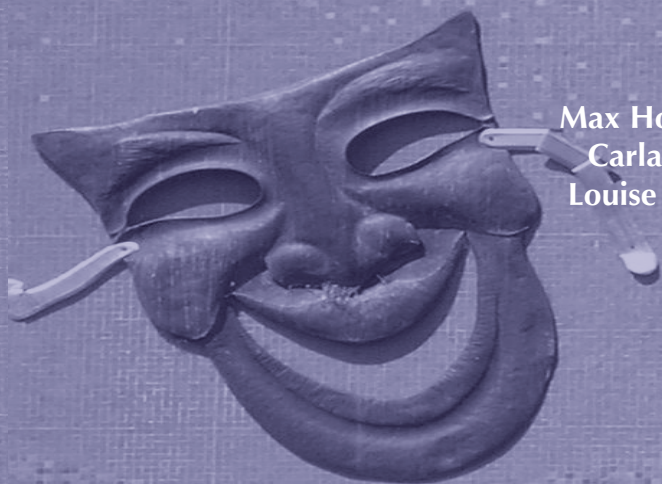


MONOGRAPH 4/2006

Experiences of hepatitis C treatment and its management

What some patients and health professionals say



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Louise Redsull

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Executive summary

Background

Since the hepatitis C virus was identified in 1989, increasingly more-effective drug therapies have been developed to treat infection with the virus. Today, treatment usually combines pegylated interferon and ribavirin in a regimen lasting for either 24 or 48 weeks depending on factors such as viral genotype. The aim of treatment is to eradicate infection that causes liver inflammation and damage, which over several decades can result in cirrhosis and liver cancer. Treatment for hepatitis C infection is considered successful if patients attain a sustained virological response (SVR), that is, if the virus remains undetectable in a patient's blood for a period of six months after treatment is over. However, current interferon-based treatments for hepatitis C are associated with significant reductions in health-related quality of life caused by side effects from the therapeutic drugs. While treatment is typically administered by a multidisciplinary team of highly skilled clinicians and allied health professionals in a hospital liver clinic, significant proportions of patients have difficulty adhering to treatment and therefore discontinue therapy.

Method

A qualitative study of both hepatitis C treatment experiences and the management of hepatitis C treatment, using in-depth semi-structured interviews, was conducted in Sydney, Australia, during 2004 and 2005. The study aimed to uncover some of the strategies that people in treatment deployed to cope with the side effects associated with treatment. A purposive sampling frame was used to recruit participants to the study. A total of 20 people who either were receiving treatment or had completed treatment within the six months prior to interview were recruited. Six health professionals who managed treatment regimens were also interviewed. Treatment

and its side effects were explored from the perspectives of both patients and clinic staff. The impact of treatment on personal relationships, work, socialising, physical and emotional health and well-being, sense of self and future outlook were investigated. Thematic content analysis highlighted key issues reported by patients and health professionals regarding treatment experiences and approaches to treatment management.

Findings

1 Side effects and coping strategies

Participants reported a wide array of physical and psychiatric side effects related to hepatitis C treatment. While many people shared common side effects, treatment was characterised as an individual experience that affected participants in diverse ways. Participants reported having difficulty separating psychiatric side effects from the negative impact on mood brought about by having to cope with chronic physical impacts related to treatment. Participants also discussed the cumulative impact of treatment, which included fatigue, insomnia, irritability, depression and cognitive impairment. Commonly accessible medications often helped to address many of the physical side effects. However, participants reported that treatment-related impacts on mood were difficult to predict, contributed to a substantial reduction in quality of life and were challenging to manage clinically. Nonetheless, participants incorporated into their treatment regime a range of medical interventions and personal coping strategies—including planning and preparation, garnering support, anger- and stress-reduction techniques, work, rest and relaxation, and adopting a healthy lifestyle and positive attitude—to reduce the severity of side effects in order to adhere to treatment.

2 Support during hepatitis C treatment

A central theme of the findings about participants' support networks during treatment were the issues of stigma and fear of discrimination. Participants discussed their concerns about garnering support: who could they trust with the information that they were being treated for hepatitis C in order to gain support? This could be especially problematic for those who continued to work.

Participants who had disclosed to partners and family generally reported having received high levels of support, but the mere act of telling loved ones about treatment did not ensure satisfactory and appropriate care at home. Changes in mood as a result of treatment interrupted family dynamics and strained relationships within normally well-functioning family units. For example, treatment at times negatively affected parents' relationships with their children. Family members had to adjust to the circumstances that arose from the impact of treatment.

Support groups also reportedly assisted people during treatment. Health professionals identified a need for such support groups and established peer-based models which allowed patients to share with others their treatment experiences and strategies for coping. These groups helped to reduce some patients' isolation, imparted a sense of connectedness, were forums for the exchange of information and ideas, and assisted those considering treatment to make final decisions.

3 Disclosure of being in treatment, and hepatitis-C-related discrimination

Disclosing that one is having treatment for hepatitis C can lead to discrimination because of the association of hepatitis C transmission with injecting drug use. When people disclose that they are in treatment for this stigmatised infection they manage it in multiple ways in order to facilitate treatment uptake, garner support and avoid discrimination. Analysis of the interview data uncovered four approaches to disclosure adopted by participants. These included: (i) non-disclosure, where participants told no one they were receiving treatment; (ii) strategic disclosure, where they told only carefully selected individuals to maximise levels of support while reducing the likelihood of experiencing discrimination; (iii) substitute disclosure, where they used a euphemism like 'treatment for liver disease' to explain hepatitis C treatment; and (iv) open disclosure, where they told anyone and everyone about being in treatment. Individual attitudes to stigma and discrimination determined how participants went about disclosure. These findings are relevant to general practitioners advising newly diagnosed patients, to health professionals responsible for initiating

and managing hepatitis C treatment regimens, to people considering treatment for hepatitis C infection and to educators developing information resources. Recognition of a diversity of approaches to disclosing hepatitis C treatment can help health professionals to provide appropriate advice to their patients.

4 Unrealistic optimism

A phenomenon that affects both patients' preparation for hepatitis C treatment and their ability to cope with it is a psychological construct referred to as 'unrealistic optimism'. This describes people's tendency to believe that they are less likely than others to experience adverse outcomes. In the context of hepatitis C treatment, unrealistic optimism becomes problematic when people believe they are unlikely to experience adverse outcomes from the side effects of treatment and do not adequately prepare themselves. Or, similarly, they believe they have protected themselves sufficiently from side effects and then ignore evidence to the contrary. Unrealistic optimism was evident in the interview transcripts of patients. Health professionals also acknowledged that their patients were at times overly optimistic. For example, participants reported that because they had not experienced mental health problems in the past, they would be unlikely to experience psychiatric side effects during hepatitis C treatment. Health professionals spontaneously raised the issue of unrealistic optimism as a phenomenon that needed to be addressed during pre-treatment counselling.

5 Resilient coping

This chapter explores the connection between marginalisation, 'resilient coping' and hepatitis C treatment. 'Resilient coping' is defined as the ability of people from normal circumstances to maintain relatively stable and healthy levels of psychological and physical functioning when confronted with a highly disruptive and potentially traumatising situation or change in circumstances (Bonanno, 2004). An emerging body of evidence indicates that even under circumstances of considerable social disadvantage people can develop adaptive coping strategies that enable them to withstand subsequent adversity. People who are receiving hepatitis C treatment are often from marginalised and socially disadvantaged backgrounds, and side effects of treatment are acknowledged to have a detrimental impact on quality of life. Participants in this study reported having coped with the side effects of treatment by adopting coping strategies learnt during past experiences of drug dependence, living with symptoms of chronic illness, poverty, coping with childhood sexual abuse and managing depression. The data suggest that protective factors and processes that allow people to cope with

the adversity associated with marginalisation and social disadvantage can assist them to cope with the side effects of hepatitis C treatment. Promoting clinical interventions that foster resilience among people receiving hepatitis C treatment might be beneficial in helping patients to stay on treatment until it is completed.

6 Strengths-based assessment in the management of treatment

Many patients receiving hepatitis C treatment have their dose reduced or discontinue treatment because of adverse side effects. However, there is no published literature that explores how health professionals prepare patients for hepatitis C treatment and only a small amount regarding the management of adverse events as a result of treatment. This chapter reports our findings on the management of treatment, with a particular focus

on how people were prepared for it. Study participants reported that they were given information about side effects and the medical strategies that could lessen the impact of these side effects. Health professionals assessed patients' vulnerabilities and support networks prior to treatment, and adopted a problem-focused approach to the management of treatment; that is, they addressed patients' crises as they arose. Health professionals discussed in interviews patients' resilient coping and the advantages of applying strategies learnt from past hardship to help them to complete treatment. We discuss the value of 'strengths-based' assessment during preparation for treatment. Further research should investigate the contribution that assessing patients' strengths can have on reducing the impact of side effects and treatment adherence. If more people can avoid reducing their doses of medication or discontinuing treatment, more will successfully clear their hepatitis C infection.

Introduction

This report is from a study into the treatment experiences of people with hepatitis C virus infection and the experiences of the health professionals who treated them. The idea for the study emerged from earlier work by the National Centre in HIV Social Research in which participants highlighted a variety of complex concerns regarding treatment. Many of those concerns are explored in this report, although other psychosocial aspects of the experience of hepatitis C treatment still require further investigation.

The hepatitis C treatments literature continues to be skewed towards basic sciences and the reporting of clinical randomised control trials. The search for better and more comprehensive treatments is undoubtedly a priority, yet in this body of clinical research there is often little acknowledgment of the lives behind the quest for an effective cure. Patients' quality of life during treatment is often a determining factor in treatment outcomes. The contribution that social research can make to clinical outcomes, particularly in

relation to improving patients' adherence to treatment, is often overlooked.

This is a qualitative study. It does not describe, for example, the proportion of people reporting 'x' or 'y' side effect during treatment. Instead the authors aimed to explore beneath the surface of therapeutic dosing and measured response to document some of the myriad treatment-related issues that patients experience. We would argue that these issues cannot be understood by using quantitative methods.

The authors hope that the findings presented in this report—and the questions they raise—will be of interest to those considering treatment, those who have commenced treatment, and clinicians and other health professionals seeking a perspective on treatment that is non-medical but complementary to medicine. We believe that our findings can make a significant contribution to improving the efficacy of treatment for hepatitis C by providing evidence that can be used to improve patients' adherence to an often long and difficult regimen.

Background

Since the identification of the hepatitis C virus in 1989, progressively more-effective treatments for the infection have been developed. Early attempts to eradicate hepatitis C deployed the antiviral agent interferon and for many years this was the standard treatment. Interferon monotherapy was at best effective in about 20% of people treated for 48 weeks (Sievert, 2001). By the late 1990s interferon was used in clinical trials with an antiviral agent called ribavirin. A combination of interferon and ribavirin was significantly more successful in eradicating the hepatitis C virus than interferon monotherapy, with around 40% of people achieving a sustained clearance of the infection (Lai, 2000).

[S]tudies indicate significant impairment in physical and mental functioning during interferon-based treatments ... due to physical and psychiatric side effects.

The aim of treatment is to decrease or prevent the chance that infection will result in progressive liver damage which can lead to cirrhosis, liver failure or liver cancer (Sievert, 2001). Elimination of the virus, or a 'cure', is defined as having attained a sustained virological response (SVR). An SVR is said to have been achieved when a polymerase chain reaction (PCR) blood test, able to detect the amount of virus in the blood, shows that hepatitis C has remained undetectable for a period of six months after treatment has ended (Sievert, 2001). In clinical trials, elimination of the virus (i.e. attaining an SVR) correlates with reports of improved health and well-being (e.g. McHutchison et al., 2001). However, the probability of attaining an SVR depends on a range of factors, including the genotype of hepatitis C virus with which the patient is infected, the extent of liver damage and the patient's age.

Current treatment for hepatitis C infection usually combines the antiviral agents pegylated interferon and ribavirin

(Manns et al., 2001; Rasenack et al., 2003). In the case of some hepatitis C virus genotypes, this combination therapy has almost doubled previous average cure rates during clinical trials (Michielsen et al., 2002). Pegylation is a process whereby interferon molecules are 'coated' in order to slow their absorption into the bloodstream, making the drug work more effectively because it is active in the body for a longer period. Dosing is reduced from three doses of standard interferon to one subcutaneous injection of pegylated interferon a week. People receive treatment with pegylated interferon and ribavirin for at least 24 weeks; to treat some genotypes of the virus, 48 weeks of treatment is required. More than 80% of people with hepatitis C genotypes 2 and 3 clear the virus, and around 50% of people with resistant Genotype 1 successfully eradicate the infection (Keating & Curran, 2003; Manns et al., 2001; Rasenack et al., 2003). This combination regimen is also effective in people considered difficult to treat (e.g. people co-infected with HIV and those with advanced fibrosis or cirrhosis) (Keating & Curran, 2003). Today in Australia, pegylated interferon and ribavirin combination therapy is the front-line defence in the treatment of hepatitis C and is included in the Pharmaceutical Benefits Scheme S100 prescriptions category, making it free of charge for affected people.

The experience of interferon-based treatment for hepatitis C infection

Past research into the experience of hepatitis C treatment has used quantitative measures of quality of life like the SF36 Health Survey and the Sickness Impact Profile (Dieperink et al., 2003). These studies indicate significant impairment in physical and mental functioning during interferon-based treatments (Fried, 2002) due to physical and psychiatric side effects (Cornberg et al., 2002; Fontana et al., 2002). The most commonly reported side effects of interferon include fatigue, headaches or migraine, nausea and

insomnia. Yet, the most often-cited reasons for patients' discontinuing interferon-based treatment are the psychiatric impacts, which include depression, anxiety, amotivation, anorexia and paranoia (Monji et al., 1998). With regard to side effects, studies suggest that standard interferon and pegylated interferon are similarly tolerated (Rasenack et al., 2003; Bernstein et al., 2002; Trejo Estrada, 2002; Perry & Jarvis, 2001, 2002). To place these impacts—often referred to as 'adverse events'—in perspective, less than 1% of people in treatment experience serious problems like loss of vision, loss of hearing, congestive heart failure, induction or exacerbation of autoimmune diseases, severe depression, suicidal thoughts and suicide, and panic attacks. However, over 30% of people receiving treatment experience depression, anorexia, weight loss, irritability, hair loss, joint pain, nausea and insomnia, and more than 50% experience fatigue, headache and muscle aches (Fried, 2002). Side effects usually disappear soon after treatment is stopped. However, they can adversely affect patients' adherence to treatment. In clinical trials, between 10% and 50% of patients on treatment reduce doses or discontinue treatment because side effects become dangerous or intolerable (e.g. Bernstein et al., 2002; Potgieter et al., 2005). For some patients, preventing the adverse effects of treatment becomes more important than trying to eradicate the virus.

There is a need for information that goes beyond observation of clinical markers to explore patients' narratives in order to address the physical, emotional and social side effects of hepatitis C treatment.

Because of the difficulties associated with therapy, the decision to commence treatment is often delayed, especially if a patient has no signs of significant liver damage, like cirrhosis, and if the symptoms of hepatitis C are not having a negative impact on their daily life (Sievert, 2001). Currently, about 1500 to 2000 people in Australia commence treatment for hepatitis C each year (Dore, 2003). Clinicians feel that, ideally, the expansion of treatment needs to proceed rapidly to curb a looming epidemic of expensive hepatitis-C-related liver disease over coming decades. Already in Australia and the US, for example, hepatitis C is the leading cause of liver transplants (Crofts, 2001). There are both barriers and incentives to the uptake of hepatitis C treatment. Previously, patients had to have a liver biopsy to be allowed access to subsidised treatment through the Pharmaceutical Benefits Scheme S100 prescriptions category. Following the removal of this criterion in April 2006 it is hoped that more people will seek treatment.

Contemplating treatment

People must juggle a range of issues when contemplating treatment. In a recent study, the issues that were important to people when deciding whether or not to commence treatment included the effectiveness of treatment, their relationship with a treating doctor/specialist, the health of their liver, access to a liver clinic and supportive medical services, potential side effects of treatment and having a supportive partner (McNally et al., 2004). People considering treatment must also take into account the possibility of being stigmatised and encountering discrimination, which can be outcomes of disclosing that they are having treatment for hepatitis C.

Pegylated interferon and ribavirin therapy for hepatitis C may be the means by which our health system can prevent large numbers of Australians from living and dying with chronic liver diseases. In the coming years more people are likely to be directed towards pegylated interferon and ribavirin therapy, given that dosing regimens have become less time-consuming, liver biopsy is no longer necessary, current injecting drug users can access treatment, those who have not previously responded to treatment can benefit from pegylated interferon combination therapy, and studies have shown that treating acute hepatitis C can prevent the onset of chronic hepatitis C infection (Santantonio et al., 2005).

From a clinical perspective, we need to develop strategies that help to keep people in treatment. Such strategies can be identified by applying qualitative research methods to a clinical treatment context. Currently, there are very few published findings of qualitative studies of people's experiences of hepatitis C treatment (Hopwood & Treloar, 2005). Nonetheless, we know from past work (e.g. Kleinman, 1988; Frank, 1995) that narratives of chronic illness have assisted many people to come to terms with disease, its treatment and associated life upheaval. Qualitative methods can uncover experiential aspects of hepatitis C treatment. Narratives can assist in developing treatment management strategies that would allow a health professional to know what effect measured increases in depression scores might have on, for example, a patient's capacity to remember important requirements like daily dosing and keeping medical appointments. There is a need for information that goes beyond observation of clinical markers to explore patients' narratives in order to address the physical, emotional and social side effects of hepatitis C treatment. Patients and health professionals might use such information to improve the management of side effects and adherence to treatment. The primary aim of this study is to contribute to the emergence of a critical and reflexive literature regarding quality of life for hepatitis C patients in treatment.

Method

A qualitative study of people receiving treatment for hepatitis C infection with the drugs interferon and ribavirin was conducted during 2004 and 2005. The study aimed to uncover some of the strategies that people in treatment used to cope with the side effects associated with interferon and ribavirin therapy. A purposive sampling frame was used to recruit participants to the study. An advertisement outlining the study was placed on an email list aimed at professionals working in hepatitis-C-related health service provision. Simultaneously, researchers contacted clinical nurse consultants (referred to hereafter as 'nurses') via a professional network. These nurses were able to recruit other nurses through their professional networks. In total, two health professionals from each of three liver clinics situated in three large metropolitan hospitals across inner-Sydney, Australia, agreed to recruit participants receiving treatment. All six health professionals were asked to inform their patients about the study and to request their participation. To be eligible for participation, patients had to have either been receiving hepatitis C treatment for a minimum of four weeks or completed treatment within the previous six months. This was so that participants could comment on the management of the regimen and the impacts of side effects on their quality of life.

Participation by those on treatment

Twenty people ($n = 20$) who were currently receiving or had recently completed hepatitis C treatment volunteered to take part in interviews. Table 1 contains the sample characteristics. Most participants had been in treatment for between eight and 48 weeks. Four participants had previously received treatment for hepatitis C; two had discontinued

previous treatment due to side effects and the remaining two had not responded to previous treatment. In an effort to 'humanise' the experience of receiving treatment, participants were each assigned a pseudonym and these names are used throughout the report when extracts from interviews are cited.

Currently, little is known about who accesses hepatitis C treatment in Australia (McNally et al., 2004). One study found that both former and current injecting drug users were less likely to report receiving treatment for hepatitis C than those who had never injected (Hopwood & Treloar, 2003). Due to an absence of further information it is not possible to compare this study sample with a national profile of people receiving hepatitis C treatment.

Table 1: Sample characteristics of people receiving treatment for hepatitis C (HCV) ($n = 20$)

| | |
|---------------------------------------|-----------------------------|
| Mean age (years) | 49 (range = 35–73 years) |
| Year of HCV-positive diagnosis (mode) | 1995 (range = 1975–2004) |
| Gender | <i>n</i> |
| Male | 13 |
| Female | 7 |
| Total | 20 |
| HCV genotype | <i>n</i> |
| 1 | 5 |
| 2 | 2 |
| 3 | 6 |
| 4 | 0 |
| 5 | 0 |
| 6 | 0 |
| Unsure | 7 |
| Total | 20 |
| Mode of acquisition of HCV | <i>n</i> |
| Injecting drug use | 8 |
| Medical | 6 |
| Unsure | 6 |
| Total | 20 |
| Length of treatment for HCV | <i>n</i> |
| 24 weeks | 11 |
| 48 weeks | 9 |
| Total | 20 |

Participation by health professionals

Six health professionals—five nurses and one social worker—were approached to give an interview and all agreed to participate. All had extensive experience in health service provision to patients infected with hepatitis C and HIV. They had a mix of postgraduate qualifications, undergraduate degrees and hospital training. The nurses had managed hepatitis C treatment regimens for between 5 and 14 years. The social worker had had 20 years' experience in counselling people with HIV and hepatitis C. All health professionals' experience of managing hepatitis C treatment had been in Australian treatment facilities. Finally, they expressed a professional interest in issues such as the health of marginalised populations, discrimination in health care and health promotion.

Recruitment and procedure

During a routine appointment with one of the health professionals, patients who were receiving treatment or who had recently completed treatment were handed an information sheet to inform them about the study and invite them to participate. The information sheet explained that the aim of the research was to learn about people's experiences of hepatitis C treatment and to uncover strategies that they used to cope with the side effects. It stressed that they were under no obligation to participate in the study and that refusal to do so would not affect their treatment, or their relationship with the clinic staff, the hospital or the university conducting the study. Those interested were invited to telephone the researchers to organise an interview, which would occur at a time following their regular (i.e. either weekly or monthly) medical appointment. Interviews with health professionals were scheduled to occur at the conclusion of their clinic shifts. Confidentiality and anonymity were assured, written consent was obtained and each interview was audiotaped. All interviews lasted between 30 and 60 minutes and were conducted in private consultation rooms in hospital liver clinics. Participants were offered no financial incentives.

Interview schedules

Two semi-structured interview schedules were used in this study. The first schedule enquired into participants' experiences of receiving hepatitis C treatment and sought information about their background and what it was like to live with hepatitis C infection. It also explored participants' knowledge and expectations of the regimen before beginning treatment, decisions to commence treatment, how clinicians prepared them for treatment, details of participants' experience of treatment so far, and details of any side effects. The impact of treatment and

side effects was explored in the context of close personal relationships, work performance, socialising, physical and emotional health and well-being, participants' sense of self, and future outlook. The interview investigated coping mechanisms and strategies that participants used to reduce the severity of side effects and to adhere to the regimen. Finally, it explored whether participants had disclosed that they were receiving treatment for hepatitis C and whether they had experienced stigma and discrimination as a result. It also requested participants' demographic details.

The second semi-structured interview schedule was designed for the nurses and social workers involved in administering hepatitis C treatment. The questions explored the procedures for interviewing and assessing patients before they began hepatitis C treatment, the clinicians' perspectives on side effects and clinical strategies to ameliorate them, and patients' coping strategies. Finally, the schedule explored issues of stigma and discrimination experienced as a result of having treatment for hepatitis C. The semi-structured format of both interview schedules enabled participants to elaborate on their answers to all questions.

Data analysis

The findings and extracts reported here are from thematic content analyses of interview data (Grbich, 1999). When conducting qualitative interviews, analysis begins at the time of data collection. Analysis thereafter followed four steps as described by Sarantakos (1993) and included (i) transcription, (ii) analysis of individual interviews, (iii) generalisation, and (iv) control. Following the transcription of audiotaped interviews, transcripts were checked for accuracy against the audiotapes and identifying information was removed. Following repeated and close reading of the information in the individual transcripts of interview, the authors independently constructed a code list of major themes that emerged from all data collected. Code lists were compared and a final list compiled. The interview transcripts were then independently coded by the researchers using the coding list. Researchers compared coding decisions and, when a divergence in researchers' coding was identified, revisited transcripts and discussed differences until a consensus was reached. The de-identified interview transcripts were then entered into qualitative software, NVivo 2.0 (Richards & Richards, 1999), and codes were applied to the text. A software program was used to search the data set and retrieve material under codes relevant to the research questions. In line with an inductive analytical approach used by Serovich and colleagues (2005), and following identification and pooling of the relevant themes from the text, coded passages were repeatedly read and compared until similarities and differences were distilled and categories could be developed, for example regarding

issues around disclosure of treatment, coping strategies, or support during treatment.

The study had ethics approval from the Human Research Ethics Committee of the University of New South Wales, three area health service human research ethics committees and one hospital research ethics committee. The main ethical considerations of the study pertained to

participants' fitness for interview. Because of the toxicity of interferon and the impact of interferon and ribavirin on physical well-being, interviews were restricted to a maximum of one hour, with most completed in 30 to 45 minutes. This time restriction minimised stress for the participants. Similarly, health professionals were interviewed at times convenient for them.

Findings

1 Side effects and coping strategies

In this chapter we report the findings on the physical and psychiatric side effects of treatment with pegylated interferon and ribavirin for hepatitis C infection, and the coping strategies that one group of people receiving this treatment adopted to enable them to adhere to the regimen. Participants described a range of physical and psychiatric side effects that impaired quality of life, and discussed various methods of coping.

We also report the findings from the interviews with health professionals about their experiences of how people coped with the treatment regimen.

Individual experiences of side effects

Participants reported unique experiences of treatment and described diverse combinations of side effects. Similarly, health professionals explained the

‘Come tomorrow, I’ll feel like a bus has hit me.’

difficulty of predicting the number and intensity of side effects an individual would experience. A nurse commented that some people required little support or intervention during treatment while others needed intensive monitoring and assistance in order to cope:

So there’s these few little groups that you almost feel guilty in getting them to come in on a monthly basis just to check on them, because you know they’ll come in, you’ll take their blood pressure, their bloods, have a five-minute chat, usually talk about a whole lot of other stuff other than treatment because they don’t have side effects. Then they go. So there’s that extreme, down to the group that are just totally knocked around by treatment.

(Nurse 1)

Hepatitis C treatment had an impact on participants’ emotional and physical well-being. Some participants reported having difficulty separating the psychiatric side effects of the treatment drugs from the negative mood brought on by debilitating physical side effects of treatment. Gerry, 48, described his difficulty in being able to distinguish the origin of his malaise:

There were only two drugs [that I received] and it’s really hard to decouple, you know. I mean, I’ve only tried the combo [pegylated interferon and ribavirin] and I can’t separate the direct psychological effect of the drugs from the fact that the physical side effects have a psychological effect.

(Gerry)

Other participants commented on the cumulative impact of side effects such as fatigue, insomnia and irritability. Gavin, 48, reported that the fatigue he experienced made it harder for him to deal with other effects of treatment. Fatigue prevented him from helping his partner with their business and interfered with his ability to maintain a positive outlook and to tolerate side effects:

If I had more energy I could deal with the headaches and, you know, I could do a few more things and feel better about myself in that regard.

(Gavin)

Participants described the cumulative impact of treatment in terms of ageing, and some believed that they had aged a number of years during treatment:

I spent more time thinking about ageing because that process, I feel, was accelerated during the treatment. I would think I probably aged two years in six months.

(Gerry)

Several participants reported that, as treatment progressed, they were able to predict when they would experience certain side effects and which would be their good and bad days. For instance, Marsden, 50, explained how his week was structured by the impact of side effects:

Come tomorrow, I'll feel like a bus has hit me. And Saturday I'll be pretty ordinary. Sunday I'll be sort of starting to come a little bit better—that's what I've found. Monday is OK and then Tuesday all right. Wednesday, Thursday—I've really only got the Tuesday, Wednesday, Thursday that are my good days in the week
(Marsden)

However, not all participants reported experiencing a predictable pattern of side effects. Helena, 49, who worked part-time, reported that her side effects were unpredictable, which made planning for work and social activities difficult:

I do have good days and then I'll go for about three or four days wiped out and then I can pick up and be really good. I can have a really good week and I can have a bad week and a half, or I can have a good week and have one bad day. It just sort of rotates like that all the time.
(Helena)

Physical side effects

Participants reported a large range of physical side effects, many of which occurred concurrently. Common physical side effects included insomnia, fatigue, headaches, myalgia

'[I]t's a bit like you take the worst hangover you've had, multiply that by three and then throw in a dose of the flu ...'

(muscle pain) and flu-like symptoms. For example, Philippe, 54, experienced a wide range of aches and pains and skin irritations during treatment:

You get all these flu pains like you get with the flu. You get sore lower back, aches and pains in your limbs ... so that's the first obvious effect of the treatment. But there are all sorts of other things, like I have a lot of trouble with my skin. I get all these rashes over my whole body. I have a lot of itchiness, where I scratch.
(Philippe)

Sean, 35, described the physical impacts of treatment as like a combination of influenza and a 'hangover':

[I]t's a bit like you take the worst hangover you've had, multiply that by three and then throw in a dose of the flu, and that period in the flu just before you go down, that 'Boy, I really feel rotten; I'd better go to bed. I'm going to collapse for the next 36 hours.'
(Sean)

Fatigue

Many participants experienced fatigue as a result of treatment. In the following extract, Helena described profound fatigue and how quickly it could manifest:

I just get so tired and so fatigued and I just have no energy. My legs feel like lead weights; my whole body is just like drained, it's gone, and I haven't got the energy for anything ... I can be very tired. I can be really good, walk from one end of the house to the other side, fine, but if I were to walk back up again I could be totally fatigued.
(Helena)

Headache and other pain

Mild and/or constant headaches and pain were commonly reported physical side effects. Barbara, a woman in her fifties, gave a description of the headache-like pain that she had experienced and alluded to an increased sensitivity to noise during treatment:

The biggest side effects ... some people call them headaches. I wouldn't actually call them headaches. They were pains, like they go through your brain like waves of pain. And the tolerance—severe noise intolerance because of that.
(Barbara)

Insomnia

Insomnia was a commonly reported problem. A nurse stated that having sufficient sleep during treatment was crucial in assisting people to deal with other side effects and to maintain libido:

Sleep is a particularly difficult one. I think if a patient's not sleeping that causes them a whole lot of other problems such as fatigue and irritability, and the low libido really starts to really kick in when the sleep's not happening.
(Nurse 2)

Impairment to quality of life

The following extracts by Alfonso and Sally demonstrated how the side effects of treatment made it difficult to do simple tasks, like exercising and socialising. When asked to identify the biggest impact of treatment, Alfonso, 47, reported that it had reduced his capacity to exercise and to complete his normal routines:

Not being able to do things that I've done in the past. As I said, sort of home maintenance or even just to go like ... Last year or at the beginning of this year, my daughters and I used to go for a walk. Now I haven't even brought up that suggestion for the moment

because we used to go for about a five km walk on a Saturday or Sunday. [Now] I wouldn't even last a half a kilometre.

(Alfonso)

Sally reported a similar experience during treatment:

Interferon is like that—takes me hours to do what normally it would take me ten minutes. And simple tasks are awful ... Oh, I no longer can make it easily to the post office. I no longer have a desire to do the shopping.

(Sally)

Psychiatric side effects

A wide range of psychiatric side effects of hepatitis C treatment was reported by participants and health professionals, and these commonly included irritability, depression and emotional sensitivity. Several participants reported that the cumulative impact of psychiatric side effects had altered the way that they responded to people:

Um, I found I've had a complete personality change. I'm not the person that I was seven months ago.

(Helena)

Irritability

Among our sample, irritability was the most commonly reported psychiatric side effect. David, 49 and married with two young children, reported being irritable with his son during a previous attempt at hepatitis C treatment. The resulting tension had had a negative impact on family relationships. At the time of interview, David was undergoing his second course of treatment and these problems were ongoing:

I just started getting really snappy around the house ... I've got a bit of a problem with my son who is just so ... well, pretty disobedient, so I just couldn't handle that and he couldn't handle me. He was only about six at the time and he couldn't understand that, you know, I was sick and so I used to go off my head a bit.

(David)

Rob, 39, attributed his growing irritability to treatment drugs. However, he delayed seeking help to ameliorate the problem. Following a reportedly uncharacteristic outburst of anger he was prescribed antidepressants to pacify an aggressive temperament induced by interferon:

I remember, before I went on to antidepressants, I was just walking down [a city street] one day and this prostitute started hassling me and I said 'No', and what did she call me? 'Scum of the earth.' I just exploded.

(Rob)

Changes in temperament and behaviour induced by treatment had mixed outcomes. Several participants saw irritability as a result of treatment as having a positive influence, for example in the workplace, as it enabled them to become more assertive:

There was this one guy, one day, he annoyed me. He did something; I mean it was quite trivial. That's the thing about this anger thing. It just came out; it was a total overreaction, out of proportion to the incident. I did, I really walked up and slammed the desk and really went off at him. But ever since that day, he's really treated me so well so, in a way, it's had some positive spin-off.

(Kate)

Depression

Participants also reported depression as a side effect of treatment. Many said they did not expect such significant psychiatric side effects. Kate recounted how depression distorted the way that she felt about her life:

But the second week or so, I just crashed. I had like a depressive episode, a really bad depressive episode. And it was at night. I remember I was home by myself and I don't know, it just sort of came over me. There was no reason, nothing had upset me that day. Suddenly I just thought, 'Everything fucking sucks' ... just all these horrible thoughts were going through my mind and I got really weepy and upset. I hated everyone. I thought of all my friends and they just sucked. I hated my job.

(Kate)

Similarly, Chloe, 49, reported that she was struggling to cope with treatment largely because of depression and the impact it was having on her world view and outlook for the future:

The major mental one, I suppose, is the depression. It's feeling that, you know, it's all hopeless and you might as well die. I mean, it's kind of like everything's meaningless and you might as well not be here.

(Chloe)

Several participants reported that, although they had not experienced major depression during treatment, there were times when the psychiatric side effects had levelled the 'peaks and troughs' that they understood as normal variations in their mood. For example, Sean discussed feeling emotionally bland and that this minimised the enjoyment he was able to feel, for example when playing with his son:

But just mentally I feel like I'm just in a bit of a twilight zone. Not up, not down; just nothing ... I'm not getting the emotional joy that you might normally get. I'm sort of a bit ... I'm just bland is probably the best way to

describe it ... Yeah, a blandness and beige, and I'm just constantly beige. I'm not bright red and I'm not black; I'm just, you know, this bland ...

(Sean)

On the other hand, Sean and others reported periods when they experienced heightened emotional sensitivity, when minor occurrences would trigger overwhelming emotional responses. Sean gives an example of an episode in which his response was uncharacteristically emotional:

I read an article about ... it was by the United Nations about trafficking of children and the slave trade and all the terrible things that are going on and I got to the end of the article and there was a great ... it wasn't just, 'Gee, that's tragic!' but there was a true sense of gut-wrenching despair that I normally would not have—that makes me sound really callous—but like it's as if I knew the people they were referring to in the cases.

(Sean)

Cognitive impairment

Participants noted episodes of cognitive impairment, including loss of memory and a reduced ability to concentrate. Sally gave an example to describe the feeling she called 'disorientation':

Like I go into a supermarket to do my shopping and it's really hard work because I can't figure out what I'm doing, why I'm there and what I'm supposed to be buying. I can get sidetracked; it can take me three hours and I can go out without anything I went for.

(Sally)

Sally's experience exemplified a tendency among participants to use personal vignettes to describe side effects that they could not articulate or those that did not have a commonly accepted generic label. Participants found it easier to give an example of a time when they experienced a particular feeling rather than to describe it directly. For example, Raymond, 73, recounted how cognitive impairment as a result of treatment interfered with the pleasure of reading and with memory function. This contributed to a sense of frustration with his illness and treatment:

I've always read a lot. My reading span is dropping a lot. I've been reading a book for a week or more and yesterday I read 30, 40 pages I had only read a day or two before. Little bits of it stuck but, basically, you know, I couldn't recall the rest of it, just the odd little bits.

(Raymond)

Coping strategies

All participants noted a number of coping strategies they had used to deal with the side effects of treatment. These strategies ranged from the use of pharmaceuticals and other medical interventions to personally devised coping mechanisms and social support. Personal coping strategies included rest and relaxation, participating in favoured activities, keeping occupied, maintaining a healthy lifestyle and identifying and utilising available support from family, friends, community services and, if possible, the workplace.

'I got great support from the psych doctor over there who put me on some antidepressants which helped me to sleep and do all that ... They [antidepressants] were essential; I don't care what anybody says.'

Medical interventions

Medical strategies ranged from the use of paracetamol, and skin care medications and products, to the use of antidepressants. Participants extolled the benefits of antidepressant therapy during treatment to ameliorate the impact of psychiatric side effects. Kate and Monica reported that antidepressants enabled them to regain a sense of normality:

I got great support from the psych doctor over there who put me on some antidepressants which helped me to sleep and do all that; and I've never been a pill-popper but I've got to say I was very thankful for those. It kept me at an even plane ... They [antidepressants] were essential; I don't care what anybody says.

(Monica)

The depression pretty much went away because I just took to the antidepressants and I felt really well and I was happy.

(Kate)

On the other hand, some participants reported that antidepressants were of no assistance and may have contributed to decreasing their sense of well-being. David believed that antidepressants had no positive impact on his mood:

I was sick and so I used to go off my head a bit and they said, 'We'll calm you down a bit,' and they put me on antidepressants and stuff like that. That didn't have

any effect at all ... except my sex life just went bang, out the door. So I wasn't too happy about that. So, yeah, I got off [antidepressants] basically.

(David)

One participant described his frustration with having to try a variety of expensive antidepressants before finding a type that suited him. Finally, he eschewed antidepressant therapy and found his own way of coping:

I'd get teary and everything like that; that's why they started me on the antidepressants. And the antidepressants made me worse. But some antidepressants will do that; you've got to go through a range until you find ones that you're happy with. Well, I've told [the nurse] I'm not prepared to do that. I don't want to try any more. Because one lot was \$28 and I think I had two tablets out of the whole course. Forget it! ... I felt worse with the medication and I thought, 'I don't care if there's another 600 out there I can try. I don't want to try them. I'll cope the way I'm coping.'

(Marsden)

Participants used paracetamol and other non-prescription medications to relieve flu-like symptoms, headaches, nerve pain and annoying but minor side effects. They were concerned about the impact on health of taking non-prescription drugs over long periods. Some were reluctant to take medications and expressed a fear of using medications such as painkillers to deal with pain related to treatment:

So I use the [anti-inflammatory painkillers] and [paracetamol] and usually I take them once or twice a day. And I can have a couple sometimes during a day or, you know, if it's a low ebb, so I just don't take anything. Because, you know, you don't want to be taking all this stuff for twelve months solidly ... So I try to have only a couple a day.

(Chloe)

You know, it's like OK, if I do get all those [drugs] out of my system, because I don't like taking all these additional things that I am taking, but I can't really cope unless I do. So it's damned if you do and damned if you don't.

(Sean)

Skin rashes were a common side effect of treatment and participants reported that it was important to address skin irritations:

And skin care I reckon needs to be started before the treatment ... We had a dermatologist come to a support group and said to use the rolled oats, you know, a bag of that in the bath. Like I tried all that when my rashes were bad. It's too late then; you need to put it into place beforehand and start using moisturisers on the skin.

(Barbara)

Adequate preparation for treatment

Participation in prolonged treatment regimens requires patients to consider beforehand the possible impact of treatment on their family and personal relationships and work obligations. Some participants reported that preparing adequately for treatment by identifying and building support networks before it began was an important strategy that helped them to cope better with the side effects. Similarly, health professionals highlighted the need to prepare patients for treatment and outlined some key considerations:

We try and talk about those things in depth before they go on treatment. 'What are you going to do?' or 'If this happens to you when you're on treatment ...' and this is why I try to talk to patients a whole lot about, things about what makes them tick, what keeps them going, what do they enjoy doing, what are the fun things in their life? So that I know, when they're having those patches, that, 'These are the things we talked about in the past that you said make you feel better, so why don't we try doing those things?'

(Nurse 2)

There was some evidence that the health professionals we interviewed harnessed patients' own strengths to help them to cope with treatment. One nurse and the social worker reported that they could help patients to cope by identifying, and then helping patients to modify, their past responses to adversity so that they could apply these to their current treatment regimen. For example:

So we talk about what they did in the past when they had some bad times or, you know, when they've had difficult patches at other times in their lives, those sort of things. And 'Did that work?' and 'Can I try [those interventions] in this [treatment] situation?'

(Nurse 2)

Several participants reported that during treatment they had used coping strategies learnt while dealing with previous adverse experiences in their lives, including drug dependency, chronic illness and social and economic marginalisation. Although the health professionals interviewed for this study did not consciously use a psychosocial resilience framework as described in the literature (see, for example, Luthar & Cicchetti, 2000; Tedeschi & Kilmer, 2005), several indicated that the interviews they held to prepare patients for treatment aimed to enhance patients' competency to withstand the impact of side effects (see Sections 5 and 6 for discussions of 'resilient coping' and 'strengths-based assessment' during hepatitis C treatment). However, more commonly, health professionals prepared people for treatment with information and counselling sessions, and patients prepared

themselves on the basis of the information and advice they received during these sessions. As Sally explained:

Well, I didn't rush into it, thank goodness. I got informed. The nursing staff here are fantastic ... said, 'It would be a good idea to organise your life so that you can optimise your living situation around these side effects.' So I did that. I prepared; I really prepared ... So I closed down my studio; that was stressful, and I packed it all together ... I did a lot. I got, you know, everything paid up and sorted out and paperwork done. I decided that my project [during treatment] was to make a lovely little garden at home.

(Sally)

Support

Participants discussed the importance of the support they received from partners, families, friends, work colleagues and support groups during treatment (see Section 2 for a detailed discussion of support during treatment). In the following extract, Monica, 55, stated her belief in the value of support and preparing for treatment, and in the importance of determination, as factors that helped her to cope with treatment and adhere to it:

And I think you have got to have support ... [Y]ou've got to be really able to take the whole thing on to start with. You've got to psych yourself into, 'No matter what, I'm going to stick to it,' because it's a very easy thing to fall out of.

(Monica)

Similarly, Chloe, 49, reported that she found support both from the liver clinic where she was treated and from people who had previously undergone treatment, who were an invaluable resource. Connecting with and talking to people who had already been through treatment provided her with an important source of first-hand information and support:

Just find the people that have been through it. Because the psychiatrists and the nurses, they haven't done it. They can only support you from an outside position.

(Chloe)

Keeping occupied

If they weren't working, several participants adopted strategies to keep themselves occupied and often set themselves small projects to do. Loren, 50, set small tasks to allow herself a sense of achievement:

I would just set myself tasks on a week-to-week basis in terms of just doing things around the home or even trying to cook a meal ... So I became task-oriented and it's as basic as just doing my washing and hanging it out,

or even hanging some of it out. For me, that is obviously part of where I need to feel valued in terms of activity and achievement.

(Loren)

Similarly, Sean gained a sense of accomplishment from doing small and easily manageable projects:

So, the things that I'm doing are just small things, they really are—sorting a photo album. Those sort of wet-weather kind of things but they give you some sense of accomplishment for the day.

(Sean)

Work

Some participants reported that work was an essential coping strategy. For example, Monica continued to work in her management job, and believed that giving up work would have made it more difficult for her to cope during the 24 weeks of treatment. Work provided Monica with stimulation and a distraction:

I was very lucky that I was working and I was working hard because it kept me going, that's another thing. You know? I don't think I'd like to be at home doing the program and not having anything to do. I think it would be the worst thing you could possibly do; you'd cut your throat. Well, I would have.

(Monica)

Similarly, David saw work as an opportunity to escape from the stress of home and family life:

So it didn't matter how I felt, I just always would still go to work because I knew that it was sort of my refuge, my refuge from home.

(David)

Setting priorities

Participants noted the importance of prioritising activities to manage the impact of fatigue. Some participants recognised and accepted their limitations when on treatment. Rather

‘The ones who do the best [during treatment] are people who are really able to set some limits on what they can do and what they can't do.’

than fighting, they focused on completing essential tasks, which they fitted in around the pattern of side effects they experienced. For example, Helena struck a balance between doing household tasks and relaxing to regain energy:

Yes, and then I really pace myself out with a lot of the things I do. Like Saturdays is my cleaning day so I've broke that up into Friday and Saturday, do it over a two-day period. If I do something in the morning, then I'll just do nothing in the afternoon.

(*Helena*)

The social worker reported that people who accepted their limitations and cut down on family, work and social activities often found treatment easier to cope with:

The ones who do the best [during treatment] are people who are really able to set some limits on what they can do and what they can't do.

(*Social worker*)

Some participants reported that prioritising personal needs and cutting down on socialising helped to ease pressure and expectations during treatment:

Patients have to actually learn to say, 'No, sorry, can't do that.' I think I must have missed about four funerals or something, which you feel really awful about but, 'No, can't go, can't go. If I go, you'd be burying me.'

(*Barbara*)

Rest and relaxation

Participants used a variety of relaxation strategies during treatment. For example, Marsden crocheted hats and gave them away to people. He reported that this simple activity was appreciated by others, which made him feel better:

I'm a tailor by trade so I make these sort of little hats and I crochet hats. I crochet anything and everything so I'm always crocheting, always ... but I do a lot of stuff and give it away and that makes me feel good and that helps me cope.

(*Marsden*)

For some, simply resting during the day was a strategy that helped them to regain their energy:

Umm, I sleep, I nap you know, I just have to. It certainly helps.

(*Gavin*)

Use of cannabis

The contribution that illicit drug use made to quality of life, adherence to hepatitis C treatment and its successful completion was acknowledged. A nurse and the social worker spontaneously offered personal perspectives on patients' use of cannabis to reduce side effects related to treatment. They reported that cannabis use was common among people in treatment and that it helped to relieve a range of troublesome side effects. While they said that they could not recommend cannabis to their patients, there was more than just a tacit acknowledgment and acceptance of the practice among some

health professionals. As is evident in the following extracts, health workers were concerned more about the frequency of cannabis use during treatment and cautioned against 'excess' or escalating use which might change the pattern of side effects. For example, feelings of depression and anxiety were believed to be affected by increasing cannabis use, although with regard to depression there was uncertainty about whether the cause was cannabis or interferon. It was generally accepted, however, that cannabis could assist people in several ways, including to overcome insomnia, and therefore was useful during treatment:

But certainly there are a few of the strategies that patients use that help us with [managing side effects]. Quite a few patients smoke cannabis and cannabis-smoking is very common (laughs). You know, I don't recommend patients smoke cannabis but they often do for relief of nausea, to help them sleep, to help with aches and pains, to help them relax. So, if they continue to do that, that's fine. I just ask them to tell me how much they're doing it and, if they increase it a lot, because it can impact on mood ... I guess those sorts of things are what patients come back and tell me about.

(*Nurse 1*)

We have got lots of clients who say, 'Look, I smoke a joint at night. Is that cool?' And I go, 'That's fine.' 'Smoke to get to sleep?' 'Fine.' But, we say, 'Just remember that when you stop sleeping, when changes happen, you've got to tell us because you may not go to sleep as well as you used to and that's because of the interferon and we might have to look at other means for that.'

(*Social worker*)

Health professionals reported that they encouraged patients to disclose openly and honestly about illicit drug use, and that this enabled the health professionals to adopt a harm reduction approach to hepatitis C treatment.

Adopting a healthy lifestyle

During pre-treatment interviews with patients, health professionals strongly recommended that patients adopt and maintain a healthy lifestyle during treatment. Many participants saw treatment as a turning point in their lives

'And there were positive aspects. I mean, it got me healthy, do you know what I mean? I was much more conscious of what I ate, really cut down on what I drank ...'

and an opportunity to make changes by implementing healthier practices. Common strategies included drinking more water, eating healthy foods, abstaining or keeping alcohol and other drug use to a minimum and doing exercise:

And there were positive aspects. I mean, it got me healthy, do you know what I mean? I was much more conscious of what I ate, really cut down on what I drank and, you know, I was much more active. I was swimming and I lost weight.

(Kate)

Having a positive mental attitude

Adopting a positive mental attitude reportedly helped people to cope with changes in ways of thinking induced by treatment. Loren, 50, used positive self-talk, a technique she had learnt from her experiences with clients who were dependent on alcohol and other drugs or were victims of domestic violence. This strategy helped her to cope with the psychiatric impacts of treatment:

Self-talk is something that, on a personal level, I've trained myself to be aware of and to re-orientate, so I will always give myself positive messages and I think that gets back to what I was saying, that I was driven to succeed.

(Loren)

Health professionals reported their admiration for people who maintained a positive outlook and a determined approach to treatment. One remarked on her patients who used treatment as an opportunity for positive change in their lives:

A lot of them are trying to take the positive out of it and, at the time with them, there's self-realisation as well ... Really a lot of them use it as an opportunity to turn the life around and, 'I'm going to cure the hep C as a change for the better.'

(Nurse 3)

Anger management

Several participants reported experiencing a personality change during treatment. They struggled with uncharacteristic changes in temperament, including feelings of anger and impatience and a low tolerance for 'playing games'. Several participants reported having walked away from potentially provocative situations because they were afraid of reacting with anger and impatience. For example, Richard, '40-ish', had reportedly learnt to manage his anger during a decade of martial arts instruction and applied these techniques during treatment. Another participant, Rob, was prescribed antidepressants following an episode of 'explosive' anger. Similarly, David reported often having walked away from family arguments until he had calmed down:

Oh, look, I'll have my say in the lounge room or dining room but then I'll think, 'Right. I've just got to get out,' so straight into the bedroom and go and listen to music. Just wait until everything settles, you know, an hour later, and reappear.

(David)

Conclusions

The data from this study revealed that participants' experiences of the side effects of treatment, and their strategies for coping, were often idiosyncratic. Participants reported experiencing a range of physical and psychiatric side effects that had an adverse impact on their quality of life. Similarly, participants adopted a wide variety of coping strategies to counter the impacts of side effects. Health professionals explained the need to prepare patients for treatment and discussed the integral role of pre-treatment interviews. In line with the results of previous research into chronic illness, participants reported gaining significant benefits from hearing about others' experiences of treatment, for example during support group meetings or from knowing others who had completed treatment. This was useful when participants were planning how they themselves would cope with treatment.

2 Support during hepatitis C treatment

In this section we look at the dynamics of support from partners, families and support groups. First we focus on support from partners and families, and then report on participants' experiences of support groups. Support is understood by clinicians as integral to the management of the psychiatric side effects of hepatitis C treatment, particularly depression. Depression is one of the most commonly reported side effects of interferon-based treatments (Bonaccorso et al., 2002), and the occurrence of mood disorders during treatment, particularly endogenous depression, is the most common reason given for discontinuing therapy (Sievert, 2001). Interferon can exacerbate symptoms in those with pre-existing depression and can induce depression in people with no prior history of the disorder.

'[I]f you were having chemotherapy for breast cancer or something ... people would be arriving at your door with a tuna casserole and helping out, but in this case it's something entirely different ...'

In the case of people on treatment with interferon, there is a salient link between receiving social support and preventing the onset of psychiatric side effects like depression. A relatively large body of research on the impact of psychosocial factors on major depression has accumulated in the scholarly literature. A variable often found to be associated with, and predictive of, depression is one's level of social support during negative life events. Social support has been significantly associated with protecting against depression in elderly nursing home patients (Jongenelis et al., 2004), among US public hospital workers (Park et al., 2004), in black students attending white educational institutions (Mimms, 2004), in primary-aged students (Abela et al., 2004), among patients with and without seasonal affective disorder (Michalak et al., 2004), and in middle-aged African-American

women (Mentes, 2004). These studies indicate that social support plays an integral role in protecting people from, or acting as a buffer against, the development and onset of major depression, or at least mediates the negative effects of depression on quality of life across a variety of social, geographic and demographic contexts. While our study has not focused specifically on the link between social support and the impacts of depression, the data highlight a complex dynamic between support from family, friends, health professionals and support groups and participants' reported experiences of psychiatric side effects from hepatitis C treatment.

Support from partners and families

A recent study conducted by McNally and colleagues (2004) explored the reasons for people's decisions to commence hepatitis C treatment. The only non-clinical factor cited as influencing decisions was whether or not a participant had a supportive partner. Given the widely acknowledged physical and psychiatric side effects of interferon and ribavirin, support from partners and families is an important social variable in maintaining quality of life over the prolonged duration of hepatitis C treatment regimens. The teams of health professionals interviewed for this present study also recognised this.

Perhaps fundamental to the issue of support are the issues of stigma and fear of discrimination (discussed further in the following section), which limited the number of people to whom participants felt they could disclose that they were in treatment, and restricted their opportunities for obtaining support. A nurse explained:

[I]f you were having chemotherapy for breast cancer or something, you know, most people would know and ... people would be arriving at your door with a tuna casserole and helping out, but, you know, in this case it's something entirely different ... My experience is that most

people go through it and they really only tell immediate members of their family and no one else knows. In some cases, it's just one person, and other people will tell nobody. I mean, I just think they're amazing, how they can then cope with that. I think it's extremely difficult.

(Nurse 3)

'I always encourage the partner to come [to the clinic] as well, especially on the first visit. It's a big experience for them, yeah, huge, huge ... as a support person ... yeah, [the treatment] totally affects everyone.'

To increase opportunities for patients to have support during treatment, the major liver clinics where we conducted interviews involve partners in the treatment process. Health professionals report that, for treatment to be successful, ideally a variety of supportive players should be involved. A nurse described her strategy for building support for the patient before treatment commenced:

I always encourage the partner to come [to the clinic] as well, especially on the first visit. And I'll say [to the patient], 'Ask your partner how you're going and ask him to keep an eye on how your mood is because they're going through it as well.' It's a big experience for them, yeah, huge, huge ... as a support person ... yeah, [the treatment] totally affects everyone.

(Nurse 4)

For some participants this model of supportive family, involving partners and children, helped them to cope with side effects and enabled them to get through treatment with minimal impact on family relationships. In the following two extracts, Alfonso, 47, and Monica, 55, acknowledged the benefit of support from a partner and family:

[W]ell, my immediate family are, yep, very supportive. They understand ... what I'm going through. I think I'm fortunate in that because I've got three teenage daughters. They understand ... [M]y wife understands ... although this has sort of disrupted my life, I try not to disrupt their lives as well, because it would make it hard for them.

(Alfonso)

I think you need the flexibility of being able to do things when you're feeling well and the flexibility of saying you're having a bad time, just curling up and going to

bed. You know? You need that flexibility. So I've been lucky because of the fact that I was able to do that—with [my husband's support]. By having that support, that helped me enormously ... You know, friends and family being supportive.

(Monica)

Disclosing to a partner and family that a patient was having treatment was necessary to gain support. However, often because of misunderstanding, disclosure did not guarantee that the nature of support was appropriate to the needs of the person in treatment. Several participants discussed the physical and psychological stressors that being in treatment placed on these relationships. For example, Barbara, a woman in her fifties, received support from her husband (who did the housework and cooking) and her daughter. While acknowledging their help, she perceived a lack of empathy with her mood swings during treatment. In this extract, Barbara expressed a wish to be alone to minimise the potential for family conflict:

[T]hey just don't understand what you're going through ... well, you can tell them but it still doesn't sink in. It's like ... any sickness that anyone can get, people just don't realise unless they're experiencing it themselves. [M]ost of the emotional feelings that I had on treatment were triggered by family. If they weren't in the picture, then I wouldn't have them. Next time, if I have it again—I'm not planning on having it again, touch wood—I'm going to move into a flat on my own. One other lady had told me that a couple of years ago. She said, 'The family just don't understand and the things that they say ...' ...because you're so super-sensitive that you just take it to heart.

(Barbara)

The tension between the need for family support and a patient's desire for peace and quiet at a time when they were vulnerable to mood swings, depression and a changing sense of self was commonly expressed. For example, Loren, 50, discussed a desire for personal space away from her children while she dealt with the challenges of treatment side effects:

[W]hen the three of them are in the house and they're really, really lively and active, that's just not what I need. I really just need some peace and quiet. [T]he [three] girls are vital, dynamic girls and they just don't quite realise the pressure they're putting me under ... I can't do anything about that. I would never discourage them from being close but, at the same time, it's definitely making it harder for me to have personal space and to feel good about myself. They probably think they're making me feel good by being there and sharing their life with me but, in fact, it works the other way.

(Loren)

Helena, 49, regretted being impatient with her husband, her primary care-giver, during treatment. According to Helena, her husband believed that the treatment should be making her feel better. However, she reported having endured a personality change with bouts of anger and depression. Often her temper would flare and household disharmony would escalate. This made her feel isolated and emotionally unwell:

[I]’ve really been like a bit abusive with [my husband] and angry with him for no reason and suddenly his patience will start to wear out a little bit ... you know, because I’ve been quick-tempered and I seem to get cranky at the littlest things he does. And it’s wrong because he has had patience with me ... There have been times there, like I think he had a bit of a misunderstanding, like, ‘You’re on the treatment so you should be getting better with this treatment.’ But this treatment, it makes you sick ... I’m like a mad woman, once every now and then ... it just changes you ... I feel like I’m alone, I’m doing this alone ... and the side effects and everything make me feel doubly worse. And then you can’t sit down and just explain how you’re feeling.

(*Helena*)

A related issue to emerge from the data was that participants’ children had difficulties coping with parents in treatment, and vice versa. For example, David, 49, discussed a problem that he had with his six-year-old son while David was on treatment for 48 weeks. He attributed his son’s differing responses to David’s illnesses and treatments to the less tangible nature of psychiatric side effects from treatment:

I mean, it’s funny because you can’t see your liver or anything like that. You know, it’s not like chemo where your hair’s falling out, but when [my wife who was diagnosed with cancer] had that happen to her, it was evident to [my young son] that something was wrong with her. So he was being as good as he could with her. With mine, he couldn’t see anything and he probably thought, ‘Well, there’s nothing wrong with you. You’re just a cranky old bastard,’ or something ... it’s nice to have the support and all that ... but it just comes down to the kids and all that. You know?

(*David*)

Similarly, Alfonso alluded to the likelihood of having experienced difficulty if he had had to cope with treatment while caring for young children:

I don’t know how [my treatment] would have been if [my three children] were sort of toddlers or young kids.

(*Alfonso*)

A nurse discussed the issue of managing young children while a parent was in treatment. She described a strategy that was adopted by some of her patients when side effects became problematic. However, rather than promote a specific strategy, she felt that individual families had to address the issue according to their family needs and dynamics:

People who have young children tend to set up some sort of mechanism in the house so that the night they’re having their injection is their night and they don’t have any responsibility for the kids. So their partner takes full responsibility for the care of the kids that night, so there’s not the normal demands and it’s a quiet time. And that works, so that’s their way of managing. That’s not something I’d be encouraging. It’s something I can suggest but I don’t encourage it because I think that’s family dynamics and I’m not in the position to make that call.

(*Nurse 1*)

Finally, participants spoke of emotional sensitivity induced by treatment as the source of irrationality, irritability, illogical behaviour and outbursts of temper which were directed at primary care-givers. Monica attributed her

‘[Interferon] makes you more sensitive. I think it makes you more sensitive to people and stuff like that.’

anger to a combination of her husband’s inability to manage under new domestic conditions while she was in treatment and a heightened ‘sensitivity’ from the treatment drugs:

I don’t think [my husband] coped all that well and I think it was just probably his way of coping ... And you’re very sensitive when you’re on the program anyway, so I suppose little things would get me going.

(*Monica*)

Similarly, Nigel reported feeling increasingly sensitive to stress during treatment and this had affected his partner:

I might come home very stressed from [guitar] teaching, really hyped up, you know. That worries [my wife]. It’s like a sensitivity issue, things like that. [Interferon] makes you more sensitive. I think it makes you more sensitive to people and stuff like that.

(*Nigel*)

Hypersensitivity, anger, hostility, depression, mood swings, irritability and impatience are some of the acknowledged psychiatric side effects of interferon-based treatment commonly referred to in the medical literature. These

changes in temperament are evident in participants' narratives. Their accounts enable a clearer appreciation of the impact of such side effects on people's primary support networks, that is, partners and families.

In this final extract, Sean alluded to a delicate balance between receiving support from a partner and family during treatment and the patient's need for space:

My wife's been terrific ... she's just a great support when I need support but she's also not sort of dithering and hovering ... she's not like that at all. But I know she's there if I need her. And we've discussed some things such as, I can feel the 'cranky man syndrome'; so we discussed that and we both know. I sort of apologised in advance and she said, 'Look, I know it's not you. I know you're not like that ...' [S]he said, 'These are the drugs.'

(Sean)

Organised support groups

Here we explore people's experiences of attending organised support groups while they were on treatment for hepatitis C. The support groups discussed here were implemented at treatment facilities and were set up by the same health professionals who prepared and managed the patients during treatment, and whom we interviewed for this study. The inspiration and energy required and the effort involved to form, promote, organise, conduct and

'I think support groups are an excellent avenue to remove that isolation, especially if they don't have the support group that they need, be it their family.'

sustain regular support group sessions were testament to the dedication of these clinic nurses and social worker. Support groups were held out of working hours and their primary aim was to create an environment in which people receiving treatment could hear about other people's experiences of it. A strong focus on peer support was maintained:

[Our clinic's support groups] were set up by me. It was about providing ... I mean, we make it very clear that the only people who are allowed to come to peer support groups are hep-C-positive people who are either ... finding out about treatment, on treatment or finished treatment ... so the only people who haven't had hep C or don't have hep C are the facilitators. So our role is to actually let them run with it, you know. A lot of people talked about, 'We can get these speakers in,' and, 'We

can do this and that,' but the reality is that's not what peer support is about. Peer support is about actually being able to talk to people, talk to other peers, about what it's like, for them.

(Social worker)

[S]o we would often have information on an educational thing and maybe somebody would present. It was always directed by what the prior group had wanted; that would be what we would present next. So it was always targeted to what our support group wanted. And then, after that, it would be the actual group talking amongst themselves.

(Nurse 1)

I think support groups are very good ... You talk about everything that you go through or what you've gone through ... And I think that having the two [facilitators] there to work it so that it goes around to everybody and everybody gets a chance just to speak or to listen to what they want to hear, or if there are new people coming on the program, just to hear from other people.

(Monica)

The clinic teams reported that these groups were often the only opportunity that some patients had to disclose that they were in treatment or had hepatitis C, and to talk openly about it. Support groups ameliorated a sense of isolation:

[T]here were a lot of patients who hadn't disclosed their status to anybody so they weren't able to talk about how they were feeling on treatment. So I was relaying a lot of people's experiences on treatment. And I thought, 'Oh, this is stupid!' So I started up a support group and it's for people who are thinking about treatment, on treatment or have just finished treatment and working towards the SVR [i.e. cure].

(Nurse 4)

I think support groups are an excellent avenue to remove that isolation, especially if they don't have the support group that they need, be it their family.

(Nurse 1)

I'd have been lost without [the support group] because it's the one time you can talk about what you're going through. I couldn't talk about it with anybody at work. A couple of friends knew I'd got hep C but ... I didn't tell any of the family ... Yes. As I say, some people would travel for a couple of hours to come to [the support group], just for that social contact and support because they couldn't get it where they lived.

(Rob)

As well as contributing to an enhanced sense of connectedness with others in a similar circumstance, participants reported that support groups reassured people that others apart from them were experiencing similar symptoms and changes in perception:

I just think the support is really, really important. We probably should try to organise more hep C support groups because [my fellowship support group] was the most important thing for me, to actually identify with people to whom I could say, 'Look, I feel so insane! I can't stand this one more minute!' Just being able to talk to people who felt like that ... It has been really important for me to connect with people that have been through it.

(Chloe)

[P]eople would mention symptoms that we had in common and I'd say, 'Oh, have you got that too?' and then that would make me feel like I'm not a psychopath. Some people's symptoms are a lot worse than mine which, in a funny, sick way, consoled me as well. I'd think, 'At least I'm not as bad as that.'

(Kate)

I think it's just a reassurance for a lot of people, and it was for me, to know that I wasn't the only one going through what I was going through.

(Monica)

At a practical level, support groups reportedly helped participants to sort out the problems they were having as a result of being in treatment, like to whom should they disclose that they were having treatment:

Yeah, that was the sort of thing we discussed often at [the support group]. What do you tell family, friends, people you work with if you don't want to tell them you've got hep C? Because I don't think anybody there had told where they worked that they were on hep C treatment. Some of them actually quit their jobs because of it. And the question was, 'What do you tell people?'

(Rob)

Several participants reported that they made the decision to commence treatment after attending a support group and hearing patients discuss their treatment experiences. Other participants commented that support groups were an opportunity to encourage people who had not been treated to commence the regimen:

[O]ne of the things that made me decide I had to do treatment, one of the reasons, was going to [a clinic-based support group]. I was sort of going there before treatment started just to talk to other people in the same situation. That did help a lot ... Uh, just looking at all these groups of guys sitting around laughing and joking about the treatment, even about how bad it is, you know. They'd just sit there and joke about losing hair and rashes and diarrhoea and everything. Most of them were sort of halfway through the treatment, so I'd

go to [the support group] and they could still laugh and joke about it, so [treatment] couldn't be that bad.

(Rob)

And we got a laugh; I tried to keep it light. I never came in all gloom and doom, especially for people starting off. You know, I'd always try to encourage them. I never would come in and complain of my own ... I'd say the positive things. And there were positive aspects. I mean [treatment] got me healthy.

(Kate)

Some participants reported that they would like to have access to a support group that discussed issues relevant to people with medically acquired hepatitis C infection. The hepatitis C epidemic affects a diverse population and some participants wished to discuss issues particularly relevant to them:

[I]t sounds like I'm casting aspersions and I'm not. One of the things that is a bit of a bother or that I would like perhaps to be available would be an opportunity for people who have hepatitis, medically acquired [to meet]... because I believe the two groups have two different needs ... [others] can't relate to some of the things I'm dealing with. Inversely, I can't relate to some of the things they're dealing with, and I think those two subsets require almost different levels of support because ... we're just facing different challenges. As I said, that's not casting moral judgments or anything like that. I'm just saying, OK, well I'm someone who has medical issues as well as [hepatitis C] and, you know, sometimes I've been along to some of the hepatitis groups, just to hear what other people say, and I sort of feel that, to be honest, I often am the odd one out ...

(Sean)

Participants reported that some people attended hepatitis C treatment support groups for a limited time, after which they ceased to find them useful or the effort it took to attend regular meetings became too difficult:

We find, though, that people who start with support groups don't necessarily keep coming; they will only come for a little while.

(Barbara)

I go to [a clinic-based support group]. I didn't go last month; I couldn't be bothered. I think that's what happens. It seems like you see other people do it for a few months and then they go, well ... you know, it goes into that depressive thing of, 'This is too hard. There's no point in doing this' ... [T]he people there are very supportive to you. But it's that energy that it takes to get you there, you know, to share the stuff and all that.

(Chloe)

Finally, clinic team members reported that many past patients were willing to remain connected with their treating clinic for a period in order to share their experiences of therapy with people entering or those currently receiving treatment. The social worker reported that past attendees were often pleased to be able to give support back to the groups from which they had received support:

[P]eople who have completed treatment and who have been in a support group keep coming back because they say that's how they pay us back; that stuff about payback ... It's interesting that they have taken that on as so important themselves. So we've probably got, you know, ten people that we could ring in a flash and say, 'We really need you to be the person who's completed treatment. Can you come to a support group?' and it's, 'Absolutely!' So we try to balance that, get one or two to come. And we do that hopefully for the first six to eight months after they finish treatment then, after that, we don't keep asking them because it's about them being able to let go from then on.

(Social worker)

Conclusion

Study participants found that disclosing that they were in treatment for hepatitis C was necessary in order to gain support, but the fact of gaining support was no panacea.

Partners, families and others sometimes misunderstood participants' support needs, and care-givers and young children often had difficulty supporting their family member in treatment, having to cope with the patient's personality changes, mood swings and depression. This suggests that, while people are receiving interferon-based treatment for hepatitis C, adaptive approaches are needed in order to preserve family relationships.

The data indicate that clinicians should be wary of assuming that because a person has disclosed that they are in treatment and have the support of family and friends, the nature and quality of the support will be appropriate to their needs. Clinicians need to understand what 'support' means to an individual about to embark on treatment. While treatment is in progress, careful ongoing monitoring of the dynamics of support may help to avert misunderstandings and stress for patients, their care-givers and clinicians.

Finally, support groups organised by clinics were forums that allowed peers to deliver information and support to those considering or undergoing treatment. The aim of these groups was to lessen feelings of isolation among patients, particularly when patients felt it was risky to disclose to others in the wider world that they were in treatment. Support groups enabled patients to compare treatment experiences, especially the impact of side effects, and to discuss the strategies that others had used to lessen the severity of these.

3 Disclosure of being in treatment, and hepatitis-C-related discrimination

Added to the disease burden of hepatitis C infection is the phenomenon of hepatitis-C-related stigma and discrimination. An emerging body of literature has focused on discrimination against people with hepatitis C in a variety of social, familial and workplace settings (Crofts et al., 1997; Habib & Adorjany, 2003; Hopwood et al., 2006). Discrimination is reported to arise from people's fear of contracting hepatitis C infection, and a disdain for injecting drug users, the population most commonly affected by hepatitis C in developed nations (Anti-Discrimination Board of NSW, 2001; Crofts et al., 2001).

Crofts et al., 1997; Burrows & Bassett, 1996). From the outset in Australia, the hepatitis C epidemic did not receive the same level of concern from governments as did the HIV epidemic in its early days. Injecting drug users were perceived by the health bureaucracy as disorganised and not constituting a 'community' in the sense that the gay community did (Hulse, 1997). The illegal status of injecting drug use and inadequate concern about the likelihood of hepatitis C crossing over into mainstream Australia are reasons given for governments being slow to respond to the epidemic.

It is questionable whether hepatitis-C-related discrimination can be reduced without significant structural changes to the context in which social relations occur. Processes that work well to improve inter-group relations that exist within the law may be stymied by criminalisation of drug use. The illegal status of drug use represents one of the most significant barriers to breaking down the group boundaries between people with hepatitis C and mainstream institutions. Challenging negative perceptions and feelings about people with hepatitis C is difficult under current conditions. Indeed, hepatitis-C-related discrimination may serve a socially adaptive function for certain powerful groups by reinforcing cultural norms and values. Discrimination by mainstream institutions against people with hepatitis C, injecting drug users, and those assumed to be either, reflects an attempt to uphold what are seen as important community values.

Evidence suggests that people avoid disclosing that they have hepatitis C infection to minimise the likelihood of experiencing discrimination (Hopwood & Treloar, 2003; Treloar & Hopwood, 2004). According to past research, whether or not people disclose a stigmatised condition, identity or practice depends on multiple factors (Munir et al., 2005): for example, the number of years of education (Kennamer et al., 2000) and being Caucasian (Petрак et al., 2001). From the HIV/AIDS literature, a theory of

Evidence suggests that people avoid disclosing that they have hepatitis C infection to minimise the likelihood of experiencing discrimination.

There are two major approaches to theorising about discrimination. The first is the 'prejudice causes discrimination' model which perceives discrimination as individualistic, overt, sporadic and episodic. This model presumes that people's attitudes and behaviour are causally linked. However, it has been critiqued for its assumption that attitudes and behaviour are always consistent (Merton, 1970). The second approach to discrimination looks beyond personal rationalisations and motivations to social structures in which discrimination is perceived to be overt or covert, routine and continual, and in which discrimination can be either intentional or unintentional (Feagin & Feagin, 1978; Herdman & Kippax, 1995; Henriques, 1984). It is useful to consider both approaches when considering discrimination related to hepatitis C.

While stigma and discrimination are experienced by many affected people during interpersonal interactions (Scambler & Hopkins, 1986), hepatitis-C-related discrimination also occurs within government departments and mainstream institutions (National Centre in HIV Social Research, 2001; Puplick, 2001;

disease progression suggests that, as an illness develops, people are more likely to disclose to account for symptoms (Holt et al., 1998; Petrak et al., 2001). With the advent of antiretroviral therapy, many people living with HIV infection no longer follow a predictable pattern of visibly declining health, so a theory of competing consequences suggests that the relationship between disease progression and HIV disclosure is moderated by the outcomes expected from disclosure (Serovich, 2001); that is, people disclose only after careful deliberation of the potential consequences, both positive and negative.

Fear of discrimination following disclosure of hepatitis C infection is a perennial concern for affected individuals, and fear influences the way people approach disclosure. Yet, to date, there has been no published research that investigates how individuals disclose that they are positive to hepatitis C or how they tell others they are receiving treatment for the infection. In response to this gap in the literature, this study asked the research question, 'How does disclosure of hepatitis C treatment proceed?' and explored approaches to the disclosure of hepatitis C treatment in a variety of settings. Here we report on the data collected. It is important to understand the multiple ways in which people manage disclosure of this stigmatised infection, particularly in the workplace (Platt & Gifford, 2003). This information is useful for people affected by hepatitis C, for clinicians managing hepatitis C treatment, for general practitioners advising people newly diagnosed with the infection, for health service providers, and for educators working in health promotion.

Our findings revealed four main approaches to the disclosure of being in treatment for hepatitis C, which consisted of 'non-disclosure' and three distinct ways of broaching the issue: (i) non-disclosure (ii) 'strategic disclosure' (iii) 'substitute disclosure', and (iv) 'open disclosure'.

Non-disclosure

Most participants receiving treatment for hepatitis C infection adopted a policy of non-disclosure in their workplace. They reported that this approach minimised the likelihood of experiencing negative consequences:

Well, I don't really tell anyone else outside of my wife, like, what I'm on, you know? Like I don't tell the people at work.

(Nigel, '40-ish')

No, [work] don't know ... I don't know how I'm actually going to last the next seven months in that position.

(Chloe, 49)

Participants who did not disclose often had to construct elaborate alibis to account for time off work or reduced capability at work. Some allowed others' interpretation of events to speak for them. For example, Sean, a 35-year-old advertising executive, reported:

I had very severe reactions to the [treatment] drugs ... I was working in the ad industry at the time. I didn't tell work I was on the treatment, but I was vomiting at work and having to run out of meetings and things and it actually got to the point ... that my employer, my boss, called me aside and said, 'Look, the ad industry being what it is, I don't know what drugs you're on but it's got to stop,' not knowing that I was actually undergoing the treatment because, yeah, I was having a lot of trouble holding it together basically, just from the physical side effects. It was very apparent; I'd sit at meetings and be perspiring and shaking when I passed a piece of paper ...

(Sean)

Sean did not want to disclose any information that might draw attention to the fact that he was on treatment and his employer assisted him by assuming that, because he was working in the advertising industry, Sean had been using illicit recreational drugs. Sean reported during his interview that he had never used illicit drugs. However, at work he was prepared to be wrongly identified as an occasional user of 'soft' drugs rather than to disclose that he was on treatment for a viral infection associated with injecting drug use. After weighing up the consequences, he tacitly accepted his employer's explanation of events and proceeded in accordance with a constructed fiction.

The social worker, who worked at a major liver clinic, explained that people's reticence to disclose that they were on treatment, especially to employers, because of stigma and fear of discrimination, could be a barrier to the uptake of treatment. She cited two cases in which, at the time of interview, workers from key service industries were having difficulty deciding whether to commence treatment because of the risks associated with disclosing to their employers:

... Like a guy we've got at the moment who is a policeman and he was really, really fearful [of disclosing] ... so we actually talked about whether he ... was going to feel well enough to carry out ... beat duties. And he agreed that he actually might not, but that he would have to talk to his boss about why ... [W]e've got another guy who's a fireman and he's very, very, very scared of disclosing, again, and that is the whole thing that impedes him starting treatment because he just felt he couldn't tell [work] ...

(Social worker)

Similarly, a nurse from a major clinic alluded to stigma and the need to respect a person's decision not to disclose, even though it had implications for the efficacy of treatment because it would be difficult for the patient to garner appropriate levels of support:

... There are families that I know of—I have one gentleman at the moment who I can't phone. He will only phone me. He is a 60-year-old man, he has grandkids, doesn't want any of his family to know that he has hepatitis C, doesn't want his wife to know. Because, for him, the whole thing is very shameful, even though he has no idea he comes from a country of high endemic rate of hep C. He doesn't know where he came into contact with it and just finds the whole thing very scary ... I think that situation is very, very hard.

(Nurse 1)

Strategic disclosure

A strategy some participants recommended was to disclose only to trusted friends, family members or colleagues in order to garner support. Helena, 49, strategically disclosed to immediate family. Helena believed that she

'I think this sort of thing sort of throws you, when you find out that you've got something and everyone else goes, "Don't tell anybody."'

had contracted her infection through sharing needles and syringes. In accordance with the theory of competing consequences, Helena had not widely disclosed her condition, nor that she was on treatment, within her extended family or workplace for fear of losing access to her grandchildren. Her husband, daughter, father and brother were the only people to know that she was in treatment. Helena reported that the rest of her family, friends and work colleagues would not approve if she disclosed having treatment for hepatitis C. Not being able to disclose openly made coping with treatment more difficult, as Helena felt isolated:

INTERVIEWER: Are there people [at work] that you can talk to [about being on treatment]?

HELENA: No. They'd totally freak, wouldn't they? I wouldn't take the risk ... I do feel isolated because I've got no friends to sit and say, 'Ay, this is what's going wrong with me.' No, I'm pretty much alone, just with my family ... I've had some bad experiences with

friends so that threw me right out. Just keep to my family and things like that.

Similarly, Monica, 55, was employed in a successful business that she said epitomised the highly pressured, competitive corporate environment. She continued to work even though treatment side effects became obvious to several of her colleagues. Monica strategically disclosed her treatment to one trusted colleague and reported that this helped to deflect attention from her decreased work performance and lessened colleagues' concerns about her health:

And nobody knew in the office. Then I got so sick that [the nurse] said to me, 'Look, you've got to tell someone,' and I said, 'I don't want to tell the directors because, you know, here I am, the boss, and I'm not coping.' So, anyway, I told [a colleague] ... and he was fantastic. He'd just say, 'Look, go home. You look dreadful.' Or, you know, I'd ring him and say, 'Cover for me. I've just got to stay in bed a little bit longer.' So it worked that way ...

(Monica)

Following careful and selective disclosure, Monica reported that her friends and a trusted colleague gave her support. However, Monica's experience of treatment awakened her to issues of stigma and discrimination, which challenged her usual 'open' nature and carefree attitude to disclosure of her infection and its treatment:

I think this sort of thing sort of throws you, when you find out that you've got something and everyone else goes, 'Don't tell anybody.' That also had an effect on me because I'm a very open person.

(Monica)

In summary, strategic disclosure had benefits over non-disclosure. This approach arose from both an individual's need to account for disease progression and from an evaluation of the risks and benefits of selectively and strategically disclosing that they were in treatment for hepatitis C.

Substitute disclosure

Participants reported a third approach to disclosure which entailed giving a substitute explanation for changes in their mood, appearance or circumstances as a result of being on treatment. This made it easier to interact and negotiate with others, such as employers, and appeared particularly effective when planning alterations to work conditions or explaining changes in behaviour, such as socialising less. Participants reported that if they told people they were being treated for 'a liver condition' rather than for hepatitis C this satisfied people's inquisitiveness and

reduced the likelihood of having to cope with a negative reaction and discrimination. Rob, a 39-year-old openly gay chef, reported that many colleagues assumed his condition was related to having HIV/AIDS but Rob told them that he was undergoing a form of chemotherapy. His colleagues then assumed he had cancer, and attributed visible changes to his physical appearance to the impact of treatment for cancer. According to Rob, his colleagues' assumptions helped to allay suspicion that he might have had a more socially stigmatised condition.

[I] suppose that's something I faced at work as well. Because, before I first started saying it was chemotherapy, a lot of people assumed it was HIV because I'm gay ... When I started making up excuses about what it was, they believed it was chemotherapy. Most people don't like talking about things like cancer and if they think you've got it it's a bit of a blank, so they leave you alone ... So [chemotherapy] was good to use because people just didn't ask questions ...

(Rob)

Similarly, when Sean had an opportunity to receive treatment for a second time, having discontinued his first regimen, he decided to use a substitute label to describe his treatment. Rather than not disclosing at all, or disclosing specific detail, he simply said that he was receiving treatment for a liver disease:

[W]hat I did this time ... I did tell them that I was on chemotherapy, pegylated interferon, to treat my liver, all of which is true.

(Sean)

Signs of the progression of disease, such as receiving treatment, meant that participants had to come up with an explanation for their changing circumstances. Substituting a euphemism for 'being in treatment for hepatitis C' was an adaptive approach that some participants used to explain to others perceivable changes in their health.

Open disclosure

Telling others openly that they were in treatment for hepatitis C was the final approach to disclosure reported by participants. Although this was risky, some participants found this the most effective approach for gaining support and were not especially concerned about the impacts of stigma and discrimination. Gavin, 48, a successful businessman, and Philippe, 54, a university lecturer, discussed the benefits of disclosing widely to explain the obvious changes in their routines and activity levels:

I talk to people about it. I don't keep it a secret. I talk to my friends, anyway, and, you know, I'm honest with my wife about how things are going and so I don't feel like it's something that I'm bearing on my own. I think

that would be hard because how do you explain the fact that, you know, you're not doing anything? So I'm pretty honest. All my friends, all the people I know, accept it.

(Gavin)

I don't care. I just tell people. So, no, I don't sort of deliberately conceal it.

(Philippe)

Such blithe attitudes to disclosure accord with previous research (Kenamer et al., 2000) which shows an association between more years spent in education and higher levels of disclosure of stigmatised identity. Philippe was the only university-educated participant in our study, and he considered it unlikely that among his milieu of friends and colleagues he would be risking ostracism by disclosing that he had hepatitis C. Similarly, Gavin was self-employed and financially successful and he

'I think there are a whole lot of different issues that impact on the way that people react and the way they deal with [disclosing treatment] ...'

perceived no risk to his work or family from disclosure. These reports are consistent with theories of class and ethnicity that indicate, for example, that people of European background who earn higher incomes are more likely than others to disclose stigmatised conditions. Similarly, health professionals in our study indicated that social and economic background influenced their patients' approaches to disclosing stigma. According to their experience, the different communities in which people mix, the closeness of their relationships and the varying levels of knowledge about the virus evident among communities often accounted for differing approaches to disclosure:

... It really comes back to the person but also their background, so whether they're of [non-European] ethnic background, professional background, working class, you know, who they're socialising with. And I guess relationships as well. So if their family relationships are very tight and this sort of thing [i.e. treatment for hepatitis C] wouldn't floor them, the family wouldn't change the relationships, whereas with others it does change their relationships. I think there are a whole lot of different issues that impact on the way that people react and the way they deal with [disclosing treatment] ... But then you get other people, you know, some of the clients I've seen at [a large metropolitan hospital], they're quite happy to sit in the waiting room and discuss their

genotypes. So, you know ... some of those people, for them they're over that stigma; it doesn't matter. Or, for the communities that they mix in, socialise in, that hep C is not a scary thing. They're well educated about it and are very comfortable with it. They understand how it can be transmitted and they have all that knowledge. So it's not as freaky for them.

(Nurse 1)

The following and final extract is a reminder of why disclosure is a salient issue for people in treatment for hepatitis C infection. A nurse discussed the ongoing issue of discrimination against those with hepatitis C in health care, which she reported was evident in the large inner-city metropolitan hospital where she worked. She lamented the lack of knowledge and compassion shown to her patients by other health professionals on the floor below her clinic:

I think there's a lot of work to be done to raise awareness and I'm quite disappointed in some health professionals, where they are still quite discriminative and judgmental towards hep C patients ... Yeah, one of the [patients'] gripes is, after seeing [the specialist] they have to get their blood taken. If they don't have it done here, they'll go downstairs and every single patient has said, 'Please don't send me there again because they can be very discriminative down there.' And some of them have got particularly bad veins because if [the nurse] has got an ex-user, they'll make the patient well aware and make it very uncomfortable, going, 'We can't get a vein and it's your fault.' And they're very rough with them. That's one thing that I've been very conscious of lately, yeah. A lot of them will come and go, 'Oh, don't send me there.' God! It must be so awful to be put in that position ... And also I've got friends who've worked on wards and they've never known that there is a treatment for hep C or are aware of the side effects. I'm just totally surprised, in this day and age.

(Nurse 4)

Conclusion

These findings show that participants had adopted various approaches to disclosing that they were being treated for hepatitis C infection, and some had chosen not to disclose. An understanding of the approaches our study participants used can be particularly useful to health professionals, such as nurses and social workers, when conducting pre-treatment interviews with patients to inform them of what to expect and to assess their suitability for treatment. When people are deciding whether to commence or defer treatment, the need to take into account the effects of treatment on their health in the workplace can be a major concern and act as a disincentive to the uptake of treatment. An understanding of our study participants' experiences of various disclosure strategies and how they worked for them can be useful in devising such strategies for others who are considering treatment. Currently, advice about the benefits of disclosure and how patients might go about it is usually given on an ad hoc basis.

Patients disclose in a bid to build supportive networks to make treatment easier to cope with and to avoid the stigma and discrimination they fear to encounter as a result of having hepatitis C. The link between our participants' motivations for disclosing, or not disclosing, and their attitudes to avoiding stigma and discrimination largely determined which approach they deployed, that is, strategically, euphemistically, openly or not at all. Disclosure can have a significant impact on the experience of treatment; telling the 'right' person in the 'right' way at an 'appropriate' time can influence how well patients cope with treatment (Serovich et al., 2005). Recognition of a diversity of successful approaches will help health professionals to advise future patients about the strategies that might work best for them.

4 Unrealistic optimism

A phenomenon that affects patients while they are both preparing for and coping with treatment for hepatitis C is a psychological construct referred to as 'unrealistic optimism'. Research across a range of health-related areas has consistently demonstrated evidence for unrealistic optimism: that is, people's tendency to believe that they are less likely than others to experience adverse outcomes (Weinstein & Lyon, 1999). Colloquially, unrealistic optimism is illustrated in the phrase, 'It won't happen to me.' The phenomenon has been demonstrated to be unrelated to age, gender, education or occupational status (Weinstein, 1987).

'They warned me about interferon and how it can change your brain structure around (laughs). I believe it [now] ...'

In the context of treatment for hepatitis C, unrealistic optimism becomes problematic when a patient believes they are unlikely to experience negative outcomes from the side effects of treatment. Similarly, it may cause problems for patients who believe they are adequately protecting themselves from side effects (Covey & Davies, 2004; Gold, 2004; Gold & Aucote, 2003). Unrealistic optimism can lead patients to delay seeking, or refuse, assistance with depression related to treatment. If unrealistic optimism goes unrecognised or unchecked, it can have a significant impact on an individual's quality of life during treatment or lead to very serious outcomes such as self-harm or even suicide.

This study examined interview data to address the following questions: Does unrealistic optimism affect how patients make decisions before treatment commences, their preparation for treatment and their ability to cope with treatment side effects? Do health professionals perceive unrealistic optimism to be an issue when preparing patients for treatment?

Patients and preparation for treatment

Unrealistic optimism was evident in the interview transcripts of both patients and health professionals. Patients' descriptions of their preparation for treatment sometimes revealed a lack of concern about the possibilities of side effects, and our data contained evidence that some delayed seeking help for significant depressive symptoms. Health professionals also spontaneously raised the issue of unrealistic optimism as something that needed to be addressed during pre-treatment counselling. The following extracts from interviews reveal unrealistic optimism expressed by patients who were undergoing treatment.

Kate, 38, reported that she was not concerned about the psychiatric side effects of the therapeutic drugs and that she began treatment without seriously considering their potential impact on her mood and quality of life:

I was still a bit blasé about the whole thing. I didn't realise the whole psychological side effects aspect of it. I just didn't worry about that at all. I just sort of punched in.

(Kate)

Unrealistic optimistic was also expressed in patients' assessment that their capacity for resilience was greater than others', an exaggerated expectation of their ability to cope, and their judgment, based on past experience, that they would not be vulnerable to psychiatric problems in the future. For example, Philipe, 54, felt he would be protected from psychiatric side effects because he was 'level-headed':

They warned me about interferon and how it can change your brain structure around (laughs). I believe it [now], but I didn't have any fears or feelings about that because I feel I'm fairly level-headed. But it did affect me; it was a lot harder than I thought.

(Philipe)

David, 49, suggested that his unrealistic optimism came from his judgment, based on past experience, that he was unlikely to experience psychiatric side effects of treatment because he had not experienced mental health problems in the past. He also assumed that he would be able to cope with side effects if he experienced any:

As I was reading all the side effects, the thing that stood out to me, well, it really didn't stand out to me, I just looked at it, it was just about all mental health [issues] and all that. I just went, 'Oh, yeah, well I've never had that problem.' So I was just ticking things off in my head. I thought, 'Yeah, yeah, I'll be fine handling this ... yeah, no worries; I've never been depressed or anything.' And I don't know. I probably basically didn't know how to handle it.

(David)

Similarly, Helena, 49, initially exaggerated her capacity to cope with the side effects of treatment, and this limited her ability to ask for assistance:

Everything was explained to me but I don't think I took it as seriously as what they ... that the side effects could really do this to you. I think it was like, 'Oh, I'll be able to get through that.' That was my attitude. But now it's actually hit, and hit good, I haven't found it so easy to say, 'Oh, you know, I can do that,' even though I've tried. It's just really not as easy as you think it is. Like, other medications and things, you think you can get on top of it, but this doesn't allow you to get over the top.

(Helena)

Chloe, also 49, believed that she would not be at risk of psychiatric side effects. She described waiting some months before seeking assistance for depressive symptoms:

I think [a doctor] told me that there can be depression which can be a side effect. So there were the two things that I watched out for and I just thought, 'I'm really positive and it's just a physical thing; it's not ...' You know? I didn't ask for antidepressants until the third month; I just got them then.

(Chloe)

Health professionals and preparation for treatment

Health professionals alluded to unrealistic optimism and the need to address it when preparing people for treatment. For example, the social worker and a nurse reported having difficulty in getting some patients to accept that they were likely to suffer side effects and then in helping them to understand the importance of modifying their usual activities in order to cope with treatment and its impacts:

The difficulties come when people want to stick to working from 8.00 to 8.00 every day and they still want to go and work out at the gym, you know, for four hours three times a week, as well as run a family and as well as everything else. That's when people seem to fall apart on treatment.

(Social worker)

People never really accept that, even when we first talk to them about treatment and you talk about side effects and tell them how it's going to make them feel. Everyone says, 'Oh, yeah, I feel like that anyway.'

(Nurse 2)

Finally, a nurse described how, in their pre-treatment interviews, some patients did not see discussion of side effects as being relevant to them. Unrealistic optimism and lack of psychological preparation meant that these patients could have difficulty coping when side effects became apparent:

I think people who start treatment for the first time, you talk to them about what the possibilities are and, you know, a lot of people say to me afterwards, 'I remember you saying that I might experience this and that but I thought, "Oh, I'll be alright and that she's being overdramatic," but then I realised you were absolutely right.' And I think people think, 'I'll be fine,' and then maybe it's a bit of a shock when maybe it's not quite what they expected.

(Nurse 3)

Conclusion

People who received treatment for hepatitis C and the health professionals who supported them spontaneously described the concept of unrealistic optimism and its impact on patients' preparation for treatment. Patients often perceived that the information and advice about the side effects of treatment provided in pre-treatment counselling sessions were not relevant to them, and that they would be able to cope with any adverse impacts of treatment. They also believed that, because they had not experienced mental health problems in the past, they would be unlikely to experience psychiatric side effects during treatment. Health professionals also identified patients' unrealistic optimism and its major impact, that patients delayed seeking help in coping with side effects.

The extent to which unrealistic optimism is demonstrated by patients undergoing hepatitis C treatment, its impact on their ability to cope and willingness to seek help require further detailed investigation. Nonetheless, these findings have implications for both practice and policy in the area of hepatitis C treatment. In practice, health professionals who assist patients to prepare for treatment and manage

side effects should be aware that unrealistic optimism has the potential to impair or influence people's judgments about their vulnerability to side effects. Unrealistic optimism may cause patients to delay seeking help when difficulties arise. (A body of literature describing some potential origins of unrealistic optimism may be helpful to health professionals exploring this phenomenon in the hepatitis C clinic [Weinstein, 1987; Weinstein & Lyon, 1999]).

For policy makers, the issue of unrealistic optimism should be taken into account when making decisions about where patients with hepatitis C infection should be referred for treatment, especially when considering the potential move of primary care for hepatitis C patients from decentralised specialist liver clinics to general practitioners. Pilot programs in Australia involve varying levels of participation of general practitioners in the delivery of hepatitis C treatment (Crooks, 2002). Our findings on the potential impact of unrealistic optimism

point to the need for the intensive, ongoing involvement of allied health professionals in the delivery of hepatitis C treatment. Without adequate training or resourcing, general practitioners are not equipped to counter patients' unrealistic judgments about how they will cope with side effects during pre-treatment consultations. And in contexts like busy regional and rural family medical practices, general practitioners are unlikely to have the resources to monitor patients sufficiently closely throughout treatment to ensure that they receive timely help in coping with any psychiatric side effects.

As is evident from the literature (e.g. Weinstein, 1987), people are ingenious in finding reasons to believe that they are at less risk than others. When providing treatment for hepatitis C, health professionals need to understand the potential impact of unrealistic optimism and be equally as ingenious in finding approaches to help patients accept an accurate picture of their susceptibility to harm related to treatment.

5 Resilient coping

Social and economic marginalisation is commonly understood to increase people's vulnerability to risk (Wilkinson & Marmot, 2003). The academic literature reports on many studies that have examined the negative impacts of marginalisation on, for example, education and employment opportunities (O'Brien, 2003; Welsh et al., 2002), physical and emotional health and well-being (Trivedi, 2002; Williams & Collins, 2004) and access to mainstream institutions (Milbourne, 2002). In recent times there have been unexpected research findings regarding people's capacity to cope during extreme hardship. It is this phenomenon, termed 'resilient coping', that we now explore.

Resilience is a prevalent phenomenon that develops from common and accessible human resources that can be found among friends, families and communities ...

Specifically, we present data that highlight our study participants' recognition that their experience of social and economic marginalisation had helped them to withstand the often severe side effects of hepatitis C treatment. Our data suggest that, with help from clinicians, patients receiving hepatitis C treatment might be able to reduce the impact of common side effects by identifying, evaluating and harnessing the strengths and resources to be found within themselves, their families, friends and communities.

The psychosocial construct of 'resilience'

Historically there has been an emphasis on problem-focused models in the field of mental health whereby clinicians treat patients' psychological problems as they occur (Gerhardt et al., 2004; Tedeschi & Kilmer, 2005). As a result, much of what we know about how people cope during difficult times comes from contexts where

help is sought by those experiencing loss and trauma (Bonanno, 2004). However, in recent decades there has been increased interest in the factors that contribute to the development of good outcomes among people who routinely or episodically experience negative life events. Research has explored the development of competence; enhancement of well-being; human strengths; and growth (Masten, 1994, 2001). An outcome of this work has been a focus on a psychosocial construct referred to as 'resilience' (Gerhardt et al., 2004; Trickett et al., 2004). Instead of being regarded as a personality trait that some people have and others do not (Luthar & Cicchetti, 2000), 'resilience' is understood in this work as emerging from a range of life situations that can be experienced by almost anyone; examples include having a strong relationship with a partner, being part of a caring family, having access to well-resourced and supportive community networks, being able to maintain good interpersonal relationships, and knowing how to make the most of one's own ability. Spirituality, self-confidence and optimism have also been shown to enhance 'resilient coping' during difficult times (Bonanno, 2004; Tedeschi & Kilmer, 2005; Walsh, 1998). Resilience is a prevalent phenomenon that develops from common and accessible human resources that can be found among friends, families and communities, and which are drawn together to enhance an individual's ability to cope with adversity. Being able to identify and utilise the protective factors and processes that can enhance resilience has implications for health and well-being.

Resilience and treatment for hepatitis C

There are several reasons for the idea of resilience, as it is described in the research literature, being relevant to the experience of those receiving hepatitis C treatment. To begin with, this treatment is administered over a long period and the widely acknowledged side effects

can make coping with treatment a difficult experience. Added to this, a majority of people with hepatitis C in the Australian population are living in socially and economically marginalised circumstances; they include former or current injecting drug users, people who are incarcerated or who have been in custodial settings, people from ethnic minority communities, indigenous Australians and youth (Dore et al., 2003). For many who exist on the margins of mainstream society, hepatitis C treatment is simply another hurdle to negotiate in lives routinely confronted by formidable challenges. During hepatitis C treatment, participants in this study often applied adaptive responses that they had learnt from past experiences of adversity as a way of coping with treatment-related impacts. Drawing on past research into similarly adverse contexts, we explore the factors and processes that participants reported had helped them to cope during treatment.

Lessons from the past

Notable in our data were participants' reports of having drawn on prior experiences of chronic illness, drug dependence, childhood abuse and social disadvantage to assist them to cope during treatment. They used their personal skills, family support, community resources, welfare organisations and support groups, and professional assistance from counsellors and psychologists. As the extracts in this chapter show, participants identified a range of protective factors and processes that had enhanced their capacity to cope during hard times in the past, and recognised that these strategies could be adapted to cope with hepatitis C treatment.

Drawing on past experience of drug dependence

Kate, 38, interviewed in the final week of a 48-week treatment regimen, reported having experienced severe muscle and joint pain during treatment for hepatitis C. However, she said that her experience of withdrawing from opioids several years earlier had taught her to cope with the physical pain of the side effects of treatment. Depression was Kate's most significant side effect during treatment and she reported that her prior experience of having received counselling during drug treatment, combined with a knowledge of how to access and use the services of mental health practitioners, assisted her in overcoming a major depressive episode during hepatitis C treatment. Kate acknowledged that her experience of withdrawing from heroin and methadone had assisted her in dealing with the physical pain and emotional swings associated with hepatitis C treatment. When she compared herself with other members of her support

group, Kate believed that she was able to cope with the side effects better than people who had not experienced what she described as intense emotional and physical pain:

Yeah, I just think that [hepatitis C treatment] is a reality that you have to deal with. That's learnt only through having been through heroin addiction and stuff like that ... and even my friends would say that to me, before I started treatment: 'You'll breeze through it! You've been through heroin addiction; it'll be a walk in the park' ... And in a way I kind of agree ... I do feel sorry for people who've never experienced ... that level of discomfort in their lives. Yes, [hepatitis C treatment] would be tough for them. But I've kind of been through it before ... just the rough knocks during my life too ... because I'd been through withdrawals and all of that, so of course I could handle, you know, itchy skin or that physical side of things ... because heroin addiction ... and actually getting off methadone was worse.

(Kate)

Treatment represented an opportunity for Kate to rid herself of hepatitis C, and eradication of the viral infection symbolically and tangibly helped her to move on from her past. Treatment also provided an opportunity for her to address several emotional issues. The protective factors that helped Kate to create a stable environment from which significant adaptive change could occur included re-establishing herself in a geographic area where she had lived as a child, with her family, friends and familiar places close by. As she explained:

So when I got back to [city] I thought ... 'What a perfect time to start treatment' ... I've got a nice little flat in [a suburb] near the beach ... I felt as fit and as healthy as I'd probably ever be, because I was off drugs and I was near the beach and I love swimming. So I thought, 'Now is probably the perfect time to do it ... I'm going to take advantage of the hospital; I'm going to see the counsellors' ... That was another project to do, to get myself sorted out ... And that's what I did. I would take advantage of the counsellors here and have very long talks.

(Kate)

Kate was able to put processes in place that helped her to cope during difficult periods and to lessen the impact of treatment. She had the support of her family, friends and the psychological services at the liver clinic where she was treated. She also made use of the Hepatitis C Council of New South Wales, which offered a range of information about hepatitis C and acted as a directory for relevant support services. She made a renewed commitment to getting fit, learnt more about her health, drew on the advice of psychologists and regularly attended counselling sessions.

Living with chronic illness

Other participants also saw treatment as an opportunity to address areas of their life that had been neglected. Treatment was a chance both to eradicate the chronic and debilitating symptoms of hepatitis C and to improve their quality of life. Gerry, a 48-year-old man who was interviewed in the final week of a 24-week regimen, reported having lived for many years with the symptoms of

‘[H]aving lived with chronic pain for the whole of my adult life basically, I already had coping mechanisms to handle those things ...’

hepatitis C infection, which included chronic abdominal pain, insomnia and lethargy. He believed that chronic fatigue had led to depression. Like Kate, Gerry reported that his long experience of coping with adverse health conditions had enhanced his capacity to deal with treatment side effects:

[H]aving lived with chronic pain for the whole of my adult life basically, I already had coping mechanisms to handle those things ... I’m used to just not being able to get out of bed for two or three days in a row. That happens occasionally; I just live with it ... [I] may be in a better position than some other people to cope with the [hepatitis C] treatment because I’m used to being in a debilitated state ... that’s not a good thing, but it’s a fact. I guess the coping mechanisms were always there, from over a long period of time.

(Gerry)

Gerry reported that in the early phase of treatment his poor lifestyle had made his side effects worse and limited his capacity to adhere to therapy. To optimise his chances of successfully completing treatment, Gerry used a resource he had identified years earlier among his social network; that is, he sought the financial assistance of a friend. Extra funds enabled him to move into an apartment that had essentials like running water. Gerry claimed that he needed to do this to complete his treatment. He reported that his improved income made it easier to establish basic healthy living patterns:

I didn’t seem to have any kind of future if I didn’t eliminate some of my health problems ... so I made a commitment to doing [hepatitis C treatment] ... [I]t’s been very good for me that I got some extra assistance during this treatment from one of my friends, without which there is no way I would have made it through,

financially. So I’m living in a much more comfortable environment than I was living in before the treatment. That helped enormously ... [A]t the beginning of the treatment, I started cooking for myself and I saved so much money on eating out which, you know, I had to do before because I didn’t have any cooking facilities—no fridge, no stove that worked, no hot water in the sink. So that lifestyle improvement made a big difference.

(Gerry)

Sean, 35, also acknowledged that he had coped with hepatitis C treatment by learning from his past experience of living with poor health. He managed by drawing on his established support networks and by doing what he had learnt to do as an outcome of living with haemophilia. Complying with strict dosing regimens was a normal daily activity for Sean:

I self-treat and have done since I was about ten. I just self-manage, self-regulate it ... I think, with haemophilia too, you tend to be a bit onwards and upwards in your approach to things. It’s like okay, right, you started Day One with haemophilia and it throws a whole lot of challenges and you sort of deal with those however you wish ... But again, I’m very much the type who won’t let it hinder me; I’ll keep forging ahead ... I’m normally a very optimistic person, very up-beat ... very much a Type A personality.

(Sean)

A factor that helped Sean was a well-developed support network which included his wife, friends and work colleagues. Determination to eradicate hepatitis C infection and an unerring optimism regarding his future health were behind his capacity to cope with the side effects of treatment. While theories of resilience have moved away from emphasising personality traits as the sole agents in coping with adversity, the literature does acknowledge that qualities like optimism and determination can assist in the development of resilient coping (Luthar & Cicchetti, 2000).

Experiences of social disadvantage

As well as earlier experiences of alcohol and other drug dependence and living with symptoms of chronic illness, several participants described traumatic childhood events and growing up in socially disadvantaged environments as contexts in which they had acquired adaptive practices. Marsden, 50, who was interviewed as his treatment was ending, reported that he had coped with interferon-induced depression by drawing on his past response to experiences of childhood sexual abuse. He described feeling happiest while alone during treatment and said that

isolating himself from other people when depressed was a strategy he had learnt as a child:

So I've coped [with depression] without any anti-depressants. So I just keep to myself. You know, I get very irritated and very short with people and I've got no time talking crap ... So I just keep to myself. I'm like a hermit at the moment, to keep ... safe, you know. So that I don't hurt anybody and I don't hurt myself. And I don't have a problem with that because, as a child being sexually abused, I put myself in an isolated world anyway to protect myself ... So I don't have a problem isolating myself and that's how I cope with the hep C [treatment] ... I realise it's not what happens in life. It's how you deal with it; you have to deal with it the best way you can. And isolating myself works ... [M]aybe the sexual abuse as a child was a lesson to be able to cope with this now.

(Marsden)

For Marsden, reducing social interaction lessened the likelihood of damaging his relationships. Certain responses to trauma, like self-imposed isolation, are typically seen as problematic. However, some strategies that appear dangerous may lead to adaptive outcomes in some contexts. Bonanno (2004) discusses the variety of pathways to resilience, often unexpected, that have appeared in past research. For example, 'repressive coping', a strategy in which unpleasant thoughts, emotions and memories are avoided, has been observed to be an adaptive strategy among one group of people with histories of sexual abuse. This process of coping seems to be an outcome of managing the emotions that arise from stressful situations rather than directly addressing the problem. Although it is not possible from Marsden's extract to assume similar mechanisms at work, he had applied a strategy that would commonly have been understood to be psychologically unhealthy (i.e. isolating oneself) and this had helped him to get through hepatitis C treatment. Isolation reduced the risk of interpersonal conflict, yet he was still able to make use of community resources and successfully interact with services that he had used in previous periods of financial difficulty, namely sponsored food vans that provided free meals to homeless and disadvantaged people. The literature describes such knowledge and use of community resources as key factors that enhance adaptation to difficult circumstances (Tedeschi & Kilmer, 2005). Combined with self-imposed isolation, these strategies facilitated Marsden's successful completion of treatment.

Past research has explored the contribution that spiritual belief might make to building resilience. Spirituality has been described as a protective factor in coping with ageing, disease and loss among some older people and those recovering from alcohol misuse (Bower, 1996; King et al., 2003). Sharing spiritual beliefs has reportedly helped

some people to foster and sustain supportive relationships and led to new understandings of the self. In our study, several participants reported that they had been long-term members of twelve-step abstinence-based fellowship groups, such as Narcotics Anonymous, following years of alcohol and other drug dependence. From these group experiences they reported acquiring personal support and life skills that were subsequently enlisted to cope with the impact of hepatitis C treatment. Chloe, a self-described former injecting drug user and alcoholic, reported having had a 16-year membership of two fellowship groups. At the time of interview, Chloe was halfway through 48 weeks of treatment and had encountered severe physical and psychiatric side effects, including major depression, anxiety, obsessive behaviour, anger, paranoia, mouth ulcers, painful skin rashes, body aches and hair loss. She described her fellowship groups and several individuals as pillars of support during treatment:

Even though I'm struggling in the water quite a lot, I have that faith somewhere in there ... I know when I go [to the fellowship groups] ... it's a good thing for me to go. Even if I'm raging and angry, I just go there and I'm in a safe, good place and I recognise that. I'm not going there to be good; I'm going there because I feel terrible. And I don't know how to heal myself ... I try and go there a couple or three times a week. I go there and I know that I'm actively participating in something that is beneficial and loving, I suppose, and forgiving ...

(Chloe)

Chloe reported that the main processes that supported her during treatment were counselling sessions, being familiar with the dynamics of support groups, praying, and walking several times a week with people from her church. She would contact support group members to vent her feelings when side effects became particularly bothersome, an effective strategy that she had learnt from her fellowship:

I just think the support is really, really important. We probably should try to organise more hep C support groups because [my fellowship support group] was the most important thing for me, to actually identify with people to whom I could say, 'Look, I feel so insane! I can't stand this one more minute!' Just being able to talk to people who felt like that ... What works for me is just to be able to go, 'Yes, I'm mad and it feels mad,' and to be able to ring someone up and cry, 'I'm really sad. This is really lonely. This is horrible.'

(Chloe)

Conclusion

People receiving hepatitis C treatment are often living in marginalised and socially disadvantaged circumstances. Paradoxically, for some people, the experience of

marginalisation may enhance resilience. Our study participants applied adaptive strategies learnt during prior adversity to enable them to cope with the difficult side effects of hepatitis C treatment. This finding is clinically relevant to health professionals managing hepatitis C treatment regimens. However, further research is needed to enable a clearer understanding of the role of marginalisation and resilient coping in the context of clinical treatment.

Promoting interventions that build resilience among people receiving hepatitis C treatment might produce beneficial outcomes. Evidence from past research into chronic illness and disability indicates that people who develop resilient coping strategies are better able to handle the demands created by disease and disability than people who have not developed protective factors and processes (Genke, 2004; King et al., 2003; Salonijs-Pasternak, 2004). An outcome of this past research has

been the growth of peer support and early intervention programs that assist children and adolescents to adjust to the hardships and limitations imposed by illness and disability. These approaches can help to empower families, build individual capacity, encourage collaboration between health care services and capitalise on the social systems that can support children and adolescents with chronic illness and disability (Epps & Jackson, 2000; Gerhardt et al., 2004; Olsson et al., 2005). Similar interventions have been developed to enhance resilience in gay men ageing with chronic illness. Strategies have been implemented to assist in coping with crises, isolation and mistrust of social institutions and these have significantly improved gay men's quality of life (Genke, 2004). In the context of clinical treatment, the 'art' in this science is for clinicians to be able to uncover strengths and domains in a patient's life that can potentially reinforce the ability to cope during hepatitis C treatment. We explore this further in the next section.

6 Strengths-based assessment in the management of treatment

Treatment for hepatitis C infection is usually managed by a multidisciplinary team of specialist physicians and nurses working in clinics attached to large metropolitan hospitals (Leone, 2002; Strinko et al., 2004; Potgieter et al., 2005). A model of shared care is adopted to manage treatment, address side effects and help patients to adhere to the treatment regimen (Australian National Council on AIDS, Hepatitis C and Related Diseases [ANCAHRD], 2003). Patients graduate from weekly to monthly appointments with their health care team once treatment has begun. Such ongoing contact enables health professionals to monitor patients in case they develop problems like blood abnormalities, a common reason for reducing doses and discontinuing treatment (Manns et al., 2001). At these facilities, patients also have access to psychologists, psychiatrists and social workers who assist them to deal with the social and psychiatric impacts of

An approach that would assist clinicians and patients to better manage the side effects of hepatitis C treatment ... might be beneficial in increasing the number of people who do complete treatment.

therapy (ANCAHRD, 2003). Clinicians understand that social and psychiatric support of patients is important to maximise their adherence to treatment and help them to complete the regimen. Nonetheless, a significant proportion of people treated in large-scale randomised clinical trials discontinue treatment, mostly because trial participants have problems coping with the side effects of treatment (Bernstein et al., 2002; Potgieter et al., 2005).

While many people do complete treatment, the experience can be challenging. An approach that would assist clinicians and patients to better manage the side effects of hepatitis C treatment and improve patients' quality of life during treatment might be beneficial in increasing

the number of people who do complete treatment. To explore this idea, we report findings from this study that (i) describe the approach to preparing patients for treatment used in several facilities in Sydney, Australia and (ii) report health professionals' perspectives on managing hepatitis C treatment. We conclude with a discussion of a method of assessment of patients' strengths that could be used alongside current approaches in pre-treatment clinical evaluations.

Clinical assessment of patients before treatment begins

In general, health professionals reportedly applied a deficits-based approach to managing treatment; that is, they planned to respond to problems as they arose. Our participants reported that their pre-treatment assessment focused on issues such as to whom they would disclose that they were in treatment and who in a patient's family, social and work-related networks would be available to support them during treatment:

I would be wanting to know if there was anyone that they could talk to about it [hepatitis C treatment]. Who would they talk to about it if things went wrong?

(Social worker)

[T]elling [patients] to perhaps inform their next of kin or their significant others and close people around them [about their treatment] so that they can gather as much support as they possibly can, so if they do run into problems on treatment there's some back-up there for them.

(Nurse 2)

Say, for example, if someone is in full-time employment and they are in a really stressful work environment ... they will need to consider, 'What happens if I need to have down time from work? What happens if I need to have a little bit of leave? What happens if I'm so debilitated that I need to reduce my hours or stop work completely?' So they need to give that

a bit of consideration and look at their projects that they're juggling during that six- or twelve-months' period ...

(Nurse 5)

Health professionals reported that pre-treatment interviews were designed to assess the likely risks to an individual during treatment, for example, whether or not they had a history of drug dependence:

[I]t brings up a lot of issues being on treatment, a lot of stuff around needles ... I mean, you're injecting yourself every week and, often, for a lot of people ... there [is] lots and lots of work that needs to be done on that before people are presented with their dose and we say, 'Go stick this in your stomach or the top of your thigh ...'

(Social worker)

‘Teamwork is imperative ...
Communication is vital. Empathy is
useful.’

Meetings held before treatment began allowed health professionals to inform people about side effects, to highlight the medical interventions that could help to lessen the impact of physical side effects in particular, and to reassure people:

I think [patients] need to know that they can contact you at any stage, that these side effects are very real, they're very predictable, that they are the norm and it's just a matter of letting us know and working out a plan of action so that they are able to cope with it.

(Nurse 1)

And it's a big help for [patients], too, to know that we've got a dietitian, counsellors, we've got a psychologist, psychiatrist, the nurses are here, you know, to give reassurance, to be realistic but to reassure as well and making them fully aware of what they're entering into ...

(Nurse 4)

[I] just talk to [patients] about what their expectation of treatment might be, what are the possible side effects that may affect them. I suppose you don't want to scare people completely with this but to be honest it is really important ...

(Nurse 3)

Certainly, allowing preparation time for treatment can have a huge benefit ... [L]istening, validating, being

organised, being professional, making [them] aware that there's an excellent communication amongst the team here. Teamwork is imperative ... Communication is vital. Empathy is useful.

(Nurse 5)

Finally, nurses and social workers used pre-treatment interviews to inform people about support groups and to discuss issues relevant to people with children, like how to cope simultaneously with side effects and children's needs. In summary, the purpose of pre-treatment interviews was to anticipate and prevent minor problems and avoid exacerbating pre-existing problems if possible, by identifying individuals' vulnerabilities and supports. The interviews were an opportunity to open up communication between clinic staff and patients, to establish a rapport and to provide a context where patients felt safe.

Health professionals' perspectives on the resilience of patients

It was common for health professionals to remark on patients' varying abilities to adjust in order to cope with the demands of hepatitis C treatment and its side effects. Nurses noted that some people withstood the impact of side effects well and were able to adapt their lifestyles according to the severity of symptoms they experienced. They also reported that, although many people receiving treatment were from low socio-economic and disadvantaged backgrounds where concerns like food, shelter and alcohol and other drug dependence often overshadowed health needs, many viewed treatment as an opportunity to make positive lifestyle changes, and that, during treatment, patients often demonstrated a revitalised engagement with their health and a renewed interest in their future. For some patients, commencing hepatitis C treatment represented a turning point, or a life-changing event involving a fundamental shift in the meaning, purpose or direction of life (King et al., 2003).

Really a lot of [patients] use [treatment] as an opportunity to turn their life around and 'I'm going to cure the hep C as a change for the better' ... But it can take a lot to get there. It's quite a journey.

(Nurse 4)

Nurses referred to patients' backgrounds as proving grounds for adaptive coping strategies. They reported that some patients successfully adapted to treatment because they could incorporate past responses to hardship and were familiar with community services and able to use them effectively. Health professionals reported that patients often had clever resolutions for complex problems they faced during treatment:

Oh, I think a lot of coping strategies that patients use do work for a great proportion of them ... [Y]eah, they tell me different things about how they manage ... so we talk about what they did in the past when they had some bad times ...

(Nurse 2)

There's also a cultural thing there too, I think ... [M]y experience with patients [who have come from developing countries] ... they're just more accepting that ... 'Well, this is the treatment, this is a side effect, this is what I've got to do to get rid of it' ... Maybe it's their life experiences so that this [treatment], for them, is a piece of cake ... [Also] patients who've had a history of depression and may have had antidepressants ... seem to cope a lot better with the mood fluctuations [associated with interferon-based treatments]. And I think that's just because they've already got those coping mechanisms there ... They know what to do, they're not frightened to put their hand up and they will seek assistance ...

(Nurse 1)

[S]ome [patients] are more resilient because they say, 'I've been through everything in life,' or, 'Life's thrown everything at me. Well, I'll be fine,' but some are really resilient like that and will tend to draw on services a lot more to help them through ... especially the co-infected guys with HIV and hep C, the gay population. They're totally different because a lot of them have already been exposed to having to be in a routine to take the antiretrovirals [for HIV] and they have already had to take notice of their lifestyle and their blood counts and all of that ... And they're very, very organised. They plan everything ... so they cope with side effects a lot better because they are more organised.

(Nurse 4)

Clinicians acknowledged a relationship between their patients' prior experiences of adversity and present ability to be resilient and cope. This association might have significant implications for patients' ability to adhere to treatment and complete the treatment regimen (Tedeschi & Kilmer, 2005).

Strengths-based assessment during pre-treatment interviews

When assessing patients before treatment begins, it may be helpful to implement an assessment procedure aimed at uncovering both the patients' strengths acquired from past experience and the human and material resources currently available to them. While our data did contain evidence of clinic staff's informally assessing strengths

during pre-treatment interviews, this was limited to identifying additional sources of support available to patients if they had problems with the side effects of treatment. On the other hand, strengths-based assessment produces a detailed picture of the quantity and quality of support that patients receive from partners, families, friends and communities, as well as measuring individuals' emotional and behavioural skills, competencies and characteristics that help to build strong, satisfying relationships with others (Epstein & Sharma, 1998). When drawn together, these factors enhance an individual's ability to cope with adverse conditions (Bonanno, 2004; King et al., 2003; Tedeschi & Kilmer, 2005).

The resilience literature can be used to guide a strategy of strengths-based assessment by means of a variety of checklists, open-ended questions and validated quantitative instruments that identify and measure individuals' risk factors and resources, such as access to support (Luthar & Cicchetti, 2000; Tedeschi & Kilmer, 2005). To illustrate, in light of consistent research findings about the importance of positive family relationships in fostering resilience (e.g. Gerhardt et al., 2004; Trickett et al., 2004), validated assessment instruments that focus on family environment (Epstein et al., 1983; Moos et al., 1994) can help clinicians to assess factors associated with positive adjustment to hepatitis C treatment, such as family support. By assessing their strengths, health professionals might assist individuals to better withstand the impacts of treatment.

Conclusion

From our data it is apparent that patients have applied adaptive and protective strategies learnt from past experiences of adversity to their experience of hepatitis C treatment as a means of enhancing their resilience. This is clinically relevant to professionals managing hepatitis C treatment regimens. These findings suggest that using strengths-based assessment during pre-treatment interviews can provide an opportunity for health professionals to learn about the adaptive and protective strategies their patients have acquired from prior experience. Strengths-based assessment can assist clinicians to determine the resources available to patients and to uncover detailed information about the availability, nature and quality of support and other resources. A focus on an individual's strengths, as well as vulnerabilities, can empower patients by acknowledging their agency as effective social beings with competencies and resources that they can use to assist their progress throughout this challenging treatment regimen.

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