

# LIVING WITH HEPATITIS C ASSOCIATED FATIGUE

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## Abstract

*A significant proportion of those infected with the hepatitis C virus experience fatigue. Currently, little is known about what this means to the affected individuals on a daily basis. This information is necessary so that those caring for this population may elicit the critical junctures in this process as perceived by the sufferer and plan how they may assist them manage their fatigue. The aim of the study was therefore to gain an appreciation of what it is like to live with hepatitis C associated fatigue. A qualitative research approach utilising a grounded theory design was employed. Theoretical sampling generated a sample of 28 participants for in-depth interview. Data analysis consisted of three coding processes; each type of coding having its own purpose and methodology. The study found that hepatitis C associated fatigue had the capacity to strip individuals of their ability to control their lives. The management strategies employed by the participants to regain control post-diagnosis were varied in type and effectiveness. Some of the participants had successfully regained control over their lives through the instigation of various strategies and were living fulfilled lives as fatigued persons. This study provides a valuable insight into what living with this symptom is like for those affected. It should afford nurses with the opportunity to deliver care that is focused and impacts in a positive manner in the lives of the fatigued hepatitis C community.*

*Key words:* Hepatitis C, Grounded theory, Fatigue

## Introduction

Hepatitis C is one of six viruses (A,B,C,D,E and G) that together account for the majority of cases of viral hepatitis. It can evoke a benign, asymptomatic disorder with a mild course but conversely it may cause progressive liver disease leading to cirrhosis and primary liver cancer. The hepatitis C virus's propensity for chronicity is one of its most notable characteristics, with approximately 85% of those infected developing chronic infection (Hoofnagle, 1997). There is a wide variation in its prevalence worldwide and the estimated global incidence is 3%, or approximately 200 million people (World Health Organisation, 1997). The most efficient transmission of HCV is associated with percutaneous exposure to blood, but this does not account for all cases. To date, no vaccine or pharmacological treatment capable of achieving widespread sustained viral clearance has been developed. Disclosures in 1994 by the Blood Transfusion Service Board that a significant proportion of women had been infected with the virus through anti-D immunoglobulin brought it to the attention of the Irish public.

Fatigue is considered to be the cardinal symptom that the symptomatic HCV population complain of, variably described as lethargy, malaise, lack of energy or easy fatigability (Desmet et al, 1994., Shakil et al, 1995., Di Bisceglie et al, 1995., Hoofnagle, 1997). Prevalence rates range from 45% to 92% percent (Lee

et al 1997., Sladden et al 1998., Poynard et al, 1998., Kenny-Walsh et al, 1999, Goh et al, 1999, Barkhuizen, 1999., Glacken, 2000). To date it has not been determined if the fatigue is related to the disease state itself, chemical mediators such as cytokines or/and other factors such as pain and depression (Heitkemper et al, 2001). Research by the present author has established that the fatigue experienced by this population is multi-dimensional in nature, having somatic, psychological and cognitive elements. There are also two distinct types of fatigue experienced, one which has a chronic insidious nature; the other being acute, unpredictable and uncontrollable in nature (Glacken, 2000).

In light of the knowledge that no vaccine or universally effective pharmacological treatment for HCV exists, it was clear that fatigue management would become one of the core nursing activities that hepatology nurses would have to engage in with patients and their families in the future. In order to engage effectively in this activity, an in-depth understanding of the experience of fatigue was required. It was in this context that the following question was advanced for exploration.

## Methodology

**What is it like to live with hepatitis C associated fatigue?**

**Research design**

A qualitative research approach was used, namely Grounded theory. Grounded theory was chosen over other qualitative methodologies because of its recognised adeptness at eliciting process and changes over time, which allows one to appreciate the possible evolving nature of the concept under examination (Gift, 1997). The methodological principles of Grounded theory as advanced by Strauss and Corbin (1990) were followed.

**Sample**

Theoretical sampling was employed, therefore the sampling process was directed by the aim of each of the three coding procedures - open, axial and selective. Theoretical saturation was achieved following 26 interviews and secondary analysis of the transcripts of two interviews previously carried out by the author in an earlier study (Glacken et al, 2001). (Table 1)

The participants varied in age from 36-64 years. The majority were female (n=20) and viremic (n=24). The participants were infected by a variety of sources, namely as a result of receiving infected blood/plasma transfusions or through needle sharing during the use of illicit intravenous drugs. In the case of two participants, the source of their HCV could not be established. None of the participants were receiving pharmacological treatment at the time of interview.

**Data generation and analysis**

The mode of data generation employed was in-depth interviewing, although in reality, as in any grounded theory study, data generation was not distinct from data analysis. The interviews were tape-recorded where the setting and participants permitted (n=24); otherwise notes were taken and the interview written up immediately afterwards(n=4). The average length of interviews was 80 minutes (range 50-180). A minimum of an additional 30 minutes was spent with each of the participants, which facilitated a debriefing session following the interviews. These sessions were not recorded. Data analysis consisted of three coding

processes, each type of coding having its own purpose and methodology.

**Trustworthiness of findings**

The trustworthiness of the data was established through a number of strategies: member checks, development of an audit trail of the analytical processes, continuous use of Paterson's (1994) reactivity analysis framework and enlisting the assistance of an individual who was Master's prepared and had expert knowledge of the hepatitis C population to review a selection of the raw transcripts and the resulting interpretation.

**Findings**

A basic social processes (BSP) emerged that the researcher believed encapsulated the experience of living with hepatitis C associated fatigue. The emergent BSP was 'struggling to redefine boundaries in order to regain control'. In this cohort, it traversed two periods in time. The first being pre-diagnosis and the second post diagnosis of hepatitis C. Pre-diagnosis, the participants tended to seek out definitional boundaries for their fatigue, while post diagnosis they sought boundaries to who they were and who they could become as a fatigued person. Both searches had the aim of regaining control. The broad categories that emerged are illustrated in Figure 1. (see over)

Only the third category 'Learning to live amid fatigue' is going to be detailed in this paper. It is the belief of the authors that this will be more beneficial to nurses working with this population in today's post diagnosis context.

**Living amid fatigue**

Receiving the diagnosis of HCV was a double-edged affair for participants; on the one hand it imposed definitional boundaries to their fatigue and heralded the end of their relentless search for its aetiology and cure. Conversely, with the knowledge that for the majority of those with the hepatitis C, that available treatment would not yield consistent positive responses, came a realisation that the fatigue being experienced was to be an abiding feature of their lives. Although the latter of the two was disheartening, the diagnosis allowed them to make a linguistic distinction between themselves and their fatigue. Assigning the source of their fatigue a medical diagnosis allowed participants to reclaim themselves as rational beings. Too often in the pre-diagnosis stage the participants had felt delegitimised by the medical community when they concluded their fatigue was not physical in origin but more likely to be psychosomatic.

**Table 1: Theoretical Sampling Process**

	INVITED TO PARTICIPATE	INTERVIEWED
Open Coding (Time 1)	15	12
Axial Coding (Time 2)	8	8
Selective Coding (Time 3)	9	6
Secondary analysis		(2)
Theoretical saturation		28

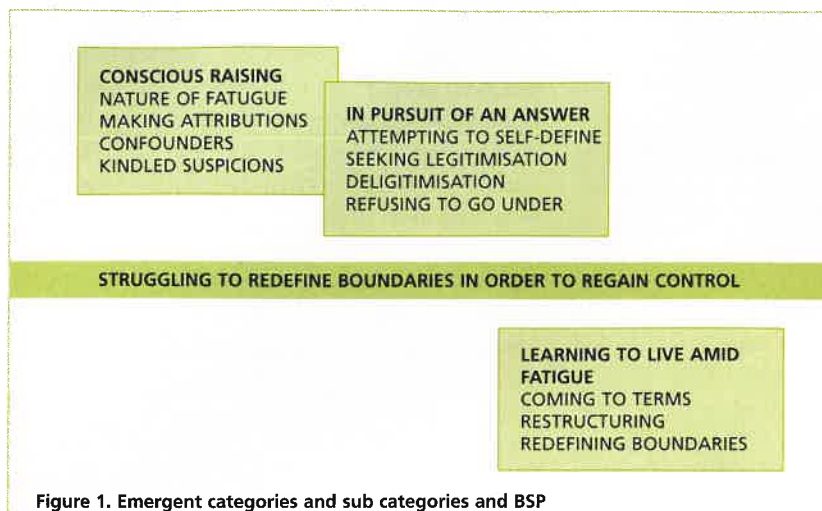


Figure 1. Emergent categories and sub categories and BSP

*It was such a relief that you were not imagining things. It has been confirmed. You would not believe it... I seem to be able to manage it better... maybe it is that I know it is not me as such... there is a reason for it. It is not just because it is in your mind or it is not because you have a low blood count [Rosaleen].*

Understanding, equipped them with a framework which allowed them feel more in control of the circumstances of their lives and, as a consequence, able to work out meaningful ways of managing their fatigue. It granted the participants permission to be more tolerant of their inadequacies and cease feeling guilty about the hardship their complaints of fatigue had imposed on those around them.

*I think I have come to the understanding that I have something in my system that I can do nothing about, right, and it causes me to have other, I can call them smaller problems, though sometimes they are big to me, you know what I mean relative to what other people have. .. Now I don't even say it much to John or the kids that I am tired, because I am not worried about it, you know. I used to have to say it because I was so worried. Now at least I am not worried about it all the time so I think that now I have a better mental attitude towards it, which I think helps, I don't think it removes the physical symptoms but I think it makes the way I cope with it easier ... you can actually sit there and say 'I am permitted to feel this bad, this heavy, this everything', you know [Hilda].*

Few social and behavioural scientists would dispute that individuals' understanding of events is a primary determinant of their response to those events. Indeed, the notion that individuals respond to the world as they view it, not necessarily as it is, has achieved the state of truism (Skelton and Croyle, 1991). The participants' interviews potently illustrated this. Participants tended to fight the fatigue when they viewed it as abnormal but, in effect, 'relinquished the struggle' upon diagnosis.

This act of relinquishment was not considered as surrendering to the fatigue but was the first step in regaining some control in their lives. The boundaries that now had to be redefined were those of the person's life. They had to refashion their lives so that they could function effectively therein as a person who experienced fatigue. Acceptance was the first proactive deed under-taken by participants in drawing the boundaries around the fatigue in their daily lives.

*My big step is that I accepted it. When I fought it and could not understand it, I was so angry and it was making it worse. It reverberates the tiredness because you have this frustration and are saying what is going on here? and I used to think I was better off dead. It was just crazy. But I think when you accept it, you let go then and breathe and just get on with it. You have to [Brigid].*

The benefits accrued by accepting one's plight in terms of a chronic symptom has been demonstrated in the chronic pain literature (Arntz and Schmidt, 1989).

Participants subsequently instigated a series of fatigue-management strategies. Knowledge of the strategies employed emanated from various sources such as family, friends, health professionals and the media. A wide variety range of strategies are utilised. An example of some are detailed below.

### Resting/sleeping

The taking of extra rest or sleep was a common strategy among the participants in the management of both the chronic and acute fatigue. For some, rest or sleep appeared to be demanded of them with the onset of the acute fatigue. Sleeping or resting at times of the acute fatigue usually resulted in temporary and partial relief of their fatigue. Resting or sleeping was also used as a means of coping with being chronically fatigued and for some participants was part of their daily routine. It was also employed as a defensive device for coping with their fatigue troughs whether they manifested physically or cognitively.

*I have what I call my fatigue management programme. I go to bed early three nights a week. I am in bed at 7.30-8pm. In the afternoons, I always take at least 35-45 minutes rest. I don't necessarily go to bed but I come out here (conservatory) and I just do nothing and you will still be tired afterwards. It takes a while to get going but I do [Kate].*

### Limitation awareness

Acknowledging ones limitations was seen as a very important aspect of living as a fatigued person. Strauss and Glaser (1975) contend that the sick person requires an intense awareness of his/her body: what it can and cannot do now, as opposed to before.



He/she must discover their limits, that is, how well and for how long they can carry on before reaching them. In this study such an astute awareness aided the participants in rewriting their guidelines for living.

*I am involved with horses but I cannot be as involved as I want to be, because I know, I wouldn't have the energy to actually keep going [Rosaleen].*

### Pacing & prioritising

Participants acknowledged that to maintain some order and control over fatigue in their lives they had to plan their activities and learn how to pace themselves. Failure to pace resulted in participants 'paying' for this indiscretion. Payment for the participants was in the form of a period of intense fatigue. Although in practical terms, the participants plans were frequently undermined by a change in their fatigue's nature from that of chronic to acute. Therefore at times, plans had to be abandoned due to "the way you get out of bed in the morning". Activities not only have to be planned in their lives but also prioritised.

*It has to be worth it. If you don't [plan], you pay for it. If there is something you really want to do, let's say with the children or go to a party, or an exhibition or something and you know about in advance, you store up your energy [Evelyn].*

### Becoming energy efficient

Through becoming familiar to the best of their ability with their daily chronic fatigue trajectories it was apparent that the participants tried to utilise as effectively as possible their periods of 'energy'. This time was seen as the time to get that little 'extra' done, unattainable when fatigued. For some their periods of activity were compressed into relatively short time spans. This seemed to be perpetuated by the unpredictable nature of their fatigue status.

*I try to get everything done as soon as I can in the day, because I don't know whether I will have the energy later on in the day [Deirdre].*

### Mobilising resources

Mobilising resources in terms of eliciting help to manage their daily lives was frequently employed. Help came in the form of other family members, home helps, nannies or au pairs. It appeared that participants often accepted this help reluctantly. Some viewed it as breaking some tacit rules which surround people's roles and that by accepting or asking for help they were infringing these. Mobilising resources also included the use of complimentary therapies such as aromatherapy and reflexology.

Unfortunately, none of the fatigue management strategies were "magic bullets" and all provided only

temporary relief with the degree of relief contingent on the nature of the fatigue.

The final subcategory in the category learning to live amid fatigue was titled 'redefining boundaries'. It, in effect, demonstrates how participants began to regain control over their lives and their sense of person-hood. This entailed various processes, which were individual to the participants such as recasting their goals in the context of diminishing energy supplies. Redefining themselves as a fatigued person entailed a change in their thought processes and an inward acceptance of their 'new capabilities'.

*I see myself as being different now. I am a person with fatigue not one engulfed by it. I have changed my boundaries and expect a little less of myself, well not less but reached at a more leisurely pace [Deirdre].*

For some, regaining control facilitated them acquiring the belief that their own behaviour could influence their fatigue experience. As Hilda explained, for a period of time it appeared that control of their life was in other peoples' hands.

*I think a lot of the problem with me, the fatigue and everything like that, was that I felt everyone else had control of my life...it seemed that the long-term outcomes belonged to someone else and I didn't like that. So, for me, I regained control when I took repossession of my life and as a result for me anyway I feel the fatigue is manageable. I think maybe eventually, as I move along to being more in control of myself, I think maybe that I may be able to prevent that really bad tiredness [Hilda].*

There was evidence that some participants had successfully integrated fatigue into their lives and were content with who they were as a person. They had recreated personal and social order which, according to Robinson (1988), is the key to successfully managing symptoms. The following account by one of the participants encapsulates the essence of this paradigm shift.

*I potter in the garden. My husband does all the heavy work, cutting grass or digging but I love pottering. I would hate to give it up. I wouldn't let myself give everything up, but you learn to know what you can do. When I say potter in the garden after a half hour, you would be quite exhausted. It is a stamina thing as well... so I come in and rest for another half an hour, an hour and then I can get up and go again. It is very much about pacing yourself, but I don't think about it anymore, because my whole life is about pacing myself. Yes, so it is integrated into my life and it is just what I am now and that's me [Kate].*

### Discussion and conclusion

The purpose of all formal inquiry and the research therein is to generate knowledge in a discipline. The generation of knowledge in the field of hepatitis C associated fatigue was particularly pertinent, given its prevalence. The virtual absence of empirical work

focusing on fatigue per se in this population, conveyed a sense that it was either insignificant in the lives of the hepatitis C population or it was of secondary importance to researchers, compared with research into the disease itself. The former, that is, that it is insignificant in the lives of the hepatitis C population can be discarded as a result of the mounting evidence that members of the hepatitis C community have a reduced quality of life (Davis et al, 1994, Carithers et al, 1996., Bonkovsky et al, 1999., Miller et al, 2001, Younossi et al, 2001, Hussain et al, 2001). Fatigue is emerging as a significant contributor to their reduced quality of life (Foster et al, 1998., Sladden et al, 1998., Ahmad et al, 1999., Rodger et al, 2000 ).

Although the process of living with HCV associated fatigue was presented in a linear fashion, nurses must be aware that often it is cyclical in nature with the type of fatigue and its degree of receptiveness to various management strategies dictating. There is a small amount of empirical literature available that has found a correlation between HCV associated fatigue and depression, anxiety and/or pain (Poynard et al, 1998., Barkhuizen et al, 1999., Dwight et al, 2000., Goulding et al, 2001). As the existence of multiple symptoms would have managerial implications, it is incumbent on nurses to establish if this assertion is true for the population they are caring for. Management of hepatitis C fatigue should comprise two stages—assessment and treatment. Assessment should be a vital and powerful part of management, rather than merely being a subordinate or prelude as, according to Larson et al (1994), symptom management begins with assessment of the symptom experience from the

patient's perspective. If assessment is properly employed, it will facilitate the hepatology nurse. To understand their patient's fatigue and facilitate them and their patient deciding on the appropriate course to be taken regarding further care and who is required to facilitate same. Surprisingly, although many interventions to relieve fatigue are advanced in the literature, to date, few have been subjected to empirical testing (Portenoy and Itri, 1999., Ream and Richardson, 1999). The available literature would suggest that to pay cognisance to the multidimensional, multi-factorial and hypothesised nature of hepatitis C fatigue, a multi-model fatigue intervention that could be tailored to the individual would appear to be the most appropriate (Lorig et al, 1994., Campbell, 1999., van-Mens Verhulst et al, 1999). This may include when all of the contributing factors to the fatigue experience have been identified, both pharmacological and non-pharmacological components. An interdisciplinary approach would also be recommended. As this study also revealed that some of the participants were turning to alternative therapies to acquire relief from their fatigue, hepatology nurses should also be proactive in pursuing the request from the Consultative Council on Hepatitis C (Mc Gee et al, 2000) to research the role of complementary or alternative therapies in the management of hepatitis C. If there is any hope that effective fatigue management could maintain or improve the health related quality of life of this population, nurses are morally obligated to examine what they are currently doing to facilitate their patients who are living with fatigue and if required augment the care they deliver.

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