

# Uncertainty and the Treatment Experience of Individuals With Chronic Hepatitis C

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## ABSTRACT

It is estimated that 75% of those individuals infected with hepatitis C are not aware of their infection. Uncertainty surrounding illness events has been described as the ultimate psychological stressor. The aim of this research study was to examine the correlation, both direction and strength, between uncertainty and the antecedents of Mishel's uncertainty in illness theory. Convenience samples of 134 individuals diagnosed with hepatitis C were recruited. Findings indicate that those unique resources available to the individual in the form of their social network and health care authority figure have the greatest influence on their perception of uncertainty surrounding illness events.

**Keywords:** health care authority figure, hepatitis C, social network, uncertainty, viral hepatitis

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Infection by hepatitis C virus claims the lives of 12,000–15,000 Americans each year.<sup>1</sup> It is estimated that 1 in every 12 individuals worldwide has either hepatitis B or hepatitis C.<sup>1</sup> Infections with hepatitis C are estimated to be up to 5 times more common in the United States than infections with the human immunodeficiency virus.<sup>1</sup> Chronic hepatitis C is a serious infection that can result in liver failure, cirrhosis, or hepatocellular carcinoma (HCC). Infections with hepatitis C, therefore, present a major health disparity in the US and worldwide.

When it comes to a life-threatening condition, according to Mishel, uncertainty regarding the extent of the illness, and ultimately its prognosis, has been described by individuals as the ultimate psychological stressor.<sup>2</sup> Chronic illness, in addition to chronic uncertainty as a psychological constant, can have detrimental effects on the individual. Diagnosis of hepatitis C, for example, comes with a number of questions and considerations. Individuals may ask questions such as: How much damage has been done to the liver? Is there a cure? Will I die from this? In most cases, the diagnosis of hepatitis C is made when the individual is in the chronic stages of the illness. The newly diagnosed chronic hepatitis C individual

must cope with the paradox of a new diagnosis of a chronic, sometimes advanced, condition.

## BACKGROUND

Viral hepatitis is the umbrella term encompassing infections from any of the hepatitis viruses. Hepatitis C infections share an acute phase that may progress to a chronic phase in some individuals. The short-term acute phase follows exposure to the hepatitis C virus and comprises the initial 6 months. The acute form is often asymptomatic or characterized by minor gastrointestinal symptoms or general malaise. In most cases the exposure goes unnoticed by the individual. The chronic form of the illness starts 6 months after exposure and may be characterized by mildly elevated liver enzymes and/or decades of normal health as the disease progresses.

From a global perspective, hepatitis C is considered the most prevalent blood-borne infection. Risk factors for transmission of hepatitis C are primarily linked with exposure to contaminated blood or blood products. According to the US Department of Disease Control and Prevention (CDC), the highest prevalence of hepatitis C virus antibodies was reported in 1998 from individuals with significant or frequent percutaneous exposures.<sup>3</sup> The highest

documented incidence rates of hepatitis C infection were among users of intravenous drugs, recipients of blood from infected donors, and hemophiliacs. Lower documented incidence rates of hepatitis C infection were reported in those with high-risk sexual behaviors and those with infrequent percutaneous exposures, such as employees in a health care setting, according to the CDC.<sup>3</sup>

The majority of individuals infected by hepatitis C are not aware of their infection because of its asymptomatic nature. It is not until the condition is well advanced that symptoms begin to manifest. An estimated 75% of individuals infected with hepatitis C are not aware of their infection.<sup>1</sup> Individuals from the “Baby Boomer” birth cohort, those born between 1945 through 1965, make up two thirds of the chronic hepatitis C infection cases in the US, according to the CDC.<sup>3</sup> Hepatitis C–associated mortality is 73% higher in this age cohort, which includes a greater risk for liver failure, cirrhosis, and/or hepatocellular carcinoma (HCC).<sup>3</sup> The US Preventive Services Task Force (USPSTF), along with the CDC, recommend a one-time hepatitis C screening for those individuals born between 1945 and 1965 as well as at-risk populations.<sup>4</sup>

### PURPOSE OF THE STUDY

With 75% of individuals unaware of their infection, new screening recommendations are sure to identify numerous cases of chronic hepatitis C. Once identified, the newly diagnosed hepatitis C individual has to cope with the paradox of a new diagnosis of a chronic, sometimes advanced, condition. This paradox causes psychological stress to individuals as they cognitively process the uncertainties surrounding the diagnosis and prognosis, as well as the stigma associated with hepatitis C. The aim of this research study was to examine the correlation, both direction and strength, between uncertainty and the antecedents of Mishel’s uncertainty in illness theory. The research question that guided the study was: What is the relationship between the antecedents of Mishel’s theory (ie, health care authority figures, years since diagnosis, treatment experience, and social network) and the chronic hepatitis C individual’s perception of uncertainty?

### LITERATURE REVIEW

Merle H. Mishel conceptualized uncertainty in illness and created a middle range theory in nursing. He defined uncertainty as the cognitive state the individual creates when he or she is not able to properly structure or categorize an event because of a lack of sufficient cues.<sup>5</sup> The individual is not able to ascribe personal meaning to events or is not able to predict outcomes; this causes some obscurity and, therefore, uncertainty occurs.<sup>6</sup> These incongruencies or unbalanced realities cause alterations in the normal psychological state of the individual, which causes stress. Mishel’s uncertainty in illness theory provides a substantive theory in which to frame a study on the uncertainties faced by those individuals diagnosed with chronic hepatitis C.

Mishel’s uncertainty in illness theory has been applied to numerous studies with a main focus on cancer patients.<sup>5</sup> The diagnosis of cancer brings about a multitude of uncertainties. Similarly, other conditions bring about a degree of confusion and various uncertainties. Chronic hepatitis C, for example, comes with a number of questions and considerations. The majority of the time, the diagnosis of hepatitis C is made when the illness is in the chronic stages. The newly diagnosed chronic hepatitis C individual has to cope with the stress of a new diagnosis of a chronic and sometimes advanced condition.

Kim and colleagues studied the differences of uncertainty in female Korean breast cancer patients based on their treatment trajectories.<sup>7</sup> Their quantitative correlational study compared symptoms as well as factors and predictors of uncertainty by treatment path among breast cancer patients. The researchers recruited 252 women with breast cancer who were in current therapy or completing their cancer therapy. It was found that those in current treatment described more severe symptomatology, as well as greater levels of uncertainty ( $P < .01$ ), than those who completed treatment. They also found age ( $\beta = 0.206$ ,  $P < .013$ ), marital status ( $\beta = 0.252$ ,  $P < .002$ ), and pain ( $\beta = 0.250$ ,  $P < .013$ ) were significant predictors of uncertainty during treatment ( $R^2 = .176$ ,  $F = 8.907$ ,  $P < .001$ ).

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