

The lived experience of men and women with hepatitis C: implications for support needs and health information

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Abstract

Hepatitis C is Australia's most commonly notified infectious disease. Health education and support strategies that are gender-specific are key components of effective management of chronic illness, yet almost no information exists about gender-specific needs of those with hepatitis C. This paper reports on a qualitative study of the experiences of diagnosis, support and discrimination among men and women living with hepatitis C in Melbourne. Content analysis of in-depth interviews conducted with 20 women and 12 men revealed gender related differences in relation to symptom recognition, health seeking attitudes and notions of social support, with men tending to dismiss the impact of their illness and their needs for education and support in comparison to women. Results highlight the need to take gender into account when addressing primary health care issues for people living with hepatitis C.

Introduction

Hepatitis C is the most commonly notified infectious disease in Australia and the majority of those who acquire this infection will live with resulting chronic illness (NCHECR 2002). Appropriate health information and social support can play a key role in the self-management of health for those with chronic illness yet this information has been poorly documented for those with hepatitis C (National Hepatitis C Council Education Reference Group 1996; Teague and Hepworth 1999). Health information and social support needs are likely to be influenced by gender (Gijssbers Van Wyk et al 1996; Hunt and Annandale 1999; Matthews et al 1999), as the experience of illness itself is likely to be socially shaped by gender roles and expectations (Broom 1998).

Gender is one of the major forces that structures an individual's opportunities and life chances (Hunt and Annandale 1999) and there is now a large literature documenting gender differences in health (Hunt and Annandale 1999; Matthews et al 1999; MacIntyre et al 1996; MacDonough et al 1999; Kawachi et al 2000). Gendered roles in response to illness have been used to explain why women are more likely than men to report symptoms for many illnesses, to seek preventive health care and to score lower on health-related quality of life (Anson et al 1993; Doyal 2000). Equally, there is a growing body of research documenting the way that gender shapes men's health, much of which illustrates poorer health maintenance and fewer health seeking behaviours compared with women (Schofield et al 2000). Indeed, gender roles for men may produce a constellation of practices that undermine their health in that the '...resources for constructing masculinities are largely

unhealthy' (Courtenay 2000: 1389). Gender constructions of masculinity may help to explain why men are less likely to report symptoms and pain, less likely to seek medical care or attend for routine check-ups, and are more likely to engage in practices that embrace risk (Courtenay 2000). For a man, giving in to the experiences of illness or disability may be seen to undermine his status, his power and his masculinity. Health-related behaviours for men and women, therefore, are shaped by gender norms and roles, and it would be expected that the experiences of those with hepatitis C and their attitudes towards diagnosis, support, health information and self-care would likewise be influenced by gender norms and practices.

At the end of 2001 it was estimated that 210,000 Australians were affected by hepatitis C, with many others undiagnosed. Over two thirds of those infected live with hepatitis C as a chronic condition (NCHECR 2002). Physically, chronic hepatitis C brings with it an array of symptoms including fatigue, nausea, aches and pains and depression which can have a serious impact on the ability to work and, more generally, on quality of life (Lin et al 1999; Dore 2001; Sladden et al 1998). Half of those infected will develop long-term signs of liver damage, with up to 20% developing cirrhosis, and a smaller number experiencing liver failure or liver cancer (Commonwealth Department of Aged Care 2001). Treatment for hepatitis C is not straightforward and the side effects are often experienced as being worse than the symptoms of the illness itself (Sievert and Kovaar 1999).

Hepatitis C also carries with it the burden of stigma, which stems in large part from its association with injecting drug use (Anti-Discrimination Board of NSW 2001). In Australia, about 80% of infections are attributed to injecting drug use, which is itself stigmatized (Elliott and Chapman 2000; Blendon and Young 1998). Those who engage in these practices may become socially marginalized because of public perceptions of injecting drug users as unemployed, homeless and involved in criminal activity (Loxley et al 1995; Hunt and Derricott 2001). Thus, hepatitis C carries a double burden: the physical impact of the illness and the social impact resulting from the stigma. The social stigma attached to hepatitis C has been identified as one of the major barriers to prevention, support and care (Commonwealth Dept Aged Care 2000). Hepatitis C therefore represents a significant public health challenge for Australia, both in terms of the suffering incurred by those affected, some of whom will have no history of injecting drug use, and in its impacts on the broader social, economic and health care system (ANCARD Hepatitis Sub-Committee 1998).

In relation to the gender specific impact of hepatitis C, very little is known. Until recently, men were more likely to be diagnosed with hepatitis C. This trend is beginning to reverse with the number of new cases of women now equal to, or in younger age groups, outnumbering men (NCHECR 2002). From a clinical point of view, differences are apparent between men and women in relation to disease progression and treatment response. Some studies have shown slower disease progression among women (Poynard et al 1997; Kenny-Walsh 1999; Wiese et al 2000), however, similar low rates of disease progression have also been demonstrated in a study predominantly consisting of young men (Thomas et al 2000). It should be noted that these were observations made from the results; these studies were not conducted with the aim of examining the impact of gender on disease and treatment. Similarly, however, it is not known to what extent gender influences the social impact of hepatitis C. Little is known of the different experiences of men and women, their health seeking behaviours, and their needs for information and social support. The overall aim of this qualitative study was to investigate the lived experiences of women and men living with hepatitis C specifically in relation to diagnosis, information, support and care.

Method

A purposive sampling strategy (Patton 1990) was used to identify men and women who self-reported their hepatitis C status. Information about the study was left with key agencies (needle-syringe exchanges, Liver Clinics, Hepatitis C Council) and staff working at these agencies assisted in informing clients whom they knew to be eligible, about the study. Potential participants were then invited to participate in an interview by the research assistants. The interviews with women were conducted in 1998 and 1999 because they formed the first stage of a survey study into women's experiences of hepatitis C (Gifford et al 2003). The majority of these female participants were recruited from a community health centre which incorporated a needle exchange facility and

injecting drug-user’s (IDU) support service. In 2000 further funding for a comparative survey of men was obtained, which also included a first stage of qualitative interviews. Most men were recruited through an injecting drug-user support service. The remainder were accessed through medical services. A theme list was used to guide the interviews (see Figure 1) and modified to take into account gender issues specific for women and men. Broadly, issues discussed included: circumstances around a hepatitis C diagnosis, experiences of the illness, access to information, access to support and health services, experiences of disclosure and experiences of discrimination.

Interviews were conducted by same-sex interviewers, audio-taped, fully transcribed, coded and subjected to content and thematic analysis (Gifford 1998; Watson and Kosky 1999). The study received ethics approval from Deakin University and a number of hospital based ethics committees.

Figure 1: Theme list for interviews

Circumstances surrounding diagnosis
Disclosure of hep C status to others
Feelings toward self & other’s reactions after diagnosis
Seeking information & increasing knowledge about hep C
Impact of hep C on lifestyle (e.g. exercise, sexual practices)
Barriers to maintaining health living with hep C
Access/need for support networks
Impact of hep C on view of health
Thoughts of the future
Knowledge and concerns about transmission

Results

Twenty women and 12 men were invited to participate in the study. Participants ranged in age from 17 to 56 years and most were current or past IDU (see Figure 2).

Figure 2: Participants’ Socio-Demographics

	Women	Men		Women	Men
<i>Age</i>			<i>Dependent Children</i>		
15-19	4	0	Yes	6	6
20-24	4	1	No	13	6
25-29	3	4	Currently pregnant	1	n/a
30-34	6	5			
35-39	0	0			
40-44	3	0			
45+	0	2			
<i>Currently Employed</i>			<i>Mean Time Since Diagnosis</i>	27.8	75.5
Yes	5	2		months	months
No	15	9	<i>History of Drug Use</i>		
Retired	0	1	Current IDU	14	8
			Past IDU	5	3
			Never used	1	1

Analysis of results yielded themes that were shared by both men and women, and others which demonstrated differences. Men and women described similar experiences of post-test counselling and had similar concerns about transmission. Key differences emerged between men and women in relation to seeking out health advice and care for their hepatitis C, in their reactions to attitudes of health care professionals, and in their perceived need for social support. The differences between men and women's narratives are shaped by gender and have important implications for prevention, support and treatment of hepatitis C.

Common experiences of men and women: Post-test counselling

Women and men were asked to describe their experiences of being tested and diagnosed with hepatitis C. With a few exceptions, both men and women described more positive experiences if they had been tested and diagnosed by a general practitioner but more negative experiences if they had been tested and diagnosed in an organisational setting such as a prison or a drug and alcohol service. For both women and men, being diagnosed in a general practice setting offered opportunities to raise their concerns, ask questions and to be able to deal with the often-expressed shock of the diagnosis. As one young woman explained:

He (GP) was...willing to go over it with me, but I was quite shocked and I just left it at that and pretended that it didn't happen. (F17:342).

Men who had received a diagnosis in a general practice setting also spoke of this experience in a more positive light compared to those who had received a diagnosis in an institutional setting. One young man described how his general practitioner gave him a lot of information at the time of diagnosis:

... about hep C, he gave me some points ... alcohol and this and that ...he says 'Go to Turning Point [a drug and alcohol centre] and find out some more.' ... he told me about hep B ... and then he says 'Oh, and what about your family?' (M4:3-4).

Both men and women who had received their diagnosis in an institutional setting generally described poor experiences with testing and diagnosis. Several men had received their diagnosis in the prison system:

There's 750 prisoners. So he goes on and tells people 'Right you've got AIDS, you've got hep C, you've got this, you've got that. Next customer.' But he wasn't rude about it. (M5:5).

Tested by a prison nurse ...just took blood, that's it. Didn't want to give you the time of day ...jab, suck, next ...they basically said it was just mandatory. (M1:6-7).

Women also reported negative experiences in receiving a diagnosis in alcohol and drug settings:

He (the GP at the detox centre) was sort of cold and...unsympathetic...it was like he does it everyday sort of thing. (F10:201).

While there were a few exceptions, overall, men and women shared more positive experiences in receiving their diagnosis in a general practice setting and less positive experiences in institutional settings.

Concerns about transmission

Men and women also shared similar concerns about giving hepatitis C to others, although their narratives about how they dealt with these concerns differed. Women discussed their concerns in relation to family and friends with particular emphasis on their children:

I am always worried that I might pass it onto me family or me friends...I wouldn't wish it onto me worst enemy. (F10:206).

The last thing I would do, would be to put my daughter in jeopardy...one of the first things that I did when I found out that I had hep C was to find out where I stood where my daughter was concerned...on her getting [it].. (F1: 7).

Although hepatitis C is not generally considered to be a sexually transmissible infection, both men and women expressed concerns about their sexual partners.

I won't have a nice girl who is straight and ...shag around with her'cos then I'll f**k her up. I wasn't in a relationship since the day I was told. (M2:3).

...with a relationship, I always tell the person ... if I've got a disease where I could transmit it to someone else, I couldn't live with that. (M5:15-16).

I make sure I use protected sex now...[and] I never ever use the same needle twice...not even my own. (F2:29).

While it was common for women to describe the actions they took to prevent transmission, amongst men this was far more variable. Some men reported their concern but then indicated taking very little action to prevent transmission:

She won't let me use her toothbrush and she won't let me drink, you know I don't care. I still do when she's not around...I don't know what you call that, stupidity or [pause] irresponsible laziness. (M1:21).

Others informed friends of their infection, but took little responsibility for protecting them from risk:

If I'm having a taste with someone, I'll say 'Look, I've got hep C ... use the same spoon, it's up to you' ... with a razor ... I say 'You can use it, but I've got hep C.' (M3:7- 8).

Finally, the strongest concern shared by both women and men was related to transmission of hepatitis C to unborn children. Both men and women expressed confusion about the risk of hepatitis C in pregnancy.

I'm a bit worried... you know if she falls pregnant, you know, the baby's gonna catch the hep C virus. (M4:5)

Both men and women complained that their doctors were not always able to clarify their concerns about pregnancy.

The first thing I said (to my doctor) is 'Right, what happens with the baby?' and it's like, 'Well, I don't know'. And that's all he could say to me, to all my questions, is 'I don't know'. (F3:56).

Thus both men and women shared concerns about transmission of hepatitis C, particularly in relation to unborn children. However, in relation to transmission generally, women more commonly talked about being proactive in taking responsibility for preventing transmission.

Differences between men and women: The illness experience and seeking health care

Similar to the other research on gender and illness (Anson et al 1993; Doyal 2000, Courtenay 2000) women in this study tended to acknowledge their illness and talked about actively seeking health information and care while men tended to dismiss their hepatitis C and avoid health care. Although some women found out about their hepatitis C through routine medical screening, such as during pregnancy, hospital admission or testing as part of a methadone program, the majority of the women talked about actively seeking out a test for hepatitis C because they were suspicious that they might have the infection:

I started getting abdomen pains and things like that, and um, I moved in the drug circle, so I had my suspicions it might be hep C. (F1:1).

Well my parents and my family they were users as well, and I knew they had hep C and so I shouldn't have been sharing with them, but I did. And 'cos I was sharing with them I knew I would have hep C and I went and got tested and I did. (F8:157).

Other women had been diagnosed because they actively sought to maintain their health in the face of a risky lifestyle. Thus, some women who were current IDUs found out about their hepatitis C as part of a regular screen for blood-borne viruses that they initiated:

I usually go the doctor every month for a blood test....because a friend stabbed me with one of her fits, dirty fits. (F4:82).

I just regularly go in and get tested, being a user...I've always been clean, and then one day I wasn't. (F2:25).

This contrasts sharply with the men in this study, only one of whom initiated their hepatitis C test and none of whom engaged in regular testing or screening for their health.

I was giving blood at the time, so I got a letter, certified mail from there, and I knew something was wrong...they said they'd withheld the last four donations I've made and that I had hep C. (M10:2).

I've not been, yeah, I've been to the doctor not once ... I don't want to know what's going on. (M6:4).

Moreover, men's narratives reflected their tendency to turn a blind eye to the consequences of their risk-taking. Thus, men explained that they had been largely unconcerned about the possibility of becoming infected with hepatitis C in comparison to women.

I just, had a dirty fit on a corrugated roof next door. It was sitting there for about 2 weeks, and I used it ... (M3:1).

Following on, women described being less surprised about receiving a positive diagnosis. Their reactions appeared to be tempered by the fact that many of them had suspected having hepatitis C prior to testing:

I assumed I had it because of my unsafe practices. (F18:359).

No, I pretty much expected it like, yeah. (F10:200).

Men, however, described that they were shocked at receiving their diagnosis while others described reacting with disbelief:

I was quite devastated. (M6:3).

I was shattered. (M8:2).

I was dying. I thought I'd be dead the next day. (M2:5).

They've gone 'Oh you've got hepatitis C'. I've gone 'What?' And they gone 'Yeah, you've got hepatitis C'. And I says 'No, I can't have. Do me again'. (M9:2).

Of particular concern were the stories some men told about receiving their diagnosis while in prison, which showed the absence of any opportunity to discuss the implications of test results:

I got it (the diagnosis) off a bit of paper...it was slipped under the door in my cell. (M1:9).

Social support, information and care

One of the most striking gender differences between men and women centered on information and support. Men, while discussing social support in the abstract, and identifying social support as an important strategy for coping with illness in general, more actively denied needing social support to help them cope with hepatitis C. Some men expressed attitudes of fatalism:

Once you've contracted hep C there's nothing you can do about it, you can't get rid of it, so I don't know what support is going to do. (M3:8).

I like to pretend that I haven't got it, that's basically what I do, yeah. (M6:5).

Others denied that hepatitis C posed a problem in their life:

I think to have support you've got to have a problem. And like again, I've said, I don't have a problem. (M1:26).

This contrasted with the women, who not only talked about the benefits of social support, but also personalized the notion of support by discussing their own strategies and sources even if they had not yet drawn on them:

My methadone doctor, yeah he's really knowledgeable...if I really need to talk to someone, I'd probably be able to with him. (F15:315).

I'd be pretty comfortable to talk to our needle exchange organizer. (F14:304).

Women were also more likely to talk about specific friends or family members who could offer support:

...I needed someone to talk to because I was laying there sick so...yeah I spoke to my Mum about it. Yeah she helped me and said 'It's gonna be alright'. (F8:173).

I really maintain a support network of friends that can keep an eye on... [me.] (F11:249).

However, while women expressed willingness, indeed a desire for social support from family and friends, many said they were reluctant to draw on this for fear of causing distress to those they loved:

I didn't tell friends around home...because I thought they will worry, and there is no need... one of them has a baby I have held. So then I thought they'll worry...so I just won't tell them. (F20:404).

She's (Mum) just going to panic that I'm going to die. (F19:381).

In relation to health information, men explained that they did not see a need for information in relation to self-care:

I've been to the doctor not once [since being diagnosed with hep C. I don't want to know what's going on ...Oh, they say 'You've got to stop doing these things'. I just keep doing them ... (M6:4).

In contrast women were more willing to seek health information as they felt this would help them better manage their hepatitis C.

I did a (hep C) telephone counselling course...just initially selfishly, because I wanted more information, I wanted to...have access to news reports...and stuff that had all been telexed so that you can read them and [find out] what's going on [and] what does it (hep C) mean for us. (F11:221).

Stigma and hepatitis C

One of the key barriers to prevention, treatment and self-care is the stigma attached to hepatitis C (Anti-discrimination Board of NSW 2001). However, women in this study described being more affected by this stigma compared to the men interviewed. Thus, while both men and women described having been treated badly because of their hepatitis C, men tended to dismiss this treatment as being irrelevant or of little consequence. For example, women were more likely to talk about having a regular GP or health service but being unhappy with what they judged to be negative attitudes towards them from these health providers.

You just feel a little uncomfortable...like they think (they'd) rather be seeing some old lady with a broken ankle or whatever...and I guess that...it's something that I've done to myself. It's like, well, you know, if you do that sort of thing, this is what you get sort of thing, yeah. (F9:181).

You just sort of feel, um, a bit of a leper, or something. (F9:182).

However, many women explained that they thought that these negative attitudes were not only directed to their hepatitis C, but also to their drug use. For example, one woman talked of her regular doctor, who she had been seeing for 12 months:

He was fine to me when I didn't use, and then when he found out I did he was just different towards me. (F8:160).

Another woman described moving to a country town, and having her medical records forwarded onto a doctor there. The new doctor knew she had hepatitis C but one day he asked how she had acquired it. She said:

I know how I answer his question is going to determine how I'm going to get treated in this town. I could lie and get treated well, or I could tell the truth and get treated like shit...I said 'through intravenous drugs'. And his whole demeanor towards me completely changed. (F11:230).

In contrast, men's narratives about these experiences revealed they often expected to be treated poorly, but were able to justify the practitioner's attitude.

If you use drugs, well you copped it right back ... It's not the way I see it, but, that's my perception of what people think about it. (M3:4).

Men described being more strategic than women when it came to disclosure. For example, several men explained that, for them, disclosure was made not because of guilt, but rather to achieve a particular outcome:

I've got a pill doctor and a regular GP, a family GP. The family GP doesn't think I use drugs, he thinks I'm the straightest and most awesome guy in the world...and the pill doctor thinks I'm a big druggie and gives me what I want. (M1:11).

Thus, while both men and women acknowledged the stigma attached to hepatitis C, women tended to talk about their fears of disclosure in relation to potential negative consequences on their personal life and their sense of self.

Here at work...most of them know about the drug using, but I've been much more circumspect about the hep C...I haven't wanted to frighten or have people judge me because of it. (F14:293)

Several women's discourses suggested they believed they deserved to be judged for having engaged in socially deviant behaviours.

I thought, well, maybe I deserved it because of the way I've carried on over the years. (F13:270).

In contrast men gave little concern to risks of disclosure or to the potential consequences on personal relationships or their sense of self or other social contacts.

Yeah, it's (telling people I've got hep C) no big thing for me really. Life goes on, you know what I mean, there's nothing I can do about it so...(M3:3).

Discussion

From this small qualitative study, clear gender-related differences emerged which have a number of implications for prevention, support and care of those with hepatitis C.

Most men and women shared unsatisfactory experiences at the time of diagnosis. Although pre- and post-test counselling in relation to the diagnosis of hepatitis C has been identified as important for both prevention and care (Watson and Kosky 1999), unlike HIV/AIDS, it is not mandatory in Australia. Guidelines developed by state and national Hepatitis Councils have however, encouraged this practice over the past 5 years and new national guidelines based on those of the National Health and Medical Research Council (NHMRC 1997) are in the process of being developed. The need for post-test counselling was clearly evident in this study from the level of concern and confusion about possible transmission of hepatitis C infection. Both men and women in this study described negative experiences in relation to post-test counselling when they had received their diagnosis in an organisational setting such as a prison or methadone clinic, where best practice guidelines should be mandatory, especially given that it is these diagnostic settings where a positive test result will be common.

Both men and women described better experiences of receiving a diagnosis in a general practice setting, however for some, this was influenced by the attitude of the GP towards injecting drug use. For many men and women, their experiences of living with hepatitis C were strongly intertwined with their history of drug use and the attitudes of health providers were identified by both men and women as playing a key role in how they reacted to their illness.

Three key gender-related differences between men and women were identified, each of which resonates with differences identified within the broader research literature. First, women were more likely to describe actively seeking out help for their hepatitis C whereas men's narratives played down their illness and related experiences of avoiding seeking out health care. Second, women went into greater detail in discussing their needs for information, social support and care for their hepatitis C, while men explained that for them social support or information was unnecessary. Finally, women's narratives reflected sensitivity to judgmental attitudes expressed toward them by health professionals, family and friends, whereas men tended to dismiss these attitudes or not take these attitudes personally.

The men in this study, as has been found in other studies of gender and illness, tended not to acknowledge their hepatitis C. This finding is important because it suggests why men may be at risk of continuing to engage in behaviours such as drinking, which have such a negative impact on the prognosis for hepatitis C. Not only are such behaviours important markers in the construction of masculinity, but in addition, to cease such activities may be an acknowledgement of the severity of the impact of the illness. In this study, men's narratives dismissed their needs for health information, support and care, while women were concerned about their hepatitis C and wanted information and support. Women worried about people's attitudes towards them, while men defended themselves against these attitudes. Even for women who were physically well, hepatitis C featured strongly in their everyday life. In contrast, men described compartmentalizing their hepatitis C, placing it to one side, and indeed making it invisible in their everyday lives.

Implications for research and practice:

This study has identified some of the ways in which gender influences men's and women's experiences of hepatitis C and shapes the way they respond to diagnosis, social support, information and health care. While these findings are consistent with the larger body of research into gender and illness (Anson et al 1993; Doyal 2000, Courtenay 2000), little attention has been given to date to gender differences in relation to social research on hepatitis C. In Australia, with few exceptions (Australian Hep Council, undated), very little gender-specific hepatitis C information is available, nor have prevention, education, treatment and support services begun to address the need for gender sensitive strategies. Health practitioners may not be aware of the impact of gender beyond the more obvious reproductive and sexual health issues of hepatitis C. This study highlights the need to take gender into account when it comes both to addressing behavioural change to reduce risks of transmission, and health education strategies in relation to living well with hepatitis C.

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