

# Disclosing a hepatitis C diagnosis: Stigmatised if you do, isolated if you don't

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## Abstract

The hepatitis C virus (HCV) is the leading notifiable disease in Australia. It is described as a stigmatised disease, as the majority of new infections are associated with intravenous drug use. The current qualitative study explored the lived experiences of those diagnosed with HCV. Fifteen participants (10 women & 5 men) who were HCV positive and not current drug users were interviewed about the impact of their diagnosis and how they have adjusted to it. The data were analysed using open and closed coding methods. Diagnosis was found to be a traumatic experience with considerable emotional impact that could be exacerbated by stigma, discrimination and a lack of information. Support is provided for a self-management construct encompassing medical, emotional and life role facets. It was concluded that positive reactions to disclosure contribute to adjustment, whereas perceptions of stigma and negative reactions to disclosure may create barriers to self-management and personal growth.

## Introduction

In the 17 years since its identification, hepatitis C virus (HCV) has become the leading notifiable disease and has reached epidemic proportions. In 2004, 194,000 people were recorded as infected with the virus and 13,000 new cases were reported (The National Centre in HIV Epidemiology and Clinical Research, 2005). Worldwide, 3% of the population is infected with HCV and approximately 80% of those infected with HCV will have a persistent chronic infection according to The World Health Organisation and Viral Hepatitis Prevention Board (WHOVHPB, 1999). Considering the extent of this problem, the low level of understanding about this virus in the community and healthcare settings is surprising (Richmond, Dunning & Desmond, 2004). Also concerning are the findings of the Anti-discrimination Board of New South Wales C-Change Report (2001) citing a high rate of discrimination toward people with HCV motivated by fear and ignorance and based on stigma. Further, HCV related discrimination was most frequently reported in the health care, employment and education settings.

Stigma is frequently associated with chronic illness in general because these conditions differentiate patients from the general population (Joachim & Acorn 2000). Although stigma is often based on race or religion, Joachim and Acorn (2000) found that physical deformities such as disability and chronic illness and character blemishes such as a weak will, dishonesty, addiction or mental illness were also bases for stigma. Because of its association with intravenous drug use (IDU), HCV can be stigmatised as a chronic illness often attributed to character blemishes and associated with addiction and drug related crime. However, Crockett and Gifford (2004) identified that the stigma and discrimination related to HCV were difficult to untangle from broader social determinants such as addiction and IDU lifestyle and research to date has comprised mixed samples of current and non-current IDU. The current study investigated the perceptions of HCV related stigma in those who were HCV positive and not current drug users.

Jones et al. (1984) noted that the ability to conceal a condition was critically important to the lived experiences of those with a stigmatised disease, that is, its 'visibility', for example paraplegia, or 'invisibility' such as HCV or diabetes. HCV's invisibility affords the choice to disclose or not to disclose the condition. The possibility of stigma and discrimination associated with HCV, means that the affected individual must decide whether or not to inform others. Although disclosure may lead to increased social support, it can also lead to negative consequences such as being discredited or rejected and isolated (Joachim & Acorn, 2000). The option of non-disclosure or 'pass for normal' and deliberately keeping the condition a secret requires the person to divide the world into a large segment that knows nothing about the condition and a very small support group who are confided in. The 'passing for normal' option may be stressful because of the fear of being discovered lying and the subsequent stigmatisation. However, it allows the person to remain 'part of the group' if undiscovered (Joachim & Acorn, 2000). Non-disclosure may limit the person's ability to self-manage the condition. Lorig and Holman (2003)

proposed three tasks of self management of chronic conditions; medical management, maintaining or finding new life roles and emotional management. Patients who do not disclose their condition restrict their ability to negotiate these tasks because they lack the possible support of healthcare professionals, their social network and the workplace.

This study explored the experiences and consequences of stigma, disclosure and non-disclosure and their impact on managing an HCV diagnosis.

## Method

### Participants

Fifteen volunteers (10 women & 5 men) aged between 35 and 51 ( $M = 44.4$  years  $SD = 2.3$ ) gave informed consent to be interviewed for the current study. They were recruited from: the Hepatitis C Council of Victoria (HCCV) support group ( $n = 3$ ) and their publication The Good Liver ( $n = 2$ ), Hepatitis C Helpline volunteers ( $n = 2$ ), Community Zero Online support group ( $n = 4$ ) and word of mouth ( $n = 4$ ).

All participants were not currently using intravenous (IV) drugs. Four had never used IV drugs and 11 had used IV drugs 10 to 27 years ago ( $M = 19$  years ago). Participants had been diagnosed with HCV for between 18 months and 16 years ( $M = 10.4$  years,  $SD = 5.6$ ) prior to the study. Most were married or in a marriage-like relationship ( $n = 9$ ) and the remainder were single ( $n = 6$ ). Nine had a diploma or higher level of education, four had certificate level and two had no tertiary education. Seven were employed two were full time parents and six unemployed.

### Materials

**Semi-structured Interview** Interview questions were developed from recurring themes in issues raised by callers to a hepatitis telephone helpline. Interview questions were drafted to reflect the aims of the study. These questions were reviewed by four experts in counseling people with HCV, and the feedback indicated that the interview questions were appropriate. Subsequently, a pilot interview was conducted with an HCV positive person to ensure the relevance of the questions and that the interview flowed well.

The final interview schedule consisted of demographic information and open ended questions designed to gain an understanding of the participants' experience of receiving their diagnosis, use of support services and adjustment to their diagnosis. Probes were used to gain clarification or elaboration.

## Procedure

Participant recruitment strategies included advertising and discussing the project in forums where potential volunteers may be present. Interested volunteers ( $n = 17$ ) were initially screened for sample criteria by telephone. The sample criteria were refined with consultation from experts in the field. It was agreed that to gain a clear understanding and uniqueness of the HCV experience, persons with other major health conditions should be excluded, for example, co-infection with HIV and hemophilia. As the current study was considering themes of adjustment, newly diagnosed persons (less than 12 months) were excluded. Current IV drug users were also excluded because of the potential for associated lifestyle factors to contribute to stigma and discrimination. Two participants were excluded: one who had another major medical condition and the other was too recently diagnosed to provide data about adjustment.

An information sheet was provided to 15 participants who met the selection criteria. Participants received payment to cover travel expenses. Participants nominated their preferred location for interview; HCCV offices ( $n = 10$ ), Swinburne University Campus ( $n = 5$ ).

### Analysing Content of Interview Data

Interview recordings were listened to and transcribed verbatim. An interpretative approach as described by Berg (2004) was taken to analyse the content of the interview data. Interview transcripts were open coded using a coding sheet developed by the researcher to assist with identifying a broad range of possible themes, to saturation point. It was determined that saturation point was reached at the 12<sup>th</sup> interview, with 148 themes. Emerging themes and sub-categories were noted by grouping open coded themes into collective theme categories. These collective themes were then identified in the interviews and defined further. During re-examination and closed-coding of the interviews, other explanations for the themes were sought and in some cases themes were re-defined. Axial coding provided descriptive statistics and patterns. In some instances a range of participant experiences of a certain topic are described and in other instances, common experiences are described.

## Results and Discussion

### Impact of Diagnosis

For most participants being diagnosed with HCV was a shock and was experienced as an intense and complex experience. Most began their story by reflecting on the lead up to what was generally an unexpected diagnosis and expressed fears about premature death and an awareness of mortality, which they attributed to a lack of knowledge about

their prognosis. The way medical professionals communicated the diagnosis and the adequacy of factual information and referrals provided impacted on stress. Diagnosis was made more distressing by inadequate pre- and post-test counselling and insensitive delivery of test results. However, some participants ( $n = 5$ ) reported positive experiences of medical communication where they felt informed, treated with dignity and referred to appropriate specialists and/or support services.

Fears about transmitting the virus to others in the past and future was an immediate concern for most, especially mothers. Participants reported initially feeling infectious, contaminated and even 'toxic' and for some this was an ongoing anxiety.

A new finding emerging in the data is a common experience of the past drug user sub-group ( $n = 11$ ). The context of past drug use was an integral and important narrative in coming to terms with their diagnosis. Participants reflected on the past and eight alluded to or spoke directly of a dysfunctional background or circumstances which were contextual to their drug use. Most ( $n = 9$ ) had at some stage experienced feelings of shame, guilt and regret about a past that most had worked hard to put behind them. Cognitive dissonance was evident as this sub-group are forced to 'meet' the 'old me', often publicly because of their HCV diagnosis. Changed values appear to make the 'old me' and the 'new me' difficult to integrate.

### **Disclosure and Non-disclosure**

Participants faced a range of psychosocial challenges as they integrated HCV into their lives. The reaction of others to their condition was cited as a substantial issue and participants tended to focus on the consequences of disclosure rather than their motivation for doing so. Telling friends, acquaintances and family about their HCV status accounted for many of the best and worst experiences of disclosure.

Non-disclosure and 'passing for normal' was a commonly used strategy in the workplace and with acquaintances. While this was successful in preventing discrimination and being discredited, at times it created other stressors such as working when extremely fatigued and keeping secrets from some, but not others.

Positive outcomes of disclosure included perceptions of greater social support, deeper relationships and relief at not being judged, which increased self-esteem. This appears to help participants manage their condition by being open about their physical and lifestyle constraints and contributing to the task of 'emotional management' in the self-management model.

Negative aspects of others knowing about their condition included being discredited, treated as infectious, discrimination, gossip and social isolation. Negative reactions in the social,

healthcare and the workplace contexts were hurtful and detrimental to participants' self-esteem. This study revealed another disclosure strategy adopted by some participants. By 'partially disclosing' participants may reveal their HCV status, but nominate the source of their infection to a non-drug using mode such as tainted blood products.

Most participants wanted emotional support, and found this in friends and family in the first instance. Most utilised some form of support service that suited their needs and all participants viewed these services positively. For many it removed a sense of social isolation and helped them to feel more 'normal'.

Participants appeared to feel their life with HCV was more manageable when disclosure was planned, when they were treated professionally in the healthcare system, when they were in or aspired to be in a supportive relationship and could utilise appropriate support services when they need it.

Most saw disclosure in the workplace as risking overt and covert discrimination. Participants' experiences of workplace disclosure were variable. Of 11 participants who discussed workplace disclosure, five said that they would not consider disclosing to anyone at work. They described their workplaces as 'conservative' or 'corporate' and felt that there would be negative consequences such as discrimination, losing control of their personal information and even 'career suicide' if they disclosed. Three of these participants described covering up symptoms at work to 'pass for normal'.

Seven participants had at some stage disclosed their HCV status in the workplace. Reasons cited for disclosing at work included wanting to be open and wanting to give an honest explanation of ill health and medical appointments. Three of the seven participants who had disclosed to colleagues subsequently experienced discrimination, and for two, this resulted in them leaving their jobs. Three interviewees had supportive experiences with two feeling personally supported by their manager and one describing how her employer's human resources policy enabled her to plan a management strategy for her health problems. Two participants described disclosing at two separate workplaces and having completely different experiences, supporting participant perceptions that the response to workplace disclosure can be unpredictable.

### **Stigma and Discrimination**

Although none were current intravenous drug users, and four had never used IV drugs, all participants perceived that they were associated with drug use as a consequence of contracting HCV. Most felt that they were likely to be judged in terms of a simple drug user stereotype. Participants commonly believed that society in general held negative stereotypes of drug users, and that drug

users were portrayed in the media as addicts, desperate and of low moral character. Moreover, drug users were perceived as current, high consumption users, addicted and likely to be involved in crime. None of the participants identified with this stereotype at the time of the interview.

Several participants believed that there was less stigma attached to those who contracted the virus through non-drug related exposure, such as a blood transfusion. However, the only person infected via transfusion felt IDU stigma intensely, reporting that she was frequently judged to be a drug user. Three participants did not feel that they could be personally discredited through the HCV-IDU association, whereas the majority ( $n = 12$ ) expressed that they perceived past or current drug use as a discreditable attribute.

When first diagnosed, most wanted to distance themselves from a drug using identity and the associated stigma. Strategies identified for 'passing for normal' included choosing not to disclose their HCV status ( $n = 11$ ), 'white lies' about how they contracted the virus ( $n = 5$ ) and initially avoiding services for HCV positive persons ( $n = 7$ ).

The stigma felt by participants was at times reinforced by discrimination in the healthcare setting, misrepresentation in the media through incorrect facts and drug user stereotypes as well as a generally poor understanding about HCV in the community. The effects of stigma were lessened by dignified treatment by healthcare workers, with participants reporting being more able to view their condition as medical rather than social and feeling 'worthy of care'.

Two-thirds of participants reported one or more incidents of discriminatory behavior by a healthcare professional. The impact of these experiences was described as 'upsetting', 'shaming', 'infuriating' and a barrier to seeking help. These participants described being treated differently during service provision because they had HCV. Complaints about discrimination consisted mainly of being treated as infectious, diminished care and occasionally, of stigmatising remarks. One participant was excluded from an education course in the healthcare field despite the acknowledgment that she posed no risk to others.

Eight participants described a time they were treated as infectious. This was often around blood handling procedures and the over use of protective barriers, such as double gloving. Diminished care by professionals ranged from being dismissive through to neglect, with participants perceiving that they would have received a higher standard of medical care if they were HCV negative. Dismissive behaviors were noted as changes in behavior after disclosure, short

consultations and resistance to provide adequate information and answering questions.

### **Self-Management**

As part of understanding and adjusting to life with HCV, many participants ( $n = 12$ ) self-monitored symptoms and managed the medical aspects of their condition through diet, rest, exercise, naturotherapy, homeopathy, chiropractor visits and taking sick leave from work. Emotional management was described mainly in terms of support from friends and family as well as accessing support services. Adjusting life roles to accommodate HCV was the third area to be negotiated in the self management model. For many ( $n = 8$ ), taking responsibility for managing their condition was described as a turning point and was often accompanied by a boost to self-esteem and the perception that life with HCV was manageable. This turning point was often discussed in the context of the limits of the medical model and disappointment with healthcare professionals. Some participants ( $n = 6$ ) described the experience of self-care as 'new' or 'a first' and for a few it was 'moving out of denial'.

**Medical and Symptom Management** Many ( $n = 9$ ) reflected on the anxiety, helplessness and frustration of not understanding the facts and implications of having HCV. Taking responsibility for self-education about HCV may arise from disappointment with health professionals, but appears to be a powerful turning point in the adjustment phase. All participants remarked on the importance for them of understanding the virus, with many describing feeling empowered and less distressed about their condition as their understanding increased. Some described that taking responsibility for researching HCV for themselves rather than relying on medical staff was empowering. The catalyst for this was often the desire to understand or self-manage symptoms where the medical model had appeared to fail.

It was common for participants to be self managing their condition through making lifestyle changes such as diet, reducing or eliminating alcohol and resting when tired. Most participants ( $n = 11$ ) reported diet related changes to either minimise or prevent symptoms. It was common among this sub-group to feel healthier than they did prior to their diagnosis.

**Emotional Management** At diagnosis most ( $n = 11$ ) knew nobody else with HCV, and several participants ( $n = 6$ ) expressed that this contributed to a sense of isolation. Several ( $n = 7$ ) had expressed disappointment that their doctor had not been able to provide emotional support or a referral to someone or a service that could.

All participants had some positive personal support from friends and/or family, but most participants ( $n = 12$ ) had sought support outside of their social circle at some stage. For some it was an

immediate response ( $n = 6$ ) and for others it was many years and a symbol of 'coming out of denial'. Nearly half of the participants ( $n = 7$ ) expressed reluctance, at some stage, to access support services because they didn't want to identify with a stigmatised or drug-user group of people.

Participants accessed the following services to gain emotional support; HCCV support group ( $n = 10$ ), a hospital support group ( $n = 3$ ), Hepatitis Helpline ( $n = 8$ ), Community Zero Online Support ( $n = 4$ ), Hepatitis C Counsellor at the Alfred Hospital ( $n = 3$ ), Counselor not connected to HCV services ( $n = 4$ ). Although all thought individual counselling would be helpful, only seven had received counselling citing their reason was because of a referral made by a health professional. Only five participants were aware of free counselling services for people who were infected or affected by HCV. In addition to providing emotional support for distress in the diagnosis stage, three participants had found longer term therapy to have been beneficial in coming to terms with their past and finding empathy for the 'old me' they had become ashamed of.

Many participants ( $n = 9$ ) expressed gaining a lot from online or face to face support groups. As well as learning factual information and self-management techniques from each other, it was common for participants to realise how isolated they had been. Other emotional benefits of support groups mentioned by participants were: feeling more 'normal', having others listen and understand their story, a sense of community, making new friends, providing support for others and feeling connected. Others felt valued by providing peer support. Participants who regularly used the online support group ( $n = 3$ ) found anonymity and the convenience of participating from home appealing.

**Maintaining or Renewing Life Roles** A major and debilitating symptom participants reported in the context of lifestyle changes was fatigue ( $n = 10$ ). Many participants struggled to maintain their work and career ambitions due to fatigue which was reported to exacerbate other symptoms ( $n = 10$ ).

Participants reported leaving the corporate sector due to the expectations of working long hours ( $n = 4$ ), changing from full-time to part-time work ( $n = 4$ ) and leaving the workforce all together ( $n = 2$ ). While there was some sense of loss for most of these participants, setting new work goals and shedding some expectations was also considered a turning point in their adjustment to living with HCV. Downshifting or stopping work was also described as 'self care' by several participants.

## Summary

Discrimination emerged as a barrier to adjustment for persons with HCV and was found to have damaging health, financial, social and emotional consequences, consistent with the findings of prior research (e.g. ADBNSW, 2001, Crockett & Gifford, 2004). Interviewees perceived that HCV was often associated with drug use and that society in general held negative stereotypes of drug users. The current findings extend prior research by removing the variables of current drug use, addiction and IDU lifestyle as the possible basis for HCV-related discrimination and stigma, establishing that those who were 'past' or 'never' drug users had similar experiences of discrimination as mixed samples. This provides evidence for the notion that HCV is stigmatised by stereotypes, rather than by the presenting attributes of those with the condition.

Positive experiences of disclosure led to beneficial outcomes such as emotional support, support to refocus life roles and a collaborative approach with healthcare professionals. Negative experiences of disclosure included outcomes such as discrimination, low self-esteem, social isolation and loss of employment. However, consistent with Joachim and Acorn, 2000, this study found evidence that being genuinely 'unconcerned about the discreditable attribute', in this context, the association between HCV and drug user stereotypes, gave resilience to HCV-related stigma.

Partial disclosure was identified in the current study as disclosing as HCV positive, but attributing the transmission mode as non-IDU, for example, a blood transfusion. A partial disclosure was described as eliciting a more sympathetic response, thus may act to increase the chance of support. This strategy was most commonly mentioned in the context of healthcare and acquaintances and is consistent with Richmond's (2006) findings that in healthcare workers, compassion was dependent on the mode of HCV acquisition.

Finally, the findings suggest some recommendations for healthcare and counseling. Adjustment appears to be facilitated by acknowledgment of the need for emotional management and appropriate referral. In counseling, priorities are to: help process the trauma of diagnosis; teach assertion skills with health professionals; and to help understand and manage the complexity of disclosure.

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