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Symptom Clusters give Insight into Hepatitis C Life Quality

Cluster Analysis Reveals Symptom Triggers and Relief Strategies

[Abridged from [Hep C Review](#), December 2006] by Carolyn A Lang M.P.H.

Based on the paper "[Symptom Prevalence and Clustering of Symptoms in People Living with Chronic Hepatitis C Infection](#)" by Carolyn A. Lang M.P.H. et al. 

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The major impact on most people with Hepatitis C is on their quality of life. Only a small proportion of those infected with H.C.V. develop life-threatening complications and studies on quality of life have tended to use questionnaires not designed specifically for H.C.V. sufferers. In general it is not clear from these surveys whether sufferers were asked to respond to a given list of symptoms or whether they were asked to generate their own list. This is an important distinction because a list compiled by the researchers may not reflect the lived experience of H.C.V. infection.

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Since 1999 I have been examining the quality of life of people with Hep C infection. Two important aspects emerged. First, participants identified a variety of symptoms they attributed to Hep C. Second, a number of participants reported episodes where clusters of severe symptoms occurred. These debilitating symptom clusters were labelled "Hep C attacks" by one participant. Using face-to-face interviews it was determined that these symptoms and symptom clusters are prevalent and severe in people living with H.C.V. infection.

Twenty-one different symptoms were identified in 188 untreated H.C.V. positive people in Queensland. This list was derived from focus group discussions with 75 people living with chronic H.C.V.. The important difference from earlier studies is that the symptoms were not compiled by investigators or clinicians, as had been done in the majority of previous studies.

The symptoms included: physical tiredness (86%), irritability (75%), depression (70%), mental tiredness (70%), abdominal pain(68%), forgetfulness (65%), sleep problems (65%), joint pain (63%), poor concentration (62%), general body pain (60%), headaches (56%), muscle pain (54%) and nausea (53%).

The most severe symptoms were sleep disturbance, physical tiredness, mental tiredness and joint pain. Women were significantly more likely than men to report physical tiredness, depression, mental tiredness, headaches, food intolerance and sensitivity to light and noise, as well as forgetfulness, poor concentration, nausea and day sweats.

Groups of symptoms were identified by 116 people, enabling a cluster analysis. This analysis groups participants together if they experience similar group of symptoms. The first cluster experienced neurological symptoms such as irritability, mental tiredness and physical tiredness. The second experienced gastrointestinal symptoms, mainly abdominal pain and nausea. The third experienced pain related symptoms and fatigue. The fourth experienced a combination of neurological and gastrointestinal symptoms while the fifth group experience headache and migraine related symptoms.

Participants were asked if they could identify the "triggers" for symptom clusters and strategies used to relieve symptoms.

Sixty percent identified triggers, predominantly stress, with regard to family matters, financial or health worries and work stress. Dietary triggers included poor diets, too much junk food, fatty foods and sugary foods.

More than 70 percent identified strategies to relieve symptoms. Sleep was acknowledged as an important strategy, either a good night's rest or a daytime nap. Dietary factors included a healthy diet, less fat and carbohydrates and more water.

It appears, then, that people do get clusters of symptoms, with most people experiencing a couple of different types of cluster. The information on triggers and relieving factors can be used to advise people how to manage their symptoms but more work is needed to understand what the factors are that cause the clusters. Further study will be needed to decide whether these symptoms are worse for H.C.V. sufferers than for other liver diseases or in healthy controls and what other factors may contribute to these symptoms.

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