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"I always felt I was a bit of a guinea pig": Illness perceptions, experience of treatment and coping in liver transplant patients with Hepatitis C Virus recurrence.

A thesis submitted in partial fulfilment of the requirements of Edinburgh Napier University, for the award of Masters by Research

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Abstract

The current study aimed to gain an in-depth understanding of the lived experience of liver transplant patients with Hepatitis C Virus (HCV) recurrence. The semi-structured interviews with seven male participants were audio-recorded, transcribed verbatim and then analysed using Interpretative Phenomenological Analysis (IPA). Three master themes were identified: 1) the experience of encountering HCV; 2) managing the diagnosis of HCV; and 3) the experience of treatment. The first theme highlighted the psychosocial consequences of being diagnosed with HCV including fears of contaminating others, a fear of disclosing the condition to others and stigma. The second theme revealed participants' resilient coping strategies such as optimism, acceptance, and adaptation that helped them to better manage the diagnosis. Participants also reported their need for support from both their loved ones and professional care providers. Finally, the third master theme focused on the experience of receiving treatment, including both the pre-and post-transplant period. Participants reflected on their participation in a number of medical trials that made them feel like "a guinea pig". Participants were found to be aware of the risk of post-transplant virus recurrence and expressed uncertainty for their futures following re-diagnosis. A new cure evoked hope for the future, fuelled a strong determination to fight the virus, and generated a lively discussion on the need for information provision. The clinical implications of this study lie, in particular, in the potential for the improvement in quality of life for patients with a current diagnosis of HCV and in those with virus recurrence that are awaiting the new treatment.

Keywords: Interpretative Phenomenological Analysis (IPA), Hepatitis C Virus (HCV), liver transplant, virus recurrence.

Declaration

I declare that this thesis is my own work. It is submitted to Edinburgh Napier University in fulfilment of the requirements for the degree of Masters by Research in Health and Social Sciences.

Signed: _____

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Date: _____

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List of Abbreviations

HCV	Hepatitis C Virus
RIE	Royal Infirmary of Edinburgh
WHO	World Health Organisation
IVDU	Intravenous Drug Users
SLTU	Scottish Liver Transplantation Unit
HPA	Health Protection Agency
PHE	Public Health England
OLT	Orthotropic Liver Transplantation
PEGIFN	Pegylated Interferon
RBV	Ribavirin
SVR	Sustained Viral Response
SOF	Sofosbuvir
NICE	National Institute for Health and Care Excellence
IPA	Interpretative Phenomenological Analysis

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Glossary of Terms

Alanine aminotransferase (**ALT**) –enzyme mainly found in the liver. Its level is measured to test if liver is damaged or diseased.

Hepatitis C Virus (HCV) – was initially called non-A non-B before it was identified (1989). Hepatitis C is a blood-borne virus that predominantly infects the cells of the liver. This can result in inflammation and significant damage to the liver.

Hepatocellular carcinoma (HCC) - is a primary malignancy of the liver and occurs predominantly in patients with underlying chronic liver disease and cirrhosis.

Interferon α (IFN-α) –a family of naturally occurring glycoproteins that have both direct antiviral and immunomodulatory activities.

Master theme- main themes that result from identifying patterns between sub-ordinate themes. They capture most accurately participant's views on the particular phenomenon under investigation.

Resilience- individual differences or life experiences that help people to cope positively with adversity, make them able to deal with stress and protect them from the consequences of adverse experiences.

Ribavirin (RBV)-is a synthetic nucleoside (guanosine) analogue with a broad spectrum of antiviral activity. RBV has been shown to be active in combination with interferon (IFN) among patients with chronic HCV.

Sofosbuvir (also known as Sovaldi) is a nucleotide analog used in combination with other drugs for the treatment of hepatitis C virus (HCV) infection.

Subordinate theme- concise statements that are produced by condensating initial exploratory comments attached to a fragment of transcript.

Sustained viral response (SVR)- lack of virus in the blood plasma 24 weeks after completion of antiviral therapy for chronic hepatitis C virus (HCV) infection.

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Epigraph

“I do as much as I can, but still learn at the end of the day, when you go to your bed at night, it (HCV recurrence) comes back to haunt you, it really does.” (Jimmy)

Chapter One: Introduction

The following chapter will first commence with an overview of the prevalence of Hepatitis C Virus (HCV), ways how the virus can be transmitted and brief symptomatology of the illness. As most participants in this study referred to the socio-political context of HCV contraction, introducing a short reference to the events leading up to contraction will be presented to contextualise participants' accounts. Then, both within the UK and worldwide, changing epidemiological patterns of HCV will be described. With a basic knowledge of the virus history and prevalence, the reader can next learn about available HCV early treatment, liver transplantation and post-transplant therapy after virus recurrence.

1.1. Hepatitis C Virus (HCV): Prevalence, Contraction & Symptomatology of HCV

HCV continues to be a major health care burden worldwide, with incidence rates of about 3% and some 170 million people affected by the virus (World Health Organisation, WHO, 2014). However, prevalence rates throughout the world have reduced following increased awareness within developed countries of blood transfusion as the major risk factor associated with spread of the virus (Sy & Mazen Jamal, 2006). After 1990, when HCV blood screening was introduced, transfusion-related Hepatitis C has virtually disappeared (Poynard, 2005). In England, infectious donations were attributed to 1 in 520,000 during 1993-98 and this subsequently decreased to 1 in 30 million during 1999-2001 (Soldan, Barbara, Ramsay, & Hall, 2003). Within the UK, it is estimated that 214.000 individuals are infected with HCV, of which approximately 37.000 reside in Scotland (Public Health England, 2014) including approximately 4.500

HCV antibody positive individuals in Edinburgh and Lothian (Health Protection Agency, 2011). At present, the prevalence of HCV among intravenous drug users (IVDU) can reach even 90% if they are HIV-infected (Sulkowski & Thomas, 2003).

HCV can lead to both acute and chronic hepatitis infection. For some individuals, acute HCV infection is a short-term disease that can be spontaneously cleared within weeks after an individual has been exposed to the virus (Poynard, 2005). However, the acute form of the virus can, if more severe and untreated, often develop into chronic infection. In fact, chronic HCV virus occurs in the vast majority of individuals infected (>80%) (Seeff, 2002), because most HCV cases are unrecognized until many years after the acute episode. The reason for this is typically the paucity of symptoms. The progression of the disease is also mostly asymptomatic and silent, therefore, the infection is usually identified only on routine biochemical screening or during the course of blood donation. In that sense, a vast number of Hepatitis C cases remain both undetected and undiagnosed and as such, the progression of the disease cannot be easily predicted.

Research has shown that progression from acute HCV infection to severe end-stage liver disease and liver-related death clearly can occur (i.e., Seef, Miller, Rabkin, Buskell-Bales, et al., 2000). Usually, it is suggested that HCV becomes terminal only when it leads to cirrhosis, the final stage of liver fibrosis (liver scarring) (Poynard, Raziu, Charlotte, Goodman, et al., 2001). However, developing complications such as hepatocellular carcinoma (HCC) or other hepatic dysfunction may also accelerate the progression rates. Thus, hepatitis C constitutes an important risk factor leading to increased morbidity and mortality.

For that reason, the end-stage chronic disease caused by HCV is currently a leading indication for liver transplantation both in Europe and the United States (Feray, Gigou, Samuel, Paradis, et al., 1994).

1.1.1 Socio-political context of HCV in the UK.

Before 1990, when HCV blood screening was introduced and transfusion-related HCV had been systematically eliminated as a major source of infection (Poynard, 2005), thousands of people with HCV were infected through blood transfusions and blood products in Scotland, in the 1970s and 1980s. During this time, developing post-transfusion non-A non-B hepatitis (NANBH) multiplied amongst blood product recipients who underwent transfusions of blood that was generated from the USA paid blood donations (Taintedblood, 2011). Most of the patients being treated for haemophilia in the 1970s (who were given contaminated blood derived from difficult to trace sources) contracted HCV and about 20% of them were also infected with HIV (Department of Health, 2007; Sabin et al., 2005).

It has been estimated that more than 4500 patients contracted HCV and/or HIV through blood transfusion, of whom approximately 2000 have died to date (House of Lords Debate, 2011). This public health disaster led to lengthy legal claims of patient groups (such as The Hepatitis C Trust and Tainted Blood) for compensation for infected individuals and their families, and a public inquiry (Department of Health, 2006). Despite resistance of ongoing UK Governments to accept those public calls, three government-funded organisations were established to financially support the victims of medically acquired HCV.

Further, two Department of Health inquiries were initiated in order to investigate the contaminated blood issue. However, ongoing UK Governments continue to argue that at the time when the contaminated blood was provided to the patients in the course of NHS treatment, there had been no wrongdoing considering available knowledge and understanding of HCV and HIV (Department of Health, 2006). In response, in January 2009 Lord Penrose established a public inquiry requiring an investigation into HCV/HIV acquired infection from NHS treatment in Scotland. The Penrose Inquiry has published a preliminary (2010) and a final report (2015) that summarizes evidence related to the contaminated blood issue in Scotland to date.

An echo of the circumstances around the HCV infection contraction in the 70s and 80s can be found in five accounts within this study. This particular group of participants is seldom a consideration within the HCV literature, although they are confronted with exceptional social challenges, including stigma and social exclusion. The lived experience of people who were infected with HCV through blood transfusions extends far beyond the personal experience. The consequences of contracting the virus through blood products supplied by the NHS over thirty years ago affect also the significant others and the whole social environment of the individuals living with HCV.

1.2 Treatment of HCV

Therapeutic decisions in chronic HCV infection have been made difficult by the clinical nature of most acute and chronic infections. This is because, in many cases, infections are not even detected unless anti-HCV or HCV RNA tests are performed. This does not lessen the danger of chronic HCV, which often does

not become symptomatic until the development of cirrhosis some 20 years following infection (Thein, Yi, Dore, & Krahn, 2008). Given these considerations, HCV is often not diagnosed for a long period after virus exposure, since patients are relatively healthy and do not seek medical help. This represents one of the major challenges in treating HCV.

However, once the disease is diagnosed, patients are offered a variety of anti-viral treatments, including interferon α (IFN-α) therapy. In the first large-scale, controlled trials when INF-α was used for treating Non-A and non-B Hepatitis (NANBH), it was shown that the therapy was well tolerated and alanine aminotransferase (ALT) levels declined shortly after the trial started (Hoofnagle, Davis, Pappas, Hanson, Peters, et al., 1986). Subsequent clinical trials confirmed a decreased ALT in about a half of participants, however, the effects of reduced levels of ALT did last in only one-fourth of patients when the therapy ended (Tine, Magrin, Craxi, & Pagliaro, 1991). The fact that only a small percentage of individuals experienced sustained benefits from this type of treatment indicated that there was a need for more effective and adequate therapy.

Moreover, IFN treatment was found to have several side effects. These include 'flu-like' symptoms, fatigue and depression (Di Bisceglie, Conjeevaram, Fried, Sallie, et al., 1989). These side effects that have often an extremely debilitating impact on patients' well-being, indicate that therapy with IFN should be carefully administered and that psychological support should be offered to treated individuals and their loved ones (Feitelson, 2002).

An alternative for Interferon monotherapy is its combination with ribavirin (RBV). HCV genotype is used to predict after-effects of this antiviral treatment. In this

sense, about 82% of patients with genotype 2 and 3 were found to derive sustained benefits from this treatment, whereas only around half of patients with genotype 1 showed the sustained virologic response (Manns, McHutchison, Gordon, Rustgi, et al., 2001; Hadziyannis, Sette, Morgan, Balan, et al, 2004). A number of side effects accompanying administration of IFN and RBV result in frequent dose reduction and low adherence to the treatment. Some studies also demonstrated that the combined therapy of IFN/RBV can unlikely lead to HCV clearance when specific preventing factors are involved (e.g. high baseline viral loads or advanced fibrosis) (Backus, Boothroyd, Phillips, & Mole, 2007)

1.3 Diagnosis of recurrent HCV after liver transplantation

As previously stated, as the disease is typically asymptomatic until many years after the acute episode, progression to severe end stage liver failure can occur. Orthotropic liver transplantation (OLT) is a life-prolonging option for many patients with hepatitis C infection. However, postoperative recurrence of infection occurs invariably in all HCV-infected liver transplant patients and constitutes a great burden on patients and the whole healthcare system. The severity of post-transplant inflammation may vary, ranging from a mild form to an accelerated recurrence of cirrhosis associated with poor outcomes (Satapathy, Sclair, Fiel, Del Rio, et al., 2011). The reinfection is usually identified in half of post-operative patients within a year after transplantation and in the majority of OLT recipients within five years of surgery (Kia, Matkowskyj, & Levitsky, 2013). Of those ‘re-diagnosed’ with HCV, only 10% to 30% of patients progress to liver cirrhosis, developing graft failure. However, once HCV cirrhosis recurs, patients only survive up to five years after transplant (Berenguer, Prieto, & Rayon, 2000).

1.4 Treatment of HCV recurrence

To increase survival rates of post-transplant patients and prevent HCV recurrence, antiviral therapy is used. This prophylactic treatment involves using pegylated interferon (PEG-IFN) and ribavirin (RBV) to achieve sustained viral response (SVR). Data suggests that applying the antiviral therapy may significantly reduce or slow disease progression (Chalasani, Manzarbeitia, Ferenci, Vogel, et al., 2005). However, only a small percentage of patients are considered suitable candidates for treatment within the first couple of weeks after liver transplantation (Shergill, Khalili, Straley, Bollinger, et al., 2005). The reason is reduced tolerability in OLT recipients, who are still recovering from surgery and require immunosuppression. Many patients terminate antiviral treatment even after one dose of interferon due to side effects and the risk of acute rejection. Thus, overall success of prophylactic treatment (20%-30%) in post-transplant patients is rather limited and associated with a high percentage of potentially detrimental effects leading to therapy discontinuation.

The pegylated interferon and ribavirin therapy is continued after virus recurrence and as in the case of the prophylactic trials, it was shown that this treatment is at least modestly cost-effective. Further, an overall survival rate was only demonstrated in patients who were able to attain an SVR, but the percentage of these responders ranged from only 25% to 45% of all post-transplant patients receiving the same treatment (Sharma, Marrero, Fontana, Greenson, et al., 2007). In summary, only a small percentage of patients benefit from antiviral therapy, while the majority of treated recurrent HCV patients appear to be unresponsive to the only available treatment.

The low effectiveness of antiviral post-transplant treatment or lack of an alternative therapy for unresponsive recipients does not seem to be, however, an existing problem anymore. A new therapeutic drug, sofosbuvir (SOF), has been approved by the National Institute for Health and Care Excellence (NICE, 2015) and was launched in the UK in February 2015. SOF-based therapy constitutes a breakthrough treatment of HCV that has demonstrated a sustained viral response rate of over 90% (i.e. Lawitz, Lalezari, Hassanein, Kowdley, et al., 2013). The new therapeutic class in combination with ribavirin, or peginterferon plus ribavirin can be used in HCV patients with genotypes 1 to 6, where genotypes 1 and 3 constitute ~90% of all HCV cases. This treatment is also a solution for the pre-existing problem with low tolerability to the peginterferon alfa that is now the only option in the course of treatment.

Patients who stayed untreated because of a number of side effects and relative contraindications associated with use of interferon, currently receive a combination of sofosbuvir with ribavirin (RBV) without including peginterferon (PEGINF). According to findings in three studies conducted by Lawitz et al. (2013), previously untreated patients with genotype 1 to 4 infection who were receiving SOF+RBV+PEGINF or SOF+RBV indicated a high Genotype 1,2 & 4) or moderate (genotype 3) sustained virologic response at twelve weeks of treatment. In the SOF+ RBV+PEGINF study, 90% recipients with genotype 1 or 4 infection were found to have a SVR at twelve weeks. In a randomised study (Bouliere, Wendt, Fontaine, Hezode, et al. , 2013)., where patients with genotype 2 and 3 receiving SOF+ RBV, those with genotype 2 demonstrated higher SVR rates than the group of patients with genotype 3, 97% to 56%, respectively. A high (81%) response rate was also identified in the third study with patients with

genotype 1 who were diagnosed with cirrhosis. The results did vary between patients with different genotypes or between patients with and without cirrhosis, however, overall rates of SVR observed in the research were still the highest that have been shown to date for the HCV population.

In sum, this chapter has introduced the reader to prevalence of HCV, ways it can be transmitted and symptomatology of the illness. Treatment at different stages of disease progression was also described. Chapter 2 will now summarise HCV literature describing biopsychosocial impact of HCV and its treatment on individuals' quality of life. This chapter will also introduce to the reader a theoretical framework that was related to the previous literature and current research.

Chapter Two: Literature review

This chapter aims to explore the wider HCV literature, focussing specifically on: 1) psychological burden associated with diagnosis of HCV; 2)the biopsychosocial impact of HCV on individuals' quality of life; 3) typical physical and psychological signs and symptoms of HCV; 4) impact of HCV on significant others; and 5) coping with HCV. Then, based on the previous research and in accordance with current findings two theoretical frameworks will be introduced and related to the context of HCV.

2.1 The biopsychosocial impact of HCV on quality of life

Symptoms of a chronic illness such as hepatitis C can have an enormous impact on both the mental and physical functioning of the infected person. Several studies have demonstrated a significant decrease in the health-related quality of life of HCV patients when compared to the general population or other control groups (e.g., Ware, Bayliss, Mannocchia, Davis, & The International Hepatitis Interventional Therapy Group, 1999; Davies, Balart, Schiff, Lindsay, et al., 1994). The most common clinical manifestations of chronic HCV infection include fatigue, depression, nausea, musculoskeletal pain or jaundice and these can significantly impair patients' vitality, social functioning and mental well-being (Shiffman, 2011; Harris & Richters, 2006). These symptoms can also be the result of antiviral treatment that patients undergo or a consequence of post-transplantation physiological imbalance.

However, before the HCV symptoms become a burden, and the anti-viral treatments and their seriously debilitating side-effects commence, patients have

to deal with the diagnosis itself. The personal impacts of a diagnosis of HCV are significant. Patients' lifestyle and the degree of social participation change depending on how they approach the diagnosis and how their community responds to their 'new social identity'.

2.1.1 Diagnosis and its impact on quality of life

Rodger, Jolley, Thompson, Lanigan and others (1999) explored the impact of diagnosis by comparing three groups of participants: individuals unaware of their HCV serostatus, those aware of their diagnosis and healthy controls. The results demonstrated that patients who were aware of their HCV serostatus indicated a significant impairment in quality of life scores in seven of eight scales: 1) vitality; 2) role limitation; 3) physical, bodily pain; 4) general health; 5) social functioning; 6) role limitation; and 7) emotional and mental health, when compared with healthy population norms. They subjectively perceived their health as being extremely poor and that this, in consequence, led to a reduction in social functioning and emotional difficulties. Individuals who were not informed about their HCV serostatus and who were sociodemographically and clinically matched with the aware group, scored significantly worse in only three measures (general health, mental health and vitality). These results clearly indicate the effect of labelling associated with diagnosis and that the diagnosis of HCV may affect (at least partially) people's quality of life. These findings have also been reported by other authors (Carithers, Sugano, & Bayliss, 1996; Bonkovsky, Woolley, & the Consensus Interferon Study Group, 1999; Koff, 1999).

Thus, receiving a diagnosis can significantly influence patients' perception of their health status, which in turn may have negative social and emotional

implications. Further, as individuals with HCV are largely marginalised within society because of a common association of infection with injection drug users, the diagnosis can evoke in them strong emotional responses.

2.1.1.1 Burden of diagnosis and stigma

The diagnosis can raise various negative emotions, which patients can internalise (e.g. self-disgust, regret and personal shame); or externalise (e.g. blame, anger and violent outbursts) (Tompkins, Wright, & Jones, 2005). Disbelief and shock are also common reactions at the time of diagnosis that can, consequently, evolve into enduring anxiety and depression. These responses to diagnosis can also lead to long-term psychosocial effects identified via patients' concerns about the health and well-being of their partners and children (Chapman, & McManus, 2012). Some people also fear the negative effect the diagnosis might have on their social relationships with others, their sexual relationships and within familial relationships in the future (Tompkins et al., 2005). Thus, the stress associated with a diagnosis of HCV affects all aspects of patients' functioning; psychological, social and physical. In fact, Castera et al. (2006) found that the emotional and psychological burden associated with HCV diagnosis was comparable to the impact of highly stressful life events such as divorce, losing one's home or being dismissed from one's job.

In this sense, patients' perception of the burden seems, to a great extent, to be determined by their beliefs about the illness and their attitudes towards it, rather than by the physical presence of significant liver disease itself. Cordoba, Reyes, Esteban and Hernandez (2003) claimed that labelling and stigma related to the diagnosis of HCV may be the major causes of the high degree of distress

experienced by infected patients. In support of these findings, Rodger et al. (1999) demonstrated that participants with HCV showed more depressive symptoms than did individuals who were unaware of their health condition.

The profound impact of diagnosis is also related to the social stigma and discrimination associated with this chronic disease. As it is the case with other blood-borne diseases such as HIV, experiences of being stigmatised because of having HCV may be related to the predominant social view that the infection is rife amongst intravenous drug users. In developed countries, the majority of people with HCV have acquired the disease via intravenous drug use (IDU) and by sharing or re-using contaminated syringes and needles (Remis, 2004). The resultant social opinion is, therefore, that individuals with hepatitis C should be blamed for contracting the virus and are seen as being a source of contagion (Herek, Capitanio, & Widaman, 2003).

This arbitrary social view often causes stigmatisation, regardless of the mode of virus transmission (Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). A common response of infected individuals towards stigmatisation of HCV is concealment of their diagnosis, which often leads to changes in lifestyle, work and social commitments (Butt, Paterson, & McGuinness, 2008). Shafer, Scheurlen, Felten and Kraus (2005) found that one-third of one hundred and three individuals with HCV chose not to reveal their diagnosis to their family, friends or even physicians for fear of rejection. Disclosure of the diagnosis to loved ones or friends can evoke mixed responses in patients themselves. Many of them perceive this act as a moral obligation towards everyone they encounter, whereas others are anxious about the unpredictable consequences of disclosure,

fearing negative reactions from loved ones or even from other drug users (Tompkins et al., 2005).

Unpredictable reactions to a diagnosis of hepatitis C have also been reported by health care providers. In their cross-sectional study of 504 people with HCV, Hopwood et al. (2006) demonstrated that 64.7% (n=326) of participants reported having experienced discrimination within health care services. In addition, higher levels of reported discrimination were found to be associated with patients' pessimism regarding the prognosis about their future and their disrupted interaction with family, friends and other social groups. These findings may suggest that reported pessimism can be related to individuals' previous experiences of healthcare discrimination. According to other studies and reports (e.g., Anti-Discrimination Board of New South Wales, 2001; Hopwood & Treloar, 2004), patients with HCV tend to avoid any interactions with medical services in order to prevent further discrimination.

Perceived discrimination in the healthcare sector can include delaying access to blood and liver testing, or even refusal of treatment (Butt, et al., 2008). These attitudes towards patients not only dictate the quality of the health care provided, but also shape perceptions of the illness in the affected individuals and their self-care management of the disease (Paterson, Butt, McGuinness, & Moffat, 2006). Moreover, stigma and discrimination that are prevalent within communities and healthcare services can not only influence patients' management of the illness and the quality of care offered, but also feed into their self-concept and biography.

2.1.2 Biographical disruption and diagnosis of HCV

According to Mike Bury's (1982, p.169) concept of 'biographical disruption', a diagnosis of chronic illness has the potential to disrupt the structure of everyday life, including people's future plans and requires a major re-evaluating of life experiences and self-perception. An important aspect of the process of biographical disruption involves the problem of uncertainty. Seeking and receiving information about the illness can alleviate some aspects of uncertainty.

Gaining knowledge is important in terms of an individual's ability to cope with chronic disease, his or her ability to disclose having the disease, and access to social support. However, it can also lead to stigma (Suarez, 2010). Thus, the results of acquiring sufficient knowledge about HCV have positive and negative aspects. In other words, having a good understanding of the disease can, on one hand, lead to self-labelling and attunement but, on the other hand, to a greater feeling of stigmatization. According to Suarez (2010), there is also a clear correlation between a high level of knowledge, a high level of disclosure and various social support groups (e.g. work and significant others).

According to Suarez (2010), accurate and more detailed knowledge can promote patients' practice of self-care, minimize the likelihood of infecting others and lead to an overall improvement in health status. Conversely, a lack of knowledge regarding the transmission of HCV or available HCV treatment (Heimer, Clair, Grau, & Bluthenthal, 2002) can cause anxiety (Davis, Rhodes, & Martin, 2004). A sense of fear and uncertainty can be enhanced by HCV's unpredictable course and limited access to medical knowledge. Therefore, chronically ill individuals often incorporate their own biographical experiences into

expert knowledge, and develop their own interpretations of the course of the illness (Williams, 1984). This approach prevents them from experiencing confusion caused by a lack of medical advice.

In her study of people who had been diagnosed with HCV, Magdalena Harris (2009), demonstrated that biographical disruption could also be contextual. She showed that the process can be dependent on previous experience of disease, marginalization or the perception of HCV within given communities. Harris (2009) indicated that contextual factors could also provide an explanation of what she described as 'narratives of unconcern'. She found that almost the same number of patients in her study described diagnosis of HCV as either a burden or as "no big deal"' (2009, p.1028).

A group of 'unconcerned' participants was also mentioned by Olsen, Banwell, & Dance (2013), who argued that HCV caused no specific concerns amongst the IDUs. In their study, most of the participants did not perceive HCV as being disruptive, but rather as an inevitable element of their lifestyle, incorporated in their identity as drug users and people living in poverty. In the case of these individuals, reactions and attitudes to a diagnosis of HCV constituted evidence of biographical reinforcement rather than of biographical disruption.

However, the majority of the current literature exploring the lived experience of HCV has emphasized the disruptive character of diagnosis. According to Hepworth and Krug (1999), disclosing a positive status and confusion regarding its implications for work and the family environment can lead to social withdrawal. They found that individuals with HCV were often re-positioned outside of family, friends and work relationships. Uncertainty about the future and social isolation

were identified in the responses of HCV patients (Hepworth & Krug, 1999; Burrows & Bassett, 1996).

Sladden, Hickey, Dunn, and Beard (1998) observed distinct reactions to HCV infection. Some of their participants reported no changes in their lifestyle following diagnosis. However, others, as in the studies mentioned above, reported a significant change in their lifestyle after receiving a diagnosis. They showed a significant decline in their general health, which affected their work performance and other daily commitments. In this regard, participants' concerns were mainly related to their occupational future as well as to commencing personal and sexual relationships. Disclosure of diagnosis often resulted in the experience of discrimination at work and isolation (Sladden, et al., 1998), and in individuals' fear of transmitting the virus to partners and children (Lowe and Cotton, 1999).

In summary, a diagnosis of HCV may affect people's personal and work commitments, their future plans and emotional stability. It disrupts their biographical continuity and requires emotional adjustment and rethinking their role in the social context. Further, diagnosis with HCV can be perceived as a highly challenging and life changing event that may influence dramatically patients' quality of life. Experiences of diagnosis are not, however, the only disruptions that are reported by patients with HCV. The recognition and acceptance of a new ill identity result in further biographical disruption, requiring management of symptoms and pursuing a healthy status. Therefore, patients with HCV decide to undertake antiviral treatments expecting improvements in their condition and quality of life.

2.1.3 Quality of life and the course of treatment

The dramatic decline in the self-reported health-related quality of life (HRQOL) appears to be related to the course of HCV treatment that poses a six- to twelve-month challenge for chronically ill patients. Physical and/or mental side effects of anti-viral treatment were found to reduce the quality of life of patients and this, in turn, reduced patients' adherence to medication (Rodis & Kibbe, 2010).

Evidence for the association between quality of life and the course of interferon therapy has been provided by several studies, which have reported a consistent oscillation from considerable decrements in HRQOL during the treatment to significant improvements in HRQOL six months after treatment, in patients with a sustained virologic response (Ware et al., 2003; Hunt, Dominitz, Bute, Waters, Blasi, et al., 1997). The pattern of improvements in measurements (e.g. social functioning, general health or health distress) was not, however, identified in patients who failed to respond to treatment regimes. Virologic non-responders declined significantly in eight of twelve health-related quality of life scales, as compared to the general health scores of patients who responded successfully to the treatment.

As therapeutic options for HCV population were quite limited until 2015 (when new, sofosbuvir treatment have been introduced) and patients had to undergo quite invasive procedures (interferon and ribavirin treatment) that were at that time widely applicable. Commonly experienced side effects with interferon monotherapy were fever, headache, muscle aches, and fatigue (McHutchison & Hoofnagle, 2000). These side effects were usually intermittent and somewhat unpredictable. The number and severity of side effects of interferon varied greatly from patient to patient, but they were more frequent when higher doses of

interferon were given to patients. In turn, experiences of more frequent side effects determined higher rates of discontinuation of therapy and decrease in health-related quality of life (Renault, Hoofnagle, Park, et al., 1987).

2.1.3.1 Fatigue

Fatigue constitutes the most frequent and most debilitating symptom that affects HCV patients' quality of life (Sarkar, Jiang, Evon, Wahed, & Hoofnagle, 2012). Fatigue remains a common complaint in the majority of HCV patients both before and during the antiviral treatment. However, the severity of fatigue increases and becomes more troublesome during the course of antiviral therapy (Hassoun, Willems, Deslauriers, Nguyen, & Huet, 2002). Patients' perceptions of fatigue as a highly detrimental side-effect of treatment can lead to the termination and/or failure of antiviral intervention (Hassanein, Cooksley, Sulkowski, Smith, et al., 2004). However, if patients are able to withstand the severity of interferon therapy and clearance of the virus is observed, the severity of the fatigue also declines. However, a clear association between specific changes in symptoms and improvements in the quality of life have not yet been demonstrated in the HCV population. Existing evidence (Hassanein et al., 2004; McHutchison, Ware, Bayliss, Pianko, et al., 2001) of correlations between successful outcomes of treatment and improvements in the quality of life, which encompasses physical functioning (i.e. fatigue), may suggest that the eradication of HCV can in turn, cause the eradication of symptoms.

2.1.3.2 Depression

The course of antiviral treatment is also associated with an increased risk of depression, which is another predominant symptom of HCV (Schaefer, Capuron,

Friebe, Diez-Quevedo, et al., 2012). In general, the prevalence of depression in HCV patients significantly exceeds the incidence of depression identified in healthy individuals at 59% versus 21% (Quelhas & Lopes, 2009; Constant, Castera, Quintard, Bernard, et al., 2005). Depressive symptoms in response to interferon treatment were found in 60% of patients receiving the antiviral therapy (Ong, & Younossi, 2004), and in some cases, they were related to suicidal intentions and self-harming episodes (Janssen, Brouwer, van der Mast, & Schalm, 1994). The association between antiviral therapy and depression is a critical predictor for patients' reduced compliance with treatment regimes. Therefore, some studies have posited that early detection and the management of the symptoms before and during therapy can increase adherence to the treatment (Dwight, Kowdley, Russo, Ciechanowski, et al., 2000).

2.1.4 Post-transplant quality of life

An impaired QoL and restricted progression to independent living have also been reported by HCV patients after receiving liver transplants. Poorer physical functioning (Singh, Gayowski, Wagener & Marino, 1999; Feurer, Kelly Wright, Payne, et al., 2002), higher rates of depression and anxiety (De Bona, Ponton, Ermani, Iemmolo, et al., 2000), and increased levels of fatigue are common (Paterson, Gayowski, Wannstedt, Wagener, et al., 2000). However, no research has provided a causal relationship between quality of life and several post-transplant symptoms. For example, it is not clear whether quality of life after liver transplantation causes the deterioration of mental and physical functioning or vice versa.

2.1.5 Quality of life and virus recurrence

Studies that aimed to assess the QoL in individuals with HCV after receiving a transplant have demonstrated that participants with recurrent HCV had a significantly impaired QoL and more depressive symptoms than did those without recurrent infection (Singh et al., 1999) and those who received transplants for other reasons (Peterson et al., 2000). In their longitudinal study, Singh et al. (1999) examined 59 transplant recipients pre-transplant, and at six and twelve months post-surgery. They found that at six months posttransplant, participants with diagnosis of HCV recurrence reported significantly lower functional status and a reduction in physical functioning from the baseline (the pre-transplant scores) than did the other patients in the control group. The HCV patients did, however, demonstrate an increase in their QoL after transplantation when compared to their pre-transplant results. No difference was recognized in the QoL scores when participants with recurrent HCV were compared with those without virus recurrence. Furthermore, a tendency towards greater psychological distress was also identified in the HCV- recurrent group at six months posttransplant. They were found to report greater levels of anger, tension, anxiety and hostility than did the control groups. The differences in the quality of life, physical functioning and psychological distress between patients with HCV and all the other patients became significantly greater at twelve months after receiving the transplant. Patients with recurrent HCV continued to score very low with regard to functional status and experienced more severe depression when compared to the results at the baseline and at six months posttransplant.

Conversely, in their longitudinal investigation (followed up after four years), Paterson et al. (2000) demonstrated that only physical functioning declined significantly in patients with HCV recurrence. These results suggested that individuals with recurrent HCV might gradually adjust to the highly stressful circumstances associated with being diagnosed with HCV posttransplant and improve in terms of mental well-being, whereas they become more physically disabling over time. However, although mental health was not as impaired as was physical functioning, other factors such as depression and mood disturbances were found to be important contributors to poor QoL in patients with diagnosis of HCV recurrence.

Lower mental and physical functioning scores at twelve months post-OLT reported by patients in the Singh et al.'s study (1999) can be related with negative impact of the diagnosis of recurrent HCV. As studies (Roger et al., 1999; Younossi et al., 2007) show, patients informed of disease recurrence score lower on quality of life surveys than those who do not know about their positive serostatus. Thus, patients' concerns and attitudes to knowledge of the diagnosis of HCV recurrence can determine lower mental well-being or HRQOL scores despite no physical manifestations of physical decreases (Singh et al., 1999; Paterson et al., 2000). As the diagnosis of HCV recurrence is mainly received within a year after transplant, patients investigated by Paterson et al. (2000) four years posttransplant could adapt to knowledge of the diagnosis and their low mood disturbance scores might reflect this shift in their attitude to their illness.

Higher psychological distress reported by patients in the Singh et al.'s (1999) study can also be influenced by another factor, such as HCV genotype, that was not assessed in this research. Paterson et al. (2000) found that HCV recurrent

patients with genotype 1b scored significantly lower on psychological variables when compared with those with genotype 1a. In this sense, there is a possibility that majority of patients recruited by Singh et al.'s (1999) might have represented HCV population with genotype 1b, and therefore, scored higher on psychological distress. In the Paterson et al.'s (2000) study, the number of patients with genotype 1b was scarce that could determine low mood disturbance scores, which stands in contradiction to Singh et al.'s (1999) findings. Thus, the discrepancy between those two studies regarding the degree of psychological impairment can be identified with regard to HCV genotype, reactions to the diagnosis of recurrent HCV, as well as, indirectly, by the specific timing of collecting HRQOL and psychological distress scores (12 months and 4 years post-transplant).

However, despite some differences between these two longitudinal investigations, both Singh et al. (1999) and Paterson et al. (2000), showed that HRQOL scores and self-reported physical functioning do not correlate with physical sequelae of liver disease. This is consistent with studies that reported slow progression of liver disease and small per cent of patients with cirrhosis (5-10%) at 2 years post-OLT (e.g., Younossi, et al., 1999; De Bona et al., 1998). Furthermore, post-transplant patients with recurrent HCV can be unaffected with cirrhosis for approximately seven to twelve years (M=9.5 years) (Gane, 2003). This small per cent of patients progressing to liver failure or cirrhosis, makes it difficult to explain, why patients in Singh et al.'s (1999) and Paterson et al. (2000) studies reported a significant decrease in HRQOL after twelve months and four years post-transplant.

The lower HRQOL scores in post-OLT patients might have been assessed more effectively and conclusively if current, generic HRQOL questionnaires (e.g., the SF-36) were replaced with transplant- and disease recurrence-specific HRQOL instruments. These new, sensitive measures that would relate to a particular stage of disease progression could provide researchers with more adequate explanations of the nuances of transplantation and HCV recurrence.

The generic HRQOL instruments that were used in studies with HCV post-OLT patients so far were designed to be applicable to a wide range of types and severities of health conditions. However, most of these HRQOL measures were not patient-centred as the criteria having been evaluated might have not been of crucial importance to the participants, or participants' response options might have been limited (Unruh, Weisbord, & Kimmel, 2005; Kalantar-Zadeh & Unruh, 2005). Thiis information-reducing approach can be changed by allowing participants themselves to define the QoL dimensions that are most important to them. These patient-specific criteria might, in turn, be elaborated through qualitative interviewing, which could give HCV researchers more in-depth and conclusive results. This instrument might identify HRQOL criteria often not captured in health surveys as being relevant for patients such as, for example, relationships, spirituality, or sexuality. (Kalantar-Zadeh & Unruh, 2005).

In this sense, spirituality and family were found to be of great importance for HCV patients in terms of the development of resilient coping and improvement of their mental well-being (Hopwood & Treloar, 2008; see the following themes of this chapter). These domains of patients' functioning after transplantation were not identified in any of the studies using generic HRQOL instruments. Thus, by extending quantitative measures to semi-structured interviewing researchers

could possibly provide more in-depth and clear explanations of, for instance, patients' decrease in mental and physical functioning, beginning a year post-transplant (Singh et al., 1999).

In summary, researchers who used quantitative instruments for measuring HRQOL in patients with recurrent HCV mainly focused on identifying and quantifying some mental (e.g., emotional problems, psychological distress, depression) and physical components (e.g., physical health, bodily pain). Their results were comparably consistent in indicating decreased overall health scores, very low physical functioning scores, as well as higher levels of depression and fatigue (Singh et al., 1999; Paterson et al., 2000). However, they could not provide an explanation of causal relationship between scores from each dimension. Furthermore, HRQOL instruments used in OLT recipients did not include a cognitive function domain and psychosocial dimensions that could clarify decreased levels of depression and emotional distress recognized in patients after twelve-month post-transplant (Sing et al., 1999; Gayowski et al., 1999).

Psychosocial dimensions have been introduced in qualitative research on HRQOL. Dudley et al. (2007) revealed that stigma and disease uncertainty experienced after liver transplantation might have an adverse impact on quality of life in HCV patients. These findings are consistent with other qualitative studies with HCV patients that identified a sense of uncertainty related to future health and life expectancy, as well as to a fear of organ rejection (Forsberg et al., 2000). The sense of uncertainty regarding the posttransplant unpredictability of patients' lives and the prospect of death seem to explain Sing et al.'s (1999) findings of

increased psychological stress and depression in persons with HCV recurrence, reported twelve months posttransplant.

This ongoing disease uncertainty, mental distress and feelings of stigma appear to accompany all stages of HCV progression and treatment. However, their impact on a patient's quality of life is shifting and is likely to change as he comes into contact with other individuals such as family members (Hopwood & Treloar, 2003).

2.1.6 Impact of HCV on loved ones

Despite experiencing fear and uncertainty, many patients decide to disclose their illness to others. This difficult step appears to be vital in order for individuals with HCV to learn to accept their condition and to deal with it effectively. For example, it is important in terms of receiving physical, emotional and financial support when their lives become strongly influenced by the treatment and its side effects (Sgorbini, O'Brien, & Jackson, 2009). However, family members of chronically ill individuals are not only caregivers, they also share the experience of the disease and losses associated with it with their partners/parents, such as the loss of independence, the loss of freedom or the loss of a former lifestyle (Eriksson & Svedlund, 2006). These losses and stresses in everyday life that accumulate in partners over weeks or even years might change the structure of their relationships dramatically. Accumulated anxieties and anger that are not communicated well or at all can create a distance between partners. However, despite the difficulties, frustration and anger, some relationships become stronger and the experience of hepatitis C brings them even closer (Sgorbini et al., 2009).

Individuals who live in these strong and stable relationships may rely on their partners in terms of moral support, as well as their help in coping with diagnosis and treatment regimens. Thus, these positive family relationships can be defined as protective factors that build resilience in relation to coping with HCV (Hopwood & Treloar, 2008). Caring and competent adults in the family are, however, only one of many adaptive and protective factors that enhance a person's ability to cope with a serious threat. I will now introduce some factors and processes that can contribute to positive outcomes in spite of exposure to severe adversity such as HCV.

2.2 Coping with HCV

According to Sachs (1991), coping strategies have an important impact on disease outcomes. They constitute a defence mechanism against either: 1) the physical and psychological stress, or 2) an enhanced stress response that interferes with the likelihood of recovery. Effective coping can reduce the stress of illness and maintain a positive self-concept and emotional balance (Ogden, 2004). It is also important to acknowledge an idiosyncratic perception of the disease amongst affected individuals and the variation in the application of coping strategies despite the identical symptomatology.

There is a paucity of research focusing on HCV and coping strategies. The impact of different psychosocial determinants (such as stigma and feelings of contamination) that add to the psychological distress of HCV is a major issue that is being investigated (Moore, Howley, D., & Bradley, 2008; Conrad, Garrett, Cooksley, Dunne, & MacDonald, 2006; Fraser & Treloar, 2006), whereas

research demonstrating what HCV patients do when they are confronted with psychosocial adversity is somewhat rare (Stewart, Mikocka-Walus, Morgan, Colman, et al., 2012). Furthermore, most of the small number of studies (Hopwood et al., 2006) investigating coping strategies in the HCV population refer to the resilient style of coping as the most adaptive and widely applied form of responding to stress-evoking adversity amongst affected individuals.

2.2.1 Resilient coping

Individuals cope with stressful life events in a resilient way when they endeavour to overcome adversity by invoking protective factors (e.g., optimism, psycho-spiritual factors) and previous life experiences (Richardson, 2002). For adults, the preservation of health and adapting successfully to acute stress in the face of chronic adversity provides key resilience outcomes (Charney, 2004). Resilient responses to stress can be perceived as potential protective factors that promote positive cognitive reappraisal and the application of active problem-focused coping strategies. In this sense, individuals facing adverse life situations tend to re-evaluate what they experience in ways that are more acceptable and positive. This reframing of adverse experiences allows them to identify alternative ways to maintain their well-being (Seligman, Steen, Park, & Peterson, 2005). Meaning-making processes utilised by resilient individuals in order to decrease stress reactivity and to promote recovery often involve religious and spiritual practices (Pargament, Smith, Koenig, & Perez, 1998). Religious strategies were found to be perceived by a few HCV patients as a method of healing (Stoller, Webster, Blixen, McCormick, et al., 2009). Many patients used prayers as a form of fighting HCV and interpreting the virus as part of God's plan. When certain aspects of HCV appeared to be overwhelming and difficult to manage on their

own, religious patients turned the illness over to God, shifting the responsibility for a possible cure or restricting the progression of the disease to a higher power. Patients' beliefs and trust in God's decisions regarding their health and well-being have been learned from past experiences when God challenged them but never failed to rescue them in the end (Stroller et al., 2009).

In their study on resilient coping amongst patients with HCV, Hopwood and Treloar (2008) found that adaptive coping strategies drawn from past experience could be used to facilitate patients' adherence to treatment and to manage the diagnosis. The establishment of a healthy lifestyle, identifying supportive social networks, staying occupied with reduced working hours, and exploring prior experiences of having been treated for chronic illness shaped patients' resilience when they were routinely confronted by treatment challenges. Hopwood and Treloar (2008) also recognised and confirmed previous findings that spirituality, determination and optimism can enhance the development of resilient coping (Bonanno, 2004; Tedeschi & Kilmer, 2005), particularly in relation to the side-effects of the treatment.

2.2.2 Side effects and coping

A detailed report by Hopwood, Treloar and Redsull (2006), reflecting on experiences of HCV treatment and its management, indicated a number of coping strategies such as planning, seeking support, remaining occupied, adopting a positive attitude and a healthy lifestyle, play an important role in reducing the side effects of highly invasive antiviral treatment. Patients' reactions to antiviral treatment and their coping strategies to reduce the effects of the treatment can be often idiosyncratic.

According to patients' accounts published by Hopwood et al. (2006), particularly important factors for maintaining mental well-being during the prolonged treatment appeared to be work or any form of activity that helped patients to stay occupied. Being occupied, even by engaging in small projects, provided patients with a sense of achievement and accomplishment. Patients who remained employed despite antiviral therapy, reported that giving up work would deprive them of the opportunity to escape from the reality of treatment, and from necessary distraction and stimulation. This approach to treatment and its consequences seems to be consistent with the findings of the study by Kausar and Yusuf (2011), which revealed avoidant coping strategies in post-treatment patients. In this regard, HCV patients seem to choose to remain occupied during the course of antiviral therapy in order to distance themselves from the stressor and to increase feelings of self-efficacy.

A sense of competence and control over the situation while receiving ~~on~~ the antiviral treatment can be also achieved by maintaining a healthy lifestyle. HCV patients tend to adopt healthy dietary practices such as drinking more water and ensuring good nutrition, while avoiding certain types of food (i.e. salt, 'spicy' food and foods containing little protein), drugs and alcohol (Stoller, et al., 2009; Hopwood et al., 2006). Some respondents in Stoller et al.'s (2009) study also emphasised the importance of eating specific foods (i.e. spinach, calf liver) and drinking specific liquids (e.g., green tea, freshly squeezed juices) because they believe in their cleansing and liver-strengthening effects.

2.2.3 Supporting relationships

Support from partners, families and support groups was found to be an important social variable in managing the physical and psychiatric side effects of

HCV treatment, particularly depression (Hopwood et al., 2006). Significant others help HCV patients to maintain their QoL during lengthy and repetitive treatment periods, and are perceived as a major non-medical factor influencing patients' decisions to begin the treatment in the first place (McNally et al., 2004). Patients' mood swings and symptoms of depression that result from the interferon treatment often make it difficult for them to remain supportive of their partners and children (Hopwood et al., 2006).

Therefore, this is the time when their partners need to take over responsibility for the children and the household. The entire family has to cope with the frequent outbursts of anger, hostility and irritability that accompany interferon treatment (Kraus, Schäfer, Faller, Csef, & Scheurlen, 2003), and which often disturb the harmony of family life. Thus, partners and children have to adjust sensitively to constantly changing circumstances and the needs of their ill partners/parents to balance their need for care and their need for private space (Hopwood et al., 2006).

The role of spouses and children also becomes extremely important in the patients' early recovery after receiving a liver transplant. They bring the family together and provide stability that can balance the emotional chaos experienced by people following surgery (Forsberg, Backman, & Moller, 2000). According to the lived experience of liver transplant recipients, family members sharing and explaining medical information to them post-transplant is of particular importance.

Having explored the extant psychosocial literature on HCV, I will now turn to the theoretical perspectives that underpin and inform the current study.

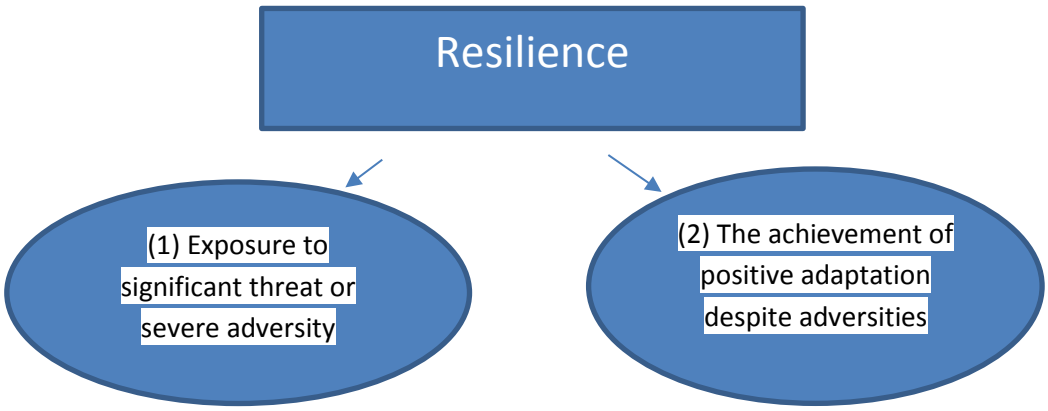
2.3 Theoretical perspectives on HCV in the current study.

Whilst existing literature on psychosocial consequences of HCV on patients' quality of life has been often focused on biographical disruption and stigma (Suarez, 2010; Harris, 2009), this is also an aim of the theoretical exploration in the current research. The theory of stigma and social identity that will be presented in this section resonates with the previously identified perspective of HCV patients and the researcher's interest in how participants' lives were affected by the diagnosis of HCV, the treatment and the recurrence of the virus. Furthermore, the secondary objective of this research is to explore the coping strategies that individuals with HCV use in order to deal with the biopsychosocial impact of HCV. According to the extant literature presented previously in this study, a coping strategy that was predominantly adopted by individuals with HCV when facing the adversity caused by illness appeared to be related to resilience. Therefore, another theoretical perspective chosen for the current study is resilience theory.

2.3.1 Resilience theory

Resilience refers to a phenomenon or a dynamic process involving adaptive coping and adjustment in the face of significant changes in life circumstances and the experience of adverse situations (Bonanno, 2004). An emerging body of evidence shows that even when confronted with highly disruptive and traumatising life events, people are able to use both their internal and external resources as protective factors in order to cope with adversity successfully (Rutter, 1990). The concept of resilience consists of two critical conditions:

Fig.1. The two-component construct of resilience (Luthar, Cicchetti, & Becker, 2000).



Thus, resilience can be perceived as a form of effective and successful coping and adaptation applied appropriately with regard to adversity (Zautra, Davis, Reich, & Nicassario, 2008). Resilient coping requires applying various supportive strategies and mechanisms that can be identified within individuals and communities. In this sense, people who more likely use resilience in response to exposure to a potentially traumatic event, have multiple social (e.g., supportive relationships, community resources) and personal (e.g., temperament) resources that help them to cope with stress and achieve positive outcomes (Hobfoll, 2002).

The adaptive and supportive factors can also include individual differences or life experiences that help people to deal with stress in the future, and which constitute protection from the development of mental health problems under stress-evoking circumstances (Richardson, 2002). Self-efficacy is essential for resilience (Rutter, 1987). A resilient person is optimistic and hopeful about the outcome of even the most difficult situations, such as chronic physical illness (Peterson, 2000). Resilient people have also good social competence and communication skills. Therefore, when they are challenged by adverse events, they also have access to more social support, an important aspect of resilience, even though they are still capable of managing life challenges on their own.

Resilience might also influence an individual's appraisal of a situation as stressful or harmless and impact his or hers coping response to it (Skodol, 2010). Resilient individuals that score high on optimism and self-esteem have been found to be more likely to engage with a problem and be action orientated in their coping strategies (Holahan & Moos, 1991). This approach results from their belief that they are capable to change the outcomes of an adverse life event for the better (Taylor, Kemeny, Aspinwall, & Schneider, 1992).

Living with a chronic illness such as HCV means resilient coping with an accumulation of stressors that can ultimately give rise to depression and anxiety (Alonzo, 2000; Chalfant, Bryant, & Fulcher, 2004). Diagnosis of HCV is generally the point at which the cascade of stressors associated with chronic illness begins to build. Receiving a diagnosis of HCV is likely to be one of the most stressful life adversities an individual experiences. However, the diagnosis does not inevitably lead to adverse mental outcomes if an affected individual demonstrates a resilient pattern with little perturbation in levels of psychological and physical well-being (Fife, 2005; Valle & Levy, 2008). Maintaining prosocial contact, having a caring family, spirituality, self-confidence and optimism can enhance individuals' resilient responses to diagnosis and their ability to cope with an ongoing adversity (Bonanno, 2004; Tedeschi & Kilmer, 2005).

The two-component construct of resilience (Luthar, Cicchetti, & Becker, 2000) can be used not only to illustrate positive responses to diagnosis of HCV but also to explain adaptive outcomes in a therapeutic context. There are several indications for the construct of resilience being relevant to the experience of receiving HCV treatment. To begin with, this regimen is long, either 24 or 48 weeks depending on factors like viral genotype. Second, the treatment drugs

interferon and ribavirin are associated with severe and sustained physical and psychiatric side-effects (Hopwood & Treloar, 2005). Finally, individuals with HCV who had undergone liver transplantation and had been diagnosed with HCV recurrence are now exposed to new challenges and burdens related to their chronic condition. Drawing on pre-transplant experience of living with HCV, they might or might not employ the factors and processes that facilitated coping during the initial treatment. Therefore, this thesis aims to explore the socio-contextual factors that enhance participants' ability to adapt to both pre-transplant and post-transplant circumstances and maintain stable level of physical and psychological well-being.

2.3.2 Social identity and stigma

Chronic illness can cause major disruption to core components of identity, such as social roles and relationships. It has the potential to reconfigure one's very social identity and cause a disruption of the expected and the 'usual' that establish people's daily routine (e.g. physical activities, work) and the self-concept (Mattingly & Garro, 2000). Anything can alter one of these, and then this alteration might very likely lead to creating a stigma (Markowitz, 1998).

The concept of stigma is a significant factor in many chronic illnesses and disabilities. When people do not meet social expectations because of features that are atypical or unwelcome, they are depreciated from being just members of society to being ostracized. Stigmatised individuals respond to societal exclusion and devaluation in a variety of ways. They often act as if the illness or disability has not affected them and can even pretend they have no impairment or less of a stigmatized identity (Joachim & Acorn, 2000). This form of reaction, however, is only possible when stigmatizing attribute is not visible.

Psychologists and sociologists have distinguished two concepts of stigma, namely felt stigma and enacted stigma (Scambler, 2004). The former refers to the way how the person who is affected perceives and internalizes the devaluating circumstances. One of the components of felt stigma is the fear of being labelled by others, even though the reason for stigmatization is not particularly evident or even visible to others. Enacted stigma, on the other hand, is related to specific responses from others towards the stigmatized individual. This type of stigma is usually associated with visible manifestations of individual's differentness.

The cultural invisibility of HCV can suggest that stigma and the social identity of affected individuals may be different from those who have visible attributes that make their disability evident and easy to target. The felt stigma might also not be clearly established when infected individuals remain asymptomatic and are not even aware that their health and well-being are at risk of deterioration. Their stigmatized identity is then exclusively defined by diagnostic experience or their interaction with medical professionals and others (Brown, 1995).

As society expects from its members to classify individuals by commonly acceptable features, illness may contribute to creating a new social identity of incapability (Goffman, 1963). In this sense, individuals who have an attribute categorized as socially unwanted (e.g., chronic illness) develop 'a spoiled identity' that leads, in turn, to intolerance and aversion. However, the extent of discrimination and the content of stigma may vary depending on how the same illness is perceived within different societies and cultures. Thus, as HCV infection occurs mainly, in developed countries, in people who inject drugs, a strong association between injection and infection can be found in the ubiquitous, stigmatising responses towards individuals with HCV (Harris, 2005).

Stigmatized individuals can also respond to stigma with resistance and rejection (Dudley, 1983). These strategies promote changes in an existing societal order and have the power to preserve positive self-identity (Stuenkel, & Wong, 2009). Finally, isolation can also be a common reaction to stigma. Individuals might limit their social circles to small numbers of people who enhance their feelings of normality and who are often afflicted in the same way (Camp, Finlay, & Lyons, 2002). These two forms of reactions to stigma can potentially be related to HCV individuals. Participants who contracted HCV through blood transfusion and who could, therefore, perceive themselves as innocent 'victims' of the socio-political system might adopt a pro-active approach to stigmatisation by, for example, speaking out against existing regulations (The Penrose Inquiry preliminary Report, 2010). Conversely, they might isolate themselves out of fear of infecting others and fear of disclosure (Lowe & Cotton, 1999).

2.4 Research objectives

This study aims to make a substantial contribution to previous research on liver transplant as a result of HCV by addressing the psychosocial consequences of HCV recurrence post-transplantation and the consequences of a new HCV treatment. It will focus chronologically on the lived experience of HCV beginning at the point of diagnosis and continue through receiving a transplant, post-transplant treatment and being offered a new cure. The psychosocial challenges accompanying this long journey of living with HCV will also be explored from the patients' perspective. This particular population was chosen for the current project as it was found to be under-researched in terms of patients' perspectives on living with virus recurrence and their coping strategies. Thus, the current study

is the first of its kind to explore HCV patients' responses towards post-transplant virus recurrence and aims to identify the factors described by the participants themselves that may influence their psychological wellbeing after having had a liver transplant and experiencing recurrence of the virus.

2.5 Aims and research questions

Much of the research to date on the outcomes of liver transplantation in patients with hepatitis C virus has approached the problem from either the perspective of the medical provider or the healthcare system (e.g. Satapathy, 2011). The current study aims to gain an in-depth understanding of experiences of HCV for patients diagnosed with infection recurrence after liver transplantation, using an Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2004; Smith, Flowers & Larkin, 2009). The primary research question is therefore:

To explore the psychosocial experience of living with recurrent HCV following a liver transplant.

In addition, there are a number of secondary research questions:

1) How do the participants' attitudes and life expectations change (if at all) after an initial diagnosis of HCV, and after being diagnosed with virus recurrence?

2) What does it mean to live with recurrent HCV?

3) In what ways is the quality of life of participants affected by liver transplant and virus recurrence?

4) How do the participants cope with their chronic condition?

5) In what ways did the new HCV cure change participants' expectations and attitudes to life?

In summary, this chapter has reviewed the extant literature in relation to the biopsychosocial impact of living with HCV, considering both the diagnosis and treatment of HCV. Studies that have been discussed in this chapter indicated that patients with HCV had a poorer generic and disease specific HRQOL than the healthy control groups and other clinical populations. Further, their self-reported impairments of quality of life have been shown not to be related to the degree or severity of the liver disease, but to other effects, such as the impact of diagnosis, stigmatization of HCV, treatment and its side effects. This chapter has also explored resilient coping employed by the HCV population to deal with the side effects of pre-transplant antiviral therapy, as well as with post-transplant health challenges. Patients with HCV were found to establish healthy lifestyle, engage in spiritual practices, seek social support and stayed occupationally active in order to reduce adverse experiences of diagnosis and treatment.

This chapter has also introduced two theoretical perspectives on resilience and stigma in order to provide an insightful framework for understanding participants' accounts in the current study. The concept of stigma was approached as a major disruptive factor in a chronic illness, such as HCV, that could lead to social isolation and rejection of affected individuals. It was also recognized that stigmatized people could respond actively to stigma with resistance. Therefore, resilience as a dynamic process involving adaptive coping and adjustment in the face of adverse situations was discussed in the context of HCV. The chapter closes with an overview of the current study's aims and objectives. Chapter 3 will now detail the research methodology applied for this investigation.

Chapter Three: Methodology

3.1. Introduction

This chapter aims to provide an overview of qualitative methodology as well as those approaches which were considered as potential approaches to data analysis in the current study. First, however, a rationale for the chosen approach (IPA) will be provided and discussed in terms of fit with the aims and objectives of the study. The process of recruitment, data collection and data analysis will follow along with ethical considerations.

3.2 Overview of Qualitative Research

Qualitative research has established itself in many social sciences, for instance psychology and nursing. There is a great variety of qualitative methodological approaches that can be used by both novices and experienced researchers and that can reflect different premises and aims of particular research. These different methods might be described as interpretative positions represented by qualitative researchers in order to engage in specific socially organized settings that they explore, describe and analyse (Miller & Dingwall, 1997).

Unlike quantitative researchers who aim to produce a set of theoretically defined generalisations derived from the critical shifting of data, qualitative researchers are not interested in identifying objectives and facts in the world, but in peoples' perceptions and experiences of their 'subjective' realities. Further, qualitative researchers do not intend to recognize any cause-effect relationships between several aspects of participants' behaviour, because they are more concerned with how individuals make sense of their behaviour and how they manage relationships within it.

In this sense, qualitative interpretation of data is not focused on finding correlations between particular variables that can be measured and observed. Thus it is not something that positivists would describe as a subject worthy of scientific study. The qualitative approach rejects a realistic view on research that assumes there is a single reality that should be investigated by scientists (using as objective and unbiased methods as possible). The qualitative researcher aims to 'see through the eyes' of participants instead (Bryman, 1988), and favours a subjectivist aim to a positivist, fact-based objectivity of context-isolated social investigation. Qualitative data are not a set of facts but are an outcome of an interaction between the researcher and participant, influenced by the researcher's own interpretations of data and biases.

Although qualitative data is to some extent biased by the researcher's descriptions and analysis, it is- for the most part- situated in participants' own interpretations as the most central data. This process allows the author to validate in-depth material that is provided by those people being studied and not by the researcher's analysis only. Qualitative data that is determined by the participants' perspective reflects the complexity of a study's subject and can be used to confirm or disconfirm existing theories, or to develop new empirically grounded theories. Most qualitative research tends to discover new information and moves from single cases to a wider understanding of a specific phenomenon under study. However, qualitative research does not seek to make excessive generalisations about investigated situations or human thoughts and behaviours. Rather, it builds a frame of reference for future investigations and offers a conclusive interpretation of a subject in its everyday context.

3.3 Qualitative Research Approaches

3.3.1 Grounded theory

Grounded theory is one of the qualitative research methods that is used both within and outside of social sciences. Glaser and Strauss (1967) who proposed this method, argued that theories developed using their model could be applied in practice situations. In this sense, grounded theory is of particular value for social work and theory-based interventions that can be tested in practice settings. Thus, if a primary aim of this study was to recognize possible implications for intervention for patients with recurrent HCV and test those in practice, grounded theory would be considered as a potential methodology to apply. Nonetheless, this research aims to capture the meaning people ascribe to HCV, and not to immerse in data and deductively test it.

Grounded theory in its design is used to build a novel theory about unknown or little-known phenomenon (Willig, 2008). It was considered as not being suitable for this Master's degree project which requires a considerable review of previous research preceding collecting data. Moreover, a major objective of this project was to understand what patients' experiences of recurrent HCV after liver transplant and not to produce a theory based on the gathered data. Therefore, this approach was deemed unsuitable both in terms of interpretation and explanation. In addition, the method of data gathering in grounded theory does not require the use of pre-structured interview schedules or does not recommend any specific preparations for data collection. Accordingly, the researcher is encouraged to proceed freely with interviews that should result in genuine interactive data (Glaser, 1992). This approach would perhaps be appropriate for an experienced qualitative researcher, however for me as a novice, a pre-formulated interview schedule was necessary to facilitate a comfortable

interaction with participants. In addition, using semi-structured interviews for the purpose of this research giving the patients an opportunity to direct the content and for the researcher to capture an inductive, idiographic perspective of the interviewees.

Grounded theory can also overwhelm with methods being used for data gathering that may include observation, interviews or diaries. This kind of variety of methods produce a large amount of data that then need to be organized into categories and groupings of categories. Constant comparative analysis is used to undo emergent patterns and transform them into other networks of categories, until new data reaches its 'saturation' (Charmaz, 2006). In order to achieve a point of saturation, which is where no new categories emerge, grounded theory requires a large amount of data and considerable time spent on its analysis. Considering time constraints and the limited size of the Master thesis, I questioned whether it was feasible to define a complete, well-defined 'grounded' theory that would not reveal signs of premature theory generation.

3.3.2 Thematic analysis

Thematic analysis (TA) can be considered as the most accessible approach for a student who is new to qualitative analysis (Braun & Clarke, 2006). It contains core elements of the data analysis procedure (i.e., familiarizing with the data, generating initial coding, searching for themes) that can be found in many other qualitative approaches (e.g., IPA, Grounded Theory) and, therefore, it may be ideal for students who then should not be obliged to give their analytical approach a label. However, despite the grounded stance of the TA's supporters (Braun & Clarke, 2006), who gave a full account of this approach and its application, for others (Dempster, 2011; McCorry, Demster, Clarke & Doyle, 2009) TA represents

a technique employed in the analysis of qualitative data rather than a methodological approach per se.

TA, unlike other qualitative research methods, is not allied to a specific epistemological position. This on one hand gives a researcher a form of analytical freedom, but on the other, it may be problematic for them to clearly explain that the method they used was thorough and rigorous. Consequently, thematic analyses can vary considerably, depending on which of the previous research and theory the recent findings are most likely to be related to. In summary, TA's lack of allegiance to the specific theoretical or ideological principles makes it difficult to progress from text analysis to meaningful results that can support researcher's theoretical predictions.

In this study, a more generic phenomenological approach was required to gather and make sense of data. It was my intention, as a researcher, to focus upon patients' experiences of a particular phenomenon that is clearly defined in the research question and grounded in an epistemological position. It was important for me to give to the reader an exact account of the method I used and the research aims I chose for my study. In this sense, TA, if understood as a specific approach that is free from theoretical and ideological background, seems to be insufficient to give a clear account of what a researcher hopes to achieve from the analytical procedure and how exactly they intend to accomplish their aims.

3.3.3 Phenomenology

Phenomenology, as a philosophical approach posits that there is a reality that can be studied, but it also states that this reality is perceived by individuals in different ways and it is these perceptions which are the focus of phenomenology.

In other words, a phenomenological stance views a person's own perception of the world as primary and every attempt to report on the individuals' experiences will result in distortion of their stories by the phenomenology of the person reporting.

Phenomenology by allowing this hermeneutic distortion formalizes the possibility of doing qualitative research, where subjectivity of the researcher's interpretation of the participant's words is approved. It rests on the premise that human experience is situational, contextual and the way people look at it depends on their particular point of view on the world. However, the authentication and enhancement of the original meaning contained in people's experience can be preserved if we, as researchers, lay aside the predominant understandings of the explored phenomena and reconsider our immediate experience of them (Crotty, 1996).

Human experience is never to be perceived in isolation, but is always based on intentionality: that is people's thoughts, actions, expectations, or feelings are always related to particular objects. Intentionality bespeaks the relationship between human beings and their world. Therefore, people cannot be described apart from their world, as their world cannot be described apart from them. In this sense, phenomenology invites us to make sense of the world that was described by us or to us, immediately and directly. The understandings that we have already ascribed to the given phenomena should then 'bracket' to the best of our ability in order to let the experience of phenomena speak to us as first (Crotty, 1996).

According to Husserl ([1936]1970, p. 258), 'bracketing off' personal bias and assumptions from interfering with the lived experience, was possible. Further, he argued that it was possible to transcend our subjectivity and reveal the world as it really is. It didn't mean pretending not to have these assumptions, but rather to

be aware of these assumptions and reflect on the extent to which they interfere with the analysis of the phenomenon. Conversely, Heidegger (1967) and Ricoeur (1981) argued that even when attempting to bracket our preconceptions, there is always an ideological position we represent while discussing the meaning of an experience, even if we are unaware of it.

Following Heidegger (1967) and Gadamer (1976) who questioned the possibility of setting aside all preconceptions and biases in one's contemplation of a phenomenon, I decided that 'bracketing' in this study would not be desirable. I believe that it is not possible to stand outside of lived experience to see things as they really are, by denying my own subjective position. Further, in accordance with a hermeneutic version of phenomenology, the interpretation and analysis that I brought to the original text, were also acknowledged as an integral part of phenomenological analysis. In this sense, I went beyond the strictly descriptive approach to phenomenological research that requires the researcher to adopt a specific attitude in which past knowledge and expertise can be bracketed off and the scientific attention can be re-focused on interpretation that lies in "phenomenological purity" (Husserl, 1931, p. 262).

3.4 Interpretative Phenomenological Analysis

In the present study, the use of interpretative phenomenological analysis (IPA) was chosen. The main focus of this method is to examine participants' subjective perception of their lived experiences and not to endeavour to create an objective description of the world (Smith, et al., 2009). Accordingly, the essence of phenomenological philosophy is the individual's experiences that comprise the world and its underlying empirical meanings (Colaizzi, 1978).

Access to these experiences depends on what participants tell the researcher about them. IPA emphasizes that the researcher needs to interpret given phenomena based on participant's account of them in order to understand their experience. The researcher's sense-making of what is happening to the participant is second order, it is participant's understanding and interpretation of their own account regarding the given phenomenon which are of primary importance. Thus, a two-stage interpretation process, or double hermeneutics, is involved in the IPA approach (Smith, 2008).

3.4.1 History of IPA

IPA has a relatively short history. As a new qualitative methodology, it was first introduced by Jonathan Smith (1996) who made a claim for an approach that could be both experiential and qualitative, and that would be a strictly psychology-centred methodology. At first, IPA was predominantly applied in health psychology research due to its early concerns with health and illness, but its application soon expanded to different disciplines of psychology that demonstrated its importance.

One of the major foundations of IPA is the philosophical approach of phenomenology, the study of experience. Edmund Husserl (1900/2001),a phenomenological theorist, argued that in order to be able to explore essential qualities of human experience, the focus should be redirected from an individual's perception of objects (as part of the outside world) to their personal reflection of those objects. Thus, Husserl's philosophical approach equipped IPA researchers to focus on the process of reflection and its meaning in identifying the real nature of experience. The founder of phenomenological philosophy recognized the aim of the phenomenological approach as a "return to the things themselves" (*Sachen*

selbst, Husserl, 1900/2001, p. 36) and claimed to set aside all that belongs to the world of prejudice and preconceptions, and what is alien to the given phenomena.

The process of going “back to the ‘things themselves’” (Husserl, 1900/2001, p.168), meaning making, gaining understanding of our experience of the given phenomenon enable us three phases of contemplation: epoché, phenomenological reduction, and imaginative variation. Epoché requires ‘bracketing off’ of pre-existing judgments and assumptions in order to be fully aware of the subject of our consideration. Phenomenological reduction continues the process initiated with the epoché. Thus, once we start to see things as they really are, beyond our preconceptions, we have to describe what we see, according to our perception and consciousness. The reduction aims to identify what makes the experience what it is, in other words, what elements or factors constitute the experiential entity. Imaginative variation, the last phase of phenomenological contemplation, attempts to answer the question: How the experience was possible to appear, thus what circumstances or dimensions should be considered as directly involved in shaping the phenomenon? At last, when both the phenomenological reduction and imaginative variation are integrated, we then obtain a complete description of the experience, the *essence* of the phenomenon.

The other major theoretical foundation of IPA is hermeneutics,the theory of interpretation.According to Heidegger’s (1927/1962) early work, people live in an interpreted world and in consequence they are themselves hermeneutic, interpreters. He also identified an obstacle to interpretation in the form of preconceptions or assumptions people bring with them to the process. However, Heidegger also defined how they can avoid the situation when their own fore-conceptions blur the interpretation of the world. The way in which people prioritize

phenomena in their interpretations may have an impact on whether or not they will allow preconceptions to affect their perception of those phenomena. In other words, if preconception dominates one's understanding of the world, then any encounter with a new concept must be subordinate to previous assumptions. The importance of the phenomena can, however, be also shifted from prior experience towards new things, and in that case, preconceptions are drawn from the new concepts. Concluding, the hermeneutic approach provides the qualitative research with an important perspective on the process of interpreting participant's views of the world and on perceptual obstacles that are inevitable in interpretative sense-making.

3.4.2 Ontology and epistemology

Epistemology is one of the philosophical stances that lies behind my chosen methodology. Maynard (1994, p.10) emphasized the importance of choosing an epistemological stance, in other words philosophical grounding, that will justify what knowledge is possible and if it is "adequate and legitimate". Hence I needed to identify and justify the epistemological stance that would be adopted in the current research and which reflected my research approach. In IPA, the researcher's epistemological stance can be largely determined by a person's need to explore and make sense of observations made in the 'health-illness' world. A researcher in response to this need can generate knowledge that can be either a reflection of his epistemological stance, the interviewee's epistemological stance or something in between the two. It seems to be impossible to separate those parallel perspectives that complement each other.

This shared reality is understood in terms of definitions, images and stereotypes (Rothe, 2007). We can play a role in the reality that will reflect our preconceptions

about it or discover and ask questions about the nature and sense of the reality. By asking questions, a researcher can identify multiple dynamic realities that may remain beyond our interpretations of them (Searle, 1995). We can formulate these interpretations in a number of contexts, but there will be never just one that can be generalized to all possible settings.

3.4.3 Validity in IPA

As quantitative research is evaluated according to the specific criteria for validity and reliability, the same procedure might be expected to be followed by researchers conducting qualitative research, respectively. Yardley (2000), writing in the context of health psychology, has produced guidelines for examining the validity of qualitative research, which were derived from different methodologies. She emphasizes four broad topics likely to be addressed by any research approach, although the ways in which these principles are applied differ widely between the various quantitative and qualitative methods. I will describe the principles in reference to IPA, as a method of choice in the current study, as well as general procedural assumptions that can be applied to other qualitative research approaches.

The first principle indicated by Yardley is sensitivity to context. The qualitative researcher can demonstrate this form of sensitivity in a variety of different ways, that is, by acknowledging the theoretical context, relevant literature background or socio-cultural factors that are relevant to the topic being studied. Research that ignores the importance of all these factors and processes influencing the object under investigation posits itself at risk of replicating what is already known (Marks & Yardley, 2004). In reference to IPA, sensitivity to context can be shown through demonstrating and taking into account the existing theoretical and empirical

literature that has been already established in the subject under investigation, as well as in terms of the methodology chosen for the research.

Marks and Yardley (2004) claim also that the quality of research is related to the rigour and commitment with which the research process is carried out. This principle can be again demonstrated in the various ways and at different stages of the investigation. Thus, in order to conduct a high quality IPA study, I initially recruited an appropriate sample that allowed me to provide a rich and in-depth data, supporting the study's topic. My commitment was also demonstrated by my personal engagement in the process of data collection, that is, when and where the interviews took place. Rigour and commitment was also demonstrated in my attentive listening to what participants had to say, and careful reflections on the participants' statements, by consistent probing and responding to relevant cues in the stories.

The third of Yardley's (2000) principles, transparency and coherence, can be directly related to the IPA paradigm and the means to apply it systematically and consistently. In accordance with IPA requirements (Smith et al., 2012), I was focused on idiographic engagement in data analysis, illustrating particularities of individual cases by using appropriate quotes, but I did also emphasize the importance of shared experiences in formulating the major themes. I used participants' extracts to support the emergent themes and my interpretation of them. Finally, it was essential for this study to communicate clearly to the reader how coherence between research aims dictated by IPA and the procedures that were used to guarantee validity of the findings, was established.

The last broad principle defined by Yardley (2000) refers to impact and importance of the research. In other words, the real validity of the conducted piece of research depends on its ultimate value for the public or the discipline that

it represents. Thus, in case of the current study, it is assumed that the findings will have a practical value for post-transplant patients with recurrent HCV, whose personal perspective on living with HCV and on professional health care was demonstrated in the form of direct quotes and in the author's analysis. This research aims to provide both the public and health professional with information about challenges that are a part of patients' everyday reality, and their needs and future expectations.

3.4.4 Rationale for Interpretative Phenomenological Analysis (IPA)

IPA that was chosen for this research foregrounds the experience of the individual, and hence provides a 'voice' for the lived experiences of a given clinical population, which is not adequately represented or evaluated by quantitative methods which target large samples.

An aim of this study was to understand how individuals with HCV interpret their experience of being diagnosed with the virus, of receiving treatment, undergoing a liver transplant and finally being diagnosed with HCV recurrence. I was interested in how participants construct their worlds, their coping system, and what meanings they attribute to their experiences. I chose IPA over any other qualitative approaches as it was concerned with the interpretation of meaning and the detailed exploration of lived experiences that were reflecting my exploratory orientation.

3.4.5 Data Collection

IPA requires rich, detailed data that could help the researcher to explore the participant's understanding and interpretation of the phenomenon under investigation. Therefore, the most suitable instrument for data collection in this

approach should be flexible in its structure. Thus, the semi-structured interview became the most popular form of exploring the participant's personal experiences of a given phenomenon. An interview schedule in this type of interviewing is formulated before the actual data collection begins and constitutes a guideline to a dialogue between participant and interviewer rather than a rigid structure that has to be consistently followed. In this method, the interviewee is given an opportunity to discuss in-depth his views, thoughts and feelings.

The researcher as an active listener should give the participant space to think and reflect fully on concerns that emerge during the interview. Questions that are asked by the interviewer should be open-ended in order to invite the individuals to provide deeper and richer disclosure. During the course of the interview, the researcher does not have to follow the order of questions included in the schedule or ask the questions each time in exactly the same manner. The way the questions are phrased or re-phrased may depend on the content of the participant's previous answers or on the way he or she responds to the questions in general. The flexible structure of the semi-structured interviewing allows also the interviewer to explore the arising important concerns in more detail by using probing. In this sense, the participant is naturally encouraged to reflect at length on issues that were mentioned by him only briefly or that were simply overgeneralised. It is essential here to be attentive to certain points in the participant's stories that can help the researcher to identify some causal links between phenomena and actions. In respect to the inductive principles of phenomenological approach, the interviewer should acknowledge that the flow and style of interviewing are means to build explanations based upon the participant's perception of the world (Katz, 2001).

3.4.6 Sampling

The logic of sampling size in qualitative research is different from the logic of the sample size used and recommended for the quantitative data collection, the same way they vary regarding the way of selecting the sample. In quantitative investigation the aim is to present probable generalization of the phenomenon. In this sense, the quantitative study needs a significant number of participants in order to build a valid argument that can be generalized from the small to a larger population, whereas qualitative research focuses on the richness of individual cases, and whether or not the information given reflects the experiences of the individual participants.

As qualitative approaches follow purposeful strategies rather than statistical formulas, this purposiveness is clearly applied in the matter of sample size. Smith et al. (2009) suggested that for a Masters research a sample of between three and six participants can be considered as reasonable. In this way, data collected and analysed would not become problematic in terms of amount of information generated. Moreover, a small sample size is typical and recommended for IPA (Smith et al., 2009) as larger samples can result in a loss of subtle inflection of meaning and subtle interaction processes in particular contexts.

3.4.7 Procedure of Analysis

IPA approach employs an in-depth qualitative analysis. Unlike quantitative and experimental methodologies, this method focuses on making sense of a given phenomenon rather than on the quantified evaluation of people's views of the phenomenon. IPA investigates an individual's personal experience while allowing both the participant and the researcher to be involved in the interpretation. When interpreting the given phenomenon, the participant can reflect freely on his or her

experiences and identify the meanings attached to them. The researcher, on the other hand, needs to be aware of his or her own preconceptions and prejudices that can interfere with sense-making from the perspective of the participants. Two aspects of the interpretation process need to be acknowledged when analysing qualitative data, namely empathic hermeneutics and understanding as an attempt to make sense of someone else's experience (Smith, 2008).

To embrace the complexity of interpretation, Smith et al. (2009) distinguished six basic stages of the process (reading and re-reading, initial noting, formulating subthemes, looking for associated emergent themes, interpreting the next interview, identifying patterns across cases) that facilitate the development of analysis and help the researcher to realize the underlying significance of those steps. Each of these steps will be discussed later in the chapter with examples of each step highlighted and supported by data.

3.5 Design and methods in the current study

3.5.1 Sample

In accordance with the qualitative paradigm, the sample in this study was chosen purposively. On my behalf, a transplant research nurse carefully selected a sample that met my inclusion criteria and constituted 'information-rich cases' (Patton, 1990, p.169) in order to explore the experiences of patients with HCV recurrence after liver transplantation. It was not my intention to generalise the findings to the entire population of HCV post-liver transplant individuals, but to understand the perspective of a small number of patients whose stories could be representative of the research question under investigation in depth. Moreover, a homogenous sample was selected for this study in order to present an in-depth interpretation of the given phenomenon in a small subgroup of post-transplant

patients with recurrent HCV. The homogeneity of the sampling in this study was dictated by practical issues such as selecting patients: 1) whose attendance at the clinics was relatively frequent; 2) while considering their safety and risk at any stage of the investigation; 3) whose challenging behaviour could have been ~~of~~ a risk to myself as a researcher; and 4) the possibility of contacting them within the time specified for the study. This study is also homogenous in terms of the gender of the research participants. Lack of a response to the study from female patients resulted in a male patients' only focus ~~on~~ regarding the research question, which can be presumed to have reduced the variation in patients' perspectives and to have simplified the analysis of the studied phenomenon.

When deciding ~~about~~ on the selection of post-transplant patients, I had to consider a number of aspects associated with both their mental and physical health that could impact on their ability to discuss the phenomenon being studied. As they are extremely physically and psychologically vulnerable shortly after liver transplantation (for example, participants might experience pain, exhaustion and depressive thoughts), I decided to interview patients at least six months after they had undergone surgery. The six months period post-transplant was considered sufficient time to have recovered with regard to every aspect of their functioning and for having overcome possible complications. The inclusion criterion of a time interval of between six and 18 months was dictated by an approximate period during which over 50% of patients were typically diagnosed with virus recurrence (Teixeira, Pastacaldi, Davis, Dhillon, et al., 2000; Toso, Cader, Mentha-Dugerdil, Meeberg, et al., 2013).

Furthermore, with regard to the inclusion criteria, all the participants in this study were over 18 years of age and were fluent in English. This was to ensure that participants were able to give written consent prior to the interviews. As advised

by the Head Hepatologist, potential participants invited to take part in this study were those who had been seen routinely at the Royal Infirmary of Edinburgh and who were not currently receiving methadone treatment. In terms of exclusion criteria, patients who had received more than one liver transplant or who had been diagnosed with other serious liver-related health conditions were not invited to part take in the study. As the aim of the study was to recruit as homogenous a sample as possible, including patients with comorbid conditions or those who had received multiple transplants could have biased the data. Further exclusion criteria included imprisonment (to protect researcher's safety), those considered by the Head Hepatologist to be too emotionally frail to partake and those possessing a current psychosis or mental health condition (all the patients who had received liver transplants had undergone a full psychiatric assessment at the unit). Adhering to these inclusion/exclusion criteria resulted in twenty-eight patients meeting the criteria for possible inclusion this study.

3.5.1.1 Participants

Seven patients took part in this study. Participants were all male with an age range from 53-68 years (M=57.3). The response rate to this study was 25%. Reasons for the small sample size obtained for this study can be related to both the time constraint on the study and the size of the population under investigation that was available during the recruitment period. 75% of potential participants did not respond to the invitation letter sent to them by transplant co-ordinators. Small sample sizes are, however, exemplary for IPA. The table below provides further information on the participants.

Table 1. Demographic data.

Pseudonym	Gender	Age	Time since transplant
Gus	Male	68	12 months
Harry	Male	56	10 months
Jimmy	Male	54	9 months
Eric	Male	53	11 months
Ted	Male	54	12 months
Steve	Male	63	23 months
Chris	Male	53	20 months

3.5.2 Recruitment Procedure

The seven patients with recurrent HCV who decided to participate in this study were recruited through the Out-Patients Department (OPD4) for Gastro-Intestinal and Liver Disorders at the Royal Infirmary of Edinburgh (RIE). In order to protect patient confidentiality and anonymity, the transplant research nurse at the RIE identified suitable patients based on the inclusion and exclusion criteria with which she was provided and distributed recruitment packs to potential participants on my behalf. The recruitment packs were either sent to patients via post (n=18) or distributed to them by the transplant co-ordinators during their routine appointments at the Out-Patients Clinics (n=10). Patients to whom the transplant research nurse sent the invitation packs via mail were expected to appear at the clinics in at least four months from the start of the recruitment process. In summary, four of the participants were invited via face-to-face recruitment and three participants responded to the Invitation Letter (see Appendix 4) sent to them via mail. The method of approaching the potential participants depended on the dates of their next appointments at the Out-Patient Clinics. Thus, patients who had visits scheduled within the next two-three months were introduced to the aim of the study personally by the co-ordinators and received their invitation letter during their appointments.

The Letter of Invitation and the Participant Information Sheet (see Appendix 5) included in the recruitment pack explained the nature of the project in detail and what was involved in participation. My contact details (e-mail) were also provided in the letter so that interested patients could express their willingness to take part or find out more about the study. Participants could also contact me via a reply-slip sent to Edinburgh Napier University, care of the Director of Studies. The RIE ~~did~~ also included a letter saying that they supported the research (see Appendix 3). Participants did opt in by returning a reply slip, which was attached to their letters in a pre-paid envelop, to me via the Director of Studies at Edinburgh Napier University. Once the potential participant had expressed an interest in participating in the study, I provided further information about the study, explained what involvement would entail and provided an opportunity to ask questions. I then advised the potential participant to take a further 24 hours to consider whether he would like to take part. After 24 hours, I then contacted the participant to determine if he was still willing to partake. I then contacted the participants' General Practitioners via post (see Appendix 2) in order to seek confirmation that their patients could participate in my study considering their current psychological and physical health. Once I had received a response from the GPs, I contacted potential participants to arrange a date for the interview to take place at the Scottish Transplant Unit at the Royal Infirmary of Edinburgh.

3.5.3 Interview design and procedure

The theoretical approach of IPA favours the use of a semi-structured interview procedure as outlined by Smith (1995). An interview schedule (Appendix 8) was prepared prior to the interviews and outlined the areas of interest to be discussed. This included asking HCV patients about the following:

1) Their personal experiences of HCV;
2) The impact of having had a transplant on quality of life and self-perceptions;
3) Expectations pre-surgery and how they changed after the transplant;
4) The experience of HCV recurrence post-transplant, and
5) The impact of re-diagnosis on their attitudes.

However, my aim was not to follow this interview schedule in any strict or rigid way. Instead, a process of reflecting (e.g., “you said there that…”) and probing (“tell me more about that”) was adopted. This allowed the participant to direct the content of the interview and prioritise issues that he felt were central to the topic under investigation.

Interviews were carried out at the Welcome Clinical Research Facility (WCRF) at the RIE where I booked private, confidential rooms in an environment with which the patients were comfortable and familiar. It was my initial intention to arrange the interviews for Tuesdays or Thursdays when the patients were attending follow-up clinics in order to save the participants’ time and travel expenses. However, most of the patients who expressed a willingness to participate were not scheduled for their visits within a couple of months from the ~~point~~ time of receiving the letters. Therefore, the interviews were scheduled on the days and times that were most convenient for them, outside of their clinic appointments. Five of the seven participants were interviewed at the WCRF at the RIE, while one participant was interviewed at another hospital facility and the other in his own household; both venues were outside of Edinburgh. With regard to the two interviews that were not carried out at the WCRF, and in adherence to the agreed lone working arrangements, I informed one of the supervisors about the visits in advance, including their location and nature, and when I expected to

arrive and leave. Afterwards, I telephoned the supervisor to report that I had arrived back safely.

Each interview was expected to last approximately one to two hours. The seven interviews that I conducted for the purpose of this study lasted between 32 and 68 minutes. Participants were once again given/had the Participant Information Sheet read to them by the researcher prior to the Participant Consent Form (see Appendix 6) being signed. An opportunity to ask questions was again provided at this point. I then asked all the potential participants three screening questions. These questions were:

1) Have you had any thoughts about harming yourself in anyway during the last 2 weeks?

2) If yes, have you had any thoughts about how you would harm yourself?

3) Have you ever tried to harm yourself in the past?

If the participant answered "Yes" to Questions 1 and 2, he would be considered "high risk" and would be excluded from the project at this stage. I would then have contacted an experienced member (a named individual) of the liver transplant team (the transplant coordinator) to deal with the situation. This individual would have been called to stay with the participant while the NHS protocol for suicidal patients was implemented. Participants would be made aware of this prior to contacting anyone.

If there was no indication of risk to a participant's well-being and all the screening questions were answered "No", I then proceeded with the first question on the interview schedule. Participants were given time to answer questions without being prompted by me or being introduced to my perspective concerning the given phenomena. The answers to the first few questions in the interview

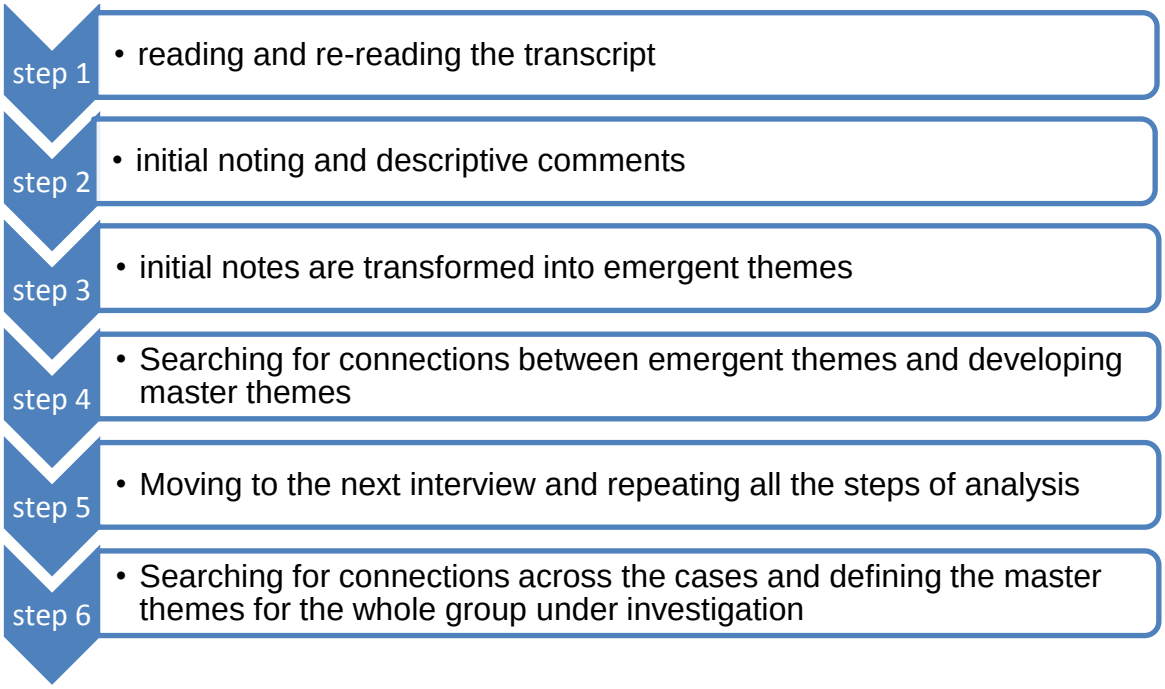
provided me with information-rich accounts that often covered more matters that were included on the schedule. Therefore, I used the interview schedule flexibly and as a guide rather than a pre-defined and required construct.

After completing the interview procedure, each of the participants received a Debrief Sheet (see Appendix 7) including contact details ~~of~~ for myself (e-mail), the Director of this Study, the Independent Advisor, the Clinical Consultant and a list of support organisations that participants could contact in the event of further questions or other issues related to the current study.

3.5.4 Analysis

In this study interviews of seven participants were analysed case by case. Each transcript of the interview was examined and described in detail following the idiographic approach to analysis (see Fig.2). In this sense, my analyses unfolded unique recollections of each participant constituting a particular example of phenomenon under investigation.

Fig. 2. Steps of an IPA analysis.



According to IPA guidelines, in the first step, I familiarized and actively engaged with the original transcript, while reading and re-reading the data. This phase allowed me to develop chronological accounts into a consistent and easy-to-follow structure of an interview. I was also coming back to listening to the audio-recordings whilst studying the transcripts. I could then recall vividly the dynamic of the interview and make some initial notes based on how the stories were told to me in person. This first stage of analysis gave me an opportunity to notice sensations and thoughts that were evoked while reading and listening to the participants' accounts simultaneously. These first impressions were captured in the initial notes and facilitated my engagement with the text. Repeated reading allowed me then to recognize how a number of relatively generic and loose patterns of explanations can lead to more in-depth and chronological descriptions of specific events.

Then, I proceeded to make descriptive and comprehensive notes that led to dividing transcript into 'meaning units' (Giorgi & Giorgi, 2003, p.23). My comments that were made to these distinguished units, with a constant phenomenological focus, reflected closely true meanings underlying participants' stories. Comments that were related to people, objects or events of great importance for the participant were indicated in the initial coding. Semantic content of these reflections and language use constituted important clues that helped me to understand reasons and consequences of the participant's thoughts, feelings and concerns. The second stage involved developing exploratory comments based on semantic content and language used in the transcript (Table 2, see below). Analysing line by line, I was focused on identifying relationships, processes and events that were of great significance for participants and that mattered for understanding their lived experience of HCV. This initial step of analysis helped

me to grow further the familiarity with participants' accounts and recognize specific patterns of meaning in their narratives.

The third stage in my analysis comprised identifying emergent themes from the transcript and initial notes. In the search for themes I attempted to condense the content of transcript and produce more concise statements from previous notes. These statements had a form of phrases that posed conceptual generalisations and psychological meaning of the most crucial points in the text (Table 2). Meaning units identified in the second stage of initial noting now underwent linguistic transformations that moved the analysis towards psychological interpretation and understanding. At that stage, the emerged themes started to capture and reflect the sense-making from both the participant's and my own perspective. Therefore, the themes are also meant, according to the hermeneutic circle, to be both interpretations of the researcher's text and a reflection of the transcript as a whole.

Table 2. Developing explanatory comments and emergent themes.

Emergent themes	**Original Transcript**	**Explanatory comments**
Uncertainty Fear of unknown	R: Gus, could you please tell me how you were diagnosed with Hepatitis C? What were you thoughts and feelings about the diagnosis? G: I was in, getting a blood sample taken and I think I was in Eastern General Hospital for something else and I don't even really know why they wanted the blood sample. It had nothing to do with what I was in for. Then, about maybe a week or two weeks later, I got a call and I think it was a letter, I can't remember. It's a long time ago, saying that are an abnormality in you liver, and could you come in on certain day. And of course the first thing you think of a liver oh my God, you know, because you can do without a kidney or this and that, you can eh...but liver, you	He found himself in a highly unclear medical situation. Obscure circumstances of medical testing. Not being told what they were investigating Recognition this is serious Fear of what symptoms may indicate

Worries Source of the infection Lack of knowledge	know, "what's the abnormality?".. I had to wait the eight days till I had the interview or the meeting, appointment to find out what it was and they came up and said this thing about Hep C which I'd never heard of before and had a chat with them and realize how I got Hep C which was from a transfusion 1986 and eh… here I was a bit concerned about it, you know, just because it was just suddenly out of the blue. And eh… another appointment was made for me, you know, going in to the hospital to sit down. I had a chat and I was told something like, "you maybe have got 15 years to live" (laughter). At that time I was, you know, they didn't really know a lot of this. So, it was a bit disconcerting… yes, when I did come here, oh my goodness, eh as anything good.	Serious concerns that accompanying the initial diagnosis received from the hospital Trying to identify the sources of infection Surprised by diagnosis and life expectancy approximation given to him in the hospital Initial perplexity after receiving the diagnosis

The fourth stage involved a more analytical ordering of themes. I aimed to establish a mapping of previously identified and chronologically ordered themes. I was here relatively selective in terms of themes I wanted to include into final set of super-ordinate themes and into the presentation of results. The decision whether to merge particular themes or exclude from further consideration depended to some extent on my research question, but it was also based on the re-evaluation the significance of comments from initial stages of analysis. Some of the emergent themes that were recognized in the previous stage clustered together, whereas some emerged as super-ordinate themes. Abstraction as a process of clustering was used for identifying patterns and connections between the emergent themes. The themes were usually grouped around chronologically occurring events in the patient's life. Thus, the diagnosis of HCV, liver transplantation, and virus recurrence constituted as a frame of reference for many emergent themes and did also help to define super-ordinate themes (see Fig. 3).

Fig.3. Abstraction leading to the development of a super-ordinate theme.

In the next, fifth step of the analysis involved moving to the next participant's account. The same four stages of the explanatory process that were applied in the previous case, were repeated in the subsequent analysis. This stage required treating the new transcript as a separate and unique entity and bracketing off the themes that emerged in the previous analysis. It was inevitable that some of the concepts that were recognized and articulated in the first case, influenced to some extent my search for patterns of meaning in the following accounts. However, a conscious recognition of similarities with the previous analysis did not prevent my search for new themes and meanings that emerged in the next participant's transcript.

The last stage of the analysis involved identifying patterns between all the cases under investigation. New chains of connections between people's idiosyncratic emotional states, ways of thinking and feeling were established in respect to the given phenomenon they reflected on. The final outcomes of the analysis organized around the super-ordinate themes based on all cases

provided me with a conclusive explanation of various aspects and quality of the individual's experience of diagnosis of HCV, liver transplant, virus recurrence and pre-and post-transplant treatment. I approached that stage of analysis by assessing the key super-ordinate themes for the whole group (see Table 3). Although, according to Smith et al. (2009), the procedure is mainly applied for larger samples, I chose it as it made the process more manageable for me as a novice. The themes were classified as recurrent when they were identified in at least three of the participant interviews. Counting like this indicated a high prevalence of particular themes across the group and it was also considered as a way to facilitate the validity of the results.

Table 3. A sample of recurrent themes.

Super-ordinate themes	**Eric**	**Steve**	**Gus**	**Ted**	**Jamie**	**Chris**	**Harry**	**Present in one third of the sample?**
Seeking information	YES	YES	YES	YES	YES	NO	YES	YES
Side effects	YES	YES	YES	YES	YES	NO	YES	YES
Stigma	YES	NO	YES	NO	YES	NO	YES	NO
Physical deterioration	NO	NO	YES	YES	NO	NO	NO	NO
Disclosure	NO	NO	YES	YES	YES	YES	NO	YES

The completed analyses of the seven interviews listed in this thesis provided information-rich account on the experience and attitudes of patients with HCV recurrence after liver transplantation.

3.6 Ethical Approval

This study was reviewed by two independent ethics committees. First, ethical approval was granted by the Faculty of Health, Life and Social Sciences

Research Ethics and Governance Approvals Group at Edinburgh Napier University in January 2014. I also sought ethical approval from the NHS Research Ethics Committee 3 (REC 3; Ref: 14/WS/0122; see Appendix 1), West of Scotland, in February 2014. A favourable ethical decision was received from the NHS Ethics Committee in June 2014 after attending two Committee meetings and addressing several issues that were raised by the members of each of the two committee. The major amendments that were carried out in respect of REC 3 guidelines were related to the inclusion and exclusion criteria, preventing screening for suicidal intention, formulating lone working protocol between supervisors and myself, and establishing a communication between participants' GPs and the researcher.

3.7 General ethical considerations

In the current study, the potentially sensitive nature of the interview questions could result in some individuals experiencing a degree of distress. In the unlikely event that participants could become upset/distressed as a consequence of the interview, they have been encouraged to discuss any upsetting issues with the resident Clinical Psychologist at the Royal Infirmary of Edinburgh or had to be immediately contacted with the transplant co-ordinator who was 'on-call' on the day of the interview taking place. Additionally, in order to address a possible occurrence of distress after the interview was completed, each participant was provided with a Debrief Sheet detailing the contact details of the Director of Studies and the Clinical Psychologist at the RIE whom they could contact. Participants were also advised that they could withdraw from the research at any time and that they did not have to answer any questions that they did not wish to.

Considering possible risks that could result from conducting this study, it was also acknowledged during the second sitting of REC3 that conducting interviews beyond the safe hospital setting, might involve risk to myself as a researcher. Although the Welcome Clinical Research Facility at the RIE was offered to potential participants as a familiar and convenient environment for the interview to take place, they might express an intention that their interview was carried out in a place of their choice. Therefore, lone working arrangements has been developed in order to protect the researcher from the risks of violence and aggression. According to the agreed operating procedures, I as the lone worker should have always ensured that someone else (e.g., my supervisors) were aware of my movements. I was obliged to tell my supervisors about any visit in advance, including its location and nature, and specify when I expected to arrive and leave. Afterwards, I let my supervisors know that I was safe.

A reasonable time was always set by my supervisors for contact. My supervisors were also updated by me if my arrival or visit was delayed or when I had to cancel an appointment. In the event of no contact from me, supervisors did in the first instance attempt to make contact directly, then to make contact to a participant whose contact details had been given to them in a sealed envelope by me. Should contact with myself and the participant still not have been established, the police would be informed followed by the university 'on call' supervisor.

3.8 Confidentiality and data handling

Participation in this study was confidential. However, confidentiality might have been limited if I deemed during conducting the interviews that there to be a risk to any of the participants. In relation to someone becoming distressed or making a statement which could give me a cause for concern to harm themselves or

others (i.e. suicidal tendencies), I, as a certified Mental Health First Aider would provide initial help and reassurance to the person. The participant would then be informed that I was obliged to contact an experienced member of staff within the liver transplant team (a transplant coordinator) in order to report the occurred situation. This individual would be contacted immediately and I would be allied in to remain with the patient while NHS protocol for suicidal patients was adhered to (e.g. contacting GP, contacting the liaison Psychiatry team, etc.). This would be discussed with the participant prior to the disclosure of information. All potential participants would be informed of this in the Participant Information Sheet and Consent Form. This procedure adheres to Section 7.1 of the British Psychological Society's Code of Conduct, Ethical Principle & Guidelines (2006).

All data that was collected was stored on a password protected computer. Only I and the Director of Studies had access to the data. All participants were also asked to select a pseudonym to which they were referred to throughout the study. Data stored on the researcher's computer for the purpose of analysis was anonymised in this way and additionally was password protected.

Chapter Four: Results

An interpretative phenomenological analysis of seven semi-structured interviews revealed three inter-related Master themes: 1) The experience of encountering HCV 2) Managing the diagnosis of HCV and 3) The experience of treatment. Each of the Master themes will be explored together with their constituent subordinate themes and in vivo coding (see Table 4, below). The themes reflect a chronological trajectory of HCV: initial diagnosis, undergoing liver transplant, post-transplant transition, virus recurrence and the most recent period of awaiting new treatment. For the purpose of the reader, it is noteworthy that the symbol (…) indicates that some text in the extracts has been omitted. The extracts presented herein have been selected as they represent the most powerful or insightful quotes and capture the essence of the theme.

Table 4. Table of Master themes and related sub-themes.

Master themes	**Subordinate themes**	**In vivo coding**
1. The experience of encountering HCV	Learning about the infected self	Identifying the source of infection
		A lack of information provision
	Psychosocial impact of HCV	Fear of contaminating others
		Fear of disclosure
		Stigma
2. Managing the diagnosis of HCV	Coping with HCV: Resilience and supporting relationships	Keeping occupied
		Adopting a healthy life style
		"I wouldn't have managed without them": necessity for practical support
		"They are part of it": impact on the family
		Optimism

	Experience of medical and social support	Mistrust in health care
		Self-sufficient approach
		Importance of social support
		"We still need to be looked after": negotiating health care
The experience of treatment	Trial and error circle	Feeling "like a guinea pig": trial and error approach to treatment
		Concerns about the side effects
	Living with uncertainty	"I was going downhill pretty quickly": being aware of impaired physical functioning
		"It's still there": facing virus recurrence
		Living with uncertainty
	New cure	Determined to 'get rid of it'
		Hope

Theme 1: Experience of encountering HCV

Life with HCV began at the point of diagnosis, an experience which for some participants was inconceivable and life interfering, but for others caused no reportable or substantial life change or disruption. Despite the initial impact of the diagnosis on participants' lives, the sense of uncertainty about the 'dormant' and unknown nature of HCV, emerged throughout all participants' narratives. First, they described their concerns about encountering the diagnosis that was, at the time they were diagnosed, vaguely understood and defined. Thus, participants found themselves in a position of 'limbo'- with no information provision by medical professionals. Consequently, with a desperate need to understand what was happening to them, they began their journey to search for meaning. The process

of learning about the illness first initiated an attempt to identify potential sources of HCV. This appeared to be an important step in making sense of why this had "happened to them". Following on from this was a process of self-seeking for more knowledge and information. Participants search for understanding only further highlighted their sense of isolation and of being let down by the very people who diagnosed their condition. The "not knowing" how to live with HCV coupled with an awareness of the potential stigma associated with the condition, caused patients a dilemma about disclosure, a fear of contaminating others and interfered with their anticipated futures. What follows will highlight the psychosocial journey of the participants and the impact that HCV had on their lives.

Learning about the infected self

Participants reported receiving a diagnosis of HCV in either primary care or in hospital after routine blood tests. They were poorly prepared for receiving the diagnosis and reported a lack of any essential advice or support provision. All were previously unaware of their condition and were not informed about the purpose of taking a blood sample, which was for HCV serology. The high level of uncertainty that accompanied the medical procedure raised in the participants' suspicion and confusion. For them it seemed to be an indicator that something was wrong:

> *"I think I was in hospital for something else and I don't even really know why they wanted the blood sample. It had nothing to do with what I was in for."(Gus)*

For many, there was a sense of ‘shock’, they were completely unprepared for their diagnosis which came ‘suddenly out of the blue’ (Gus). They were taken for tests in obscure circumstances or while being treated for different conditions, but in neither of these situations they were informed of the nature of tests. Awaiting the blood test results one of the participants was not even aware that he was sitting in an HCV clinic (Jimmy). The not knowing why the blood samples were taken evoked initial feelings of puzzlement, amazement, and fear that were enhanced by the unexpected news of a diagnosis. Jimmy seemed to dissociate in response to the diagnosis by redirecting his thoughts and shutting the news out by building the imaginary wall around the self:

> *“When they took me in, and when they told me I thought of bricks, because I had no idea how, or where I’d got this.” (Jimmy)*

Considering the lack of knowledge about the virus at the time when they all received the diagnosis of HCV, participants could have been infected for years and only the presence of some HCV symptoms such as jaundice (Ted), or liver pains (Harry) became a reason for their health concerns. Thus, while for many, the blood test was perhaps the first indication that ‘there’s something not right’ (Jimmy), for others, the occurrence of symptoms was already a cause for concern:

> *“(…) it was the jaundice, that's what they say, because my skin all went yellow. But I found out it was Hep, but I didn't know whether it was Hep C or what, because they didn't know a lot about Hep C in these days.” (Ted)*

For all, however, regardless of the occurrence of symptoms, the diagnosis highlighted the ‘silent’, ‘dormant’ nature of their condition. Even those, who could have prepared themselves for the possibility of the diagnosis by noticing the physical indicators, were oblivious to what was happening within their bodies:

> *“I thought it was lying dormant. I thought – and then when the doctor said, no, it was there. It was just eating away, all the time, at your liver.” (Ted)*

This view of the virus being temporarily inactive and not affecting the system, was abruptly demystified, when the doctor revealed the destructing impact of it on Ted’s liver functioning. For Ted, there was a sense that the virus was consuming him, corroding his liver in- it was a silent killer. The fact that many patients were not affected by the virus until diagnosis, heightened their initial shock and the sense of bewilderment of the virus occurrence. The virus seemed not to interfere with patients daily functioning until they started treatment for it. Treatment was considered to bring it ‘back out’ from the dormant state. For Ted, treatment became a trigger of virus activation that threatened his life stability and anticipated future:

> *“I thought it was just lying there and hadn't been disturbed until I got treated for it. And then when I got treated for it, that's when it came back out again.”(Ted)*

Given the lack of knowledge about the effectiveness of HCV treatment, patients became easily confused by their asymptomatic health condition and arrived at mistaken conclusions, such as:

"I actually thought my hepatitis went away. As I say, after a week in hospital and then, as I say, I just got on. I thought I was done, because I never had any trouble." (Ted)

Ted seemed to hold expectations of moving on with his life, leaving HCV behind him after hospitalisation period. Attending treatment appeared to be associated by participants with a successful cure. Therefore, when the virus turned out not to be cleared, they seemed to experience disappointment and frustration. Many others, who have never experienced any drawbacks that could have been associated with a given diagnosis, and lived with the virus 'lying dormant' for years not knowing of it, never perceived the illness as a challenge or burden that they had to struggle with. For them, discovering a condition that had persevered in their bodies for so many years gave them a sense of helplessness, a feeling that 'there was nothing' they could do about it and that the control over their life was lost. Living with HCV appeared to be a permanent state with no perspective for a change even after a part of their body, infected organ was removed and replaced with the healthy one:

"When I got told I had the virus there was nothing I could do because I'd had it for years and years, and I didn't even know I had it. But once I got the liver transplant, I says, "I've got that and I've still got this virus." And that probably preyed on my mind a bit, but there's nothing I could have done about that. [] There's nothing you can do, you know." (Steve)

Difficulty in accepting the initial diagnosis resulted from the fact that many participants were diagnosed in the 70s when there was still a lack of knowledge about the virus and its consequences. As a relatively unknown condition, HCV was not properly explained or defined to the patients, therefore, they could only acknowledge the diagnosis that was given to them, and hope for treatment in the future. However, the reactions to this factual uncertainty fluctuated from acceptance to perplexity when threatening diagnosis-related predictions were made by professionals:

> *"I had a chat and I was told something like, "you maybe have got 15 years to live" (laughter). At that time I was, you know, they didn't really know a lot of this. So, it was a bit disconcerting…"* (Gus)

Thus, the impact of the informational gap seemed to unsettle and bewilder participants who were suddenly faced with a diagnosis for life that was not sufficiently explained by medical evidence. The lack of knowledge made participants also feel that the diagnosis was all they could be given. They were informed that they were ill and 'were dissed' with the burden of uncertainty. Consequently, the initial fear and shock experienced after receiving the diagnosis was amplified by a sense of isolation, of being on their own with an unknown disease, and an overwhelming uncertainty about their future. Participants found themselves in 'limbo' where nobody could tell them '*this is what was going to happen in the future' (Eric).*

According to participants' accounts*, 'no information at all'* and no professional care was provided to them in the 70s and 80s when most of them received their diagnosis. Possible medical interventions were anticipated in the future, but

nothing was applied at the time of diagnosis. Being left in this zone of nothingness, participants tried to identify their own sources of information. They were trying to take control of a situation that seemed to be unmanageable:

> *"(…) When I first got diagnosed the first thing I did was I contacted the haemophiliac Society and I still have all the papers away back to that time. (…) they were the only people I could think of. There was no Hep C Trust or anything." (Gus)*

There was a determination to recognize any possible sources of information and seek answers that could not be obtained from health providers. Participants were searching newspapers and found out that some *'studies were on and they were funding what they could do'.* Sources of information were not always official and validated, and they could be simply '*from word of mouth',* from other people affected by HCV or involved in the process such as Haemophilia Scotland.

After the initial shock and consternation of receiving the diagnosis, participants then began to ponder the source of the infection. Many were relatively certain in identifying circumstances and ways in which they contracted the virus. Two of the participants (Ted, Steve) recalled in their youth sporadic injecting drug use incidents, which they believed were the cause of their HCV positivity. A single drug use from the past made Steve sure about how and when he had contracted the virus. Ted, in turn, did not mention just a single episode of injecting himself and struggled to be more exact about the time when he could have gotten the virus. However, they both accepted personal responsibility for contracting the virus as a result of 'totally naive' early life experiences of heroin use. There is a sense of remorse, guilt and shame in Steve's account where he confessed that

he ‘never took drugs’ in his life and ‘never even touched it’, apart from this one time when he was 21 years of age. Genuine regret peppers his account:

“It was the worst thing in my life I’ve ever done.”(Steve)

For others, the source of infection was considered to be: either sexually transmitted (Jimmy) or transmitted through blood transfusion (Eric, Gus, Harry, Chris). Although the source of the infection here was still the subject of ‘dispute’, all five participants could easily trace the infection to a time when a major operation took place in their lives or to a specific treatment involving blood transfusion. For these participants, the situation was considered unjust and undeserved:

“I contracted Hep C through contaminated blood given to me for treatment for my haemophilia.”[] “You’ve got it.” [] “Somebody gave it to me. I didn’t go out there and stick a needle in me…” (Eric)

Thus, unlike for Steve and Ted who contracted the virus through their own risk behaviours, the others’ reports were peppered with a sense of anger and blame. They had received ‘dirty blood’, ‘contaminated blood’ and, therefore, the virus occurrence was not perceived by them as being their fault. They expressed a real need to escape personal blame for something that was “done to them” by others and not by themselves. Identifying culprits for their situation seemed to absolve them of all responsibility. Eric who was also contracted with the virus at the time when no blood screening was in place, blamed both political and health sectors that were responsible for providing the infected blood:

"(…) it shouldn't have happened, that is basically it." [] All these thousands of people that have been affected by the Hep C they shouldn't have happened and that's why we are fighting at the moment."[…] we try to get answers because nobody is saying, "It was me that did it." All we want is somebody to say, "It was the national health's problem, the government did it and then let's do something about it.""(Eric)

Eric appeared to use the plural pronoun 'we' to emphasize the shared experience of injustice and enhance the gravity of the situation. Like Eric, many other participants reported a need for someone to take responsibility for the situation and for that situation to be rectified via effective treatment:

" (…) because I am not into the blame culture and as I say I didn't like the Prime Minister and all that and I will never forgive her that but I am not getting into the blame culture and living my life that way. I just feel we need to get on and get these drugs developed and see where we can go from there. That's basically where I am. (Gus)

Participants' responses to the diagnosis seemed to depend how they contracted the virus. Patients who had the infection transmitted through injecting themselves showed a tendency to self-blame and to adopt avoidant thinking (e.g. Ted who '*never really thought too much of it'* or Steve who accepted his helpless stance that *'there's nothing'* he '*could have done about that')*. On the other hand participants who received contaminated blood through transfusion, took a more pro-active approach to the situation they were forced into. They accepted their

right to blame other people who were responsible for “giving them” the virus and the right to claim treatment in a form of compensation for the terrible mistakes from the past. The past was still on Gus’s mind and it was something he would *‘never forgive’* but like others, he recognized the need to *‘use it as a means for improvements for the future’* and ‘*get on and get a cure for it’.*

While most of the participants speculated the source of infection and had varying degrees of certainty as to how it was contracted, for others (Eric, Chris) there was no such source of certainty. Jimmy seemed to feel lost and constantly worried because of his unsuccessful search for clear explanations of receiving the virus:

“Still to this day I’m out of my mind where, and how I could’ve got that.”(Jimmy)

Jimmy’s complete lack of certainty regarding the source of his infection caused that he, unlike other participants, as the only one put no blame on anyone and not on himself, in particular.

In summary, a number of potential sources for contracting the virus are recognized: sexual transmission, blood transfusion during two major operations, or contact with an infected relative. All seem to be feasible explanations for infection occurrence, but none of them seemed to give a definite answer. This uncertainty caused participants unresolved distress and a feeling of mental unsettlement.

Psychosocial impact of HCV

The initial diagnosis of HCV affected all the participants despite some assertions of ‘no thoughts given’ (Ted). Participants were all aware that a positive HCV status had a considerable psychosocial impact. For example, as participants revealed their accounts, it was clear how the diagnosis led them to a number of

personal sacrifices, such as a decision of not getting involved in romantic relationships. An awareness of the infectious nature of HCV caused distress when interacting with others. Stigma, often associated with HCV resulted in a fear of disclosing HCV to others and a fear of contaminating others consequently resulted in social withdrawal. Fear of disclosure seemed not to depend on how participants contracted HCV but on stereotypical views accompanying the diagnosis. A risk of being perceived as a drug addict or as an untouchable outcast preyed on participants' minds.

Participants felt strongly about the preconceptions people held about HCV. Eric was aware of places "where a lot of people see the stigma where a lot of Hep C is a bad word." Those preconceptions led to the shift in an attitude towards the infected person:

> *"Like people's attitude towards me changed like I was a leper sort of thing." (Chris)*

Chris' extract demonstrated how HCV, a potentially treatable viral infection that is wrongly perceived by the society, could distort a way the infected person perceived his condition and himself. A status of being HCV positive degraded the patient to the rank of an outcast that was rejected by his environment. In this sense, stigmatizing evoked and deepened the sense of participants' social exclusion, both amongst family members and friends:

> *"(…) it has changed a lot I don't see people as much, and I never get invited to their house and they seem to think that they'll catch something off of me, but I've told them you cannot catch it. (Chris)*

Chris' account revealed that people were ignorant about the virus and his modes of transmission. This reminded him of "the AIDS virus when it first came up'. Any attempts to rationally explain to his friends the risks of contamination were made in vain because "*they're still wary and it's a bit of a downer"*. Chris expressed a strong need for people to understand his situation and how his body was affected by their unfair reactions. He wished that they could feel what he felt, that they *"look inside to how my body felt at being excluded".* This marginalisation occurred not only within the wider social network but also within close family relations. Contact often became limited to phone calls and visits became even more restricted:

> *"I'll speak to them on the phone or they'll text me as regards to them visiting or getting invited to their house (…)" (Chris)*

While for Chris not seeing friends and relatives was a sacrifice that was imposed on him causing a feeling of exclusion, for Harry keeping his cousins and friends away from his household, was a conscious decision made by himself in order to protect them from receiving the virus:

> *"So I told them not come to our house, not to bring their kids to our house… Even my friends stopped coming (…) the first three months I completely ignored all the people." (Harry)*

The disappointment and frustration from not seeing friends and relatives, and in relation to reactions to their condition, were enhanced when Jimmy recognized

that people who hold these preconceptions possessed the knowledge necessary to avoid this kind of stereotypical thinking:

> *"There was a couple of times where my niece was there (…) and wanted something for the kids and it was in my mum's house and I said to her, "Oh I'm going to the kitchen I'll get you it." And her mother, who is a nurse herself, jumped up and shouted, "No, you'll not bother, I'll get it." I thought, that's a big one, she's a nurse, she should know." (Jimmy)*

Disclosure, therefore, could be an anxiety-provoking act where participants feared unpredictable and disappointing reactions from others. For Jimmy, fears to disclose HCV extended to potential partners:

> *"After I was diagnosed I was scared to go into a relationship (…) something I don't think I will, ever have another one, because I don't think I can turn around and say to a female, I'm sorry but I've got Hep C, or I've had Hep C. Because I think they'd just about turnabout and walk out the door on you. So, it's kind of, it's sad in a way knowing that – I don't think I could get into a relationship knowing that, to have to tell somebody that and then knowing they might just walk through the door, reject you, and just walk out the door altogether."(Jimmy)*

The burden of living with HCV awaked the reality of a lack of any positive future intimate romantic relationships in Jimmy's life. His despair seemed to be endless

and even a possibility of clearing the virus would not give him sufficient confidence to enter a romantic relationship. The diagnosis in this sense, appeared to be a life-long sentence characterised by a fear of rejection and isolation.

The decision of disclosure appeared to be not only embedded in fear of potential negative responses to the diagnosis, but depended also on the recognized source of the infection. Steve who expressed regret for injecting himself in his youth and who seemed to be ashamed of how he contracted the virus, decided not to disclose his HCV even to his closest family. His significant others were only informed about liver cirrhosis as an official reason for his need for liver transplantation:

> *"(…) none of my family knows [] When I found out about the cancer they didn't know from where it was." (Steve)*

A sense of being responsible for contracting HCV through injecting himself seemed to determine his decision of avoiding disclosure. Conversely, disclosure did not constitute an issue when participants contracted their virus through blood transfusion and when they void of any personal responsibility of contracting HCV:

> *"I know a lot of people have a stigma about Hep C but I've got no – I'll tell everybody that I've got it because it wasn't my fault."(Eric)*

As a consequence of perceiving oneself as a victim in the whole situation, participants had great ease in sharing the diagnosis with "*anybody that wants to know*", in particular with those who showed interest and support. There seemed to be no stigma and instead, unconditional family and friends' support where

participants were clear and honest about their past and regretted nothing about what had happened to them. However, the ease in the way they perceived their health condition did not mean that HCV had no impact on their lives. Diagnosis evoked a lot concerns about the health and well-being of their partners and children.

Thus, disclosure could be perceived as an act of courage but also as an act of caring for others. Participants disclosed themselves to make their family and friends aware of their condition and to give them an opportunity to protect themselves. In participants' reports, there was a clear indication of several precautions they had undertaken out of concerns for others, especially members of their families and friends. A fear of contaminating others with the virus caused them to make difficult decisions about limiting their participation in community living and when meeting with friends and family to be *"very careful from the other people children are not to catch an infection" (Harry).*

The precautions that had a clear purpose of protecting the vulnerable others could, however, also have a form of self-limiting and self-controlling thoughts and behaviours:

> *"Even if you're, if I'm in my mother's and I'm maybe cutting something, careful not to cut yourself, it's weird." (Jimmy)*

The fear of contaminating others could lead the participant to a state of constant alertness and precaution that became part of his daily routine:

> *"As soon as you open your eyes here, you're conscious, right be careful." (Jimmy)*

Jimmy's life seemed to be characterised by excessive acts of precaution to prevent others from contracting the virus. Jimmy tended to anticipate potentially hazardous situations that could possibly increase risk of infecting others. A simple situation, such as cutting himself shaving, was perceived as a high-risk incident that would prevent him from leaving the house until the wound *"dries up",* making it safe for him to be in the company of others.

Participants also reported disruption in terms of avoiding holidays:

> *"What happens if something happens on your holiday and you're taken to hospital, and you're unconscious, and they start tampering about with you, and there's blood everywhere. You don't want to go on holiday." (Jimmy)*

Thus, HCV constrained peoples' everyday existence and made them carefully judge every step they took in life. The diagnosis appeared to prevent participants from making any future plans. Uncertainty regarding how their condition could change within days or what could happen when on holiday stopped them from making any definite decisions. In this way their holidays were postponed for months or years out of fear of an organ rejection that "could kick in" suddenly or unpredictable medical circumstances that *"could happen at any time"* and in any place.

The participants' former lives seemed to be gone forever. However, they appeared to hold on to the hope of regaining the active life that was taken from them with the diagnosis. Their accounts revealed how they envisaged themselves engaging in former activities without living in fear of putting others at risk. This was, however, dependent on whether or not the virus would be

‘cleared’. Being ‘cured’ brought hope for the future and the possibility of regaining freedom, but participants were also sceptical of this ever being a realistic possibility:

> *“I’ll get rid of the Hep C and then I can start thinking about going on holidays, and I can go this, and I can do that. But, it doesn’t work that way, does it?” (Jimmy)*

As with the disclosure issue in terms of building a new romantic relationship, the diagnosis of HCV seemed to be a constant and unresolved obstacle for Jimmy. The perspective of clearing the virus brought no relief or certainty in his reflections. For others, plans seemed not be on hold until the moment of clearing the virus, Gus made plans despite his current health concerns, and difficulties attaining travel insurance. He clearly expressed determination in that he was “*not going to stop going on holiday”* or he was not going to stop fulfilling his idea of pro-active living. His determination could have his source in the fact that he contracted HCV through no fault of his own. Therefore, when confronted with inevitable HCV consequences, he decided to appreciate the unpredictability of life and became determined to make the most of his

Theme 2: Managing the diagnosis

Participants in the current study reported a number of coping strategies that allowed them to live life despite the adversities related to HCV diagnosis. These strategies ranged from various resilient forms of coping, to seeking medical support and relying on the support of their significant others. Participants appeared to incorporate all of these coping mechanisms in their treatment regime, but also used them to deal with any consequences of living with a chronic

illness. Resilient coping (e.g. keeping occupied, optimism, adapting health lifestyle) allowed them to maintain a relatively balanced and healthy level of functioning, despite the often detrimental effects of HCV treatment and its side effects. Social support also appeared to be important, although the extent to which this support was required varied amongst participants. In particular, participants emphasized the invaluable contribution made by family and friends to their recovery and their ongoing support was considered central for improvement in their quality of life.

Coping with HCV: resilience and supporting relationships

Patients with HCV experienced a number of side effects of HCV treatment and a continuous deterioration caused by the illness itself. In response they had to develop and apply adaptive coping strategies. These strategies appeared to be beneficial in improving adherence to treatment and in facilitating adaption to a change in social circumstances. Participants in this study tended to manage the challenges of their condition by keeping occupied, adjusting their former lifestyle to current health requirements, spirituality or simply by accepting their situation. Participants also emphasized the need for family and friends support in coping with the daily challenges of living with HCV.

Support from loved ones ranged from emotional support to physical assistance before, during and after the antiviral treatments. All participants described the role of family as not only necessary but as crucial for their recovery and survival. Their attendance and adherence to the treatment seemed to be completely dependent on support from the family. There is a sense of an enormous debt of gratitude to their loved ones:

"They were the main support. Just travelling, even travelling, when I was in they could visit us every day from Glasgow in the mornings. Some of them were here in the afternoon, some at night, they split it up so that I had a visit all time. And when I got out I had to come here once a week for two weeks, and then it was twice a month, so obviously I had to rely on family for coming here, which was great, you know, I wouldn't have made. I would definitely not have made it." (Steve)

Although participants' attempts to adapt to the reality of ongoing infection and a series of treatments appeared to be dependent on the help from others, they also tried to manage their lives on their own by, for example, adopting a healthy lifestyle. Common strategies they used included refraining from alcohol, cigarettes, and some foods that made them ill and caused liver irritation. They did not only adhere to dietary advice from the medical team, but they changed their eating habits based on their own bodily reactions. Implementing a healthier lifestyle, allowed participants to develop a sense of control over their illness and made them realize that they themselves could change the way they felt:

"The most important thing is to refrain from such foods which is not good for the Hep C or the liver. And also alcohol and the… What's called the thing is… The smoke. I don't smoke. I don't drink. And even refrain from the foods. I am taking Warfarin now but I want to… And that morning before the surgery... Before the surgery also ten years before when I ate some grapes and felt something

is different. I stopped the grapes. Why I have the grapes when it's not good for my liver. So I feel something different." (Harry)

Self-management and change in health behaviours seemed to be facilitated by participants' positive mental attitude. Despite adversities such as unsuccessful treatment outcomes and virus recurrence, participants reported very optimistic view that 'things can only improve'. Their optimism, although it might seem to be unrealistic, was based on rational expectations for future cures, they learned to anticipate these over the years. They also seemed to be focused more on the present experience of health improvement rather than on the ongoing infection:

"I would just say to people, just advise, try and stay positive. It's something that you've got. The only cure there is if it's not cured, and you've got to go for it. You've got to go for it. Try and keep yourself fit, do what they tell you, you'll come out the other end, and just get on with your life after that."(Gus)

Getting a new liver appeared to be for many of the participants a milestone in rediscovering their lives and was pivotal for attitudinal change. Post-surgery, nothing seemed to limit their lives (as it had in the pre-transplant period) and their expanded optimistic view gave them an impression that they had 'everything to look forward to'. Many of the participants emphasized that they had learned to live for the present moment and to accept 'every day as it comes'.

For two participants (Steve, Harry), a positive attitude and acceptance of living with HCV seemed to be grounded in their religious practices. Harry used prayer,

first, to decrease stress when waiting on the decision as to whether he would be on the transplant waiting list and second, when awaiting the transplant itself. The fear of possible negative outcomes of the surgery and of death itself seemed to be overwhelming and difficult to manage. However, prayer and fatalism appeared to ease this distress:

When it (liver transplant) was coming I just prayed to God and at that moment I prayed for a while, which we pray regularly and that's it. My wife as well and so all the family and some of our friends came and they prayed to Allah, *(Harry)*

After a long, uncertain and stressful wait to receive a transplant, a challenging period of post-transplant recovery then ensued. Participants seemed to be aware that without the emotional and physical support from their family members they would have had to stay in hospital and rely on medical care alone. They emphasized the huge psychological burden that was caused by their poor physical condition after transplant. They reported physical weakness and depressive thoughts that would not be possible to overcome without constant encouragement from their family:

> *"I wouldn't say suicidal thoughts, but just stupid thoughts going through your head. As I say, if you stayed yourself, you would need help because it does play on your mind, you know what I mean? Just stupid things. What am I really doing because I'm just lying here, I'm doing nothing, because you can't do nothing. [] But no, if you didn't have a family round about you, you'd need to stay in hospital. You'd need help from a psychiatrist to say, "Look, that's*

normal for you to have all these daft things running through your head." But my family were there for me."(Ted)

Great importance of family support in recovery was often emphasized by participants. They also revealed a sense of responsibility and protecting mode towards their loved ones, who sacrificed their lives to look after them. They seemed to stay 'strong' and well for their family knowing how 'hard' and 'disappointing' the journey through HCV treatment was for them as well. In a reciprocal manner, they appeared to perceive their families need for support as being just important as the help they required themselves. Participants were fully aware of the burden that their illness brought upon their partners and that they were considered an integral 'part' of the HCV situation. Participants seemed to feel a responsibility for their families who were in a way fated to share their lives and destiny with them:

"They need to get a little bit more I think. There should be somebody there I think supporting them. Okay, fair enough, maybe a nurse or something popped in just to say 'everything is going well' but that's it. I think they should get a little bit more I think. [] They are part of it. Even though I'm going through it they are dealing with it just as much as I am. They've got to live with me."(Eric)

After a long period of recovery from liver transplant, participants reported that staying employed was an important form of coping that helped them to maintain a sense of stability and achievement. For Gus the decision to get back to work after his liver transplantation seemed to be a triumph over illness, a way of

regaining control over his life and a reminder of what a ‘normal’ life might be. His goal to return to work motivated him to stay active, despite his diagnosis:

> *“I set my target to get back to work and that to me was important. Because that to me was normality, getting back to a normal thing because people used to say, “Why do you wanna go back to work? You should be retired at your age and that. And for me that was a big thing, it was a victory.”(Gus)*

For others, returning to work was too ‘big step’ that turned out to exceed their physical abilities. The consequences of resigning from ones job seemed to have tremendous impact on participants’ psychological well-being. Some participants (Steve, Gus) reported their job was ‘one of the major things’ that they missed after transplantation made them feel depressed and purposeless. The routine related to work appeared to protect their self-worth. Being deprived of their daily work rituals, seemed to mean for the participants a deprivation of normality, health and self-confidence.

However, over time participants who did not return to work appeared to adapt strategies to keep themselves occupied. The job-related routine that was lost irreversibly seemed to be replaced by new tasks, consisting of small goals and targets, but nevertheless giving the participants a sense of purpose in everyday life. Engaging in these everyday activities appeared to release them from the entrapment and isolation that HCV had brought to their lives. It also evoked a sense of personal freedom and allowed spontaneity to re-enter their lives again:

"I just try to get up and go out every day. Like I say, I came out, let's say November, no, it was October, after the good weather came I was out every day. But after the transplant I went out for my paper and things, going out, I managed to after a wee while be able to go for messages and things, and walked round to my family, so that's what I've done rather than stay in, so that was good."(Steve)

When engaging in everyday routines, participants seemed to also apply downward comparison as a coping strategy. They compared themselves to less fortunate HCV patients and seemed to draw from it an additional motivation and energy:

"I just thought to myself, "Listen, I got that, a lot of people have got that (new liver) and not been as lucky as me." A lot of people have what I had and waited, didn't even make the liver transplant they were that ill, but I was that way, I've managed to get this liver transplant after three months, and I've got through it. And thank god I did. So you think of other people, that I was fortunate and how I came out, and I did come out on a Sunday." (Steve)

This account is peppered with a relief and gratitude for receiving an organ that saved Steve's life. His words are also a nod to gravity and unpredictability of his former health status that is still other people's faith. He seems to feel indebted to all those patients who had not received the new liver and obliged to attend worship and pray for them. The organ he received thus appeared to be a gift from God that others were deprived. Further, religious beliefs that helped him to get

through the journey of transplantation, now help him to cope with the guilt of survivor.

Experience of medical and social support

Resilience and an ability to cope with adversities related to HCV diagnosis and treatment could have been either enhanced by professional support or additionally challenged by their inadequacy. Participants' reports about the medical care they received, oscillated in tone from great respect and praise to disappointment and reproach. Negative emotions were expressed in relation to the side-effects of interferon treatment and an informational gap regarding the new sofosbuvir cure. Conversely, the acknowledgment of professional support was present when the procedure of liver transplantation was recalled.

Participants felt strongly about not being informed about the side-effects of various treatments they had received. Participants seemed to be completely lost and 'didn't know what was going on' when they were assigned to HCV treatments. They were unaware and unprepared for the consequences of treatment until they experienced the first associated side-effects. They seemed to be deprived of basic information as to what possible outcomes they could expect. This appeared to limit their opportunities to approach the treatment in a pro-active manner. In essence, they had no option but to react when they could have been pro-active:

> *"Where, as if, they told me there was likely to be these things. Some of the things that could happen before it, then… I would have been prepared and I would have understood that this is all kicking in. There'll have to be an adjustment. So they're very bad that way. I would like to*

know what the possibilities could be over the next few months. It's not till it happens to you and they say: "Oh, yeah…" (laughter)…so…yeah."(Gus)

Like Gus's, many other narratives reflected the participants' sense of being abandoned by the medical profession, expressed as being 'ditched onto transplant co-ordinators' (Gus) and not receiving the care and information they deserved. Being deprived of an opportunity for a consultation with a doctor seemed to evoke strong feelings of disappointment and negligibility. Consequently, participants reported being perceived as not 'high-category' where pre-transplant patients receiving new treatment were considered to be more important.

Negative feelings regarding medical providers seemed to shift when participants left the discussion about the sofosbuvir treatment and reflected on the professional care they had received more generally. Participants reported a trusting and appreciative attitude towards all medical providers. They emphasized the availability and competency of transplant co-ordinators that were their main source of information:

"[…] they gave you quite a lot of support because it was quite – your clinic appointments are quite regular after it and then because the Hep C has still been bothering me – if I didn't have that they would have been yearly, that's the way it should be, but because of the Hep C it's been more regular for me to come back here. But the coordinators are great; if you've got any problems you just pick the phone up to them. They are only a telephone call away if

you needed any help, any questions, they are always there. If you want any information you ask them, you don't ask the doctor." (Eric)

Although participants emphasized the 'need to be looked after' by their medical providers, they also indicated clearly that they never needed any medical 'aids' or additional physical support. Thus, they sought professional advice in terms of treatment and side effects while incorporating a self-sufficient approach to their physical care, relying only on their own determination to 'build the strength up' and necessary family support.

In terms of emotional support, participants did not indicate the need for help from health care providers. Many of them reported contacting support groups or speaking to other HCV patients in order to find reassurance and help. They appeared to rely on this form of support and information provision more than on what they heard from their doctors. They seemed to be able to build clear expectations based on other patients' accounts and gain greater insight regarding their treatment and its consequences:

"Tell us what that guy that had it a year after me. After I spoke to him I was, 'Yeah that's made me feel…' because I know it's not just me it's happening to. He's gone through the same, so it must be a normal side effect of the operation or the medication and that's what's happening and that's why it's happening, but before it was because is what's happening (…)" (Chris)

There was an ambiguous approach to meeting other patients and listening to their experience in the pre-transplant period. For some of them contacting post-transplant patients before their own surgery was extremely important and reassuring, whereas for others it only reinforced the emotional burden and sense of isolation:

> *"When I went there I was the only one that was on the list; they already had their transplants."[…] we went away because it was upsetting Simone because he kept talking about how good it was. Okay, that's good that you know what to expect but it's not helping me really all that much I'm still waiting."(Eric)*

Eric seems to emphasise a need for stage-appropriate support for HCV patients. People he had met at the support group meetings were at an advanced stage, a stage that he desired and perhaps a stage he feared he wouldn't reach. A fear of unpredictability and uncertainty evokes a sadness and withdrawal.

Theme 3: The experience of treatment

Participants reported their journey through HCV treatment chronologically. Their experience of the various phases of medical interventions overlapped in many ways and evoked similar physical and psychological reactions. All participants started with a variety of pre-transplant treatments mostly containing interferon that induced several detrimental side-effects. Then, they described their experience of being on the transplant list and receiving the transplant. The new

organ was not, however, a guarantee of a full recovery and virus clearance. Therefore, participants found themselves searching for a new cure that could treat the recurrent virus and give them hope for an illness-free future.

Trial and error- feeling "like a guinea pig"

Participants in this study reported unique experiences of their pre-transplant treatment and indicated a number of detrimental physical and psychological side effects of some of the medical interventions. They all seemed to be unprepared for what was happening in the aftermath of the trials, however, they all decided to attend the treatment as anything is better than nothing. Subsequent treatments offered them hope when they were staring death in the face.

However, a lack of information before and after treatment resulted in feelings of irritation and disappointment. According to the participants' reports they seemed to confuse physical symptoms (e.g. sweating, cold, fever) with flu-like-symptoms or simply called them 'complications'. These unspecified side-effects made them feel 'not totally in control' of their actions and emotional responses. Some participants reported outbursts of anger and frustration as a consequence of the interferon treatment. Their aggravated irritability caused them to be 'dead-quick-tempered' and 'snap' at family members without any reasons. Reported mood swings ranged from aggravated anger to depression.

The extent of the experienced side effects appeared to be difficult to define. Extreme physical and mental states seemed to change within seconds, not giving the participants the possibility to predict or control their bodily reactions and mood swings. There was no continuum of experienced symptoms, but highly disruptive physical and mental reactions that could not be controlled. This experience of a

total loss of control, however, did not provide Eric with a belief that he should not be blamed or be responsible for his actions or words. He seemed to be aware of what he had done to others and that it was inappropriate and out of character:

> *"[…] the treatment itself was horrendous. You were sick, you were in depression, you were angry, and you didn't want to talk to anybody. I stayed in my bed. The smallest little thing just set you off. . You were shouting at the kids, you were shouting at the wife, but you were up – sometimes you were up but the majority of the time you were down. You would feel as though you had a major flu attack. It was – you were sweating, you were cold. So it was really, really bad." (Eric)*

Eric's extract here, suggests a deprivation of self-control over his mood and he seemed to be helpless in the face of the mood disturbances. He encountered a state where his mood could suddenly change from deep depression, to extreme anger and a manic state. In turn, this mania seemed to trigger social withdrawal as a defence mechanism to prevent angry outbursts towards loved ones and friends.

Other participants reported decreased self-awareness when discussing aggressive reaction to treatments. They seemed to have great difficulty in comprehending what was happening to them. In this sense, they appeared to rely on reports from their friends and relatives, rather than on their own first-hand recollections. Most of the participants also struggled to identify themselves with the behaviour they displayed as a result of interferon treatment. They seemed to seek an escape from their past actions, by emphasising that it was not them who

acted so impulsively, because they were ‘not like that’. It was as if the treatment had completely taken over them:

> “there was difficult to understand what was happening to you, you know, but it wasn't something that was made you going to kill somebody, you know....nothing like that or go fighting or nothing, just felt not totally in control, which was an unusual thing for me.” (Gus)

‘Horrendous’ side effects and unsuccessful treatment seemed not to stop participants from exploring other available drug trials. They appeared to perceive each treatment as a unique opportunity to overcome their debilitating condition. Subsequent treatments became a synonym of an opportunity that could not be missed, because it appeared to be a potential way out and gave them hope for the future:

> *“One of them, one of the trials was very bad, but that was the one I was quite happy to, the new landing hospital was quite happy to go into these trials, because well sort of thing that was there was a chance, and also it was a way of moving forward to the next stage of trials etc.” (Gus)*

Participants appeared to try anything and everything offered to them, even if that meant to go ‘on placebo’ treatment that could have caused no change in their health condition. It was notable that none of the participants seemed to express any strong emotions such as disappointment or frustration when describing treatment failures. In fact, one participant (Eric) emphasised that his ‘wife was more upset’ than he was, when the virus ‘came back’. Their non-responsiveness

and persistence in seeking new treatments might give a sense of how they attempted to make the poor treatment outcomes more bearable. They appeared to accept unquestioningly that ‘a dozen different tablets’ were ‘tried on’ them ‘in different combinations’ and that several treatments they attended appeared to be unsuccessful. Focussing on the future and not the past supported their determination and treatment adherence.

Participants’ attitudes to the treatment and their adherence seemed to be, however, dependent on the trust they put in their medical providers. Many reported severe negligence from hospital staff that caused their confusion, disappointment and shock. They appeared to perceive themselves as being mistreated when they were extremely vulnerable and desperately needed support and reassurance. An unexpected medical error related to diagnosis was interpreted as yet another failure in patient care:

> *“I was on a treatment for, I don’t know maybe five or six year ago. [] That was, I think it was just injections. I took that for a year and that was another shocker, because I went back to hospital to get bloods done and was told it’s cleared. I thought, great. “But we want to see you again in a couple of months.” So I went back in a couple of months and they turned around and said, “We made a mistake” which was a kick in the teeth. You know, how can you make a mistake with that sort of thing? To tell you it’s cleared and then all of a sudden, no. That was another where hospital let me down.”* (Jimmy)

Jimmy has been humiliated by unfair treatment and negligence of the medical staff at a time when he needed their support most. People, his life depended on, disappointed him and made him suffer mentally after horrible mistake they made.

In the end, however, participants appeared to accept their helpless position of a 'guinea pig' in endless medical trials. They also accepted that they might not be informed about the potentially serious consequences of undertaking treatments and that these treatments might be just as unsuccessful as all of those they had tried in the past. Participants seemed to rely on medical doctors hoping that 'they are trying to get rid of it (virus)'. Thus, on the one hand participants perceive themselves as 'guinea pigs', whereas on the other hand they accept their status of a trial subject.

In summary, continuous participation in antiviral therapies seemed to disturb participants' identity as healthy individuals. A sense of helplessness was sensed here-they were placing all of their trust in the hands of a medical profession who had let them down so badly, so many times in the past. Consequently, they experienced concerns and frustration, but they also appeared to tolerate it and put their lives in the hands of others in the hope that subsequent treatments would free them from the burden of HCV. At times, they appeared desperate and extremely determined in their attempts to get the new cure and 'get rid of the virus'. However, their attitude appears to be justified when the fear of dying and the increasing risk of not being able to survive another day became a reality.

Living with uncertainty

Uncertainty was further heightened by participants' awareness of a rapid deterioration in their physical functioning, particularly a year before transplant.

Some of them just carried on with their lives until ‘it really took hold’, started slowing them down and interfered with their daily living. That was also the time when they had to confront the inevitability of a transplant that they attempted to repress in previous years. They seemed to delay facing reality, immersing themselves in a relatively stable health condition until such a time that their health could not afford them to delay no longer:

> *“I suppose in a way you always wondered what would happen, how you would feel and everything. But I always took the attitude just get on with life. But then, when I started to go downhill after that, you know, they had mentioned you know a number of years before, you know this...I always knew there was always a transplant at the end of it, even if they didn't work the treatments now, there is always a chance of transplant. I didn't go into, you know, what that meant really, until when I started go downhill 2013.”(Gus)*

Further, when the transplant was considered as the only life-saving option, participants were then confronted with the related, subsequent challenges and uncertainties (e.g. expecting a place on the transplant list). None of the participants appeared to know how long it would take to receive the decision and if they got a positive one, how long they would have to wait for the transplantation. Awaiting the decision seemed to be ‘endless’, even the shortest period of time felt an eternity, when their life was at stake. They became impatient and expressed their frustration by questioning the meaning of keeping them on hold.

Uncertainty of what would happen to them in the near future evoked desperate indagation:

> *"Why is it taking so long? Why is it taking them two months to write this? Why am I not there? Why is it taking so long? And when you think back it wasn't that long but it's long to me because it's another two months down the line where I should have started two months. Who knows what lengths of time that you are going to be on the list? Nobody knows." (Eric)*

Eric seemed to feel lost and abandoned, when all he needed was information provision and reassurance. Feeling alone, in this critical moment, when participants were so fragile and hanging in the balance, would determine their fate and a sense of helplessness and desperation.

Some participants also did not know that considering their poor condition, there was a real possibility of not receiving the transplant. They appeared to be confused and deeply disappointed when they discovered the real purpose of pre-assessment was to verify 'whether or not they should go on the list' and not as they assumed to understand how much they 'needed to be looked after'. Paradoxically, their deteriorating health status that brought their cases to the stage of transplant consultation, could have also declined their chances of getting onto the transplant waiting list. Therefore, a feeling of relief, calm or joy accompanied the news that they were going on the list. The power of the long-awaiting decision was for some participants and their partners extremely overwhelming causing a small breakdown and an awaking of future expectations:

“They told me, you’ve been accepted, you’re on the list and I just broke down, totally. I think, I’m going to start getting my life back here. Then of course you don’t know how long you’ve got to wait, it’s just your luck I suppose.” (Jimmy)

This happiness and relief was short lived and quickly replaced with worry, fear and eschatological thinking. Their hope appeared to be tinged with fear of not receiving the transplant after all. Two of the participants (Harry, Eric), reported that because of their very rare blood group, there was a real possibility of not finding a suitable donor in time. Therefore, the fear of dying before they could receive a transplant, seemed pronounced and very real. Participants were aware they could die ‘anytime’ whilst awaiting the transplant and feared that they would not live another year.

This fear of dying did not dissipate them even when they had reached the transplant stage. They were told by surgeons about possible fatal outcomes of the operation and about ‘the amount of people that died on the operating table’, which all heightened their pre-transplant anxieties. The information given to them prior the operation evoked eschatological thinking and an accelerated awareness of their own mortality. Uncertainty of the outcome made them feel extremely vulnerable and helpless. A matter of their survival and their faith appeared to be beyond their control:

“They said, "You might die on the operating theatre. Your liver might be rejected so you've got to go onto the super list, and that's a case of you first to get a liver." That's quite

scary as well, saying if I'm going for a liver transplant and that liver doesn't take, how am I going to survive until they get me a new one because I don't – you've not got that long to go. I don't know if it's a day or two days, I don't know. But it'd be a case of I'm first to get a liver in the United Kingdom and it's pretty scary." (Ted)

Uncertainty about survival of the transplant was expressed by all the participants. They were scared about dying on the operating table. They appeared to be particularly worried about the fact that they 'might never see' their relatives again and that their partners would have to deal with their death and its consequences. They tended not to share their fears with anyone to 'not scare people' with saying that they 'might not be back'. Their priority became to protect their loved ones from despair by covering their own worries and uncertainty. A moment when the fear of dying accelerated and 'kicked in' was for the majority of the participants the point at which they were taken in to the operating theatre:

"The worrying one is when you're actually on your way there and – in your head, you know what to expect, but you don't know. And when you get taken down, on the way through it and when you're getting taken down in that theatre, you think to yourself, is this it? Is this my last breath sort of thing?"(Jimmy)

Jimmy's and some other participants in the current study, revealed stark realisation of their own mortality and how fragile their lives were at that moment in time. Everything appeared to be suspended here, fixed on this one moment of

liver transplantation where their life hangs beyond the balance and depends on others.

Some participants reframed the seriousness of the situation they were in, by reassuring themselves that they were ‘strong enough to get through the operation’. Further, their irrational optimism also appeared to be expressed regarding the outcomes of the transplant. Some seemed to strongly believe that they would be able to survive the procedure, as if they were predestined to live and not to die. Conversely, others appeared to accept the worst scenario assigning the outcome to predestination, something that seemed to be beyond their control leaving them only with prayers and hope. By accepting the fact that their survival was beyond their control, they started to adopt a fatalistic approach:

> *“So maybe something happened but I also said when it happened it happened. This is Allah brings, Allah, God so it’s happen it will happen but we’ll pray to God and something happen better for me. That was the only hope.”(Harry*)

Once more, the successful transplant that they prayed for and hoped for, did not, again, release their fears and uncertainties. HCV recurrence was ‘sort of hanging over’ them, like ‘a shadow, a thing on the new liver that did not let them forget that they would never fully recover or ‘get rid of their illness’. Despite all the efforts from the side of medical providers, a transplant gave the participants no guarantee of clearing the virus. However, knowing that there was a chance of recovery was enough:

> *"At first I thought, 'Oh well one side of the transplant that will be my clear than clean', but then I thought about it and I did ask the doctor and he says, 'No it could re-infect you because they can't take it all out' even with a blood transfusion, he said, 'Even that there could still be traces in that' so I settled for that, but as long as I got the new liver."(Chris)*

Finding out about virus recurrence after transplantation appeared to bring other participants to a realization that they were '*on the downward slope again'* and that *'a continuous circle with the Hep C'* was never ending. Their way through illness and treatment appeared to be, at that point, an endless Sisyphean cycle. Consequently, the lack of positive outcomes made them to express their helpless position that there was no point of trying anymore, because it seemed that they were 'not going to get anywhere' despite the constant efforts.

Feelings of helplessness in the face of reoccurring HCV appeared to be additionally enhanced by the unknown extent of HCV on the new liver. The majority of participants emphasized the aggressive, 'attacking' nature of the recurred virus that viciously 'came back with a vengeance'. Participants seemed to make a deliberate attempt to humanize the recurrent infection and make the reflections very personal. It appeared to reveal their need for creating a tangible enemy that endangered their health and well-being, one that they were constantly battling against.

Participants then began to turn their attention to their new organ, in particular, they focussed on preserving the new liver and protecting it as far as possible. Despite this, concerns of organ rejection was 'could happen at any time' (Gus).

New cure-"if they can get rid of it, I'll be over the moon."

Information about a new cure with the potential to clear the virus, formed a solid foundation of hope for HCV patients after transplantation. Participants seemed to associate new treatments with something that could only 'improve things' and prevent them from suffering 'badly'. The cure regained and intensified a sense of future possibilities in their lives. Clearing the virus seemed to restore their positive attitude to life and brought back enjoyment and hope. It also appeared to have the potential to erase everything that made their lives a constant struggle:

> *"So when I become healthy I can do a job. I can enjoy my life. It's so… You know enjoy the world. I became good and so is there is no other complication, no problem." (Harry)*

The participants' hopes for a disease-free life seemed to be slightly counterbalanced by fears of detrimental side effects of treatment. Most of the participants tended to look back and identify situations that were burdensome and prevented their adherence to the previous treatments and getting the virus clearance (as discussed previously). Participants were deeply concerned about possible side effects and worried about 'what could go wrong' in the course of the treatment. They recalled vividly symptoms like 'sickness, dizziness, and sleeplessness' that affected them in the past, and they appeared to fear liver rejection as a consequence of taking new treatment. However, no matter how detrimental were the effects of the past medical trials, and how the new cure could affect their new liver, they seemed to be desperate to receive it anyway and put themselves 'forward for anything':

"It depends how bad the side-effects were. But if I thought I could with them then I would carry on, it's only twelve weeks. I mean it sounds a long time, but it'll be worth it in the end I suppose." (Jimmy)

Most of the participants identified a number of factors that could stop them from attending the new sofosbuvir treatment, such as organ rejection, side effects or uncertainty about its effectiveness in post-transplant patients. However, all these fears and uncertainties that the novel therapy evoked, seemed to not only have a rational explanation. Participants appeared to identify obstacles and contraindications for the new therapy in order to protect themselves from disappointment and frustration that could result if the sofosbuvir treatment failed. This might also relate to the way they had learned to adjust to the challenges of living with HCV and a series of treatments they had undertaken over years.

Two participants, who completed the sofosbuvir treatment and cleared the virus successfully, reported being seriously ill after receiving it. Here again, the sense of determination and hope of being 'virus-free' supported their adherence to the course of treatment. As participants who were still expecting the treatment, they started instilling hope that was not based on 'much evidence' or 'exact science', but they were still 'hoping for the best', and kept their 'faith' all along. When the treatment was considered successful, a sense of freedom was reported, giving birth to a new, healthy identity:

"After it was clear I was a different person because that always hanging over me after the transplant. There's a shadow, a thing on the new liver, the hepatitis C is

attacking it, once I got clear, different, great, so it was."

(Steve)

In summary, this section showed how participants' outlook on life and themselves had shifted diametrically as soon as they found out that they had cleared the virus or when they could just imagine themselves to be cured. A sense of determination and often desperation accompanied their need to be considered for the new cure and to 'get rid of the virus', which seemed to stand in their way to happiness and enjoying their lives fully. Hope appeared to strengthen their resilience in the light of uncertainty of possible side-effects and detrimental long-term consequences of sofosbuvir treatment. There seemed to be nothing that would stop them from becoming 'a trial and error' or 'a guinea pig' in the new treatment, as long that would mean to them 'no need to go on the other stuff' and saving the new liver.

Chapter Five: Discussion

This chapter will provide an overview of the findings from the current study and will discuss them in the wider context of the HCV literature. A reflection on the author's personal experience of conducting this study will then follow. The strengths and limitations of the research will then be outlined and recommendations for future research will be made.

5.1 Summary of Findings

Three master themes and seven subordinate themes have emerged during the course of this study- as a result of using interpretative phenomenological analysis (IPA) in the process of data analysis. An interpretation of how participants had encountered their HCV diagnosis resulted in identification of: 1) various psychosocial aspects of being infected with the virus, and 2) how they initially learned about the illness. Being diagnosed with HCV was for most of the participants in this study, a powerful life event that brought about a immense sense of uncertainty and loss in their lives. Participants reported that their initial uncertainty relating to the diagnosis was mainly determined by a lack of information provision. Subsequent consequences of receiving diagnosis were recognized in terms of changes of participants' social identity and their experience of stigma.

The second theme revealed different ways of managing the challenges and burden of living with HCV. Participants' approaches towards the illness were found to be very pro-active and problem-focused. Resilience and seeking help from family members were two main strategies observed in dealing with adversities related to diagnosis. An emphasis was also put on the need for

professional medical support at the time of the uncertainties that were noted to accompany several antiviral treatments and post-transplant/virus recurrence related deterioration.

The third theme took the reader through a chronological journey of HCV treatment. This was again defined by uncertainty, unpredictability and insecurity. A lack of sufficient support and information provision, regarding endless medical procedures, evoked a disruption to participants' identities. Their sense of self was reduced to the status of 'a guinea pig' that has to persistently pursue new treatments in order to survive. Their attitude towards those treatments appeared to be determination and hope driven.

5.1.1 The experience of encountering HCV

According to Bury (1982), a typical initial reaction to diagnosis is a feeling of uncertainty. Participants in this study repeatedly expressed their fear of the unknown, disbelief and shock due to lack of knowledge regarding HCV; observations which have been previously described in the literature (Tompkins et al., 2005; Suarez, 2010). However, although many of the participants reacted intensely to their diagnosis, not all of them did. Some of the participants in this study seemed not to be unaffected by receiving the news about their illness and carried on, with their daily routine uninterrupted.

Other patients, on the other hand, indicated a profound change in their quality of life. This detrimental effect was caused by labelling associated with the diagnosis itself; as previously recognized in the literature (Rodger et al., 2003).Moreover, an illness that had been asymptomatic and had no impact on participants' lives for years, unexpectedly started to significantly interfere with

their daily functioning. Also, participants' perception of the worsening of their condition could have been determined to a great extent by their beliefs regarding the illness and attitudes towards it, rather than actual reactions to the presence of deleterious symptoms of liver disease (Castera et al., 2006).

A similar division in approach to diagnosis has been noted in previous research (Harris, 2009; Olsen et al., 2013). These differences demonstrate how the reaction to diagnosis can be dependent on the context. Those participants who contracted HCV through injected drug use reported that receiving HCV did not disrupt the structure of their everyday lives. Since it was recognised as an inevitable consequence of their actions. Also, due to high rates of HIV in this population, perhaps HCV was perceived as lesser of those two negative health outcomes. As previously recognized (Olsen et al., 2013), these individuals seemed to accept that the infection was incorporated in their identity of former drug users.

However, although some of the participants seemed to be unaffected by the diagnosis itself, it did change how others responded to them and treated them. This resulted in a disruption to their social identity. Poor knowledge about the infectiousness of HCV, and associating the disease exclusively with intravenous drug use, were found to fuel stigma against infected individuals (Butt et al., 2008; McCreaddie, Lyons, Horsburgh, Miller, & Frew, 2014; Hill, Pfeil, Moore, & Richardson, 2014). Feelings of social isolation and loneliness, as a direct consequence of stigmatisation, were also exposed in the majority of accounts- as also reported in the existing literature (Hill et al., 2014; McCreaddie et al., 2011).

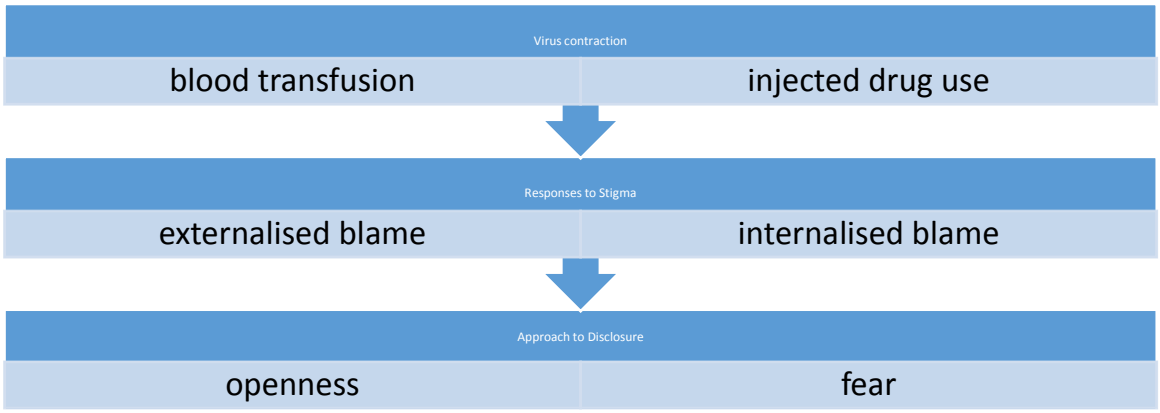
This current study revealed that the stigma could also be related to strong emotional responses. According to previous findings (Tompkins et al. 2005), a diagnosis of HCV might raise considerable negative emotions that participants then appeared to direct against themselves (e.g. regret and shame) or towards others (e.g. blame and anger). Blame and anger, in terms of the stigma of HCV, can be understood as attempts to resist or reject the existing situation. These reactions were found to promote changes in a societal order and have the power to preserve positive self-identity (Stuenkel & Wong, 2009). Therefore, participants in the current study who reacted strongly to the diagnosis also indicated a very pro-active approach towards socio-political circumstances relating to HCV and appealed for their transformation.

Conversely, participants who were only focused on internalizing blame and regret in terms of contracting HCV (by injecting themselves), adopted a rather passive attitude towards general issues of HCV and indicated a tendency to isolate themselves from it. This reaction to stigma was found to be typical amongst affected individuals who often limited their contacts with society to enhance their feeling of normality (Camp, Finlay, & Lyons, 2002). The participants' sense of normality and distancing themselves from the diagnosis, was, in addition, facilitated by the initial lack of symptoms typically associated with HCV. This 'invisibility' of the stigma helped them to deny the salience of the diagnosis (Suarez, 2010).

The sense of stigmatisation was expressed differently by all participants in this study; which supports previous findings by Zickmund et al. (2003) who indicated that stigmatisation affects all infected individuals, despite their source of infection. However, as this current study has newly found, there are differences in terms of

how various groups of affected participants can react to diagnosis. Thus, it was shown that 'victims' of contracting the virus through blood transfusion tended to externalize their blame, whereas former drug users internalized blame. These new findings seem to consequently lead to differences in their approach to disclosure and coping (see Fig. 4).

Fig.4. Differences of responsiveness to stigma and disclosure amongst participants in the current study.



Thus, a fear of stigma and rejection determined participants' decision about the disclosure of their HCV status to their family, friends and society in general. One of the participants in the current study chose not to reveal his illness to relatives. This is a common reaction amongst HCV patients, previously supported in wider literature (Schafer et al., 2005). Fear of disclosure was also found to be an obstacle in building new romantic relationships or keeping previous contacts in other participants. Thus, diagnosis of HCV can lead to a long-term impact on patients' ways of interacting with the family, friends and society, which is consistent with earlier findings (Tompkins et al., 2005).

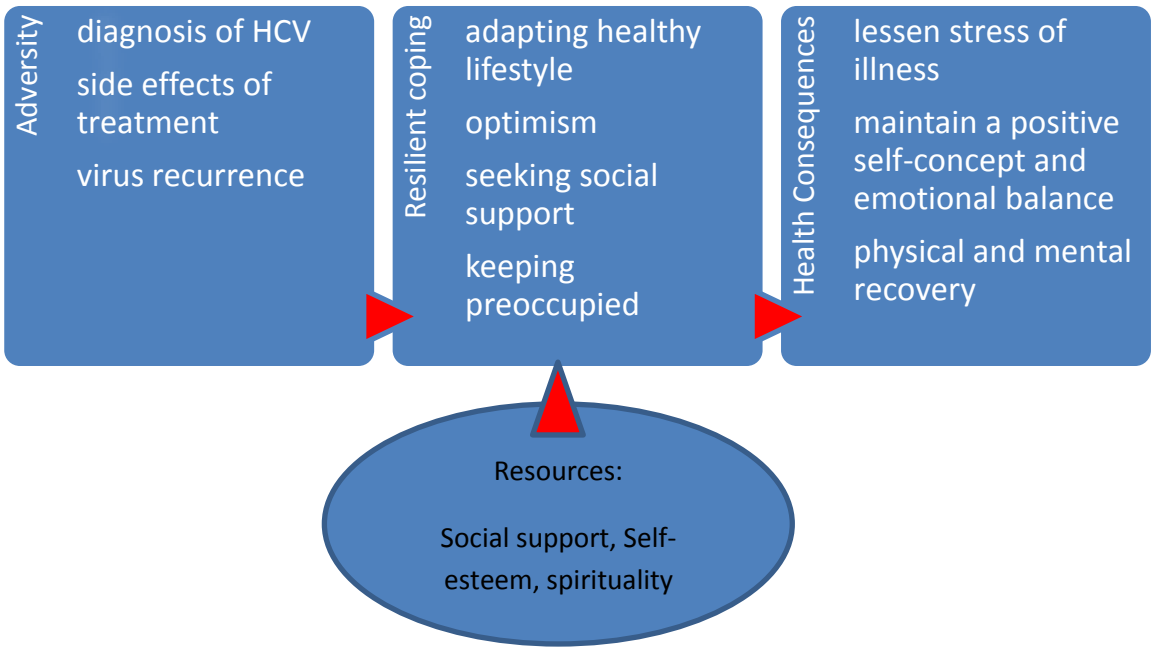
This attitude seemed to be related to participants' concerns about compromising the health and well-being of others- an observation that was also highlighted in previous research (Tompkins et al., 2005). This protective mode in approach to others often resulted in the limiting of participants' contacts with friends and their

children, sometimes even in living in solitude. In this sense, findings in the current study extend those of the previous literature, by highlighting the inter- and intrapersonal consequences of HCV infection.

5.1.2 Managing the diagnosis of HCV

In this study, participants indicated resilient coping mechanisms in response to diagnosis with HCV, prolonged treatment and its severe side effects (Fig.5). The chronic disease that, until last year, was perceived as untreatable, constituted extreme hardship that could be maintained only if patients have a certain capacity to cope with it. This capacity can emerge from a range of external resources, including a caring family and wider social network, as well as from the strengths and resources that can be identified within individuals themselves. By successful recognizing, evaluating and applying these resources, people with chronic illness can enhance their resilience in stressful times this can have positive implications for their health and well-being (Tedeschi & Kilmer, 2005).

Fig.5. Resilient coping model produced based on data in this study.



When considering HCV as a chronic life adversity, resilient responses appeared to be a highly adaptive way of protecting and self-maintaining participants' well-being. Findings of this study revealed participants' involvement in religious practices and fatalism. As previously supported in the extant literature (Bonanno, 2004; Stoller et al., 2009; Pargament et al., 1998), spiritual meaning-making processes were identified in two patients' accounts. One of the participants used his religious beliefs to decrease his stress reactivity towards the adversity of treatment (Steve) whereas another participant turned the illness over to God, interpreting his own outcome as being part of God's plan (Harry).

The importance of establishing a healthy lifestyle was also found to be protective in the process of shaping participant's resilience to HCV (Hopwood & Treloar, 2008). Accordingly, participants in this study utilized the positive health behaviours in order to effectively deal with uncertainties related to living with HCV. This strategy appeared not only to be a guarantee of physical improvement, but also gave them a sense of control over their condition, which was recognized in previous research (Hill et al., 2014). Participants did not only follow the dietary advice from medical staff by applying the new routine, but they also seemed to recognize for themselves food that prevented their recovery and compromised their relatively stable health status.

Hopwood and Treloar (2008) recognized that work and keeping occupied as were essential coping strategies in HCV patients. Consistent with their findings, participants in this study were found to emphasize the importance of being employed or engaged even in small everyday tasks. Adherence to a daily routine provided them with a sense of purpose in life and became a synonym of normality. When they were deprived of their daily activities and responsibilities, their social

identity was disrupted. The well-known structure of their everyday life and their self-concept had to be fundamentally reconsidered (Bury, 1982). Therefore, they were determined to stay employed or engaged in their daily tasks in order to maintain their sense of stability, self-worth and 'normality'.

The pro-active, problem-focused coping that promoted a sense of control over their condition also enhanced their positive mental attitude. An applied positive approach can, in turn, enhance the development of their resilience in the face of chronic adversity (Bonanno, 2004; Tedeschi & Kilmer, 2005). As is typical with resilient people, who were found to be hopeful and optimistic even when facing chronic illness (Peterson, 2000), most of the participants in the study adopted positive overview of the illness and future treatment. Their optimistic approach to life in general facilitated their sense of improvement and 'freed them' from experiencing life through a narrow, illness-related lens.

Support from significant others and support groups were also found to be important variables in maintaining the physical and psychological consequences of HCV treatment (Hopwood et al., 2006). In this study, participants emphasized their need of support from family and friends for coping with adversities related to their treatment. Being aware of their own vulnerability and limited physical abilities following liver transplant or antiviral therapy, they acknowledged the invaluable role of their partners and children in their fight with HCV and recognized the need for support for their loved ones. These findings constitute an important indicator for potential primary carer-focused interventions (Chapman & McManus, 2012).

Participants also reported being trusting and appreciative of their medical supporters, recognizing their engagement and competence. However, the gratitude and general positive view of medical professionals was often counterbalanced with strong feelings of disappointment and negligibility at times.

An urgent need for more information about the sofosbuvir treatment, and for seeing a doctor regarding this treatment, facilitated their negative and doubtful attitude towards healthcare providers in general. This builds on previous research revealing a negative experience of receiving insufficient information and help from medical staff (Bailey, Armour, Kirk, & Jess, 2009) and how such insufficiencies can affect individuals' sense of control over HCV (Hill et al., 2014).

5.1.3 The experience of treatment

The experience of the antiviral treatment that participants were receiving before transplantation, and often also after the operation, was described by them as highly detrimental- both in terms of physical and psychological side-effects. Their accounts are consistent with previous research investigating the side effects of interferon and ribavirin therapies (Rodis & Kibbe, 2010). Many participants reported outbursts of anger and frustration as well as sudden mood swings, and finally a number of physical debilitating symptoms.

These side effects not only had a huge impact on the patients themselves but also significantly affected their families and friends. Unexpected and misunderstood symptoms disturbed family dynamics and, often evoked a need for withdrawal and a sense of losing the control over their own lives. This feeling of a lack of control over their actions caused the majority of participants to experience symptoms of depression; which has often been reported in the previous literature (e.g. Ong & Younossi, 2004).

The lack of control was also a result of participants' uncertainty regarding treatment for HCV and decision making related to it. Sustained uncertainty about receiving, and effectiveness, of subsequent treatment for HCV has already been highlighted (Hopwood and Treloar, 2005; Sgorbini et al., 2009). This uncertainty

and lack of control over the process of treatment did not, however, stop participants in the current study in their determination and adherence to treatment. Despite an ongoing burden of unsuccessful treatments, the hope for a future cure was present in their accounts; an attitude also recognized in existing research (Hill et al., 2014).

As the current study included patients who were either before or after the new sofosbuvir therapy, certain differences were identified in their approach to treatment and future life. Uncertainty regarding decline of their health, as a consequence of virus recurrence, was an ongoing burden described by five pre-treatment participants. This uncertainty was consequently reinforcing their lack of control over their lives and future. Conversely, two participants who had already received the new treatment and cleared the virus, experienced a sense of liberation and complete control over their future. Thus, this study has demonstrated how a limited framework of uncertainty, that is related to the diagnosis of a chronic illness (Bury, 1982), can suddenly shift towards a framework of possibilities and future certainty when a sense of healthy identity is regained through successful outcomes of treatment.

5.2 Clinical Implications

Participants in the current study highlighted the difficulties they were facing while undergoing pre-transplant anti-viral treatment, liver transplant and post-transplant therapy. The biggest issue at these stages of treatment seemed to constitute a lack of information provision and limited contact with medical doctors. The informational gap caused both participants and their family members to feel lost and confused when they experienced unexpected side effects or a sudden health

deterioration in their health following HCV treatment. Therefore, some participants argued that there is a need for being as informed and prepared as possible regarding the consequences of HCV treatment.

Learning more about the current and anticipated treatments would lessen a sense of being ‘a guinea pig’ in a set of experimental trials and help participants regain their sense of control over their illness. In addition, the possibility of receiving this information from medical doctors directly could resolve doubts and fears that seem to stigmatize participants’ post-transplant existence. As participants’ trust in medical providers had been challenged over the course of prolonged treatment, being seen by transplant doctors might also facilitate a successful attempt to rebuild a well-functioning patient-physician relationship.

In terms of implications for treatment, participants’ accounts revealed a need for interventions aimed at family counselling at each stage of living with HCV. Participants often indicated how HCV seriously affected their loved ones. Therefore, it is suggested that individual therapy should be provided for primary caregivers, who are otherwise not provided with any form of organized support. The important role of the family in the participants’ recovery also provides a rationale for counselling specifically focused on primary caregivers.

The fear of disclosure and engaging in sexual relationships that were recognized in this study, constitute an important implication for therapeutic interventions for both affected individuals and their current (or potential) partners. Attending a counselling session with loved ones would allow patients to explain their HCV status in a safe environment and help them to improve the communication in their relationships after disclosure. The fear of engaging in sexual relationships could

also be verified during the couple counselling and bring some clarity in terms of real and potential risks of sexual intercourse with people with HCV.

5.3 Recommendations for future research

Although findings of the current research provided a rich and explanatory account of the experience of life with recurrent HCV from the patients' own perspective, they also opened up several possibilities for future research. Reflecting upon changing medical circumstances of individuals currently being treated for HCV, present research constitutes an important fund of knowledge that could be elaborated upon and supplemented in the near future by subsequent qualitative or quantitative investigations.

First, some of the participants' accounts revealed that HCV has not only a huge impact on those directly affected by the virus but also on their significant others. Therefore, it is recommended that an exploration is conducted upon the experience of HCV from the perspective of family members, who are usually the primary and the only caregivers of infected individuals. According to participants' accounts, at times the diagnosis and consequences of HCV treatment affected the partners and children more than the participant. Paradoxically, loved ones were not offered any form of support, neither physical nor psychological. Therefore, through exploring primary caregivers' experience of HCV, future research might recognize essential implications for intervention focused specifically on family members. Given the reluctance to disclose their HCV status to partners (or potential partners), the feasibility of family/couple counselling could be explored to: 1) improve interpersonal communication in relationships at the point of diagnosis; and 2) resolve ethical issue regarding not informing partners who could be at risk of infection.

Second, the sample of this study was homogenous in terms of gender, consisting exclusively of male participants who, in addition, represented congenial age range. Thus, it would be interesting to explore the experience of HCV diagnosis and treatment from the female patients' perspective. Considering that women were mainly identified as caregivers in the present research and are associated with this role in society in general, it may be of interest to explore their experience in the opposite role.

5.4 Strengths and limitations of the study

Several strengths and limitations have been identified throughout the process of conducting this qualitative research and will now be discussed in turn.

5.4.1 Strengths

This research provided an in depth exploration of a small, vulnerable clinical population living with an ongoing, potentially life-long, viral infection. It revealed valuable socio-political background information related to the context of virus contraction and vague diagnostics given in the 70s and 80s which, to a great extent, shaped patients' lived experience of HCV. The group of patients that was introduced in this study has largely been overlooked by studies that mainly focused on HCV patients with a recent history of injected-drug-use.

Another strength of this study was the fairly homogenous sampling that allowed me to produce a detailed analysis of the lived experiences of a particular group of individuals with HCV. Consistent with Smith et al. (2009), my aim was not, however, to treat all the participants in this group as identical cases but to utilize the obtained uniformity of some basic social factors (e.g. family support, stigma) and theoretical indicators (e.g. the resilience theory) to identify psychological

variability (e.g., different coping strategies, attitudes to life with HCV) within the group. Consequently, I was able to achieve reasonable data saturation while reducing generalizability of the results.

An important advantage of this study constitutes its inherent flexibility and context sensitivity. Flexibility and sensitivity characterized all stages of this research: the data collection, analysis and definition of the findings. Use of semi-structured interviews gave the participants the freedom to respond in their own way and enabled me, as a researcher, to explore anticipated and unanticipated areas of lived experience of HCV. Moreover, according to Patton (1990) who claimed that qualitative data is iterative, I could go back and forth between collected data, analysis and findings, allowing emergence and evolution of more aspects of the same phenomenon, which would not be possible if the design of the study had been rigidly predetermined. The experience of HCV amongst patients in this study would also not be fully understood if it had been extracted from the socio-political context associated with the contraction of the virus and from the family context that played a significant role in maintenance of the participants' physical and mental well-being.

Yardley (2000) who has produced a set of guidelines for assessing the validity of qualitative research, emphasized the importance of applying following principles: sensitivity to the context; rigour and commitment with which the research is carried out; transparency and coherence; and the impact and importance of the research. I believe I demonstrated understanding and adhered to each of the principles. I have introduced the theoretical context, relevant literature background and socio-cultural factors that were relevant for the topic studied. In terms of the Yardley's second principle, I demonstrated my commitment by my personal engagement in the process of data collection, that

is, when and where the interviews took place, as well as in my attentive listening to what participants had to say, and careful reflections on the participants' statements. Furthermore, I was focused on idiographic engagement in data analysis, illustrating particularities of individual cases by using appropriate quotes, but I also emphasize the importance of shared experiences in terms of formulating the major themes. Finally, this study has a practical value for post-transplant patients with recurrent HCV. It provides both the general public and the health professional with information about challenges that are a part of patients' everyday reality and that reveal implications for future interventions.

5.4.2 Limitations

A major limitation of the current research is the reduced possibility for generalizing its findings beyond the seven individuals who were studied. In order to achieve generalizability of the results obtained in this study, further investigations involving larger population sampling and additional studies conducted in respect of the present topic would be required. Conducting more longitudinal studies, following individuals with recurrent HCV through their journey, would also be of great importance. These would provide reflections on the most recent experience of an illness that had been discovered only retrospectively in this study.

Other limitations of the current research included the confined accessibility to patients with HCV (exclusively gained through NHS clinics) and the low response rate to the project. As the contact with patients could only be initiated by the transplant co-ordinators during clinic visits or through the invitation letters, I had to completely rely on their actions and decision making. More participants could possibly have been obtained for this project if they had been recruited through

various support groups or through the transplant clinics, but by direct involvement of the researcher during the recruitment process. Furthermore, the small pool of potential participants was additionally limited by concentrating this study exclusively on the HCV population in Scotland.

5.5 Reflection on the research

5.5.1 Reflection on the recruitment process

As I received an unconditional REC approval for my study in June 2014 (see Appendix 1), transplant co-ordinators in the Scottish Liver Transplant Unit at the RIE were provided with copies of the inclusion and exclusion criteria, twenty recruitment packs and a research protocol, so that they could identify, on my behalf, patients that were suitable for this research and send the Invitation Letter and the Participant Information Sheet to potential participants. Unfortunately, due to miscommunication within the transplant team and a busy period in the transplant unit, in the first two months of recruitment, no invitation letters were distributed to patients. As a result, recruitment was initiated in January 2015 by direct involvement of the Head Hepatologist and the Senior Research Nurse in the Transplant Unit. The response rate in the first two months after the first recruitment letters were sent was small (n=3) but relatively regular; approximately two patients a month expressed their interest and participated. However, despite fairly regular interviews in the first three months, in April 2015, I was not able to access any more patients who would meet my criteria. The number of patients who met my criteria and whom I had invited to my study by the end of March 2015 was relatively small; approximately 23 individuals, of which only four had responded and been interviewed. Given the poor response rate and accessibility, the Senior Transplant Research Nurse, who guided me through the recruitment

process, advised me to open up the inclusion criteria from 6-18 months to 6-36 months post-transplant. This amendment was approved by NHS ethics. Invitation packs were re-sent to participants who had been approached at the beginning of the recruitment period and three further participants were then reached. At this point, I decided to close recruitment as no further participants met the inclusion criteria and I had reached the anticipated end of the data collection period. The achieved sample was exemplary of recommendations by Smith et al. (2009) for a Master thesis.

According to the original research protocol, that was submitted to both ethics committees, I proposed to recruit between six and eight patients with HCV recurrence and between six and eight primary caregivers of those patients. It was my intention to widen the perspective on the infection diagnosis, recurrence and liver transplantation by introducing an in-depth account of caregivers' experiences. However, none of the caregivers responded to the research invitation. Patients who were approached, in the first instance, with the recruitment pack, were also provided with a letter for their primary caregivers which was included in the patient's envelope for them to pass on to their primary caregivers, if they wished to.

The reasons as to why the primary caregivers did not respond included: 1) non-disclosure of HCV to loved ones (n=1); 2) partners considered too emotionally fragile by participants (n=2); 3) not fluent in English and unable to give a written consent (n=1); and 4) unknown (n=3).

5.5.2 Personal reflections

During the process of carrying out this study I became aware of a number of issues that can occur when investigating a clinical population in a medical setting.

The RIE, where the majority of interviews were conducted, was chosen firstly for the researcher's and patients' safety. It was also a place that all participants were familiar with, therefore, it was assumed they would feel more confident and natural while being interviewed there. However, despite my status as a research student being emphasized both in the Participant Information Sheet and upon meeting participants, some of the participants misinterpreted my role in the clinical setting, assigning me a status of a hospital employee. Whenever I noticed an indication of patients' confusion regarding my role, this was explained and clarified again.

However, I often had the impression that participants still seemed to be somewhat unaware that the current study was not related to, and had no impact on, their recent medical treatment. For example, some participants appeared to expect a detailed explanation of the new antiviral therapy and possible professional advice. They seemed to have particular anticipations of the interview in terms of their participation in sofosbuvir treatment and perceived me as a mediator between them and the hepatology unit. Despite continuous clarification of the research being entirely independent from their medical care, these erroneous assumptions were often evident.

Using IPA as a method of investigation was a new (and at times challenging experience) as I had not previously conducted any qualitative research. I had to exert caution with the nature and type of questions I asked and seek clarifications on answers I received to ensure I was understanding participants experiences from their own perspective. As a novice qualitative researcher, I often sought feedback from my supervisors including ongoing feedback on the process of coding, analysis and the clustering of initial themes. As the project progressed, I gained confidence and independence as an analyst.

5.6 Study Conclusions

The aim of this study was to gain an in-depth understanding of the experience of living with recurrent HCV following a liver transplant. I achieved this by exploring participants' accounts that guided me through the subsequent stages of their life with a HCV diagnosis. The reports gave me an insight into several idiosyncrasies and similarities in patients' attitudes and expectations, both prior to and after liver transplantation. Individual differences in the ways participants tried to manage the virus were identified, as well as a variety of resources utilised for coping. However, all participants were found to be strongly determined to fight HCV and were looking positively towards a virus-free future. Their resilience in the face of prolonged adversity of chronic disease accompanied them from the moment of the diagnosis, throughout the detrimental antiviral treatment, liver transplantation, and diagnosis of virus recurrence until the present moment, when they had either already cleared the virus or were still awaiting the new HCV cure.

Through exploring the experience of living with recurrent HCV, the current study made an important contribution to previous research addressing a unique journey of HCV re-diagnosis. It has explored intra-personal and inter-personal consequences virus recurrence and indicated potential implications for individual and couple/family therapy which should be adapted to the needs of patients and their loved ones at specific points in time. The periods of pre-and post-transplant antiviral treatment were found to be extremely challenging for both participants and their families, and therefore, should be further investigated and addressed in terms of mental support.

In addition, a paucity of a clinical population with medically acquired HCV exists within the wider literature- this group constituted 70% of respondents in this current study. The socio-political context of their diagnosis seemed to be omitted in the scientific investigations in the U.K. as well as analyses of their unique social challenges and unique perspective on the diagnosis. Their approach to diagnosis and coping strategies differ from those applied by the participants who acquired HCV through intravenous drug use. Consistent with the work of Jacalyn Duffin (2005), who recognized 'two diseases'- two forms of HCV- the first associated with 'contaminated' blood transfusion ('innocent') and the second acquired through IVDU ('guilty'), this study recognized both forms of HCV. Further, the characteristics of these two groups were elaborated in the current study by identifying two new, distinct, patters between methods of virus acquisition, reactions to stigma and participants' approaches to disclosure.

This project has also revealed significant shifts in patients' attitudes following encountering the news of the new HCV cure or after successful completion of the treatment. Hope and optimism about the future and regaining the 'old' healthy self were predominant in their responses. Thus, this research was the first qualitative study that has revealed the attitudes of people with recurrent HCV to the new antiviral therapy. Their experience and expectations were unique as, unlike individuals who have been recently diagnosed with HCV, they have had to live long years with the diagnosis and experimental treatments, in uncertainty and fear. For participants in this study, who either received or are expecting the new treatment, it is a life-saving and life-changing option that they have been desperately awaiting for decades.

The implications of this study lie particularly in the potential for improvement in the quality of the lives of patients with recurrent HCV, who are still waiting to receive the ‘new cure’. Gaps in the knowledge about the new treatment, and the need for greater clarifications in terms of its side-effects and effectiveness, were indicated by some of the participants. In addition, considering the high level of psychological distress and the high prevalence of depression identified in patients with the poorer long-term quality of life after liver transplantation, it is argued that counselling and psychological intervention should be provided along with the post-transplant antiviral therapy. Also, according to participants’ accounts, additional care and support should be provided for their significant others who are, as primary caregivers, also significantly affected by numerous challenges related to the diagnosis and treatment of HCV.

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Appendix 1

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 3
Ground Floor – The Tennent Institute Western Infirmary
38 Church Street Glasgow
G11 6NT www.nhsggc.org.uk

Miss Anna Krzeczkowska

Date	27th June 2014
Your Ref	
Our Ref	
Direct line	0141 211 2123
Fax	0141 211 1847
E-mail	WOSREC3@ggc.scot.nhs.

Dear Miss Krzeczkowska

Study title:	**Experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation: an interpretative phenomenological analysis.**
REC reference:	**14/WS/0122**
Protocol number:	**n/a**
IRAS project ID:	**153106**

Thank you for your letter of 17 June 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC.

A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact, wosrec3@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Appendix 2

GP Information Letter

<<Supervisor's name and address>>

<<insert GP's Name>>

<<Address>>

<<Postcode>>

Date:

Dear Dr ...,

Re: (Patient name, age and DOB)

Patient X has been in contact recently to express his/her intention to participate in a qualitative study exploring their personal experiences of recurrent hepatitis C virus following a liver transplant. Together with Professor … , this study will be carried out by Anna Krzeczkowska (an MRes student at Edinburgh Napier University) and will be closely supervised by Dr… and myself.

More specifically, Edinburgh Napier University and the Out-Patients Department (OPD4) for Gastrointestinal and Liver Disorders at the Royal Infirmary of Edinburgh, are interested in the personal experience, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation. This project is interested in learning more about what the diagnosis of virus recurrence and liver transplantation has meant for your patient.

Your patient will take part in an interview about his/her experience of hepatitis C virus infection recurrence after liver transplantation. The researcher will ask him/her to tell her about his experience of living with hepatitis C virus.

We will arrange for the interviews to take place at the Welcome Clinical Research Facility at the RIE where we can book private and confidential rooms. If possible, we will arrange the interview on a day when your patient will be attending for a follow-up appointment with his/her hepatologist.

The potentially sensitive nature of the interview questions may result in some individuals experiencing a degree of emotional distress. In the unlikely event that a participant/your patient becomes upset/distressed as a consequence of the interview, they will be encouraged to discuss any upsetting issues with the resident Clinical Psychologist at the Royal Infirmary of Edinburgh. A debrief sheet will also be provided for a participant detailing the contact details of the Chief Investigator (myself) and the Clinical Psychologist at the RIE whom he/she can contact should they experience any emotional problems as a result of the interview. The participant will be also be advised that he/she can withdraw from the research at any time and does not have to answer any question(s) that he/she does not wish to.

Participation in the study will be completely confidential. However, confidentiality may be limited if the researcher (research student), who will be conducting the interview deems there to be a risk to the participant/your patient. In relation to someone becoming distressed or making a statement which gives cause for concern (e.g. expressing suicidal tendencies), the researcher as a certified Mental Health First Aider will provide initial help to the person. She will provide reassurance. The participant will then be informed that the researcher will contact an experienced member of staff within the liver transplant team. This individual would be contacted immediately and would remain with your patient while NHS protocol for suicidal patients was adhered to (e.g. contacting you as the patient's GP, contacting the liaison Psychiatry team etc.). This would be discussed with the participant prior to the disclosure of information. Your patient will be informed of this within the participant information sheet and consent form. This procedure adheres to Section 7.1 of the British Psychological Society's Code of Conduct, Ethical Principle & Guidelines (2006).

Patient X has consented for me to contact you to inform you about his/her participation in this study and is aware of the possibility that you might be contacted if there is a risk to his/her well-being. Please let me know if there is any reason why this patient of yours should not take part in a study of this sort.

If a reply has not been received within 14 working days, confirming the patient's suitability to take part in the study, then the patient will **not** be contacted. Please do not hesitate to contact me if you have any queries.

Yours sincerely,

Appendix 3

Liver Unit

The Royal Infirmary of Edinburgh
51 Little France Crescent

Edinburgh EH16 4SA

28 January 2014

To whom it may concern

Dear Sir or Madam

I am happy to support the study of Ms Krzeczkowska in patients with recurrent hepatitis C post liver transplantation. The liver transplant coordinators and I will help in recruiting subjects for the study once all approval has been obtained

Yours faithfully,

Professor of Hepatology

Appendix 4

Letter of Invitation

Experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation: an interpretative phenomenological analysis.

Edinburgh Napier University is working in collaboration with the Scottish Liver Transplant Unit at the Royal Infirmary of Edinburgh on a research study looking at experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation. We are recruiting people who were diagnosed with hepatitis C virus infection recurrence after liver transplantation, and their primary caregiver to take part. We hope you will tell us what it is like to live with hepatitis C virus, from your own perspective. It is up to you to decide whether or not to inform your partner or family member about the project. Please bear in mind, that partaking of your caregiver is NOT a requirement of your participation in this study. We appreciate your personal view and do understand if you do not want to involve your caregiver in this project. However if you would be willing for your primary caregiver to take part in this study, please find an additional envelope and an invitation letter attached to this letter that you can pass on to your caregiver.

This project will involve taking part in a one-to-one interview with the researcher. The interview is just like a chat with the researcher asking you about what is like to live with hepatitis C virus, how your life has changed after liver transplantation and the things you find most difficult about being diagnosed with virus recurrence. Although the researcher has some questions that she would like to ask you, we hope that you will just talk about what is important to you. The interview will last approximately 1-2 hours (but could be less or more). The interview will take place in private. The project is completely confidential. You will be given every chance to stop or withdraw from the project at any time without having to give a reason. Participation/non-participation/withdrawal from the study at any time will not affect your current/future care in any way. It is important that you understand that that there are no direct benefits for you in taking part. You will, however, play an important part in raising awareness of what it means to live with hepatitis C virus and to suggest improvements for future support/care. Please see the Personal Information Sheet attached to this letter that will give you full details about the study.

Please note that you do not have to take part in this project if you do not want to. It is completely voluntary.

If you would like to know more about the study or are willing to take part in it, we would ask you to send us an e-mail or to return the reply-slip attached. Should you have any questions, please do not hesitate to contact the research team:

Researcher's name: Chief Investigator:

Thank you for reading this letter

Please see below for the reply slip

_ _

Please cut this reply-slip out and send it in an attached envelope to the researcher.

Please tick (√) appropriate box:

1) I would like to know more about the study and I give you my consent for contacting me through contact details indicated below in order to discuss the project further;

☐

2) I would like to take part in the project and I give you my consent for contacting me through contact details indicated below:

☐

Name ____________________________ Date ________________________________

Telephone_________________________

Email__________________________________

Appendix 5

Edinburgh Napier UNIVERSITY

Participant Information Sheet

Study Title: Experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation: an interpretative phenomenological analysis.

1. **Invitation Paragraph**

You are being invited to take part in a research study looking at the personal experience, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation. Before you decide whether or not to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read through the following information carefully and discuss it with others, if you wish. Please ask me if there is anything that is not clear or if you would like more information.

2. **What is the purpose of this study?**

Edinburgh Napier University and the Out-Patients Department (OPD4) for Gastrointestinal and Liver Disorders at the Royal Infirmary of Edinburgh, are interested in the personal experience, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation. This project is interested in **YOUR** experiences of living with hepatitis C virus. We are interested in learning more about what the diagnosis of virus recurrence and liver transplantation has meant for **you**.

3. **Why have I been invited?**

We are contacting patients who were diagnosed with hepatitis C virus infection recurrence following liver transplantation and who were treated at the RIE in order to ask you to take part in this study.

4. **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be read this information, have an opportunity to ask questions and then you will be asked to give your written consent. If you decide to take part, you are still free to withdraw at any time, without giving reason and without your rights or future care being affected. It is important that you understand that a decision not to take part (or a decision to withdraw at any stage) will not affect the standard of your care or any future care that you require.

5. **What will happen if I take part?**

If you decide that you would like to be involved, you will take part in an interview about your experience of hepatitis C virus infection recurrence after liver transplantation. I will ask you to tell me about your experience of living with hepatitis C virus. You can talk about any aspect of your life that you wish. Sometimes, I might ask you to elaborate on something that you have said previously. I might also ask you give me some examples. Please remember that you do not have to answer any questions that you do not want to. I

simply want to understand what the diagnosis of hepatitis C virus infection recurrence means for you. With your permission, I will record the interview on a digital voice recorder. This is just so that I can give you my full attention and so that I can type the interview up at a later date. This is a normal procedure for this type of project.

6. Will direct quotations from my statements be published?

We will publish direct quotes from you but these will be anonymised by the use of pseudonyms.

7. Where and when will the interview take place?

We will arrange for the interviews to take place at the Welcome Clinical Research Facility at the RIE where we can book private and confidential rooms. If possible, we will arrange the interview on the day when you will be attending for follow-up appointments with your hepatologist. However, if you prefer that your interview is carried out in a place that is more convenient and comfortable for you, this can be arranged.

8. What are the possible disadvantages and risks of taking part?

It is possible that you might become upset due to the sensitive nature of the questions. Please remember that you do not have to answer any questions that you do not wish to. If you do feel uncomfortable, embarrassed or upset at any time, please just ask me to stop. You are free to withdraw from the research at any time.

9. What are the possible benefits of taking part?

There are no direct benefits for you in taking part. However, we hope that by your participating, we will gain a better understanding and deeper insight into what it means to live with hepatitis C virus.

10. What happens when the research stops?

After all of the interviews have taken place, they will be analysed by a member of the research team. The results may then be published in scientific journals and presented at relevant conferences. It is important that you understand that your name and personal details will always remain confidential and your name will be encoded under a false name agreed in the beginning of the interview. Under no circumstances would they ever be revealed in journal articles or at a conference.

11. What if something goes wrong?

If you have a complaint about any part of the research project, you must express that complaint to either the researcher, to Dr … (Supervisor of the study), Dr … (Director of the study), Prof … (Professor of Hepatology at the RIE) or to the NHS Research Ethics Committee 3.

12. Will my taking part in this study be kept confidential?

No-one beyond the research team will receive any information about you or your participation. Before we begin the interview, you will be asked to give me a false name. We will refer to that name at all times. This is to protect your anonymity. The tape recording of your interview will remain within a locked filing cabinet at Edinburgh Napier

University until the researcher has typed it up. No-one but the researcher can access your data. It will then be deleted. The data gathered will be safely stored on a password-protected PC at Edinburgh Napier University, to which only I will have access. All data will be kept until the end of the assessment process, which is due by June 2017, and then will be securely deleted.

Confidentiality in this study may be limited if I will deem, while conducting the interview, there to be a risk to you. In the event that you will become distressed or make a statement which gives cause for concern, I will as a certified Mental Health First Aider provide initial help to you. I will also need to contact an experienced member of staff within the liver transplant team (The Transplant co-ordinator <name>) who would be allied in to remain with you and contact your GP in order to inform him about the situation. However, this would be discussed with you prior to the disclosure of information.

13. Contact for further information:

Researcher's name: Anna Krzeczkowska

E-mail:

or

Director of the study: Dr …

Edinburgh Napier University

Sighthill Court

Edinburgh, EH11 4BN

Tel.

14. Independent contact person for further information:

If you would like to talk to someone who knows about this research project but who is not directly involved in it, please contact:

<Name of the independent contact person>

Edinburgh Napier University

Sighthill Court

Edinburgh

EH11 4BN

Thank you

Appendix 6

CONSENT FORM

Title of Project: **Experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation: an interpretative phenomenological analysis.**

Name of Researcher: Anna Krzeczkowska

Please tick (√) appropriate box:

1. I confirm that I have read and understand the Participant Information Sheet dated..... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

YES ☐ NO ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

YES ☐ NO ☐

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Edinburgh Napier University and from regulatory authorities, or where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

YES ☐ NO ☐

4. I agree to my GP being informed of my participation in the study.

YES ☐ NO ☐

5. I agree to an experienced member of staff within the liver transplant team to be contacted if the researcher deems there to be a risk to my health and safety.

YES ☐ NO ☐

6. I agree to having the interview audio-taped.

YES ☐ NO ☐

7. I agree to publication of direct quotations from the interview by maintaining my anonymity.

YES ☐ NO ☐

8. I agree to take part in the above study.

YES ☐ NO ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

Thank you for agreeing to take part in this research

Appendix 7

Participant Debrief Sheet

Experiences, attitudes and expectations of hepatitis C virus infection recurrence after liver transplantation: an interpretative phenomenological analysis.

Thank you for participating in the project. I appreciate your time. If you have any questions, concerns or you would like to find out about the results of the study, after the assessment will be finished, please do not hesitate to contact

The researcher of this project:

Anna Krzeczkowska by email:

The Director of the study:

The independent advisor:

Should you have any questions or concerns about anything you have discussed in the interview, please contact:

<designated person at the The Royal Infirmary of Edinburgh>

or any of the organisations listed below:

- Waverley Care, support service for patients with HIV and hepatitis C virus by telephone: 0131 558 1425 or by email: david.cameron@waverleycare.org.

- C Plus, 22 Laurie Street, Edinburgh, EH6 7AB; Tel: 0131 478 7929; email: cplus@addaction.org.uk.

- Hepatitis C Trust helpline: 0845 223 4424 or 020 7089 6221 (open 10.30am to 4.30pm Monday-Friday); or contact the organisation by email: helpline@hepctrust.org.uk.

- The Samaritans by email: jo@samaritans.org or by telephone: 08457909090.

Appendix 8

Interview Schedule

1. Tell me about how you were diagnosed with hepatitis C. What thoughts/feelings did you experience?

2. What impact has the diagnosis had on your life?

3. Tell me about your experience of hepatitis C virus.

4. When you were told that you needed a transplant, what were your thoughts? Hopes? Fears?

5. What were your expectations of the liver transplantation? In what ways have they been met/not met?

6. In what ways were you prepared for what you experienced after the liver transplant?

7. Tell me about your life after the surgery. How has life changed for you since?

8. How did you feel when the hepatitis C recurred?

9. What impact has the diagnosis of infection recurrence had on your life?

10. In what ways were you prepared for being diagnosed with the infection recurrence? Were you given any information, prior or after liver transplant, about possible outcomes?

11. What impact have the liver transplant and the diagnosis of the infection recurrence had on your relationships with others (e.g. partner, family, friends etc).
12. In what ways have your relationships with others changed as compared to the period before liver transplantation? How does that make you feel? How do you cope with that?
13. What has been the most challenging aspect of the recurrence? Why?

14. Considering the whole experience since the liver transplantation, can you think of anything that you would describe as positive?

15. What are, in your opinion, the major difficulties you have experienced since being diagnosed with the virus recurrence. What or who influenced how you coped with them?

16. How would you describe your experience of all your treatment and support from health professionals you are currently receiving? To what extent have they met your expectations?

17. Is there any form of support/medical care that you think would be helpful for you? If so, in what ways might it be helpful?

18. What or who would you say are your primary sources of help/support? In what ways are they helpful/not helpful?

19. What advice would you give others who are concerned about how they might cope after a liver transplant?

20. Is there anything else that we have not covered that you feel is important for me to understand experience of hepatitis C virus infection recurrence after liver transplantation from your perspective?