practice and hepatitis C prevention policies. As Davis *et al.* (2004) have stated, harm-reduction policies need to work towards decoupling the link between hepatitis C and HIV in injecting communities, so that hepatitis C is no longer perceived as of lesser relative risk. Comprehensive

information provision about hepatitis C and safe injecting practices, as well as widespread access to sterile injecting equipment is an obvious priority. Also important is the increased provision of structural and social supports for people who inject drugs so that daily experiences of bodily and social dys-appearance are minimised. The finding that participants who expressed unconcern at diagnosis were currently injecting could lead to the conclusion that people who inject drugs do not care about their health. The author of this paper hopes to have refuted this assumption by illustrating how narratives of unconcern to diagnosis are reflective of a myriad of contextual and embodied issues such as: the nature of the medical encounter, access to information, community identification, and prior experiences of structural constraints, stigma and bodily dys-appearance.

In exploring these factors, the contextual nature of biographical disruption becomes evident, thus problematising the generalised applicability of Bury's theoretical framework. As other studies have shown, Bury's original conception can be widened to include occasions of biographical flow (Faircloth *et al.* 2004) or reinforcement (Carricaburu and Pierret 1995) whereby illness onset can be experienced as congruent rather than, or as well as, disruptive. Such biographical flow was evident in many of the narratives of participants who spoke of hepatitis C diagnosis as of little concern. This study supports, and adds to, the findings of previous studies which trouble biographical disruption by making explicit the impact of community normalisation as well as experiences of dys-appearance to participants' health and illness understandings. These findings and the combination of theoretical frameworks provide a unique perspective and a different set of tools for understanding the meaning-making processes involved in the diagnosis and lived experience of hepatitis C.

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