

## The experience of fatigue for people living with hepatitis C

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QUALITATIVE

# Persons with hepatitis C experienced fatigue as being multidimensional with severity dependent on intensity, duration, and frequency

Glacken M, Coates V, Kernohan G, et al. The experience of fatigue for people living with hepatitis C. J Clin Nurs 2003;12:244-52.

How do persons living with hepatitis C experience fatigue?

#### **DESIGN**

Grounded theory.

## **SETTING**

Ireland.

#### **PARTICIPANTS**

28 participants with hepatitis C who were 36-64 years of age {mean age 41.5 y}\* (71% women). Most participants were infected with hepatitis C as a result of receiving infected blood or plasma transfusions or through needle sharing during the use of illicit intravenous drugs.

#### **METHODS**

Indepth interviews were done until theoretical saturation was achieved. 24 interviews were tape recorded. Notes were taken of the other 4 interviews. Mean duration of interviews was 80 minutes (range 50–180 min). After the interviews, each participant spent ≥30 minutes in a debriefing session. Open, axial, and selective coding processes were used. Analysis included making constant comparisons and asking questions of the data. Memos were kept to help formulate thoughts and insights about emerging categories. Member checks were done to ensure trustworthiness of the data.

#### **MAIN FINDINGS**

Participants perceived the nature of fatigue to be pernicious in its onset, nature, dimensions, and severity. No universal fatigue onset trajectory emerged. Some participants were able to recount the onset and progression of their fatigue, whereas others experienced its evolution to be an insidious process. Hepatitis C fatigue emerged as being multidimensional in nature, with 2 distinct types: chronic and idiopathic. Chronic fatigue appeared to be a permanent type of fatigue with varying intensity (eg, severe or constant low grade). Idiopathic fatigue was transient but recurring and caused distress because (1) it was unpredictable in occurrence and duration, and (2) it's intensity could be so acute that participants felt they had no control over the fatigue and that "life" had to be put on hold until the fatigue had disappeared. Both chronic and idiopathic fatigue had physical, cognitive, and affective dimensions, with varying degrees of intensity that were unique to the individual. The physical dimension referred to a feeling of heaviness such that participants felt they would collapse

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with the weight of their bodies. The cognitive dimension manifested itself as forgetfulness and lack of concentration. The affective sensation of fatigue was experienced in an array of emotions including anger, frustration, anxiety, and depression. Severity of the fatigue experience was considered as a combination of intensity, duration, and frequency.

#### CONCLUSIONS

The fatigue experience of persons living with hepatitis C was multidimensional. 2 distinct types of fatigue emerged—chronic and idiopathic-and each had physical, cognitive, and affective dimensions. Onset of fatigue had no universal trajectory, and severity of fatigue was considered as a combination of intensity, duration, and frequency.

\*Information provided by author.

## Commentary

he study by Glacken et al adds a new dimension to our understanding of idiopathic and chronic fatigue as a response to illness. Although the study used a grounded theory approach, it did not result in substantive theory, but did provide an informative description of the multidimensional fatigue experience among people living with hepatitis C

According to Levine, fatigue is a sign that the body is using energy for healing.<sup>2</sup> Why then, does fatigue have so many "faces?" Levine would suggest that although fatigue associated with various illnesses may have similar manifestations, its unique characteristics are based on an individual's responses to internal stimuli (eg, the disease process) and external stimuli (eg, social support). Although Glacken et al acknowledge that the fatigue experienced by individuals with hepatitis C is similar to fatigue associated with other conditions and illnesses, the aching felt in hepatitis C is not part of the "universal" experience of fatigue.

Study findings remind us of the importance of monitoring the effect of stress on the perception of fatigue. Although interventions are recommended for fatigue, the investigators suggest these with caution because few interventions have been empirically tested. Perhaps most importantly, the investigators acknowledge the primacy of the patient's experience of fatigue. It is important to note that individuals who live with fatigue will tell nurses what works and what does not work for them. Perhaps, attending to the individuals' experiences and their success with interventions will be the best way to develop a science of caring for clients with fatigue.

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