

Recovery from hepatitis C treatments

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MONOGRAPH 6/2009

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Max Hopwood



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Executive summary

- For some participants, clearing hepatitis C infection resulted in renewed energy, improvements in mood and relief from worrying about future health consequences of hepatitis C infection.
- However other participants had difficulty noticing any improvements in their health following treatment, while some perceived that new health problems had emerged after treatment.
- Participants who did not clear hepatitis C infection reframed treatment non-response in order to cope with the stress that it provoked. Reframing was assisted by factors like improved liver function test results and the likelihood that more effective treatments will become available in the future.
- Of the 27 participants in this study, 25 reported persistent physical and psychological side effects/symptoms after completing hepatitis C treatments.
- Eleven participants said that their symptoms had lasted for up to one year after treatment had finished and 14 participants said that their symptoms had lasted for more than one year after treatment.
- Cognitive impairments like fatigue and 'brain-fog' were the most commonly reported ongoing side effects/symptoms. Ongoing physical symptoms like muscle aches and skin problems were also commonly reported. Persistent physical and psychological symptoms impacted on everyday activities like sleeping, socialising and employment.
- Informed consent procedures did not address the post-treatment period and participants were not forewarned of the possibility of ongoing side effects after treatment. Similarly, participants said that they were given unrealistic expectations about increased energy levels and improved quality of life from clearing infection.
- The end of treatment was a time when participants' demand for information was high.
- Little or no information was provided by specialists about what patients could expect in the months after treatment, and what to do and where to go if they experienced health problems.
- The clinic environment often intimidated participants and was a barrier to them seeking post-treatment information and medical care regarding persistent health problems.
- Specialist physicians rejected an association between the treatment regimen and participants' accounts of persistent side effects/symptoms.
- On the other hand, most participants perceived a direct causal link between treatment and their ongoing symptoms.
- The clinics and specialists' private practices had no comprehensive treatment termination protocols.
- Access to clinic staff, support and resources were severed after the administration of drugs had ceased.
- The notion of treatment 'success' was contested by participants. Clearing infection did not necessarily translate to feeling well. On the contrary, it could actually mean feeling worse than before treatment.
- Re-adjustment to life after treatment was difficult and exacerbated by persistent symptoms and no end of treatment referrals, support, information or advice.
- The post-treatment period often involved repairing relationships which were damaged during treatment.
- Participants' difficulties with emotions, strained relationships and trouble in coming to terms with non-response were exacerbated by a lack of post-treatment information, advice, referrals, support and medical care to address ongoing symptoms.
- The effects of treatment on wellbeing can last longer than the 24 or 48 week regimens.

Key recommendations

Introduction of survivorship programmes

The findings presented throughout this report raise concerns about current government strategies which are committed to increasing the number of people who undertake hepatitis C treatment by 2012. Evidently, many people do not clear their infection after having treatment and some people experience ongoing ill health caused by persistent side effects. Therefore, either the development of a more efficacious and tolerable treatment is required, or significantly more resources need to be allocated toward increasing the range of supports and health care services that are available to people during and after treatment for hepatitis C infection before more people with hepatitis C can be expected to consider treatment.

Post-treatment impairments to health and quality of life, problems of attribution regarding symptoms, poor access to information, and re-adjustment problems are all issues which could be addressed through end-of-treatment information, care and support programmes. These data indicate that at least some people, perhaps many, would benefit from an end of treatment protocol which addresses ongoing health and informational needs. Post-treatment information, referral and support programmes could assist with re-orientation to everyday life. Programmes should be available to those people who feel that they need a period of further support after treatment, or who are manifestly experiencing substantial treatment-related physical and mental health problems that require ongoing medical care. Some programmes may be developed and delivered by the treating liver clinics. Other programmes

like post-treatment information and telephone-support services may be provided exclusively by the state-based hepatitis councils. A similar and successful programmatic approach has been developed for survivors of cancer in the US and elsewhere. One example is the Memorial Sloan-Kettering Cancer Center Survivorship Programme in New York City. Development of a post-treatment programme for both hepatitis C treatment responders and non-responders could be based on models used for other chemotherapy patients, and modified for the specific requirements of people who have completed hepatitis C treatments. These programmes could also include counselling to help reduce the isolation, frustration, anxiety and disappointment which can overwhelm people at such a vulnerable time.

Further recommendations

Treatment-population based survey of people's health, wellbeing and quality of life from six months to at least two years post-treatment is required. This survey will determine the prevalence of ongoing health problems among people treated for hepatitis C infection.

Informed consent protocol used to prepare people for interferon-based treatments for hepatitis C infection should be expanded to include information about the risks of ongoing health problems caused by the therapeutic drugs. People considering or commencing treatment need to be alerted to the possibility of ongoing treatment-related impacts for lengthy periods after treatment finishes, even if survey findings indicate that the risk is small.

Introduction

Hepatitis C is a highly infectious blood borne virus that can cause serious liver damage, and it is often resistant to eradication via treatment with antiviral drugs (Crofts et al., 2001). Since identification of the hepatitis C virus (HCV) in 1989, medical research has focused on the effectiveness of interferon-based therapies to lessen the impact of symptoms and to eradicate chronic infection (Sievert, 2001). A cure is achieved if, following a blood test to detect virus RNA, hepatitis C remains undetectable for a period of six months after treatment is completed. Past research has shown that elimination of hepatitis C from the body can lead to reported improvements in measures of health-related quality of life (Ware et al., 1999).

While rates of viral clearance have improved significantly in recent years, the toxicity of antiviral drugs and the duration of treatment—either twenty four or forty eight weeks depending on factors such as viral genotype—present significant challenges for patients. In large randomised controlled trials of hepatitis C treatments there are high rates of dose reduction and treatment discontinuation due to the side effects of the therapeutic drugs (Bernstein et al., 2001). Patients in trials usually discontinue interferon-based treatments because of psychiatric impacts, which include depression, anxiety, amotivation, suicidal ideation, anorexia and paranoia (Majer et al., 2008; Raison et al., 2005; Dieperink et al., 2000; Kraus et al., 2000). Similar side effects have long been reported in children and adults receiving interferon-based treatment for other diseases such as melanoma (Caraceni et al., 1998; Merimsky & Chaitchik, 1992).

According to the clinical literature, side effects usually disappear soon after

interferon-based treatment stops, however evidence of persistent neurotoxicity, or ongoing impact to the central nervous system, exists among people treated for both hepatitis C (Monji et al., 1998; Reichenberg et al., 2005) and cancer (Meyers et al., 1991). In one study, fourteen cancer patients reported incapacitating psychiatric side effects long after they had completed treatment with interferon alpha, and the authors suggested that in some cases interferon-related neurotoxicity is irreversible (Meyers et al., 1991). Similarly, there are reports of persistent physical side effects including sarcoidosis—a skin disease—in those treated for hepatitis C (Hurst & Mauro, 2005), and in some people an immune system disorder—autoimmune thrombocytopenia—has developed six months following completion of pegylated interferon and ribavirin treatment (Elefsiniotis et al., 2006).

Pegylated interferon and ribavirin therapy is currently the best treatment available for hepatitis C infection; it is important to balance understanding of its therapeutic benefits against the risks associated with its widespread use. Given that there is no vaccine for hepatitis C infection, treatment and education are currently the only preventative measures available to reduce hepatitis C transmission rates. It is vital to monitor post-treatment outcomes on quality of life because the advent of persistent health impacts for example will have implications for efforts to maximize the uptake of treatment. While there are new treatments in the pipeline, interferon-based regimens for hepatitis C infection will remain the best practice approach for the foreseeable future, and the phenomena explored in this study will remain relevant to a significant number of people who are considering treatment in the years ahead.

Description of the study

Background to the study

Presently, about three thousand people commence treatment for hepatitis C infection each year in Australia. However there is very little information in the research literature about the types of issues which people experience in the period following completion of hepatitis C treatment. The implications of either clearing or not clearing hepatitis C in relation to overall quality of life are poorly understood. Given this, the National Centre in HIV Social Research (NCHSR) conducted an interview-based study in 2008 and 2009 which aimed to investigate a range of outcomes from hepatitis C treatments. Specifically, the findings of this study explored (i) the impact of different treatment outcomes on participants' quality of life; (ii) participants' perceptions and experiences of post-treatment symptoms; and (iii) participants' access to post-treatment health services, referral, information and support.

Method

Participants were recruited in New South Wales and Victoria via advertisements placed in *The Hep C Review* and *Good Liver*, quarterly publications of the Hepatitis C Council of NSW and Hepatitis C Victoria respectively. To be eligible for participation in the study, people had to have completed an interferon-based treatment for hepatitis C at least six months prior to the interview. Participants were interviewed via telephone or face-to-face. Most had received treatment in NSW and Victorian metropolitan clinics and specialists' private practices. However one participant had received treatment in Queensland at a metropolitan liver clinic, and another had been treated at a metropolitan hospital in the United Kingdom immediately before moving to Australia in 2008.

Participants

Participants were aged from 26 to 57 years, with an average age of 46 years (Table 1). The sample comprised 27 people, which included 14 women and 13 men. Most participants had been treated for genotype 1 during 2006 and 2007. In all, 22 participants had been treated once, four participants had been treated twice, and one participant had received interferon-based treatments three times. Of the 27 participants, 12 had cleared hepatitis C after treatment, 13 had not responded to treatment, and two participants did not know if they had cleared their infection at the time of interview. All participants in this study were assigned a pseudonym.

Qualitative method

The study used a qualitative method to explore post-treatment outcomes. An aim of this method is to provide a detailed understanding of phenomena; in this case, participants' experiences and perspectives on hepatitis C treatments. In-depth interviews allowed researchers to understand what it felt like to have particular side effects or symptoms after treatment and how these impacted on participants' quality of life. In-depth interviews were conducted with people who reported good post-treatment health outcomes, and those who had ongoing health-related problems after treatment. Two overarching themes were identified in these data (Braun & Clarke, 2006). They were: (i) renewal and recovery following viral clearance or non-response, and (ii) the clinics' (and private specialists') end of treatment protocols including post-treatment provision of healthcare, information and support.

Often people who have had more extreme experiences self-select to be part of qualitative research. Indeed two participants in this study described themselves as 'outliers', meaning they believed that their

personal experiences of the post-treatment period were highly unusual. However, all accounts of post-treatment outcomes are important to document. People with 'unusual' experiences to report contribute to understanding the range of all possible outcomes. The reason for highlighting the more problematic post-treatment experiences as this report

does, is to: (i) describe the difficulties that at least some participants had in coping with the post-treatment period; (ii) inform the development of future treatment-population based studies of ongoing health impacts; and (iii) help to find ways to address ongoing post-hepatitis C treatment problems.

Findings

Feeling renewed from clearing hepatitis C infection

The following section highlights the theme of renewal, which was described by several participants who had cleared their hepatitis C infection. The theme illustrates how interferon-based treatments, when successful, can restore health and provide

"I just feel like something has shifted. I'm able to do more in my day. I have a bit more stamina. I'm able to cope with it better. That's wonderful."

a sense of rejuvenation by freeing people from the physical and psychological constraints that are imposed by hepatitis C infection. Renewal implies that the treatments have restorative powers and that people behave, feel and think differently after they have been through the treatment regimen. The theme 'renewal' evokes the power of modern medicine to transform lives for the better.

For example, Jasmine reported that she had felt contaminated and depressed when living with hepatitis C. After treatment had successfully cleared her infection, the change in the way Jasmine felt and how she viewed her life was significant:

It's been terrific ... it has all been good. Like I know some people have ongoing issues, but I didn't ... And my mood is, you know, I have real zest for life. Like I'm much, much happier, and the difference between how it was is just incredible. (Jasmine, 54, cleared HCV, treated in 2007)

Similarly, Mary spoke about noticeable increases in energy and an improved capacity to function after clearing her infection:

I just feel like something has shifted. I'm able to do more in my day. I have a bit more stamina. I'm able to cope with it better. That's wonderful. I think it shows how much the hepatitis C does impact. I knew it was impacting on me.

When you've lived with it for a very long time and it's quite subtle and it's quite insidious ... [then] your conception of what's normal has changed ... You don't know ... So I feel a real difference. (Mary, 35, cleared HCV, treated in 2007)

The post-treatment period was a time when participants looked forward to overcoming isolation and, for some, a sense of shame. Some saw clearing hepatitis C infection as an opportunity to build new relationships:

I guess a bit of guilt has been lifted ... when I used to think about having sex with another woman, I used to get feelings of guilt. Like, 'I would really like to have sex with her, but I have got hep C, so maybe I shouldn't. Like it's a bit wrong. Those kind of thoughts. (Nugget, 29, cleared HCV, treated in 2006)

Most participants in this study had either stopped or reduced their illicit and licit drug use during treatment and the post-treatment period. Stopping drug use, including alcohol and cigarettes, had opened up new experiences and different ways of thinking which enabled some people to gain new perspectives on old 'issues'. These participants viewed both treatment and the post-treatment period as times of heightened self-awareness:

I had a bit of an epiphany during my treatment, as I call it ... Besides being awful, [treatment] was a great time for a reflection, self reflection. Because I didn't drink, I didn't take anything... nothing. [It's] probably a long time since I've been that straight, except for the interferon ... Believe me I've noticed a few things. I call it BT and AT ... Before treatment and after treatment ... [T]o me it's like separating my life. It's like before and after. Now we're finished with that bit, it's moving on ... never going back there again. (Sandra, 47, cleared HCV, treated in 2007)

[B]efore treatment, I always wanted to be in a place that I wasn't. I always

wanted to be fit and healthy. I used to smoke, I always wanted to quit smoking ... But it took all the treatment to get rid of all my bad habits, to make me realise smoking wasn't me ... So the treatment pushed me off the train tracks that I was on, and put me on to the train tracks that I always wanted to be on ... (Josh, 26, cleared HCV, treated in 2006).

Partial 'renewal' after treatment

Not all participants who had successfully cleared hepatitis C infection described a sense of being renewed. Some, like Elly, acknowledged that while they no longer had hepatitis C they were still concerned about the consequences for their future health of having had a chronic infection:

I think for me, it's not like I was sick and now I'm healthy. I sort of feel like I've gotten better, but I will still have liver problems ... So it's not like a clear line in the sand for me ... I think there is a good chance that I do have the cirrhosis though and I do have to get it looked at ... (Elly, 42, cleared HCV, treated in 2006)

Others had difficulty deciding if there had been any improvements in their life from clearing hepatitis C. For example, Joanne expressed conflicting opinions when asked if she felt renewed; for her there was no tangible improvement from clearing hepatitis C, but she acknowledged a new optimism regarding her future:

[B]ecause there is nothing concrete that has changed. It is not like all of a sudden I am in a better house, and I have got a better job, and I have got a better boyfriend, and I have gone on better holidays. Life is still the same as it was pretty much. So I wouldn't say it's a new me. It's still me [laugh] ... I couldn't really think of a huge difference unfortunately. I shouldn't say that. There has been a huge difference in it. I mean, I am not getting symptoms from hep C anymore. I feel like a burden has been taken off me. And I do feel like I have made an investment into my future now ... (Joanne, 41, cleared HCV, treated in 2007)

Conclusion

Among the twelve participants who had cleared their infection, a minority claimed that their quality of life at the time of interview had noticeably improved. These participants said that they had more energy and their mood was better. Most participants were relieved from worrying about the future health consequences of hepatitis C infection however some who had cleared their infection were still concerned that hepatitis C may have caused damage which would compromise their future health.

Recovery after hepatitis C treatments

The theme 'recovery' was evoked by almost all participants in this study, whether or not they had cleared their infection. This was because the majority of study participants took months, and sometimes years, to overcome the impact of treatment. Recovery was particularly difficult for people when treatment had failed. The following section highlights issues pertaining to recovery among people who had not cleared hepatitis C infection after treatment.

When treatment fails, there is nothing that can be done to change the outcome. All that anyone can do in such a situation is to look for ways to cope with the stress (Lazarus & Folkman, 1984) that treatment failure provokes, in order to make a bad outcome more bearable. Participants in this study for whom treatment had not cleared their infection usually expressed disappointment, anger, frustration, fear and/or sadness at hearing the news of their non-response and realising that there was nothing that they could do to change it. These initial reactions were often followed by efforts to reframe treatment non-response (Satir, 1983). Reframing is an emotion-focused coping strategy whereby people look at events in their lives from a different viewpoint. In this study, reframing indicated that participants had commenced a process of accepting their poor treatment outcome. Reframing was helped by participants' awareness of trials of future treatments which promise to be more effective and tolerable than the current regimen:

I find my mind works like you get a bit of bad news and pretty soon after your mind starts to try and turn it round and look for the best in it, look for the positive and look for ways to deal with it I suppose. So, I started sort of saying to myself, well you know there's other things [i.e., new treatments] around the corner ... (Patrick, 50, non-responder, treated in 2006)

Re-framing of non-response was helped by information gleaned from clinicians and hepatitis councils. This stated that treatment had been worthwhile even if it had not cleared infection, because it had given the liver a brief respite from the ravages of a high viral load. Participants' recovery and their acceptance of treatment's failure to clear infection were assisted by seeing liver function test results improve following treatment:

I sort of had a talk with the gastroenterologist about it, and basically he sort of made me feel a bit better in that he said "Well, but having the treatment you have basically cleared your system of it for X amount of time, which is not going to do you any harm in the long term." And my blood levels have been actually better

post-treatment than pre-treatment even though I have still got the virus. So I am happy about that side of things. So that made me feel a bit more positive about it being worth while going through the regime every week, and every day with the tablets ... So I don't see now that it was a waste of time. And hopefully there will be some other treatments come. (Nathan, 52, non-responder, treated in 2006)

[B]ecause it [treatment] hasn't been successful, that makes one hell of a difference obviously. So you're not getting that pick up ... one of the good things ... I hadn't been able to get my ALTs under control. They were always in the 150, 160 mark ... After the treatment ... I have results around the 50 mark. (Chris, 52, non-responder, treated in 1993, 1999 & 2005)

Nonetheless, adapting to the reality of ongoing infection despite one or more courses of treatment was difficult for most participants. Another psychological coping strategy, known as downward comparison, was commonly used. This is when an individual increases their sense of wellbeing through comparison with less fortunate others (Wills, 1981). For example Alice, the oldest participant in this study had gone through 48 weeks of treatment in 2006. Witnessing the hardships of poverty in India where Alice had lived before coming to Australia had helped her to contextualise and accept her non-response to treatment:

I've been many places. I've seen a lot of stuff. It just puts everything into perspective. I don't see the point in saying 'Why is it happening to me?' I don't have problems if some people say that. I'm not critical of somebody who says that. Their experience is different. I've been so lucky to have the experiences that I've had. That I can truly say. (Alice, 57, non-responder, treated in 2006)

Reframing and downward comparison were not strategies that everyone automatically assumed. The failure of treatment to eradicate infection was profoundly disturbing for some participants. At times news of treatment failure

“I think [the news of my non-response] hit me more the next day. I was pissed off real bad actually. I was really pissed off.”

took a while to sink in, and when it did some became overwhelmed by the implications. These participants tried to find their own ways to cope with the stress that not clearing infection provoked. Some had to first overcome their anger at the treatment regimen for making them feel so terrible, for so long, for no gain:

I think [the news of my non-response] hit me more the next day. I was pissed off real bad actually. I was really pissed off. (Tom, 54, non-responder, treated in 2006)

Accepting treatment non-response was often difficult because it involved participants facing their fear of the future, or accepting that their future will be different to how they had always hoped and imagined. Virginia's narrative below resonates with a phenomenon observed among some cancer patients and referred to as a loss of future memory. This describes the profound disappointment in people who are mourning the failure to realize the future they had planned and anticipated for themselves:

I thought I was going to clear! I really did ... and my drug use and ill health and all of that was going to be a memory. And I cannot begin to tell you what a dream that was for me ... I remember having all these fantasies about my life post-clearance. Just interactions with people, or extending our mortgage to do renovation, or all these lovely fantasies, and I was never going to have to explain [hepatitis C] to anyone. I was never going to have to be afraid anymore. (Virginia, 43, non-responder, treated in 2006)

Virginia had initially coped with her disappointment by participating in chat room discussions on a website dedicated to hepatitis C treatment experiences. However, she had stopped visiting the site since becoming alarmed when hearing about other non-responders' health problems. Virginia was very anxious about her health at the time of interview:

Oh, gosh, without doubt the number one thing is fear. I am a lot more fearful. And I hate that. I live with fear almost every day. And I think it is because I am now symptomatic ... with the presence of symptoms comes the fear, so that is the biggest thing for me ... I do ruin my current quality of life by worrying about what all these symptoms mean, and where I am going to end up. So I am playing this constant tug-of-war between the part of me that wants to live a quality life, and not be afraid, and to just enjoy the present, and then the part of me that sinks under, and has got an extremely sore stomach, is sore all over, is afraid. So I think to define how it has been after treatment, is that battle. (Virginia, 43, non-responder, treated in 2006)

Treatment failure and learning to cope with it required self-reflection and this could eventually lead to a heightened self-awareness. For some participants, increasing self-awareness took time to emerge. But even when participants had gained significant personal insight from being through treatment, they were still vulnerable to having good and bad days:

Yeah, it was still about a year after treatment before I could get to the point where I could see ... I was negatively reinforcing old patterns. And I felt that now I haven't cleared the virus and there is no hope for me. Then I started adopting a new way of thinking. Even though I didn't cure the virus and I still live with hep C I'm going to have the best life I can have anyway. So I started shifting the focus from not curing the virus onto having the best life regardless of still having hep C. And that was a major change for me to get where I am today. Which is I feel a lot freer, than being weighed down by it all. Sometimes I have a bad day, when I'm not feeling well, I feel a bit sad, but I don't go down emotionally, because I used to get sucked into that depression thing about it. (Leonora, 52, non-responder, treated in 2005).

Participants for whom treatment had not cleared infection usually said that they would need to alter some of their risk behaviours and lifestyle patterns in order to reduce the impact of ongoing hepatitis C infection on their future health. Reducing drug use, supplementing diet and increasing exercise were key strategies used by participants to enhance their health while living with ongoing infection:

I pretty much stopped drinking and I figured if I can maintain that, and do the same with ... not just alcohol but minimise sort of any kind of pain killers ... I try to make sure that my diet is as good as I can afford it to be. Take whatever supplements I can afford to take on a regular basis. As I said I kind of added an exercise thing to that ... that was my theory, that if I just kind of lived as high quality a lifestyle as I possibly can, with regards to my [health] ... then that's got to have an effect ... (Joe, 38, non-responder, treated in 2005)

On the other hand, not all participants in this study for whom treatment had failed to clear their infection had made life-style changes to protect their health. Some had indicated that they were struggling to cope. Two years since completing treatment for the third time, Chris was experiencing chronic fatigue and he had resumed injecting while on an opiate substitution treatment programme. Asked whether *not* clearing infection had affected the way he cared about his health and wellbeing, Chris reported:

I wouldn't be taking the H [heroin] if I cared that much. Honestly I wouldn't be ... Everything gets put off, because of lack of energy. Particularly at the moment, because of the H. That really does slow me down a lot ... [But] you're looking at two and a half years of interferon, plus the bupe, plus heroin; that really brings you up to a long period of time where you're not normal. (Chris, 52, non-responder, treated in 1993, 1999 & 2005)

Recovery from treatment was particularly difficult for people who did not clear hepatitis C. The period of recuperation after treatment was a time when they were

often simultaneously coping with treatment-related health problems while trying to come to terms with the confinement imposed on their life by the continuing presence of infection. Often, via the psychological processes of reframing and downward comparison, participants learned to cope with the stress that the failure of treatment triggered. Some resolved to take better care of their health and keep abreast of developments in new treatments. However others were overwhelmed by the implications of ongoing hepatitis C infection, and anxiety and fear of the future had seriously diminished their quality of life.

Health and wellbeing after treatment

This section further explores the theme 'recovery'. It focuses on a variety of reported post-treatment health problems and how they compromised participants' quality of life during recovery from treatment. These problems affected people who had cleared hepatitis C and those who had not. Of the 27 participants in this study, only two reported that they did not have any post-treatment symptoms. On the other hand, 25 participants out of 27 reported ongoing physical and psychological symptoms. Of these 25 people, six said that their symptoms had resolved within six months of finishing treatment; five participants said that their symptoms had lasted for between six months and one year; and eight participants said that their symptoms persisted for between a year and two years after treatment. A further six participants reported post-treatment health problems which had lasted for between two and eight years. Finally, two participants said that their symptoms were new and appeared after treatment was over.

These health problems were perceived by participants to be the result of treatment because the symptoms were the same as, or similar to, the side effects that participants had experienced during treatment. Throughout the report the terms side effects and symptoms are used interchangeably to describe ongoing health problems after treatment is completed.

Ongoing psychiatric symptoms

Psychiatric symptoms following treatment completion varied widely from depression and anorexia to poor concentration and forgetfulness. However there were some striking commonalities between reports too, as seen in the extracts below. The most commonly reported psychiatric symptoms were persistent cognitive impairments like 'brain-fog' which affected approximately 12 participants in this study. These symptoms were particularly difficult to manage without some form of medical and psychological

"The one thing that I've really noticed ...
I feel less intelligent. I cannot express
myself very well. I've lost a lot of words.
Does that make sense?"

assistance, as they affected a range of functions and activities like memory and socialising. Some participants expressed concern that treatment may have caused permanent brain damage because their speech and concentration were badly affected and they had noticeable declines in other areas of cognitive functioning:

You have got me on a good day today, but I sometimes... I can't... I just lose words. I can't form ... You know, I just can't really think. Can't follow a train of thought. I am just a bit like a goldfish. (Merrick, 43, non-responder, treated in 2004)

I am less mentally alert than I was. I find trouble drawing words, and trying to recall things. It just doesn't come as clearly as it might have once. (Nicole, 43, cleared HCV, treated in 2007)

The one thing that I've really noticed ... I feel less intelligent. I cannot express myself very well. I've lost a lot of words. Does that make sense? I stumble to get the word out ... I feel like I've lost a few IQ points. Does that make sense? ... I can't speak properly either ... I can't think of the words ... Simple words. Words that I would use normally in everyday language ... I still struggle to find certain words when I'm talking to people. Especially adjectives, things like that. (Sandra, 47, cleared HCV, treated in 2007)

Previous research has found that interferon alpha-induced confusional states are typically characterised by disorientation, lethargy, somnolence, psychomotor retardation, difficulties with speaking and writing, Parkinsonism and psychotic symptoms (Raison et al., 2005). The post-treatment cognitive impairments and psychiatric impacts reported in this current study are consistent with these previous findings. Post-treatment psychiatric symptoms were similar or identical to the psychiatric side effects reported by people during treatment. They had affected fundamental aspects of participants' personalities and reduced their desire and capacity for example to socialise. Below, Matt who had been affected by cognitive impairments and depression during and after treatment perceived that his usual patterns of socialising and style of interacting with people had substantially altered:

Yeah, I don't want to socialise with people at all. That is actually against my nature, because before [treatment] I was very social, outgoing. And now absolutely I don't want to socialise with other people ... Actually I put these people on hold. I don't talk with them. They actually talk with my wife, but I don't seek any relations ... So I rather go back and don't meet them ... it is direct effect [of treatment]. (Matt, 49, non-responder, treated in 2007)

Ongoing physical symptoms

Another commonly reported post-treatment outcome was ongoing physical symptoms. These ranged from general aches and pains to impotency. Skin problems were also common; for some, these were a minor annoyance, but for other participants skin problems led to extreme itchiness and infections which affected their ability to sleep. Being unable to sleep had serious impacts on participants' general health and wellbeing. Ongoing physical symptoms affected participants' capacity to function at a variety of levels, such as in the workplace:

I never had problems with my skin. I mean when you get to my sort of age you sort of know what you have a tendency to have and what you don't. I never had skin problems, but the last 2 years [I've had] a lot of skin infections and like fungal infections ... and I've got one at the moment. And I'm kind of back to not sleeping because the itching is driving me nuts ... I had the skin problems during treatment. And now I've had them at least three times in the last 2 years ... I just seem to be prone to skin things where I wasn't prone to skin things before [treatment]. (Annie, 48, cleared HCV, treated in 2006)

The side effects do last for a considerable time after. The actual physical side effects of the drugs last for several months. I was still feeling unwell up until about three months. I would say even longer for the aches and pains in my joints. I would say my shoulders and everything was so sore for even 4 or 5 months after treatment. (Johnny, 47, cleared HCV, treated in 2007)

Two men in this study said that during treatment, and up to the time of their interview, they had lost interest in sex and had problems with sexual functioning. Both men said that this was very unlike them:

I forgot the one very important thing for men. It is after this treatment I am actually impotent. One hundred percent impotent. So before I was like a bull, but now I can't actually... (Matt, 49, non-responder, treated in 2007)

[W]e didn't do anything while I was on the treatment. I was too bugged, and I had not the inkling anyway. And before treatment I think we were quite normal, if anything more than normal, because it was still a fairly new relationship. But no, I haven't got the energy to bother anymore, and I haven't got the sex drive anyway ... I think it was once this year. I think it might have happened once last year. But I might not ever bother again. (Tom, 54, non-responder, treated in 2006)

The implications of these conditions for quality of life are as varied as the symptoms; among other things, they can detrimentally affect intimate relationships and social re-adjustment.

Psychiatric and physical post-treatment symptoms were sometimes so incapacitating that they compromised participants' ability to perceive and avoid everyday risks. Some were unaware of their vulnerability to risk and

"That's something the doctors don't look at, which I think they should ... whether someone is safe to be driving or not ... if you've got concentration and severe fatigue problems, then you are probably not safe driving ..."

carried on as they normally would. For example, Alexis and others said that they were a potential danger to themselves and anyone around them when they were driving cars and operating machinery after treatment:

And then I went back to work ... and I still wasn't driving, because I didn't feel safe. That's something the doctors don't look at, which I think they should ... whether someone is safe to be driving or not ... if you've got concentration and severe fatigue problems, then you are probably not safe driving, and particularly not driving for extended periods ... I drove to pick up the kids from school ... [but] I did a couple of stupid things one day, and my sister was in the car, and so that made me aware of them ... I thought "No, that's it. I'm not safe." (Alexis, 53, cleared HCV, treated in 2004)

Post-treatment psychiatric and physical health impacts constituted the main burden of recovery from treatment. However, several participants also spoke of the difficulties they had in managing their expectations about the health benefits, like increased energy, that they believed would accrue from clearing infection. Participants said that they had formed exaggerated expectations on the basis of

information usually obtained from clinicians while they were being prepared for treatment:

I kept waiting for this surge of energy and people would then say 'Oh don't worry it can take 6 months.' And then they say 'It can take a year.' Up to about a year I was kind of hanging out for this transformation or something. I was going to get all this energy back and not feel tired and kind of feel a little bit more clear headed. And it kind of just didn't really happen. I just feel exactly the same as I did before I started. (Annie, 48, cleared HCV, treated in 2006)

Informed consent

Many participants were surprised and perplexed by continuing symptoms and newly emerging health problems after completing treatment. Pre-treatment preparation and informed consent protocols had not forewarned them of the possibility that side effects could continue after treatment had finished. For example, Josh said emphatically:

They told me nothing. Nothing. Zilch ... I have never heard a word from the doctors, the nurses, anyone at the hospital about what to expect or feel after treatment. (Josh, 26, cleared HCV, treated in 2006)

Given that half the people treated for genotype 1 do not clear their infection after 48 weeks of treatment, information about the risk of post-treatment difficulties would have influenced some participants' decision to commence treatment. Matt indicated that he would have declined treatment if he had been told about the possibility of persistent treatment-related health problems:

The information that I got before the treatment, there was something about side effects, but nothing about what could happen after treatment ... the most important is if I knew before what will happen after treatment, or during treatment, I will never ever put myself on such [a regimen] ... 50% actually is not enough. (Matt, 49, non-response, treated in 2007)

It is possible that some participants had been warned of ongoing health risks before they had started treatment, but that they had forgotten. Or they may have experienced information-overload while being prepared for treatment.

[P]eople need to be told, and reminded, that there is a risk that the effects of treatment can last longer than 24 or 48 weeks ...

Similarly, some may have not read information statements (if indeed they had received them), or they may have misinterpreted the information provided to them. Nonetheless, people need to be told, and reminded, that there is a risk that the effects of treatment can last longer than 24 or 48 weeks, and that there is a risk that some of these effects may be irreversible.

The findings of this study highlight a need for research which describes for example the proportion of people who are treated that go on to experience persistent health problems, and how these affect their quality of life. These findings would help people make an informed decision about starting treatment.

Information needs after treatment

Participants often said that they found it impossible to locate reliable information about the health problems that people face once treatment had ceased. The clinics sometimes provided snippets of information to patients at the end of treatment but it reinforced the belief that side effects always subside within a couple of months of finishing treatment. Participants wanted to hear about post-treatment health outcomes from another authoritative source, particularly when their side effects had lasted longer than a couple of months. They also wanted information about how to address specific ongoing health impacts from treatment:

It would be good to know whether there is any data that suggests whether [persistent skin problems] could be connected to the hep C treatment, and therefore any suggestions about how the skin problems might be handled ... If anyone's actually researched that, it would be good to know. Is there something different you should do with your skin after hep C treatment to decrease your chance of getting all these kind of skin infections and fungal infections or whatever? (Annie, 48, cleared HCV, treated in 2006)

Participants searched the internet to find reliable sources of information based on research about issues ranging from skin problems to sexual dysfunction. However they were frustrated by an absence of information on any topic to do with post-treatment health outcomes:

I am always trying to look for more information. Because I get my wife on the computer ... she racked every computer site about hep C in the world earlier on ... Nothing. I can never remember [seeing] anything ever about post treatment. Ever! (Tom, 54, non-responder, treated in 2006)

Participants were often grateful for the work of the state-based hepatitis councils as these organisations were

seen to be one source of authoritative information. The Councils have services like telephone help-lines where some were able to have a post-treatment discussion with empathetic and knowledgeable staff members who often had first-hand experience of treatment:

Well, I kind of got all of the support that I needed after treatment, because I finally got onto the Hep C Council of Victoria. And see they have a help line ... I rang them, and got onto to this great guy ... The first conversation that I had with him ... was around the time I'd stopped, and I learned more from him in the first ten minutes than I had from any of my doctors. And I sort of started talking to him regularly and it was like just 'Oh, yes! I finally have someone I can talk to! A sane voice, who understands what I'm going through.' Because he's been through it [treatment] ... (Elly, 42, cleared HCV, treated in 2006)

But many people completing treatment do not know about the information and services which are provided by the state-based and national hepatitis councils, unless they are recommended and referred to these organisations by someone.

Conclusion

The previous sections have highlighted some post-treatment health problems as participants had experienced them and how these problems impacted on their quality of life. While not all the reported side effects/symptoms remained for long periods after treatment, some did, and many of these constituted potentially serious health issues. Of particular concern were the long-term consequences of cognitive impairments like 'brain-fog' that affected participants' ability to function in a variety of contexts. Participants in this study said that while being prepared for treatment they were not alerted to the possibility of sustained psychiatric and physical post-treatment side effects, nor the impact these could have on their daily activities. Finally, the previous sections also highlighted the difficulties participants had with locating information to help understand and address ongoing health problems after treatment.

Attributing the cause(s) of ongoing symptoms

This section draws attention to the problems that participants had in attributing the cause of ongoing physical and psychological health problems after treatment; were they an outcome of the treatment drugs, difficulty adjusting to finishing treatment, underlying liver damage, or in those people who did not clear their

infection, the return of hepatitis C? Or were their health problems a mix of all or some of these possible causes, and if so how much was attributable to each one? Naturally, the study participants were curious to understand the reasons behind persistent health problems.

The problem of attribution is articulated by Julie when she proposes three possible reasons for her ongoing depression;

“The depression hasn't completely gone, but how much of that can I put down to the hep C or the treatment or life circumstances, I don't know.”

however she was given no information after treatment and she had no way of knowing how much each possible cause contributed to her problem:

The depression hasn't completely gone, but how much of that can I put down to the hep C or the treatment or life circumstances, I don't know. I don't know how to quantify what percentage is from treatment ... it was because of the treatment that I needed to go on the anti-depressants ... I don't know if it has continued to affect me since the treatment or not, because I don't know how to quantify it. (Julie, 48, non-responder, treated in 2000)

With regard to those participants for whom treatment had not cleared their infection, being able to correctly attribute the source(s) of ongoing post-treatment health problems had implications for their decisions regarding future treatment. For example, Joe had not responded after 48 weeks of treatment. He cited several possible explanations for his ongoing poor health. His decision to attempt a future treatment however is contingent on understanding more about the long-term impact of the therapeutic drugs, continuing hepatitis C infection and underlying liver damage:

Well, I did the treatment and then it took me at least 12 months to recover ... But the idea that it might be the virus that is causing me to be so lethargic all the time means that I kind of feel like I don't really have much choice. If I get an opportunity to do some new drug or whatever then ... it kind of feels like I don't have a choice ... but again that's the question: is it actually the virus causing my lethargy and what not or is it something else? ... I don't know that I would think that it was *all* about the treatment. My sort of rational mind says ... 'Okay, it's a combination of the virus with my fibrosis.' That's how I kind of understand it [but]

I don't know if that's sort of accurate or ...? (Joe, 38, non-responder, treated in 2005)

Many in this study said that they wanted to see research findings, particularly estimates of the proportions of people who had experienced post-treatment health problems which were attributable to interferon-based treatments. They wanted to know about the effects of the therapeutic drugs on things like immune function, mood, eye-sight, hearing, memory and thinking and they wanted to know how long the effects lasted. Some believed that the pharmaceutical companies should provide more information about persistent side effects and the long-term impacts of hepatitis C treatments. Participants often referred to the large number of people online who report persistent side effects and ongoing poor health after treatment. These online stories alarmed participants and

“I guess I would have to say that I am grateful to have cleared the disease ... Having said that, my quality of life is not what I thought it would be ... I think I would like to know from the drug companies' perspective, what the long term effects are that they have come up with. I would like to know that ...”

provided further evidence that for some reason they had not been fully informed about the possible impact of the regimen on their health before they had started treatment:

I guess I would have to say that I am grateful to have cleared the disease ... Having said that, my quality of life is not what I thought it would be ... I think I would like to know from the drug companies' perspective, what the long term effects are that they have come up with. I would like to know that ... I said to my doctor "What do the drug companies themselves say? What are their studies on this?" ... I was prepared to believe that I was an outlier ... that perhaps I was just one of the really unlucky ones, but apparently there are thousands of people [reporting post-treatment problems]. (Nicole, 43, cleared HCV, treated in 2007)

Conclusion

A proportion of the after-effects of hepatitis C treatments may be attributable to adjustment disorders which are sometimes evident in people transitioning from health to illness or illness to health. For example, the end of

treatment is noted as a difficult period among people with cancer, where people have problems adjusting to life following intensive chemotherapy. In this context, people may experience problems in adapting to changed health conditions and a new set of life circumstances that that brings. However, some post-treatment difficulties among cancer patients are understood to be a result of cognitive impairments related to the impact of chemotherapy (colloquially referred to as 'chemo-brain'). Similarly, a proportion of post-hepatitis C treatment adjustment difficulties are likely to be attributable to the ongoing impact of side effects from the treatment drugs. In which case, to assist people to re-adjust there needs to be greater access to information about persistent side effects and an option for further medical care after treatment to address these side effects. Problems with attribution and re-adjustment were also exacerbated by false or exaggerated expectations caused in part by a selective use of pre-treatment information, and an absence of ongoing clinical engagement with post-treatment problems. Re-adjustment to life after treatment is discussed in more detail later in this report. The following section continues investigation of participants' belief that their post-treatment health problems were at least partially caused by persistent side effects.

Persistent 'side effects'

Participants reported that specialists usually trivialised or dismissed their testimonies of ongoing side effects from treatment. They were told that the levels of interferon and ribavirin in their systems reduce quickly, and disappear completely, after treatment ceased. Therefore, according to specialists, any ongoing health problems could not be caused by the therapeutic drugs. Conversely, participants often perceived a direct causal relationship, and were perplexed by specialists' rejection of any association between treatment, persistent side effects and longer-term health impacts. For example, treatment had cleared Collette's infection eight years earlier and at the time of her interview she reported chronic fatigue and 'brain-fog' which she said had continued in the years since her treatment. These conditions had prevented her from holding down a fulltime job. She was frustrated that her symptoms were not acknowledged as at least partially attributable to treatment. Collette had not received any referral from the specialist that treated her nor had she received follow-up care from her clinic for these symptoms:

[T]he main thing that bothered me was my brain ...
[The doctors] weren't even interested in it afterwards ...
[W]hen I came to the 12 months after the treatment,
and I was still feeling that way, I think then they should
have kind of maybe followed up a bit more or referred

me onto different people ... instead of just shrugging their shoulders and saying "Look well we don't know when you're going to get better" ... but really that should have been a red flag for them ... Also ... I had more symptoms after treatment than before. It was like the treatment was worse than the disease, definitely ... I'm definitely worse after the treatment. (Collette, 39, cleared HCV, treated in 1999 & 2000)

When ongoing symptoms affected participants' mood and ability to think, clinicians sometimes characterised these people as malingerers and hypochondriacs. Consequently, some people in this study had battled self-doubt and had questioned their perception of a link between treatment and their poor mental health. Nonetheless, after some time, Elly felt confident enough in her own perception to reject her specialists' referrals to a psychiatrist:

[Y]ou know how they have this term 'brain fog' ... well for me that's a bit of a misnomer. For me it was more like dementia ... I was told that it was all in my head ... and was referred to see a psychiatrist. And I can assure you that it wasn't ... but when two specialists tell you that something must be in your head ... I thought 'Well, I have really got to look at this. Maybe I am depressed and I don't realize it.' But I wasn't ... I just think it's really important because it just seems like this whole 'It takes one or two months to get over' which the doctors are currently all sort of saying is just simply not true. (Elly, 42, cleared HCV, treated in 2006)

Speculation regarding the origin of post-treatment health problems led several participants to seek the assistance of their general practitioners. However, their general practitioners usually did not know much about hepatitis C treatments:

The weird thing is that every month that I go to see the doctor, and I say to him "My joints ache and my back hurts, and I wake up in the night with my fingers and feet sort of tingling sometimes, and my hearing loss, and the ringing in my ears" and all that sort of thing. Every month he sort of says "Oh, polyarthralgia, or arthritis". He sort of makes up something different every time I go in ... But it doesn't explain why ... I have still got skin sensitivity, and I can't use any soap or anything like that. I would have to try to wear cottons and all that kind of thing ... [My GP] has also said what [my specialist] says, that all these symptoms go within six months of you being off the treatment. Whereas for me they didn't ... (Nicole, 43, cleared HCV, treated in 2007)

Sometimes, symptoms did not emerge until shortly after treatment finished. For example, Deacon started to experience skin problems several weeks after his treatment had ceased. He persevered in finding answers—and a remedy—and it was eventually confirmed by the specialist

that treated him that this condition was indeed related to treatment:

... [T]here is a rare side-effect [of hepatitis C treatment] called sarcoidosis where sarcoidal granuloma form ... They can be fatal ... when I finished treatment I came up in all these lumps all over my body ... Eventually I convinced one doctor to send me to an ultrasound ... in between this I was also emailing [my specialist] and I said '... are there any rare side-effects I should know about?' ... he didn't tell me about any rare side-effects ... when I emailed [my specialist with the ultrasound result], he says "Oh, yes. I had another patient." There is six documented cases of it. Of it coming up after treatment, rather than during treatment ... About four or five weeks after treatment. (Deacon, 53, non-responder, treated in 1991 & 2006)

As highlighted in the introduction to this report, previous studies have identified the emergence of new physical symptoms in patients after they had completed treatment (Hurst & Mauro, 2005; Elefsiniotis et al., 2006). Similarly, for some participants in this study, psychological symptoms emerged after treatment. These presented significant issues, as access to the treating clinics' psychologists and counsellors were withdrawn by the time symptoms appeared:

I knew from talking to people that it wasn't going to be easy when I stopped [treatment]. But I didn't expect the psychological stuff to come in like it did. I was expecting it to happen when I was on the interferon. So I stopped and I got really depressed ... My mood was going up and down. The physical stuff was happening, really up and down. The way I explained it to myself, it was *like* drug withdrawals and I mean it was like drug withdrawals. My body had become habituated to these drugs I was putting into it. It was like now it was trying to regain equilibrium ... one day I was incredibly speedy and ... other days I would be exhausted and very depressed. It was horrible. (Mary, 35, cleared HCV, treated in 2007)

Finally, because of the difficulties participants had obtaining information from their clinic about persistent side effects and symptoms they often turned to the internet as an alternative source of information. Some web-postings from former-patients presented anecdotal evidence about serious ongoing treatment-related side effects, which provoked further anxiety in participants. These postings included testimonies of irreversible damage caused by interferon-based hepatitis C treatments. Irreversible damage to cognition has been previously documented in the context of interferon-based cancer treatments (Meyers et al., 1991). In the minds of some participants in this present study, the lack of clinical research into post-treatment health problems among

"[T]he website I found, it had sort of a conspiratorial sort of feel to it. And I don't sort of subscribe to that way of thinking ... but that is where people are pushed to. Because all of these people are feeling the kind of things that I am feeling and experiencing it, and not getting a proper education for it."

people treated for hepatitis C, and their specialists' disengagement with these issues, was feeding online rumour and hysteria:

[T]he website I found, it had sort of a conspiratorial sort of feel to it. And I don't sort of subscribe to that way of thinking, although it is kind of enticing a little bit when you are feeling quite crappy. To want to have to blame someone, and to think of a big picture, and drug companies, and cartels and that sort of thing. But that is where people are pushed to. Because all of these people are feeling the kind of things that I am feeling and experiencing it, and not getting a proper education for it. (Nicole, 43, cleared HCV, treated in 2007)

Conclusion

Repeatedly in this sample, participants recounted health problems which they perceived as having at least some connection with treatment for hepatitis C. Persistent treatment-related side-effects and new symptoms that emerge after treatment raise the question of the clinics' duty of care, and when it ceases. Is it ethical to withdraw clinical services and put people back on the street without any after-care, support, information or avenue for referral when some people, who may have no other support options available to them, are still heavily affected by the treatment drugs, and often for considerable amounts of time? A lack of opportunity for patient feedback—as well as a lack of clinical research into persistent treatment-related impacts on health—may reinforce a sense among some clinicians that after treatment is completed, all side effects and symptoms disappear, people return to normal and everything is alright.

End-of-treatment protocols

This section draws on a second major theme which was identified in the study; the clinic. It explores end of treatment protocols and highlights participants' accounts

that once their treatment had finished they were cut-off from further access to clinic staff, health care advice, medical remedies to address persistent side effects, support services and information resources.

Generally, participants in this study expressed a great deal of admiration and gratitude for the work of clinicians. However, specialists were often perceived as pre-occupied with participants' clinical markers and disinterested in anything that they could not measure. While there were several notable exceptions, participants characterised specialists as poor communicators and they appeared disengaged with the concerns of patients. These traits had implications for the provision of adequate end of treatment protocols and follow-up care. Some said that their specialists did not allow them enough time to talk about their health problems during their final appointment, and when receiving their PCR test result at a subsequent appointment. For example, after his treatment Tom had experienced a variety of health problems like chronic fatigue, memory problems, and his libido had all but disappeared:

Like my bloke [the specialist] said ... 'No, you are not cured. Come and see me in about a year's time.' And when I did see him in that year's time, he said 'No need for you to see me for a couple of years now at least.' That was it. Just got up 'Good bye.' No chatting about nothing [that was worrying me] ... He does his job, that's all he wants to do, I think. (Tom, 54, non-responder, treated in 2006)

As noted earlier, the end of treatment was a time when participants' information needs were high. However there was no evidence presented in this study of a systematic, patient-centred termination procedure where participants could be referred to sources of information and advice. This underpinned many of the problems that participants

"[The virus] came back ... but that issue wasn't really dealt with post treatment ... It seemed to be left up to me to do anything from there on ..."

reported and compromised their ability to recover and move on after treatment. Apart from a reminder to come back for their PCR test, participants were not given any information, referrals, counselling, or assistance with ongoing health problems. They often felt abandoned by their clinic:

[The virus] came back ... but that issue wasn't really dealt with post treatment ... It seemed to be left up to me to do anything from there on, rather than them say: 'Here is a list of contacts if you need to talk to anybody

post-treatment, or whatever' ... (Nathan, 52, non-responder, treated in 2006)

When participants were asked why they did not contact their clinic to seek advice and information about treatment non-response and ongoing health problems, they said they either hadn't considered seeking their advice, or they felt too intimidated by the clinic, or they were too embarrassed to complain. As a result, some potentially serious ongoing treatment-related health problems were left unaddressed. For example, Joanne said that she had become anorexic during treatment. More than two years after completing treatment she still had evidence of an eating disorder however she had not alerted her specialist or sought help from her clinic because she said there was no end of treatment protocol that encouraged her to feed back ongoing health problems to her clinic. If there had been a structured system of post-treatment follow-up care it would have enabled her eating disorder to be monitored and treated:

Yeah, I liked food. I could quite easily eat my three meals a day and snacks in between. Now [since treatment] I have got to make a conscious effort that I eat one good meal a day ... Yeah, maybe I should tell the doctors one day. I haven't been back to them for a year. Because that one hasn't gone. I have still got that one (Joanne, 41, cleared HCV, treated in 2007)

Instead of encouraging patients to keep the clinic informed of progress or problems after treatment, nurses 'signalled' to patients, or explicitly stated, that after they had been discharged the clinic's services and supports would no longer be available to them. These messages were major barriers to the participants contacting their clinic for help:

I guess there must have been some kind of signalling that this was the cut off and it didn't occur to me to call the clinic [for post-treatment help] ... I suppose it might have been good to have access to a CNC for a period post [treatment] ... to have felt kind of okay, to sort of bother them with that kind of stuff, post treatment I suppose. Until some of those things settled down. (Annie, 48, cleared HCV, treated in 2006)

I felt a little bit that once the treatment [finished] and I had that six months follow-up, and you are sort of off their books then so to speak. I felt that there was just like a line that you had come to, and you weren't sort of able to go past it ... like if you needed to speak to the psychologist or something ... I suppose I basically put it down to a couple of sentences [the nurse] said was just that "Well, the treatment is finished, you have been through the post-treatment side of having your testing." And she gave me the impression that was sort of the end of the road. And I just didn't really feel that I was invited as such to make any further contact. (Nathan, 52, non-responder, treated in 2006)

In this study, at the end of treatment, information or advice was only provided to those who had an opportunity to make an enquiry and who were confident enough to ask for it. Often the information provided was inconsistent, vague and unhelpful:

After treatment ... I asked them, "How long would it be before I feel better?" They said "We're not sure, a few months to a year ... You know... you should be feeling okay in six months." ... Yeah, and that was it. (Sandra, 47, cleared HCV, treated in 2007)

No. There wasn't any concrete advice. There was that 'the interferon should be gone all together by a month or so' ... that sort of thing ... 'You might feel tired for a very long time'. I asked 'When can I expect to feel better?' They said two months ... It wasn't really advice. (Johnny, 47, cleared HCV, treated in 2007)

Jarred said his clinic had no end of treatment protocol nor did they provide advice about for example the risks associated with drinking alcohol, and it was only because he had taken the initiative to ask that this vital issue was addressed:

I did ask 'Shall I stay off drink for a while?' ... So it was like 'Oh, well perhaps you ought to stay off of that.' But it was pretty vague ... that is one thing I think they could be a bit better with ... helping people after they have finished treatment, giving more advice about what to expect ... I suppose about things like drinking. Can you start drinking when you are off treatment? Or should you wait three months, six months? (Jarred, 47, unknown, treated in 2006)

Participants felt that their clinics' resources were too stretched to allow enough time for them to discuss issues which they perceived to be important for their recovery, at the end of treatment:

You really have a very short amount of time with them [at the end of treatment] ... I had to write down all the questions I had, because I would forget. I would be in a fluster ... and it was a very short amount of time ... They don't have the time ... You did feel a bit cast adrift onto the world again ... because [treatment] is an emotional journey too ... I guess it would have been good to have a really good debrief, or something. (Jasmine, 54, cleared HCV, treated in 2007)

“... [S]o you have all the support on treatment and then after treatment there's nothing. Even though you are still sick ...
Yeah, that upsets me.”

Finally, participants said that re-adjustment to life after treatment was compromised by the clinics' non-existent or inadequate treatment termination protocols. The abrupt way that treatment concluded had caught some off-guard:

... [S]o you have all the support on treatment and then after treatment there's nothing. Even though you are still sick ... Yeah, that upsets me. (Leonora, 52, non-responder, treated in 2005)

Conclusion

The increasing numbers of people with hepatitis C who are entering into treatment increases the likelihood that limited healthcare resources are a primary factor in the reported absence or inadequacy of treatment termination protocols. However, given the range of persistent side effects and the possibility of newly emerging symptoms reported by participants in this study, a comprehensive end of treatment protocol comprising information, advice and referrals for counselling and further medical care should be available to patients as this would significantly help their re-adjustment and transition back to health and wellbeing.

What is 'successful treatment'?

I have kind of turned into a nervous person ... it is like my nerves have been sort of shot to pieces or something from the treatment. It's been, I think it's been eight months now ... [The specialist and nurses] they just said 'You know a month or two after treatment, you will wake up, you will feel amazing, you will just feel fantastic.' (Elly, 42, cleared HCV, treated in 2006)

Participants said that during their pre-treatment interviews clinicians held out the promise that treatment would quickly lead to dramatically improved health and a sense of rejuvenation. For a couple in this study, treatment lived up to that promise, however many others believed that this promise was unrealistically optimistic and that the speed of recovery and treatment success should not be 'talked up' as much as they are. Rather than containing objective, factual information, some participants viewed the clinicians' pre-treatment rhetoric about recovery time and the restorative powers of clearing infection, like that reported above by Elly, as misleading, because it did not reflect their personal experiences of recovery from treatment.

In light of slow recovery times, persistent post-treatment side effects and ongoing health problems, participants in this study questioned the definition of successful treatment. Treatment success to participants was a contestable concept, as some, including those who had cleared infection, reported that their health was poorer after treatment than it was before treatment. For example, Collette's long-term health problems which she perceived

to be an outcome of receiving two years of treatment, where disregarded and over-shadowed by her specialist's focus on blood test results. When concern about clinical

"They follow up like I said for 12 months and all they really look at is your blood test results ... for them that's success. To me it's not."

markers took precedence over concern about wellbeing some participants questioned the relative value of clearing infection against a loss of quality of life:

I don't think they follow up for long enough. They follow up like I said for 12 months and all they really look at is your blood test results ... for them that's success. To me it's not. I've spent 10 years pretty much in my lounge room in my pyjamas. (Collette, 39, cleared HCV, treated in 1999 & 2000)

Among those participants who had not responded to treatment, some were angry about lingering side effects and poorer post-treatment quality of life. They were especially annoyed about what they perceived to be the clinics' provision of selective pre-treatment information. These participants provided the most critical voice in this study regarding hepatitis C treatment:

I am very disappointed and I regret that I went for this treatment ... Treatment didn't work, but that I was told that it will be 50/50, so I wasn't expecting much. But actually I feel worse now than before treatment ... [I'm disappointed] not that I don't get [rid] of the virus, but just that I got these symptoms ... they actually worry me more [than hepatitis C infection]. (Matt, 49, non-responder, treated in 2007)

Considering that there is a risk of lingering side effects and irreversible damage to health leading to poorer post-treatment quality of life, some participants in this study

'... if they want more people to go through treatment, I think they will have to find a drug that's not so onerous. Because for a lot of people [treatment is] not probably gonna be worth it.'

queried approaches which encourage more people with hepatitis C to have treatment, particularly for people with the difficult to eradicate genotypes:

If I had genotype 1, there is no way I would have done the treatment. Like to go that long, feeling that dreadful for the amount of hep C sort of effects I was having. Because the cost-benefit doesn't add up. I'd have had to have more medical evidence to tell me that I was high risk category for cirrhosis or liver cancer or something to go through a year of that kind of treatment ... if they want more people to go through treatment, I think they will have to find a drug that's not so onerous. Because for a lot of people [treatment is] not probably gonna be worth it. (Annie, 48, cleared HCV, treated in 2006)

Some participants refuted their specialists' claims that eradicating infection always leads to improved health and wellbeing. Some were angry and disillusioned with the public health 'spin' and their doctors' advice to get treated when their usual level of health and wellbeing was substantially diminished following treatment. For at least some people, 'successful treatment' will remain a contestable concept:

[My doctors] have done the job that they had intended to do. [Doctor X] has intended to get rid of this disease out of my body, and she has done that ... But as far as my quality of life goes, I can't say that that has improved. In fact I can tell you now that I have a lesser quality of life now than I did prior to treatment. (Nicole, 43, cleared HCV, treated in 2007)

Re-adjustment to life after treatment

Participants often found it hard to re-adjust to life after treatment. Underpinning the problems with re-adjustment were many of the issues discussed previously in this report. These included no access to information about post-treatment health problems, exaggerated expectations of recovery speed and health improvements, uncertainty in attributing the causes of ongoing health problems, and participants' sense that the clinics were disinterested in participants' health problems after their hepatitis C treatment had stopped. Often treatment had altered aspects of participants' personality, and ongoing health problems made it difficult to resume normal activities, like work. Participants had to learn how to relate again to partners, friends, family, and work-mates. Similarly, participants' had to re-adjust their daily routines after treatment as they no longer had to take medications and keep appointments at the clinic:

I felt like I lost myself for twelve months. And the treatment was such a focus that I had to force myself to do nothing all through treatment ... Afterwards it's the adjusting "What do I fill my life with now?" Because it [treatment] was such a focus for twelve months. Really intensely. ... having to work back to where you were

before treatment, that has been quite difficult ... It has taken me a long time ... (Josh, 26, cleared HCV, treated in 2006)

The interpersonal dynamics which existed between some clinicians and participants during treatment also affected re-adjustment. For example, presenting as a 'model-patient' - that is being compliant, adherent and motivated - was seen as helpful when interacting with the clinic team. Some participants reported presenting and behaving in ways they knew would please clinicians throughout treatment, regardless of their actual emotional state and physical condition. While this might have made the task of administering the therapeutic regime easier for the clinic, it came at an enormous personal cost for some patients and it compromised their ability to quickly re-adjust to life after treatment:

The nurse and the specialist ... called me their 'poster pin up boy' for treatment. I was so engaged and never missed an appointment; never missed a dose, went to every psychiatrist. I was so engaged in everything. They didn't see ... all they saw was this extraordinarily calm person sitting in front of them asking them pertinent and relevant questions, taking it all in, doing it all. They didn't see necessarily the effort and the crying. (Johnny, 47, cleared HCV, treated in 2007)

Similarly, in some health promotion literature regarding hepatitis C treatments there is advice for people to adopt and maintain 'a positive attitude' during treatment. However the health benefits of a positive attitude are contested in the research literature (e.g., Holt & Stephenson, 2006). While past studies have suggested a range of theories about why positive thinking *might* affect health, it is likely that a positive attitude functions indirectly, for example by identifying the bearer as someone of good moral character who is doing all they can to help themselves. In spite of this, caution is needed as an appeal to maintain a positive attitude can lead to behaviour which could undermine the integrity of the therapeutic relationship and ultimately add to the emotional burden of treatment and readjustment. For example, Mary, Leonora and others in this study tended to down-play potentially important health issues, censor information or lie if they thought the truth would not please their specialist:

I remember asking [my specialist] before I started treatment "Is there anything that you can sort of put your finger on that might explain how people do through treatment?" He said "A positive attitude". So ... the times after that I did [fake a positive attitude] ... I do remember bringing that to the floor, because I knew that he would respond to that [laughing] ... I was aware that that was a preferable attitude as far as getting a

positive response from the physician. I was right [sigh]. (Mary, 35, cleared HCV, treated in 2007)

Participants who had invested heavily in adopting a positive attitude felt disenchanted and powerless when treatment was not successful. They realised how limited their control over the outcome of treatment actually was. Coping strategies like reframing and downward comparison were difficult to implement and sustain when cynicism and disillusionment with treatment set in:

I felt really disappointed, because ... even though I read stories in the Hep C Review about people going through treatment: 'Oh a positive attitude is really important to have if you have cleared the virus or not.' Well, I had a really positive attitude. I was really sure that I was going to clear the virus ... So even after all of that I just felt a bit like 'Well, I had a positive attitude, well what went wrong?' So I was kind of questioning all of that. (Leonora, 52, non-responder, treated in 2005)

Presenting as a good patient and adopting a positive attitude to treatment is fine so long as it is a reflection of one's actual experience of self and health. It becomes a concern if people perceive that unless they do present in this way they will be seen as 'a difficult patient' and therefore not receive the clinicians' full engagement and support throughout treatment. From the point of view of clinicians, for a patient to pretend to be well when they actually are not could have unfortunate consequences, particularly if a patient is affected by depression or a similarly concealable but potentially serious disorder.

Emotions & relationships after treatment

Hepatitis C treatments are more than bio-medical regimens aimed at eradicating an infection; as one participant described it, treatment is also an 'emotional journey'. Because of the psychoactive properties of the antiviral agents, interferon and ribavirin, and the psychological changes and challenges that people encounter during the regimen, emotions were often frayed and unstable by treatment's end. The following narratives describe participants' accounts of changes which affected their emotions and relationships, and they point to the difficulties some had with recovering their sense-of-self in the post-treatment period.

Friends, partners and other close personal relationships were often the target of participants' anger and frustration during treatment. Participants were at times unaware of their behaviour, and those around them had to endure their emotional changes until treatment finished and their mood improved. For example, Kade was interviewed six months after finishing treatment and he was just becoming aware of the changes in him during treatment and the impact these had on his loved ones:

"I know now that when I was on the treatment I was being a pork chop ... You know, like an idiot. And now I do know, I can even feel in the relationship with my partner, my kids, friends and family and stuff like that, I am actually okay to be around now ... the people who knew I was on treatment were the ones I really picked on, and they were fine. I mean, I almost had a licence to do it, so [after treatment] all bridges were repaired."

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Partners of people receiving treatment were in a good position to see and appreciate the benefits of clearing infection:

I think that I'm probably a little bit easier to live with ... [My partner] said that I'm different. He's said that he can notice a difference between how I am when I finished and before I started ... [H]e can see a remarkable difference ... That's really gratifying. (Mary, 35, cleared HCV, treated in 2007)

Non-response to treatment placed a strain on relationships particularly when the after effects of the treatment drugs were being felt for prolonged periods. For example, persistent side effects like fatigue, headaches and impotency, together with the news of Matt's non-response, had taken their toll on his marriage. At the time of interview, Matt was desperate to find solutions to improve his health, and marriage problems, which he perceived were a direct outcome of treatment:

So [impotency] also I believe impact on relationship with my wife. Another, tiredness. That I am tired, so

another thing that I feel pain, and if you are in pain you can't do much more ... Look, my wife is intelligent woman, and she understands what is going on. Together when we talk about it we can cope. But we have hope that this will pass. If not, what can I say? (Matt, 49, non-responder, treated in 2007)

This final narrative reflects participants' sense of losing control over their health after not responding to treatment. Some were fearful of the future and found it difficult to remain optimistic in light of what they had endured during treatment and the abrupt withdrawal of medical care and psychological support services after treatment:

The biggest impact would be my emotional state about it. Because I was so looking forward to [treatment] working, and then I could work on getting my liver fixed a bit better ... That part particularly seems to be worse than still being in pain. Still knowing that I have the virus ... I was out there to kill it, and I was going to beat it, but I didn't beat it. So I felt like it beat me, so that sort of made me feel a bit ... depressed, I guess covers it. Because ... usually, you cut your finger and you can heal yourself, but I can't do that. (Germaine, 51, non-responder, treated in 2005)

Conclusion

There is a risk that after treatment physical and mental health will be affected for months and perhaps longer. For at least some people, re-adjustment to life after treatment, including social adjustment, will be a gradual process. This process could be assisted by the development of comprehensive treatment termination protocols and programmes which provide information, ongoing medical care and support for people who need further assistance. Participants' difficulties with emotions and strained relationships were exacerbated in the post-treatment period by a lack of information, advice, referrals and opportunities for obtaining support and addressing ongoing symptoms. The evidence presented throughout this report reveals that at least some people require a period of health care, counselling and ongoing support after treatment. A comprehensive end of treatment programme could help address the emotional impacts from treatment, relationship difficulties and problems with adjustment to non-response. Such programmes are especially important in the context of hepatitis C treatment, as many people who receive treatment are from lower socio-economic circumstances and do not have access to the full range of supports that middle-class health consumers often have.

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Appendix

Table 1: Sample case-characteristics

| Pseudonym | Gender | Age | HCV status 24 weeks post-treatment | Genotype | Number of treatments | Year of treatment |
|-----------|--------|-----|--|----------|-----------------------------|---------------------|
| Alexis | F | 53 | HCV-negative ¹ | 1 | 1 | 2004 |
| Alice | F | 57 | HCV-positive ² | 1b | 1 | 2006 |
| Annie | F | 48 | HCV-negative | 2 | 1 | 2006 |
| Collette | F | 39 | HCV-negative | 1 | 2 | 1999 and 2000 |
| Chris | M | 52 | HCV-positive | 1 | 3 | 1993, 1999 and 2005 |
| Deacon | M | 53 | HCV-positive | 1 | 2 | 1991 and 2006 |
| Elly | F | 42 | HCV-negative | 1 | 1 | 2006 |
| Germaine | F | 51 | HCV-positive | 3 | 1 discontinued ⁴ | 2005 |
| Jarred | M | 47 | Unknown ³ | 1a | 1 | 2006 |
| Jasmine | F | 54 | HCV-negative | 3 | 1 | 2007 |
| Joanne | F | 41 | HCV-negative | 3 | 1 | 2007 |
| Joe | M | 38 | HCV-positive | 1 | 1 discontinued | 2005 |
| Johnny | M | 47 | HCV-negative | 1 | 1 | 2007 |
| Josh | M | 26 | HCV-negative | 1a | 1 | 2006 |
| Julie | F | 48 | HCV-positive | 1 | 1 | 2000 |
| Kade | M | 47 | Unknown | 3 | 1 | 2007 |
| Leonora | F | 52 | HCV-positive | 1b | 1 discontinued | 2005 |
| Mary | F | 35 | HCV-negative | 3 | 1 | 2007 |
| Matt | M | 49 | HCV-positive | 1 | 1 | 2007 |
| Merrick | M | 43 | HCV-positive | 1 | 1 discontinued | 2004 |
| Nathan | M | 52 | HCV-positive | 3 | 1 | 2006 |
| Nicole | F | 43 | HCV-negative | 1 | 1 | 2007 |
| Nugget | M | 29 | HCV-negative | 4 | 1 | 2006 |
| Patrick | M | 50 | HCV-positive | 1 | 2 | 2006 |
| Sandra | F | 47 | HCV-negative | 2b | 1 | 2007 |
| Tom | M | 54 | HCV-positive | 1b | 1 | 2006 |
| Virginia | F | 43 | HCV-positive | 1 | 2 discontinued twice | 2006 |

1 HCV-negative = cleared HCV infection

2 HCV-positive = non-response to treatment

3 Had not received PCR test results at time of interview

4 Treatment was discontinued.

Table 2: Duration and type of post-treatment symptoms

| Pseudonym | Duration of major self-reported post-treatment effects | Self-reported post-treatment effects at time of interview |
|-----------|--|--|
| Alexis | 1.5 years | fatigue, cognitive effects ¹ |
| Alice | >6 months | none |
| Annie | 1–2 years | skin infections, fatigue |
| Collette | 8 years | fatigue, 'brain-fog' |
| Chris | 2 years | fatigue |
| Deacon | >1 year | headaches, fatigue |
| Elly | 8 months | anxiety |
| Germaine | 3 years | tinnitus, pain, insomnia, depression |
| Jarred | 6 months | none |
| Jasmine | 2 months | none |
| Joanne | 1–1.5 years | anorexia |
| Joe | 2.5 years | various cognitive effects |
| Johnny | 1 year | various cognitive effects |
| Josh | 3–6 months | various physical effects ² |
| Julie | 7 years | various physical effects |
| Kade | 3–5 months | none |
| Leonora | 2 years | various physical effects |
| Mary | 2 months | various physical effects |
| Matt | 7 months | various physical and cognitive effects |
| Merrick | 1–2 years | various cognitive effects |
| Nathan | 3 months | fatigue |
| Nicole | 1.5 years | tinnitus, skin problems, various cognitive effects, depression |
| Nugget | no effects | none |
| Patrick | no effects | none |
| Sandra | >8 months | various cognitive effects |
| Tom | 1.5 years | various physical and cognitive effects |
| Virginia | 1.5 years | various physical effects |

¹ This category included psychiatric symptoms like depression and anxiety, as well as cognitive deficits like poor memory, poor concentration, inability to think clearly and/or speak properly, and inability to write/read at participants' pre-treatment levels.

² This category included muscle aches and pains, migraine, sore stomach/liver region, fatigue, low libido, impotence, oral/dental problems, hair loss/changes, hearing and eyesight problems, and skin problems.