

Living with Hepatitis C

Exploring the journey from diagnosis
to treatment and beyond

HEPATITIS PARTNERSHIP

INFORM • EMPOWER • SUPPORT

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FOREWORD

The Hepatitis C Partnership was established in 2015 in order to ensure that clients' voices were amplified in the national discussion about Hepatitis C and influence how we respond to it. Whilst things have moved on in terms of treatment, significant challenges remain in ensuring that the voices of those affected by Hepatitis C and others impacted by the virus are heard. People with Hepatitis C often still face stigma, and regularly encounter health professionals who are uninformed about the virus. There are still large numbers of people with Hepatitis C in Ireland who remain undiagnosed, putting them at risk of developing serious liver problems. This report is a much-needed reflection of the problems faced by thousands of people across the country who have hepatitis C. It also points us towards client led responses in relation to Hepatitis C, peer support is cited as being highly beneficial – even the process of being involved in the study was reported as a positive one. The significantly more positive experiences patients have had with the new treatments, compared with the old, interferon-based ones, make it easier than ever for hepatitis C to be eliminated as a public health concern, provided the political will is there.

The Hepatitis C Partnership is fully committed to working towards the Irish government commitment HCV elimination by 2026, to see the elimination of Hepatitis C as a serious public health concern moving forward; this is eminently achievable. The experiences shared by clients in this report highlight the urgent need to raise awareness of the virus particularly amongst service providers, increase the numbers of people being tested and, ultimately, treat more people in order to eliminate Hepatitis C as a public health concern in Ireland, with an implicit understanding that practical and emotional support is needed throughout. A total of 25 people took part in both group discussion and structured one to one interviews- both those who are waiting for treatment, and those who have completed it. We particularly wanted to explore the psychological and social impacts of living with the disease, the aspects that are not always the focus. The questions were devised in a way to help us understand the perspectives of the individuals involved. Participants came from a variety of agencies around the city, and we thank them all for the openness and honesty with which they responded, and the time that they gave to the study.

Nicola Perry
Chairperson
Hepatitis C Partnership

INTRODUCTION

The Hepatitis C virus is a blood borne virus which can manifest in either acute or chronic infection. Approximately 55–85% of those with the virus will develop chronic Hepatitis C which can progress to liver cirrhosis, liver failure and liver cancer. The World Health Organisation estimates that between 130 and 150 million people globally have chronic Hepatitis C, and that Hepatitis C-related liver diseases will account for 700,000 deaths annually. Hepatitis C prevalence is highest in Africa and Central and East Asia with Egypt having the highest prevalence rate of Hepatitis C worldwide (largely due to contamination of blood products) (Franks et. al, 2000). Hanafiah and others in their 2013 study estimate that the Hepatitis C virus is present in approximately 2.4% of those living in Western and Central Europe and 2.9% of those living in Eastern Europe. It has been shown by the Global Burden of Disease Study 2010 that across European Union countries mortality from Hepatitis C exceeds HIV/AIDS mortality by over seven times (Cowie, 2014). This is likely to be at least partly due to the fact that until recently the treatments available for Hepatitis C have been of limited effectiveness in comparison with treatments for HIV/AIDS (Negro, 2014).

This study will look at Hepatitis C within an Irish context where the virus remains a clinical and public health challenge. A 2011 study estimates that approximately 20,000-50,000 people in Ireland have chronic Hepatitis C (between 0.5 and 1.2% of the population), a figure in line with other Northern European countries (Thornton et. al., 2012). In 2015 a National Hepatitis C Treatment Programme was set up by the Irish state which aims to eliminate the virus in Ireland by 2026. Until 2014 interferon was the treatment mostly used for Hepatitis C across the world and continues to be used. The drug has only limited success in clearing the virus (success rate was around 50% depending on the Hepatitis C genotype and liver damage sustained) and often caused severe side effects. New treatments, known as Directly Acting Antivirals (DAAs), mean that the chance of clearing the infection after treatment is now over 90%; approximately 700 people in Ireland have received this treatment since 2014 and the clinical criteria for eligibility to treatment has recently been expanded (Treloar and Rhodes, 2009). The significance of this study is that it looks at the lived experience of those with Hepatitis C in Ireland by presenting accounts from the twin perspectives of those who have undergone treatment which has cleared

the virus, and those who are still awaiting treatment. This study aims to specifically identify: participant's experiences of receiving a Hepatitis C diagnosis, the emotional burden that living with the virus entails, the treatment barriers which those with the virus often confront, and the potential that life holds post successful treatment, its life changing benefits but also the worries and obstacles which can occur when the condition has been resolved physically.

Profile of those with Hepatitis C in Ireland

A viral hepatitis that was non-A, non-B was discovered by researchers in 1979 and was initially thought to be benign. It was not until 1989 that the new strain of Hepatitis was isolated and was named Hepatitis C; researchers estimated that 170 million people across the globe were already infected with non-A, non-B viral hepatitis at the time of its discovery (Houghton, 2001). By the late 1980's, in large part due to the AIDS epidemic, screening processes for blood and blood products were being introduced in Western European countries. In Ireland screening of blood and blood products began in 1991. However, screening processes before 1994 were not always reliable; it is estimated that around 1700 people were iatrogenically infected with Hepatitis C before 1994 (Thornton et. al, 2012), a large percentage of whom were women who had contracted the virus through receipt of the Anti-D Immunoglobulin injection in Irish hospitals between 1971 and 1994.

In the current study the majority of those who participated contracted the virus through drug use. There is a large body of research that establishes a linkage between injecting drug use and Hepatitis C. Currently in Ireland the population most at risk of contracting the infection are those injecting drug users; HSE records for example, indicate that 80% of new cases recorded of Hepatitis C in Ireland in 2014 were found amongst the injecting drugs use population (HSE, 2014). Similarly Thornton and others in their study of the epidemiology of the virus in Ireland suggest that 80% of those who were recorded as being Hepatitis C positive between 1989 and 2004 contracted the virus through use of drugs (though again it should be noted again that this number/percentage again is calculated only from the 76% of cases for which it was possible to confirm the most likely risk factor). Thornton et al (2012) suggest receipt of contaminated

¹ It should be noted that this number/percentage is calculated only from the 49% of cases for which there is data available for.

blood or blood products (in Ireland, where transmission was before screening of blood and blood products began, or in another country) is responsible for around 16% of cases during the period they examined. Sexual exposure and accidental exposure to blood/body fluids (including assault) were also perceived as risk factors for transmission (Thornton et. al., 2012).

It has been suggested that there are differences between how those who contracted the virus through drug use and those who were iatrogenically infected are treated by the Irish state and this difference in treatment clearly plays a role in the lived experience of those with Hepatitis C. Those who were iatrogenically infected by the State are eligible for a range of primary care and hospital services and the HSE maintains a National Hepatitis C Database for people infected through blood and blood products which serves as a useful tool in researching the virus and helping to plan and evaluate health services. In 2004 the Eastern Regional Health Authority (ERHA) sought to create a register of Hepatitis C antibody-positive drug users, with the aim of capturing the journey from diagnosis to specialist assessment. A more recent strategy produced by the Irish government- the HSE's National Hepatitis C Strategy 2011-2014, has sought to produce a more comprehensive analysis of Hepatitis C prevalence within this jurisdiction. This strategy does seek to capture with inclusivity all those infected with Hepatitis C and in particular targets marginalised populations who are more likely to contract the virus including injecting drug users. The report contains a large number of comprehensive recommendations covering everything from provision of targeted anti-natal screening for populations at risk of Hepatitis C infection to needle exchange programmes in prisons, stating that all strategies deemed budget neutral or cost effective will take precedence.

It has long been established that Hepatitis C carries both a physiological and psychological burden. Golden et. al (2006), for example, completed a study in St. James's Hospital, Dublin of 87 persons awaiting treatment for Hepatitis C. The study sought to investigate stigma, mood and adjustment to illness in those with Hepatitis C. The study included both those who had contracted the virus through receipt of blood or blood products and those who had contracted the virus through injecting drug use. In relation to stigma associated with having Hepatitis C the authors found a "strong dimension of fear of disclosure (...) together with dimensions of social isolation and social rejection". Interestingly high levels of these feelings were discovered in those who had contracted the virus through injecting drug use but also in those who were iatrogenically infected through receipt of anti-D Immunoglobulin injection or blood transfusion. Notably the lowest levels of these feelings were found in

those who had contracted the virus iatrogenically through receiving treatment for hemophilia and those who did not know how infection had occurred.

The unique psychological presentation of Hepatitis C and its growing recognition as a public health concern has now been recognised globally. This awakening has fuelled a series of strategies in different jurisdiction throughout the world. In Europe both Scotland and Portugal are notable in terms of the treatment plans they have developed for those with Hepatitis C. The Scottish government prioritised the treatment of Hepatitis C in 2004 and set about creating a Hepatitis C Action Plan, which has proved hugely successful. Indeed the Scottish approach to the management of the virus is often mentioned as a gold standard for treatment implementation. As a consequence of their treatment strategy rates for those with Hepatitis C presenting for treatment were increased. Through this plan marginalised populations have been granted greater access to both testing and treatment for the virus; drug centres increased testing for the virus and the percentage of prison inmates receiving treatment increased from 4% of all persons to 11% between 2007 and 2014 (Wylie et. al, 2014). Following implementation of the strategy the rate of new infections among injecting drug users was estimated to have been almost halved after only a few years. It is now believed that the voluntary sector and health and university institutions played a large part in generating the political will responsible for the accomplishments of the plan (Wylie et. al, 2014). In a similar fashion Portugal has recently taken a very significant step in the management of Hepatitis C by approving universal treatment of all those infected. 5,500 persons had begun treatment with DAAs by April 2016 and a 96% sustained virological response (SVR) was recorded in those who had finished treatment (AidsMap, 2016).

² See the website of the Consultative Council on Hepatitis C

³ The HSE notes in 2012 that this database is still under development.

⁴ It should be noted that the Irish government has been slow to implement the recommendations from a previous strategy report on Hepatitis C commissioned by the ERHA in 2003. A working group created the report which looked at means of prevention, treatment and surveillance of the virus. Some of the recommendations of the unpublished final report were implemented but many were not (HSE, 2012).

⁵ 1,052 cases were treated in 2012-2013, a jump from 468 cases treated in 2007-2008 (Wylie et. al., 2014).

REVIEW OF THE LITERATURE

The literature on the impact of Hepatitis C often focuses on impact of the virus on mental health. Numerous studies have shown that those with Hepatitis C have a reduced quality of life and a greater propensity for mood disorders. (Barboza et. al, 2016; Foster, Goldin & Thomas, 1998; Moles & Van der Linden, 2001; Rodger, Jolley, Thompson, Lanigan & Crofts, 1999; Yates & Gleason 1998; Yovtcheva, Rifai, Coughlan, Sheehan, Hickey & Crowe, 2002;). Whilst those with chronic illness are more likely to experience depression than the general population (Boing, 2012), depression rates among those with Hepatitis C are higher than those with other chronic illnesses. This finding has led to differing theories in the literature of why this might be the case. One possible explanation is that the process of the virus itself, the high risk of psychiatric disorder already existing among the population subgroups that contract the virus, and the stigma that having the virus entails is responsible for the increased levels of depression found (Golden et. al, 2006).

In the study of the various forms of depression experienced by patients receiving treatment for Hepatitis C in St. James's Hospital in Dublin by Golden and others, the conclusions are stark. The authors found that 50% of participants had either a current or lifetime diagnosis of depressive disorder, and that 40% of participants had either a current or lifetime diagnosis of anxiety disorder. The study suggests that experiencing depression is thought to make the lived experience of Hepatitis C worse in a variety of ways; They suggest the effects of depression in those with Hepatitis C become pervasive, affecting all aspects of the individuals life, leading invariably to "poorer work and social adjustment, lower acceptance of illness, higher illness stigma, poorer reported thinking and concentration, and higher levels of subjective physical symptoms" (Golden et. al., 2005: 431). Treatment effects on the physiological and mental health of the individual have also been noted. A welter of studies for example, has been produced recording the side effects of interferon alone and combination treatments with ribavirin. These studies indicate significant psychiatric effects can be produced amongst individuals during treatment. (Dieperink, et. al., 2003; Budhram, 2014; Quarantini, 2007; Małyszczak et. al., 2006; Asnis, 2006). These effects may not be long lasting. The authors of a review of the literature on depression experienced upon completion of Hepatitis C treatment (with interferon alone, and combination interferon and ribavirin) assert

that Health Related Quality of Life (HRQoL) has been found to return or surpass baseline level by 24 weeks post successful treatment (Whiteley, 2005). They point out however that the end-point of a study will have the potential to impact on its findings; many studies are carried out either 12 or 24 weeks post-treatment, at which time the positive emotional response after clearing the virus is still powerful and may influence findings. They note that these positive effects may wane over time (Whiteley, 2005).

As noted, it has been posited that depression or other mood disorders in those with Hepatitis C are believed to be compounded by the stigma associated with having the virus. Perceived stigma has been found to have a huge impact on those with Hepatitis C and carries with it the potential to act as a barrier to seeking care (Butt, 2008; Crofts et. al, 1997; Wallace, 1998, Harris, 2013). Other barriers to the management and treatment of the virus have also been identified. These factors include a lack of awareness or information, active addiction, fear of treatment side effects, poor adherence to medical intervention, co-morbid conditions, lack of trust in health workers, and psychiatric illness. Systemic service provider factors include reluctance on the part of services to treat current or former drug users and referral delays (McGowan, 2012; Morrill et. al, 2005; Myles et. al, 2011; Thomson et. al, 2005).

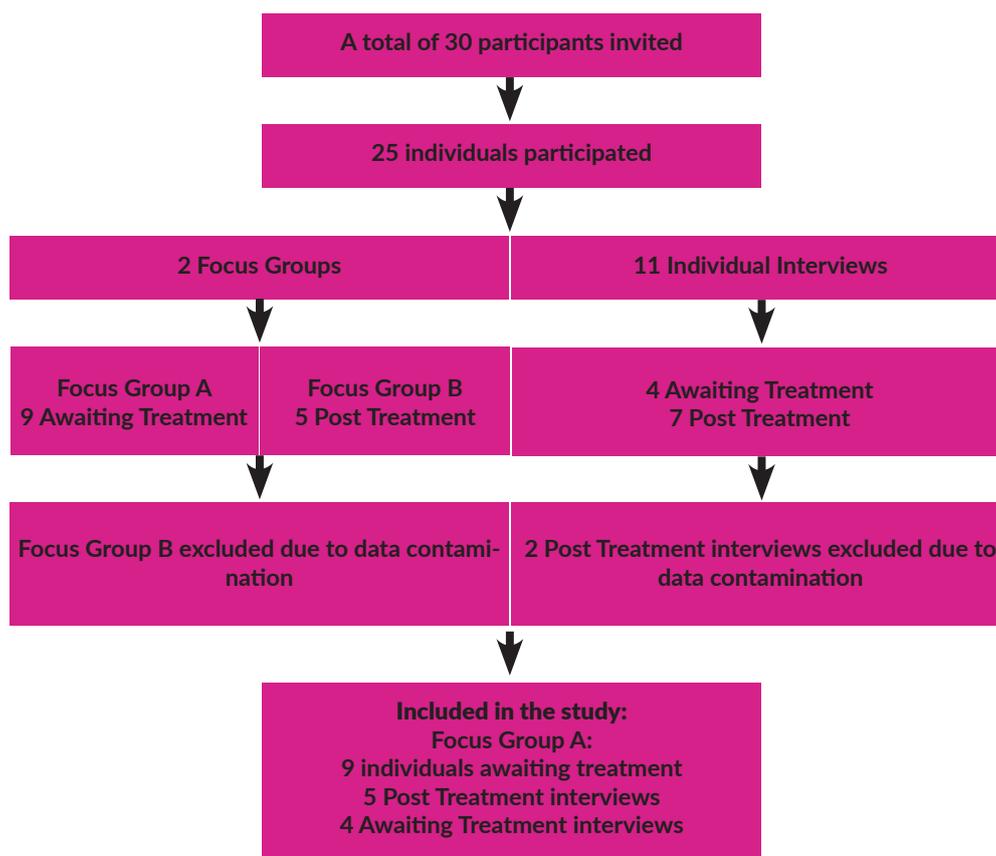
An Irish study which examined the experience of 36 people with Hepatitis C in a range of primary and secondary care services in the greater Dublin area identified a number of barriers and factors facilitating testing, management and treatment (Swan et al, 2010). Among the primary barriers which the authors identified were the perception that the investigations and treatment were worse than the infection itself, feeling well, and not seeing the virus as particularly harmful. Additional barriers mentioned included having only limited knowledge of testing sites, ineligibility for treatment and not being referred for specialist treatment. The authors also found that other competing interests, specifically employment, education and addiction, were prioritised ahead of receiving care for Hepatitis C. Finally it was noted that the relationship which persons had with their health professionals was found to shape their level of engagement, the more positive the relationship the higher the level of engagement found (Swan et al, 2010).

6. Interferon-alpha alone and combination treatments of pegylated interferon plus ribavirin, and alpha interferon plus ribavirin

METHODOLOGY

This study adopts a phenomenological research design incorporating focus groups and semi-structured interviews. The use of the phenomenological approach provides an opportunity to explore and to gain an in-depth understanding of the lived experiences of people diagnosed with Hepatitis C from their own perspectives. The narrative will be guided and presented through the five distinct phases of living with Hepatitis C. These phases are: Diagnosis, Living with the Hepatitis C Virus, Awaiting Treatment, Treatment and Post-Treatment. The study will place emphasis on the psychosocial impacts of the diagnosis for the individual, the process of waiting and accessing treatment, and their quality of life post-treatment.

Participants were recruited by Hepatitis C Partnership. The age range of participants is between 25 to 45 years old. The majority of participants were no longer in active addiction; several were in receipt of methadone maintenance therapy. A total of 25 people participated in both the focus groups and semi-structured individual interviews. Two focus group interviews were conducted with (a) 9 individuals who have been diagnosed with Hepatitis C and are awaiting treatment and (b) 5 individuals who have received Hepatitis C treatment. A further 11 individual interviews were conducted with individuals who were either awaiting treatment or had received treatment. It was decided that one of the focus groups and two of the individual interviews could not be used in the study due to contamination of data; the final number of participants is as illustrated in the table below.



The interview schedule for the semi structured interviews was compiled based on the themes and domains previously covered in many published qualitative studies that explored the lived experiences of people with Hepatitis C virus. To ensure that all information was gathered accurately interviews were audio recorded, with the consent of all participants, using a Dictaphone. All

identifying information (e.g. personal details about the participant or family members) gathered were anonymised. Pseudonyms were used to protect the identity of the participants. A token of a €20 voucher was given to everyone who participated in the study as an appreciation for their time.

THE LIVED EXPERIENCE OF THOSE WITH HEPATITIS C

This study explored the experiences of people diagnosed with Hepatitis C. The analysis presented here is based on the transcripts of a focus group and 9 individual interviews with people who were either still waiting for treatment or had undergone treatment. Our discussions with those who have experienced Hepatitis C identified 4 main themes: Information provision, Barriers to accessing treatment, Support and Psychosocial impact/ Burden of Hepatitis C.

1. INFORMATION PROVISION

a. Diagnosis

Overall it was noted that information regarding the exact nature of Hepatitis C, its presentation, management and treatment was limited amongst the participants interviewed. Tellingly this lack of information could in many cases be traced back to their initial diagnostic experience. The majority of those interviewed recounted that the process with which their diagnosis was presented was unfeeling, casual and lacked sufficient thought for their wellbeing. Some indicated that their active addiction prejudiced the health professionals they dealt with. Many others indicated that they were not provided with adequate information on Hepatitis C at the time of their diagnosis. Thus they were often left confused as to what the diagnosis would mean for them. Many had little option but to resort to accessing information from their peers or in later years researching the virus via the internet in an attempt to ascertain its modes of transmission and the possible impact on their day to day lives.

In examining the experience of those interviewed, the authors needed to be cognisant of the time within which many of those interviewed received their diagnosis. The majority received their diagnosis in the early nineties, during a period when a HIV epidemic was feared. In this context Hepatitis C was seen as the lesser of two evils, and information within services with regard to its effects limited. This lack of awareness can be discerned in the experiences of those interviewed. For example, one participant was tested for viral Hepatitis before the Hepatitis C virus was discovered and was told she tested positive for non-A, non-B Hepatitis. The participant understood that she did not have Hepatitis A or Hepatitis B but did not understand that she did have a strain of viral Hepatitis (which would later be labelled as Hepatitis C) until much later when she realised that a non-A, non-B diagnosis was significant through hearing discussions among her peer community. The lack of information within services may have been responsible for the apparent harshness of the treatment those interviewed experienced. For example two participants recounted they discovered that they had contracted Hepatitis C when it was mentioned in passing while they were receiving medical care for an unrelated issue. Understandably, in

an environment where information was sparse, some participants expressed a sense of panic and dread.

**'I thought it was like a death sentence, ...I am going to be dead in 2 years or 3 years'.
(Awaiting treatment- Kevin)**

One participant who had been told in prison of her diagnosis recounted that she tried to kill herself due to her lack of knowledge of what she had contracted. Strikingly however, for many participants this lack of information provided the foundation for the misconception that Hepatitis C was not a potentially fatal illness. They did not realise the significance of the diagnosis upon receiving it and were simply relieved that they had not contracted HIV. As explained earlier, it is possible that these reactions are a function of the time and contextualised to the era when the predominant concern amongst injecting drug users was the contraction of HIV. This view is supported by the reaction of one participant who spoke of being diagnosed around the time that the Anti-D scandal broke in the Irish media, thus she understood the significance of her diagnosis.

**'The way it was when I was going through addiction was it's only the Hep, it's not the virus, it's only the Hep and then I was like sure it's only the Hep'.
(Focus group - Awaiting Treatment)-Joan**

The fact that many of those interviewed received their diagnosis whilst in prison seems to have compounded the confusion and burden around their condition. Many participants offered compelling testimony regarding the lack of care for their wellbeing and the lack of doctor-patient confidentiality. Several reported they had simply been called to the medical wing, handed a brown envelope and told they had the virus without any follow-up. They spoke of the prison medics having a careless attitude towards their personal information and as being generally poorly informed as to the condition. Interestingly one participant was cognisant of the need and potential of providing Hep C services within prison.

'20 years ago I was diagnosed. I'm getting angry listening to everyone there. I think the front line for Hepatitis for drug users in Ireland is in prison, a few of the lads might remember prison officers going round with a brown envelope and they would put you up on stage.'

(Focus group - Awaiting Treatment) - Luke

b. Mixed Information

One recurring term mentioned throughout the interview process was 'Dormancy'. A commonly held perception amongst participants was that the Hepatitis C virus could remain dormant in the body without causing damage over time. Participants reported they had heard that Hepatitis C could go through phases of dormancy, and had had this confirmed by both health professionals and the participants' peer-community. Many people who took part in the study were unsure as to whether or not this was true or whether the idea of dormancy was a myth. They were also unsure as to whether the virus in a period of such dormancy meant that they could not contaminate others.

'I was told It's not active so you'll be alright'
'My interpretation was that it's not active'

(Focus group - Awaiting Treatment) - Karen

'Still to this day people do say to me mine is dormant and cos I'm training them I just say there's no such word as dormant anymore, You need to go back to your doctor or your consultant and ask them to redo your tests'

(Post-Treatment)-Alison

Again, the knowledge which the participants and their peers had of the effects of HIV may have confused the matter further and in an attempt to explore where the commonly used term 'dormant' came from, one participant explained:

'We were all diagnosed with Hepatitis C but we were looking at people dying before our eyes with HIV and looking at people with Hepatitis walking around fairly fresh looking. That's where that came about'

(Focus group - Awaiting Treatment)-Luke

Participants indicated that they received little initial information about Hepatitis C and that the information that was available was oftentimes contradictory, thus at times leading to misguided and potentially harmful behaviours. They cited their sources of information on Hepatitis C as primarily doctors, leaflets on Hepatitis C, and their peer community. As will be discussed further in this study, participants- especially those awaiting

treatment, often reported a negative or unfulfilling relationship with health professionals. It would appear from the narratives of the participants that they were more likely to seek out information about Hepatitis C from peers. The lack of information/misguided information impacted on their daily lives as some were more fearful of cross-contamination than was necessary as will be discussed under the next heading.

'Word on the street was all I knew. Chinese whispers, add-ons. Never had the full story until the past couple of months.'

(Focus group - Awaiting Treatment)-Henry

c. Fear of Cross-Contamination

Being exposed to inaccurate and inadequate information can amplify misconceptions leading to poorer outcomes for people with Hepatitis C, particularly in relation to accessing treatment and self management practices. Fear of cross-contamination particularly amongst family members and friends played a significant role in the majority of participant's lives. The mixed and confusing information which participants reported they received significantly influenced their concerns regarding cross-contamination. The nature of the virus and the means of transmitting it were so poorly explained to participants that they ended up with confused ideas on how the virus can be spread. This process generated unwarranted fears. Some held the belief that they might spread the virus through their saliva e.g. by the using of the same cup. Several participants felt this lack of information placed their family at risk.

'I knew it was a blood to blood borne virus or disease but no one actually came to me and told me like what way to go about protecting myself or my kids or my family or anything like that.'

(Post- Treatment) - Alison

Participants worried about passing on the virus through everyday items such as toothbrushes, razors, plates, cups and utensils, as well as through sexual exposure. Indeed it was apparent there was a consistent routine shared across all participants interviewed, designed to protect against cross-contamination. Interestingly even amongst those who had cleared the virus, these habits were difficult to break. It is worth noting this fear of cross contamination was not unfounded. Several participants had spent time around family members whilst being in a period of active addiction and did not take sufficient care to avoid cross-contamination during this time. One participant mentioned an incident whereupon it was suspected that a family member had been infected with Hepatitis C.

'I thought I had infected one of my family because they pricked themselves on a syringe in the house, but I didn't thank god' (Focus group - Awaiting Treatment) - Bernard

2. SUPPORT

a. Level of support

The level of support reported by participants varied. Several reported getting a great deal of help from their family members, and some reported getting help from their peers to cope with the impact of having Hepatitis C. However there were others who indicated that they received support from neither their family nor from any other source.

'I had all the support around me from family, from (refers to community scheme), my co-workers, my peers' (Post-treatment)-Daniel

Participants also stated the need for organised supports. Whilst such support could be in the form of organised peer-supports and/or support from healthcare professionals, participants primarily emphasised the benefits of organised peer to peer supports which they perceived to be manifest and much needed. Indeed several participants mentioned that the chance to take part in a focus group for this study was of therapeutic benefit in-itself; one participant remarked that no-one had ever asked him for his story before.

The need for a continuum of support throughout all stages of the process was something that was discussed with participants. Several participants suggested that support should be available for the different stages of Hepatitis C: diagnosis, awaiting treatment, during treatment, and aftercare.

'There's no support groups for people on treatment you know and I think there should be, cos when you're on it it's a very lonely place and you think you are going mad cos of what you're experiencing and all and if you had a group with other people that's going through the same thing, you could talk about it and then help one another' (Post-Treatment)-Alison

This feeling of isolation was a commonly expressed emotion, as was the opinion that the dearth of supports reflected in some way the nature of their condition but perhaps most tellingly the manner by which they contracted the illness. Those who received even minimal levels of support fully acknowledge its profound benefits.

'When you're in a group everyone's experience is different you're getting support from them, you're learning from them as well'

(Post Treatment- Daniel)

b. Dealing with Health Professionals

Participants reported strong feelings of frustration arising from inadequate support provision and that these feelings were often further exasperated by their dealings with the health professionals. Often they felt judged, blamed and that they received less concern and a poorer quality of service because they were deemed to have brought the virus on themselves. There was often a difference of attitude in this regard between those awaiting treatment and those post-treatment. Of those who had undergone treatment several mentioned a specific nurse or professor who stood out to them as someone who had helped them through the treatment.

'Even in (mentions an acute hospital in Dublin) you are like lepers. They patronise you'

(Focus group - Awaiting Treatment)-Luke

'The nurse used to see me at half 7 in the morning so I didn't miss work. I can't speak highly enough about (mentions acute Dublin hospital).'

(Post-Treatment)-Conor

3. BARRIERS TO ACCESSING TREATMENT

a. Treatment Waiting Time

Most participants expressed that the duration of time between initial diagnosis and treatment was debilitating. Indeed many commented that they had received scant contact with any health professional and that any support or contact they received only came after they had personally pushed for services. Some participants perceived the long delays in accessing treatments and the strict criteria as deliberately constructed obstacles to treatment. Many participants had reached a stage where they wanted to get their life back on track and clearing the Hepatitis C virus was an essential part of this; being told that they were not sick enough to receive treatment therefore caused them immense frustration.

'Since 2002, I've been waiting, they always say come back next April. I pushed it on them this year and they've started to contact me now. If I hadn't pushed for it they would have been still telling me come back next year.

(Focus group - Awaiting Treatment)-Henry

b. Treatment Criteria

The issue of treatment criteria was at times contentious and generated a variety of perspectives from participants. Whilst consensus around most other areas was clear, access to treatment was surprisingly viewed very differently by those who were awaiting treatment and those post-treatment. There was a general consensus among all the people awaiting treatment in the study that one's liver will have to be really bad (affected by liver cirrhosis) before treatment would be provided. On the other hand the majority of those who had undergone treatment emphasised the importance of ensuring that being substance free was part of the treatment criteria.

A big part of moving on is to have the treatment so that you can move on with your life. (...) Then you're going up there and being told that you have no chance of getting treatment because your liver isn't bad enough.

(Focus group - Awaiting Treatment) - Bernard

'I don't abuse alcohol, I don't drink. I think that plays a big part of it. I got clean, that's how I got access to the treatment. From being clean and keeping the appointments'

(Post-treatment)-Daniel

4. PSYCHOSOCIAL IMPACT/ BURDEN OF HEPATITIS C

a. Social Isolation (Feeling Isolated)

Participants indicated that stigma in its various guises was a defining characteristic of their experience of living with Hepatitis C. Many expressed strong feelings of loneliness, isolation and exclusion; they felt that they could not disclose their virus for fear of being judged, separated, or acted against. Words and phrases such as 'leper' and '2nd class citizen' came up several times among participants. This attitude was particularly evident within the prison system in which participants felt that they were stigmatised for having Hepatitis C.

'It's like leprosy, if someone has leprosy they'd give them a wide berth. You get people like that in town. People are very narrow minded when it comes to the likes of hepatitis, oh don't go near him you might catch it.'

(Awaiting Treatment)-Dominic

Some had not told their family or partners about their Hepatitis C diagnosis until a long time after they received it and in a few cases participants had still not told members of their family. This was due to a range of factors which were often interlinked including stigma; feeling

unworthy of engaging with family members as though unclear, mixed information about modes of transmission. Some also acknowledged that they knew so little about the virus that they did not feel confident sharing news of their condition and this was further compounded by the lack of knowledge among the general public about Hepatitis C. Others did not tell family members about their condition so as not to cause them undue worry, still more commented that the relationship with their family were already fragmented; in some cases participants had become distant from families while in active addiction.

'At home, I used to be terrified because I hadn't told my partner'

(Focus group - Awaiting Treatment) - Hugh

Interviewer-The rest of your family, how do they feel?-

'I haven't told them. It'd probably just scare them, they would probably think, ah he has hepatitis he's gonna die you know, they wouldn't know much about it.'

(Awaiting treatment)-James

b. Dealing with Side Effects of Hepatitis C Treatment

Participants experienced a range of side effects including fatigue, insomnia, heightened emotional responses, mood swings and skin rashes. Many of those interviewed expressed a pervasive fatigue which significantly interfered with their capacity to carry out their every day routines. Others complained of feelings of confusion, of experiencing a fugue like state, as one person stated he could meet someone in the street and the next day would not recognise having met them before or even remember their names. Similar experiences were shared by other participants.

Several participants reported they experienced violent episodes while on treatment which had resulted in them being taken off the treatment itself. In one case a participant whilst on treatment became so unstable he received a criminal conviction for aggressive behaviour. The type of treatment which participants received was time dependent; the older treatments generally came across as harsher on participants than the newer treatments. Participants clearly felt that the side effects they experienced were related to the treatment as they emerged only upon treatment commencement.

'Your head races, you can't sleep, you're anxious, you're sweating. I got a little bit angry on it as well cos I was so irritated. It was like, and your body's so sore, someone tips off you or anything you just want to jump and then some days I just wanted to stay away from people.(...)Some days I'd break down crying and other days I would want to kill people.'

(Post-Treatment)-Alison

For participants who were awaiting treatment, the stories they heard from those who had undertaken treatment often served as a deterrent to the treatment itself. One participant explained:

'It's only recently that I went to a seminar (...). I took it all in and I was like I'd rather just be like this than suffer the side effects for a year.'

(Focus group - Awaiting Treatment)-Henry

It was clear from those interviewed that newer treatments were becoming available and that these treatments had been refined and improved. With reference to the newer treatment, another participant reported that people often think it is going to be worse than it is, but for him, he reported experiencing few effects and felt a 'bit off some days'. He stated drinking more water helped him through it. All of those interviewed felt that more up to date information was a requirement but generally the consensus was that improved information was needed across the board regarding the availability and effect of newer treatments.

c. Physiological Effects of the Virus

In addition to the psychological strains and impact of the diagnosis, many of the participants suggested that the virus had had a significant effect on their cognitive performance, specifically their memory and concentration levels, and on their general levels of energy. Many participants awaiting treatment expressed a pervasive fatigue which significantly interfered with their capacity to carry out their everyday routines. In participant's accounts of the impact of fatigue they mentioned how it affected their ability to work, their ability to look after their children or, in the case of one participant, grandchildren, and their libido. Others complained of feelings of confusion; they felt their brain was no longer sharp. One participant stated that he had already forgotten the interviewers' names despite having heard them only minutes ago; another recalled meeting a person with whom he had recently been on a course and completely forgot their name. However it should be noted that some of the participants' acknowledged it was a challenge to unscramble whether these reported effects were due to Hepatitis C or from what they acknowledged as the effects of many years of substance use; however many were of the view that the fatigue and problems with memory and concentration were down to the virus.

'I used to always work, even though I was an addict I would work to pay for my drugs. Now I don't think I could work, the fatigue'
(Focus group - Awaiting Treatment) - Shane

(Talking in relation to memory loss)

We have all been on drugs for 25 years..I'd like to know is it the gear or the hep C, the coke or what? Now I'm sitting here thinking no it's the hepatitis.

(Focus group - Awaiting Treatment) - Karen

The impact of the virus was different for a small number of participants who stated that they had no issues with cognitive performance or levels of energy. A few participants felt that having Hepatitis C had not affected them in any way.

'I've never had any trouble with it. I have it over 10 years like.'

(Awaiting Treatment) - James

d. Mental Health

Throughout the interview process, it became evident that many of those who had been diagnosed with the condition experienced a degree of what can in most cases be best described as dysthymia, or a persistent mild depression. Many participants had been diagnosed and were on medication for depression.

'I never suffered from depression but I'm on anti-depressants now. I cried all the time'
(Focus group - Awaiting Treatment) - Joan

Several of those who had successfully underwent treatment also indicated they felt that post-treatment they had developed severe mental health conditions including depression and heightened anxiety. One additional issue which was apparent was self reproach and self blaming. Several stated that they only realised what they had lost and missed out on when they had fully recovered. Some truths appeared unpalatable and troubling.

'A lot of self-pity comes in to it for me. It's only using supports, even a group like this, even talking and sharing is like bringing to life what goes on in my head and trying to make sense of it'

(Focus group - Awaiting Treatment)-Henry

e. Treatment Experience

There was a general sense of relief for the majority of participants when they had completed their treatment successfully. Participants described the specific benefits of no longer having Hepatitis C. They indicated that being clear of the virus improved their relationships with family and friends. Several mentioned how happy their family were when they heard the news that they were virus free. A reoccurring theme among both participants who were awaiting treatment and those who had received treatment was the need to tell new partners of their Hepatitis C positive status. The benefit of not having to worry about this or of passing on the virus through sexual exposure was mentioned by participants.

'It brought me back into my family. It brought me back into contact with people, the support I got off people; it made me respect people more as well.'

(Post-treatment)-Eoin

Participants also described the improved physical health that they experienced upon successfully clearing Hepatitis C and described the feeling of no longer having to worry that the virus would affect their physical health and decrease their life span in terms of having a weight lifted off their shoulders.

'The last 15 years of my life, how much Hepatitis is after impacting on my life. I sit there and I'm drug free and I'm Hepatitis C free. I feel 20 times younger than what I was. I'm just after getting everything back, my health, and my peace of mind. Yeah I just broke down crying'

(Post-treatment)-Seamus

It was evident from post treatment participant accounts that they had engaged with Hepatitis C treatment services around the same time or shortly after completely ending a period of active addiction. It was clear they saw both drugs and Hepatitis C as undesirable substances in their bodies and to experience the full benefit of being clear of one; they had to also be clear of the other. Having successfully cleared the Hepatitis C virus and given up substance abuse several participants spoke of having been given a second chance at life.

'It opens your eyes, to say right, I've a second chance here to make things better, to make things better for my children, to make things better for my partner'

(Post-Treatment)-Daniel

f. Post-Treatment Difficulties

Participants discussed the reaction of their bodies after finishing treatment. It was clear from participants that each experienced different side effects and that the side effects occurred with differing degrees of intensity

depending on the individual. In the same way participants had differing reactions to the completion of the treatment; some felt that they were back to normal after a relatively short period of time.

'I'm off the treatment a month now. It's still now affecting me sleep wise, I haven't got my sleep back. But the head and agitation and all is starting to slow down a little bit'

(Post-Treatment) -Alison

In contrast several people in the post-treatment phase reported experiences of huge emotional instability. One participant articulated how he felt in the immediate aftermath of his treatment.

'I'm a lot healthier. I just couldn't feel it, I was very sad. I never felt like harming myself I just kept breaking down crying. It's got a lot better; I actually deal with it now. I appreciate life a lot more, it's still there but it's not as bad as it was. The treatment is almost out of my body, it takes about 7 months'

(Post-treatment)-Daniel

Another participant recounted a similar experience; He initially developed depression in the aftermath of undergoing successful treatment.

'But the main thing that came out of, if you're talking about any side effects or anything is that I suffered from anxiety attacks after treatment and I got very depressed. I actually was medicated for depression and all.'

(Post-treatment)-Eoin

DISCUSSION

Many of the themes which emerged from the discussions with participants corroborate the findings of other studies which examined the effects of Hepatitis C, both those which looked at the virus from a clinical point of view, and those which examined the lived experience of those with Hepatitis C. This discussion will look at the previous literature concentrating in particular on that which has emerged from an Irish perspective. It should be noted that some of the key priority areas which this study is concerned with are in line with the areas the National Hepatitis C Strategy 2011-2014 prioritises, namely information provision, links between different services; (for instance) between community services and prison services, and improvements that must be made in the prison service; it is clear that these are areas that have been identified previously by the Irish health services as problematic. Similarly this study is aligned with and will contribute to the realisation of the HSE's Strategic Programme Direction (2016 – 2026) of the National Hepatitis C Treatment Programme whose eventual goal is the elimination of Hepatitis C in Ireland by 2026.

Diagnosis: The study afforded insight into the often negative experience of those who received their Hepatitis C diagnosis while in prison. A number of the participants suspected that they had contracted the virus while in prison as the scarcity of needles available led to needle sharing. A census published in August 1999 showed the prevalence rate of Hepatitis C among Irish prisoners (of a sample of 1205) was 37%. Prevalence rates for Hepatitis B and HIV were significantly lower at 9% and 2% respectively. The National Hepatitis C strategy 2011-2014 does acknowledge the importance of a better strategy to deal with the prevention and incidence of Hepatitis C in prison and has a range of recommendations including the provision of needle exchange programmes and of support programmes for those with Hepatitis C.

The finding that participants often felt relief at having been diagnosed with Hepatitis C and not HIV has been replicated in many studies, and is also a feature of the Swan et. al. (2010) study.

Living with the Virus/Awaiting Treatment: Participants were found to expend effort on the keeping up of habits, some unnecessary, to prevent cross-contamination. A 2006 study similarly found that participants made significant behavioural changes, many of them

unnecessary (Zacks et al.). In regard to common activities the authors found that those with Hepatitis C were "47% were less likely to share drinking glasses, 14% were less likely to prepare food, and one-third of subjects were less likely to share a towel." Among the authors recommendations are that educational programmes and counselling be made available for persons with Hepatitis C in order to reduce unnecessary changes in behaviour as well as perceptions of stigma. The study highlights the potential link between receiving mixed information and therefore not fully understanding how the virus is spread which can lead to unnecessary behavioural changes, and an increase in perceived levels of stigma.

In the Golden et. al. (2006) study it was found that increases in depression scores were proportionate to increases on the scale which they used to measure stigma. The authors noted that stigma can also affect how someone accepts their illness and adjusts to having the virus, both socially and in the work environment, as well as how they feel their memory and concentration has been impaired. The majority of participants in this study perceived themselves to be doubly stigmatised due to the manner which they contracted the condition (it is notable that some participants felt that this stigma persisted even when their drug use was stabilised or entirely ceased) it is therefore likely that the high levels of stigma which the participants felt had a considerable impact on their mental health.

As discussed previously stigma is believed to directly impact on mood disorders. Many of the participants had experienced mood disorders. Participants often found it difficult to define the cause of the depression which they suffered as often they had experienced a range of potential risk factors including incarceration and long-term substance abuse. (As was noted previously it has been posited that a diagnosis of Hepatitis C in such marginalised populations might mean a higher risk of experiencing mood disorders than in the general population). It also should be noted that participants in this study had experienced the Hepatitis C virus for an inordinate period of time; the majority of those interviewed stated that they had been living with the condition for the greater part of their adult lives. This has the possibility of worsening potential mood disorders. As Devine (2009) found, the longer an illness is experienced the more systemic the depression a patient suffers is likely to be.

7. See Whiteley et. al who in their 2014 study cite a host of studies which share this finding.

Some participants had the view that resources were being marshalled to ensure that only the most 'worthy' would receive them. This finding is consistent with previous research. Rhodes et. al. (2013) investigated former and current drug user's expectations of treatment through qualitative interviewing. The authors assert that among current and former drug users there is a culture of "rationed treatment expectation", whereby they do not expect to receive treatment for Hepatitis C within the same timeframe as non-drug users. According to the authors this is a most harmful culture as it has the potential to reduce efforts to seek help which in turn can lead to delays in treatment.

Treatment Barriers: It is believed that an unconstructive relationship with health professionals can act as a treatment barrier as there is a wealth of literature that demonstrates that trust in health professionals affects numerous important health-related behaviours. Ostertag et. al. (1996) for example found that when dealing with

Hepatitis C patients the quality of the relationship between the individual client and health professional affects a range of outcomes including willingness to seek care/use health services, uptake and adherence to treatment, patient disclosure, and behavioural change. Treolar et. al. (2009) propose that a trusting relationship with their health professionals and clinics can help to ameliorate the stigma that those with Hepatitis C might experience.

Post-Treatment: A recent qualitative study involving former and current drug users found that a narrative of both recovery from drugs and from Hepatitis C was central to the accounts of those who had received treatment (Rhodes et. al., 2013). The language that participants used was similar to that of the participants in this study. Participants often invoked phrases associated with cleanliness, talking about clearing the virus and being free of active addiction in terms of cleansing the body (Rhodes et. al., 2013).

RECOMMENDATIONS

For the study participants, the initial diagnosis of Hepatitis C was largely a disconcerting and deeply troubling experience accompanied by fear, anxiety, isolation and a strong feeling of helplessness. The early provision of support services at the initial diagnostic stage would have considerably eased the stated psychological burden placed upon these individuals.

1. It is therefore recommended that referral pathways are established with specialist support organisations, and polydrug use support organisation, these referrals to be made immediately on diagnosis.

This study confirmed that the changing nature and form of Hepatitis C leads to individuals experiencing a range of differing psychosocial and physiological difficulties at different time in their hepatitis C Journey. A treatment process which adequately reflects the fluctuating course of the illness and which provides timely and tailored supports was clearly needed by those interviewed.

2. It is recommended that a continuum of care be developed for Hepatitis C sufferers from diagnosis to post-treatment and delivered through community support organisations which should include both mediated group based support and individual support.

The need to re-evaluate the information provision, access to information and the functionality of the information currently provided to people with Hepatitis C became evident in this study. Efficient provision of fit-for-purpose information would have ensured that people were adequately informed about the condition, that mixed-messages and common misconceptions of Hepatitis C were addressed, and that there was a greater awareness of the latest treatment options available.

3. It is therefore recommended that various options of effectively disseminating information be explored. This will include making available detailed information to be disseminated on the Hepatitis C website, outlining in particular the differences between the older and newer treatment regimes. A range of communication mediums should be explored including podcasts. Facebook, YouTube and other social media should also be used.

The majority of those interviewed indicated that they had experienced significant challenges and responses to the treatment process itself. Many described the process as an emotional rollercoaster, characterised by exhilarating highs and deep and emotionally paralysing lows. The lived emotional experiences in this study were remarkably consistent within the narratives provided by virtually all participants.

4. It is recommended that post-treatment care be developed and provided in both a group and individual format for at least 6 months post-treatment to address the emotional and psychological difficulties identified by many of the participants in the study. A CBT approach has proved useful in working with sufferers of other chronic illnesses and should be explored for this group.

A number of the study participants were diagnosed while in prison. Their retrospective narratives of diagnosis experiences in the prison were largely negative. These personal accounts were in the past and it is understood that changes have been made for the better in relation to how those diagnosed with Hepatitis C while in prison are treated. Many of the practices described have now ceased.

5. Best practice guidelines should be followed when dealing with prisoners with Hepatitis C. The needs of those in the prison system should be taken into when developing a continuum of care.

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