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Living with Hepatitis C

Narrative of Chaos and Quest

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Hepatitis C is a highly prevalent disease that, within industrialised countries, is largely confined to people who are current or former drug injectors. In Australia and New Zealand approximately 1 percent of the population is living with chronic Hepatitis C yet both public awareness and political action regarding the disease is scarce. Hepatitis C is a stigmatized condition primarily because of its connection with illicit drug use and secondarily due to public ignorance and fear around transmission.

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In this article I will provide a brief outline of findings from a research study conducted in Auckland and Sydney that explored individuals' experiences of living with Hepatitis C. I use the work of Sociologist Arthur Frank (1995) who described three types of illness narratives; restitution, chaos and quest. I found Frank's theory particularly useful as a framework for analysing the way my study participants talked about their illness, and for understanding the narrative differences between participants.

Participants were recruited by a research notice distributed through the New Zealand Hepatitis C Resource Centre, The Hepatitis C Council of New South Wales, the Auckland and Sydney Narcotics Anonymous fellowships and the website [Hep. C Australasia](#). For recruitment the only criterion was that each participant was to have, or have once had, Hepatitis C. Participants comprised twenty-two women and eighteen men who ranged in age from twenty-five to sixty-three years and were diagnosed with Hepatitis C from 1989 to 2005. Nineteen participants estimated that they had lived with the virus for over twenty years. Interviews lasted from one to two hours and were loosely structured around central themes.

Stigma and disclosure

All of the participants felt Hepatitis C to be a stigmatised condition and many were reluctant to disclose. Wariness around disclosure often results from previous bad experiences; over half of the participants reported a negative reaction from others when they informed them of their Hepatitis C status.

For those who tend not to disclose their illness, support options can be limited. The majority of participants favoured a strategic mode of disclosure; that is they only disclosed in circumstances where they felt safe or where they predicted a beneficial outcome. Matthew recounts a painful experience of rejection which highlights the advantages of a cautious approach. He cried as he related his experience to me:

It has been extremely difficult. I would come-out of my isolation to church on Sunday; it would sort of be my big deal for the week. And I would be excited to meet different men and I would introduce myself ... and really be having a good conversation with them and then would turn around to say hello to another mate and they would disappear. And it freaked me out, because I would sort of look at myself, you know, what is going on here, am I too open, am I telling them stuff at the wrong time, or can't they handle it or what's going on, you know.

Interviewer: So had you told them that you had Hepatitis C before they disappeared?

I was just open about my situation, of having hepatitis C, being a solo dad, being on the benefit, and just being isolated, and hey I'd like to be your friend sort of thing (he cries). (Matthew, 49)

Matthew's desire to be accepted with his litany of stigmatised positions; solo father, beneficiary, chronic illness, isolation, and loneliness is distressing in its naiveté. In our contemporary success oriented society to be open in this way is to risk denigration. To gain esteem

and human connection one often needs to be guarded and strategic; adept in the ruse of conformity.

Illness Narratives

The Restitution Narrative

One of the reasons that Matthew was shunned is that his story is the antithesis of that which society desires to hear; the restitution narrative. Frank describes this in the following way: "yesterday I was healthy, today I am sick, but tomorrow I'll be healthy again" (Frank, 1995, 78). The restitution narrative is about the triumph of medicine. While this may fit with the treatment of acute illness, it has little resonance for the chronically ill whose sickness is more long-term. The restitution narrative is akin to Parson's (1951) sick role where illness is a temporary deviance alleviated by medical intervention. It belongs side by side with the liberal ethos of individualism and the primacy of work. Matthew in announcing his vulnerability, his beneficiary status, his long-term illness, and his loneliness, does not draw upon socially validated narratives and therefore has a long history of being shunned by people who cannot cope with his candour.

It was difficult to find an example of the restitution narrative among participants' interview material, which indicated for me its redundancy for people living with Hepatitis C. However, one participant framed his illness within a very strong medical framework. Before we met, David sent me graphs of his liver function test results from 1981 and used them as a tool in the interview pointing out how different periods in his life coincided with his fluctuating liver levels. David had been on Hepatitis C treatment twice unsuccessfully and stated that he would do it again, as:

At the end of the day what I am doing is I am buying time, I am buying time by concentrating on good health, no alcohol, low fat, high fibre, and exercise in order to buy time so the medicos of the world can come up with the panacea that addresses, resolves and extinguishes my Hepatitis C ... So in answer to your question, would I go back on treatment, well shit I'd go back on treatment if it is going to buy me time. (David, 55)

David's emphasis on buying time and waiting for treatment evinces a belief in restitution, that ultimately his Hepatitis C will be resolvable; he just has to do the right things and wait until "the medicos of the world" come up with a solution.

The Chaos Narrative

Frank's second narrative type is that of chaos. While the restitution narrative comforts in its possibilities of a happy ending, the chaos narrative threatens: it displays an indiscriminate whirlpool of unsolvable problems, into which anyone may be sucked. The irony of the chaos narrative is that when the chaos is truly being lived it cannot be articulated. The chaos narrative may be seen as an anti-narrative; it indicates troubles so deep they cannot be fully verbalised. Thus, the chaos narrative is hard to hear; it expresses pain and lacks coherence, temporality or narrative order (Frank, 1995). This passage from Laura is an example of a chaos narrative; it is fractured, both in content and form:

And I can't go home, it is just getting harder and harder, and my health it is just a blow-out, how can I put that in words when I am there, and the lawyer said to me, and I said I am complete, I am content, I can drink every night and it doesn't affect me, and I know if I was drinking every night here I'd be fucked. (Laura, 42)

Laura is a single mother on a benefit with a young son who also has a severe illness. This is relevant in that I found that the strongest predictors of a chaotic narrative were poverty, unemployment and lack of adequate social supports. These were narratives by people who felt marginalised by society, both in having a stigmatised disease and also lacking access to the socially validated narratives of health, career and conspicuous consumption. I interviewed Sarah while she was in bed; knocked out by her illness. She spoke of a mutually reinforcing combination of fatigue, illness and poverty:

Well today I am sick. I was going to clean up the house and move, but I am too sick to do it, I can't do it, I don't have the nerve to do it, I don't have enough nervous stamina to get through. The more I think, I think it's your own fault, and then I think back and I have actually got no clothes, I am sitting here with my pyjama jacket on and trousers with holes in them, I've got two pairs of socks and an old pair of shoes, a pair of stockings that need replacing ... There is no money for clothes or haircuts or anything like that. There is nothing. (Sarah, 54)

While lives punctuated by distress, illness and poverty are common for those marginalised by the restitution narrative, society does not want to know. Within our neoliberal society a chaotic life is often seen to be the fault of the individual, requiring personal not structural change. However, structural deficiencies can cause chaos. Poverty, lack of adequate support structures, and a discriminatory medical system all add to individuals' feelings of not being able to cope; of being subsumed by their disease.

The quest narrative

Frank's final narrative type is that of the quest. The quest narrative is that of illness as a journey: a voyage of self-discovery where illness is accepted and used.

While the hero of the restitution narrative is medicine and the chaos narrative is fractured and hard to hear, the quest narrative looks for a meaning in illness and is thus, a more palatable and positive telling. It is important however, not to overvalue the quest narrative. It is akin to the restitution narrative in a way in that it is comfortable for others to hear and is not attainable for all. Laura in expressing how hepatitis C has made her a "better person" iterates a narrative of quest:

Back then when I was using if you had told me I could have got a disease it wouldn't have mattered, I still would have done it, I had no self-respect, and today I have learnt, I have become a better person because of it, a sick person, but better person. I've learnt so much about myself because of this. (Laura, 42)

In using the same participant to illustrate both the quest and chaos narratives I wish to show that these narrative types are not exclusionary; they can all exist in one person's story, with different narratives dominating on different occasions.

Quest and Narcotics Anonymous

Frank's narrative types, especially those of quest and chaos, provided a way to understand the disparity in how participants recruited through different networks articulated their experience. I found the quest narrative arose predominantly in participants who were recruited through Narcotics Anonymous (N.A.). Although some respondents in this group were economically disadvantaged, they belonged to a strong social network; one which encouraged talking about vulnerabilities and in which many people had hepatitis C. It appeared that a number of these respondents had through their association with N.A. developed a quest narrative in which illness is accepted and seen as a journey, often one of self-discovery.

This excerpt from the *N.A. Basic Text* articulates a quest narrative. Here, addiction is premised as an ongoing disease; however, with the help of the fellowship, addicts can achieve a life "beyond their wildest dreams":

We realise that we are never cured, and that we carry the disease within us for the rest of our lives. We have a disease, but we do recover. Each day we are given another chance ... The program works a miracle in our lives. We become different people. (N.A. 1988:8)

Kate felt that belonging to N.A. had improved her illness experience. "Working the steps" had helped her to alleviate anger which she connected with the health of her liver:

What else has helped me is, this is going to sound silly, just getting rid of my resentments, 'cause that is kind of from your liver, shitty liver you know, so doing that, Step Four was really healthy for getting rid of all that crap and anger. (Kate, 41)

Narcotics Anonymous operates on the "disease concept": that addiction is a disease, and therefore, not a moral or criminal issue. The participants who belong to N.A. are cognisant of a quest narrative in relation to growing and learning from their addiction; thus it is easier for them to adopt this outlook in relation to their hepatitis C. While N.A. does not normally provide support for hepatitis C, the make-up of membership means that many members have the disease due to past intravenous drug use. For these people, N.A. also provides the opportunity to meet and talk with others who have hepatitis C thus alleviating the silence and stigma associated with the disease.

Conclusion

Frank does not connect his narrative types to contextual factors such as economic position and social supports whereas I found that social and economic marginalisation often correlated with a more chaotic narrative. The stigma of hepatitis C meant that many participants felt obliged to silence their narrative of illness, so that when it did emerge in interviews it burst forth, often with a great deal of emotion, with temporal jumps and tangential diversions. The effect of being able to regularly share with others the impact and experience of an illness such as hepatitis C was seen in the participants from N.A. who, accustomed to voicing an illness narrative, were calmer and spoke of the value of a supportive peer network. Mutual help groups such as Narcotics Anonymous are interesting in that they provide not only a social network of peers but a framework within which illness can be framed as a quest.

Restitution, the dominant and socially acceptable narrative, was rarely found in the tales of my participants. The redundancy of this narrative for the chronically ill meant that, following Frank's theory, the narratives that were predominantly utilised were those of chaos and quest. These narratives are not exclusionary; both were present in most interviews. However, quest occupies a more socially acceptable format and those participants who belonged to the Narcotics Anonymous fellowship were familiar with its articulation. Common, particularly amongst former dependant drug users, was a framing of their former life as chaotic, looked back upon through a narrative of quest. For those, however, who lacked such support frameworks, chaos was often ongoing, and this was the narrative that dominated. Chaos is uncomfortable for a society primed to the restitution narrative and the ideal of autonomous liberal subjectivity. The primacy of work and the negation of ongoing sickness meant that many participants chose to silence their narrative of illness in order to gain societal approbation.

In order for the experiences of those like Sarah, Laura and Matthew to be validated, narratives need to be available that value the experience of illness, and recognise that chaos is an integral part of everyday life. The stigma of unemployment and inadequacies of income and social supports undoubtedly exacerbate a narrative of chaos and these are central issues that need to be addressed.

Unfortunately our contemporary neo-liberal culture emphasises personal over structural change. As a society we need to work against this, looking beyond notions of individual responsibility to work on affecting structural changes, including increased social supports and different ways of viewing unemployment and chronic illness. This includes a willingness to hear and recognise the chaos narrative as a valid part of the life story.

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