PATIENT PERSPECTIVES

Living with hepatitis C and treatment: the personal experiences of patients

Myra Sgorbini, Louise O’Brien and Debra Jackson

Aim. The purpose of the study was to explore the issues surrounding chronic hepatitis C, combination therapy and its impact on personal relationships to enhance understanding of the experiences of patients living with hepatitis C. This paper focuses on the experiences of the patients and their partners’ experiences will be published separately.

Background. Patients with chronic hepatitis C who have active inflammatory changes on liver biopsy may undergo combination therapy with interferon and ribavirin. For some patients, the adverse effects of combination therapy are so severe that it can potentially place an enormous stress on personal relationships.

Design. The study was informed by Heideggerian phenomenology.

Methods. Purposive sampling and semi-structured interviews of five patients and their partners were conducted between 2004–2006 in Sydney Australia, to obtain a rich description of their experiences.

Results. The findings from this study revealed that chronic hepatitis C and combination therapy had an enormous impact on the lives of the patients, their partners and families. The illness and treatment had significant physiological effects that had an impact on quality of life; however, the social and psychological consequences of living with a highly stigmatised disease with an unknown course and outcome cannot be underestimated.

Conclusion. The results of this study lend support to the effectiveness of providing equitable services to persons diagnosed with chronic hepatitis C. However, additional research is needed to explore gender, socioeconomic, sexual-orientation, transmission, cultural, religious and genotype differences in this group to address their needs better.

Relevance to clinical practice. Nurses play a significant role in educating patients with chronic hepatitis C, advocating for them and helping them to achieve a reasonable state of well being. Through deeper understanding of their experiences of illness and treatment, nurses can move beyond the medical oriented approach to care.

Key words: chronic hepatitis C, interferon, nurses, nursing, phenomenology, ribavirin

Accepted for publication: 27 October 2008

Introduction

Over 210,000 Australians have been exposed to the hepatitis C virus (HCV) and over 80% of them will go on to live with chronic hepatitis C (CHC) and its debilitating effects (Law et al. 2003, Aitken et al. 2004). As many as 20% of people with CHC will develop cirrhosis over a period of 20 years (Sypsa et al. 2005). Cirrhosis due to HCV is now the most common indication for liver transplantation in adult Australians and a cause of primary hepatocellular carcinoma (Farrell & Cossart 1999). Currently, there is no vaccine to prevent HCV.

Authors: Myra Sgorbini, MN (Hon), RN, Clinical Nurse Consultant, Royal Prince Alfred Hospital, Camperdown, NSW, Australia; Louise O’Brien, PhD, RN, Associate Professor of Nursing, University of Western Sydney, Mental Health Nursing Research Unit, Cumberland Hospital, Parramatta, BC, NSW, Australia; Debra Jackson, PhD, RN, Professor, Editor, College of Health & Science, University of Western Sydney, Penrith South DC, NSW, Australia

Correspondence: Myra Sgorbini, Clinical Nurse Consultant, Royal Prince Alfred Hospital, Missenden Road, Camperdown, NSW 2050, Australia. Telephone: 61 2 9515 5438.

E-mail: myra.sgorbini@email.cs.nsw.gov.au

© 2009 The Authors. Journal compilation © 2009 Blackwell Publishing Ltd, Journal of Clinical Nursing, 18, 2282–2291
doi: 10.1111/j.1365-2702.2009.02806.x
infection and no postexposure prophylaxis (Shepard et al. 2005).

The treatment for CHC is combination therapy with pegylated interferon and ribavirin (Zic 2005). Combination therapy is associated with many unpleasant side effects, several which are psychological in nature (Dolan 1997). People with CHC on combination therapy will go through phases of depression, anger, frustration and despair as a result of the symptoms and side-effects.

Purpose of the study
There has been little nursing research conducted on hepatitis C patients undergoing combination therapy. This study aimed to explore the issues surrounding CHC and combination therapy with a particular focus on how it affects relationships between patients and their partners.

Literature review

Hepatitis C
Previously known as non-A non-B hepatitis, HCV may have existed since the 1940s and possibly longer but it was only identified in 1989 (Shepard et al. 2005). Several strains of the HCV are divided into six major groups designated genotypes 1–6 and specific subtypes of these genotypes have also been identified (Purcell 1997).

People with HCV undergo genotyping before commencing treatment because the genotype serves as a guide to optimal treatment duration and is predictive of patient response to treatment (Strader et al. 2004). Genotype 1 is more resistant to treatment hence patients require a 48-week course of therapy and genotypes 2 and 3 have a high probability of favourable response hence patients require 24 weeks of treatment (Zic 2005).

The risk factors frequently cited as accounting for the bulk of HCV transmission are blood transfusions from unscreened donors, injecting drug use, unsafe therapeutic injections, healthcare related procedures and other percutaneous exposures such as tattooing, body piercing and acupuncture (Shepard et al. 2005). HCV has been recognised globally as a major cause of chronic liver disease. The World Health Organisation estimates the prevalence of HCV infection is 2%, representing 123 million people (Shepard et al. 2005).

Treatment of chronic hepatitis C
Interferons (IFN) are naturally occurring antiviral proteins that act by directly inhibiting viral growth and replication and by stimulating the host immune response against infected cells (Korevaar & Sievert 1999). Pegylated IFN are chemically modified versions of IFN, to which an inert, nontoxic, water soluble compound called polyethylene glycol (PEG), has been attached (Zic 2005). Adding the PEG to the IFN reduces its elimination rate from the body thereby increasing the amount of time the IFN is effective (Luxon et al. 2002), allowing for weekly PEG IFN injections rather than three IFN injections per week (Ward & Kugelmas 2005).

Ribavirin (RBV) is an oral antiviral agent but its mechanism of action against HCV is not completely understood (Pawlotsky et al. 2004). Used on its own, RBV has been shown to be ineffective against HCV infection (Bodenheimer et al. 1997). However, when used in combination with PEG IFN, it results in higher success rates with more than 80% of those with genotypes 2 and 3 and around 50% of those with genotype 1 successfully eradicating the infection (Keating & Curran 2003).

Between 1500–2000 Australians commence treatment for CHC each year (Dore et al. 2003). The cost of a 48-week course of combination therapy is around US$30,000, and there are additional expenses for monitoring and outpatient services (Hoofnagle & Seeff 2006). In Australia, combination therapy is included in the Pharmaceutical Benefits Scheme $100 prescriptions category, making it free of charge for patients (Hopwood et al. 2006a).

Combination therapy is associated with unpleasant adverse effects that require monitoring (Tables 1–3). The dose of PEG IFN and RBV can be adjusted according to the patient’s clinical, haematological and biochemical conditions. However, response rates are lower for patients who do not complete the entire course of treatment or who receive <80% of the required dose (Ward & Kugelmas 2005).

Living with hepatitis C
Most people who are diagnosed with HCV infection react with some degree of shock, fear and denial. The impact of diagnosis is felt even more by those who had no suspicion or who may have denied high risk activity in the past (Katz 1997). A study of 98 newly diagnosed individuals in Islamabad by Gill et al. (2005) found that HCV diagnosis was significantly more stressful than divorce and loss of source of income.

The symptoms of CHC tend to be non-specific, intermittent (Table 4) and most patients are asymptomatic during the first ten years of infection (Pritchard-Jones 2000). Quality of life is affected by CHC and influenced by other variances such as relationship problems, treatment, stigma and fear about...
rejection and transmission. Previously independent patients may suddenly become emotionally, financially or physically dependent on family members. A Swedish phenomenological study of four female spouses of chronically ill patients, found that both the patient and the spouse experience losses as a consequence of chronic illness such as loss of aspirations, loss of being ‘ordinary’ and even loss of freedom (Eriksson & Svedlund 2006).

For many, CHC means having to live with uncertainty and hopelessness, as ‘cure’ may not be realistic. Netuveli et al. (2005) provided evidence from a national survey in England of 9298 people that quality of life is the most desired and possibly the only achievable outcome in patients suffering a chronic illness with no possible cure.

Stigma, disclosure and discrimination

Richmond et al. (2004) conducted a systematic review of the literature and concluded that stigma associated with an infectious disease is caused by fear of the illness, fear of contagion and fear of death. A study by Schafer et al. (2005) evaluated the disclosure behaviour of 103 Germans with CHC and found that 25% preferred not to communicate their disease to significant others for fear of rejection.
The fear associated with a blood borne infection is linked to its association with drug abuse, promiscuity and perversity. A study on stigmatisation and quality of life of 257 Americans with CHC revealed that the three most commonly perceived reasons for stigma were society’s association of CHC with HIV/AIDS, the attribution of promiscuity and the assumption that the person with CHC was an injecting drug user (Zickmund et al. 2003). Several studies revealed that stigmatisation occurred in the health care setting and identified hospitals, general practice and dental surgeries as places where hepatitis C-related discrimination frequently occurred (Zickmund et al. 2003, Richmond et al. 2004, Hopwood et al. 2006b). Discriminatory practices included refusal to provide services to people with CHC, discriminatory treatment while providing a service and breaches of confidentiality and disclosure issues (Richmond et al. 2004).

**Methodology**

**Phenomenology**

The philosophical framework for this study was informed by Heideggerian phenomenology. Phenomenology attempts to unravel meanings as we live them in our everyday existence. It examines the particular experiences of unique individuals in a given situation, which fits with the aim of this study: to examine the illness and relationship experiences of patients with CHC and their partners during combination therapy.

Phenomenological studies use the language of the participants to reflect as accurately as possible the meanings embedded in the experience (O’Brien 2003). A basic premise of Heideggerian phenomenology is that we all share the tradition of storytelling and that the telling of stories is a way we communicate with others and make sense of our worlds (Moloney 1997).

**Study design**

**Participants**

Purposive sampling technique was used and involved the conscious selection of participants to include in the study. The criteria for inclusion were that participants be: over 18 years of age, diagnosed with CHC and on combination therapy, involved in a partnered relationship and living with their partners.

There were five participants who volunteered and fulfilled the inclusion criteria. Three participants were recruited from liver clinics and two participants contacted the principal author after they read an advertisement in the HepC Review, a publication of the Hepatitis C Council of New South Wales. The participants’ age ranged from 32–54 years and they had been together with their partners for an average of 14 years. All the participants had children aged from 7–23 years at the time of the interviews. All the participants were on combination therapy for 48 weeks however, only three disclosed having genotype 1. One participant had two previous unsuccessful treatments and another had one unsuccessful treatment.

**Data collection and management**

Data for this study were collected using semi-structured interviews that lasted between 30–90 minutes and conducted by the principal author in different locations which included the liver clinic, business office and the participants’ homes. The interviews were audiotaped, transcribed verbatim by a professional transcriber and checked against the tape by the principal author.

The participant interviews began with an open-ended question: ‘Living with hepatitis C and undergoing combination therapy, what is it like for you?’ Little structure was applied to encourage open dialogue and probing questions were asked when the participants said very little. The probing questions used were determined by the course of the interview (Table 5).

**Analysis**

All audiotapes were repeatedly played and the transcriptions were read several times to gain a feeling for the whole. Accuracy was enhanced through re-reading of the transcriptions while listening to the audiotapes. The words, phrases, sentences or paragraphs that stood out were highlighted in each interview transcript. Meaning units were grouped together and organised into themes and sub-themes. The themes that emerged were discussed at length within the academic team to ensure they flowed logically from the findings and to validate the narrative interpretations of the text.

**Rigor and trustworthiness**

Early factors that contributed to this study’s rigor and trustworthiness were the recognition of a phenomenon that merits investigation and identification of a purpose for the study. Another factor that enhanced rigor included the purposeful selection of participants who could provide in-depth descriptions of the phenomena under investigation (O’Brien 2003). The fact that the interviews were audiotaped and transcribed verbatim provided an assurance of at least verbal accuracy (Koch & Harrington 1998). The ultimate test of the
study’s integrity is its usefulness, its contribution to current knowledge as well as clinical practice and the potential to inspire further research (Milne & Oberle 2005).

Ethical considerations

Approval for this study was granted by the appropriate Research Ethics Review Committees. All the participants were informed of the purpose of the research, its procedures, risks/discomforts/benefits, the right to withdraw and all gave consent to voluntary participation. All data are secured in locked storage and anonymity was maintained by coding and using pseudonyms.

Results

The findings are summarised into themes and sub-themes (Table 6). There tends to be some overlap because themes are not discreet entities but reflect aspects of the whole experience.

Experiencing illness and treatment

Suffering poor health

The diagnosis of HCV infection was unexpected and devastating for the participants and raised feelings of shock, fear, denial, anger and sadness. It appeared that their initial reactions were similar to the grieving process:

Firstly you go through the normal runs of emotions which is normally denial, ‘it can’t be me’ and then you go through a stage where you get angry. (Jake)

The participants described how their daily lives were strongly influenced by the symptoms of CHC and the side-effects of combination therapy. The symptoms and side-effects experienced by the participants included: rash, pruritus, pain, fever, flu-like symptoms, cough, headaches, shortness of breath, poor concentration, irritability, grumpiness, short temperament, lack of sense of humour, mood swings, depression, withdrawn behaviour, suicidal thoughts, exacerbated snoring, poor eyesight, tiredness, exhaustion, fatigue, lack of energy, reduced stamina, weakness, lethargy, ‘hung over’ feeling, decreased libido, feeling disabled, mouth ulcers, insomnia and poor appetite.

The CHC and combination therapy has been shown to have a significant physiological effect on quality of life and as a result all the participants struggled to maintain a meaningful life. The symptoms and side-effects reported by the participants ranged from mild to severe. Participants described feeling unwell, the limitations imposed by CHC and IFN and how these affected their work, lifestyle and the people around them.

<table>
<thead>
<tr>
<th>Experiencing illness and treatment</th>
<th>Keeping a secret</th>
<th>Sharing the experience</th>
<th>Enduring struggle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering poor health</td>
<td>Disclosing the illness</td>
<td>Lending a hand</td>
<td>Sustaining finances</td>
</tr>
<tr>
<td>Managing ill health</td>
<td>Encountering stigma</td>
<td>Relating with partners</td>
<td>Dealing with health professionals</td>
</tr>
<tr>
<td>Feeling isolated</td>
<td>Parenting through adversity</td>
<td></td>
<td>Looking ahead</td>
</tr>
</tbody>
</table>

| Table 6 Themes and sub-themes |

© 2009 The Authors. Journal compilation © 2009 Blackwell Publishing Ltd, *Journal of Clinical Nursing*, 18, 2282–2291
It slowed me right down, it has made my life very limited and withdrawn. It has meant that I can work less and that if I choose to work then I am totally exhausted and don’t do anything else, which isn’t good for the family. (Rita)

For the person with CHC on combination therapy, the psychological side-effects of IFN can add to the complexities of daily life. Depression can intensify as experienced by one of the participants who had a history of depression and developed suicidal ideation during treatment, regularly consulted a psychologist and was prescribed anti-depressant medications:

Because of the depression, you sort of have depression and ... interferon makes it worse... so you have to look at... ending it. (Luke)

Managing ill health
Participants managed their symptoms and side effects by performing minimal tasks, discovering what their limitations were and working around these restrictions. They were also able to determine what worked best for them in terms of relaxation and some were able to direct their energy to maintain their fitness. Having an outlet such as exercise, studying and a cohort of like minded friends helped to distract them from their symptoms and restore balance in their life:

I’m trying to keep things simple and doing less and being really careful about pacing myself. I go to bed earlier, read a book and I breathe out and relax. (Jane)

It was going to the gym that helped take my mind off it. I do AA [alcoholics anonymous] and have friends from the meetings that I can talk to about my problems. I go to TAFE [college]. (Anne)

I foster dogs from the pound so it gets me walking and it also gives me a social outlet because I might just say hello to another dog owner. I have a cup of tea with a girlfriend once a week just to get out of the house to have a chance to talk about how I am feeling. (Rita)

Feeling isolated
Participants felt inhibited as a result of CHC and combination therapy. They experienced a feeling of being shut in and acknowledged that the only way to have some breathing space was to withdraw from their family. They described how their social life had been put on hold as the effects of CHC and combination therapy had imposed restrictions:

It’s kind of like sometimes I feel a bit claustrophobic and I just feel sort of like I need to back off. I feel my social life is hindered. I can’t go dancing like I used to, go to the pub, I don’t do that anymore. (Jane)

Other members of the family needed outlets for their frustration from the accumulative stresses of daily life. Unfortunately, the participants were unable to take part in many of these outings due to the limitations imposed by their illness hence they felt isolated and despondent:

My husband will have some activities for the kids which they will do together but a lot of the time I won’t participate, so again it means that I am not here for practical reasons or, because they need to let off a bit of steam, let off a bit of energy, whatever. (Rita)

Keeping a secret

Disclosing the illness
There are several misconceptions about CHC in the community, hence, the participants preferred to keep their status to themselves rather than risk having to face up to the scrutiny of how HCV was acquired. Participants also avoided sharing information with their children to preserve their relationships:

Society doesn’t know very much about it. I have to keep it a secret to fit in society. I sort of don’t talk about it to my kids, they could be playing and say ‘Dad has got this’. (Luke)

Participants felt many health care professionals held prejudiced views and lacked knowledge about CHC. One of the participants is a healthcare professional and her colleagues held a strong opinion that people with CHC do not deserve an expensive treatment that is government funded:

I am very careful at work because the treatment is very expensive and a lot of people have the view that ‘the money would be better spent on other things’. (Rita)

Encountering stigma
The participants in this study described a lack of information and knowledge of CHC in general. The stereotyped assumption that all people with HCV are injecting drug users affected the way the participants were treated by health care personnel:

So the one thing that I hate is the judgmental nature of the medical system about the assumed use of intravenous drugs...you are often treated as a number and depending on who the people you are dealing with, you feel like cattle. (Jake)

Participants described that due to the stigma attached to HCV, the level of support that someone with CHC might receive was less when compared to someone with a chronic illness that does not carry a stigma:
One of the things that I think is different about HepC is the stigma about it. This sort of belief that it’s largely an illness of intravenous drug use that people have only themselves to blame and I have medically acquired HepC but the stigma is still very real and so I think it means that you have less support than you might have if you had some other chronic illness. (Rita)

Sharing the experience

Lending a hand
Participants acknowledged that support from loved ones is vital during treatment. The partners were in the background listening, comforting and encouraging the participants during treatment. They were also there in a practical way by adapting the home, shortening their working hours and working from home to try and keep their daily lives as close to normal as possible:

He is very supportive with physical things, doing stuff with the kids, things that need doing around the house ... he gets to work considerably later and he works less hours and he certainly organises his work around being able to do that, like being the primary carer, in terms of the two children. (Rita)

Participants described having to draw on practical support from family members. One participant disclosed receiving financial support from one of his sons, to assist with family needs:

The eldest boy works and doing quite well ... and now he is there to support as we need to, he lends us money when we need to, all that sort of stuff. (Jake)

Relating with partners
Participants described how the psychological side-effects such as mood swings, irritability and short temperedness compounded their physiological symptoms. Altogether, these symptoms became barriers to communication and made the participants focus on themselves at the expense of others. Self care became the top priority, followed by the children’s needs, while the needs of the partners came last. These meant that intimate relationships with their partners had suffered mainly due to the participants’ poor physical, mental and emotional health:

I think treatment makes you very self-centred. And I might manage to think about what the kids need, but I don’t think a lot about what my husband needs. That sort of, is very much the third level of priority. When I am really exhausted I get really irritable, at my worst, I kind of just keep bursting into tears and bursting into anger and that is not a nice situation and it always means we have big arguments, everybody is yelling at each other...Mainly because of tiredness I have had no libido, no interest in sex for years and sex is very bonding in a relationship...I am dead, I am tired. But I think that is from HepC and interferon doesn’t make it, it accentuates it. (Rita)

Parenting through adversity

Often participants felt that CHC and treatment added another level of complexity to their relationships with their children. They felt that their children were deprived due to their inability to provide support and acknowledged that the ramifications include missed opportunities to develop and socialise:

The boys used to play sports but it got too hard for us because they do separate things and I haven’t got the stamina and the energy. (Luke)

My daughter hasn’t been doing well at school so it’s been hard. She’s such an affectionate child and very demonstrative and she doesn’t always get that from me. I feel quite suffocated because I just...I’m just so exhausted. (Jane)

Negative aspects of the experience for children included witnessing frequent arguments among parents. One of the participants revealed that her son’s challenging behaviour was possibly related to the frequent arguments:

My son gets very angry and what I hear is yelling, banging doors, whinging. You know, like I notice when he is happy because it is rare...he is just unsettled and not very happy...he is nine and a half and he has got a problem with wetting the bed. (Rita)

Several participants acknowledged the positive aspects to the experience and expressed a sense of gratification in watching their children develop sensitivity, and assume added responsibility in the home. For some of the participants and their families, the illness and treatment experience provided them the opportunities for bonding:

They have grown up much quicker than I think they would and they know that they are doing something special. (Anne)

It was very difficult, so despite that, the bonding between the family, if anything, it had brought us closer during that time. (Jake)

Enduring struggle

Sustaining finances

For some of the participants it was unclear what the future held as they suffered a chronic illness without a guaranteed cure. They voiced concern for their family’s future and this caused apprehension. Participants looked forward to the
end of their treatment with optimism, however, they conceded that CHC will invariably linger given that only 50% will be successful at eradicating the HCV infection:

So I suppose my initial thought was, well what is going to happen if I am not here and basically I have been the one who has been the bread winner in the last 20 years or so. So that would have been a scary thought, I think especially for my wife. (Jake)

Dealing with health professionals
Participants believed that, because of a lack of knowledge, understanding and resources, services were not available to provide holistic care hence, the focus of care was directed towards the treatment of the illness and not the patient as a person. Participants also described how health care professionals were unable to respond with compassion and respect because of their underlying negative attitudes to CHC:

My experience of the medical fraternity is that they are diagnosis focused not patient focused and they don’t care what they put you through as long as they discover what is wrong with you and how to treat it. (Jake)

Looking ahead
Participants held fears of a threatened future based on the risk of complications related to CHC, the lingering effects of IFN as well as any ensuing unresolved conflicts. For those who had several courses of IFN without success, they remained cynical about the treatment outcome however, they were confident that the treatment had slowed the disease progression hoping that in time a cure would become available:

Part of my head says ‘this is your life forever, you’re always gonna feel this way’. (Jane)

I am a little pessimistic having been through two lots of treatment now, so I almost expect that my liver will fail. (Jake)

Summary
This study found that CHC and combination therapy had a significant physiological and psychological effect on quality of life and the participants described their struggle to maintain a meaningful relationship with their partners and children. Strategies for coping appeared in the narratives but most obvious were their descriptions of the effects of stigma on their lives. Participants also felt that many health care professionals held prejudiced views and lacked knowledge about CHC.

Discussion
CHC and combination therapy caused serious impairment of the participants’ physiological, mental and emotional well being (Dolan 1997, Dusheiko 1997, Oon 1999, Hoofnagle & Seeff 2006). One of the most common side effects of IFN suffered by the participants was depression and this compounded their situation. IFN is known to cause severe neuropsychiatric syndromes including depression, suicidal ideation, paranoia and confusion (Rataj et al. 2005).

Routine activities of daily living became burdensome and the participants’ role shifted from independence to dependence. Family members became an important source of physical, emotional and financial support. The partners’ workload increased as they took over most of the housework. The participants’ temporary inability to fulfil their role created the opportunity for their partner to experience a new side to themselves (Altschuler 1997).

However, frustration, irritation and anger were often directed at the partners. The pressures brought on by CHC and treatment, combined with the stresses of everyday life, became accumulative and led to conflicts between the participants and their partners. Poor communication was another source of anxiety and feelings that were withheld or were not well communicated resulted in greater distance between spouses. Participants described a change in their intimate and sexual relationships because the effects of CHC and treatment contributed to a loss of sexual desire and satisfaction (Larsen et al. 1998).

The participants decided it was better not to talk to others outside the family about hepatitis C given the stigma and prejudice attached to HCV. Not all the participants in this study acquired HCV through injecting drug use but they described how society associates HCV infection with injecting drug use and HIV. All are seen as conditions brought upon oneself by behaviour for which society has little sympathy or understanding (Morton & Johnson 1996).

Participants described altered relationships with family, friends and relatives and reported a loss of social networks because of poor health and the stigma attached to HCV. These findings are consistent with a report by Richmond et al. (2004) that confirmed people with HCV infection feel the impact of stigma and discrimination which affects their social interactions, social networks, self-esteem and quality of life.

The participants felt that health care professionals presented a negative attitude and lacked understanding of CHC. This study and several other studies revealed that discrimination occurred in the health care setting (Zickmund et al. 2003, Richmond et al. 2004, Hopwood et al. 2006a,b). A
study by Hopwood et al. (2006a,b) found that those likely to have experienced higher levels of discrimination felt isolated from family, friends, neighbours and groups and also felt pessimistic about treatment and the future.

Despite the difficulties, some participants felt that their relationships had deepened and became stronger as the experience provided them the opportunities for bonding and testing the depth of their relationships. Eriksson and Svedlund (2006) reported that infirmity had brought couples closer together, even strengthening their relationships.

Another positive aspect of the experience described by the participants is the sense of satisfaction children felt in being able to perform tasks that were traditionally the parents’ role. Children and young adults whose parent has CHC and receiving treatment have taken on a caring role both for siblings and their parent and according to the literature, this led to self-reliance and increased confidence (Morton & Johnson 1996, Eriksson & Svedlund 2006).

**Limitations**

A limitation of this study was the small sample size. Findings cannot be generalised because this study examined the experiences of CHC and combination therapy and its impact on relationships, providing in-depth interpretation from the stories of individuals.

**Recommendations for future research**

Additional research is needed to explore gender, socioeconomic, sexual-orientation, transmission, cultural, religious and genotype differences in the CHC population to better address their needs. Understanding of the experiences of CHC and treatment in these different populations could lead to the development and delivery of more effective nursing care.

**Relevance to clinical practice**

This study suggests there is considerable room for improvement in the health care of people with CHC, starting from improving pretest and posttest counselling, delivery of nondiscriminatory care, information provision, communication and psychosocial screening to identify patients in need of early intervention to prevent the exacerbation of preexisting conditions, thus reducing the costs of subsequent evaluations and treatments. Not all health care providers are educated in CHC, treatment and management. There is an opportunity here for nurse practitioners with advanced skills to provide skilful management and education of patients with CHC.

They can assist patients in managing their symptoms and if well managed, can influence patient compliance with treatment and enhance their chance of eradicating the HCV infection.

**Acknowledgements**

We would like to acknowledge the participants in this study for their time and their courage in sharing their experiences. We wish to thank Susan Holdaway, Janelle Twomey, the Hepatitis C Council of New South Wales and Traid for their assistance at various stages of the study.

**Contributions**

Study design: MS, LOB; data collection and analysis: MS and manuscript preparation: MS, LOB, DJ.

**References**


Moloney MF (1997) Hermeneutic research doesn’t take a PhD. *Journal of Nursing Scholarship* 29, 9.


