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Project Title: Uncertainty and Watchful Waiting in Chronic Hepatitis C

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Abstract: DESCRIPTION (provided by applicant): Hepatitis C Virus (HCV), the most common blood-borne infection in the U.S., affects at least 4 million individuals with more than 35,000 new cases occurring each year. Further, up to 85% of those with acute HCV will develop chronic hepatitis C (CHC); the CDC has projected a fourfold increase in the number of CHC patients between 1990 and 2015. Many CHC patients are potential candidates for treatment with combination interferon therapy and approximately 50% of patients electing treatment will have a sustained viral response (SVR). However, the benefits of therapy are less clear for asymptomatic patients, those with co-morbid illnesses and older patients. Further, treatment has been associated with severe side effects such as depression and excessive fatigue, and because of these side effects and the limited efficacy of treatment, 40% of patients discontinue therapy and 10% forego therapy. Thus, approximately 50% of CHC patients are not undergoing active treatment but instead are watching, waiting, and monitoring their disease. The proposed 3 year exploratory longitudinal descriptive study will examine the trajectories of CHC patients' fatigue, musculoskeletal complaints, depression, and QOL over an 18-month period. We will also examine the associations of demographic variables, illness markers, and illness uncertainty with these trajectories. The specific aims are to: 1) identify potentially distinct classes of trajectories (e.g., stable, declining, perhaps improving) of CHC-related symptoms and quality of life among patients who are watching, waiting and monitoring, and to identify the demographic and illness markers associated with particular trajectories of change; 2) examine the associations of these symptom trajectories and QOL with illness uncertainty; and 3) explore the concerns of patients living with chronic hepatitis C that may be unique and unaddressed with quantitative measures. The sample will consist of 120 English speaking men and non-pregnant women who have been diagnosed with CHC and receive their care at the Duke Liver Clinic. Quantitative and qualitative methods will be used to analyze the data. The newness of the disease, the paucity of descriptive studies, and absence of nursing intervention trials for CHC patients is alarming. Watching, waiting, and monitoring under conditions of uncertainty is a critical issue for patients with CHC and this study will provide the first descriptive data on their symptom and QOL trajectories and thus new knowledge for practitioners and policy makers. In addition, this knowledge will be used to refine an Uncertainty Management Intervention for Watchful Waiting, which has been successfully used with elderly men with prostate cancer, for future testing among these CHC patients.