

Fatigue and Hepatitis C: a focus group study

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ABSTRACT

Fatigue is often undiagnosed by health professionals as it is still seen as a nonspecific symptom without standard evaluations and effective treatments. Fatigue is present across many different diseases and has a profound effect on the quality of life of patients. However, it is still difficult to measure because of the lack of specificity of currently used self-report instruments. Patients with chronic hepatitis C infection, (HCV), experience fatigue as one of the most debilitating symptoms. The purpose of this study was to explore the types and dimensions of fatigue experienced by patients with HCV, identify specific terms they use to describe fatigue and assess how it influences everyday activities. Sixteen individuals with HCV (56% female, aged 58.1 ± 3.7 years) participated in three focus group sessions. The focus group sessions lasted between 60 and 90 minutes and were digitally recorded via audiotapes. Recorded focus groups' audiotapes were analyzed through thematic analyses. The analysis suggested two primary categories of fatigue experiences. These were: capacity and engagement in activity. *Capacity* refers specifically to an individual's sense of how much energy they have to do life activities or their maximum ability to produce energy. The word *energy* is the ability to perform work and includes one's ability to access or utilize, expend, and restore it. The phrase *engagement in activity*, comprised two domains: initiation (getting started or being motivated) and personal satisfaction (value of the activity). This investigation helped to identify important domains of fatigue experienced by those with HCV. The findings augment our current understanding of fatigue for this group because the domains of fatigue and the terms used to describe it are not commonly represented in the most frequently used fatigue assessments.

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Introduction

Fatigue has been defined as a subjective, unpleasant symptom, which incorporates feelings that range from tiredness to total body exhaustion.¹ Although fatigue is a common with nearly 10% of population, at any one time, experiencing fatigue that lasts more than six months, it is often not assessed in clinical settings.² This lack of assessment is probably due to a variety of reasons, including: the lack of consensus definition of fatigue, current assessments of fatigue are insensitive, non-specific, and uni-dimensional that may miss important dimensions of fatigue, and fatigue is an *invisible* symptom.

Hepatitis C Virus (HCV) is one of the diseases where fatigue is particularly prevalent and has an impact on individuals' lives. HCV is a blood-borne viral infection that causes both hepatic and extrahepatic manifestations. Acute infection with HCV often fails to clear in roughly 75% of carriers, leading to chronic HCV infection.^{3,4} The chronic condition may lead to liver cirrhosis, hepatocellular carcinoma or liver failure, all accompanied by extrahepatic manifestations such as debilitating physical and mental symptoms.^{5,6}

Fatigue, cognitive impairments and depression are the most common symptoms in HCV.^{3,7-11} Fatigue specifically, has been shown to negatively impact the health-related quality of life of those with HCV.^{12,13} Up to 97% of HCV infected patients have reported experiencing fatigue during the course of their disease,¹⁴ and 88% of infected

patients report experiencing some form of fatigue every day.¹⁵ Not only is fatigue one of the most common symptoms reported by patients, it is regularly described as the worst and most debilitating symptom.^{7,9,10,16} Treatments for HCV often worsen fatigue symptoms in patients, further impacting a patient's quality of life.¹⁷

Fatigue is often undiagnosed by health professionals as it is still seen as a nonspecific symptom without standard evaluations and effective treatments.^{7,10,11,14} Since its features can vary widely from individual to individual, fatigue is often overlooked and undertreated by physicians. Many patients report feeling like their doctor does not take their fatigue seriously.¹⁸ Patients also often attribute their fatigue to the increasing demands of modern-life, resorting to self-treatment. The gap between the experience of patients and their physicians' understanding of their accounts may be explained by the both the lack of physician resources and awareness, as well as the lack of a consistent way to measure and define fatigue. As a result, fatigue has many consequences on patient quality of life, their families, and costs to the healthcare system.¹⁹ This emphasizes that we need to more thoroughly define the features and domains of fatigue so that it can be identified and treated more efficiently.

Though fatigue is considered by healthcare professionals as a symptom, it is nonetheless classified as nonspecific and therefore marked by the complexity of psychological, social, and medical factors that characterize patients with nonspecific complaints since the era of modern medicine.²⁰ Inasmuch as clinicians are trying to optimize the well-being of their patients, however, that goal relies on sound tools to evaluate both real and perceived deficits in a way that can be used for the particular patient over time.²¹ Although there are a wide array of tools that assess fatigue, there is no instrument that can provide both specificity and sensitivity for measuring fatigue.²¹ The lack of a specific and sensitive tool along with the lack of a consensus definition of fatigue is the perfect storm that leads to under diagnosis and under recognition of this important symptom. It is time to allow patients to express their experiences with fatigue so that the medical field can more properly assess and then treat this life changing complaint.

We need to more fully understand the specific aspects of fatigue that patients are experiencing and its impact on their lives. Obtaining a more detailed account of fatigue may lead us to improved treatment approaches that could alleviate this multi-faceted and complex experience. Asking patients to discuss their symptoms and their impact on their lives may help expand the vocabulary we can use to describe and measure fatigue. The aim of this study was to explore the different dimensions of fatigue by adopting a qualitative approach that would ensure that we would understand how respondents understood and were able to express their experiences with fatigue.

It was essential to investigate this aim with qualitative

methodology, so we chose to approach it by means of focus groups. The main purpose of focus group research is to gain insight from respondents that would not be feasible using other methods (*i.e.*, surveys).²² We were interested in how the patients themselves describe fatigue and therefore we wanted them to use their own words and not just survey responses. Focus groups are often used as tools to develop concepts for questionnaires.²³ Fatigue needs to be investigated more broadly since a definitive definition of this symptom does not exist. If we are to be successful in treating fatigue within the context of HCV, first it is necessary to understand the full extent of experiences of patients with HCV. This will allow appropriate assessment tools to be designed and provide targets for potential intervention.

Materials and Methods

Participants

Sixteen subjects were invited to participate in one of three focus group sessions. These participants were identified from a current list of patients seen at an outpatient liver clinic. Potential participants were contacted via phone to gauge interest and determine availability. Inclusion criteria included diagnosis of chronic hepatitis C (confirmed in medical records) and ability and willingness to provide informed consent. Any condition, which in the opinion of the investigators would make the subject unsuitable for enrollment, such as documented history of mental illness was grounds for exclusion. All participants presented with HCV, seven of whom were currently on treatment with combinations of medication-based therapies. Additional participant characteristics are provided in Table 1.

Table 1. Participants' characteristics.

	N (%)
Number of participants	16
Gender	
Male	7 (44)
Female	9 (56)
Age (Mean±SD)	58.1±3.7
Marital status	
Married	7 (44)
Single	5 (31)
Divorced/widowed	2 (12)
Genotype	
1A	9 (56)
1B	5 (31)
Unknown	2 (12)
Past treatment non-responder	8 (50)
Achieved sustained virologic response	5 (31)
Diagnosed cirrhosis	5 (31)

SD, standard deviation.

Procedure

Participants provided written informed consent prior to participating in the focus group session and the Institutional Review Board at Inova Fairfax Hospital approved this investigation. Focus group discussion was led by a moderator (author AAW) and facilitated via prepared discussion prompts (Table 2). The focus group sessions lasted between 60 and 90 minutes and were digitally recorded via audiotapes. The purpose of focus groups in this study was to encourage participants to explore the dimensions of fatigue by using terms that uniquely represented their feelings of fatigue, how they thought it would be best communicated and how it impacted their lives. The use of focus groups for providing information to help design assessments and surveys has long been established.²⁴ In addition, the focus group methodology was chosen since it allows flexibility. Because we did not want to impose our own preconceived dimensions of fatigue into the discussion, we made sure that the prompts were quite general. The focus group strategy allows the moderator to probe issues in depth, address new issues as they arise, and ask participants to elaborate on their responses.²⁴ In addition, participants can be more comfortable talking in a group rather than an individual interview and these interactions between participants can generate more discussion.

Table 2. Focus group discussion prompts.

Prompt 1

Can you describe the feeling of *fatigue* that you associate with CLD?
 What does *fatigue* feel like specifically to you
 Is that different than how others use the word *fatigue*
 Does the amount of *fatigue* you experience change over time?

Prompt 2

How does it affect your daily living?
 Is there anything that you avoid doing?
 Is there anything that you miss, for example that you can't do?

Prompt 3

How do you manage in daily life when you have this feeling of *fatigue*?
 Do you have any trick or strategies?

Prompt 4

Has the *fatigue* caused you any distress?
 Can you describe the distress?

Prompt 5

Has anyone offered you advice about dealing with *fatigue*?
 What was it?
 Did it help?

Prompt 6

If there was one thing that someone could have done/said to help you with your *fatigue* what would it be?

CLD, chronic liver disease.

Analysis

To understand, explore, and explain fatigue, qualitative content analysis was used. Recorded focus groups' audiotapes were analyzed to code words, sentences, or paragraphs. Categories were then generated based on codes with shared content by multiple researchers (authors CS and SA). The category development involved the sorting of the codes into key ideas. These key ideas were created by examining the participants' choice of words, considering the group context, and looking for consistency among groups and group members. Then these categories were linked together into themes, trying to remain as close to the language used by the participants as possible. The development of themes was a collaborative effort by all of the authors.

Results

After three focus groups were conducted, saturation had been reached with no new areas of fatigue being endorsed in the third focus group. One of our goals was to elaborate the terms used, refine what was meant, and use them as a basis for our thematic description. The following are the terms that are noteworthy: i) capacity refers to the amount of energy available for use, like gas tank capacity; ii) access refers to the ability to get gas to engine, like the fuel pump or fuel injector; iii) depletion refers to energy being lost, such as running out of gas; and d. restoration refers to the ability to refill energy, such as filling the gas tank. Example quotes were selected and highlighted in the results section to help document this thematic structure.

Dimensions of fatigue

Given the diversity of patient history and the wide variety of symptoms that can occur in patients with HCV, initial analysis focused on identifying how fatigue was described, and then to determine if there was consensus among the participants on these descriptions. We created a word cloud to represent the most commonly used words in describing fatigue (Figure 1). Fatigue seemed to be present continuously in many of the individuals. One participant stated *That 2 or 3 p.m. [tiredness] thing that most people have, that lasts all day for us.*

As participants discussed fatigue, it was clear that two different dimensions of fatigue were endorsed: physical dimensions of fatigue and mental (non-physical) dimensions of fatigue. Reported physical health concerns included muscle weakness, shortness of breath, inability to move or eat, sleeping problems, and detrimental weight loss. The physical side of fatigue also included reports of constant tiredness despite adequate hours of sleep, feeling so burnt out that it was difficult to get out of bed, the need for immediate rest once energy runs out, and many reports of constant and difficult recovery from bouts of fatigue.

Another felt that forcing themselves to access energy allowed them to accomplish more than they otherwise might.

Sometimes it's not as bad but it's like you said, you've got to force yourself to get out and once you're going you can. On a Saturday, for me to get out of the house before 3 p.m. is huge. If I don't have to do something, I won't.

Metaphors of motion and cars were frequently utilized by patients to describe the fatigue and energy relationship. Sometimes this referred to a gas tank being quickly emptied, not being able to fill it up or even get to a gas station.

One participant expressed that the energy is present, but she cannot access it.

I don't have a lack of energy, it's an inability to access that energy. It's like a car that won't start. There's gas in the tank but the car won't start. The fatigue part of it is like sitting there all day, turning the key over and over, but it won't start.

Depletion

Participants indicated that the rate of depletion of energy also influences their sense of capacity. Depletion was conceptualized as how quickly a patient's capacity or level of energy diminished and negatively affected their functional abilities. This is a major physical problem affecting the participant's ability to function as well as a psychological stressor. Participants expressed great frustration by the change in their previous level of energy and it proved to be an emotional topic for some. This category also helps to illustrate the differences in the way in which different participants coped with the depletion.

One participant noted that they preferred to expend their energy until completely depleted.

I just make it to my bed and I'm lying there. So even if I want to go I just can't do it. It's like mind over matter and I'm just going to burn until I can't burn anymore and burn out.

Some firmly expressed that their depletion did not allow them to exceed their limited activity.

If I got up today and worked a whole 8 hour day, I wouldn't make it until tomorrow.

Restoration

Restoration also emerged as a theme that was consistently mentioned in all three focus groups. Restoration refers to the process in which fatigue levels can be mitigated and then how quickly and effectively they are able to recover that loss of energy. When speaking about their fatigue, many expressed that their capacity for restoration does not exist in the way one would hope, returning energy to baseline naturally, but instead is seen as how one must behave in order to ensure that proper recovery occurs.

Restoration proved to be a difficult process for many and responses demonstrated a wide variety of experiences.

Sleep was acknowledged as a major strategy for restoration but it did not seem to be effective based on feedback:

Naps can help recharge but doesn't completely get rid of fatigue.

Naps don't help at all.

Even when I sleep well at night, I'm still tired during the day.

To sleep and still wake up feeling run down is a bad feeling.

Exercise was a frequently endorsed strategy for restoration but some observed serious issues with recovery:

When I was doing yoga, when I did go to the gym, it did make me feel better but it would take me days to recover from.

I normally go to the gym every day and then by 3 o'clock I'm fatigued. But if I miss doing any kind of workout, the fatigue is worse.

The frequently utilized car metaphor was applied to restoration with the comment that without proper consideration for rest, it can be detrimental:

Now that I'm not going to the gym, it's kinda like a car slowly running out of gas. Sooner or later you'd better stop and get the fill up or you'll just be dead on the side of the road. Just stalled out. So I gotta get back to doing some of the stuff you don't feel like doing but you know if you do, everything else will get better. Things as well as your outlook will get better.

Engagement in activity

Another overarching theme that developed was representative of patients' personal initiation and desire to complete activities. While the capacity theme focused on the physicality of activities, this grouping was utilized to classify individuals' attitudes when facing fatigue and the ability to successfully mobilize. Thus this term was used to denote willingness and frequency with which participants took part in activities and was further defined by these subsections: initiation issues and personal satisfaction.

Initiation issues

One of the primary barriers to activity was initiating activity due to motivation, not energy level. Patients reported lack of motivation, which resulted in an inability to engage in activities without external stimuli. Lack of initiation seemed to cause distress and impacted their ability to engage in activity. Participant feedback regarding initiation issues focused on how difficult it was for them to overcome internal lack of motivation to engage. Their statements included:

I only sleep sometimes 5 hours, 8 hours at the most a night and that's all I need but I still have no energy during the day. It's not like I'm tired in that way where I want to sleep all day long, lying around. My problem is that I'm awake and I have no energy, no motivation, no drive, no wanting to get out and get things done. It's like, what's wrong with me? I'm just watching the hours go by and the days got to go by until next thing you know its time for me to go to bed. Next thing you know it's the same thing again but I'm not getting stuff done during the day, getting things accomplished. If I have to put things off I do until I can't put them off no more.

My mental self can see myself getting up but my physical self can't do it. Frustrating because I want to.

Almost every day I wake up right at 9 o'clock. I only sleep 5-8 hours a night, but I still don't have energy during the day. I'm awake and I don't have any motivation. Just sitting and watching the hours go by until it's time to go to bed, and I'm not getting anything done during the day. I'd keep putting it off until I didn't have to put it off anymore.

I will put off going to the grocery store until there is nothing else in my refrigerator because I know I will have to get up and walk around the store. But once I get out and get going, then I get things done and I'm really happy I accomplished. But getting that first step, getting going is the hardest part.

Personal satisfaction

While the manifestations and consequences of fatigue varied, a common theme was participants expressing varying degrees of dissatisfaction and distress with their current situation. This subcategory of personal satisfaction referred to both patients' general disposition and their specific concerns regarding getting things accomplished. Some were frustrated by an inability to get things done while others expressed dissatisfaction with what they are currently able to get done.

One of the major concerns expressed in this theme was that those participants who can get things done were not satisfied with the results. Participants who reported this as their main concern felt a fair degree of frustration at the loss of former abilities. Many felt that they could complete activities that were essential (*i.e.*, attending work and coordinating personal and family care) but were unable to do additional things they deemed important (*i.e.*, produce higher caliber work, support family and friends as much as they would like) or had to at least scale back on the intensity of activities.

I'm busy a lot and I make sure I don't over-schedule myself but it makes me kinda sad because I'm always a go, go, go type of person. A lot of times I burn myself out by going so fast.

Affects activity schedule because I have to balance activity and can't do all the things I want to do.

Discussion

People who use the word *fatigue* may experience a variety of bodily sensations that are interpretable as symptoms to the medical community. Indeed, this study showed that fatigue is a term that has different meanings to individuals and is used in a variety of ways to describe this multifaceted symptom. The participants used the term fatigue to describe both physical and mental components. Our research group has frequently questioned whether people experiencing fatigue can effectively communicate fatigue experiences through standardized fatigue tests. Our goal for this research was to gain an understanding of the nature and breadth of experiences of fatigue for those with HCV in their own words. The use of focus groups (qualitative methodology) was essential to accomplish this goal.

It was apparent that commonly used standardized fatigue questionnaires do not include many of the fatigue domains that were discussed by those with HCV. The results of this investigation expand the spectrum of fatigue symptomatology and may provide a first step in the development of new evaluation tools.

The multiple terms used to describe fatigue along with the overall findings of this study strongly suggest that a uni-dimensional conceptualization may not adequately assess fatigue. Currently the symptom of fatigue is not widely understood, and most research fails to specify the multiple meanings and variations behind the fatigue symptom.^{7,8,10,11,25} Our findings highlight these widely varied meanings of fatigue.

The severity and impact of fatigue on patients emphasizes the need for more accurate assessment of fatigue in patients with HCV. Understanding the multifaceted nature of fatigue and focusing on the specific symptoms of fatigue being experienced (*i.e.*, physical or mental or both) is important as these different aspects of fatigue may require different treatment methods.

A limitation of our study is that it did not address causes for fatigue. Many of the focus group participants reported suffering from chronic disease and comorbidities such as obesity, diabetes, depression and hypertension all of which may contribute to fatigue or its impact. About half of our patients were also currently undergoing treatment for HCV. Medications and other treatments could also have contributed to feelings of fatigue. It is interesting to note that regardless of the presence of absence of comorbidities, the participants seemed to describe a common language to express their symptoms. The focus group sessions did not have participants share their lived experiences and how their different experiences affected their fatigue. Therefore, our data do not include the contextual experiences of the participants and the relationship be-

tween the context and their experiences of fatigue.

Another limitation is the small sample size of our investigation. However, we stopped recruitment because we felt strongly that saturation was reached among the three focus groups, with explanations and experiences being very similar between all groups. A limitation of the utilization of focus groups is that the group setting can influence the responses of individuals, which can be especially problematic when a dominant member of the group monopolizes discussion. We did not specifically notice this issue in our analysis, but it is an inherent limitation to focus groups. In addition, many of the authors are experienced fatigue researchers and these experiences with fatigue could have biased the content and categorization of the participants' experiences.

These findings strongly suggest the need for further research on this topic. An overall goal of further research into fatigue should be the development of a detailed assessment that incorporates the domains of fatigue endorsed by patients in this study: physical vs. mental, capacity (including access, depletion, and restoration) and engagement in activity (including initiation issues and personal satisfaction). Participation of patients will be essential in the creation of this assessment tool. It is clear from the current study that patient input is critical in fully understanding the experience of fatigue.

Conclusions

In conclusion, this study found that within the focus group setting, the word *fatigue* for patients with HCV has meanings and dimensions not frequently included in standardized fatigue metrics. These focus group participants confirmed what has been reported by many investigators, that fatigue has a disruptive effect on their lives. The diversity of fatigue experiences highlights the importance of developing assessments that address the observed domains of fatigue.

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