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Living with Hepatitis C : A Literature Review, & The Physical, Psychological and Social Impacts of Hepatitis C and the Effects on Quality of Life

Narelle Cockman
Edith Cowan University

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Living With Hepatitis C: A Literature Review

**The Physical, Psychological and Social Impacts of Hepatitis C and the Effects on
Quality of Life**

Narelle Cockman

**A Report Submitted in Partial Fulfilment of the Requirements for the Award of
Bachelor Arts (Psychology) Honours Faculty of Community Studies, Education and
Social Sciences, Edith Cowan University.**

Date of Submission : 29 October, 2001

Declaration

I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text

Signature: _____

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Date: _____

13/5/02.

Acknowledgments

There are a number of people who I would like to thank for their help and support over the last year.

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Living With Hepatitis C: A Literature Review

Narelle Cockman

Edith Cowan University

Abstract

Hepatitis C (HCV) is a blood borne virus that affects the liver. It has become one of the most widespread blood borne viruses in Australia, now reaching epidemic proportions within the population. Given that HCV is a chronic long-term illness, with long term effects, a positive diagnosis potentially impacts on various aspects of a person's life. The aim of this paper was to review HCV related research to examine what it is like for people living with the virus and the possible personal and social impacts of a positive diagnosis. The nature of HCV, including current incidence and prevalence rates, natural history, transmission and treatment are discussed. Recent quantitative and qualitative research focusing on the various impacts of hepatitis C and the subsequent effects on quality of life are then critically explored. While formal research in this area is relatively limited, the available evidence suggests that individuals living with HCV experience a wide range of personal and social impacts, resulting in a significant decline in quality of life. The need for further understanding of this serious public health issue is discussed and possible directions for future research are identified.

Living With Hepatitis C : A Literature Review

1. Introduction

Since its identification in 1989, hepatitis C has become one of the most widespread blood-borne viruses throughout Australia (Department of Health and Aged Care (DHAC), 2000). It is thought that the hepatitis C virus (HCV) has existed since the early 1970s, but was known only as 'non A - non B' hepatitis for approximately twenty years (Standing Committee on Social Issues (SCSI), 1998). The nature of the hepatitis C virus is unique in that there is a considerable lag between the time of infection and the onset of consequences (SCSI, 1998). Therefore, the seriousness of the virus and the extent to which it affects the population is only just beginning to be recognised. It is now understood that hepatitis C has reached epidemic proportions and has become a major public health issue in Australia (DHAC, 2000).

While there has been a large amount of research on the epidemiology (Dolan, 2000; Dore, 2000a), prevention (Wodak & Crofts, 1996) and treatment (Sievert & Korevaar, 1999) of hepatitis C, relatively few studies have documented the extent to which a positive diagnosis impacts on various aspects of a person's life (Garrett & Conrad, 2001; Burrows & Bassett, 1996; Crofts, Louie & Loff, 1997). Hepatitis C is a chronic illness for the majority of people, thus in order to provide adequate care and support, it is imperative to understand the meaning that a positive diagnosis has for the person (Lin, Barker & Batey, 1999; Loveday, Deakin & Neophyton, 1999). Furthermore, while it is important to understand how the medical aspect of the virus affects the person, the emotional, psychological and social components also need to be acknowledged (Hepworth & Krug, 1999; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek & Wiener, 1984).

This paper is a review of the literature relevant to hepatitis C and the possible personal and social impacts of a positive diagnosis. Firstly, a profile of hepatitis C, including, current incidence and prevalence rates, natural history, transmission and

treatment will be discussed. Research focusing on the various impacts of hepatitis C and the subsequent effects on quality of life will then be critically explored. Finally, gaps in the literature will be identified and future directions for research will be acknowledged.

2. Hepatitis C : A Profile of the Virus

Hepatitis means inflammation of the liver, which can cause damage to liver cells (Hepatitis C Council of WA (HCCWA), 1998). There are several different causes of hepatitis, including chemicals, alcohol, drugs, impaired immune systems and viral infections such as hepatitis A (HAV), hepatitis B (HBV) and hepatitis C (HCV) (DHAC, 2000; HCCWA, 1998). A laboratory test for hepatitis C has been available since 1990 and it has since been discovered that there are at least nine different strains of HCV with which people can become co-infected (Australian National Council on AIDS and Related Diseases (ANCARD), 1998; DHAC, 2000; HCCWA, 1998). Currently there is no vaccine available for hepatitis C so for many people the virus is a life long condition (Lowe & Cotton, 1999).

2.1 Prevalence and Incidence

Prevalence refers to the total number of people in a population who have the virus at a specific point in time (SCSI, 1998). Current estimates suggest that over 200,000 people have been infected with hepatitis C in Australia (DHAC, 2000; ANCARD, 1998). Prevalence has also been cited as approximately 1% of the population which equates to one person in every 100, being HCV positive (HCCWA, 1998). The Hepatitis C Sub-Committee suggest that if current transmission rates continue, prevalence figures are likely to double by the year 2010 (ANCARD, 1998).

Incidence refers to the number of people who are newly infected with hepatitis C each year and reflects the rate at which the disease occurs (DHAC, 2000). Current estimates of incidence rates suggest that approximately 11,000 new HCV infections occur each year (DHAC, 2000). Since the screening of blood supplies in 1990,

approximately 90% of these new infections are believed to be from injecting drug use (Lowe & Cotton, 1999; ANCARD, 1998).

In many respects hepatitis C is a relatively new virus, which is reflected by the difficulty in obtaining accurate figures on the prevalence and incidence of the disease (SCSI, 1998). Prevalence studies to date have obtained data by screening selected sub-groups, none of which can be described as a representative sample of the general community (ANCARD, 1998). Instead, the prevalence of hepatitis C has been estimated in sub-populations including injecting drug users (Selvey, Denton & Plant, 1997; Wodak & Crofts, 1996), blood donors (Archer et al., 1992) and prisoners (Dolan, 2000).

Most prevalence studies of hepatitis C amongst injecting drug users have reported consistent rates of 50% - 70% since the 1970's (ANCARD, 1998), however some studies have reported figures as high as 94% (Gaughwin, Dodding & Ali, 1994). Blood donors have much lower prevalence rates, with an average of 1% of the population testing positive for hepatitis C (ANCARD, 1998). Studies within prisons have reported higher prevalence rates of approximately 35% amongst general prisoners and up to 80% amongst prisoners who are also injecting drug users (Dolan, 2000).

It is acknowledged that a number of methodological problems associated with HCV epidemiology means that estimated prevalence and incidence rates should be interpreted with caution (Lowe & Cotton, 1999). There are limitations with current testing technology in that tests do not distinguish between acute, newly acquired infections and chronic, long-term infections (DHAC, 2000). Therefore, accurate and reliable data concerning incidence rates of hepatitis C in Australia are very difficult to estimate (ANCARD, 1998). Furthermore, due to the absence of representative population based information, it is still uncertain about the actual number of people who are HCV positive (SCSI, 1998). Despite numerous studies of hepatitis C within specific populations, it is clear that research is still needed to monitor prevalence and incidence

within the general community if a clearer picture of the epidemic is to evolve (SCSI, 1998).

2.2 Natural History of Hepatitis C

It has been noted that hepatitis C attacks and damages liver cells, however the extent of damage and the natural history of the disease can vary between people (HCCWA, 1998). The initial phase of infection is described as acute hepatitis C which occurs approximately 6 to 10 weeks after exposure and usually lasts between 2 and 6 months (Marinos, Pirola & Locarnini, 1999). During this time levels of the virus are high, however acute hepatitis C appears to be symptomatic in only 25% of cases, so most of the time the acute phase goes unnoticed (Marinos, Pirola & Locarnini, 1999; HCCWA, 1998).

Although the body produces antibodies to fight the virus, it is not eliminated in the majority of cases and the infection becomes chronic (HCCWA, 1998). Chronic hepatitis C infection is defined as persisting for more than six months and refers specifically to the duration of the virus and not the severity of the disease (Lin, Barker & Batey, 1999). Chronic hepatitis C infection can lead to a wide spectrum of liver disease ranging from various levels of damage through to cirrhosis (scarring of the liver), however HCV is a very slow acting virus and can take up to 30 years to cause damage (Lin, Barker & Batey, 1999).

In a recent review of studies concerning the natural history of hepatitis C, Dore (2000a) reported the following outcomes if 100 people were infected with the virus. Approximately 15 to 35 people will clear the virus within 2 to 6 months of infection, thus only experiencing the acute phase of hepatitis C. However, clearance of the virus does not lead to immunity and these people can be re-infected if they are subsequently exposed to the virus. The remaining 65 to 85 people will not eliminate the virus and will develop chronic hepatitis C infection. Some of these people will never develop any liver damage and others will experience some level of damage after an average of 13

years (HCCWA, 1998). It is believed that of the people who develop chronic HCV infection, 5 to 10 will have progressed to cirrhosis after an average of twenty years, with increased risk for those with sufficient alcohol consumption or co-infection with HIV or hepatitis B. About 3 to 5 people with hepatitis C related cirrhosis will be at risk of liver failure or hepatocellular carcinoma (HCC) after thirty to forty years of infection.

One of the difficulties in predicting the progression of hepatitis C, is that once chronic infection has been established, the course of the virus appears to differ enormously among individuals (Dore, 2000a). Furthermore, the factors that influence clearance of HCV or the progression to cirrhosis or advanced liver disease are not clearly understood (Dore, 2000a; ANCARD, 1999). The lack of clinical illness for the majority of people with newly acquired HCV means that most people do not know they are infected, resulting in a small sample of cases and limited follow-up in many studies of HCV progression (Dore, 2000a).

It is also acknowledged that a major limitation of natural history studies is that most of the data comes from those who have acquired their infection via blood transfusions (Dore, 2000a; ANCARD, 1999). It is possible that the progression of hepatitis C may be different in those who have post transfusion infection as opposed to the more common community-acquired infection (injecting drug use) (ANCARD, 1999). Therefore, as most hepatitis C infections in Australia are a result of injecting drug use, research on the natural history of the virus may be invalid (Dore, 2000a). Dore (2000a) also notes that a large number of studies are conducted on selective clinic-based groups such as liver clinics, suggesting there needs to be more data made available from representative population based research.

2.3 Transmission

Hepatitis C is a blood-borne virus that requires blood-to-blood contact for infection to occur (HCCWA, 1998). It is relatively robust and only minute amounts of blood are needed to infect someone, during both the acute or chronic phases of the virus

(HCCWA, 1998). Studies of hepatitis C risk factors have suggested that around 80% of people that are positively diagnosed in Australia, were exposed through injecting drug use (Dore, Pritchard-Jones, Fisher & Law, 1999; ANCARD, 1998). Approximately 7% acquired hepatitis C through the receipt of blood or blood products, and 13% were infected via other routes such as tattoos and needlestick injuries (ANCARD, 1998). The various routes through which hepatitis C is transmitted will now be examined further.

2.3.1. Injecting drug use.

Sharing needles and syringes, as well as other drug injecting equipment including water, swabs and spoons, poses the highest risk of transmitting or acquiring hepatitis C (Dore et al., 1999; MacDonald & Wodak, 1999; HCCWA, 1998). The highly infectious, robust nature of the virus and the large pool of infection among injecting drug users, are factors that influence the high level of risk associated with injecting behaviour (Wodak & Crofts, 1996). Prevalence of hepatitis C is strongly associated with the duration of injecting, with the rates being as high as 40% after two years of injecting and approximately 90% to 100% for those who have injected for more than ten years (Crofts et al., 1993). Although there has been some recent evidence suggesting a decrease in the sharing of injecting equipment and therefore rate of transmission (Dore et al., 1999), some sub-groups of users are still at high risk of becoming infected with HCV, particularly in prisons where prevalence is very high (Dolan, 2000) and young people who are new to injecting (Williams, 2000).

The principal strategy for preventing HCV transmission from injecting drug use, is to avoid re-using any injecting equipment (MacDonald & Wodak, 1999). Such initiatives include the provision of needle and syringe exchange programs, peer based education for injecting drug user groups on safer injecting practices, methadone maintenance programs and education and prevention activities in prisons (Williams, 2000; Lowe & Cotton, 1999). However, despite these preventative efforts many people

still choose to share injecting equipment due to various factors such as lack of access, lack of knowledge or as part of an intimate, trusting relationship, consequently increasing the chances of transmitting or contracting hepatitis C (Williams, 2000).

2.3.2. Blood transfusions and blood products.

Since the screening of blood supplies in 1990, transmission of hepatitis C through blood transfusions and blood products is extremely low, with approximately one case per 250,000 donations (Dore et al., 1999; HCCWA, 1998). Furthermore, due to the recent introduction of more sensitive nucleic acid testing for hepatitis C since June 2000, the risk of transmission from blood transfusions in Australia is virtually eliminated (DHAC, 2000). For people who received blood transfusions or blood products prior to 1990, a moderate risk of contracting hepatitis C exists (HCCWA, 1998). This risk is the highest for haemophiliac patients or those who had multiple transfusions prior to the screening of blood supplies (Dore et al., 1999).

2.3.3. Unsafe tattooing and body piercing.

Tattooing and other skin penetration procedures such as body piercing have also been implicated as risk factors for the transmission of hepatitis C (Thompson, Hernberger, Wale & Crofts, 1996; HCCWA, 1998; MacDonald & Wodak, 1999). It has been suggested that such procedures pose a medium to high risk, particularly if not carried out under sterile conditions (HCCWA, 1998; Dore et al., 1999). There is the potential for transmission to occur from client to client if tattooing needles and piercing equipment are not sterilised between clients, or if tattoo ink tubs are shared (Communicable Disease Control Branch (CBCD), 1999). Transmission can also occur from operator to client, or client to operator if the body artist does not use standard safety precautions for skin penetration procedures, such as wearing disposable gloves (CDCB, 1999).

2.3.4. Needlestick injuries / occupational transmission.

Despite common belief, often due to media reports, the risk of transmitting the

hepatitis C virus through needle stick injuries is relatively low (Dore et al., 1999). However, given the blood borne nature of transmission, healthcare workers are potentially at risk of exposure to hepatitis C (SCSI, 1998). It is believed that the estimated risk of transmission following a needle stick injury involving HCV positive blood is about 4% (HCCWA, 1998). To put this figure into perspective, the risk of hepatitis B and HIV transmission following exposure to positive blood, is 30% and 0.4% respectively (HCCWA, 1998).

There has been limited research on occupationally acquired HCV infection in Australia, however one project by the National Centre in HIV Epidemiology and Clinical Research (NCHECR) monitors occupational exposure to HCV among healthcare workers in Australian hospitals (MacDonald, Correll & Dore, 2000). Since project monitoring began in 1995, no workers were reported as acquiring hepatitis C following exposure to the virus in the workplace. However, the authors noted that testing rates at three months after exposure were low and it is possible that there may have been workers who were infected and chose not to report this information (MacDonald, Correll & Dore, 2000). Despite the small amount of research conducted in this area, the risk of HCV transmission through occupational exposure or needlestick injuries appears to be low. Nevertheless, there is a risk and healthcare workers should be encouraged to adhere to standard safety precautions when conducting exposure prone procedures.

2.3.5. Other modes of transmission.

Hepatitis C transmission through routes other than those already discussed is generally thought to be uncommon, however any behaviour that involves blood-to-blood contact is potentially a risk for the transmission of the virus (Dore et al., 1999). Household transmission of hepatitis C appears to be extremely rare, although the possibility of blood to blood contact exists if toothbrushes, razors or similar items are shared, however there is no conclusive evidence to support this (MacDonald & Wodak,

1999).

It is generally recognised that hepatitis C is not a sexually transmitted virus and studies have concluded that sexual practices not involving blood, are considered to be very low risk (Dore, 2000b). Contrary evidence suggests that approximately 10% of people with hepatitis C in the United States report acquiring the virus through sexual exposure (SCSI, 1998). It is possible however, that for many people it is more favourable to report sexual transmission, rather than admit a history of injecting drug use. Despite inconclusive evidence about whether or not hepatitis C is transmitted sexually, general agreement is that:

Sexual transmission is of very low prevalence. A very low proportion of new cases. There is argument about whether it is very, very low or just very low, but it certainly would not be more than one percent of all new transmissions (Wodak evidence, cited in SCSI, 1998, p. 91).

The risk associated with mother to child transmission (vertical transmission) is unclear, with figures estimating that less than 5% of babies will acquire the virus from a mother with hepatitis C (HCCWA, 1998). It is thought that high levels of virus in the mother at the time of pregnancy is the strongest risk factor for vertical transmission of hepatitis C (MacDonald & Wodak, 1999), however maternal co-infection with HIV has also been associated with an increased risk of transmission (Papaevangelou et al., 1998).

2.4 Treatment

Currently, there is no vaccine or effective cure for hepatitis C infection, however there are treatments and therapies available that seek to reduce viral replication and inflammation of the liver (Sievert & Korevaar, 1999). The goal of these treatments is to produce a sustained response (SR), which is defined by normal liver function tests and undetectable levels of the virus at either six or twelve months after the completion of treatment (Sievert & Korevaar, 1999). At present there are two types of anti-viral

treatments in Australia, interferon monotherapy and interferon combined with ribavirin (combination therapy) (Sievert, 2000). Studies suggest a significant advantage of combination therapy over interferon therapy alone, however both available treatments have limited success rates (between 19% and 64%) (Poynard et al., 1998). More recently, it has been suggested that the use of newer, longer acting ('pegylated') interferons may further increase sustained response rates, although trials are still being conducted to determine their effectiveness (Sievert, 2000).

Anti-viral treatment provides many people with a sense of hope that the virus may be eliminated, however it brings its own set of adverse physical and psychological side effects, which in turn can impact enormously on the life of the individual (Burrows & Bassett, 1996; Sievert & Korevaar, 1999). Reported side effects include nausea, flu like symptoms, weight loss, diarrhoea, anaemia, anxiety, depression and in some cases suicidal ideation (Sievert & Korevaar, 1999). The debilitating effect of these symptoms can often cause people to cease treatment and thus lead to feelings of failure and hopelessness (Burrows & Bassett, 1996). In addition, it has been noted previously that treatment is only successful in a limited number of cases, so there are significant numbers of people who complete the course of treatment and either do not respond or relapse after a few months (Sievert & Korevaar, 1999). This again can lead to feelings of hopelessness, disappointment and anger in those who 'fail' treatment, as it is often viewed as the last chance or the last hope for eliminating the virus (Burrows & Bassett, 1996).

2.5 Hepatitis C and HIV: A Comparison

The main characteristics of hepatitis C, including the prevalence, natural history, transmission and treatment have been discussed, thus providing a general overview of the nature of the virus. At this point it would be useful to summarise the features of hepatitis C by making a comparison with HIV, a virus of which the general community is relatively more aware (see Table 1) (NCHECR, 1999).

While some strong parallels can be drawn between the two viruses, there are also some striking differences (Orr & Leeder, 1998). For example, hepatitis C and HIV are both infectious blood-borne viruses, both went unrecognised for a period of time and both primarily affect populations who are socially marginalised (Orr & Leeder, 1998). However, hepatitis C was identified much later on the epidemic curve than HIV, and therefore a much larger pool of infection already existed within the population (Orr & Leeder, 1998). When compared to HIV, hepatitis C is a much more infectious and robust virus and therefore is more readily transmitted through the sharing of drug injecting equipment and needle stick injuries (Wodak & Crofts, 1996). Serious health complications occur more quickly in those with HIV in comparison to the slow acting nature of hepatitis C (Wodak & Crofts, 1996).

Table 1

Summary of HCV and HIV: A Comparison

Feature	HCV	HIV
Start of epidemic	early 1970's	early 1980's
Prevalence	200, 000	18, 000
New infections / year	11, 000	500
Proportion of population infected	1 %	0.1 %
Mode of transmission	blood to blood contact	blood to blood contact sexual transmission
<u>Highest risk behaviour</u>	<u>injecting drug use</u>	male homosexual contact

It is clear that hepatitis C has become a widespread virus of epidemic proportions. Given the probability that a massive pool of unknown infection exists in the population, it seems certain that a significantly high number of people will be living with chronic liver disease, and the associated consequences, in the very near future (Orr & Leeder, 1998). Attention needs to be given to the seriousness of this public health

issue, and in doing so the level of awareness and understanding of what hepatitis C means for the person needs to be increased.

3. Impacts of Hepatitis C

Given that hepatitis C is a chronic, long term illness, the importance of research examining the personal and social impacts of hepatitis C infection and subsequent quality of life, has only recently been acknowledged (ANCARD, 1999). As a result, the amount of research focusing on the consequences of hepatitis C infection and quality of life has increased, however it is relatively limited and the impacts are still not clearly understood.

Quality of life (QOL) is generally defined as an individual's overall satisfaction with life and sense of well-being (Koff, 1999). Although quality of life is a concept that everyone intuitively understands, it is difficult to define and measure, due to the subjective nature of the term (Swain, 2000). Therefore, hepatitis C research has mainly focused on the more narrowly and specifically defined concept of health related quality of life (HRQOL), which aims to estimate the impact of chronic illness on various domains, including physical functioning, somatic sensation, psychological status, social interactions and sense of well being (Koff, 1999). Research in this area has utilised both quantitative, and more recently qualitative methodologies, to identify the various personal and social impacts of hepatitis C and how these affect changes in HRQOL. The relevant literature will be discussed in more detail.

3.1. Quantitative Assessment of Health Related Quality of Life (HRQOL)

To date, the measurement of HRQOL among people with hepatitis C, has most frequently been undertaken through the use of multi-item questionnaires and self report survey instruments (Swain, 2000). Typically these measures are designed to assess an individual's perception of illness and quantify the impact on their life (Swain, 2000). The main instruments used to measure HRQOL among hepatitis C populations, are generic questionnaires such as the Short-Form 36 (SF-36) (Ware & Sherbourne, 1992)

and hepatitis C specific assessment tools such as the Hepatitis Quality of Life Questionnaire (HQLQ) (Bayliss, Gandek, Bungay, Sugano, Hsu & Ware, 1998) and the Chronic Liver Disease Questionnaire (CLDQ) (Younossi, Guyatt, Kiwi, Boparai & King, 1999).

3.1.1. Short-form 36 (SF-36).

Perhaps the most common measurement tool to be used in hepatitis C research, is the Short-Form 36 (SF-36), a generic questionnaire designed to assess health related quality of life (Ware & Sherbourne, 1992). The SF-36 is a multi-item scale which measures eight health related concepts, namely physical function; social functioning; role limitations due to physical problems; bodily pain; mental health; role limitations due to emotional problems; vitality and general health perceptions (Ware & Sherbourne, 1992). The SF-36 is self-administered, is rapid and easy to complete and has shown to have acceptable reliability and validity among various populations (Koff, 1999).

Studies utilising the SF-36 among people with chronic hepatitis C, are only relatively recent and generally they have demonstrated a significant decline in all eight sub-scales of the SF-36 for those infected with the virus, when compared to healthy controls (Bonkovsky & Woolley, 1999; Carithers, Sugano & Bayliss, 1996; Foster, Goldin & Thomas, 1998). Although the results from these studies indicated that people living with HCV had lower quality of life across all domains, the greatest reductions appeared to be on the physical sub-scales as opposed to the categories measuring mental and emotional health, suggesting that the greatest impact of HCV was of a physical nature (Foster et al., 1998; Bonkovsky & Woolley, 1999).

Foster et al. (1998) also compared quality of life in people with chronic HCV, with those who were infected with chronic hepatitis B. Interestingly, HCV participants scored lower on all domains of the SF-36, however scores were only significantly poorer in areas of social functioning, physical role limitations and vitality (energy and fatigue) (Foster et al., 1998). These results suggest that the reduction in quality of life

among HCV participants could not be attributed to the degree of liver inflammation, and therefore the nature of impairment associated with HCV may be qualitatively different to the symptoms associated with HBV (Foster et al., 1998).

Bonkovsky and Woolley (1999) also evaluated the effect of chronic hepatitis C on HRQOL by using the SF-36. The main aim of this study was to determine whether treatment of 642 participants with interferon therapy, subsequently improves HRQOL. Similar results to Foster et al. (1998) were reported, with baseline measures of HRQOL being significantly lower across all domains of the SF-36 for HCV patients, when compared to healthy controls (Bonkovsky & Woolley, 1999). In addition, when compared to non-responders, it was found that those who had a sustained response to treatment, showed a significant improvement in HRQOL within five of the eight subscales, six months after treatment had ceased (Bonkovsky & Woolley, 1999). One significant flaw in this study was that participants were not blind to their responses during the treatment phase. In other words, participants knew whether or not they were responding to interferon and this awareness may have influenced their perceived health status (Swain, 2000).

There are also some general limitations of studies that have used the SF-36 to measure HRQOL among people with hepatitis C and therefore results should be interpreted with caution. Most studies compared HCV participants with 'healthy' rather than 'normal' control populations, therefore the differences in perceived quality of life may appear to be more pronounced than what is actually the case (Swain, 2000). Another big problem with the SF-36 is the fact that it is a generic assessment tool, which is useful for direct comparisons of HRQOL between people with hepatitis C and other populations, however they are based on the assumption that chronic illnesses impact on people in similar ways (Swain, 2000; Garrett & Conrad, 2001). In addition, the use of generic questionnaires gives rise to the possibility that information regarding

disease-specific impacts and changes in functioning can be lost (Borgaonkar & Irvine, 2000).

3.1.2. Hepatitis C specific measures of HRQOL

The use of generic instruments to measure HRQOL and the awareness of their associated limitations, has led to the recent development of assessment tools that are specific to hepatitis C. One such attempt has been by Bayliss et al. (1998) who developed the Hepatitis Quality of Life Questionnaire (HQLQ), a 69-item questionnaire designed to measure both generic functioning and disease-specific health outcomes. The HQLQ included all eight scales from the SF-36, in addition to measures of nine other generic and hepatitis C specific health concepts. Bayliss et al. tested the questionnaire on people with chronic hepatitis C who were receiving interferon treatment and found that participants scored lower on the generic scales than patients with other chronic illnesses, and worse than a healthy general population. Although the disease-specific scale scores were also found to be lower for hepatitis C, the HQLQ appeared to have no significant advantage over using the SF-36 alone (Bayliss et al., 1998). Furthermore, so far the HQLQ has only been used with participants who are receiving interferon treatment and the effectiveness of this questionnaire on untreated hepatitis C populations, is yet to be determined.

Another disease specific instrument called the Chronic Liver Disease Questionnaire (CLDQ) has also been recently developed and is designed to measure HRQOL in people with chronic liver disease, including hepatitis C (Younossi et al., 1999). Literature, expert opinion and patient focus groups, were used to generate the 29 item questionnaire, which focuses on six domains that impact on quality of life for people with chronic liver disease: fatigue, activity, emotional function, abdominal symptoms, systemic symptoms and worry (Younossi et al., 1999). The CLDQ has been shown to have a number of advantages including short and easy administration, moderate test-retest reliability after six months and appears to discriminate between

people with varying degrees of liver damage (Younossi et al., 1999). The CLDQ is still in the initial stages of being utilised to assess HRQOL in people with hepatitis C and more research is needed to evaluate its efficacy, however the CLDQ exhibits a number of potential strengths which may allow future widespread application among this population.

3.1.3. General limitations.

Both generic and disease specific measures of HRQOL are in the beginning stages of development, particularly with respect to hepatitis C. Nevertheless, results from studies conducted so far, have suggested that people living with hepatitis C experience a significant decline in quality of life, with the greatest deficits appearing to be physical in nature. It has been argued however, that using questionnaire type tools to assess HRQOL does not directly address the mechanisms underlying the apparent decline (Koff, 1999). In other words, this method of assessment demonstrates that there are impacts of hepatitis C that have a detrimental affect on quality of life, but they do not specifically explain what these impacts are or why they affect quality of life (Koff, 1999). Despite this limitation, HRQOL assessment tools have a very important place in hepatitis C related research and can be used to evaluate treatment efficacy and enhance knowledge of the virus (Borgaonkar & Irvine, 2000).

3.2. Qualitative Research: Personal and Social Impacts

Recent interest in identifying and understanding the potential impacts of hepatitis C, has led many researchers to adopt a qualitative approach to explore these impacts in more detail (Garrett & Conrad, 2001; Burrows & Bassett, 1996). It is argued that qualitative inquiry is better suited to develop an understanding of personal meaning, while revealing important insights into human experiences (Miles & Huberman, 1994). Research in this area has attempted to explore the impacts of hepatitis C by conducting in-depth interviews or focus groups, in order to understand the personal experiences of people living with the virus (Crossen, Brunton, Plumridge

& Jang, 1999; Burrows & Bassett, 1996; Garrett & Conrad, 2001). Unfortunately, the amount of formal research in this area is relatively scarce and much of the current knowledge regarding the personal and social impacts of hepatitis C, has come from personal submissions (SCSI, 1998) or anecdotal evidence provided from case notes or workers in the field (Lowe & Cotton, 1999). However, the research suggests that a positive diagnosis of hepatitis C results in a range of physical, psychological and social impacts, which will be discussed further.

3.2.1. Receiving the diagnosis

For many people, receiving the news that they have contracted hepatitis C, is a shocking and traumatic experience (Burrows & Bassett, 1996). In most cases, it appears that people are generally informed by their doctor, however some people have reported being told over the phone or via letters from blood banks (Crossen et al., 1999; Burrows & Bassett, 1996). While a small minority of participants in Burrows and Bassett's study were satisfied with the amount of information and support they received at the time of diagnosis, there have been a large number people who were unhappy with the way they were informed (Crossen, et al. 1999; Burrows & Bassett, 1996). Pre-test and post test counselling is designed to reduce the impact of a positive diagnosis by providing sufficient information about possible outcomes, educating the person on the risk of transmission and ensuring that there is adequate support available (McCoy, Watson & Kosky, 1999). Unfortunately, studies have indicated that the number of people who actually receive this counselling are limited (Crossen et al., 1999; Burrows & Bassett, 1996), and many people experienced increased stress and anxiety due to the lack of information and uncertainty surrounding the outcomes of hepatitis C infection (Garrett & Conrad, 2001; Crossen et al., 1999; Lowe & Cotton, 1999).

3.2.2. Physical symptoms.

By far the most commonly reported physical symptom of chronic hepatitis C has been fatigue, ranging from minimal or episodic lethargy, to overwhelming and

debilitating exhaustion (Burrows & Bassett, 1996; Garrett & Conrad, 2001). One of the reported difficulties associated with fatigue is the unpredictability of onset, which for many people means they can not plan for more than a day at a time (Glacken, Kernohan & Coates, 2001). The experience of fatigue for many people with hepatitis C has also been reported to contribute to a reduction in social mobility and thus can influence a sense of isolation (Glacken et al., 2001).

Other common physical symptoms include nausea, headaches and pain in the right side of the abdomen, however muscle aches, intolerance to fatty foods, skin rashes and weight loss have also been reported (SCSI, 1998; Burrows & Bassett, 1996). It has been noted previously that people on interferon or combination treatment, may also experience adverse physical symptoms (see section 2.4). It is important to note that participants in these studies generally did not experience symptoms all of the time and they could be more or less severe on different days (Burrows & Bassett, 1996).

Garrett and Conrad (2001) found that the physical impacts of hepatitis C were often surrounded by feelings of uncertainty, in particular the unpredictability associated with the onset of symptoms and what that meant in regards to the progression of the virus. White and Lubkin (1998) suggest that the uncertainty and unpredictable nature associated with many chronic illnesses can have enormous implications for the individual, often resulting in a number of psychological effects, which will be discussed further in the next section.

3.2.3. Psychological and emotional impacts.

Studies suggest that a positive diagnosis of hepatitis C may also create significant psychological and emotional impacts (SCSI, 1998). As noted in the previous section, it appears that in many cases the presence of physical symptoms can often lead to psychological effects such as depression, mood swings, anxiety, stress and decreased self esteem (Loveday et al., 1999). Depression seems to be the most commonly cited psychological effect (Burrows & Bassett, 1996), and appears to be more significant in

those who have been diagnosed for more than five years, or for those who are over fifty years of age (Kraus, Schafer, Csef, Scheurlen & Faller, 2000). This suggests that the amount of time that a person knows they have hepatitis C, could possibly influence their emotional state (Kraus et al, 2000).

Other psychological impacts of hepatitis C such as short term memory loss (Garrett & Conrad, 2001), irritability and 'shattered dreams' have also been reported (Burrows and Bassett, 1996). An interesting exploratory study by Glacken et al.(2001), found that the majority of participants experienced an altered self concept and decreased self esteem, following a positive diagnosis. Many participants considered themselves as 'contaminated', 'dirty' and 'unclean', mixed in with feelings of anger, bitterness, fear, frustration and a sense of hopelessness (Glacken et al., 2001). It has also been reported that the ambiguous nature of HCV can lead to a reduced sense of control and uncertainty about the future (Garrett & Conrad, 2001).

3.2.4. Coping and support

A cross sectional study by Kraus et al. (2000), explored coping styles among people with chronic hepatitis C. These authors found that the most common coping mechanism was problem solving behaviour, however distraction and self re-evaluation were also frequently employed (Kraus et al., 2000). Other reported methods of coping with physical symptoms such as fatigue, have been diet and exercise (Garrett & Conrad, 2001), and stress management techniques such as meditation, yoga and counselling (Sladden, Hickey, Dunn & Beard, 1998).

Social support has shown to be an important factor in reducing the negative impacts of a positive diagnosis (Glacken et al., 2001). Many participants in New Zealand based research reported that friends and family provided the greatest amount of support, while others mentioned their general practitioner and hepatitis C support groups (Crossen et al., 1999).

3.2.5. Effect on family and relationships.

Reports of personal experiences have suggested that hepatitis C can have a negative impact on family and relationships (Burrows & Bassett, 1996; SCSi, 1998). Fear of transmission to partners and children appears to be a common example, even though the risk is very low (Loveday et al., 1999). This can lead to a reduction in the amount of interaction with partners and children. Examples given by women have included being cut off from their families because of hepatitis C due to fear and confusion concerning the risks of transmission (Gifford & O'Brien, 2001). Some examples of comments given by women include:

I used to be able to hug them (my family) and kiss them and now I'm not allowed to touch them or anything (Gifford & O'Brien, p12.)

I planned to have children in the next few years and that's really scary because it's not something I want to pass on to my kids. Do I have a right to marry this man and have his children if I'm going to put my kids at risk? (Gifford & O'Brien, p12.)

Other impacts on family are influenced by the ability to have the physical energy to look after, raise and interact with children, which for many people is greatly reduced (SCSi, 1998). Some people have reported negative attitudes, behaviour or rejection from partners and friends, mainly due to fear and ignorance, while others have reported positive support and the strengthening of relationships (Burrows and Bassett, 1996).

3.2.6. Effects on work.

Many people with hepatitis C have found that the virus can have a devastating effect on the ability to continue their jobs and careers, due to increasing fatigue or stress (Burrows & Bassett, 1996). In a study exploring the experiences of women, it was found that the difficulty in gaining and maintaining employment led to negative financial implications and economic hardship (Gifford & O'Brien, 2001). Other reported impacts have included having to leave current jobs, engaging in a total career

change or being sacked because of a reduced ability to keep up (Burrows & Bassett, 1996). Another serious impact of being diagnosed with hepatitis C, is the experience of discrimination, stigma and isolation in the work place (Lowe & Cotton, 1999), and exploration of this issue will be discussed further in section 3.2.8.

3.2.7. Disclosure.

While there is no legal obligation to disclose hepatitis C status, it appears to remain a big issue and can have significant impacts for many people (HCCWA, 1998). Disclosure was a major issue for the women in Gifford and O'Brien's (2001) recent study. The dilemma facing these women, and indeed many people with hepatitis C, is the choice between telling someone their status in order to gain support or warn them of potential risk, and the real fear of being rejected or being subjected to stigma and discrimination (Gifford & O'Brien, 2001; Burrows & Bassett, 1996). Many people have experienced adverse consequences within family, friends, relationships and work and personal anecdotes include:

I need some information to send to my brother who won't let me touch his kids. Telling my family was the biggest mistake I ever made (Burrows & Bassett, p.25).

I've lost a lot of people - if I make coffee at my house people won't drink it and I haven't seen some of them since telling them (Burrows & Bassett, p.26).

Other people have reported that although disclosure can be difficult, it can be a positive experience:

I'm fortunate because a friend of mine is also positive. She's very supportive and helpful...telling people is part of the process of accepting it (Burrows & Bassett, p.25).

Whether the experience of disclosure is positive or negative, the decision to do so often creates a lot of stress and anxiety and the impact can be quite significant (Burrows & Bassett, 1996). For example, for some people, the fear of potential

rejection is so great that they choose not to involve themselves in relationships (Garrett & Conrad, 2001).

3.2.8. Discrimination and stigma

There is a growing amount of literature that powerfully reveals the extent to which people living with HCV experience stigmatisation and discrimination. Stigma is a socially constructed concept associated with shame and discredit, whereas discrimination is the differing treatment or action which is based on stigma (Ward, Coleborne & Fort, 2000). It is suggested that characteristics which contribute to the stigmatisation of many chronic diseases include an unclear cause or progression, ineffective treatment, transmissible nature and association with an already marginalised group (Saylor & Yoder, 1998). All of these factors are characteristic of hepatitis C and therefore various degrees of HCV related stigma and discrimination are present in the community, largely as a result of negative attitudes towards injecting drug users (Ward et al., 2000; SCSL, 1998; Burrows & Bassett, 1996).

Research by Crofts, Louie and Loff (1997) reported that the range of settings in which hepatitis C discrimination occurred was extensive. The majority of discrimination incidents were reported to have occurred in health care settings (56%), while others had occurred in domestic settings (22%), occupational settings (20%) and recreational settings (5%). A wide range of discriminatory incidents were also reported by participants in Burrows and Bassett's (1996) study. A large number of people noted that the negative attitudes they experienced, were influenced by the assumption that people with hepatitis C are injecting drug users, and a high level of discrimination was reported as coming from health care workers (Burrows & Bassett, 1996).

When someone gets cancer from smoking, they're treated respectfully in hospital. Whereas with hepatitis C it's 'You knew it (injecting drug use) could be dangerous. You deserve what you get'. They want to get you out as quickly as possible. (Burrows & Bassett, p.33).

Dealing with stigma and discrimination is often an everyday reality for people living with hepatitis C and can have a significant impact not only on the life of the individual, but also on the lives of their family and friends (Ward, Coleborne & Fort, 2000). Reported impacts of stigma have included devalued sense of self, diminished self esteem (Gifford & O'Brien, 2001), secondary health care, ending of relationships and termination of employment (Crofts, Louie & Loff, 1997).

These experiences appear to be a common link between many studies exploring the impacts of hepatitis C and some have suggested that it has become a secondary and underlying epidemic that people living with the virus have to deal with (SCSI, 1998). The recent acknowledgement of the widespread extent of hepatitis C related discrimination, has led to the National Hepatitis C Strategy stating the reduction of discrimination, particularly in healthcare settings, as a national priority (DHAC, 2000). It is clear that more research is needed to further understand the extent and nature of hepatitis C related stigma and discrimination, in order to reduce the impact of this significant issue.

3.3. Development of a Socio-Cultural Perspective

Although research exploring the impacts of hepatitis C is relatively new, qualitative studies have begun to provide a clearer picture of how these impacts affect quality of life. However some researchers have argued that hepatitis C is primarily viewed as a medical condition, with emphasis on the impact of physical symptoms (Hepworth & Krug, 1999). It has also been suggested that the non-physical effects of hepatitis C are typically represented as being located within the individual and as individual problems (Hepworth & Krug, 1999). A recent change in thinking has led some researchers to view hepatitis C as not only a medical, physical or individual problem, but as a virus whose impacts are influenced by social, cultural and political factors (Glacken et al., 2000; Hepworth & Krug, 1999). These researchers argue that a positive hepatitis C diagnosis accompanies a range of impacts to which they have to

adapt, and these changes are not only derived from psychological reactions, but also from the social and cultural relationships in which the individual is embedded (Hepworth & Krug, 1999).

This viewpoint is consistent with Bronfenbrenner's (1979) systems theory, which argues that an individual exists in, and is influenced by a series of interconnected systems, within their environment. Bronfenbrenner's theory has long been associated with human development, however a similar framework could be applied to the experience of chronic illnesses (Strauss et al., 1984). For example, some aspects of hepatitis C such as symptoms of fatigue and depression (Burrows & Bassett, 1996; SCSI, 1998), affect the person at an individual level which Bronfenbrenner describes as the microsystem. Impacts at a social level, including negative impacts on work, family and relationships (Burrows & Bassett, 1996; SCSI, 1998) and inadequate pre-test and post-test counselling (Crossen et al., 1999) could be described as the mesosystem (Bronfenbrenner, 1979). Negative community attitudes and social policy are aspects of an even broader environmental context, which Bronfenbrenner calls the exosystem.

A systems or socio-cultural approach also suggests that impacts at one particular level of the system will have implications for other levels of the system (Bronfenbrenner, 1979). For example, in relation to hepatitis C, the fear of discrimination may have an effect on the working environment. While some current research has hinted at the potential applicability of an ecological approach to understanding the personal and social impacts of hepatitis C, no such study has attempted to apply a systems framework to understand these impacts.

4. Overview and Future Directions

It is clear that hepatitis C has become a widespread virus of epidemic proportions within the Australian community. Given the current prevalence and incidence rates, it is probable that a significantly high number of people will be living with chronic liver disease, and the associated consequences, in the very near future (Orr & Leeder, 1998). There is currently no vaccine, or cure, and treatment is not successful in many cases, so HCV is for most people a life long condition with long term effects. As a result, attention needs to be given to the seriousness of this public health issue, and the level of awareness and understanding surrounding the impacts of hepatitis C needs to be increased.

In comparison to the amount of research on the epidemiology, prevention and treatment of hepatitis C, relatively few studies have documented the extent to which a positive diagnosis impacts on various aspects of a person's life (Garrett & Conrad, 2001; Burrows & Bassett, 1996; Crofts, Louie & Loff, 1997). Quantitative studies have utilised both generic and hepatitis specific assessment tools to measure the concept of health related quality of life. Generally results have indicated that HCV can lead to a significant decline across all areas, particularly within the physical domain. However, quantitative quality of life research is limited in the amount of detail that can be provided about the nature of the impacts and how the person is affected. The further development of hepatitis specific assessment tools and the increased use among people with HCV, is needed to improve the efficacy of these instruments.

In reviewing the qualitative literature, a more detailed picture of personal experiences has emerged. There appears to be a wide range of impacts for people living with hepatitis C, ranging from physical symptoms such as fatigue, to the experience of stigma and discrimination. The findings from these studies not only indicate significant personal impacts for the individual, but social impacts as well, however more research needs to be conducted. In order to provide adequate care and support for people living

with hepatitis C, it has been recommended that further knowledge is needed in order to understand the impacts of a hepatitis C diagnosis, and how they affect quality of life (DHAC, 2000). Research is needed to explore how hepatitis C impacts on the physical, psychological, social and cultural environments of an individual, and how these different spheres can impact on the experience of hepatitis C.

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Aims and Scope

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The *Journal* will publish quality research and debate in health psychology, and is committed to a breadth of outlook that:

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Running Head: IMPACTS OF HEPATITIS C

The Physical, Psychological and Social Impacts of Hepatitis C and the Effect on Quality
of Life

Narelle Cockman

Edith Cowan University

Abstract

Hepatitis C (HCV) has become one of the most widespread blood borne viruses in many Westernised countries and a positive diagnosis can significantly impact on various aspects of a person's life. Using a systems perspective, the present study aimed to explore the physical, psychological and social impacts of HCV on 12 participants who were living with the virus in Perth, Western Australia. Qualitative semi-structured interviews were conducted, and content analysis revealed six main themes: *finding out; being infectious; disclosure; stigma; symptoms; dealing with it*. A comprehensive systems framework is used to understand and explain the impacts of HCV and how these affected participants' quality of life. The findings have implications for providers of health care, helping services, the general community and makers of government policy.

Keywords: Hepatitis C, qualitative research, impacts, systems framework, discrimination

The physical, psychological and social impacts of hepatitis C and the effect on quality of life

In the past decade, hepatitis C (HCV) has become one of the most widespread blood-borne viruses, creating a major public health issue in Australia (Department of Health and Aged Care (DHAC), 2000). It is estimated that over 200,000 people have been infected with hepatitis C and up to 11,000 new infections are reported each year (DHAC, 2000). Hepatitis C affects the liver and is transmitted via blood to blood contact, with the large majority of infections resulting from the sharing of injecting drug equipment (Hepatitis C Council of WA (HCCWA), 1998). Other modes of transmission include unsafe tattooing, body piercing or receiving blood transfusions prior to the screening of supplies in 1990 (HCCWA, 1998). Approximately 80-85% of people who contract the hepatitis C virus become chronically infected and may experience various ranges of liver damage, possibly leading to cirrhosis, liver cancer or liver failure (Dore, 2000; Lin, Barker & Batey, 1999). As there is no vaccine available for hepatitis C and treatment is not successful in a significant number of cases (Standing Committee on Social Issues (SCSI), 1998; Sievert & Korevaar, 1999), for many people hepatitis C is a life long condition with long-term effects (Lowe & Cotton, 1999; SCSI, 1998; Loveday, Deakin & Neophyton, 1999).

There has been a large amount of research on the epidemiology (Dolan, 2000; Dore, 2000), prevention (Wodak & Crofts, 1996) and treatment (Sievert & Korevaar, 1999) of hepatitis C, however the importance of examining the personal and social impacts of HCV infection and subsequent effects on quality of life, has only recently been acknowledged (ANCARD, 1999, Garrett & Conrad, 2001; Burrows & Bassett, 1996; Crofts, Louie & Loff, 1997). Quantitative research has utilised both generic and disease specific questionnaires to measure health related quality of life (HRQOL) among people living with hepatitis C. Generally it has been suggested that the hepatitis C virus is associated with a significant decline in quality of life, with the greatest

deficits appearing to be physical in nature (Bonkovsky & Woolley, 1999; Bayliss et al, 1998; Foster, Goldin & Thomas, 1998).

While it is widely acknowledged that physical symptoms undeniably affect quality of life, a number of qualitative studies have suggested that other issues such as disclosure, family and relationship impacts also appear to be serious concerns for people living with hepatitis C (Burrows & Bassett, 1996; Garrett & Conrad, 2001; Crofts, Louie & Loff, 1997). In addition, there has been a growing body of literature which indicates that discrimination and stigmatisation are frequently experienced by people with the virus, largely as a result of negative attitudes towards injecting drug users (Ward, Coleborne & Fort, 2000; SCSi, 1998; Burrows & Bassett, 1996). Crofts, Louie and Loff (1997) interviewed a number of people with HCV about their experiences of discrimination and found that the range of settings in which hepatitis C discrimination occurred was extensive, with a large proportion of incidents taking place in health care settings.

Hepatitis C has been commonly viewed in the literature as a medical or physical problem which primarily impacts on the individual. However, a recent change in thinking has led some researchers to view the experiences of hepatitis C in a wider context, with impacts being influenced by social, cultural and political factors (Glacken, Kernohan & Coates, 2001; Hepworth & Krug, 1999). These researchers argue that a positive hepatitis C diagnosis accompanies a range of impacts to which people have to adapt, and these changes are not only derived from the psychological reactions of having a chronic illness, but also from the social and cultural relationships in which the individual is embedded (Hepworth & Krug, 1999).

This viewpoint is consistent with Bronfenbrenner's (1979) systems theory, which argues that an individual exists in, and is influenced by a series of interconnecting systems, within their environment. Bronfenbrenner's theory has long been associated with human development, however a similar framework could be

applied to the experience of chronic illnesses (Strauss et al., 1984). For example, some aspects of hepatitis C such as symptoms of fatigue and depression (Burrows & Bassett, 1996; SCSI, 1998), affect the person at an individual level, which Bronfenbrenner describes as the microsystem. Impacts at a social level, including negative impacts on work, family and relationships (Burrows & Bassett, 1996; SCSI, 1998) and inadequate pre-test and post-test counselling (Crossen et al., 1999) could be described as the mesosystem (Bronfenbrenner, 1979). Negative community attitudes and social policy are aspects of an even broader environmental context that Bronfenbrenner calls the exosystem.

A systems or socio-cultural approach also suggests that changes at an individual, social or cultural level, will ultimately have implications for other levels of the system (Bronfenbrenner, 1979). For example, in relation to hepatitis C, physical impacts such as fatigue (individual) may have an effect on the working environment (social). While some current research has hinted at the potential applicability of an ecological approach to understanding the personal and social impacts of hepatitis C, no study has attempted to apply a systems framework to understand these impacts.

Furthermore, in order to provide adequate care and support for people living with HCV, it has been recommended that further knowledge is needed to understand the impacts of a positive diagnosis (DHAC, 2000). Using a systems perspective, this study sought to examine the experiences of people living with HCV and explores the physical, psychological and social impacts of the virus. In addition, the present study aimed to develop a framework in which the impacts of HCV could be clearly understood, and how these aspects affect quality of life for people living with the virus.

Method

Design

A qualitative approach, using semi-structured interviews, was adopted for the present study in order to understand the experiences of people who were living with hepatitis C. It is argued that qualitative inquiry is better suited to develop an understanding of meaning while allowing a free and open forum to expose regularities and reveal insights to human experiences (Miles & Huberman, 1994). While quantitative research focusing on hepatitis C has indicated that people living with the virus experience a reduction in quality of life, it does not explain what the specific impacts are or how they affect quality of life (Koff, 1999). Qualitative research is valuable as it allows an in depth exploration of the personal and social impacts of hepatitis C and can reveal details that quantitative inquiry may miss.

Participants

The aim of this study was to explore people's experiences of hepatitis C, therefore it was essential that participants had the required knowledge and understanding of these experiences. It was decided that purposeful, maximum variety sampling would be used to select participants who were positively diagnosed and living with hepatitis C. Purposeful selection allows the sample to be information rich (Patton, 1990), while selecting participants from a large variety of backgrounds will increase the transferability of the findings (Nagy & Viney, 1994). The participants were recruited through the Hepatitis C Council of Western Australia, the Haemophilia Foundation of Western Australia, and from the general community.

Twelve participants took part in this study, 6 males and 6 females. All participants lived in the capital city of Perth metropolitan area, and had been positively diagnosed with the hepatitis C virus. Participant's ages ranged from 23 to 61 years, and despite the fact that no age limits were placed on the sample, 10 out of 12 were middle aged (37-51 years). Four participants were single, six were either married, had partners

or were in a defacto relationship, and two of the participants were widowed. Seven participants believed they contracted hepatitis C through injecting drug use, four believed they contracted the virus through blood transfusions or blood products and one participant did not say.

Materials

The materials for this study included a semi-structured interview schedule (Appendix A) and an audio tape recorder. The semi-structured interview schedule was chosen as a number of advantages using this method of interviewing have been reported. For example, the semi-structured format facilitates empathy and rapport with the participants, allows for greater flexibility during the interview process and tends to produce richer data (Smith, 1995).

The interview schedule included 13 open ended questions that were designed to elicit discussion about the impacts of hepatitis C at a personal, social and cultural level. The development of these questions was guided by concepts from the literature and were also examined by a professional who had extensive experience and knowledge in the area of hepatitis C, in order to assess whether the questions were appropriate and adequate. Questions focusing on personal impacts included 'What symptoms, if any, have you experienced as a result of hepatitis C?' and 'How do you cope with these symptoms?' Examples of questions that related to social impacts, focused on sources of support and interpersonal relationships, such as 'What or who are your sources of support?' and 'How do you think hepatitis C has impacted on you socially?' Questions designed to explore impacts at a cultural level focused on the time of diagnosis and aspects of discrimination, for example 'Tell me about your experience of learning that you have hepatitis C'.

Procedure

With permission of the Hepatitis C Council of WA, advertised invitations (Appendix D) to participate in the study were placed in newsletters and were distributed

at support groups and public meetings. Advertisements were also placed at the Haemophilia Foundation of WA and in two local community newspapers. People who wished to participate were able to call the researcher on the given phone number. Once contact was made with the participant, a convenient time was set up to conduct the interviews. Most interviews were conducted at the Hepatitis C Council of WA, however this was not possible for some participants and in those cases the interviews were conducted in the participant's home.

Prior to the commencement of each interview, the participant was given an information letter (Appendix B), which outlined the nature of the study, what they were required to do, confidentiality, voluntary participation and the freedom to withdraw at any time. After the opportunity to ask questions or discuss any concerns, informed consent was obtained (Appendix C) and the interview was conducted and tape recorded. The interviews took between 25 and 60 minutes to complete and were conversational in nature. Given the possibility of participants experiencing negative emotions or distress as a result of sharing personal experiences, referrals to the Hepatitis C Council Information and Support Line and 24 hour support lines such as Crisis Care, were made available to all participants. At the completion of the interviews, the audio tapes were transcribed, coded and analysed by the researcher.

Data Analysis

The data was analysed using a method that focused on analysing qualitative data from semi-structured interviews (Smith, 1995). This process involved carrying out a number of steps for each transcript, in order to understand the content and complexity of meanings and experiences from the participants' point of view. Each transcript was read through a number of times and key words, concepts, interesting points and summaries were recorded to provide a general feel of each participant's experience of living with HCV. Using these notes, a list of themes was then generated for each transcript. A question ordered matrix was also used to display key responses to each

question, with rows representing each participant and columns representing the interview questions (Miles & Huberman, 1994). Through using these methods, similarities and connections between participants were identified, and recurring issues were organised into a list of master themes and sub-themes that represented the experiences of participants. The original data was then re-examined and coded for actual instances of the main themes.

Credibility is described as the extent to which the findings represent the actual values, feelings and beliefs of the participant and is similar to the concept of internal validity (Nagy & Viney, 1994). In order to maintain credibility, emerging themes were checked against the raw data throughout the analysis process and interpretations were checked with a number of participants. Reliability was maintained by establishing an audit trail, which documented details of how the data was analysed, including methods of data reduction and verification of conclusions (Morse, 1994).

Findings

The above method of analysis revealed six main themes, which best illustrated the experiences of living with hepatitis C and the various impacts associated with the virus. The main themes were Finding Out, Being 'Infectious', Disclosure, Stigma, Symptoms and Dealing With It. Each of these themes included a number of sub-themes and will be discussed below.

Finding Out

The first main theme related to participants' experiences of 'Finding Out' about their positive HCV diagnosis, and was important because this was the time when the first impacts of the virus were felt for many people. When asked to tell their story about how they found out, participants described the way they were told, the information they were told and how they reacted (Table 1).

Most participants were informed that they were HCV positive from doctors or via blood banks, after they had donated blood. One participant was informed through

the mail. None of the participants knew much about hepatitis C at the time of their diagnosis and for most it was totally unexpected, suggesting that no pre-test counselling had occurred. It also seemed evident that in most cases, adequate post-test counselling was not performed. Participants explained that they either received no information about HCV whatsoever, very limited information such as 'don't drink alcohol or eat fatty food', or wrong information such as 'don't have sex', 'don't touch food with out gloves' or 'if you don't have treatment you will get cancer and die'. This led to unnecessary stress and anxiety, as people had no idea what HCV was or what it was going to do to them. Only one participant out of twelve felt they received adequate information at the time of diagnosis.

Participants' reactions to a positive diagnosis were divided into three types. There were those who viewed a HCV diagnosis as being 'no big deal' or did not see it as being an important part of their life at the time. This appeared to be a common reaction for injecting drug users who at the time had many other stressors in their lives and did not view HCV as a priority. Some people reacted to HCV with the relief that it was not HIV, and viewed HCV as 'the lesser of the two evils'. Others felt 'freaked out', 'shocked', 'stunned', 'devastated', 'frightened' and 'angry' and in some cases suicidal, often as a result of receiving limited or wrong information. In addition, some participants were under the impression that HCV was a fatal disease and that they were going to die, which created significant amounts of stress and anxiety for the individual and their families.

Table 1

Responses Relating to Finding Out

Way They Were Told	"...he said (<i>the doctor</i>) well look, we might as well test you for hep C...and then I got a letter in the mail saying I was hep C positive...that was it, that was it" (P11)
Information Told	"I was told nothing except that it was a possibly fatal disease...and he was disapproving and um no information what so ever actually" (P7)
Reaction to Diagnosis	"It just freaked me out basically that I'd got it and there was no cure and I'd have to have treatment...um...and it just totally stunned me yeah."(P1)

Being 'Infectious'

A positive diagnosis of hepatitis C immediately impacted on participants in that they were suddenly aware that they had a transmissible virus and were able to 'infect' other people. 'Being 'infectious'' and the associated implications, was another theme that reflected participants' experiences of hepatitis C (Table 2). One of the biggest concerns for participants was the fear of transmitting the virus to somebody else and the constant worry of people coming into contact with their 'infectious blood'.

The fear of transmission impacted considerably on many aspects of the participants' lives. Some people left their place of employment because they were afraid they were placing people at risk by staying at the workplace. Others reported that it had affected the relationship with their past or current partners by causing strain and tension, particularly when they cut themselves or when having sex. The fear of transmitting HCV to family members and particularly children resulted in a significant amount of stress and people described becoming extremely vigilant in keeping things clean and hygienic. In some cases, participants felt that they shouldn't go and visit family members with children because they didn't want to infect them. Being pregnant and transmitting to future children were also huge concerns for a number of both male

and female participants, even though they were aware of the relatively low risk associated with mother to child, or household transmission.

Another impact associated with being 'infectious', was participants' sudden awareness of being different to everyone else because they had 'bad blood'. This seemed particularly relevant for those people who were regular blood donors and found out via the blood banks. A diagnosis of HCV immediately meant that they could no longer donate blood, which led to feelings of exclusion or unworthiness. It was also reported that the simple event of cutting a finger, or the presence of even a minute amount of blood served as a reminder that they had this infectious virus and therefore were different to others. Some participants described feeling 'dirty and degraded' because they had this 'yucky type of virus' and in some cases felt isolated or like they were the 'odd one out'.

Table 2

Responses Relating To Being 'Infectious'

Fear of Transmission	<p>"It's affected me and my partner on so many levels, it's stolen my sex life, hepatitis C has stolen it, what can I say...it took it away and still now I'm trying to get it back together" (P9).</p> <p>"I think there's a two year period where you don't know if you've passed it on to your child... I hate to think that I've started a life off with that as well. (P10).</p> <p>"I'm a qualified butcher and I can't work as one any more... I just stopped working because I was rather concerned...I'm just very, very careful." (P13)</p>
Bad Blood	<p>"Oh the other thing that upset me was that for all these years my husband had gone and given blood every six months, and when they told me I had hep C they scrubbed him off the blood bank and said we no longer want you"(P12).</p>

Disclosure

One of the areas that appeared to impact greatly on participants was the third main theme of 'disclosure'. Participants' views on disclosure were basically divided into two categories, those who did not disclose their HCV status to certain people, and those who did. The reasons why participants did not disclose were mainly due to the fear of a negative reaction, whereas those who felt they should disclose did so in order to keep people safe and to warn others of the risk of transmission (Table 3).

The issue of deciding whether to disclose positive HCV status to someone was a significant source of stress and uncertainty for the majority of participants. There appeared to be a dilemma between telling someone due to the fear of transmission, and not telling them due to the possibility of negative consequences. This internal conflict was particularly highlighted in relation to telling current or future partners. While most participants felt that partners should know about their HCV status, disclosing posed the risk of rejection or some other negative reaction, which is closely linked to the stigma associated with hepatitis C. For some people, the fear of negative reactions had led to feelings of loneliness and isolation, as they were scared to get close to people.

In addition to choosing whether or not to disclose, another source of stress involved knowing when to tell, how to tell and what to tell, and there was a lot of worry and confusion surrounding this issue. When asked about their experiences of disclosure, participants described both positive and negative reactions from different people. For example, some people found that telling friends or family members resulted in greater levels of support, while others experienced the ending of friendships or relationships as a result of disclosure. In addition, for the people who contracted HCV through injecting, disclosure would often mean revealing a history of injecting drug use, which in turn brought out feelings of shame and fears of being judged or rejected.

One significant area of uncertainty and mixed feelings appeared to be whether or

not one should disclose to health professionals. While some participants felt it was their responsibility to inform doctors and dentists of their status, others felt that doctors, dentists and nursing staff should be protecting themselves anyway, and they shouldn't have to inform these people that they were HCV positive because of the stigma attached. Nevertheless, a number of participants were severely chastised and labelled as 'irresponsible' by certain health professionals because they had not revealed their status immediately, and therefore had 'put all the staff at risk'. One participant described the experience as:

"...the doctor talked to me like a piece of shit cos I didn't volunteer that I had the virus...they took my blood before I could tell them anyway and afterwards they came and asked me why I didn't tell them and how I got it and made me feel shit-house." (P1)

These experiences most commonly led to feelings of shame or anger and often increased already high levels of stress and anxiety for these participants.

Table 3
Responses Relating to Disclosure

Fear of Negative Reaction	<p>"If there wouldn't be the possibility of negative reactions then you'd feel pretty comfortable...but you know there would be negative reactions so you just keep it to yourself, you know?" (P5).</p> <p>"...she wants to know but I don't know whether to tell her, I think she would accept it but I'm not sure...I've worked on this relationship and I don't want to lose it." (P4)</p>
Keeping People Safe	<p>"I always felt that why shouldn't I tell somebody if there's a chance they could get it from me, why shouldn't I tell them?" (P12)</p> <p>"I do warn people, if I'm not asked directly and there is a concern for the other person, I'll always say 'yep I've got it' " (P13)</p>

Stigma

One of the most salient themes to emerge among participants was the stigma associated with HCV and the impacts that were experienced as a result (see Table 4). All participants had either directly encountered the effects of stigma via discriminatory actions, or were acutely aware and subject to negative community attitudes linked with HCV. The range of settings in which participants experienced discrimination was wide, including the workplace, police, dentists and the church. However for these participants, discrimination was most often experienced within health care settings. Some examples included a doctor announcing the participant's HCV status in front of the rest of the hospital ward, the use of different medical equipment and postponing medical surgery due to positive hepatitis C status.

Negative attitudes towards HCV were largely perceived as being related to the stigma associated with injecting drug users or the lack of education about the nature of HCV. Participants had experienced negative or judgemental attitudes from different people in the community, including family, friends and doctors, and described feelings of being 'looked down upon' or like 'everyone was judging' them. These negative attitudes were often associated with feelings of shame or low self-esteem, and in some cases led to the termination of friendships or reluctance in asking for health advice.

The stigma associated with injecting drug users was particularly emphasised when participants talked about the distinction between whether they contracted the virus through injecting or blood transfusions. Blood transfusions were viewed more favourably, which was related to the idea that contracting the virus was beyond the person's control, whereas a diagnosis of HCV through injecting was seen as being self-inflicted and was more likely to be linked to negative attitudes and stigma. However participants from both groups reported being subject to the stereotypes of hepatitis C being a 'junkie's disease' and 'all people with hepatitis C must be drug users'.

Participants also linked the stigma associated with HCV to the general

community's lack of education about the nature of the virus. This lack of knowledge led to unnecessary levels of fear about transmission, often as a result of seeing HIV and HCV as the same virus, therefore raising the same levels of fear and stigma. A number of participants thought that the key to reducing the level of HCV related stigma in the community was to increase awareness and education surrounding hepatitis C so there would be less fear.

Table 4

Responses Relating to Stigma

Experiences of Discrimination	<p>"...the thing I remember is being prodded and poked...a guy tried to unbutton my shirt with a pen because they didn't want to touch me" (P6).</p> <p>"Oh well, I mean he used to use a standard metal tray ... but for me he'd bring out the disposable tray so he could throw it away, that sort of thing" (P11).</p>
Stigma Related to Injecting	<p>"Well just that in hospital they told me you know you've got hep C and how did you get that...I just got treated like a junkie...in my case I'd rather keep quiet or say I got it through a blood transfusion, there's a stigma attached to it." (P1)</p>
Negative Community Attitudes	<p>"Just the way they look down their nose at you, maybe not what they say but the delivery of what they say is more than just blatant and obvious...you kind of squirm out and feel like scum" (P5).</p>
Lack of Education	<p>"Now if the public could have some knowledge about transmission, they'd be less scared of us, there'd be less stigma" (P6)</p> <p>"What worries me the most is the people who don't understand the true facts about hepatitis C" (P13)</p>

Symptoms

A number of impacts were highlighted within the theme of 'Symptoms', including the physical and psychological symptoms of HCV, treatment and the ambiguity of the virus (Table 5). Only three participants reported having significant physical impacts as a result of hepatitis C, with by far the most common symptom being excessive fatigue. The experience of fatigue led to a number of physical restrictions, which in turn impacted on relationships and the ability to work. For example the physical nature of one participant's job led to a slower work rate, which eventually resulted in the loss of that job.

A positive diagnosis of hepatitis C was also associated with a number of psychological impacts, particularly to do with self-concept. Some participants believed that living with HCV led to a more positive self-concept, by caring more about themselves and others. In some cases, contracting HCV gave participants a reason to move out of a lifestyle that they believed was no good for them. Others viewed themselves in a more negative light as a result of contracting HCV and reported feelings of guilt, anger and depression. It was interesting to note that for those who contracted HCV through injecting, having the virus was a constant reminder of their past and often accompanied feelings of shame, regret and self-blame.

Stress, depression and anxiety also seemed to be related to participants' increased awareness of mortality, which was also linked to the ambiguous nature of the virus. Many participants were unsure if the symptoms they experienced were due to hepatitis C or from something else. The uncertainty surrounding the progression of HCV also appeared to be a factor that increased levels of stress, reflected by concerns that it was not known how much time was left before the hepatitis C 'got worse'.

Four participants had been on anti-viral treatment and generally found that they experienced more physical and psychological side effects resulting from treatment, than from the virus itself. Side effects included nausea, fatigue, muscle aches, weight loss,

thinning hair, aggression and depression. All four participants described treatment as a negative experience with half of them having to cease treatment as the effects on their physical and psychological well being were too great. For the other two, although the side effects had a negative impact, treatment was seen as a form of hope that they could beat the virus. Treatment and the associated side effects also had huge implications for the participants' relationships, families and ability to work. Relationships had ended due to the significant strain that treatment had placed on them, and one person was no longer able to work, leading to financial implications.

Table 5
Responses Relating to Symptoms

Physical	"I've been totally drained...I would sleep a fair bit when I was working I'd just come home and go to bed and that was it...mainly I'm just physically stuffed" (P4)
Psychological	"Well it was just the stupidity of it, you know I was so careful and that one time I wasn't...fuck, every time I go to have a blood test I re-live that night...I don't know why I was so stupid" (P1)
Ambiguity of Virus	"I don't know whether next time I go for a liver test its going to be high and its going to affect me next year or it's not going to affect me at all' (P12)
Treatment	"Yeah the treatment is absolute agony, screws your head, stuffs up your relationships, but it gives you a light at the end of the tunnel..." (P4).

Dealing With It

A number of methods were used as a way of coping with living with hepatitis C and these were reflected within the theme of 'Dealing With It' (Table 6). Participants had adjusted to living with HCV by attempting to gain some control over the virus. This was achieved in a number of ways which included educating themselves about HCV by finding out as much information as possible, and making positive lifestyle

changes such as reducing alcohol intake and eating healthy foods. However, it was mentioned that not drinking alcohol immediately restricted participants' social lives and led to negative consequences such as feeling like an outcast.

Table 6
Responses Relating to Dealing With It

Gaining Control	"...we gathered up as much as we could (<i>info</i>)...so we learnt a lot about it that way and basically didn't panic as much" (P13)
Don't Think About It	"I probably don't think about it much any more...I just get on with life and enjoy it" (P12)
Support from Others	"...that's what the hepatitis group did for me, after the fourth week I felt like yeah, I'm a worthwhile person and I'm not alone.." (P4)
Part of a Journey	"Sometimes I just briefly sit and look at the experience and most times there is something there that I can learn from...it's helped uncover the true me" (P9)

Some participants did not really dwell on the fact that they had hepatitis C and saw it as 'no big deal.' Those people chose not to think about it and believed they should just get on with life and enjoy it. Support from others was seen as extremely important for some people and most support was given by family and friends. A number of people found the greatest support came from others who were also living with hepatitis C, whether it be people who were already in the participant's social circle, or through support groups. Finally, a number of people had developed a very positive view of hepatitis C and saw it as part of their life journey. Living with HCV was described as a learning experience, which had resulted in both personal and spiritual growth.

Discussion

The purpose of this study was to examine the experiences of people living with HCV and explore the physical, psychological and social impacts of the virus. The findings suggest that a positive HCV diagnosis results in a wide range of interrelated impacts which affect many aspects of an individual's life. Using a systems framework similar to that developed by Bronfenbrenner (1979), it appears that HCV impacts on the personal, social and cultural environments of an individual. In addition, the results suggest that external factors within different levels of the system, also impact on an individual's experience of living with HCV (Figure 1). These findings support and further strengthen the socio-cultural view of HCV reported by a number of researchers (Hepworth & Krug, 1999; Glacken et al, 2001).

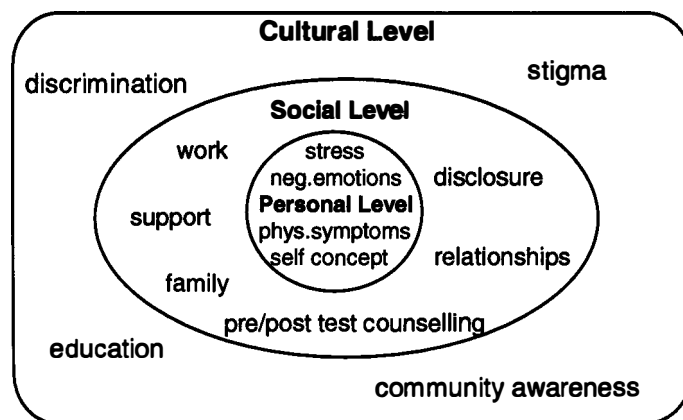


Figure 1. Participants' experiences of the physical, psychological and social impacts of HCV, using a systems perspective.

Most research to date has focused on the impact of HCV at what could be described as the personal level of the system, often reporting a significant decline in physical health or psychological well-being (Foster et al, 1998; Loveday, Deakin & Neophyton, 1999). Interestingly, the physical impacts of HCV were not of great concern for the people in this study, with the majority of participants not experiencing

any physical symptoms at all. This finding is noteworthy given that most information and research available on HCV focuses primarily on the physical symptoms of the virus. Furthermore, the majority of information or advice that was given to the participants at the time of diagnosis by doctors' or other health professionals was largely to do with the physical effects of HCV. Results from this study suggest that physical decline in health is not always an issue for people living with HCV.

In contrast, the greatest impacts at a personal level for participants in this study appear to be psychological effects such as high levels of stress, feelings of anxiety, and negative self concept. However, it is interesting to note that this impact on psychological health does not only result directly from aspects of the virus itself, but also appears to be significantly influenced by external factors from within the individual's social and cultural environment. For example, the progression of the HCV virus is very ambiguous and the uncertainty that is associated with this can lead to high levels of stress and anxiety. However, factors at a social level such as the information given when diagnosed, reactions from family and friends, concerns about disclosure and transmission were more likely to directly influence individuals' levels of stress, anxiety and self concept.

Research by Glacken et al (2001) suggests that a HCV diagnosis is not an isolated, personal experience that impacts only on the individual's physical and psychological health, but one that immediately affects the lives of family and friends. The findings from the present study further support this research as it indicates that a positive HCV diagnosis has a far greater impact at a social level. Not only did participants report immediate effects on family and children due to fear of transmission, but were also very concerned about how HCV had affected their relationships, workplace and how to disclose to other people.

External factors at a social level also appear to greatly influence an individual's experience of living with HCV and subsequent quality of life. It has been noted

previously that the reactions of family, partners, work colleagues and friends to a HCV diagnosis can significantly impact on the psychological health of the person with the virus. In addition, the level of support that an individual has in their social environment can positively impact on a person's experience of living with HCV.

Another factor within the social environment that significantly impacts on an individual's experience of living with HCV is the quality of pre and post test counselling given by doctors or other health professionals. Pre-test and post test counselling is designed to reduce the impact of a positive diagnosis by providing sufficient information about possible outcomes, educating the person on the risk of transmission and ensuring that there is adequate support available (McCoy, Watson & Kosky, 1999). Unfortunately, this study supports findings by others who have suggested that the numbers of people who actually receive this counselling are minimal (Crossen et al., 1999; Burrows & Bassett, 1996). It is clear in this study that a large amount of unnecessary stress and anxiety was directly influenced by a lack of information, lack of preparation and misinformation given before and after the diagnosis.

While a positive diagnosis of HCV does not appear to impact on an individual's cultural environment per se, results from this study clearly suggest that external factors within the cultural environment significantly impact on the experience of living with HCV. Discrimination and stigma associated with HCV appear to be over-arching cultural factors which have extensive negative social and psychological impacts for people living with the virus. Stigma within the community appears to negatively impact on the individual's social networks including family, relationships, friends, work and can be directly related to the issue of disclosure. This in turn can lead to social isolation due to the fear of discrimination, and a negative view of the self due to rejection and being subject to stereotypes. It also seems evident that most people with HCV are subject to the stereotype of being a 'junkie' or 'druggie', despite whether they

contracted it through injecting drug use or not, which suggests that there is a significant lack of community awareness and education surrounding the nature of HCV and how it is transmitted.

Perhaps one of the more surprising findings was the extent to which people are subject to discrimination and judgmental attitudes within health care settings, a finding that has also been reported by a number of other researchers (Crofts, Louie & Loff, 1997; Burrows & Bassett, 1996). One explanation for these negative attitudes by doctors and other health professionals could be a lack of training and education on HCV related issues. Nevertheless, this study further highlights previous findings which suggest that dealing with negative community attitudes and discrimination is often an everyday reality for people living with HCV (Ward, Coleborne & Fort, 2000).

The qualitative approach adopted in this study was the most appropriate method to seek understanding of personal experiences. It is acknowledged however that this method of inquiry results in some limitations of the study. The findings reported in this study reflect the experiences of the participants and cannot be generalised to every person who has hepatitis C. In addition, it is noted that analysis of qualitative data is somewhat subjective and reflects the author's interpretations of the participants' personal experiences. To further strengthen the findings of this study, future qualitative research is needed to explore the impacts of HCV, perhaps using a less structured interview schedule. Despite these limitations, the value of this qualitative research is significant as it provides a rich and detailed insight into the range of social and cultural impacts associated with hepatitis C, which other methods may fail to recognise (Miles & Huberman, 1994).

Interestingly, the wide range of personal, social and cultural impacts reported in the present study, create a number of implications for health and helping professionals, the general community and makers of government policy. Providers of health care and/or support to people with HCV need to shift their focus from a view in which the

virus primarily impacts on physical health and psychological well being, and begin to adopt a more holistic approach towards the ways that HCV impacts on a person's life. There needs to be awareness that people living with HCV may have other concerns other than those that are health related and need support regarding issues such as disclosure, relationships, having children, transmission and dealing with discrimination. In addition, doctors and other health professionals should be aware of standard pre-test and post-test counselling guidelines and need to adhere to them, given the negative consequences that are associated with the lack of information or misinformation at the time of diagnosis.

Furthermore, there are a number of serious implications for health professionals, as well as the general community, surrounding the significant amount of HCV related stigma and discrimination that is experienced by many people living with the virus. Discrimination within healthcare settings particularly needs to be addressed as health professionals are viewed as the people to go to for support and advice in regards to health issues. If people living with HCV are reluctant to go to doctors for help or advice out of fear of being judged, the likelihood of people accessing these professionals is reduced and individual health and well being can be seriously compromised. Increased training for doctors and education for the community on HCV issues would potentially raise general awareness, reduce the fear associated with transmission and help dispel the stereotypes that often fuel judgemental attitudes and discriminatory behaviours. At a wider community level, government policy makers need to monitor anti-discrimination laws and make sure that policies are well known and adhered to in the community.

Studies that examine the extent to which a positive HCV diagnosis impacts on various aspects of a person's life are relatively few and although important findings have been documented, there is still a great deal of scope for future research. An interesting next step from the present study would be to conduct a quantitative study

that assesses these results with a larger number of participants, to see if the findings could be generalised to a larger population. In addition, HCV related stigma and discrimination is clearly a significant issue for people living with the virus and ways to reduce judgemental attitudes and behaviour need to be addressed in future research. It would also be interesting to conduct a study that examines health professional's attitudes and knowledge towards HCV related issues, given the extent of discrimination in health care settings. Finally, future research could also begin to focus on the potential impacts that a positive HCV diagnosis has on family members, partners and children of people who are living with the virus.

In conclusion, it seems that a more holistic view of HCV needs to be adopted to provide adequate care and support for people living with the virus. It appears that the physical symptoms of the virus itself and potential decline in health are not necessarily perceived as the biggest impacts of HCV. In contrast, the most distressing impacts can arise from the psychological and social effects of living with a stigmatised, infectious illness and dealing with the subsequent attitudes and reactions within the immediate social environment and wider community.

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Appendix A

Interview Schedule

The following interview schedule can be used as a guide. The questions do not necessarily have to be asked in the presented order.

A : Background

1. To start with can you tell me your age, sex, and marital status.
2. When do you believe you contracted hepatitis C?
3. How do you believe you contracted hepatitis C?

B: Impacts at Individual Level

4. What symptoms, if any, have you experienced as a result of hepatitis C?

Prompt questions include

- Physical?
 - Psychological?
5. How do you cope with these symptoms?
 6. Is there anything that you find you could do before, that you can't do now?
 7. Has having hepatitis C made a difference to the way you see yourself as a person? If so, in what way?

C: Impacts at Social/Interpersonal Level

8. What or who are your sources of support
9. How does that help you?
10. How do you think that hepatitis C has impacted on your life socially?

Prompt questions include

- family?
- friends?
- work?
- relationships

D: Impacts at Cultural Level

11. Tell me about your experiences of learning that you have hepatitis C.

Prompt questions include

- How were you informed?
- What information did the doctor / health professional tell you?
- How did you feel / react?

12. Can you tell me about any other ways that hepatitis C has had an impact on your life?

- discrimination?

13. Is there any thing else you would like to share about your experience of living with hepatitis C?

Appendix B

Participant Information SheetInformation Sheet

My name is Narelle Cockman and I am a volunteer at the Hepatitis C Council of WA, as well as a fourth year university student at Edith Cowan University. I am currently conducting research with people who are living with hepatitis C and am particularly interested in the impacts that hepatitis C has on different aspects of a person's life. This research has been approved by the Edith Cowan School of Psychology Ethics Committee.

The research will involve taking part in a tape recorded interview with myself, to share your experiences of living with hepatitis C. No names will be recorded on the tapes. The interview should take approximately one hour of your time. The aim of this research is to identify personal and social impacts of hepatitis C and will hopefully lead to further knowledge, better understanding and support for people living with hepatitis C.

I understand that some issues will be potentially sensitive for some people so please be assured that any information that you share during the interview will be held in the strictest confidence. An independent person will be helping out with the transcribing of the interviews, however your name will not be on these tapes. Responses and quotes may be used as part of a thesis but at no time will your name be reported. At the conclusion of this research, a report on the findings will be available upon request.

Your participation in this research is totally voluntary. You are not obliged to answer any particular question and may withdraw from the research at any time, without consequences. Referral to the Hepatitis C Information and Support Line and Crisis Care is also available at any time.

Please keep this information letter for your reference. If you have any questions or concerns about this research, you can contact myself (Narelle Cockman) on 0418 918 028, or my supervisor Lis Pike at the School of Psychology on 9400 5535.

Appendix C

Participant Consent Form

Informed Consent

I (the participant) have read and understand the information sheet and any questions I asked were answered to my satisfaction. I agree to voluntarily participate in this research and realise that I may withdraw at any time. I also understand that the findings will be reported and I will in no way be identifiable.

Participant _____ Date _____

Researcher _____ Date _____

Impacts of Hepatitis C

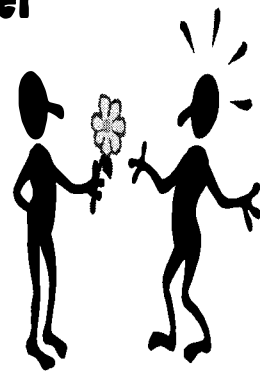
How Has Hepatitis C Impacted On Your Life ?

Stress?

Fatigue?

Relationships?

Discrimination?



I am a volunteer at the Hepatitis C Council of WA and a fourth year university student. I am very interested in hearing about your experiences of hepatitis C for my research. If you are interested in sharing your experiences with me in a confidential tape recorded interview, I would love to hear from you!!!

Please contact me, Narelle Cockman on 9378 9281.