Living with Hepatitis C and Treatment: A Phenomenological Study of the Experiences of Patients and their Partners

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Statement of Authentication

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

M Sgorbini

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Abbreviations

CHC: chronic hepatitis C
HCV: hepatitis c virus
IFN: interferon
NSW: New South Wales
PEG: polyethylene glycol
RBV: ribavirin
Abstract

Among the estimated 210,000 Australians living with the hepatitis C virus, over 80% will go on to live with chronic hepatitis C and its debilitating effects. Patients with chronic hepatitis C who have active inflammatory changes on liver biopsy may undergo combination therapy with interferon and ribavirin. Adverse effects of combination therapy can be variable in their nature, intensity and severity. They may be mild, reversible, moderate, or serious and life-threatening. For some patients the adverse effects are so severe that it places enormous stress on partner relationships.

Through a phenomenological approach using purposive sampling and semi-structured interviews of five patients and their partners, this study aimed to explore the issues surrounding chronic hepatitis C, combination therapy and personal relationships. The purpose of the study was to enhance understanding of the experiences of people living with the illness and undergoing treatment. The complexities that hepatitis C and treatment brings into the personal lives of people have led me to this study because there is a need to understand their impact on the personal relationships of patients and their partners. Through deeper understanding of their experiences, nurses can move beyond the medical oriented approach to treatment towards a holistic approach.

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. Both had significant physiological effects that impacted 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.
The participants’ narratives provided a rich description of their experiences and offered insight into the life world of people living with chronic hepatitis C and combination therapy, and their partners. The themes that emerged from the study were: experiencing illness and treatment; keeping a secret; sharing the experience; and enduring struggle.

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. Nurses also have the important role of providing partners with information and support that will assist them as caregivers. 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 and religious differences within this group to better address their needs.
Chapter 1: INTRODUCTION

“My illness has limited my capacity to work, seriously questioned my ability to be an effective parent, partner or friend, and prevented me from participating in my community. I feel isolated and often through that isolation robbed of the necessary tools to combat negativity and hopelessness”. (Submission 67, Standing Committee on Social Issues, 1998)

Introduction

Every hour of every day one person in Australia is being infected with the hepatitis C virus (HCV) as reported in *Hepatitis C: The Neglected Epidemic*, an inquiry into hepatitis C in New South Wales (Standing Committee on Social Issues, 1998). Over 210,000 Australians have been exposed to the HCV (Law et al., 2003). While some of these people will clear the virus without medical intervention, over 80% will go on to live with chronic hepatitis C (CHC) and its debilitating effects (Aitken et al., 2006).

CHC is associated with the development of hepatic fibrosis, cirrhosis and hepatocellular carcinoma (Zic, 2005). As many as 20% of people with CHC will develop cirrhosis over a period of 20 years, which in the longer term can lead to hepatocellular carcinoma (Sypsa et al., 2005). End stage liver disease caused by HCV has emerged as a leading indication for liver transplantation (Singh et al., 2002).

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, Finelli & Alter, 2005). Transmission of HCV infection through occupational, perinatal and sexual exposures occurs with much less efficiency compared with transmission through large or repeated percutaneous exposures (Harvey, 2001).

In Australia, where the highest HCV prevalence is among middle-aged people, injection drug use has been the dominant mode of transmission for the past three decades and accounts for 80% of current infections (Dore, Law, MacDonald & Kaldor, 2003). HCV can easily be transmitted amongst injection drug users by the sharing of drug paraphernalia. Fewer sharing partners are required to sustain HCV transmission than are necessary for other blood borne viruses (Murray, Law, Gao & Kaldor, 2003).

The importance of hepatitis C as a health issue was highlighted by the New South Wales (NSW) Government’s Response in May 1997, when the Legislative Council’s Standing Committee on Social Issues was asked by the Hon. Dr. Andrew Refshauge, then Minister for Health, to inquire into, and report on, the incidence and impact of hepatitis C in NSW. During the course of the inquiry, the committee took evidence from some of Australia’s most eminent hepatitis C specialists. In addition, experts in drug and alcohol, epidemiology, virology and public health service providers as well as health consumers affected by hepatitis C submitted evidence. Having considered and addressed all of the relevant issues, the Committee formed some key recommendations. These included:

a) the need for policies to deal with all facets of hepatitis C;
b) the provision of information;

c) the need for more research across a range of areas including the personal, social and economic impact of hepatitis C;

d) a multi-faceted approach to prevent the spread of hepatitis C and that;

e) hepatitis C within the state’s correctional system must be addressed as a matter of urgency (Standing Committee on Social Issues, 1998).

These recommendations demonstrated that hepatitis C is a disease that debilitates and is an epidemic that can no longer be neglected.

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

The partners of people living with hepatitis C play a significant role in the management of CHC. People with CHC on combination therapy may become dependent on their partners to meet their practical and emotional needs therefore, some partners may find the dual role of primary caregiver and breadwinner overpowering. This relationship imbalance can affect the wellbeing of both the individual with CHC and their partner.

Nurses are actively involved in the care of the patient with CHC on combination therapy. From the initial clinic visit, to the moment the decision is made to commence combination therapy and throughout the treatment period, nurses serve as liaison
between the patient, medical specialist, pharmacist, social worker, psychologist and other allied health professionals. Nurses provide patient education regarding HCV, treatment procedures, medications, side effects and injection techniques.

Nurses are also present during the patient’s visits to the outpatient clinic to perform routine procedures such as obtaining and recording observations, performing urinalysis and blood collection. Patients who require information about self-management, or who have anxieties regarding their therapy, frequently make telephone contact with nurses. Nurses therefore have a critical role in the care of patients with CHC.

**Purpose of the study:**

This study aimed to explore the experiences of combination therapy with a particular focus on how it affects relationships between patients afflicted with HCV and their partners.

**Justification of the study:**

There is a perceived gap in the delivery of health care to patients with CHC and their partners during combination therapy. This is an observation made by the researcher and based on feedback from patients attending a liver clinic in a metropolitan Sydney hospital and confirmed by a NSW government inquiry that recommended research into the personal impact of hepatitis C (Standing Committee on Social Issues, 1998).

There has been little nursing research done on hepatitis C patients undergoing combination therapy to improve nursing practice and health outcomes. This study
aimed to explore the issues surrounding CHC, combination therapy and personal relationships using a phenomenological approach. The findings of this study will contribute to a better understanding and attitude towards people living with CHC and undergoing combination therapy that will have implications for the improvement in health care delivery.

**Positioning myself in relation to the thesis:**

I worked in the area of hepatology and cared for people with HCV in a range of settings. I have attended to their care as inpatients, as outpatients and in a community setting. As a nurse, I have been a major source of information and support for people with HCV, whether they are on treatment or not.

I have been a facilitator of a support group for people living with HCV and I have counselled patients on an individual basis. Clinic patients with HCV would openly discuss their symptoms, no matter how personal. For many, the physical symptoms led to depression, anxiety about the future and social isolation. Some patients suffered from loss of self-confidence, loss of self-esteem, lack of energy and loss of income. Others had self-image problems and felt incompetent because they were no longer able to perform tasks as expected. I was able to gain insight into the personal experiences of people with HCV.

Community ignorance about HCV can add to patient anxieties and the stigma associated with HCV complicates their situations even more. People with HCV cannot talk about their illness openly. This often leaves their partners to absorb everything, but only if they are aware of the HCV status of their partner. Whether the symptoms are physical or psychological, I have witnessed its impact on the person
with HCV and their families. I observed as relationships disintegrated and ended in separation or divorce.

The complexities that HCV brings into the personal lives of people have led me to this study. There is a need to understand the impact of HCV and treatment on the personal relationships of patients and their partners. As health care professionals, we aim to provide holistic care for our patients and their families. We can effectively deliver care if we understand not only the illness but also the patients under our care.

**Thesis Outline**

*Chapter 2: Literature Review*

The literature review provides an overview of chronic hepatitis C infection, combination therapy, the experience of chronic illness and living with hepatitis C. A subheading of living with hepatitis C includes discussion on the experience of diagnosis, symptoms and its effects on quality of life. Another subheading explores the issues surrounding stigma, disclosure and discrimination. The literature review also examined the family oriented approach to care, caregiving and holistic nursing care.

*Chapter 3: Methodology*

The methodology chapter provides an overview of qualitative research, Heideggerian phenomenology, its origin and definition. The phenomenological framework examines the role of language, meaning and understanding, the position of the researcher and the role of self-reflection in phenomenology. The study design illustrates the method and provides information about the participants, data collection, data management and
analysis. Ethical considerations are also presented in this chapter exploring the issue of consent, privacy and confidentiality, risks and discomfort, and potential benefits.

**Chapter 4: Findings**

Chapter 4 reveals the findings that emerged from the interviews with the study participants. The findings are summarised into themes and sub-themes and quotations are presented to convey the participants’ view. The themes that emerged from the study were: experiencing illness and treatment; keeping a secret; sharing the experience; and enduring struggle.

**Chapter 5: Discussion**

Chapter 5 examines the findings that emerged from the study and the discussion will draw a parallel with the literature regarding the lived experience of patients living with a chronic illness on treatment and the lived experience of the partners.

**Chapter 6: Conclusion**

The final chapter presents the study’s strengths and limitations, implications for nursing practice and recommendations for future research.

**Summary**

CHC is a major public issue in Australia, yet little is known of the needs of people living with HCV. CHC causes significant deterioration in a number of key areas including physical wellbeing, levels of pain, general health, vitality, social functioning, ability to work, emotional and mental wellbeing (Dolan, 1997). It is important to highlight the fact that any chronic illness places enormous stress on personal relationships. CHC is no exception. The enormous emotional commitment that goes
into helping a partner through an illness can ultimately drain an individual’s resources to the point that they are no longer able to see their partner in the same light once health has been restored (Batey, 1997).

Nurses play an important role in the care of the patient with CHC on combination therapy. They are in a unique position to provide patients and their partners with education and support to help maintain their well being. There has been no nursing research study in Australia to provide information regarding the impact of CHC and combination therapy on partner relationships. By discovering the meaning of this phenomena for these group of individuals, a new understanding of the experience can be constituted by health care professionals, and thus facilitate effective assessment and care of future patients experiencing the same phenomenon.

Chapter 2: LITERATURE REVIEW

“...I think perhaps they could have ... called us in as a family or at least called my wife and I in and attempted to ... allay fears or show some concern”. (Hanseens, North & Park, 1997)

Hepatitis C

Hepatitis C is inflammation of the liver caused by the hepatitis C virus (HCV). The virus may have existed since the 1940s, possibly longer, yet it was only identified in
Chapter 2: LITERATURE REVIEW

“...I think perhaps they could have ... called us in as a family or at least called my wife and I in and attempted to ... allay fears or show some concern”. (Hanseens, North & Park, 1997)

**Hepatitis C**

Hepatitis C is inflammation of the liver caused by the hepatitis C virus (HCV). The virus may have existed since the 1940s, possibly longer, yet it was only identified in
1989 (Shepard et al., 2005). The HCV was explicitly identified and genetically mapped by the Chiron Corporation in the USA using recombinant molecular technology, which at that time was a new methodology, dependent on the latest advances in immunology, cloning, genetic engineering and microbiology (Dolan, 1997). Before the virus was identified in 1989, hepatitis C was known as non-A non-B hepatitis.

Several strains of the HCV are divided into major groups called genotypes. A total of 6 major genotypes have been identified and designated genotypes 1 through 6 (Purcell, 1997). Specific subtypes of these genotypes have also been identified. People with HCV undergo viral genotyping before commencing treatment because the genotype is predictive of patient response to treatment and is used as a guide to optimal treatment duration (Strader, Wright, Thomas & Seeff, 2004). HCV genotype 1 is more resistant to treatment hence patients require a 48-week course of therapy, and HCV genotypes 2 and 3 have a high probability of favourable response hence patients typically require 24 weeks of treatment (Zic, 2005).

HCV has been recognised as a major cause of chronic liver disease worldwide. The World Health Organisation estimates the prevalence of HCV infection is 2%, representing 123 million people (Shepard et al., 2005). Cirrhosis due to HCV is now the most common indication for liver transplantation in adult Australians, and an important cause of primary hepatocellular carcinoma (Farrell & Cossart, 1999). Currently, there is no vaccine to prevent HCV infection and no post-exposure prophylaxis for HCV (Shepard et al., 2005).

Treatment of Chronic Hepatitis C
Combination therapy with pegylated interferon and ribavirin is the standard treatment regimen for patients with HCV infection (Hui & Sung, 2005). 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). IFN penetrates virus-infected cells, where it can exert its effect on the nucleus of the cell to inhibit intracellular viral replication (Oon, 1999).

Pegylated interferons are chemically modified versions of IFN, to which a polymer or long chain of an inert, non-toxic, water soluble compound called polyethylene glycol (PEG), has been attached (Zic, 2005). Adding the PEG to the IFN reduces the rate of elimination of IFN from the body and thereby increases the amount of time the IFN is effective (Luxon, Grace, Brassard & Bordens, 2002). Previously, treatment had been with IFN alone, but the addition of PEG to the IFN gives it a much longer bioavailability, allowing for weekly injections rather than three 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). RBV acts as a modulator of the immune system but appears to have minimal direct activity against HCV replication (Hoofnagle & Seeff, 2006). RBV used on its own, has been shown to be ineffective in the treatment of HCV infection (Bodenheimer et al., 1997). However, when RBV is used in combination with pegylated IFN, it results in higher success rates with more than 80% of those with genotypes 2 and 3 clearing the virus, and around 50% of those with genotype 1 successfully eradicating the infection (Keating & Curran, 2003).
The goals of combination therapy are to inhibit viral replication if not eradicate HCV infection, prevent cirrhosis, hepatocellular carcinoma, liver failure and improve quality of life (Fleming, 2002). The standard dose of pegylated IFN is 180 micrograms or 1.5 micrograms per kilogram by subcutaneous injection once a week, and RBV is administered orally with a total daily dose between 800 mg to 1200 mg depending on genotype and patient weight (Ward & Kugelmas, 2005).

Currently, about 1500 to 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 (around A$40,000) and expenses for monitoring and clinic visits need to be considered in weighing the costs of therapy (Hoofnagle & Seeff, 2006). In Australia, combination therapy is included in the Pharmaceutical Benefits Scheme S100 prescriptions category, making it free of charge for people with HCV (Hopwood, Treloar & Redsull, 2006).

Combination therapy is associated with many unpleasant adverse effects that require close monitoring (see Table 1, Table 2 and Table 3). IFN may cause severe neuropsychiatric syndromes including depression, with suicidal ideation, paranoid psychoses and confusion (Rataj et al., 2005). The dose of pegylated 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 less than 80% of the intended total dose (Ward & Kugelmas, 2005).
## Table 1: Adverse Effects of Interferon

**General:** Flu-like symptoms including fever, rigors, headache, myalgia, rhinorrhea, anorexia, dizziness, malaise, fatigue, lethargy, dehydration, pruritus (most of these symptoms are alleviated by over the counter medications).

**Specific organs affected:**
- **Hepatotoxicity:** Raised ALT (alanine aminotransferase) and further accelerated decompensation of liver function on higher doses.
- **Renal toxicity:** Serum creatinine >1.5 mg/ml or creatinine clearance <80 ml/day can lead to renal decompensation.
- **Marrow:** Transient decline in neutrophils and platelets.
- **Neurological:** Headaches, confusion, insomnia, impaired concentration, irritability, forgetfulness, short term memory loss, mood swings, agitation, aggressive reactions, depression and suicidal tendencies.
- **Cardiovascular:** Hypotension, syncope, tachycardia and cardiotoxicity in high doses.
- **Respiratory:** Shortness of breath, minimal hair loss, myalgia, arthralgia, back pain and peripheral neuropathy (numbness, tingling sensations).
- **Gastrointestinal:** Nausea, vomiting, diarrhoea, constipation, irritable bowels and abdominal pains.
- **Reproductive:** Irregular menstruation and loss of libido.

**Others:** Production of autoimmune antibodies and antibodies against some commercial preparations of IFN, thyroid problems, watery eyes, blurred vision, rash and injection site inflammation.

Adapted from Oon, 1999

## Table 2: Adverse Effects of Ribavirin

**General:** Shortness of breath, dizziness and malaise.

**Laboratory:** Haemolysis and anaemia.

**Cardiovascular:** Myocardial infarction (serious adverse effect with pre-existing coronary artery disease).

**Neurological:** Stroke (serious adverse effect with pre-existing cerebrovascular disease).

**Reproductive:** Teratogenicity (known to cause birth defects/abnormalities).

Adapted from Hoofnagle & Seeff, 2006

## Table 3: Serious Adverse Events Reported with Interferon Therapy

<table>
<thead>
<tr>
<th>Neuropsychiatric</th>
<th>Autoimmune thyroid disease</th>
<th>Autoimmune hepatitis</th>
<th>Systemic lupus erythematosus</th>
<th>Primary biliary cirrhosis</th>
<th>Septicaemia</th>
<th>Graft rejection</th>
<th>Extrapyramidal-ataxia</th>
<th>Paraesthesia</th>
<th>Seizures</th>
<th>Relapse in substance abuse</th>
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<tr>
<td>Psychosis</td>
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<td>Autoimmune hepatitis</td>
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<td>Depression/suicide</td>
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<td>Delirium</td>
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**Skin:**
- Psoriasis
- Erythema multiforme

**Systemic:**
- Hepatic decompensation
- Bleeding
- Cardiac arrhythmia
- Sudden death
- Dilated cardiomyopathy
- Hypotension
- Acute renal failure

**Other:**
- Retinopathy
- Pulmonary interstitial fibrosis
- Hearing loss

**Laboratory:**
- Granulocytopenia
- Hyperthyroidism
The Experience of Chronic Illness

Chronic illness is any disorder that persists over a long period that can affect physical, emotional, intellectual, social, or spiritual functioning (Anderson, Anderson & Glanze, 1998). Living with chronic illness represents a distinct way of being-in-the-world, a way of being that affects one’s sense of self, one’s relationships with others, one’s ability to interact in the surrounding world, one’s family and professional life, one’s ability to exercise control and to be autonomous, and one’s relationship with one’s body (Toombs, 2004).

The initial response of a patient to the diagnosis of a chronic illness can vary significantly. In a phenomenological hermeneutic study by Eriksson and Svedlund (2006), they found that almost every aspect of life is altered when someone is diagnosed with a chronic illness and the diagnosis brings with it physical and emotional alterations. Altschuler (1997) claimed that a diagnosis of illness invariably evokes fears and anxieties about loss of functioning, changes in physical appearance, pain, discomfort, and separation from loved ones and peers through hospitalisation. Grief is also experienced as the person grapples with the imagined loss of the life they thought they would have.

Illness transforms people into patients and the challenges, complications and problems created by the illness needs to be addressed and resolved. Zabora, Loscalzo and Weber (2003), based on published literature and clinical experience, explained that the
diagnosis of chronic illness may be hampered by the presence of symptoms and this make it difficult for patients to lead a productive or meaningful life. To live with chronic illness is to live a certain kind of life. The chronically ill person may have to live with restrictions to daily activities, attending countless appointments and endure painful medical procedures. Routine activities of daily living can become burdensome and wearisome. Being chronically ill could also mean having to be dependent on others for physical care (Toombs, 2004).

Chronic illness has long been described as a process that is broken into stages whereby the chronically ill person follows a predictable trajectory. This implies that the chronically ill progress through stages as part of the journey. The trajectory model developed by Corbin and Strauss is based on the belief that the course of chronic illness can be divided into various phases, and is capable of being shaped and managed (Corbin, 1998). Halcomb and Davidson (2005) utilised this model in describing recovery from traumatic injury and reported that the same model had been successfully applied to conditions such as stroke and multiple sclerosis. These demonstrate that the trajectory model is a useful framework that can potentially enhance the nursing care of chronic illness sufferers.

Paterson (2001) offered an alternative view and presented the shifting perspective model of chronic illness, which was derived from a metasynthesis of 292 qualitative research studies that found living with chronic illness was an ongoing and constantly shifting process in which either illness or wellness is in the foreground. This model suggests that patients who maintain a wellness perspective find meaning, hope and better quality of life, however, they may be required to assume an illness perspective when receiving health care services. The model recommends that the focus on chronic
illness must extend from how it affects the patient’s physical well being to how the
patient views illness in a wider psychosocial and psychological context (Paterson,
Thorne, Crawford & Tarko, 1999).

Following the diagnosis of chronic illness, patients begin a transition by progressing
from the initial feelings of fear and denial, to acceptance and modification of their
lives in order to deal with the condition. In a study by Kralik (2002), that aimed to
understand the experiences of 81 midlife women with chronic illness, the findings
revealed that transitions in chronic illness experience involve movement from
extraordinariness, described as life with illness, to ordinariness, described as finding a
place for illness to fit into daily life, and sometimes back again. These processes were
found to be nonlinear and likely to recur throughout a chronically ill person’s life.

The person with chronic illness may be compelled to re-examine their self-concept in
the new situation and reconsider plans and expectations for the future. Adopting a
positive psychological outlook is thought to facilitate the transition towards
acceptance of the illness as individuals learn to re-prioritise, look to the future and see
beyond the illness (Glacken, Kernohan & Coates, 2001). Sutton and Treloar (2007)
explored the experiences of 36 people with hepatitis C within two models of chronic
illness [illness trajectory and shifting perspective] and they found that focusing on
illness can cause anxiety, while a wellness perspective places distance between the
patient and the illness and can lead to an appreciation of life and other people.

Chronic illness need not be severely incapacitating, and even when it is, the individual
is only episodically, if at all, a patient wholly in the hands of a health professional
(Toombs, 2004). In describing the differences between acute and chronic disease treatment, Holman (2004) reported that treatment for chronic illness occurs primarily in ambulatory settings and can often be provided well by different health care professionals in the home, schools and community centres. CHC can be treated almost entirely at home unless the person with HCV is unable to cope.

For many, chronic illness could mean having to live with uncertainty and hopelessness, as the hope of a “cure” might not be realistic. In the absence of cure, chronic illness must be managed over time as it evolves with shifting severity, pace and treatments (Holman, 2004). Netuveli, Wiggins, Hildon, Montgomery and Blane (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.

In summary, chronic progressive illness means much more to the patient than simply a mechanical dysfunction or discreet disease process (Toombs, 2004). A diagnosis of chronic illness is devastating for the patient and this affects his or her physical, emotional and psychological well being. Adjustments are necessary to accommodate the challenges that chronic illness brings, with the aim to live a meaningful life. The quality of life of the chronically ill can be affected by other variances such as stigma associated with the illness, fear about transmission, and problems with regards to personal relationships.

**Living with Hepatitis C**
Diagnosis, Symptoms and Quality of Life

“My life has changed. I was once full of energy, now I have none…my housework never gets done. I have lost interest in the world. Depression takes over”.

(Submission 7, Standing Committee on Social Issues, 1998)

Those who are diagnosed with HCV infection face a period of adjustment as they attempt to integrate this change in health status into everyday life. Most react with some degree of shock, fear and denial, even if they strongly suspected they might be infected. The impact of the HCV 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 recently diagnosed individuals in Islamabad by Gill, Atiq, Sattar and Khokhar (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 and intermittent (see Table 4). Most people with CHC will be asymptomatic during the first ten years of infection (Pritchard-Jones, 2000). The most commonly reported symptom is fatigue; other symptoms include lethargy, right upper quadrant pain, malaise, headache, nausea, loss of appetite and weight loss (Dolan, 1997). Schafer, Scheuren, Felten and Kraus (2005), on reviewing the literature for studies dealing with the emotional situation of patients with CHC, found that they consistently show a considerably increased rate of emotional and psychiatric strain as well as a significantly impaired quality of life.

<p>| Table 4: Symptoms Reported by Patients (very few people experience all of these) |
|---------------------------------|---------------------------------|---------------------------------|
| Flu-like illness                | chest pain, palpitations        | irregular blood sugar          |
| abdominal pains                 | chronic fatigue                 | loss of appetite                |</p>
<table>
<thead>
<tr>
<th>indigestion</th>
<th>frequent urination</th>
<th>aversion to fatty foods</th>
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<tbody>
<tr>
<td>irritable bowel syndrome</td>
<td>fluid retention</td>
<td>headache</td>
</tr>
<tr>
<td>abdominal bloating</td>
<td>poor sleep</td>
<td>irregular menstruation</td>
</tr>
<tr>
<td>diarrhoea</td>
<td>night sweats</td>
<td>severe PMT</td>
</tr>
<tr>
<td>joint pains</td>
<td>dizziness</td>
<td>loss of libido</td>
</tr>
<tr>
<td>depression, mood swings</td>
<td>spider naevi</td>
<td>itchy skin</td>
</tr>
<tr>
<td>adverse reactions to alcohol</td>
<td></td>
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</tbody>
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Adapted from Dolan, 1997

A Swedish study by Soderberg, Strand, Haapala and Lundman (2003), on the experiences of five husbands living with women with fibromyalgia, described the wives experiences of being treated with doubt and disbelief as a consequence of the invisibility of the symptoms causing a lack of understanding and support for their plight. This experience is particularly common in most people with HCV who do not look ill, but do experience fatigue, pain and depression. Support from family members, particularly spouses, is thus very important for the person with CHC.

In a study in Melbourne of 91 individuals with HCV, Rodger, Jolley, Thompson, Lanigan and Crofts (1999) found that HCV infection affects quality of life on two levels: physiologically (for example fatigue and nausea) and psychologically (the burden of living with a stigmatised disease with an uncertain trajectory). Spiegel, Younossi, Hays, Revicki, Robbins and Kanwal (2005) examined 15 studies on health related quality of life in people with CHC to compare them with healthy people and found that people with CHC had lower quality of life than healthy people, and the impact was greatest in social and physical function, general health and vitality.

In Australia approximately a third of people living with CHC are women and a comprehensive review of the literature by Thein, Haber and Dore (2003) found gender to be associated with disease course and treatment, with a possible lower risk of disease progression and a better treatment response among women. A Dublin study
conducted by Coughlan, Sheehan, Hickey, and Crowe (2002), where quality of life was assessed using instruments such as the SF-36 and the General Health Questionnaire-30, found that the quality of life of 93 women diagnosed with medically acquired HCV was significantly lower than the healthy British female population.

Several studies suggest there is considerable room for improvement of health care for people living with CHC. A comprehensive social survey of women’s experiences of living with HCV in Australia was conducted by Gifford, O’Brien, Bammer, Banwell and Stoove (2003) in ACT and Victoria in 2000 and found that overall, the 462 women had poorer mental and physical health than the general population. A similar study to investigate men’s health concerns, social life and relationships was conducted in Victoria by Gifford et al. (2005) in 2002 that revealed men were more likely to have ignored the symptoms than women and 35% rated their health as ‘fair’ or ‘poor’ compared with 18% of men in the general population.

Managing CHC involves major alterations in lifestyle to control symptoms or prevent them from recurring. The physical symptoms of chronic HCV infection lead, for many, to depression and mood swings, anxiety over the future, social isolation, loss of self esteem, the development of mild paranoia and acute stress regarding the decline of control over one’s life (Loveday, Treloar, Elek, Steele & Hopwood, 2005). As a result, the entire shape and texture of the world as experienced is altered for the person with CHC.

**Stigma, Disclosure and Discrimination**

“I have seen the questions in the eyes of the few close and trusted friends I have disclosed to and feel a strong urge to reassure them that I’m not a ‘druggy’ but an
‘innocent’ victim – this then also appals me as no one deserves this disease or the stigma associated with it. No one is innocent or guilty – HCV does not discriminate, people do!!” (Submission 81, Standing Committee on Social Issues, 1998)

Whether diagnosed with a condition like cancer, AIDS, HCV or fibromyalgia, reactions to chronic illness relate not only to physical symptoms but also to the metaphors and images ascribed to each condition. Stigma can be defined as a distinguishing mark of social disgrace or a construction of deviation from some ideal or expectation (Taylor, 2001). Richmond, Dunning & Desmond (2004) conducted a systematic review of the literature and concluded that stigma associated with an infectious disease is generally caused by fear: fear of the illness, fear of contagion and fear of death.

The fear associated with a blood borne infection is undoubtedly linked to its association with images of drug abuse, promiscuity and perversity. An American study on stigmatisation and quality of life of 257 patients with CHC revealed that the three most commonly perceived reasons for stigma were society’s association of hepatitis C with HIV/AIDS, the attribution of promiscuity, and the assumption that the person with hepatitis C was an injecting drug user (Zickmund, Ho, Masuda, Ippoloto & LaBrecque, 2003).

Despite attempts to shift public attitudes, depictions of blood borne infections are dominated by blame, punishment and retribution. Blood borne infections such as HCV and HIV are often seen as a condition brought upon oneself by behaviour for which society has little sympathy or understanding (Altschuler, 1997). This relates to the
metaphor of sin in that those who are infected have the virus because they were engaged in specific activities of which many people do not approve and they are thus responsible for their disease (Katz, 1997).

Stigma is a complicated issue that is more likely to thrive in an environment of ignorance and half-truths (Valdiserri, 2002). Several factors generate hepatitis C related stigma that includes ignorance about transmission, lack of awareness of the impact of hepatitis C on the health of affected people, and socio-cultural attitudes towards injecting drug use (Richmond et al., 2004). In a study of stigma and its effects on 9 European American women with HIV/AIDS conducted between 1995-1997, Carr and Gramling (2004) found that the women delayed seeking health care, avoided their family members and friends, and concocted elaborate tales to hide their medications and symptoms.

Several studies revealed that stigmatisation occurred in the health care setting and identified hospitals, general practice and dental surgeries as the environments where hepatitis C-related discrimination occurs most frequently (Zickmund et al., 2003; Hopwood, Treloar & Bryant, 2006; Richmond et al., 2004). 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).

The impact of stigma and discrimination affects self-esteem, social interactions, employment opportunities, quality of life and reduces willingness to access health services. Hepatitis C have isolated and stigmatised people who were already often discriminated against and isolated within society. For example, most of the people
with blood borne infections who previously used, or are currently using drugs, will also be affected by poverty, poor housing, and may not have had a positive experience of education and employment (Morton & Johnson, 1996).

Social support may be the key to reducing isolation and has been identified as an important factor that contributes to health related quality of life for people living with a chronic illness (Johnston, Jones & Burns, 1998). Cormier (2005) suggests that support groups for patients and families coping with HCV may aid in fostering social support, may assist the person living with CHC in coping behaviour, and may result in less uncertainty and anxiety.

Issues about what information can or should be shared with family, friends, employers and colleagues are extremely complex. In an ethnographic study in Zimbabwe during 2001 and 2002, where approximately one third of adults are HIV infected, it was found the stigma, discrimination and resulting isolation means that people do not easily, if ever, disclose their diagnosis (Duffy, 2005). A German study, conducted by Schafer et al. (2005) to evaluate the disclosure behaviour of 103 individuals with hepatitis C, found that 25% of patients with chronic HCV infection preferred not to communicate their disease to significant others for fear of rejection.

Stigma affects not only the individuals with CHC but also their families. Many families are fearful of censure and disapproval from others and may choose to maintain secrecy (Katz, 1997). Families avoid having to face up to the complex issues of how the virus was acquired, often with associated feelings of guilt, and involving subjects people least like to talk about: drug use, sexuality and death as a possible outcome.
(Morton & Johnson, 1996). The pressure of confidentiality is difficult to cope with, as the ethics of secrecy can be problematic: failing to share information may have implications for the health of others and secrecy could prevent other family members from reaching out to their friends for support.

**The Family and the Caregiver**

“The worst impact is on my family. My children don’t really understand except that Mum is tired and cranky and money is tighter because Mum can’t even do as much part time work as before. My husband (an incredible support) is working longer hours to make ends meet as well as often coming home and making dinner or other jobs traditionally mine”. (Submission 12, Standing Committee on Social Issues, 1998)

The family remains the fundamental unit of society where the most intimate communal life takes place. The family is a social unit whereby each member plays a specific role in relation to each other. Davis and Magilvy (2000) explored how chronic illness is experienced and managed by families in rural Colorado and the interviews with 42 Americans revealed that the experience of chronic illness is complex and multifaceted emerging from interrelationships among individuals, families and communities. Martire (2005) conducted a systematic review of 12 studies on the efficacy of involving the family in psychosocial interventions for chronic illness and concluded that family members play an important role in a patient’s recovery from and adjustment to chronic illness.
The family can be affected by the patient’s symptomatology, activity restriction and need for emotional support or physical assistance. When illness strikes, there tends to be some reorganisation of the family hence roles may be reversed or altered. A family living with a member who has a chronic illness is believed to vacillate between hope and despair, suffering and possibility (Chesla, 2005). Mahoney (2001) conducted a study to understand the family’s experience with chronic illness and found that the family underwent a thematic process that progresses from disruption of the normal course of life, to incoherence where ‘things’ do not make sense, to reconciling when the family unit attempts to resolve the disruption or incoherence.

Chronic illness can bring about physical discomfort or pain, may lead to dependence on another at a practical and emotional level, and may limit paid employment with restricted access to the outside world. 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 caused by added responsibility (Eriksson & Svedlund, 2006).

The study by Eriksson and Svedlund (2006) also found that the spouses experienced feelings of detachment from their partner’s lives, changes in their relationships because of their partners’ disabilities and loneliness despite living together as a couple. This finding is similar to that of Soderberg et al. (2003) that revealed living with a chronically ill spouse led to isolation and loneliness. Being a primary caregiver can be, and usually is, a full-time and overwhelming job. This is complicated by the fact that the partner may already have a full-time job and other pressing family responsibilities.
For the caregiver of a family member, there is not such a clear choice, because of affectional ties or family obligations (Schofield, 1998).

Chronic illness introduces imbalance to relationships and can have a profound impact on the psychological wellbeing of individuals and couples. Wright (2005) purported that good marital functioning is never more important than when facing chronic physical or mental illness. Medalie (1997) described chronic illness as difficult to adjust to and there may be periods of frustration, irritation and anger, often directed at the very people whose love and support are needed most. A study exploring the partners’ experiences of chronic illness, by Kuyper and Wester (1998), found that chronic illness affects the relationship between spouses in many ways and can give rise to feelings of shame, guilt, resentment, increasing isolation and limiting availability to one another.

Wright (2005), based on literature and clinical experience, claimed that a distressing reaction to chronic illness common to men and women is the feeling they are bringing less to the marital relationship than their healthy spouse. This invites deeper emotional suffering in addition to physical suffering. Gauthier et al. (2007) conducted a longitudinal study on quality of life and depression in neurodegenerative disorder patient-caregiver couples and found that patients seem to be aware that their spouses get more and more burdened over time.

Partners often are afraid for the patient and themselves as they, too, face change. These fears and anxieties can have an extensive impact on couples, affecting decision-making as well as sexual relationships. Larsen, Miller and Ostrow (1998) claims the symptoms of chronic illness such as pain and fatigue set limitations to sexual life
because they contribute to loss of sexual desire and satisfaction. The nature of HCV can mean that partners may feel anxious about having sexual relations or concerned about perceived risk to their own health. In the study by Eriksson and Svedlund (2006), it was revealed that fewer social connections and altered sexual relationships are regarded as negative experiences by patients and spouses, however, positive experiences confirm that the infirmity has brought the couples closer together, even strengthening their relationships.

Caregiving can affect employment opportunities and can drain the family’s financial resources. In a study of caregivers, Schofield (1998) reported that caregiving presented difficulties where caregivers worked, for example they experienced interruptions to their work, less energy, fewer hours of paid work, or needing to take unpaid leave. The partners may have to provide financial help for previously independent spouses or alter their lifestyles to accommodate a sick spouse (Travis & Piercy, 2002). Financial hardship can affect caregiver’s emotional wellbeing and reduce the capacity to buy services and other practical items, which help in caregiving, as well as the social, therapeutic and recreational resources that enhance the quality of life of the caregiver, care-recipient and other family members (Schofield, 1998).

The financial, physical and emotional difficulties make the task of caring for an ill person an enormous job. A quantitative study by Kemler and Furnee (2002) found that spouses of people with chronic illness were forced to devote more time to household maintenance and this resulted in less time for personal needs and leisure activities. The competing demands of work and caregiving can relatively affect the spouse caregiver as they experience exhaustion, fatigue and stress; and time and
emotional dilemmas in balancing competing responsibilities and/or meeting their own needs (Schofield, 1998).

The study of Soderberg et al. (2003) found that partners had difficulties in always being present, considerate, sensitive and understanding of their spouses’ needs, which affected their own mood. A case study involving 4 couples found that spouses who accompany the patient to clinic visits are reluctant to talk about themselves because they think the health professionals do not care, or because of a lack of time, or because they do not think their needs are as significant as that of their partners (Duhamel, Dupuis, Reidy and Nadon, 2007). Therefore, it can be construed the patients received greater support from their doctor, nurse or counsellor but the partners’ needs were often overlooked.

A common feature of caring for a spouse with a chronic illness or disability is dealing with difficult behaviour (Schofield, 1998). Some partners observe enormous changes in the patient and find they cannot cope. Previously independent partners may suddenly become emotionally, financially, or physically dependent on others for help. Partners may fear being trapped into staying in a situation that feels frighteningly restrictive or destructive. For some, the only way of continuing to support one another is by achieving greater distance between them through formal separation (Altschuler, 1997).

However, it is a mistake to view caregiving as typified by burden, by negative effects on the partner’s physical, emotional, social and financial wellbeing. Eriksson and Svedlund (2006) found that overall, most partners acknowledged the satisfaction, self-reliance and increased confidence they had gained through managing demanding
and difficult situations. Most partners feel supported by family and friends and most obtain a great deal of satisfaction in caring for their loved one (Schofield, 1998). A partner’s temporary or permanent inability to fulfil a role creates the opportunity for the other to experience a new side to themselves (Altschuler, 1997).

Chronic illness has considerable impact on the lives of children who may experience emotional and physical neglect, and a lack of consistency in who takes care of them if at times temporarily relegated to the care of relatives and friends. Morton and Johnson (1996), based on their experiences of working with families affected by HIV in Scotland, described that many children and young adults whose parent is ill may have taken on a caring and parenting role both for siblings and for their parent. This experience is similar to children of people with HCV, who could potentially be isolating themselves from their peers because of embarrassment and protecting themselves from hostile community responses due to their parent’s hepatitis C status.

Children will often have witnessed the bouts of illness in their parents and perhaps the conflict amongst the adults surrounding them (Morton & Johnson, 1996). Altschuler (1997) purported that the healthy parent’s negative response to a partner’s illness, such as being unable to contain feelings of anger and depression, can mean that children effectively lose not one but both parents during crises. In contrast to this opinion, Soderberg et al. (2003) described a deeper relationship between the husband and children as a consequence of the wife becoming ill as the husband had more responsibility and participation in the children’s upbringing.

**Holistic and Family-Centered Nursing Care**
Nurses practicing holistic care focus care on the whole person and not on diseases. Sourial (1997) analysed the holism concept in the nursing literature and found that holism advocates the view of the whole person that goes beyond their physical or medical care. Diluzio and Spillane (2002) defined holistic nursing care as understanding health and illness as involving the whole person that is body, mind and spirit.

Holistic care draws from some of the healing arts espoused by Florence Nightingale. She saw nursing as a holistic endeavor, where attention to sunlight, diet, fresh air, and quiet, and clean surroundings were viewed as essential for health and healing (Diluzio & Spillane, 2002). Folsom (1999), based on 15 years of clinical holistic nursing in New York, found that a combination of relaxation techniques, imagery and therapeutic touch help to redirect patients’ attention, distracting them from pain and discomfort, and allowing them to achieve a powerful relaxation response.

A holistic nursing approach to symptom management is well suited to the increasing numbers of people with chronic illness. Haworth and Dluhy (2001) developed an interaction model in 1999 called the Negotiated Symptom Management, that aimed to link nurses and clients to elicit an accurate understanding of symptoms and involving the clients in symptom management decisions. This interaction model is the result of an extensive literature review on client-nurse interaction and holistic nurse theorists. Haworth and Dluhy (2001) concluded that effective symptom management is dependent on hearing and attending to the lifeworld of the client and claimed that nursing clinicians espousing a holistic approach increase their understanding of the
personal, social and cultural influences of the clients and their attitudes to health and illness.

Because in holism all dimensions are considered equivalent, the spiritual and sexuality dimensions, which are often overlooked and misunderstood, should also be equally considered. Koslander and Arvidsson (2007) conducted 12 interviews with mental health care clients in Sweden using a phenomenological approach and found that patients wish to have their spiritual needs addressed by nurses. Earle (2001) conducted an extensive review of nursing, disability and social science literature and argue that the biopsychosocial approach and the notion of ‘whole’ person seem particularly significant, however the lack of attention to patient sexuality is identified.

Holism in relation to nursing is the view that the individual who is being cared for is a whole, integrated being that comprises the mind, body, emotion and spirit, who cannot be reduced to parts and treated separately. Although symptom management and relief is a primary goal, the emphasis for the nurse remains on the person and not the symptom. By being attentive to the whole being, the nurse is in a position to improve client satisfaction and deliver sensitive care (McSweeney, Allan & Mayo, 1997).

Family-centered nursing care aims to improve the health of a family or any of its members by identifying and addressing individual and family health needs. Powers, Goldstein, Plank, Thomas and Conkright (2000) conducted patient, family and staff interviews at the University of Kentucky Hospital in 1994 and found that central to patient and family-centered care are the patient’s and the family’s right to make
informed care decisions, and the health care providers’ responsibility to accept those decisions.

The study of Powers et al. (2000) also found that the care plans nurses routinely map out for patients are one of their major time management tools, however, it does not often involve the patient in the development of the care plan. The client expects to become an integral member of a client-clinician team wherein both participants contribute to the process (Haworth & Dluhy, 2001). As consumers become better informed about treatment options, they expect to be more involved in their health care decisions and are less willing to simply “follow doctor’s orders”.

Family members participate in and follow the care of the chronically ill family member. Based on interviews of 44 family carers and 78 staff in 15 Northern Ireland nursing homes, Ryan and Scullion (2000) found that family caregivers should be involved in all aspects of care because they have biographical expertise, which they should be encouraged to share with nurses to achieve high quality holistic care. This finding can be applied to other nursing specialities as a general concept. The nurse-patient relationship is strengthened when patients and their families participate more extensively in their care (Powers et al., 2000). Good quality care is best delivered by nurses who have gained a deep understanding of the patient and a good working relationship with the family (Ryan & Scullion, 2000).

When a chronic illness occurs in a family member, the family functioning undergoes a major transition. Family caregivers need encouragement and information to help them to continue their participation in the care of their loved one. Nurses have technical
expertise, which could be passed on to family caregivers to enable them to make a comprehensive contribution to the care of their relative (Ryan & Scullion, 2000). The role of the nurse is to deliver, or teach the family, the care the client needs that the family are unable to provide due to their lack of knowledge and skills.

Information about the illness is regarded as useful in helping caregivers understand their relative’s symptoms and behaviour problems, and become more positive about their own role in the treatment process (Schofield, 1998). Findings of a study of telephone-based interventions in Finland from 1997-1998 indicated that when the patient’s condition deteriorated, the family’s need for information increased and furthermore, that supportive telephone call intervention is an alternative and additional form of family support (Kaunonen, Aalto, Tarkka and Paunonen, 2000).

Confusion due to lack of or conflicting information about the illness, prognosis, treatment, access to formal services and problems communicating effectively with health professionals have negative outcomes and can greatly reduce patient satisfaction (Schofield, 1998). Drawing on 30 in-depth interviews with family caregivers conducted in Ontario, Wiles’ (2003) revealed that formal support was effective where services were good quality, where the relationship between health care professionals and those receiving care were respectful and continuous, and where services perceived as appropriate were provided.

Knowledge is reassuring and information about services enables patients and spouse caregivers to get practical and emotional support other than that provided by family and friends (Duhamel et al., 2007). The dilemma for health care professionals
concerns the amount of information to provide, the timing and the approach because overloading patients and caregivers with information or the insensitive delivery of information can have negative effects. Improved communication between family caregivers and health care professionals and sensitive delivery of information has the potential for an improved working relationship that can only prove beneficial to all concerned (Ryan & Scullion, 2000).

The support patients receive from family during illness is crucial both in adaptation to the illness and recovery from it. Martire’s systematic review (2005) revealed that 5 out of the 12 studies showed consistent evidence that a family oriented approach was more beneficial than patient-oriented intervention and in the remaining studies, the more efficient approach depended on several variables such as gender, strategies and follow-up. Farvis (2002) reported that current literature advises health care professionals to regard families as allies and partners in treatment and care because they are able to offer information and practical assistance in care planning and implementation.

**Summary**

CHC and combination therapy are debilitating and affects the physical, psychological, emotional, intellectual and social functioning of the patient. The patient with CHC on combination therapy lives with uncertainty and hopelessness because cure is not always achievable. In this situation, maintaining a satisfactory quality of life should be the aim of nursing care.
Stigma is a complex issue associated with CHC as blood borne infections are often linked to surreptitious acts which society finds repulsive. Ignorance about the mode of HCV transmission had led people to shun patients for fear of contagion. As a result, patients with blood borne infections avoided social gatherings and were isolated. Peer support may be a key to reducing isolation and improve the well being of people living with CHC.

Illness extends beyond the patient to touch a wide range of people, family, friends, relatives and colleagues. In dealing with hepatitis C, those involved in the management of patients need to recognise that patients do come with partners (Batey, 1997). The partner is the most intimately related person to the patient who is most often the primary caregiver with the greatest responsibility (Callahan, 2003). Therefore, partners may also require support to remain considerate, sensitive and understanding of their spouses’ needs.

We live in an age of technological development. Advances in medical technology have heralded enormous optimism in the treatment of CHC, both for patients and professionals alike. However, there is a need to recognise the impact both CHC and combination therapy can have on the lives of patients and their partners. The findings of this study will assist nurses to improve their understanding and care of patients with CHC on combination therapy thus improving the quality of life of this marginalised group. Hence, the goal of care has been broadened to encompass not only the cure of CHC but, as importantly, assisting patients and their families to live well in the face of ongoing incapacitation.
Chapter 3: METHODOLOGY

Introduction

Qualitative research evolved from the behavioural and social sciences as a method of understanding the unique, dynamic and holistic nature of human beings (Burns & Grove, 1997). Qualitative research is inclusive of a number of methodologies, philosophies, methods and procedures; however, they all focus on the everyday life, interaction and language of people. All these different approaches and methods of inquiry are part of the interpretative approach (Holloway, 1997). The philosophy directs the questions that are being asked, the observations that are being made and its interpretation.

The philosophical framework for this study is informed by Heideggerian phenomenology. Phenomenology provides a framework within which to examine experiences – it is both descriptive and interpretative. The purpose of phenomenology
is to describe experiences as they are lived in an effort to understand and give them meaning (Byrne, 2001). It examines the particular experiences of unique individuals in a given situation, which fits with the aim of this study: to examine the relationship experiences of patients and their partners during combination therapy.

The study focuses on the individuals living with chronic illness and their partners, where CHC and combination therapy may be experienced as a profound threat to their relationship. The person with CHC and his/her partner describe the illness and treatment experiences. It might be said more accurately that the illness and treatment experience – as opposed to the brute facts of the disease process – is the experienced phenomenon.

The purpose of this chapter is to briefly discuss Heideggerian phenomenology. The aims of the discussion are to show what is involved in investigating the life-world experiences of people with CHC and undergoing combination therapy, and, to show what must be taken into consideration to obtain adequate descriptions of the experiences.

**Why Phenomenology?**

Phenomenology’s philosophy and approach is well suited to nursing enquiry. Phenomenology has found appeal in nursing research because it reflects values and beliefs that are coherent with nursing and allows questions to be explored that are important to nursing (O’Brien, 2003). Research that helps us understand our patients’ experiences contributes valuable nursing knowledge (Moloney, 1997). By discovering the meaning of a certain phenomena, a new understanding of the experience is created
and this aids the assessment and care of future patients experiencing the same phenomenon.

From a phenomenological point of view, to do research is always to question the way we experience the world, to want to know the world in which we live as human beings (Van Manen, 1990). Kvigne, Gjengedal and Kirkevold (2002) used phenomenology to explore the life-world of women suffering from stroke providing understanding of female participants’ post-stroke experience, coping and quality of life. Koch (1999) also used phenomenology to explore the experiences of older patients admitted to an acute hospital. The meaningful experiences that participants conveyed during these studies made sense of the situations in which participants find themselves. These studies provided a constructed reality of the participants’ experiences at a particular point in time.

Understanding the patient perspective is a valued goal of nursing practice and depends on the nurse’s ability to listen to patients and envision changes in their life. If the core of nursing is the expression of caring through an interpersonal relationship, then the most appropriate research methods should be drawn from phenomenology (Marks-Maran & Rose, 1997). The meaning and significance of certain phenomena will need to be appropriated by anyone who hopes to benefit from such insight (Van Manen, 1990). The richness, really, is how well somebody else can use it (Morse, 2007).

**Origin and Definition**

Phenomenology is the study of phenomena and the appearance of things, and the discovery of their meaning is the ultimate purpose of such research (Boyd & Munhall,
Phenomenology attempts to unravel meanings as we live them in our everyday existence. In this focus upon meaning, phenomenology differs from other social or human sciences which may focus not on meanings but on statistical relationships among variables, on the predominance of social opinions, or on the occurrence or frequency of certain behaviours (Van Manen, 1990).

Phenomenology has its historical roots in philosophy. Phenomenologists argue that science was preoccupied with explaining natural objects or events, whereas the understandable meaning of these objects and events was taken for granted and received little attention. Franz Brentano (1838-1917), a philosopher and psychologist, provided the groundwork for phenomenology and believed its philosophy could answer questions about the concerns of humanity (Holloway, 1997). Edmund Husserl (1859-1938) was Brentano’s student who introduced the concept of the ‘life-world’ and central to his approach was the fundamental recognition of experience as the ultimate ground and meaning of knowledge (Koch, 1999).

Martin Heidegger (1889-1976) was Husserl’s colleague, and like Brentano and Husserl before him, also launched on a never-ending search for the meaning of being (Fleming, Gaidys & Robb, 2003). Heidegger believed that people’s existence is always connected with the world in which they live and that the two cannot exist without each other (Holloway, 1997). Heideggerian phenomenology addresses questions concerning meaning in the practical everyday life of people and seeks to provide an interpretation of the practical understanding of human actions and experiences (O’Brien, 2003).
A research study that pursues a certain problem is completed when the problem is solved (Van Manen, 1990). Phenomenology strives to interpret meanings rather than explain, and attempts to understand rather than solve a problem. Phenomenology focuses on practical living in terms of individuals’ views and experience of the phenomena of concern and its value in their everyday lives. Phenomenological questions ask for the meaning and significance of the phenomena, so that they can be more deeply understood. A question that can utilise a Heideggerian approach to research is: ‘How is this phenomenon understood through experience of the phenomenon?’ (O’Brien, 2003).

**Phenomenological Framework**

*Role of language, meaning and understanding*

Phenomenology is firstly a philosophy that attempts to understand ‘being in the world’. It can inform research that explores the experiences of people in their world. The data collection strategy involves the participants verbally describing their experiences of a phenomenon. Kvigne et al. (2002) gained access to the life-world of women suffering from stroke through in-depth interviews and the informants’ openness in describing their experiences. Phenomenological studies use the language of the participants in the study to reflect as accurately as possible the meanings embedded in the experience (O’Brien, 2003).

To come to the meaning of the phenomenon participants have to tell stories. 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). To tell is to recount and reveal. To tell a tale is to disclose experience so that its significance is discernible (Toombs, 2004).

In phenomenology, the interview serves very specific purposes, to obtain the participant’s description of the experience. It is used as a means for exploring and gathering experiential narrative material that may serve as a source for developing richer and deeper understanding of a human phenomenon (Van Manen, 1990). Smith (1998) conducted a phenomenological study in Scotland of six problem drinkers and through in-depth interviews was able to obtain meaningful descriptions that made sense of the situations in which the drinkers found themselves. The researcher experiences the phenomenon through the participant’s descriptions and ultimately reaches a common understanding with the informant.

**Position of researcher**

Understanding a phenomenon includes the merging of experiences offered by the participants, the researcher’s interpretation of situations explicated in journal notes, by the researcher’s personal and professional background and by selected literature (Koch, 1999). Researchers bring their interests to the data, upon which meaning and significance may be read into it. Therefore, the researcher is part of the research and not isolated from it. Heideggerian phenomenology requires the researcher to acknowledge their own ‘being-in-the-world’ (Todres & Wheeler, 2001).

Having worked in the area of hepatology and having cared for people with HCV, I have gained insight into the phenomena of concern. According to Heidegger, it is precisely one’s preconceptions or unity of understanding that channels new ideas and
guides interpretation (Maggs-Rapport, 2000). The researcher is understood to have a preliminary understanding of what is going on, knows that the question is a legitimate one and can envisage possibilities that may emerge from the study (O’Brien, 2003).

**Role of self-reflection**

Heidegger believed that through earnest reflection, one might become aware of many assumptions as the researcher acknowledges his/her own background and uses it in collecting and interpreting data. A premise for phenomenological philosophy is that one can achieve deeper insight on the basis of one’s own experience (Kvigne et al., 2002). Reflection on lived experience forces one to recognise the manner in which social attitudes to chronic illness and disability can impact on social practices (Toombs, 2004). It affects the way people with HCV are treated by others, as well as influencing their feelings about themselves and the extent to which they can flourish as members of society.

**Study Design**

**Participants**

The participants of phenomenological studies are chosen because of their experience of the phenomena being studied and because of their ability to articulate that experience (O’Brien, 2003). The richness of the data is more important than the number of participants in the study. Because of the depth of the research interviews and their analysis, the sample is generally small (Holloway, 1997). Two to ten
participants are usually sufficient in a phenomenological study (Boyd & Munhall, 2001).

Purposive sampling technique was used for this study. Purposive sampling involves the conscious selection by the researcher of certain subjects or elements to include in the study (Burns & Grove, 1997). The criteria for inclusion in this study were that participants must be over 18 years of age, had been diagnosed with CHC and on combination therapy, or whose partner is on combination therapy, involved in a partner relationship and living with their partners. The participants must be in the relationship for two years or more to be able to demonstrate some degree of relationship stability. Both the patient and their partner had to be willing to participate, but consideration would be given to patients whose partner did not want to participate and vice versa.

There were 10 participants (5 couples) who volunteered and fulfilled the criteria for inclusion in the study. The participants’ age ranged from 32 to 54 years and as couples had been together for an average of 14 years. All the participants had children with ages ranging from 7 to 23 years of age at the time of the interviews. All the participants with CHC were on 12 months combination therapy. One participant had two previous unsuccessful treatments and another had one unsuccessful treatment.

The employment status of participants with CHC on combination therapy varied. One participant remained in full time employment in the health care profession during the treatment period. One participant used to be a manager but was made redundant due to company restructure. Another participant lost his trade job because he could not
cope with the manual tasks due to the symptoms of CHC and the side-effects of the treatment. One participant worked in the health care profession but went on sick leave, workers compensation and then leave without pay for the duration of the treatment. One participant was on home duty and studied part time at TAFE.

In the group of partners of participants, one partner was working part time to supplement the family’s income. One partner was on home duty. Three partners were working full time with one working as a tradesperson, another was an academic and one was self-employed.

Participant recruitment was accomplished through advertisement in the quarterly publication of the Hepatitis C Council of NSW, the *HepC Review*; and through health care professionals from liver clinics within NSW who informed their clients of the study and referred them on with permission to the researcher. Three couples were recruited from liver clinics and two couples contacted the researcher after they read an advertisement in the *HepC Review*. All the participants lived in NSW.

**Data Collection and Management**

The interview is considered the main method of data collection in phenomenological research as it provides a situation where the participants’ descriptions can be explored, illuminated and gently probed (Kvale, 1996). Interviews are designed to elicit as full and as rich a description of their experience as the participant can share (Stainton, Harvey, McNeil, Emmanuel & Johnson, 1998).
Notes of nonverbal information may give a more complete picture of the interview. The language of the body may both reinforce and weaken what is said, or may even communicate a message at odds with what is expressed verbally (Kvigne et al., 2002). The observation notes are the researcher’s descriptions and not those of the participant. Notes taken during or following the interview are useful to provide comment on feeling-tone, body language and the researcher’s experience of the interview (O’Brien, 2003).

Notes can be incorporated into the text to reveal the way in which the researcher participates in collecting the data. Noting for example the body’s self-representation with regard to appearance and the care taken with one’s appearance, movement and function can form a basis for questions and thus for greater depth in the informant’s own descriptions (Lowes & Gill, 2006). Data from observation serves to produce the best construction of the participants’ experiences, and contributes to the trustworthiness of the research process (Koch, 1999).

Conducting an interview is a delicate task. The climate, tone and mood between the researcher and participant will be decisive for whether the participant opens his/her life-world for the researcher or not (Kvigne et al., 2002). They must establish a good dialogue, and this is the first and foremost responsibility of the researcher (Kvale, 1996). One may call it entrusting oneself to someone else without receiving the same trust in return. Full disclosure of the research requirements and a willingness to share some of the researcher’s personal details during recruitment is one way of establishing a participant’s trust (Cloyes, 2006).
The interviewer should create a permissive atmosphere and help the participants to feel free to relate (Lindseth & Norberg, 2004). The researcher conducting the interview, therefore, requires certain skills such as the use of reflection, clarification, requests for examples and description, and the conveyance of interest through listening techniques (Wimpenny & Gass, 2000).

An understanding of people and sensitivity are important for the quality of the interview and thus also of the data (Kvigne et al., 2002). A researcher therefore requires insight in order to effectively facilitate a conversation about sensitive topics in a way that does not hurt the participant’s feelings. Furthermore, the researcher’s patho-physiological knowledge about HCV and knowledge about how people react to serious illness were important in interviewing people with HCV. The researcher’s knowledge helped inspire a sense of trust and enhanced the ability to probe more deeply when required.

Data for this study were collected using semi-structured interviews. The interviews of two participants were conducted in tutorial rooms at the liver clinics where the participants received treatment. Two interviews were conducted in the business office of two of the participants and six participants were interviewed in their homes. Two couples were interviewed together at their request and six participants were interviewed separately.

The interviews lasted between thirty to ninety minutes. The interviews were audiotaped, transcribed verbatim by a professional transcriber and checked against the tape by the researcher. Non-verbal behaviour was described through notes written shortly following the interviews.
The researcher initiated the participant interviews by asking an open-ended question: ‘Living with hepatitis C and undergoing combination therapy, what is it like for you?’. For the partners the interviews commenced with the question: ‘Your partner is living with hepatitis C and undergoing combination therapy, what is it like for you?’. The probing questions used by the researcher focused on the effect of CHC and combination therapy on personal relationships.

The interviews required open dialogue and focused on the experience, therefore little structure was applied by the researcher. When the participants said very little, the researcher gained access to descriptions by asking probing questions. The questions used were determined by the course of the interview and examples of probing questions can be seen on appendix 3.

The researcher did not seek participant validation to verify the findings. Participant validation could be problematic for participants searching for their individual accounts of their experiences who may not recognise them within the synthesis of data that was produced (Milne & Oberle, 2005). Furthermore, once fixed in writing, the text takes on a life of its own and has meanings hidden from its original author (Smith, 1999). The researcher exercised caution by not returning the transcripts for participant validation to protect against overwhelming reactions when reading the description of their own suffering (Smith, 1999). And as far as the data was concerned, the fact that the interviews were tape recorded and transcribed verbatim provided a guarantee of at least verbal accuracy (Koch & Harrington, 1998).
**Analysis**

There are a series of processes used to analyse phenomenological data. It involves reading the entire disclosure of the phenomenon to obtain a sense of the whole and re-reading the same disclosure again with the intention of discovering themes that illuminate the meaning of the experience (O’Brien, 2003). To understand a text is to follow its movement from sense to reference: from what it says, to what it talks about (Lindseth & Norberg, 2004). Essential meaning must be studied and revealed in the interpretation of text. This is part of the ongoing process of reading and writing, and, re-reading and re-writing.

Analysis of phenomenological data is aimed at understanding the participants’ experiences through identification of themes. Thematic analysis refers to the process of recovering the themes that are embodied and dramatised in the evolving meanings and imagery of the work (Van Manen, 1990). It involves searching the data for related experiences with similar meaning. The texts are examined by comparing the emergent themes across and within groups to discover common and shared ideas.

One way of performing thematic analysis is a method whereby the whole text is read and divided into meaning units. A meaning unit can be part of a sentence, a sentence, several sentences or a paragraph that conveys just one meaning (Lindseth & Norberg, 2004). They can be parts of stories, or instances that have similar meanings within participants’ stories (Crist & Tanner, 2003). In a study by Arpanantikul (2004) of the midlife experiences of 32 Thai women, data analysis was carried out by grouping together similar units of meaning into themes and sub-themes.
The aim is to examine the themes identified in relation to each other and to the whole, reflecting upon the meaning and essence of the experience for each participant, and formalising a consistent description of the structure of the phenomenon under study across participants (Burns & Grove, 1997). By reflecting on the data, the researcher expects to uncover common themes that stem from the ‘significant statements’ (Boyd & Munhall, 2001). The task is to hold onto these themes by lifting appropriate phrases or by capturing in singular statements the main thrust of the meaning of the themes (Van Manen, 1990).

All audiotapes in this study 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. The meaning of “how has the experience of treatment affected the participants” and “what does it mean to be in a relationship when one partner is being treated”, were then outlined.

Meaning units from the analysis were grouped together and organised into themes and sub-themes. The differences were duly noted. The themes that emerged from this study were discussed at length with the researcher’s principal supervisor and co-supervisor to ensure they flowed logically from the findings and to validate the narrative interpretations of the text. Returning to the audiotapes to listen to the tone of participants’ voices gave additional meaning to the text and the ample use of direct quotations ensured credibility of findings.
The transformation of phenomenological data into text is the product of analysis and writing is an important part of the analytical process. The researcher is an impartial observer who has the complex task of documenting a compelling account of the findings that emerge. Phenomenological writing is a creative process that goes beyond narrative description to uncover meaning and understanding (O’Brien, 2003). The findings are expressed using everyday language rather than abstract scientific language and verbs are better at revealing lived experience than nouns (Lindseth & Norberg, 2004). Throughout the interpretive process, writing and re-writing develop the interpretation (Crist & Tanner, 2003).

The extent to which meaning is implicit or imposed by the researchers’ own interpretation and assumptions demonstrates reflexive writing (Savage, 2000). There may be different perspectives on the phenomenon where readers may derive another interpretation of the findings, however, this does not mean the researcher’s interpretation is or is not justifiable (Webb, 1999). The reader will decide if the product of research is believable or plausible (Koch & Harrington, 1998).

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 can provide in-depth descriptions of the phenomena under investigation (O’ Brien, 2003). Ensuring openness of the participants to their story, accurate transcription of interview audiotapes and considerable use of quotations within the text added credibility to the findings.
The rigor and trustworthiness of this study can be measured through an honest description of the methodological process and the provision of evidence to support the findings (Koch & Harrington, 1998). An account of the methodological process was clearly addressed in this chapter and the findings and discussion in the following chapters. 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**

**Consent**

Informed consent is the most fundamental ethical principle that is involved in this study. The principle of respect for autonomy which concerns an individual’s self-rule and choice must be considered first in terms of consent (Todres & Wheeler, 2001). This allows for the right to refuse participation in research that can be exercised at any stage of the research process. In a study of the experiences of problem drinkers, Smith (1998) believed that repeatedly verifying the participant’s willingness to participate emphasized the ethical importance of ongoing consent.

All the participants in this study were informed of the nature and purpose of the research and all gave consent to voluntary participation without coercion. All the participants signed an informed consent form, which described the purpose of the research, its procedures, risks and discomforts, its benefits and the right to withdraw. The right to withdraw is an important safeguard for the participants. The researcher made clear to the participants that they are completely free to refuse to participate in
the study and/or to withdraw from it without fear of retribution – even after they have agreed to take part.

Privacy and Confidentiality

Based on the right to privacy, the participant has the right to anonymity and the right to assume that the data collected will be kept confidential (Burns & Grove, 1997). Confidentiality involves a clear understanding between researcher and participant concerning the use of the data provided (Holloway, 1997). Anonymity is maintained by coding rather than using names. In the publications of this study, there was no identification of participants or their place of treatment.

The right to privacy is an important right that was upheld in this study. The participants’ privacy is protected as they were all informed, consented to participate in the study and voluntarily shared private information with the researcher. All data collected were secured in locked storage in the office of the researcher’s supervisor for five years.

Risks and Discomforts

Participant risks and discomforts

Participants with chronic illness may be experiencing difficulties, and this requires extra sensitivity on the part of a researcher. Often the phenomena that nurses explore are sensitive human experiences and the process of interviewing may be emotive for both the researcher and the participant (O’Brien, 2003). The potential risks and
discomforts that are likely to occur can include anxiety, embarrassment or stress associated with responding to certain questions. Although nurse researchers are concerned to protect participants from harm, experienced qualitative researchers point out that people who cannot tolerate talking about a sensitive topic will not do so (Smith, 1999).

The participants in this study decided what aspects of their personal lives were communicated to the researcher. The researcher was also conscious of the participants’ body language and practised attentive listening. Some participants experienced minimal to moderate distress during interviews as indicated by their long pauses or teary eyes. Support and debriefing was offered by the researcher and all the participants were offered referral to a counselling service. The participants in this study did not require support and counselling following the interviews.

**Researcher risks and discomforts**

Qualitative interviewers do experience emotional upheaval as a result of the interviewing experience. Sword (1999), in a study of prenatal care of low-income mothers, felt compassion for their difficulties, a sense of sadness regarding their hopelessness and anger at their stigmatisation and negative experiences with service providers. Similarly, the researcher in this study did experience a sense of pity for participants, helplessness and powerlessness to assist.

Support systems, including debriefing, are stressed in the literature as a means of processing painful emotions, dealing with unanticipated reactions, controlling bias and balancing information (Beale, Cole, Hillege, McMaster & Nagy, 2004). Sources of
support for the researcher in this study include family members, colleagues, academic supervisors and other experienced researchers.

**Potential Benefits**

It is believed that the telling of a story is the way we come to understand another’s lived experience, and that narration can be healing. O’Brien (2003) claims that participants in phenomenological research often identify that the process is therapeutic and a number of studies have also indicated that research interviews have therapeutic potential (Smith 1999, Stiles 2002).

Lowes and Gill (2006) suggests that participants have different motives for participating in research and although participants acknowledge that interviews may be painful, they also said they expected them to be positive experiences. Smith (1999) listed seven potential benefits of taking part in qualitative research interviews: catharsis, self-acknowledgement, sense of purpose, self-awareness, empowerment, healing and providing a voice for the disenfranchised.

The participants did not directly benefit from the conduct of this study. However, some of the participants felt a sense of relief by simply verbalising their feelings and describing their experiences. One participant in this study responded by saying that it was precisely the opportunity to verbalise his thoughts and feelings that was helpful.
Another participant recognised that the whole experience had been very positive and therapeutic in that it provided new insights for her.

**Summary**

The study participants’ description of their experiences of a phenomenon through in-depth interviews and their openness in describing their experiences were used to reflect on the meanings rooted in the experience. To enhance understanding of their ‘being in the world’, the researcher drew on the language of the study participants. The researcher applied her background knowledge during data collection and interpretation of data to achieve greater insight into the phenomena.

The phenomenological approach used in this study proved suitable in investigating the life world of people living with CHC and their partners during combination therapy. It allowed issues to be explored that are important to guide the care of people with CHC and undergoing treatment. The approach has helped in understanding the participants’ experiences which contributed valuable knowledge to the nursing profession.

The following chapter will reveal the findings from the study. The participants’ narratives provided a rich description of the participants’ experiences and offered insight into their life world. Quotations are presented in the next chapter to convey the participants’ view.
Chapter 4: FINDINGS

Introduction

This chapter will explore the findings that emerged from the interviews with the study participants. The findings regarding the lived experiences of patients living with CHC on combination therapy, and findings regarding the lived experience of their partners are summarized into themes and sub-themes. Themes are not discreet entities but reflect aspects of the whole experience. For this reason there tends to be some overlap. For instance, the sub-theme of feeling isolated has elements of stigmatisation also reflected on the sub-theme encountering stigma.

Quotations are presented in this chapter to convey the participants’ view and illustrate the themes and sub-themes. Pseudonyms are used to protect the identity of all the study participants. The participant information is listed in a tabular format (see Table 5 below).

<table>
<thead>
<tr>
<th>Couples</th>
<th>Patient with CHC on combination therapy</th>
<th>Partner</th>
<th>Number of children</th>
<th>Years together</th>
</tr>
</thead>
<tbody>
<tr>
<td>Couple 1</td>
<td>Jake</td>
<td>Sandra</td>
<td>2</td>
<td>24</td>
</tr>
</tbody>
</table>
Themes

The themes that emerged from the study were: experiencing illness and treatment; keeping a secret; sharing the experience; and enduring struggle. The various sub-themes describe aspects of the main themes (see Table 6 below).

<table>
<thead>
<tr>
<th>Couple 2</th>
<th>Rita</th>
<th>Paul</th>
<th>2</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Couple 3</td>
<td>Luke</td>
<td>Debbie</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Couple 4</td>
<td>Anne</td>
<td>Brian</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Couple 5</td>
<td>Jane</td>
<td>David</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 6: Themes and sub-themes

<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></td>
<td>Parenting through adversity</td>
<td>Looking ahead</td>
</tr>
</tbody>
</table>

Experiencing illness and treatment

All of the participants provided a description of their experiences of dealing with CHC and treatment. They recounted how the diagnosis of CHC, its symptoms and the adverse effects of combination therapy had affected their lives. The participants with CHC on combination therapy also described how it affected not only their physical but also their psychological and emotional well being.

Suffering poor health
The participants in this study experienced a variety of feelings and emotions from the diagnosis of CHC. The diagnosis raised feelings of shock, denial, anger, and sadness. Mourning following the diagnosis of CHC was an expected reaction experienced by one of the patients. The family was seen as an important source of support for the patient particularly during the period of diagnosis.

Well really I think first, the most difficult thing is when you first discover you have got Hepatitis C, firstly you go through the normal runs of emotions, as you would, which is normally denial, ‘it can’t be me’, and then you go through a stage where you get angry and all those sorts of things, and family obviously, at that time especially, are probably more important than any other time. (Jake)

Both patients and their partners 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 described 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.

Participants felt inhibited as a result of CHC and combination therapy. One patient experienced a feeling of being shut in and acknowledged that the only way to have some breathing space was to withdraw from her family.
... I actually feel that I’ve withdrawn a bit from my family. It’s kind of like sometimes I feel a bit claustrophobic and I just feel sort of like I need to back off. (Jane)

The symptoms and side-effects reported by the patients ranged from mild to severe. One patient described feeling unwell, the limitations imposed by CHC and IFN, and how these affected her work, lifestyle and the people around her.

... 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, anything outside of work, which isn’t good for the family. (Rita)

Depression was one of the common complaints reported by eight participants. For one of the patients experiencing tiredness, irritability, and not coping very well, the prospect of not working added to her frustration that ended in a serious bout of depression.

... two months ago I was sort of seriously depressed and really fed up and not coping so well ... because I was getting overtired and irritable especially in the evenings. But I was also, I was very scared about not working. (Rita)

For the person with CHC on combination therapy, the psychological side-effects of IFN can add to the complexities of daily life. One of the partners described her concerns about the psychological side-effects of IFN and feared that it could exacerbate the feelings that are already overwhelming her partner.
The one thing that concerned me was that one of the side-effects would be depression and bad moods and that … because at the moment he has got a lot to feel down about, because he lost his job about a month and a half ago and that affected him quite a bit. (Sandra)

The depression can intensify as experienced by one of the patients who developed suicidal ideation, consulted a psychologist regularly during treatment and was prescribed anti-depressant medications. This particular patient had a history of depression prior to combination therapy, and IFN exacerbated the depression to the point of accommodating suicidal thoughts.

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

For some of the participants, it was not entirely clear which symptoms were caused by CHC and IFN and which were age or work related. This caused uncertainty and confusion for one patient as to whether the symptoms will persist following combination therapy.

… taking it up at my age, there’s so many things where I think ‘gosh am I like that because I’m getting older and I’m tired or is this the treatment?’ and it’s quite scary because part of my head says ‘this is your life forever, you’re always gonna feel this way …. (Jane)

Managing ill health

Strategies to improve health and wellbeing were employed by the participants to enable them to cope with the myriad of symptoms caused by CHC and IFN. This sub-theme describes how this challenge was met by patients and their partners.
There were participants who developed a detailed plan in preparation for combination therapy with their families. It involved chores that needed to be performed by certain members of the family. It also involved disclosure to several friends so that their support can be solicited. For one of the patients, disclosure in the context of seeking support diminished paranoia about who knew what and how they knew.

*We organized this, wrote this plan about how we would manage, while I was on treatment all kinds of things. I just treated it like a work project, very detailed plan and that meant we had to let people know what we might ask them for help with and that meant telling a few more people … but I used to be paranoid about talking about it.* (Rita)

Various strategies were applied by the patients to combat the symptoms of CHC and the side effects of IFN. These included walking, fostering dogs from the pound and having people that they can turn to for help and support. These strategies have provided much needed distraction from the stresses of everyday life as experienced by one of the patients.

*So I knew that walking was good for depression … so my occupational therapy has been to foster dogs from the pound, so it gets me walking … and it also gives me just the social outlet that I can cope with because, I might just say hello to another dog owner but you know a couple of times a week at least, I will see people that I know. The other thing I try to organize was that I will have the equivalent of 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)
Patients managed their CHC and IFN side effects by performing minimal tasks and discovering what their limitations were and worked around these restrictions.

_I’m trying to keep things simple and doing less, and being really careful about pacing myself._ … (Anne)

The participants on combination therapy were also able to determine what works best for them in terms of relaxation. Taking time to wind down was essential for one of the patients in maintaining a sound mind and body.

_Probably the things that I do do, is I go to bed earlier than I used to and that’s really special to me now. That time when I will go to bed and read a book. That’s my bit of taking care of myself I suppose, that time that I really just sort of breathe out and relax and I’m doing exactly what I want to do just for me._ (Jane)

A lack of concentration and forgetfulness had led to frustration as experienced by some of the patients. They acknowledged that at times they felt they were physically present but mentally absent. However, they developed different approaches to deal with the lack of concentration as expressed by the following participants.

_... but I am also not driving more than five or ten minutes, because I can’t, I just think my concentration is too poor to be safe ... you know basically I am not here, physically here, but that is about it._ (Rita)
I started taking fish oil tablets for concentration. Sometimes I don’t have the focus. But little things like I’ll miss a tablet. Which is not me to do things like that, missing a tablet. I know how imperative it is to follow the regime and I’ll miss a tablet. (Jane)

The patients acknowledged that losing their temper presented difficulties both in the work and home environments. Controlling one’s temper, for one of the patients, involved serious reflection and the conscious decision to adjust to the situations that gave rise to this unwarranted behaviour.

But I was also very conscious of it, you know, conscious of the fact that I do have a short fuse, so I try as much as possible to control it. I became conditioned that if I lost my temper, I would know and I would just walk out … you do evaluate what you are, what you do wrong, what can be improved. (Jake)

The hope of a better day kept the patients motivated despite minor setbacks. The patients persisted and maintained a positive outlook which offered distraction from the effects of CHC and combination therapy.

But often I think it’s a mind over matter thing so I just keep pushing and go, and some weeks are better than others. My style is more about pushing myself and getting past it, getting over it and hoping the next day is gonna be a better day. (Jane)
A patient who was not particularly affected by fatigue, but suffered many of the psychological effects of IFN, was able to direct her energy to maintaining her fitness. Having an outlet such as exercise, studying and a cohort of like minded friends helped restore balance in her life.

I was going to the gym, on the walking machine, that helped me take my mind off it. I have friends I can talk to, ‘cause I do AA and have friends from the meetings that I can talk to about my problems ... I go to TAFE.

(Anne)

Whether a patient or a partner, it became evident that one way of coping with the everyday pressures is to have someone to talk to. Ventilating emotions restored one of the partner’s psychological wellbeing.

So, I have got people there if I need them and I have got my Mum, I can talk to my Mum on the phone. (Debbie)

Patients acknowledged that it was equally important for their partners to develop their own coping strategies and to receive support in order to maintain their well being.

One of the strategies he uses is just to, physically disappear. Yeah, sort of block it out, he will either go in the study out in the back or he will go in the lounge room and watch television ... he usually goes for a swim, that is one of the ways he looks after himself, gets some time for himself.

Having a support network for your partner ... I organized a couple of good friends to be the support people for him. (Rita)

Feeling Isolated
Participants described how their social life had been put on hold as the effects of CHC and combination therapy had imposed restrictions. One of the patients longed to have her previous way of life restored once the treatment is completed.

*I feel my social life is hindered. I can’t go dancing like I used to, go to the pub, go dancing, go drinking, I don’t do that anymore. I don’t do what I used to do and I’m looking forward to getting my life back at the end of this you know…. (Jane)*

The impact of stigmatisation was felt by all the participants and this affected their social interaction. A previous drug and alcohol problem compounded the isolation for a couple on the study. The partner described how their family had learned to protect each other by segregating themselves away from their family and certain people.

*... our social group is our tight family, Anne, me and kids ... we were isolated from family and from this people and that people, so it was hard, we were protecting each other from the outside people attacking ... some of the kids’ friends’ parents wouldn’t let their kids come to our house because Anne had alcohol problems and I had a drug problem. So you just build those walls up to protect your family ... now, because of the side-effects of treatment, people think, ‘is she drinking again?’ .... (Brian)*

It was clear that the isolation not only affected the patient but also the partner. The restrictions that CHC and combination therapy imposed meant that the partner was limited to the social activities that the patient could tolerate.
I think sometimes I really disappoint him, he’s always going, ‘let’s go to the movies’, ‘let’s go here’, ‘let’s go out to dinner’. I don’t want to go to the movies, I’m tired … I just want to sit at home. (Jane)

Because the partners were busy dealing with the competing demands of work and caregiving, they saw their needs as of no great concern. One of the patients conveyed her concerns for her partner who did not have the social outlets needed for sustaining a healthy emotional well being.

The trouble is he doesn’t have anyone to talk to whereas I have AA, I do some stuff with the HepC council and I ring them and I have my mother I always ring quite often and I have friends who I talk to … he doesn’t go to AA and doesn’t talk to anybody about it. (Anne)

Other members of the family needed outlets for their frustration from the accumulative stresses of daily life. Unfortunately in many of these outings, the patients are unable to participate due to the limitations imposed by their illness. For one of the patients, this was isolating and has led to despondency.

On the weekend he has been really good with the kids … he will have some activities for them 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. They need to do things and I need to take it quietly. (Rita)
Keeping a secret

As it emerged in this study, society tends to associate CHC with drug use and this was experienced by all the participants. This prejudiced view of “what kind of people” have CHC caused much anxiety for the participants. Many people with CHC do not fit the stereotype yet the moral judgment has been made by society. This theme describes whether the diagnosis of CHC was disclosed to family, friends and co-workers. The sub-themes describe the experiences of stigmatisation and its impact on the participants.

There are several misconceptions about CHC in the community, hence, the participants would rather keep it to themselves rather than risk having to face up to the scrutiny of how HCV was acquired. The fear of identification has meant that one of the patients had to keep CHC a secret.

*Society doesn’t know very much about it … I have to keep it a secret to fit in society … you can’t come out and tell people ... keep it a secret. (Luke)*

CHC was too complicated for the patients’ children to comprehend and there was an underlying concern about what children might do with the information. Hence, the patient decided to keep the condition a secret from his children to avoid any negative consequences.

*I sort of don’t talk about it to my kids … in case they … they are too young, they could … they could be playing and ‘Dad has got this’ .... (Luke)*
Trying to keep the treatment from family members meant that one patient had to take his medication in secret to avoid the continued discussions that can result from witnessing the IFN injections.

*I tried not to let the treatment impact on the family. So even to the point where I try to take medication when they don’t know. Only because I don’t want it to be something that is dwelled upon. (Jake)*

One of the patients worked in drug and alcohol services and recounted how her daughter experienced difficulties with her job and condition. The patient had avoided sharing information with her daughter to preserve their relationship. However, the patient had to disclose her condition after her ex-partner had revealed her CHC with their daughter.

*She has trouble with my job, she’d rather me do a different job, she’s a bit funny so I didn’t want her to find the injection and things so I went to great lengths … for her not to know. But her father, who I’m not living with, decided he would tell her one day … and so of course she came home with the information and I had to fill her in so she could at least have an understanding of it. (Jane)*

For another patient who also worked in the healthcare profession, her colleagues’ held a strong opinion that people with CHC do not deserve an expensive treatment that is government funded. Keeping CHC a secret has led to paranoia about who knew, who disclosed or how they found out.

*Which also, is one of the other reasons why I am very careful at work … is because the treatment is very expensive and a lot of people have the*
view ‘that the money would be better spent on other things’ and I think that, that is partly because they see people with HepC as not being a particularly deserving type of people, that attitude is very strong for people in the health profession. (Rita)

**Disclosing the illness**

Some of the participants have chosen to disclose CHC with their families and friends. However, the disclosure has been limited to those close to them as the experience of one of the partners.

*Our family knows, they are all quite good about it, my Mum always asks how he is going and is he going alright … but our friends, none of them knows. (Debbie)*

Disclosing CHC and combination therapy in the workplace was a courageous option that one of the patients performed to prepare the people that he worked with. It was obvious that the patient sought an open and honest line of communication in his workplace. In his endeavour to gain his colleagues’ support and understanding, he placed a great deal of responsibility and trust upon them. His colleagues returned this trust by respecting the patient’s honesty and working around his health limitations.

*I chose to, I didn’t have to … when I was first diagnosed and particularly for the first round of treatment because I didn’t know what the side-effects, how they were going to impact on me … so I told all the key people that reported to me and those that I reported to. (Jake)*
As described by the participants, attached to disclosure was the complex task of providing information and reassurance to alleviate any doubts or anxiety on those receiving the information.

*Some of our friends know that he has HepC. It is amazing because a lot of people aren’t aware of what HepC is about … they are a bit worried that they can get it from Jake and I say, ‘no the only way you can is through a cut and that’ …. (Sandra)*

Patients felt apprehensive at what others might think they were suffering from. One patient felt the need to inform her son’s teachers that her treatment may affect her child’s performance in school.

*But anyway I talked to the teachers, the key teachers and the principal, to let them know that it might not be an easy year, but I didn’t talk about HepC, so, ---(son’s) teachers said, ‘are you having chemotherapy or something like that?’. I said, ‘yes, something like that’. I mean what do people think, you have got cancer or you have got AIDS? (Rita)*

**Encountering stigma**

The participants described the varied reactions to CHC that included prejudice, tolerance and acceptance. The mode of HCV transmission can have a significant effect on the way CHC is perceived. Not knowing how they acquired HCV was a source of frustration for some of the participants as people with CHC, from their experiences, are labelled as injecting drug users.
The participants in this study described a lack of information and knowledge of CHC in the community and on several occasions on the part of health care personnel. One sticking point was the assumption that the patients who participated in this study were all injecting drug users. One of the patients felt that this assumption affected the way he was treated by health care personnel and that at times he felt disregarded.

*So the one thing that I hate is … is the judgmental nature of the medical system about the disease and the assumed use of intravenous drugs. And for that matter, the unfortunate thing about doing these [clinical trials] is that you are often treated as a number and depending on who the people you are dealing with, you feel like cattle. (Jake)*

Some of the participants’ narratives drew attention to the fact that their HCV was not acquired through injecting drug use. Upon reflection, one of the patients was able to ascertain how the HCV was acquired.

*The only thing you do obviously is to go through all the things you have done in your life and try to examine exactly what point of time it was that you contracted it. But the reality is, it is very, very difficult. Unless you have had a blood transfusion or have got tattoos, I think that is where it came from, but I don’t know, I really don’t know, it could be from a haircut, it could be from anything. (Jake)*

Patients described that due to the stigma attached to HCV, the level of support that someone with CHC might receive was less, 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 that … the stigma about it. This sort of belief that it is because, 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)

It was evident that the experience of stigma attached to CHC extended to the partner. One of the partners described that both the community and a number of health care personnel held prejudiced views.

The only down side of it, is that, like when you tell people about it … ‘are you a drug addict?’. When I was pregnant with my first son and I was at the hospital and I told them that Luke had HepC, the first thing that comes out of their mouth was, ‘is he a drug user?’ .... (Debbie)

Stigmatisation from partners was also reported. One partner implied that injecting drug users were HCV carriers therefore they should take responsibility to check their status. This participant also described how bad he felt for his partner, however, displayed an underlying resentment by suggesting that his partner has only herself to blame for acquiring HCV.

I believe a lot of them suspect they have got it but don’t bother to check it. The worst thing for me is that I feel bad for her. She’s not sick but just not on top of the world you know, just like when you have the flu … I feel bad for her, but not real bad, I feel OK, it’s her own fault. (David)
Sharing the experiences

Trying to incorporate CHC and combination therapy into daily life is a demanding task, which often takes time and also involves the family. The partners in this study saw themselves as important support for the patients. This theme examines the impact of CHC and combination therapy in the home environment and on marital relationships.

Lending a hand

Participants on combination therapy acknowledged that support from loved ones is vital during treatment. The partners were in the background listening, comforting and encouraging the patients in their struggle. Partners were also there in a practical way by adapting the home, shortening their working hours and working from home as described by one of the patients on the study.

…”he gets to work considerably later, and he works less hours and he certainly organizes his work around being able to do that, like being the primary carer, in terms of the two children … we have a study with the computer that is networked from work, so he can work from home and he is tending to work from home one day a week. (Rita)

Partners described a heavier workload and changed distribution of work at home when the patients could not carry out some of the housework. Traditionally, the female patients had been the primary caregiver and husbands described how they had taken over this role. The husbands were cleaning, vacuuming, doing laundry, cooking, shopping and taking care of the children.
Well, my husband needs to do most of the things with the children. I am in bed in the morning and Paul gets everybody out, lunches made, takes them to school, takes them to their activities and picking them up in the afternoon … earlier on I had that role. (Rita)

I do the washing and hanging up the clothes most of the time. She did cooking yes … we just share the jobs. (David)

Significant others have also been a source of support in practical ways. For one of the couples on the study, their son provided financial support when required to assist with family needs.

The eldest boy works at the same company I worked at, so he is full time there 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)

Some patients revealed that their partners’ support were limited to assisting with tasks that imposed physical limitations on the patients. However, understanding the patients’ irritability proved too difficult for some of the partners. For one of the couples, it was obvious that the partner was unable to cope with changes in the patient’s personality or behaviour.

He is very supportive with physical things, doing stuff with the kids, things that need doing around the house, like I avoid lifting, carrying, heavy jobs and he is very obliging with things like that, he can understand. Things that he doesn’t understand, or that he thinks are unreasonable, which to me is like, that are not rational, and feeling so
often not rational, he has a lot more trouble with. So we don’t cope very
well with my irritability. (Rita)

Patients conveyed appreciation for their partners’ efforts, described how their partner
had been very supportive in many ways and acknowledged their own misgivings.
However, there was an underlying sense of resentment for not being able to complete
certain tasks as expected.

As far as my partner, I think he’s a saint ‘cause I think he’s put up with a
lot. He’s never said it was too much for him. That’s the way he is but I
think he’s minimising his own effort. But David’s got a lot more work and
he frustrates me cause there’s things he forgets … I know that I’m
unreasonable…. (Jane)

Tasks that were traditionally the wife’s domain became a source of conflict when not
performed in the same standard by the husband. One of the partners felt frustrated at
being unable to appease his wife despite his efforts to maintain a household and
performing tasks not to her standard. The demands and suggestion that his efforts
were substandard often led to conflicts and this was emotionally draining for the
partner.

It is funny I mean people often think I’m doing a really good job in terms
of helping the situation with the family and the treatment, that is right,
but emotionally I find it very hard to be, you know, the sort of thing that
you would expect … she tends to want and have everything done when she
wants it done … and I find that very hard. She’s not all the time
unreasonable, but it’s severed our relationship that I find very hard to …
some of the things, like cooking, I may not be able to cook as she does, it’s totally possible but not good enough and so I do it, so I put up with the arguments and her comments … either I give in, or she gives up … and so what happens is either I do what she wants to avoid an argument or I don’t do what she wants and then nothing is resolved. So we just go on and argue about something else. (Paul)

Another participant described how his partner was never pleased with his attempts at housework. His narrative implied that his efforts were considered as mediocre by his partner.

I go over to the kitchen and… Anne will say ‘it doesn’t take me this long to do it’, ‘you should be doing it this way’, ‘you should be doing it that way’ … it’s not good enough that I’m doing it …. (Brian)

In various ways, significant others have been supportive both practically and emotionally of their loved ones during combination therapy. However, one of the partners felt helpless as she witnessed her partner’s ongoing struggle.

... very hard, because I feel like I can’t do anything. I can’t do anything to help him, I can be there and I can support him and I can go to the meetings and I can do things like this for him, but it is hard, it really is hard. (Sandra)

There was variability in the experiences of partners. Not all the partners described unpleasant experiences. One participant denied any negative feelings about the effects of CHC and combination therapy on their lives.
Having Hepatitis C didn’t really affect it at all. I don’t get affected easily. She may say that she’s made it hard for me but she has not. I’m quite easy going. And I just take it with a pinch of salt. (David)

Couples tried to keep their daily lives as close to normal as possible despite the difficulties with CHC and combination therapy. Keeping a positive attitude and trying their best to maintain a household, enabled one of the couples to see past the current situation. Relying on each other was also seen as important in achieving balance.

She believes in the fact that I will be able to get through whatever the problems are, whether it be my health, or finding a new job, and bringing money in to help us survive … to ensure that the house is running, the kids are looked after and the bills are paid and all those sorts of things. She is a lot better than me at it and simply related to making sure all the bills are paid and just little things that need to get done, at certain times, get done, she is better than me. (Jake)

Relating with partners

Living with CHC and combination therapy can significantly affect the way the patient interacts within the family unit. One patient revealed how the combination therapy made her focus on herself at the expense of others. Self care became her top priority, followed by her children’s needs, while the needs of her partner came last.

… I think treatment makes you very self-centred, the focus is on you all the time. And I might manage to think about what the kids need, but I don’t think a lot about what Paul needs, I do, but not very much. That sort of … is very much the third level of priority. (Rita)
The partners described how difficult it was to adapt to the patients’ changing behaviour. This required one of the partners to be sensitive, understanding and show greater consideration than before.

A couple of times, I had to be careful of what I said to him because I noticed that he snapped a bit ... his moods were a little bit up and down ... I have to be careful and think of what I say, before I say it. (Sandra)

Psychological side-effects such as mood swings, irritability and short temperedness were exhibited by participants on combination therapy. These symptoms became barriers to communication. For instance, unintentional and insensitive remarks led to arguments as described by one of the patients.

... 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. (Rita)

Other couples described the effects of IFN highlighting the communication difficulties to the point of exasperation. For one couple tenacity on the part of the patient and the inability to accommodate this behaviour on the part of the partner caused conflicts.

It’s hard talking to Anne in some stages of the treatment ... because she [will] argue her point, but not listen to your point ... it gets to a stage where I don’t talk ... I will just back off and go away because my point of view is not getting across, her point of view is not getting across, cause I’m not listening to her, I’ll shut down and she’ll shut down for me so
you’re just battering each other with this verbal … and no one is listening
to each other. (Brian)

The added pressures brought on by CHC and IFN, combined with the stresses of everyday life, overwhelmed one couple on the study. The patient described how they felt ill equipped to deal with stressful situations.

Because, the basic point is … we barely manage with the normal day to day stuff, extra things are a real problem, even when in the longer run they are quite important. We struggle to have the time and energy to deal with anything that isn’t … well with everyday stuff as well. (Rita)

Participants described their views regarding their constrained communication with their partners. One participant felt her partner was withholding feelings and thoughts to protect her but this excluded her from participating in the experience and undermined her role as support person.

I think he bottles some things up … because I have got a depression problem and I take a depression tablet and I think … he would rather handle it himself, than worry me. So he knows if he wants to talk to me about anything, I will sit and listen. (Sandra)

Feelings that are not well communicated can result in even greater distance between spouses. One of the partners developed doubts about the relationship which led to feelings of insecurity and ultimately to distrust.
... there’s like a wall there to say, ‘no get lost I’m not interested’, and you just think, ‘well what have I done’ or ‘maybe she’s having an affair’ ...
... but all these things come in to your head.... (Brian)

Patients revealed that intimate relationships with their partners had suffered due to tiredness caused by CHC and combination therapy. One patient agreed that intimacy is important, however, her poor health was unable to sustain an intimate relationship.

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 we are never in bed together awake and it was before treatment as well. But I think that is from HepC and interferon doesn’t make it, it accentuates it. (Rita)

Irrational behaviour, unmet expectations and existing tension between some couples on the study, had led to serious disputes that ultimately ended in temporary separation. One of the partners described that the marriage was lacking romance but denied that CHC and IFN caused the arguments. However, it is understood that both exacerbated the situation.

So our arguments [occur] quite often, almost all the time ... I walked out once and wanted to walk out a lot more times. I walked out before, before treatment. So that was not new ... you know temporarily, I moved out ...

Some of the things that we used to argue about before, of course we argue about now, we have a lot of friction ... and so our relationship is already, well not as loving as or romantic as a marriage might be as we argue all
the time … I mean this is what was wrong with the marriage before and it’s been exacerbated. (Paul)

Some couples dealt with conflicts better than others. An open and honest communication following an argument was paramount in resolving conflicts as described by one of the partners.

He likes to sit down and talk about it, where I would rather go off and cool down. No, we have always been able to talk about things and so that has always been good…. (Sandra)

As the effects of CHC and combination therapy put added strain on personal relationships, one participant described a strategy they implemented to help break down those barriers.

… if there is something to talk about that needs to be talked about, he will ring me in the middle of the day. I am too zonked in the morning and I am too tired in the evening…. (Rita)

For some of the patients and their families, the illness and treatment experience, along with other significant events in the family, provided them the opportunities for bonding and to test the depth of their relationship.

So this was all sort of going on at once, no job, Sandra’s bad back, the younger son’s bad back, her mum not being well and my treatment and then of course, losing a family member basically [pet dog]. So all of that was very difficult, so despite that, the bonding between the family, if anything, it had brought us closer during that time. (Jake)
Participants expressed an optimistic view that their relationships would last beyond combination therapy. Having lived through their own parents’ broken marriages has given one couple the insight and the will to sustain a troubled relationship.

… I felt that there was a degree of confidence, because we had been through so much already in the marriage … I think our marriage will hang together … well both of us came from broken homes … even though you know we argue a fair bit it’s not better to have a separation … as for the kids well, I think we’ll try to hang in together … as for the treatment, well it’s an extra strain. (Paul)

Some participants could not help but appreciate their stable relationship when compared to others that disintegrated during combination therapy. This gave one of the partners the confidence to endure.

I used to go with Jake to Hepatitis C meetings in Parramatta … there weren’t too many partners who used to go, because a lot of marriages had broken up through it and just to sit and listen to people say, ‘my marriage broke up’ and that, I realized how very, very lucky I was. (Sandra)

Parenting through adversity
All of the participants in this study faced balancing the influence of CHC and combination therapy with the demands of parenting and concerns for the emotional development of their children. It was evident the participants were concerned about their children’s ability to cope and their relationships with their parents, siblings or peers.

Often parents felt that the illness and the therapy added a level of complexity to their relationships with their children. One patient described the effects of CHC and IFN, and its impact on her parenting role. She acknowledged that the ramifications were felt by her daughter and had affected her performance in school.

>I don’t have the energy to do a lot of things with ---(daughter), so she’s felt me probably pull away a bit ... ---(daughter) hasn’t been doing well at school so it’s been hard ... but she’s fairly frustrating and exhausting, so even that’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 don’t know I’m just so exhausted .... (Jane)

Parents felt that children were deprived as they were unable to offer full support to their activities. For the children, this had led to missed opportunities to develop and socialize.

>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, the energy. (Luke)
Negative aspects of the experience for children included frequent arguments among parents involved in this study and the effect this had on their children. One of the patients revealed that her son’s challenging behaviour could be, but not conclusively, a direct result of frequent arguments.

---(son), um (long pause) ... gets very angry and frustrated but he doesn’t know he is angry, he just feels angry and wants to express it or just, you know ... but what I hear is yelling, banging doors, whinging, you know like, I notice when he is happy because it is rare. (Rita)

Another participant described a similar experience to verify that their children were not exempt from the effects of quarrelling. Their children did rise to the challenge in order to protect themselves.

It’s pretty hard, we’ve had a few screaming matches, like yelling matches, and the kids stand up for themselves ... I noticed the kids are pretty fed up this year too. (Brian)

Parents believed their children to be affected by the constraints of CHC and combination therapy. For the son of one patient, the fact that he was witness to the arguments between his parents made matters worse. The son’s stress was manifested through bed wetting. It was evident from the patient’s narrative that such occurrences presented additional obstacles.

But, he is just unsettled, and not very happy and even things like, he is nine and a half and he has got a problem with wetting the bed ... we have been on a program where it has reduced to once every three weeks ... but now he is back to every second night, and we just can’t keep up with what
needs to be done. It is just, the day to day things we struggle to keep up with, let alone extra things like that. (Rita)

Some parents admitted their repeated arguments were a cause for concern. One parent acknowledged that the children were drawn into the arguments but denied it had any serious effects.

Well, it is always a worry isn’t it … when we’re arguing with each other all the time, it drags them into it as well … they get involved in arguments, that is not good but they’re still very loving and close so in terms of their behaviour, outside of the house, people would probably find it difficult to know. (Paul)

A number of participants acknowledged the positive aspects to the experience. Children had to help more around the home, and assumed added responsibility and participation in carrying out chores. This experience had led to a feeling of satisfaction for the children of one of the patients which can potentially boost their confidence.

So the kids came up with their own roster to take on more duties and send me back to work … they have grown up pretty much quicker than I think they would … and they know that they are doing something special ….

(Anne)

One patient described how her daughter had become responsible with the help of prior information regarding the treatment, an open communication and support from a
counsellor. Parents expressed a sense of gratification in watching their young children develop sensibly during such a stressful period.

She is very caring, responsible kid ... it doesn’t appear to have done her any harm at all, I mean, the opposite almost, she has grown up, she is more caring ... so ---(daughter) did know a bit of what to expect ... yeah, and I even lie in bed in the morning and I will hear ---(daughter) and she will be making the lunches, and I guess in some ways, she is being a little Mum, she will be singing and it is so nice to hear her singing. (Rita)

Participants described how family bonding was interrupted during illness and that rare moments spent bonding with family were not taken for granted. This demonstrated that family support was essential in improving the patient’s well being.

Before treatment I would cook breakfast on Sundays and like we might have pancakes or muffins, and late breakfast in the sun. Last Sunday the kids got a packet of muffin mix, and made muffins for breakfast and coffee and fresh orange juice ... so that was almost weekly before, and twice since I have been on treatment something like that happened, and because it was rare, gee it was nice, it was really lovely. So when you can do things you appreciate them and you don’t take them for granted. (Rita)

Enduring struggle
Several participants acknowledged that combination therapy presented a temporary disruption to their lives. Others have accepted that CHC will always be present and will involve patterns of gradual deterioration and periods of good health interspersed with relapses. Most of the participants conceded they may not return to their previous level of health.

**Sustaining finances**

Participants have described increased financial difficulties in the form of reduced income or no income, as the patients were unable to work as they did previously. The financial difficulties became an added source of strain in the relationship as described by one of the participants.

*There’s our financial problems too, so … money is important, but that was one of our problems … we argue a lot about money …. (Paul)*

For some of the patients it was unclear what the future held as they suffer a chronic illness without a guaranteed cure. One patient voiced concern for his family’s future and this caused apprehension just by thinking about it.

*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 Sandra. (Jake)*

The same participant’s narrative described their financial difficulty that was not necessarily due to CHC and combination therapy. However, it remained an important feature in its interrelation with the illness and treatment experience.
... we had moved to Sydney to start a business and within six weeks, the business went down the tubes. Which meant not only did we lose things associated with that and our house and everything else, six weeks later I was diagnosed with HepC. Then about four weeks after that, I started a new job. In between times we had to sell Sandra’s car to survive etc etc ... so I put this treatment off actually for six weeks to go to the US at their [employer] request and came back and they decided ... they didn’t want me there anymore. So we have got probably to the end of September before we run out of money ... but obviously puts added pressure on the family .... (Jake)

Dealing with health professionals

The participants on combination therapy described a lack of knowledge and understanding within the health care profession. This affected the way they were treated as patients. One of the patients believed that because of a lack of resources, services were not available to provide holistic care for the patient, hence, the focus of care was directed towards the treatment of the illness and not the patient as a person.

... 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. They are not as focused on how this will impact on your life, which is why this whole thing is really good [the research]. There is not enough analysis of what it is this person needs, what do they need psychologically, anything else ... but I know part of that is due to a lack of money ... it is also an attitude thing. (Jake)
There was variability in the information delivered by health care professionals. The health care professionals tend to underrate the symptoms while other patients exaggerated.

*The medical people will talk about being irritable ... the patients, what I heard, was they talk about feeling murderous, well thank God, I haven’t felt murderous.* (Rita)

Participants described how health care professionals were unable to respond with compassion and respect because of their underlying negative attitudes to CHC.

*The way the clinic is set up, you go there and find this tiny sign that says ‘take a number’. If you don’t speak English, you don’t know to do it. If you don’t take a number, the girls behind the desk get the shits with you, because they expect that you should know. The best thing that could possibly happen is for the roles to be reversed on them one day ... a lot of the people that come in are scared, they have just been diagnosed, they don’t know what to expect, their best language is not English. So they are a little bit abrupt with them at times.* (Jake)

**Looking ahead**

This sub-theme describes participants’ views, plans and hopes for the future. They hope for an optimistic future, but also 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.

Participants were eagerly looking forward to the end of the treatment period. One patient believed that only a well balanced person with a supportive family can negotiate the minefield that is CHC and IFN.

_I have complained about it, ‘I can’t wait till it finishes’ and David probably can’t wait either. After experiencing this, you really have to have your life together. To get from one side of this to the other._ (Jane)

Most participants felt uncertain about the possibility of any lingering effects of IFN. One of the partners described how his wife’s symptoms are affecting her outlook on life and worried that the effects of combination therapy will be permanent.

_She said to me lots of times that she’s worried, it felt to her that this is what it’s gonna be like for the rest of her life._ (David)

For those who had several courses of IFN without success, they remained cynical about the treatment outcome. One patient, however, was hopeful that the treatment will slow the progression of the disease until such time when a more effective treatment regime is discovered.

_I am a little pessimistic having been through two lots of treatment now, and being a male and genotype 1, so I almost expect that my liver will fail. But the benefit of being on treatment is that it will arrest the deterioration of the liver whilst I am on it and give more time for them to_
Several participants conceded that CHC will invariably linger for life and keeping a positive mindset is crucial in attaining a reasonable state of wellbeing. After going through the feelings of shock, disbelief, anger and sadness, one of the participants has finally reached acceptance.

*It is a chronic disease, but the reality is you can live with it. You accept that this could potentially affect the length of your life but you also accept that there is a zillion other things that could affect the length of your life...you sort of treat it like it is there and you are doing whatever you can to do about it.* (Jake)

**Summary**

It was evident from the participants’ narratives that CHC and combination therapy had an enormous impact on the lives of the patients, their partners and families. The diagnosis of HCV infection was unexpected and devastating for the participants and raised feelings of shock, fear, denial, anger and sadness. CHC and combination therapy has been shown to have a significant physiological effect on quality of life and as a result all the participants with CHC described their struggle to maintain a meaningful life.

Strategies for coping appeared in the narratives but most obvious in the participants’ descriptions of their experiences were the effects of stigma on their lives. Participants described how HCV was often associated with HIV and injecting drug use. Because
of the stigma, discrimination and fear of rejection, the participants have had to keep HCV a secret and were cautious when accessing health care services where they have to disclose their HCV status. Participants felt many health care professionals held prejudiced views and lack of knowledge about CHC. This affected the way they were treated and resulted in unsatisfactory care.

The restrictions imposed by CHC and treatment led to role changes within the family. The partners in this study saw themselves as important support for the patients and had taken on the role of primary caregiver. This affected the partners’ employment by sometimes shortening their work hours, working from home or even taking leave from work. On several occasions the partners felt emotionally drained because being a spouse, parent, primary caregiver and breadwinner was an overwhelming and demanding job. The children also had to help more around the home and this proved to be a positive experience as they learned to become more independent and confident.

The behavioural changes in the patient and the physiological effects of CHC and combination therapy made it difficult for the couples to maintain an intimate relationship. Moreover, the frequent outbursts of anger and serious conflicts intensified the tension between the couples. Communication posed a challenge as the patients struggled to maintain rational behaviour and their partners strived to have a handle on ensuing issues. The repeated arguments affected not only the participants but also their offspring, who were sometimes drawn into the arguments. The participants described that
witnessing their parents’ frequent outbursts and conflicts affected the children and this was manifested in their behaviours (yelling, screaming matches, bed wetting). Nevertheless, there were positive aspects to the experience of living with CHC and combination therapy. Participants described that family bonds were strengthened, that they learned to appreciate one another and these gave them the confidence to endure. The partners felt they had developed self-reliance, increased confidence and felt a sense of satisfaction as they took on added responsibility. The participants described how their children acquired greater independence and confidence in being able to assist and care for their unwell parent and siblings.

Participants looked forward to the end of their treatment with optimism, however, they conceded that CHC will invariably linger given that only 50% to 80% will be successful at eradicating the HCV infection (Keating & Curran, 2003). Nevertheless, they were confident that the treatment had slowed the disease progression hoping that in time a more effective treatment regimen would become available.

The narratives provided a rich description of the participants’ experiences and offered insight into the life world of people living with CHC and combination therapy, and their partners. The participants were able to articulate the illness and treatment experience and how the experience posed a threat to their relationship. The following chapter will further discuss the findings in relation to the literature review.
Chapter 5: DISCUSSION

Introduction

The findings from this study revealed that CHC and combination therapy have significantly affected the lives of the participants. The narratives revealed that partner relationships were strongly influenced by CHC and combination therapy that ultimately affected relationships within the family unit. This chapter will discuss the findings that emerged from the study. The discussion will draw a parallel with the literature regarding the lived experience of patients living with a chronic illness on treatment and the lived experience of the partners.

Experiencing illness and treatment

Suffering poor health

The various responses to the diagnosis of CHC that were described by the participants ranged from shock and denial to anger, fear and sadness. This finding is consistent with a study by Sutton and Treloar (2007) where participants experienced many negative feelings such as shock, fear and denial following diagnosis with hepatitis C infection. Schafer et al. (2005) also reported that several studies revealed a considerably increased rate of emotional and psychiatric strain that led to a significantly impaired quality of life. This provides evidence that the diagnosis of HCV infection has considerable effects on the psychological and emotional wellbeing of the person receiving the diagnosis.

The symptoms and effects of CHC and combination therapy as described by the participants were also consistent with the literature. These symptoms and side effects had a profound impact on several aspects of the lives both for the affected participants and their partners. The physical symptoms imposed limitations on the patients’ daily
lives that affected their employment and in some cases, their role as primary caregiver and homemaker. CHC and combination therapy causes significant deterioration in a number of key areas including physical well being, levels of pain, general health, vitality, social functioning, ability to work, emotional and mental well being (Dolan, 1997; Dusheiko, 1997; Oon, 1999; Hoofnagle & Seef, 2006). Routine activities of daily living became burdensome and wearisome and in all cases the patients’ role had shifted from independence to dependence.

The psychological and emotional wellbeing of the participants with CHC on combination therapy were seriously impaired. Depression is one of the most commonly reported side effects of IFN and was experienced by the participants in this study to varying degrees. IFN is known to cause severe psychiatric conditions including depression, suicidal ideation, paranoia and confusion (Rataj et al., 2005). The physical symptoms of CHC also lead, for many, to depression and mood swings, anxiety over the future, social isolation, loss of self esteem and the development of paranoia (Loveday et al., 2005).

**Managing ill health**

The participants with CHC applied different approaches during combination therapy to enable them to cope and to help them manage during the treatment period. These strategies involved detailed planning, performing minimal tasks, exercise, ventilating emotions, relaxation techniques and self control. A combination of these strategies allowed the patients’ to redirect their attention, distracting them from pain and discomfort, and allowing them to achieve relaxation (Folsom, 1999).
The actions taken above demonstrate that a holistic approach to symptom management was adapted by the participants. It was evident that participants saw their health and illness as involving the body, mind and spirit (Diluzio & Spillane, 2002). Relief of the physical effects of combination therapy was their primary goal however, emotional support was also seen as essential in enhancing the patients’ coping abilities, emotional adjustment, self-esteem and psychological wellbeing (Langford, Bowsher, Maloney & Lillis, 1997). Quality of life became a most desired outcome as participants resigned to the fact that combination therapy is not a guaranteed cure for their HCV infection (Keating & Curran, 2003). Hence, the goal of care has been broadened to encompass not only the cure of disease but, as importantly, assisting patients to live well in the face of continuing infirmity (Toombs, 2004).

*Feeling isolated*

Participants with CHC on combination therapy described altered relationships with family, friends and relatives and reported a loss of social networks. The symptoms and effects of CHC and combination therapy imposed limitations on their social life. The impact of stigmatisation also affected their social interaction while a previous drug and alcohol problem compounded the isolation for some of the participants. 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 resulting isolation means that people with HCV infection are less likely to seek the help and support of friends, family and health care providers (Duffy, 2005).
Social support was described by patients as important for how they cope with stressful situations. The patients’ social network had a significant role in how they managed CHC and combination treatment. Social support has been identified as an important factor that contributes to health related quality of life for people living with a chronic illness (Johnston et al., 1998). Hence, patients employed various techniques to solicit attention so that significant others could make time, not simply as a patient requiring help but as a person needing the attention of other humans (Toombs, 2004).

The findings demonstrate that the isolation affected not only the participants’ with CHC but also their partners. The partners’ were restricted to social activities that the patients’ health could tolerate. Partners devoted more time to household maintenance and had less time for personal needs and leisure activities (Kemler & Furnee, 2002). Partners were also fearful of disapproval from others and had chosen to keep their spouses’ CHC a secret thus preventing the partners from reaching out to others for support (Katz, 1997). All these resulted in reclusion and isolation which became a barrier to achieving a reasonable state of wellbeing for the partners during their spouses’ treatment period.

For friends and relatives who knew about the HCV infection, they found it difficult to see and understand the patient and the family’s situation because of the indistinct symptoms of CHC. This experience was particularly common in most participants with CHC who do not look ill, but do experience fatigue, pain and depression. The patients were not severely incapacitated and if no explanations are plausible for people about their illness, it is difficult for others to make sense of their experience (Toombs, 2004). In a study by Soderberg et al. (1999) participants reported similar experiences.
of being treated with doubt and disbelief as a consequence of the invisibility of the symptoms and felt a lack of understanding and support for their plight. CHC is a condition which is able to be almost entirely treated at home and treatment occurs primarily in ambulatory settings (Holman, 2004).

**Keeping a secret**

The reasons cited by the participants for keeping CHC a secret from others included a lack of knowledge and understanding of HCV infection and the fear of contagion. The general community’s misconception that HCV infection is a drug addict’s disease had led the participants to maintain their HCV status a secret from their children, friends and relatives. Participants were disturbed by the community’s response to HCV sufferers that they have only themselves to blame and are responsible for their disease (Katz, 1997).

All the partners in this study knew of their spouses’ CHC, however, some of the participants preferred to keep the HCV infection a secret from their children as the condition is too complicated to understand and they are concerned their children may not be able to cope with it. The participants feared the HCV infection could alter their relationships with their children and some were also anxious about what their children might do with the information. Schafer et al. (2005) found that 25% of patients with CHC preferred not to communicate their disease to significant others for fear of rejection.

The participants decided it is better not to talk to others outside the family about HCV infection and treatment, particularly given the level of stigma and prejudice they
know they will have to face (Morton & Johnson, 1996). There is even a general opinion from within the health care profession that such an expensive government funded treatment is wasted on HCV infected individuals who are assumed drug addicts. This finding is consistent with the literature that found most patient reported discrimination occurred in health care settings and identified hospitals, general practice and dental surgeries as the environments where hepatitis C-related discrimination occurred most frequently (Zickmund et al., 2003; Richmond et al., 2004; Hopwood et al., 2006).

**Disclosing the illness**

Disclosing CHC and combination therapy was limited to very close family and friends of the participants. The stigma, discrimination and resulting isolation meant that participants did not easily disclose their diagnosis (Duffy, 2005). Through non-disclosure, the participants avoided having to face up to the complex issues of how the virus was acquired (Morton & Johnson, 1996).

Disclosure in the workplace took place in some cases to prepare colleagues for the effects of CHC and combination therapy. The participants sought the support from colleagues which they needed to get through the treatment period. For the participants, emotional support following disclosure was essential and involved the provision of caring, empathy and trust that was important in enhancing their coping abilities, emotional adjustment, self-esteem and psychological wellbeing (Langford et al., 1997).

**Encountering stigma**
Not all the participants in this study acquired HCV infection through injecting drug use, however, it has become apparent that society associates HCV infection with injecting drug use as experienced by the participants. HCV is also associated with HIV and both are seen as conditions brought upon oneself by behaviour for which society has little sympathy or understanding (Morton & Johnson, 1996). The fear associated with HCV is therefore linked to its association with images of drug abuse, promiscuity and perversity (Altschuler, 1997).

The lack of knowledge about CHC within the health care profession was described by participants as a common cause of stigmatisation and discrimination in the health care setting. The stigma attached to CHC extended to the partner that resulted in ambivalence in the service provided by health care professionals. Stigma is a complicated issue that thrives in an environment of ignorance and half-truths (Valdiserri, 2002). An investigation by the Anti-Discrimination Board of NSW in 2001, reported that the health setting is where discrimination frequently occurred (Richmond et al., 2004). In a similar study by Hopwood et al. (2006), they 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.

**Sharing the experience**

The family was seen as an important source of support for the participants with CHC on combination therapy. Family members provided care and physical, emotional and financial support to the patients in this study. This finding is consistent with the study by Ryan and Scullion (2000), of the role of families in chronic illness, which found
that supportive families who are actively involved in caring for the chronically ill enhanced the quality of care.

**Lending a hand**

Because of the patient’s illness and treatment, family roles were reversed or altered (Altschuler, 1997). The partner is the most intimately related person to the patient who became the primary caregiver with the greatest responsibility (Callahan, 2003). The findings from this study revealed that the partners have had to take more responsibility at home and described an increased workload as they took over most of the housework.

For the partners who have a full-time job and other pressing family responsibilities, the increased workload led to difficulties in finding time for their own interests as they instead gave priority to joint activities with the whole family. The partners experienced loss of freedom caused by the added responsibility (Eriksson & Svedlund, 2006). The competing demands of work and caregiving affected the partners as they experienced exhaustion, fatigue and stress; and time and emotional dilemmas in balancing competing responsibilities and meeting their own needs (Schofield, 1998).

The partners felt they gave their spouses adequate practical and emotional support during the treatment period. However, most partners reported that their spouses were never completely satisfied with their efforts and found cause to complain. Frustration, irritation and anger were often directed at the partners whose love and support were needed most, and this, proved difficult for the partners to adjust to (Medalie, 1997). This led to the partners feeling resentful, frustrated and even angry about the situation
and the restrictions that CHC and combination therapy brought into their lives (Altschuler, 1997).

Nevertheless, there was a sense of satisfaction derived from the caring experience as described by the partners. This finding is consistent with the study by Schofield (1998) who found that most partners gain an enormous sense of satisfaction from caring for their loved one. Overall, the partners in this study acknowledged the satisfaction, self-reliance and increased confidence they had gained through managing demanding and difficult situations (Eriksson & Svedlund, 2006).

Reliance on one another was also a positive experience as described by participants. The patient’s temporary inability to fulfil their role created the opportunity for the partner to experience a new side to themselves (Altschuler, 1997). Support from family members, particularly spouses, was therefore very important for the person living with CHC on combination therapy (Soderberg et al., 2003).

**Relating with partners**

It was difficult for the partners to witness their spouses’ struggle with CHC and combination therapy. Helplessness and distress were felt by the partners as they watched how the effects of CHC and treatment drained their spouses’ life and spirit. For the partner, guilt, frustration or embarrassment about their own health made it difficult to share personal concerns (Altschuler, 1997).
The partners experienced difficulties in coping with the psychological and emotional changes of their spouses and these affected their own psychological and emotional wellbeing. This finding is supported by Schofield (1998) who acknowledged that a common feature of caring for a spouse with a chronic illness is dealing with difficult behaviour. This is also consistent with the findings by Kuyper and Wester (1998) that partners had difficulty in always being present, considerate, sensitive and understanding of their spouses’ needs, and this affected their own mood.

The partners needed an outlet from the pressures of daily life to maintain their own wellbeing. However, they found it difficult to do this without risking isolating the patients even more. Support for the partners is equally important during the treatment period. The enormous emotional commitment that goes into helping a patient through CHC and combination therapy, can ultimately drain the partner’s resources (Batey, 1997).

Poor communication was also a source of anxiety among the participants in this study. Feelings that were withheld or were not well communicated resulted in greater distance between spouses. Enhanced communication between spouses was deemed important in conflict resolution as experienced by the participants. An open and honest communication allowed some of the participants to resolve their differences. Improved communication and sharing information has the potential for an improved relationship that can only prove beneficial to patients and their partners (Ryan & Scullion, 2000).
The added pressures brought on by CHC and combination therapy, combined with the stresses of everyday life, became accumulative and had led to conflicts between the spouses in this study. The participants felt that they were drained of the resources needed to deal with these accumulative stresses which resulted in marital tensions. Chronic illness introduces imbalance to relationships, altering how needs for closeness and distance are experienced and managed, impacting on the psychological wellbeing of individuals and couples (Altschuler, 1997).

The partners in this study described how they were able to cope with their spouses’ difficult and irrational behaviours. However, repeated outbursts and constant arguments had led to strained marital relationships and ultimately to temporary separation between spouses. This finding is consistent with the literature that described repeated demands to cope with side effect related emotions and symptoms have led to marital tensions, breakdowns in relationships and separations (Batey, 1997).

CHC and combination therapy influenced intimate relations between husband and wife as participants described a change in their intimate and sexual relationships. The patients’ fatigue and mood swings set limitations on their sexual life. The symptoms of CHC and the side effects of treatment set limitations to sexual life because they contribute to loss of sexual desire and satisfaction (Larsen et al., 1998).

Despite all of the difficulties, some participants felt that their relationships had deepened and became stronger as the experience provided them the opportunities for bonding and to test the depth of their relationship. Eriksson and Svedlund (2006)
reported that in several studies on chronic illness, participants described fewer social connections and altered sexual relationships which were regarded as negative experiences, whilst positive experiences confirmed that infirmity had brought the couples closer together, even strengthening their relationships.

**Parenting through adversity**

Living with CHC and combination therapy had a significant effect on the patients’ interaction within their families and had influenced their relationships with their children. Adjustment to the illness and treatment required the patients to prioritise and focus on their own personal needs before meeting the needs of other family members, most especially their children. This is a manifestation of a loss of control over one’s life as the effects of CHC and combination therapy lead to acute stress regarding the decline of one’s health (Schofield, 1998; Loveday et al., 2005).

According to the participants, a negative aspect of the experience is the patient’s inability to participate in leisure activities and this is similar to the finding by Soderberg et al. (2003) who reported that chronic illness imposed limitations that subsequently affects family life. Other negative aspects of the experience include the children witnessing frequent arguments and bursts of anger among the parents. The children have often witnessed bouts of illness in their parent with CHC and conflict amongst the adults surrounding them. The healthy parent’s negative response to the patient’s illness, such as being unable to contain feelings of anger and depression, meant that children received less attention from not just one but both parents during these crises (Morton & Johnson, 1996; Altschuler, 1997).
In contrast, “a deepened relationship” with children was also evident through the interviews with the participants. Partners described greater responsibility and participation in the children’s upbringing, and it seemed as if the patient’s incapacity had a positive influence on the partner-child relationship (Soderberg et al., 2003).

Another positive aspect of the experience, as described by the participants, is the sense of satisfaction the 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 and parenting role both for siblings and for their parent and this, according to the literature, had led to self-reliance and increased confidence (Morton & Johnson, 1996; Eriksson & Svendlund, 2006).

**Enduring struggle**

**Sustaining finances**

Participants reported that the family’s finances were negatively influenced by the fact that the participant with CHC could not work as they did before treatment. Work was influenced and limited by the symptoms of combination therapy for the participant with CHC. This meant less time spent at work, changes in occupation and in some instances the participants with CHC on treatment were forced to stop working. Previously independent, patients may suddenly become financially dependent on their partners for assistance (Travis & Piercy, 2002).

Financial hardship reduced the capacity to purchase the social, therapeutic and recreational resources that could enhance quality of life for the participants and their children. As a consequence, some of the partners had to assume more responsibility
for the family’s finances as they had to provide financial support. Unfortunately, the partners’ experience with employment was similar to that of the previously employed patient, for example they experienced interruptions to their work, less energy, or needing to take leave to care for their sick spouse (Schofield, 1998).

**Dealing with health professionals**

The participants struggled to get HCV accepted by society. The participants felt that health care professionals presented a negative attitude and lack of understanding for their situation. Participants believed that apart from the stigma attached to HCV, one other reason for this negative attitude was the fact that CHC is an illness without visible symptoms. This is similar to the findings by Soderberg et al. (2003), who reported that most people with chronic illness experienced being treated with doubt and disbelief as a consequence of the invisibility of their symptoms, and this had led to a perceived lack of understanding and support for their plight.

The impact of stigma and discrimination reduced the patients’ willingness to access health services. This study and several other studies revealed that stigmatisation occurred in the health care setting and discriminatory practices included: refusal to provide services to people with CHC; discriminatory treatment while providing a service; and, breaches of confidentiality and disclosure issues (Zickmund et al., 2003; Richmond et al., 2004; Hopwood et al., 2006;). It is vital to address the misconceptions that health care professionals may have about HCV infection in order for them to understand and better care for their patients.
Confusion due to lack of or conflicting information about the condition, its prognosis and treatment options, and problems communicating effectively with health care professionals had negative outcomes and greatly reduced participants’ satisfaction in the care provided. Information about services enabled participants to obtain practical and emotional support other than that provided by family and friends (Schofield, 1998; Duhamel et al., 2007). According to Corbin (1998), it is important that the healthy spouse receives the same information as the ill person, so that the illness can become part of the family.

It is particularly important to understand how people with CHC and their families experience the illness. Kuyper and Wester (1998) emphasized that the key factors for supporting people with chronic illness and their families are the attitude and communication skills of health care professionals. Soderberg et al (2003) highlighted the need for communication based on a shared understanding between people with chronic illness and health care professionals in order to deliver efficient care and support.

**Looking ahead**

Participants with CHC on combination therapy went through phases of depression, anger and frustration. Experiencing the illness and treatment affected the participants’ outlook and caused uncertainty regarding the outcome of treatment and the future. A diagnosis of CHC invariably evokes fears and anxieties about loss of functioning,
changes in physical appearance, pain and discomfort (Altschuler, 1997). For the participants, CHC meant having to live with uncertainty and hopelessness, as combination treatment is only successful at eradicating the HCV infection in 50%-80% of the cases (Keating & Curran, 2003).

While participants with CHC had initial strong reactions to the diagnosis such as shock, denial, fear and grief, this study and a similar study by Sutton and Treloar (2007) revealed that in time participants overcame these initial feelings, accepted the HCV diagnosis and adapted to the changes it created in their lives. Adopting a positive psychological outlook is thought to facilitate the transition towards acceptance of the illness as individuals learn to re-prioritise, look to the future and see beyond the illness (Glacken et al., 2001).

Summary

The findings from this study demonstrate that combination therapy significantly affects the health condition of the patient with CHC and the partner relationship. The psychological and emotional state of the patients was greatly affected during treatment and their somatic symptoms also increased. The combination therapy was troublesome for the participants as the side effects had significantly affected family and social life. Furthermore, partners described increasing responsibility and work in the home in providing support for their partners with CHC on treatment, and the need to meet their families’ physical, psychosocial and financial needs.

The findings adequately demonstrate that the labile physical, psychological and emotional state of patients during combination therapy became a barrier to effective
communication between the couples. Lack of effective communication led to repeated arguments and marital tensions. The adverse symptoms of patients, its effect on the partners and the strained relationship had made it difficult for the couples in this study to maintain an intimate relationship.

The experience of stigma and discrimination was also a predominant feature in the life world of the participants and this affected the way they accessed health care services. Participants approached services with trepidation as they knew very well that most health care professionals held prejudiced views about people with CHC. The findings in this study conform with the literature on CHC, chronic illness and treatment experience.

The shifting perspective model of chronic illness, purported by Paterson (2001), can be applied to participants with CHC who maintain a wellness perspective thus finding meaning, hope and better quality of life, however, they had to assume an illness perspective when receiving combination therapy. This study also revealed that transitions in the participants’ experience involved movement from life with CHC, to finding a place for CHC to fit into daily life and sometimes back again, which supports Kralik’s (2002) findings, that the chronic illness experience involves movement from extraordinariness to ordinariness.

Chapter 6: CONCLUSION

Introduction
The effects of CHC and combination therapy extended beyond the patients as it affected their families, with the spouses receiving the brunt, as they are the most intimately related person with the greatest responsibility as primary caregiver. In time, participants with CHC came to accept the diagnosis with the support of family members. Support from family members, particularly the spouses, was very important for the patient who has to live with such a highly stigmatised chronic condition. This final chapter will discuss the strengths and limitations of the study, implications for nursing practice and recommendations for future research.

**Strengths and Limitations**

This study has two limitations. The findings cannot be generalized because this is not the purpose of qualitative research (Burns & Grove, 1997). This study investigated the particular experiences of unique individuals in a given situation, which was the aim of the study: to investigate the relationship experiences of patients with CHC and their partners during combination therapy.

Another limitation was the sample size. The sample size was small yet considered adequate to achieve variation and to maintain depth in the analysis (Holloway, 1997). The small sample may be a limitation but also a strength as it allowed in-depth interpretation and analysis of the data (Boyd & Munhall, 2001).

The depth of data collected is another strength of this study as the participant narratives were rich and profound. The aim of this study was accomplished because of the openness of the participants to their story which allowed their experiences of CHC and combination therapy to be explored. The meaningful experiences revealed in this
study made sense of the situations in which the participants found themselves and provided a constructed reality of their experiences.

**Implications for nursing practice**

Within a nursing perspective, managing symptoms such as pain, fatigue, dyspnoea or weakness requires an understanding of the patient’s experience and meaning associated with each symptom. It is essential for nurses to understand their patients’ experience of CHC and treatment because they reveal patient needs and a myriad of other issues in which nurses can intervene to help patients improve their coping skills. Nurses therefore play a significant role in educating patients, advocating for them and helping them to live with this chronic condition. Nurses also have the important role of educating the patients and their significant others about how to prevent transmission of the HCV.

This study suggests there is considerable room for improvement in the health care of people with CHC, starting from improving pre-test and post-test counselling and information provision. Psychosocial screening and prospective interventions can help reduce distress in patients while increasing their quality of life. Psychosocial screening will identify patients in need of intervention and treatment and early psychosocial interventions may also prevent the exacerbation of pre-existing distress and decrease somatic complaints, with associated reduction in the costs of subsequent evaluations and treatments.

As combination therapy for CHC is often debilitating, with side effects that are sometimes severe and with no guarantee of efficacy, nurses have a significant
obligation to ensure non-discriminatory care and support. The patient’s ability to undertake and remain on combination therapy is affected by their motivation for treatment, the severity of side effects, impact of treatment on work and relationships, issues around drug and alcohol use and the availability of medical and social support. Nurses may reduce the negative impact through appropriate and sensitive delivery of nursing care and making appropriate referrals.

Nurses who communicate frequently and openly with their patients are able to identify and treat most of the adverse effects of combination therapy before these side effects can disrupt treatment and require serious attention. An informed nurse can manage most of the side effects of combination therapy and if well managed, this directly influences the patient’s compliance with treatment that will enhance their chance of eradicating the HCV infection.

The study revealed that it is not only people living with CHC on combination therapy who experience a change in their lives. The relationships between the spouses are impacted and the whole family life is influenced and limited by CHC. This knowledge has to be taken into consideration by nurses in care planning. Accordingly, interventions specifically designed to enhance the communication between patients and partners will improve the psychological well being of both, helping patients to become aware of their partners’ needs and for the partners to become capable of accepting their challenging but important role.

Family members, especially the partners, provided the participant with CHC with care and support. Emotional and practical support is one vital aspect of coping with CHC
and patients look to family members for that support. Partners are an asset to holistic care and can provide a wealth of information that can be utilized by nurses to enhance a patient’s quality of life. On the other hand, nurses can provide partners with information and support that will assist them as caregivers.

Service providers often do not have the staff or the time necessary to provide optimal support and education of people with CHC on combination therapy. Additionally, not all health care providers are educated in CHC, treatment and management. There is an opportunity here for nurse practitioners who have advanced skills to provide skilful management of patients with CHC and patient education. Of particular importance is the nurse practitioner’s ability to manage patient care before, during and after treatment.

**Recommendations for future research**

Additional research is needed to further 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 will lead to the development and delivery of more effective nursing care.

Family psychosocial intervention for chronic illness is a promising strategy and research is needed to determine whether a family-oriented versus patient-oriented approach to CHC management is more beneficial. Given the findings from this study that confirms families are affected by CHC and the current health care trend in involving families in patient care, such research might be worthwhile. In a study of a
family-oriented approach to CHC management, it is recommended the study assess the outcome for both the patient and family member to determine the approach’s efficacy.

Further studies are also required on depression caused by CHC and treatment. This would provide insight into the psychological consequences of living with CHC and treatment and would provide useful information needed to better understand how patients experience the burden of depression and to explain the unique features associated with living with depression and HCV infection. Findings from such a study could result in the development of a depression screening tool specific for CHC patients. Early detection and intervention for depression in CHC patients will enable them to commence and remain on combination therapy while maintaining a reasonable state of psychological and emotional well being.

**Conclusion**

The diagnosis of HCV infection was often an unexpected and devastating discovery for the participants in this study. The participants with CHC were not a homogenous group. HCV transmission may have occurred through a past dalliance with drug use, or a blood transfusion prior to 1990, or other percutaneous exposures, rather than as a result of current injecting drug use. The shock of the diagnosis could be exacerbated by discriminatory practices in the health care facility, a lack of pre-test and post-test counselling, or even informed consent to test for HCV. It is important for nurses to offer their patients pre-test and post-test counselling and refer them to an appropriately trained member of the health care team for these services. Equally important is the patient’s informed consent to
test for HCV and nurses should endeavour to provide the patient with the relevant information to assist them in their decision making.

While CHC and combination therapy have been shown to have a significant physiological effect on quality of life, it is important not to underestimate the social and psychological consequences of being diagnosed with a highly stigmatised disease with an unknown course and outcome. Much of the worry and distress felt by the participants is due to stigma and uncertainty. Stigma and discrimination may alienate people with CHC and make them reluctant to undergo screening, treatment, or access other health care services, thus reducing their access to information about transmission and prevention.

Regular staff education is fundamental to stay abreast of new treatment modalities. Clinical supervision should also be offered to all health care professionals to facilitate critical reflection on prejudices and beliefs. These strategies would enable the health care professionals to deliver sensitive and effective care, education and support for patients with CHC on combination therapy and their partners.

Because of its slow disease progression, society is only now beginning to suffer the cost of the HCV epidemic. The burden of HCV infection is quite substantial and given the current trends, CHC will continue to have a global impact on health services in the future (Dore, Law, MacDonald & Kaldor, 2003). As a consequence, the mortality rate associated with CHC is expected to rise significantly in the next decade. The development of an effective treatment that will totally eradicate the HCV infection
and perhaps an effective vaccine that will prevent HCV infection is most anticipated. However, it is highly unlikely that these will become available soon. In the meantime, implementation of effective preventive strategies, increasing HCV awareness and increasing availability of treatment are necessary in order to control the consequences of HCV infection in the future.

To this end, nurses should provide patients and their partners with information on HCV transmission to prevent the spread of the virus. Nurses working in the field of hepatitis C could be involved in raising awareness through participation in promotional campaigns and by promoting understanding of CHC amongst colleagues and visitors to the health care facility. By networking with other health care professionals within the specialty nurses are also able to feed back to their workplaces new treatments, services or strategies that will enhance the care of their patients.

Nursing care of the person with CHC on combination therapy should encompass not only the relief of symptoms but also effective communication with patients. Sensitivity to patients’ responses to illness is essential as they need more than just technical information about CHC and combination therapy. Medical treatment emphasises patient care management with the most advanced technology available. With this focus on objective data, nurses often lose sight of the value of effective communication. All this requires is the willingness to put aside the nurses’ own prejudices and to be available for patients and their partners to listen and empathise. Nurses espousing reflective practice further enhance their skills and improve their practice. This allows nurses to offer the full range of support the person with CHC
tell them that they need to live their lives as productively and fully as is possible within the limits of their illness.

The findings from this study will be useful in clinical work with patients with CHC and their partners and could serve as a foundation for the development of support systems delivered by a multidisciplinary team. Within health care services, where different professions and perspectives are integrated, it is important to regard the patient’s understanding of HCV and treatment as a mutual source of information for the effective delivery of care.

The findings from this study will be disseminated among nurses and other health care professionals through publications and conference presentations in order to promote understanding of the needs of patients with CHC on combination therapy and their partners. Based on the findings from this study health care professionals could develop strategies for providing adequate information and appropriate support to patients and their partners during treatment.

REFERENCES


REFERENCES


Morse, J.M. (2007). What is the domain of qualitative health research? *Qualitative Health Research, 17*(6), 715-717.


APPENDICES
Appendix 1: Participant Information Sheet and Consent Form
PARTICIPANT INFORMATION SHEET

Title of Project: Living with Hepatitis C and Treatment: A Phenomenological Study of the Experiences of Patients and their Partners.

Name of Investigators: Myra Sgorbini
Dr. Louise O’Brien (Supervisor)
Dr. Debra Jackson (Supervisor)

What is the purpose of the Study?:
The study aims to explore the extent to which interferon therapy affects personal relationships among people with hepatitis C and their partners. It will seek to identify their psychosocial needs during interferon therapy to enable us to develop a program of providing information and professional guidance to patients and their partners concerning specific health matters.

Who will be invited to enter the Study?:
You are invited to participate in this research study involving patients undergoing interferon therapy for long-term hepatitis C and/or their partners.

What will happen on the Study?:
If you decide to participate in the study, you will be asked to sign this document and attend an interview. The interview will be held after 12 weeks of your or your partner’s treatment period. The date, time and location of the interview can be negotiated with the researcher. The interview may last for 40 minutes and will be audiotaped. Each participant will be asked a similar set of questions each. These questions will relate to your personal relationships during interferon therapy. You may not directly benefit from this study. However, you may find relief by simply verbalising your feelings and lived experiences. Your participation in this study will be kept confidential and your name will not be made known to anyone other than study personnel.

Are there any Risks?:
The demand will be of your time in attending the interviews. Because the study will explore your inner feelings and thoughts, you may experience anxiety, embarrassment or stress associated with responding to certain questions. If you should become distressed during or as a result of the interviews, support will be offered by Traids counselling services.
Do you have a Choice?:
Participation in this study is voluntary and you may withdraw at any time. Refusal to take part in this study will not affect the usual treatment of your or your partner’s condition.

Contact details:
If you have any problems while on the study, please contact Myra Sgorbini:

- Working hours Telephone No: (02) 9515 6111 (ask to page 88107)
- After hours Telephone No: 0414 409 935
- Traids Counselling: (02) 9843 3143

Ethics Approval:
This study has been approved by the Ethics Review Committee of the University of Western Sydney (protocol number HE 01/066), Royal Prince Alfred Hospital (protocol number X05-0229) and Westmead Hospital (protocol number HREC2000/11/4.17 [1128]). Any person with concerns or complaints about the conduct of this study should contact the Ethics Committee Secretary on:

- University of Western Sydney: 47 360 169
- Royal Prince Alfred Hospital: (02) 9515 6766
- Westmead Hospital: (02) 9845 5555

CONSENT TO PARTICIPATE IN RESEARCH
Title of Project:  Living with Hepatitis C and Treatment: A Phenomenological Study of the Experiences of Patients and their Partners.

Name of Investigators:  
Myra Sgorbini  
Dr. Louise O’Brien (Supervisor)  
Dr. Debra Jackson (Supervisor)

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by ____________________________ (“the researcher”) and I acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

3. I acknowledge that I have been given time to consider the information and to seek other advice.

4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.

5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

6. I acknowledge that this research has been approved by the University of Western Sydney Human Ethics Research Committee.

7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

Name of participant _______________________ Date of Birth ____________________

Address of participant _________________________________________________

Signature of participant _______________________ Date: ____________________

Signature of researcher _______________________ Date: ____________________

Appendix 2: Advertisement in HepC Review
“My illness has limited my capacity to work, seriously questioned my ability to be an effective parent, partner or friend, and prevented me from participating in my community. I feel isolated and often through that isolation robbed of the necessary tools to combat negativity and hopelessness”. (Submission 67, Standing Committee on Social Issues, 1998)

Many people with long term hepatitis C are considered for combination therapy. Side effects of treatment may be mild, moderate, or serious and life threatening. For some people the side effects are severe enough that it places enormous stress on personal relationships. A research study is being conducted by the University of Western Sydney, with the assistance of Traids, which aims to explore the extent to which combination therapy affects personal relationships among people with hepatitis C and their partners.

The participants must be over 18 years of age, on or whose partner is on combination therapy for 6 or 12 months and involved in a personal relationship. One interview will be conducted with the participant at a convenient location to be arranged. Participation in this study is voluntary and confidentiality is assured.

For more information or if you would like to participate in this study, please call Myra Sgorbini on 0414 409 935 or on 9515 6111 then ask for pager 88107.

Appendix 3: Interview Probing Questions
Probing Questions for the Patient

1. Living with hepatitis C and combination therapy, what is it like for you?
2. In the past week or so, describe a typical day in your home.
3. How do you cope with the symptoms and side effects of hepatitis C and combination therapy?
4. In what way, do you think, has combination therapy affected your relationship with your partner?
5. Please describe the support provided by your partner during treatment.
6. Please describe how your partner copes with the added responsibility.
7. Tell me about your or your partner’s employment situation. How has combination therapy affected your employment or the family’s finances?
8. Please describe how the challenges of hepatitis C and treatment affected you and your partner. How has it affected your marital relationship?
9. How has hepatitis C and combination therapy affected the care of your children? Please describe how your children cope during this period.
10. Please describe the reaction of your family, friends, colleagues and health care providers to hepatitis C and combination therapy. How are they able to support you?
1. Your partner is living with hepatitis C and combination therapy, what is it like for you?

2. In the past week or so, describe a typical day in your home.

3. In what way, do you think, has hepatitis C and combination therapy affected your partner?

4. Please describe the support you provide your partner during treatment.

5. Please describe how you cope with the added responsibility.

6. Tell me about your or your partner’s employment situation. How has combination therapy affected your employment or the family’s finances?

7. Please describe how the challenges of hepatitis C and treatment affected you and your partner. How has it affected your marital relationship?

8. How has hepatitis C and combination therapy affected the care of your children? Please describe how your children cope during this period.

9. Please describe the reaction of your family, friends, colleagues and health care providers to hepatitis C and combination therapy. How are they able to support you and your partner?

Appendix 4: Research Ethics Committee Approval

Appendix 4-A: Western Sydney Area Health Service Approval
6 December, 2000

Ms Myra Sgobini
Clinical Trials Coordinator
Storr Liver Unit
Westmead Hospital

Dear Ms Sgobini,

Research Proposal: "Living with Hepatitis C and Interferon: A Phenomenological Study of the Relationship Experiences of Patients and their Partners."

Your research proposal was considered at the meeting of the Western Sydney Area Health Service Human Research Ethics Committee on 28 November 2000. The Committee found no ethical objections to your proposal and agreed to give its approval subject to amendment of the Participant Information and Consent Forms as follows:

- The Chief Investigator's name should be at the beginning of the Participant Information sheet and the full list of contact names and telephone numbers at the end.
- The sentence regarding the Patient Representative should read "If you have any concerns regarding the conduct of the study you may contact the Westmead Hospital Patient Representative, Ms Jillian Gwynne Lewis, telephone 9845 7014."
- The ethics application mentions that the interview would be recorded. This is not mentioned on the Participant Information sheet, nor the storage security details.

The signature of the investigator's supervisor should be obtained, together with the written consent of the participants' treating doctors.

Please note that approval of this research proposal applies to the ethical content of the trial and individual arrangements should be negotiated with heads of departments in those situations where the use of their resources is involved (e.g. nursing etc.). The Committee requests you notify them of the commencement date of the study or the date which subjects are recruited.

In accordance with the NH&MRC Statement on Human Experimentation 'Supplementary Note 1', the Committee requires you to furnish it with a brief report on progress at the end of 12 months.
In all future correspondence concerning this study, please quote your approval number HREC2000/11/4.17(1128).

The Committee wishes you well with your project.

The project approval becomes operative when the attached copy letter, signed and dated in acknowledgement, is received in the Research Office, together with the items listed above.

Yours sincerely

Dr Howard Smith
Secretary
Western Sydney Area Health Service
Human Research Ethics Committee
2 May 2001

Myra Sgorbini
Clinical Research Nurse
Storr Liver Unit
Westmead Hospital NSW 2145

Dear Myra

Research Project: Living with Hepatitis C and Interferon: A Phenomenological Study of the Relationship Experiences of Patients and their Partners HE 01/066

You are advised the Committee has reviewed your application submitted to the Westmead Hospital Ethics Committee and formally noted the ethics approval.

You are advised that the Committee should be notified of any further change/s to the research methodology should there be any in the future. You will be required to provide reports on the ethical aspects of your project upon request.

The Protocol No. HE 01/066 should be quoted in all future correspondence about this project. Please contact the Human Ethics Officer, Kay Buckley on tel: 47 360 169 if you require any further information.

The Committee wishes you well with your project.

Yours sincerely

Professor Elizabeth Deane
Chairperson
UWS Human Ethics Review Committee

Appendix 4-C: Sydney South West Area Health Service Approval
8 September 2005

Ms M Sgorbini
Donor Coordinator
PGA-ICS, Level 3
Royal Prince Alfred Hospital

Dear Ms Sgorbini,

Re: Protocol No X05-0229 - “Living with Hepatitis C and Interferon: a phenomenological study of relationship experiences of patients and their partners”

The Executive of the Ethics Review Committee, at its meeting of 1 September 2005, considered your correspondence of 23 August 2005. In accordance with the decision made by the Ethics Review Committee, at its meeting of 10 August 2005, approval is now granted to proceed.

You are asked to note the following:

- This approval is valid for four years, and the Committee requires that you furnish it with annual reports on the study’s progress beginning in September 2006.

- This approval relates to the ethical content of the study only, and you are responsible for the following:

  - negotiating individual arrangements with the Heads of service departments in those situations where the use of their resources is involved,
• arranging an identity pass for any researcher who is not employed by the Sydney South West Area Health Service. You and the researcher should present yourselves at the Security Department, Level 5, Building 64, Royal Prince Alfred Hospital with a copy of this approval letter, and

• if appropriate, informing the study sponsor that the membership and procedures of the SSWAHS Ethics Review Committee (RPAH Zone) comply with the National Statement on Ethical Conduct in Research Involving Humans.

• If you or any of your co-investigators are University of Sydney employees or have a conjoint appointment, you are responsible for informing the University’s Risk Management Office of this approval, so that you can be appropriately indemnified.

Yours sincerely,

Lesley Townsend
Secretary
Ethics Review Committee (RPAH Zone)

HERC:EXCOR05-09