I, Christopher L. Fowler, hereby submit this work as part of the requirements for the degree of:

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This work and its defense approved by:

Chair: Linda S. Baas, Ph.D., R.N.

Theresa Beery, Ph.D., R.N.

Wei Pan, Ph.D.
Illness Representations, Coping, and Quality of Life

in Patients with Hepatitis C

Undergoing Antiviral Therapy

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By

Christopher L. Fowler

Associate of Applied Science in Nursing, Miami University, Oxford, OH 1991
Bachelor of Science in Nursing, Columbia Union College, Takoma Park, MD, 1995
Master of Science in Nursing, University of Cincinnati, Cincinnati, OH, 1999

Committee Chair: Linda S. Baas, PhD, R.N.
Abstract

Illness Representations, Coping, and Quality of Life
in Patients with Hepatitis C Undergoing Antiviral Therapy

Background: An individual’s personal view of illness is determined by a variety of factors including the cause of the illness, its consequences, the chronicity of the illness, the symptoms experienced, and the potential for recovery. Hepatitis C, a chronic illness caused by a viral infection, is increasing in prevalence and those infected often do not realize it until irreparable liver injury has occurred. Some individuals may be treated with medications that can eradicate the virus and prevent further liver injury; however, side effects of this therapy can be severe. The overall aim of this study was to explore the relationships among illness perceptions, coping, and quality of life in patients with chronic hepatitis C who were undergoing treatment with antiviral therapy. To date, no one had explored these concepts in persons with chronic hepatitis C.

Methods: A single-sample, cross-sectional research design was used for this study. The study was conducted at an outpatient treatment center in Dallas, Texas, for individuals infected with hepatitis C. A convenience sample of 99 individuals was recruited. Data were collected using self-report information obtained from a Demographic Data Form, the Revised Illness Perception Questionnaire (IPQ-R), the Ways of Coping Questionnaire (WCQ), and the Medical Outcomes Study Short Form-36 version 2 (SF36v2). Correlational statistical analysis was used to determine the relationships among illness representations, coping strategies, and quality of life. Multiple regression analysis was used to determine the predictive ability of the dimensions of
illness representations on the dependent variables of emotion-focused coping, problem-focused coping, mental health, and physical health.

**Results:** Significant correlations existed between many of the dimensions of illness representations, coping strategies, and quality of life. The regression analysis demonstrated that illness representations are predictive of coping strategies and quality of life. Illness representations were better at predicting emotion-focused coping strategies and mental health ($R^2 = .50$ & $.58$, respectively) than they were at predicting problem-focused coping strategies and physical health ($R^2 = .38$ & $.46$, respectively). All regression equations had substantial residuals, indicating that more accurate prediction of the dependent variables was possible. Further exploration of these variables is warranted using path analysis.
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Chapter 1--Introduction

Background

An individual’s personal view of illness is determined by a variety of factors including the cause of the illness, its consequences, the chronicity of the illness, the symptoms experienced, and the potential for recovery. Leventhal, Diefenbach, & Leventhal (1992) refer to this personal view of illness as an “illness representation.” These illness representations change over time and directly influence the coping strategies an individual uses to deal with the problems and emotions associated with the illness. Various emotional and physical outcomes result.

One illness that is becoming more prevalent in the United States is chronic hepatitis C, a virus that causes liver injury and eventually leads to the development of excessive fluid in the abdomen, changes in mental status, and high risk for bleeding. Individuals with hepatitis C often do not realize that they are infected with the virus until irreparable liver injury has occurred and a liver transplant is required. However, individuals who have not developed end-stage liver disease may be treated with medications that can eradicate the virus and prevent further liver injury. The side effects of this therapy can be severe and often necessitate discontinuing the therapy.

The overall aim of this study was to explore the relationships among three variables in a sample of patients with chronic hepatitis C who were undergoing treatment with antiviral therapy. This chronic illness is often undetected for years, has a variable course, and often occurs in marginalized individuals. To date, no one has explored these concepts in persons with chronic hepatitis C. This chapter provides an overview of chronic illness and the physical and emotional challenges faced by individuals with an illness that is chronic in nature. It also
provides a discussion of the diagnosis and management of hepatitis C. Finally, the purpose of this research study is described. The theoretical underpinnings of the study are described in Chapter 2.

Chronic Illness

Advances in many disciplines of the health care sciences have resulted in a dramatic decrease in the number of deaths from illness. This decrease in mortality has resulted in an increase in the prevalence of chronic illnesses. These illnesses are managed in a variety of settings, including the home, at work, and in the community setting, rather than within the medical system at a hospital or nursing facility (Han, Lee, Lee, & Park, 2003; Silverman, Musa, Kirsch, & Siminoff, 1999). The ways in which individuals live and the never-ending advances in health care will continue to have a major influence on health and overall well-being and will result in an increase in the incidence and prevalence of chronic illnesses.

Because many chronic conditions are rarely linked to a specific cause, they are managed but not cured. In the United States, 125 million people currently live with one chronic condition and 60 million people live with more than one chronic condition (National Chronic Care Consortium, 2003). Chronic illnesses are now the leading cause of death and disability in developed countries and their prevalence is increasing as the population ages (Cioffi, 1991; Hampson, 1997; Kutner, Cardenas, & Bower, 1992). In fact, aging with a chronic health condition has become a widespread phenomenon (Kutner, Cardenas, & Bower, 1992). With the advances that have occurred in health care technology, research regarding chronic illness has changed from identification of measures that will extend life to the development, testing, and implementation of measures to support health-related quality of life. The desire for an improved
quality of life has become a particularly important outcome of medical service provision (Raphael, Renwick, Brown, & Rootman, 1996).

Individuals with both acute and chronic illnesses are taking a more active role in their health care and expect their beliefs regarding their illness to be considered in medical consultations and selection of treatment (Weinman & Petrie, 1997). In order to interpret and respond to the wide variety of problems encountered when dealing with a chronic illness, individuals create their own models or representations of their illness (Weinman, Petrie, Moss-Morris, & Horne, 1996). These representations include factors such as chronicity, consequences, and severity and subsequently determine the coping strategies that are used both directly and indirectly to deal with the illness. It is evident that an individual’s representation of the chronic illness guides the development and achievement of goals and the evaluation of the outcomes of coping strategies. As well, quality of life may be related to these cognitive representations of illness and treatment (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004).

Symptoms are important triggers of health-related behaviors because of the central role that they play in the overall illness appraisal process (Siegel, Schrimshaw, & Dean, 1999). There is an emphasis on concrete symptom experiences both in formulating representations and in guiding appraisal of the efficacy of coping behaviors. Individuals often make health care decisions on the basis of regimen difficulty and current symptoms, rather than the long-term benefits of behavior that are inherent in the medical model of disease management. Purposeful behavior aimed at overcoming illness is based on perceiving and monitoring illness-related cues, processing illness-related information, and comparing this information with the existing system of health beliefs (Heszen-Niejodek, 1997). A lack of congruity between the health care practitioner’s and the patient’s beliefs regarding the cause of the chronic illness and subsequent
management can impact the psychological and physiological outcomes of their disease process (Orbell, Johnston, Rowley, Espley, & Davey, 1998). For example, a health care provider and a patient may have differing beliefs regarding the origin of the patient’s chronic hypertension. If the patient does not believe that obesity and poor dietary choices impact their hypertension, the prescribed lifestyle modifications may not be undertaken.

An individual’s representation of illness serves as a guide in the processing of information and leads to an interpretation of the information and subsequent health-related behavior. Much research has identified a relationship between the patient’s perception of illness and adherence to a specified medical regimen for management of the disease (Hagger & Orbell, 2005). Using a theoretical framework that identifies how patients identify and cope with specific types of information regarding health care events provides a rationale for selecting information and initiating actions that can be expected to benefit patients. Psychological processes and outcomes are central to understanding and treating physical disease (Holahan, Holahan, Moos, & Brennan, 1995). In many chronic diseases, however, the medical model, with its focus on the elimination of symptoms and the cure of illness and disease, is limited in its ability to explain the results of the psychological effects of the patient’s condition (Fortune, Richards, Griffiths, & Main, 2002). A model that takes into account the patient’s view of illness will lead to a more holistic approach to patient care and may result in improved physical and psychological outcomes.

Because chronic diseases now cause approximately eighty percent of all deaths in Western countries, a theoretical framework that assists the health care provider in understanding the cognitive and emotional processes that occur throughout the course of the illness can provide information of benefit to health care providers. Improvement in the congruity of the health care
provider’s and the patient’s perceptions regarding the chronic illness will result (Maes, Leventhal, & de Ridder, 1996). As objective measures of illness severity do not fully address the patient’s general or disease-specific health status, the individual’s perception of health-related quality of life is an outcome that should now be measured in studies of the effects of disease and treatments (Fujisawa et al., 2000; Khan et al., 1995; Raphael et al., 1996).

A definition that describes both the physical and psychological components of chronic illness is appropriate. Han et al. (2003, p. 140) define chronic illness as “a state of disease with irrevocable pathological change, lasting for more than three months and eventually causing permanent disability.” Germino (1998) further describes chronic illness as unremitting, persisting over time, pervading all aspects of life, and having a trajectory that varies in its predictability and controllability. Chronic illness is continuous and without a predictable resolution (National Chronic Care Consortium, 2001).

Dealing with the transition from diagnosis to treatment and management of a chronic illness can be difficult. Chronic illness has a significant impact on the quality of life of affected individuals and the range of problems experienced varies greatly from person to person (Dekkers, 2001; Petrie & Moss-Morris, 1996). Even individuals with the same chronic illness deal with different daily problems and with varying degrees of success (Heijmans & de Ridder, 1998). According to Nerenz & Leventhal (1983), there is a self-illness relationship in individuals with a chronic illness. This concept relates to the overlap between representations of illness and representations of self. There are three possible ways that the illness representation can relate to the self-system: 1) total involvement with the illness permeating every aspect of living; 2) encapsulation of the illness with patients seeing only a portion of their life being affected; and 3) freedom from illness but at risk of relapse.
Individuals with a chronic illness encounter a variety of problems when engaging in activities of daily living and respond differently and with a variety of strategies to manage those threats. They also vary in their desire and ability to adhere to recommended lifestyle changes, surveillance, and treatment options (Hampson, 1997). Chronically ill individuals are faced with diagnostic uncertainties, disability, dependency, social stigma, life-style changes and other self-management tasks, and must become adept at crisis intervention, symptom management, the medical regimen, cost management, and prevention of complications which disrupt the individual’s normal activities (de Ridder & Schreurs, 2001; Dekkers, 2001; Strauss et al., as cited in Han et al., 2003). These problems can affect spiritual, psychological, social, and family processes and trigger responses of a physical, behavioral, cognitive, and emotional nature (Germino, 1998; National Chronic Care Consortium, 2001). As such, individuals with a chronic illness are challenged to preserve emotional balance and a positive self-image, to maintain a sense of competence and mastery, to sustain relationships with family and friends, and to prepare for an uncertain future (de Ridder & Schreurs, 2001). Because of its long-term effects on all areas of life, chronic illness requires vigilant attention to all details of the illness to ensure adequate self-management in terms of symptoms, treatment, and side effects of treatment (Brown et al., 2001; Han et al., 2003).

For those individuals with a chronic illness, the meaning and the quality of their lives is judged subjectively within the confines of cultural, social, and environmental standards and norms (Han et al., 2003). As such, individuals with a chronic illness must redefine their reality by creating new meanings of health and illness when old meanings are no longer sufficient (Germino, 1998). Silverman et al. (1999) found that many individuals with chronic illnesses must modify social activities and environments and request assistance from family and friends in
order to carry out activities of daily living and to cope with illness-related symptoms. Because of the physical and psychological changes that occur with chronic illnesses, those affected individuals often fail to develop new self-images that are as satisfying as their self-image prior to the development of the illness (Dekkers, 2001). Because chronic illness affects so many aspects of life, treatment providers must consider the ordinary life of the individual with goals of enhancing self-esteem, promoting social adaptation of the person and the family, and lessening pain, disappointment, and frustration. As well, treatment must focus on self-care and living with life-long impairment (Han et al., 2003).

Hepatitis C

Viral infections increasingly result in chronic disease. This is particularly true for hepatitis C, which results in chronic illness in over 80% of infected patients. The existence of a viral hepatitis other than hepatitis A and hepatitis B was first noted in 1974 when epidemiologic findings documented that most cases of post-transfusion hepatitis were related to a virus other than hepatitis A or hepatitis B. Originally, the disease was given the name “non-A, non-B hepatitis;” the name was changed to “hepatitis C” after identification of the virus in 1989 (American Academy of Pediatrics, 1998; Coppola et al., 2004; Hoofnagle & Heller, 2003; Iosue, 2002). Hepatitis C is the most common blood-borne infection in the United States. It is estimated that 7-10% of people who received transfusions in the mid-1980s became infected with the hepatitis C virus (Greenberger, 1998). Because of mandatory testing of the nation’s blood supply, the current risk of contracting transfusion-related hepatitis C is minimal.

The hepatitis C virus (HCV) affects close to three percent of the world’s population, approximately 200 million people. It is the most common cause of chronic hepatitis and cirrhosis and is the most predominate indication for liver transplantation in the USA (Rodriguez-
Rosado, Perez-Olmeda, Garcia-Samaniego, & Soriano, 2001; Vachhani & Bank, 2002). Acute hepatitis C accounts for twelve to sixteen percent of the cases of acute viral hepatitis in the Unites States and has decreased significantly over the last fifteen years with the development of tests for HCV antibodies in donated blood and the decline in injection drug users from the high prevalence in the 1960s, 1970s, and 1980s. Chronic infection with the HCV affects 170 million people worldwide, including 2 to 3 million individuals in the United States (Hoofnagle & Heller, 2003; Lee & Harrison, 2005). In some parts of the world, more than 10% of the population is infected with chronic HCV (Lapane, Jakiche, Sugano, Weng, & Carey, 1998). Thirty thousand to thirty-six thousand new infections occur annually (Chung, 2005; Coppola et al., 2004; Iosue, 2002; Lehman & Cheung, 2002).

Although the incidence of acute hepatitis C is decreasing, largely due to better screening of the blood supply and the enactment of more stringent universal precautions, the recognition of patients with chronic hepatitis C infection continues to rise (Lee & Harrison, 2005). Because many of these persons are less than 50 years old, a significant future disease burden is expected and a high rate of newly discovered cases is likely to persist (Hilsabeck, Castellon, & Hinkin, 2005; Iosue, 2002; Lee & Harrison, 2005). Testing of blood donors reveals that 0.1 percent to 0.6 percent are positive for antibodies to HCV and approximately 70 percent of these also harbor HCV RNA, indicating chronic infection (Hoofnagle & Heller, 2003). The economic impact of chronic hepatitis C infection in the United States alone is projected to exceed $1 billion per year in direct medical costs between the years 2010 and 2019. Medical and work-loss costs resulting from HCV-related liver disease reach more than $600 million annually (Iosue, 2002; Shehab, Orrego, Chunduri, & Lok, 2003).
Chronic infection with HCV is often subclinical and a high proportion of patients are unaware of infection. Seventy-five percent of patients are not jaundiced and have only non-specific symptoms. Five percent of people infected with HCV are completely unaware of their infection. In fact, hepatitis C infection is often asymptomatic until severe liver damage becomes apparent decades after the initial infection (Dusheiko, 1996; Greenberger, 1998). It is estimated that only 25-30% of patients infected with HCV are sufficiently symptomatic to seek medical attention (Mendez et al., 2001). Most patients discover their chronic HCV status by routine serologic testing during blood donation or insurance screening (Iosue, 2002). This paucity of symptoms leading to diagnosis limits incorporation of HCV treatment into clinical practice (Gerlach et al., 2003).

**Transmission**

HCV is transmitted most efficiently through parenteral routes, such as blood product transfusion, intravenous drug abuse, accidental needle sticks, and prenatal infection. Other modes of transmission include intranasal cocaine use, sexual transmission, medical procedures, hemodialysis, household contacts, and perinatal spread (Chapko et al., 2005; Hoofnagle & Heller, 2003; Hoshiyama, Kimura, Fujisawa, Kage, & Kato, 2000).

Prior to 1992, the most common mode of transmission was through infected blood product administration. Because of routine testing for antibodies to HCV in donated blood, transfusion-associated HCV infection now occurs in less than 1 per 100,000 transfusions and accounts for only four percent of acute HCV infections (Iosue, 2002). Currently, the most common risk factor for acquiring acute hepatitis C is through injection drug use due to the ongoing risk of exposure, accounting for 50-60 percent of cases (Chung, 2005; Hoofnagle & Heller, 2003; Iosue, 2002). Intravenous drug users have an average HCV prevalence rate of
eighty percent. In fact, 80-90% of intravenous drug users test positive for HCV within 12 months after beginning injection (Iosue, 2002; Lapane et al., 1998; Renou & Halfon, 2005). Because of shared routes of transmission, co-infection with hepatitis C, hepatitis B, and HIV is common and has been estimated to be between sixteen and twenty-five percent (Lee & Harrison, 2005; Sterling, 2003).

Because of the risk of exposure to infected blood, certain groups experience a higher prevalence of HCV infection than is present in the rest of society. These groups include patients on hemodialysis, institutionalized or incarcerated individuals, and veterans. The spread of HCV infection in hemodialysis units is mainly due to nosocomial transmission from patient to patient (Barril & Traver, 2003). HCV prevalence rates may be seven to nine percent in veterans due to prior and current injectable drug use; this prevalence is approximately four-fold the national average (Hauser et al., 2002).

Pathology of HCV

Hepatitis C is a single-stranded ribonucleic acid (RNA) virus belonging to the family Flaviviridae (Hoofnagle & Heller, 2003; Rodriguez-Rosado et al., 2001). A distinctive feature of HCV is the diversity of its RNA sequence. When RNA sequences differ by greater than 30% between samples, a different genotype is said to exist; currently there are six identified HCV genotypes (Novick et al., 1997). Within genotypes, a 10 to 30% variation in RNA sequencing is identified as a subtype. In the United States, genotype 1a comprises fifty-seven percent of the cases of hepatitis C; genotype 1b accounts for seventeen percent. Genotype 2a accounts for four percent; genotype 2b accounts for an additional eleven percent. Genotype 3 accounts for seven percent, and genotypes 4, 5, and 6 account for the remaining four percent. Clinically, the identification of HCV genotype is important in determining likelihood of response to treatment,
with genotypes 1 and 4 more likely to be resistant (Apolinario et al., 2002; Hoofnagle & Heller, 2003).

HCV replication occurs primarily in the liver after binding to a cell-surface receptor followed by entry of the virus into the hepatocytes and uncoating of the viral genome (Fanning et al., 2001; Hoofnagle & Heller, 2003; Shaffer, 2000). Liver histology of chronic HCV is characterized by hepatocellular injury, necrosis, portal and parenchymal inflammation, and variable degrees of fibrosis. Approximately thirty percent of patients with chronic hepatitis C will have persistently normal liver enzymes (Lee & Harrison, 2005). Patients with normal enzymes and no symptoms may have significant inflammation, and patients with normal physical findings and hepatic synthetic function may have considerable fibrosis (Romagnuolo, Jhangri, Jewell, & Bain, 2001; Shehab et al., 2003).

A liver biopsy can be useful in determining the likelihood of progression of liver injury in chronic hepatitis C. Liver biopsies are not, however, without risk. A liver biopsy is associated with pain in 30% of patients, severe complications in 0.3%, and death in 0.03% (Garcia & Keeffe, 2001; Imbert-Bismut et al., 2001). Liver biopsy results are reported as a “grade” and a “stage.” “Grading” refers to the assessment of the activity of the liver disease and the amount of hepatocellular injury and inflammation. “Staging” refers to assessment of the degree of fibrosis or permanent architectural liver damage (Hoofnagle & Heller, 2003; Romagnuolo et al., 2001). The histological hallmark of chronic hepatitis C is an infiltration of lymphoid cells in the portal tracts that disrupts the limiting plate, invading the surrounding parenchyma and leading to periportal or “piecemeal” necrosis (Apolinario et al., 2002). Chronic HCV progresses to the development of fibrosis, and fibrosis leads to the irreversible scarring and nodule formation that
characterizes cirrhosis (Iosue, 2002). Moderate or severe inflammation and fibrosis have been associated with a more rapid progression to cirrhosis (Garcia & Keeffe, 2001).

Cirrhosis caused by hepatitis C occurs more frequently in men, in those infected after age 50, in those individuals with a high hepatic iron content, and in patients who consume more than six ounces per day of alcohol. HCV genotype also plays a role in the development of cirrhosis (Iosue, 2002; Ramalho, 2003). The height of serum aminotransferase levels, duration of known infection, history of acute hepatitis, source of infection, and body weight generally do not correlate with the stage of fibrosis (Hoofnagle & Heller, 2003).

*Acute versus Chronic Infection*

Acute HCV infection produces a wide range of clinical presentations, from asymptomatic to icteric illness. Fulminant hepatic failure attributable to acute HCV infection is rarely observed. Acute HCV infection can be separated into four phases: incubation, preicteric, icteric, and convalescence. The incubation period for acute hepatitis C lasts an average of 50 days (range of 15 to 75 days), during which HCV RNA becomes detectable in serum and levels of the virus gradually rise. Patients at this time are not symptomatic and antibodies to HCV (anti-HCV) are usually not detectable. The preicteric phase of the illness usually begins within 2 to 4 weeks of appearance of HCV RNA and is identified by a rise in serum aminotransferase levels. During this time, patients may experience malaise, weakness, poor appetite, nausea, low-grade fever, muscle aches, and right upper quadrant pain. Rash, hives, and arthralgias may also be present. During this time there are sharp increases in serum alanine aminotransferase and HCV-specific T cells can be detected (Chung, 2005). The icteric phase of HCV begins with the appearance of dark urine and may be followed by jaundice that lasts four to six weeks. Symptoms typically worsen and it is at this time that the patient is likely to seek medical care.
During the icteric phase, most patients are positive for HCV RNA, but only fifty to seventy percent have developed HCV antibodies. The convalescent phase begins with resolution of symptoms and return of appetite and stamina. Serum aminotransferases usually normalize within a few weeks of HCV RNA becoming detectable and titers of HCV antibodies rise (Hoofnagle & Heller, 2003).

An average of fifty-five to eighty-five percent of patients with acute HCV infection progress to chronic HCV infection (Chapko et al., 2005; Chung, 2005; Coppola et al., 2004; Gerlach et al., 2003; Glacken, Coates, Kernohan, & Hegarty, 2003; Iosue, 2002). Chronic hepatitis C is defined as the presence of antibody to HCV with intermittent or persistently abnormal liver function tests for more than 6 months or the presence of viremia for those with persistently normal liver function tests (Hoofnagle & Heller, 2003; Lehman & Cheung, 2002). After chronic HCV infection is established, spontaneous resolution is uncommon. More than 98 percent of patients with chronic HCV test positive for anti-HCV. The remaining patients usually have some form of immunodeficiency preventing development of the HCV antibody, such as hypo- or agammaglobulinemia, HIV infection, renal failure, or treatment with immunosuppressive agents. Titers of anti-HCV rise later during acute hepatitis C and achieve higher and more sustained levels in patients who develop chronic infection than in those with acute hepatitis C that eventually resolves. The course of chronic hepatitis C may be milder in younger individuals and in women.

Severe complications related to chronic hepatitis C are rare during the first two decades of infection (Hoofnagle & Heller, 2003). Patients with HCV do not die as a result of the viremia; they become ill and die because of the complications of cirrhosis and the associated pathology, including portal hypertension, ascites, GI bleeding, and hepatocellular carcinoma (Lieber, 2001).
Twenty-five to thirty-five percent of patients with chronic HCV progress to cirrhosis, with an estimated 8,000-10,000 deaths occurring every year (Lehman & Cheung, 2002; Ramalho, 2003). Five to ten percent of those with chronic HCV infection develop cirrhosis within ten years and up to twenty percent develop cirrhosis within twenty years of onset (Coppola et al., 2004; Cotler et al., 2000; Hoofnagle & Heller, 2003; Lee & Harrison, 2005). Cirrhosis renders liver tissue dense and impermeable and impairs the organ’s ability to filter blood and metabolize nutrients (Shaffer, 2000).

Chronic HCV infection is strongly associated with hepatocellular carcinoma, occurring in five percent of patients with HCV (Lin & Keeffe, 2001; Moussalli, Opolon, & Poynard, 1998; Rodriguez-Rosado et al., 2001). In patients with hepatitis C who drink even moderate amounts of alcohol, hepatocellular carcinoma develops in as many as fifty percent (Lieber, 2001). In immunocompetent persons, hepatocellular carcinoma typically develops 29 years after infection (Koziel, 2005). Serum alpha-fetoprotein (AFP) levels and hepatic imaging are widely used to screen for hepatocellular carcinoma in patients with chronic hepatitis C (Gonzalez & Jacobson, 2005).

Quality of Life in Patients with Hepatitis C

Quality of life is a subjective concept with many dimensions. The term refers to objective life conditions (such as current functioning, living conditions, and access to resources) or to subjective indicators of well-being, such as satisfaction with specific areas of life and with one’s life in general (Test, Greenberg, Long, Brekke, & Burke, 2005). It includes health, personal accomplishments and resources, life situation, spirituality, activity level, and social support. Previously authors have defined quality of life as a multidimensional, subjective, personal evaluation of and satisfaction with the physical, social, psychological, and vocational
aspects of one’s life (Baas, Beery, Fontana, & Wagoner, 1999). Most measures of quality of life include an evaluation of the impact of health on several dimensions of life including psychological, social, occupational, and physical domains (Burgess, Carretero, Elkington, Pasqual-Marsettin, Lobaccaro, et al., 2000). Global quality of life includes a broad and general evaluation of one’s life. Quality of life, however, can be affected by general health status and by a specific disease. Measures of health-related quality of life are frequently used to evaluate how a health problem changes the quality of life in a variety of dimensions.

Health-related quality of life focuses on self-assessment measures that are related solely to health status. Health-related quality of life is a multidimensional construct that consists of biological and physiological domains, symptom status, functional status, and health perceptions (Bennett, Perkins, Lane, Deer, Brater, et al., 2001). Physical health influences psychological well-being and an individual’s psychological state influences the perception of physical well-being (Burgess et al., 2000). Infection with HCV impairs health-related quality of life even in the absence of severe liver pathology (Iosue, 2002; Thein, Krahn, Kaldor, & Dore, 2005).

Multiple studies have demonstrated that patients with chronic HCV infection score worse than matched controls on health-related quality of life indices (Barkhuizen et al., 1999; Cotler et al., 2001; Forton et al., 2001; Forton, Taylor-Robinson, & Thomas, 2003). In hepatitis C patients on antiviral therapy, health related quality of life decreases with treatment then returns to the pretreatment level within 24 weeks after discontinuance of therapy. Components of health-related quality of life most often affected by antiviral therapy were: role-physical, vitality, social functioning, and role-emotional (Ware, Bayliss, Mannocchia, Davis, and the International Hepatitis Interventional Therapy Group, 1999). Quality of life may be related to the individual’s cognitive representations of illness and treatment (Covic et al., 2004).
Those who are hepatitis C positive also suffer from poor mental health with depression, anxiety, stress, and a sense of hopelessness commonly being reported (Copeland, 2004; Forton et al., 2003; Hilsabeck et al., 2005). These psychological difficulties may impair health-related quality of life in patients with HCV (Lehman & Cheung, 2002). The most common psychiatric disorder in persons infected with HCV is depression, with approximately twenty-eight percent of patients meeting diagnostic criteria for major depressive disorder, dysthymia, or other depressive disorders. Anxiety disorders are the second most common psychiatric disorder, with rates ranging from eighteen to twenty-six percent. Bipolar disorder, psychotic disorders, and personality disorders have even higher prevalence rates of six percent, seventeen percent, and thirty percent, respectively in veterans with hepatitis C (Hilsabeck et al., 2005). Other neurocognitive difficulties include problems with concentration and slowed information processing speeds. The pattern of neurocognitive deficits in HCV-infected persons is suggestive of frontal-subcortical dysfunction, with complex attention, concentration, information processing, and psychomotor speed being impaired. High levels of neuropsychiatric symptomatology are associated with decreased health-related quality of life (Hilsabeck et al., 2005).

Many extra-hepatic manifestations of HCV infection are possible with rheumatic symptoms being among the most common (Barkhuizen et al., 1999; Iosue, 2002). Barkhuizen et al. found musculoskeletal pain to be present in over seventy-five percent and fatigue was present in over fifty percent of all patients in a university-based hepatology clinic. In fact, fatigue is the cardinal symptom of hepatitis C infection, reported by thirty-nine to one-hundred percent of HCV-infected persons (Forton et al., 2003; Glacken et al., 2003; Hilsabeck et al., 2005). It is
multidimensional in nature and is both acute and chronic (Glacken et al., 2003). These symptoms are unrelated to the severity of liver disease, route of infection, or antiviral therapy.

Other extra-hepatic manifestations of hepatitis C occur in thirty to forty percent of patients. These include hematologic disorders (mixed cryoglobulinemia, monoclonal gammopathies, lymphoma), autoimmune disorders (hypothyroidism, sialoadenitis, idiopathic thrombocytopenic purpura), ophthalmologic disorders (corneal ulcers, uveitis, scleritis, sicca syndrome), renal disorders (membranoproliferative glomerulonephritis, membranous nephropathy), and dermatologic disorders (porphyria cutanea tarda, leukocytoclastic vaculitis, lichen planus) (Lee & Harrison, 2005; Mendez et al., 2001).

Hepatitis C is largely a disease of injectable drug users, a marginalized and unpopular group in society (Copeland, 2004). In their study, Zickmund, Ho, Masuda, Ippolito, and LaBrecque (2003) found that fifty-seven percent of hepatitis C patients experience stigmatization attributable to HCV infection. The researchers defined stigmatization as “attitudes expressed by a dominant group which views a collection of others as socially unacceptable.” This stigmatization was associated with an increase in emotional problems. Stigmatization can affect the self-esteem and quality of life of the affected individuals. Three themes developed to explain why participants felt stigmatized: 1) society’s association of hepatitis C with HIV/AIDS, 2) society’s association of hepatitis C with promiscuity, and 3) society’s association of hepatitis C with substance abuse. Stigmatization in the workplace and by healthcare workers was also present in addition to hardships within the participants’ own families.

*Treatment of Chronic HCV Infection*

Therapy for HCV infection is aimed at eliminating active viral replication and clearance of the virus, with the benefits of inhibition of fibrosis progression, prevention of hepatic failure,
and prevention of hepatocellular carcinoma. Treatment costs approximately $10,000 for 6
months and $18,000 for 1 year of antiviral therapy, including monitoring of laboratory tests.
Treatment of compensated cirrhosis costs between $34,000 and $53,000 over the patient’s
lifetime (Iosue, 2002; Sacks et al., 2004).

According to the National Institutes of Health Consensus Development Conference on
Management of Hepatitis C (2002), current indications for treatment include individuals 18-60
years of age who have HCV RNA in serum, elevated serum aminotransferase levels, a liver
biopsy showing fibrosis or moderate-to-severe necroinflammatory activity, and no
contraindications to treatment. All patients with chronic hepatitis C are potential candidates for
treatment, especially those at risk for ultimately developing cirrhosis. Factors predictive of a
good response to therapy include infection with genotypes 2 or 3, female gender, age less than
40, HCV RNA titer less than 2 X 10^6 copies/ml, and minimal liver fibrosis (Romagnuolo et al.,
2001).

Relative contraindications to therapy are decompensated liver disease, coronary or
cerebrovascular disease, renal insufficiency, solid organ transplantation, severe neuropsychiatric
disease, anemia or bone marrow insufficiency, active substance abuse, and active autoimmune
disease. Absolute contraindications to treatment include pregnancy, breast-feeding, and the
inability to practice birth control (Lee & Harrison, 2005; Lin & Keeffe, 2001).

Clearance of hepatitis C virus is more likely in those treated with alpha interferon than in
untreated patients (Koff, 2000). Alpha interferon was first shown to improve serum
aminotransferase levels and liver histology in chronic hepatitis C in 1986 when the disease was
still known as non-A, non-B hepatitis. It was approved by the Food and Drug Administration in
Interferons are naturally occurring cellular proteins with a variety of actions, including induction of an antiviral state in their target cells, cytokine secretion, recruitment of immune cells, and induction of cell differentiation (Pawlotsky, 2003). They are produced predominantly by leukocytes in response to viral infection and they inhibit replication of many viruses (Lin & Keeffe, 2001; Moussalli et al., 1998). Synthetic interferon reduces serum alanine aminotransferase levels, improves histological activity, and eliminates HCV RNA. It has been associated with a decreased incidence of hepatocellular carcinoma (Kainuma et al., 2002).

Pegylated forms of alpha interferon are slow-release, long-acting formulations of interferon that have been developed and have improved response rates even further with an overall sustained virologic response rate of fifty-four to fifty-six percent. With pegylated forms of interferon, the rate of absorption following subcutaneous injection as well as renal and cellular clearance of the drug is reduced, allowing the steady state concentration of drug in plasma to be prolonged (Lee & Harrison, 2005; Lin & Keeffe, 2001; Pawlotsky, 2003). The usual dose of interferon depends on the formulation and product. Standard alpha interferon is given three times weekly by subcutaneous injection; the pegylated forms of alpha interferon are given once weekly.

Ribavirin is a drug used in addition to interferon. The drug exerts broad-spectrum antiviral activity against viruses and leads to intracellular virus stasis (Moussalli et al., 1998). Ribavirin’s effects are related to its capacity to modulate the immune response and possibly to enhance the action of interferon alpha by accelerating the clearance of infected cells (Pawlotsky, 2003). Ribavirin is usually administered orally twice daily.

Initially, the rate of response for a 24-week course of alpha interferon was only five to fifteen percent. Extending therapy to 48 weeks increased the sustained response rate to twelve to
twenty percent. The addition of ribavirin to alpha interferon increased the rate of sustained virologic response to 35 to 45 percent (Coppola et al., 2004; Cotler et al., 2001; Lee & Harrison, 2005). A 24- or 48-week course of interferon plus ribavirin is now standard therapy for patients with chronic hepatitis C (Hoofnagle & Heller, 2003; Koff, 2000; Nilda & Alvaro, 2000; Soffredini et al., 2004).

Patients with genotype 1 require a 48-week course of therapy (Hoofnagle & Heller, 2003; Iosue, 2002). A 24-week course of therapy was found to be similar in efficacy to a 48-week course of therapy in patients with genotypes 2 or 3 regardless of initial viral level. Overall the sustained virologic response is now approaching 60 percent. When divided into specific genotypes, the sustained virologic response rate for genotype 1 is 42 percent to 56 percent and the sustained virologic response for genotypes 2 and 3 is 76 percent to 82 percent (Lee and Harrison, 2005; Sacks et al., 2004).

**Patterns of Response to Therapy**

Responses to therapy can be categorized on the basis of normalization in serum aminotransferase levels (biochemical response), disappearance of HCV RNA (virologic response), and improvement in liver cellular histology (histologic response). The primary end-point for most trials of antiviral therapy has been a 6-month post-treatment sustained virologic response (SVR) rate, representing the proportion of patients who remain HCV RNA-negative six months after completing therapy. Sustained treatment-induced virologic clearance is highly correlated with biochemical improvement, continued absence of circulating virus, improved histology, and improvements in health-related quality of life (Koff, 2000; Moussalli et al., 1998).

A 6-month, post-treatment, sustained virologic response is a reliable surrogate marker for the success of therapy. Ninety percent of patients who have a sustained virologic response also
have normal serum aminotransferase levels and eighty percent to ninety percent have improved histology (Sacks et al., 2004). The rate of development of hepatocellular carcinoma in patients with a sustained virologic response is far less than in patients who do not respond to treatment.

Patients who develop a sustained virologic response most typically have a rapid and immediate decrease in aminotransferase levels accompanied by disappearance of detectable serum HCV RNA within one to three months of starting treatment. Patients with higher initial HCV RNA levels and those with genotype 1 may take longer to become HCV RNA-negative. Evidence suggests that patients have a greater chance of achieving a sustained virologic response if they are able to maintain their ribavirin and pegylated interferon doses at eighty percent of the baseline dose for eighty percent of the treatment period (Lee & Harrison, 2005).

Predicting non-response to therapy is important in limiting the duration of therapy in instances in which a poor response is likely. The best characterized factor that allows for early discontinuation of treatment is the continued presence of HCV RNA after 24 weeks of treatment as 98 to 99 percent of patients who ultimately have a sustained virologic response become HCV RNA-negative by twenty-four weeks of treatment (Hoofnagle & Heller, 2003; Soffredini et al., 2004). Persistence of serum HCV RNA or a less than $2 \log_{10}$ (100-fold) decrease in viral load at week twelve of treatment accurately predicts non-response to pegylated interferon plus ribavirin. Serum levels of HCV RNA higher than 30,000 IU/ml at week 12 of therapy seem to predict non-response to both standard and pegylated interferon combined with ribavirin (Soffredini et al., 2004). The response to therapy at week twelve can be predicted by measuring the viral load in serum. Patients with a $2 \log_{10}$ drop in virus or undetectable HCV RNA should be continued on therapy as the overall SVR for these patients approaches seventy percent. If the viral load has not decreased by at least 2 logs from baseline, therapy should be discontinued as the percentage
of patients who will develop an SVR is less than two percent. Nearly ninety-eight percent of patients who achieve an SVR are cured of HCV infection (Lee & Harrison, 2005; Pawlotsky, 2003).

A response to therapy with subsequent relapse occurs in some patients treated with interferon, occurring most commonly with interferon monotherapy and with short courses of treatment. The return of HCV RNA after stopping therapy is usually rapid; at least ninety percent of patients who relapse will have detectable HCV RNA within five weeks after stopping treatment. Relapse more than 6 months after discontinuation of therapy is uncommon, which is the reason for using the 6-month post-treatment HCV RNA result as the marker for sustained virologic response. Those with a prior response to therapy but who subsequently relapse have the highest chance of achieving a SVR with newer forms of therapy in the future.

As many as half of all patients treated with alpha interferon and ribavirin are virologic non-responders and never become HCV RNA negative during treatment. If the patient was treated with a combination interferon-ribavirin therapy and was considered a non-responder, additional treatment with combination pegylated interferon-ribavirin results in a SVR in only six percent to ten percent of cases (Lee & Harrison, 2005; Lin & Keeffe, 2001; Pawlotsky, 2003). Pharmacologic trials are ongoing to determine treatment modalities for non-responders and responder-relapsers.

Side Effects of Combination Therapy

Health-related quality of life scores improve with successful antiviral treatment (Forton et al., 2001; Iosue, 2002). However, side effects of antiviral therapy are severe enough to require discontinuation in ten to twenty percent of patients and dose reduction of interferon and/or ribavirin in forty to forty-two percent of patients (Iosue, 2002; Lin & Keeffe, 2001). An
influenza-like syndrome after the initial injection of alpha interferon is common. Symptoms usually begin six to eight hours after the first injection and persist for eight to sixteen hours. The symptoms may be delayed and persist longer with the pegylated forms of interferon. Most often these symptoms include fever, chills, malaise, muscle aches, headaches, nausea, diarrhea, fatigue, mental disorders, alopecia, hematological changes, thyroid dysfunction, and poor appetite (Iosue, 2002; Lin & Keeffe, 2001).

Other side effects include nausea, myalgia, abdominal discomfort, pruritis, skin disorders, pruritis, diarrhea, headaches, throat congestion with chronic rhinitis, sinusitis, throat irritation, earache, hyperuricemia, cough, depression, and nervousness (Moussalli et al., 1998). These side effects are usually mild and tolerable but can be unpredictable in severity and timing and result in a reduced quality of life.

Alpha interferon is myelosuppressive, resulting in decreases in red blood cell, white blood cell, and platelet counts. Ribavirin causes hemolysis of red blood cells and a mild leukopenia. Neutropenia is another common side effect (Lee & Harrison, 2005). This myelosuppression and hemolysis results in anemia commonly being seen in patients treated with combination pegylated interferon and ribavirin. More than fifty percent of patients will experience at least a 3g/dL drop in hemoglobin during therapy, usually within the first two to six weeks of therapy. Additionally, alpha interferon can induce autoantibodies. One to three percent of patients develop an autoimmune disorder while on therapy with thyroiditis being the most common autoimmune disorder (Lin & Keeffe, 2001).

Psychological side effects of antiviral therapy are also common (Cheung & Ahmed, 2001; Hoofnagle & Heller, 2003). A study by Howes & McKenzie (2000) found that sixty-three percent of patients experienced neuropsychiatric side effects after starting interferon therapy.
Seventeen to thirty-five percent of patients develop some degree or worsening of depression, irritability, anxiety, post-traumatic stress disorder, or moodiness. Depression is the most common psychologic problem and is often accompanied by fatigue, lethargy, and lack of interest in usual activities. It usually develops within the first twelve weeks of therapy. Other common neuropsychiatric side effects include irritability, emotionality, anxiety, sleeplessness, encephalopathy, confusion, coma, and acute psychosis. Patients may present with apathy, mood disturbances, anhedonia, insomnia, sexual dysfunction, or cognitive impairment. Suicides have also been reported (Lee & Harrison, 2005; Lehman & Cheung, 2002). These side effects negatively impact quality of life.

The reported incidence rates of interferon-induced Major Depressive Disorder (MDD) range from 0-70% for all diseases and from 0-44% for those receiving treatment for chronic HCV infection (Hauser et al., 2002). Adjunctive antidepressant treatment can reverse interferon-induced depression and thus allow continuation of antiviral therapy. However, interferon-induced depression may become sufficiently serious to result in dose reduction or even premature discontinuation of therapy, negatively impacting the patient’s quality of life (Kainuma et al., 2004). Symptoms generally resolve rapidly, within 2 weeks of stopping interferon alpha (Howes & McKenzie, 2000).

Clearly, individuals infected with chronic hepatitis C experience difficulties not only because of the hepatic and extra-hepatic signs and symptoms related to their infection, but also because of the difficulties inherent in antiviral therapy. The difficulties faced include both physical and psychological manifestations of the disease and its treatment as well as stigmatization from members of society. This can impact both health-related quality of life and one’s overall sense of well-being.
Purpose of the Study

The purpose of this study was to examine the relationship between illness representations, coping strategies, and quality of life in individuals undergoing treatment for hepatitis C. The results of the study will provide data to support the development of a framework useful in assisting patients who are receiving treatment for their hepatitis C.

Specific definitions based on the theoretical framework that will be presented in the following chapters will be used in this research study. Illness representations are defined as schematic representations of illness and health-threatening conditions based on an individual’s beliefs about the identity, cause, consequences, control, and timeline of their illness. Generalized coping is defined as, “the constantly changing cognitive and behavioral efforts to manage, reduce, or tolerate external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Lazarus and Folkman further define specific coping strategies as being problem-focused or emotion-focused in nature with problem-focused coping strategies being used to manage the situation and emotion-focused coping strategies being used to manage the emotions associated with the stressor. Quality of life is defined as, “a person’s well-being that stems from satisfaction or dissatisfaction with areas that are important to him or her” (Ferrans, 1990, p. 15). Quality of life may be global in nature (referring to one’s overall satisfaction with functioning, living conditions, personal accomplishments, spirituality, and social support). Health-related quality of life, however, focuses only on satisfaction with health status (symptoms, functional status, and subjective perceptions of health).

Research Questions

Three research questions were addressed in this study:
• Are problem-focused and emotion-focused coping behaviors significantly correlated with physical and mental health in HCV patients undergoing antiviral therapy?

• Are the components of illness representations predictive of problem-focused and emotion-focused coping strategies in HCV patients undergoing antiviral therapy?

• Are the components of illness representations predictive of physical and emotional quality of life in HCV patients undergoing antiviral therapy?

**Summary**

This chapter presented an overview of chronic illness and hepatitis C and introduced the concepts of illness representation, coping, and quality of life. Chronic illnesses such as hepatitis C impact individuals in a variety of ways and certainly impact many aspects of quality of life. Research questions have been identified and pertinent theoretical definitions were proposed. Chapter two will provide a discussion of Leventhal’s Common-Sense Model of Illness Representation and Lazarus and Folkman’s Transactional Theory of Stress and Coping. A thorough review of the literature pertaining to both theories will also be discussed.
Chapter 2--Theoretical Framework

This chapter provides a discussion and literature review of Leventhal’s Common-Sense Model of Illness Representation. The concept of coping and Lazarus and Folkman’s Transactional Theory of Stress and Coping will then be discussed. A review of the coping literature pertinent to the overall study will be presented. Finally, a brief discussion of the interaction between illness representations and coping will be presented.

The Common-Sense Model of Illness Representation

In the late 1960s and early 1970s studies of the result of fear communications on health-related behaviors demonstrated that the development and implementation of an action plan were related not only to fear itself, but to some changed way of the individual’s thinking in regards to the health threat. This finding led to the development of the Theory of Self-Regulation, which is currently referred to as the Common-Sense Model of Illness Representation (Diefenbach & Leventhal, 1996).

The Common-Sense Model (CSM) provides an overall framework that integrates social and contextual factors with an individual’s cognition and affect and was formulated to explain illness-related behavior, including adherence to treatment recommendations within the context of chronic illness (Horne & Weinman, 2002; Leventhal et al., 1992). The model depicts a self-regulative system that integrates both cognitive and emotional illness representations, coping procedures used to manage the illness representation, and criteria used by the individual to evaluate the outcomes of the coping processes (Hagger & Orbell, 2005; Leventhal et al., 1992). Its developers propose that individuals construct schematic representations of illness and health-threatening conditions according to the concrete and abstract sources of information available to
them. Interpretation of this information is the first step in the process of seeking help, engaging in a coping strategy, or adopting an illness management regimen. According to the model, health and illness behaviors and the outcomes of those behaviors (e.g. quality of life) are the product of the combined action of the representation of specific illness threats and of the coping processes used to manage the stimuli (Brownlee, Leventhal, & Leventhal, 2000).

According to the Common-Sense Model, the individual is an active problem solver who deals with two phenomena simultaneously: 1) the perceived reality of the health threat; and 2) the emotional reactions to that threat (Diefenbach & Leventhal, 1996). The CSM identifies the factors involved in the processing of information by a patient regarding the disease or illness, how this information is integrated to provide a personal view of the illness and how this personal view guides coping behaviors and outcomes (Hagger & Orbell, 2005). This individual view of illness explains coping behaviors and outcomes in chronic illness.

The CSM emphasizes the importance of concrete symptom experiences in formulating cognitive illness representations and guiding appraisal of the efficacy of coping (Horne & Weinman, 2002). Symptoms signal a change in body functioning and often provide the impetus for health-related action. For patients with a chronic illness, monitoring symptoms becomes a daily experience. Symptom perception involves the conscious cognitive interpretation of somatic information gathered by the senses while symptom interpretation refers to the interpretation of the meaning of the somatic information. Symptoms activate a cognitive search process that results in the construction or elaboration of illness representations. Symptom management involves adaptive responses to chronic illness that influence physical health, psychological well-being, and quality of life (O’Neill & Morrow, 2001).
Illness representations are multidimensional and have a common content across illnesses. Multiple cultural, social, and psychological factors influence the development of illness representations, the perceived availability of treatment and prevention, the subsequent behaviors, and the criteria used for evaluating outcomes of treatment. Personal and environmental factors include prior illnesses, an individual’s somatic self, depression, activity level, and personality traits such as optimism or attributional styles. Social and cultural factors include the ease with which the sick role is implemented, the consistency of the individual’s beliefs with the main cultural environment, and the consistency of the individual’s beliefs with the beliefs of the health care provider (Diefenbach & Leventhal, 1996; Leventhal et al., 1992). Irrelevant past experiences and social myths can predominate in the interpretation of the stimuli and generate illness representations and self-regulative systems which are false. From the perspective of the CSM, successful treatment requires the replacement of a self-regulative system that is false with one that is coherent and valid (Leventhal et al., 1992). Figure 1 depicts the relationships among the concepts in the Common-Sense Model.

Figure 1  Depiction of the Common-Sense Model of Illness Representation
**Stimulus**

Health threatening information is the key stimulus that results in the formation of the illness representation (Hagger & Orbell, 2005). Information regarding a health threat can come from a variety of sources, such as bodily sensations, information from health care providers and medical tests, advice and reactions from other people, and reports in the media (Benyamini, Gozlan, & Kokia, 2004). According to the CSM, this stimulus is interpreted and elaborated upon by the individual to form a more complete picture of the illness threat. These representations of illness change over time and guide subsequent actions (Leventhal et al., 1992). When the stimulus is internal (i.e. a somatic sensation or symptom), the individual attempts to assign meaning to that sensation. The meaning assigned depends upon the similarity or dissimilarity of the stimulus to prior illness episodes or upon the patient’s beliefs about another illness such as cancer or multiple sclerosis. When the stimulus is external (e.g. a news report or the occurrence of an illness in a loved one), the illness representation is checked against the individual’s sense of his or her health and perceived susceptibility to disease (Diefenbach & Leventhal, 1996; Fortune, Richards, Griffith, et al., 2002). High perceptions of risk about some hazard may result in anxiety. However, an inappropriately low perception of risk may result in failure to take preventive actions resulting in death or injury (Gordon, 2003).

An individual experiencing illness may develop a range of problems which are pertinent to that individual while others experiencing the same condition may have their own unique experiences. In order to make sense of and respond to these problems, patients create their own models or representations of their illness which then influence their coping and care-seeking behaviors. The process is regarded as self-regulatory because the three components of the model (illness representation, coping, and appraisal) interrelate in order to maintain the status quo;
therefore, if an individual’s normal state of health is disrupted by illness the model proposes that the individual will be motivated to regain the balance (Searle & Murphy, 2000).

*Illness Representations*

According to the CSM, illness representations guide coping behaviors and influence both psychological and physical outcomes. An individual determines the nature of a threat, appraises the resources to deal with the situation, and then engages in cognitive and/or behavioral actions to cope and lessen the impact of the perceived stressful situation and functional limitations (Livneh & Wilson, 2003; Puhl & Brownell, 2003). Appraisal of the situation is highly dependent upon one’s own personal construction of what a particular illness is, how it occurred, and the likely outcomes. The ways individuals perceive and respond to a health threat depend on the ways the health threat is represented in their own minds. These illness representations are derived from prior experiences and guide the processing of information in a fashion consistent with prior knowledge. Patients have their own beliefs about their illness and plan their actions to confront the problems at hand on the basis of these beliefs. Leventhal suggests that individuals will exhibit a characteristic illness representation profile for each illness according to its symptomatic features and chronicity (Hagger & Orbell, 2005).

Illness representations serve as the goals or targets for coping, and coping is appraised or evaluated against these representations (Fortune, Richards, Griffith, et al., 2002; Helder et al., 2002). Three sources of information are used to construct illness representations: 1) the generalized pool of illness information currently in the culture; 2) informal social communication or information obtained more formally in direct contact with health care practitioners; and 3) the individual’s personal illness experience (Shaw, 1999).
Five components make up the cognitive illness representation: 1) cause; 2) consequences; 3) controllability/cure; 4) identity; and 5) timeline. These dimensions of the overall illness representations are interrelated and function as groups of beliefs instead of as single cognitions (Covic et al., 2004). The *cause* component defines the patient’s beliefs regarding what caused the illness (i.e. genetics, poor lifestyle choices, bacteria, etc.). The *consequences* component includes the individual’s beliefs about the impact of the illness in terms of personal experiences, economic hardships, emotional stress, social role, etc. The *controllability/cure* component includes the individual’s beliefs regarding the responsiveness of the stimulus to interventions implemented both by the individual and by health care providers. The *identity* component includes the disease label and the individual’s ideas about the somatic representations of that disease. It is an essential component of the illness representation and emphasizes the importance of somatic sensations as a trigger for cognitive and emotional processing. The *timeline* component includes the individual’s beliefs about whether the illness is acute, chronic, or cyclical in nature (Diefenbach & Leventhal, 1996; Leventhal et al., 1992).

Emotions are an integral component of the CSM. Simultaneous with the development of the cognitive illness representation, an emotional representation develops that is more subjectively experienced by the individual, creating feeling states such as depression, annoyance, anger, and anxiety. Emotion can function in one of two ways. If the emotion is accompanied by an action plan, it can motivate the individual to engage in health care activities. If the emotion is overwhelming, however, little or no action will be taken (Diefenbach & Leventhal, 1996). Emotional representations are related to the cognitive representations and can influence cognitive illness representations in multiple ways including affecting the onset and progression of existing disease, increasing the difficulty of self-diagnosis and the decision to seek further care, altering
attention to and the interpretation and elaboration of representations of somatic states, and affecting behavioral decisions in response to somatic changes (Leventhal et al., 1992). Emotional representations lead to specific coping strategies and appraisal processes and are likely associated with emotion-related outcomes (Diefenbach & Leventhal, 1996; Leventhal et al., 1992). Because of the simultaneous processing of both cognitive and emotional illness representations, the model is referred to as a “parallel processing model” (Hagger & Orbell, 2005).

*Coping*

The categorization of the stimulus and the development of the cognitive and emotional illness representations lead to the selection and implementation of coping strategies directed toward management of the illness representations (Diefenbach & Leventhal, 1996; Leventhal, Leventhal, & Robitaille, 1998). Illness representations are directly related to coping and, via coping, are related to outcomes. Thus, coping is assumed to play a mediating role between illness perceptions and outcomes (Heijmans, 1998; Helder et al. 2002). A prerequisite for any mediation relationship is to establish that the independent variable (illness representations) is related to the dependent variable (health outcomes) (Hagger & Orbell, 2005).

Adherence to treatment is often viewed as one of the behaviors that the patient can adopt in an attempt to cope with their illness. It was proposed by Horne & Weinman (2002) that adherence decisions are influenced by an interaction of personal beliefs about the necessity of the treatment for maintaining or improving health and concerns about the potential adverse effects of adherence. In deciding whether to adhere to a treatment regimen, the patient must decide whether the illness warrants treatment and whether the treatment is appropriate for their illness. Health care providers must understand the factors that influence an individual’s adherence to a
treatment regimen or health behavior for the management of illness and to identify appropriate targets for intervention (Hagger & Orbell, 2005).

**Appraisal**

The final stage of the CSM involves appraisal of the outcomes of the coping interventions. The components of the cognitive and emotional illness representations establish questions and play a critical role in the appraisal of the effectiveness of these coping procedures (Diefenbach & Leventhal, 1996; Leventhal et al., 1992). The appraisal process includes determining barriers and facilitators to the successful performance of coping procedures, gains and losses experienced during the performance of coping procedures, and judgments regarding the efficiency and the effectiveness of the coping procedures (Leventhal et al., 1998). During the appraisal process, the progress of the coping actions is evaluated and compared with the anticipated and actual outcomes. Questions such as “Did the treatment have the desired effects?” are asked (Diefenbach & Leventhal, 1996; Leventhal et al., 1998). The appraisal of the coping strategies and their outcomes functions as a feedback loop and provides further stimuli, influencing and possibly altering the cognitive and emotional illness representations and leading to the implementation of new coping strategies (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2005). This feedback loop promotes the cyclical nature of the self-regulatory model.

**Illness Representations and Outcomes**

Studies of illness perceptions based on Leventhal’s model have been undertaken to determine the impact of illness representations on desired physical and psychological outcomes. Interestingly, the content of the personal models developed is predictive of some outcomes,
regardless of the coping strategies used to manage the illness representation (Griva, Myers, & Newman, 2000; Jopson & Moss-Morris, 2003).

**Consequences**

Petrie, Weinman, Sharpe, & Buckley (1996) found that lower scores on the perceived consequences subscale were associated with earlier return to work and that beliefs in major consequences were associated with the greatest amount of disability in post-myocardial infarction patients. Heijmans and de Ridder (1998), Orbell et al. (1998), Petrie et al. (1996), and Weinman et al. (1996) found that higher functional activity in patients with osteoarthritis, chronic fatigue syndrome, Addison’s disease, and myocardial infarction was associated with lower perceived consequences. Additionally, Heijmans and de Ridder (1998) found more perceived consequences were negatively associated with social functioning, mental health, and vitality.

Moss-Morris et al. (2002) found that fewer perceived consequences were associated with positive affect in post-myocardial infarction patients. Similarly, further research in rheumatoid arthritis patients revealed more severe consequences of illness to be correlated with depression (Murphy, Dickens, Creed & Bernstein, 1999). Fortune, Richards, Griffith, et al. (2002) found that stronger perceptions of serious consequences in psoriasis patients accounted for a larger portion of the variance in depression, disability, worrying, and psoriasis-related stress.

Helder et al. (2002) reported consistent findings in a discussion of studies using the CSM as a theoretical framework. They reported that more severe perceived consequences are associated with poor physical and psychological well-being. Similarly, in a group of patients with end-stage renal disease, more severe consequences of illness were negatively correlated with well-being (Fowler & Baas, 2006).
Control/Cure

The primary component of illness perceptions most strongly correlated with depression in rheumatoid arthritis and osteoarthritis patients was control/cure (Murphy et al., 1999; Orbell et al., 1998). Additionally, Moss-Morris et al. (2002) found that more personal control was associated with positive affect in post-myocardial infarction patients. Heijmans and de Ridder (1998) found more perceived control in chronic fatigue syndrome patients and in patients with Addison’s disease was associated with higher mental health scores and greater vitality. In end-stage renal disease patients, personal control has been predictive of mental health (Covic et al., 2004). A higher perception of control over a situation was also found to be associated with less state anxiety and higher self-efficacy (Endler, Kocovski, & Macrodimitris, 2001; Weinman et al., 1996).

Griva et al. (2000) reported that more perceived control was positively associated with adherence to diet and exercise plans in patients with Type 1 diabetes mellitus. Petrie et al. (1996) found a lack of perceived sense of control to be associated with non-attendance at cardiac rehabilitation sessions in post-myocardial infarction patients. Helder et al. (2002) reported consistent findings in a discussion of studies using the SCM as a theoretical framework. They report that stronger beliefs about the controllability or curability of illness have positive effects on well-being.

Identity

Identity
In a study of patients with myocardial infarction, Weinman et al. (1996) found disability and health distress were positively correlated with stronger illness identity and Moss-Morris et al. (2002) found that lower identity scores were associated with positive affect in post-
myocardial infarction patients. Illness identity also explains a portion of the variance in anxiety and depression (Fortune, Richards, Griffith, et al., 2002).

Horne and Weinman (2002) found that identity scores were positively correlated with the number of asthma-related visits to the general practitioner in the previous six months. In addition, higher identity scores upon admission to the hospital for patients experiencing a myocardial infarction were associated with later sexual dysfunction (Petrie et al., 1996).

Helder et al. (2002) reported consistent findings in a discussion of studies using the SCM as a theoretical framework. They report that a strong illness identity has been associated with poor physical and psychological well-being. Griva et al. (2000) reported that higher identity scores were positively associated with adherence to diet and exercise plans in patients with Type 1 diabetes mellitus.

Timeline

Petrie et al. (1996) found that more acute perceptions of illness were associated with earlier return to work. Similarly, in a study of patients with myocardial infarction, Weinman et al. (1996) found more disability, more health distress, and lower self-efficacy were correlated with a more chronic perception of illness. Alternatively, Heijmans and de Ridder (1998) found in patients with Addison’s disease that more chronic perceptions of illness were associated with higher physical functioning.

The perception of a chronic course of illness in patients with renal disease was associated with better personal control and physical well-being. How patients viewed their illness timeline was predictive of physical functioning in the same sample of patients (Covic et al., 2004). Conversely, Moss-Morris et al. (2002) and Heijmans and de Ridder (1998) found more acute representations of illness were associated with positive affect in post-myocardial infarction
patients and in patients with Addison’s disease. Helder et al. (2002) reported consistent findings in a discussion of studies using the SCM as a theoretical framework. They reported that a perceived long duration of a disease (more chronicity) was associated with poorer physical and psychological well-being.

**Emotional Representation**

A better understanding of illness was associated with a lower emotional response to illness in patients with end-stage renal disease. Additionally, lower emotional responses were related to and predictive of better physical and mental health scores (Covic et al., 2004). In an additional study with end-stage renal disease patients, more emotions provoked by illness were significantly correlated with lower quality of life (Fowler & Baas, 2006). Similarly, Moss-Morris et al. (2002) found that lower scores on the emotional representation subscale were associated with positive affect in post-myocardial infarction patients.

**Intercorrelations**

Significant intercorrelations between components of emotional and cognitive illness representations have consistently been reported. Patients with weaker emotional reactions to their illness generally have fewer perceived consequences (Covic et al., 2004; Hagger & Orbell, 2005). A sense of control is often associated with fewer symptoms, a more acute view of illness, and fewer consequences. Identity has been negatively correlated with self-rated health in myocardial infarction patients (Weinman et al., 1996).

In a study of patients with end-stage renal disease, significant correlations between the components of the cognitive and emotional illness representations did exist. Identity was positively correlated with a cyclical view of illness, more consequences, and a stronger
emotional representation. A more chronic view of illness was positively correlated with more consequences and negatively correlated with personal control. A more cyclical view of renal disease was positively correlated with consequences and stronger emotional representations. The severity of perceived consequences was positively correlated with the emotional representation (Fowler & Baas, 2006).

Hagger and Orbell (2005) performed a meta-analysis of studies using Leventhal’s CSM as a theoretical framework. Although there were some inconsistencies in the results of the studies analyzed, some consistent findings did emerge. Identity was consistently negatively correlated with control/cure but positively associated with chronicity and more severe perceived consequences of illness. Perceived control was negatively correlated with chronicity and with the severity of perceived consequences.

**The Concept of Coping**

Coping can be viewed from a variety of perspectives using a multitude of theoretical frameworks. The content of the coping literature as it relates to those with a chronic illness has progressed over time and now frequently includes information related to subjective interpretations of illness and the relationship between the interpretations and coping processes. This section discusses coping as it relates to chronic illness, including the conceptual shifts that have occurred over time. One of the most well-known theoretical models on coping is discussed and a review of the literature related to that model is presented.

Chronic illness places almost universal demands on those affected (Felton & Revenson, 1987). Chronic disorders with an unpredictable course can test an individual’s adaptive capacities even further as work, relationships, and future plans must be examined from a different point of view (de Ridder, Depla, Severens, & Malsch, 1997). By upsetting everyday
routines, chronic illnesses cause uncertainty, threat, and unexpectedness for patients and those close to them. This uncertainty affects various activities or even the person’s whole existence. As a consequence of being ill, an individual’s lifestyle is permanently changed and everyday activities are threatened as the person risks being stigmatized by society (Kyngas et al., 2000; Pierret, 2003; Roesch & Weiner, 2001).

Coping is an important predictor of well-being and mental health in persons who experience critical life events or suffer from chronic or life-threatening diseases (Vollrath, Torgersen, & Alnaes, 1995). Research supports the belief that high involuntary stress reactivity (emotional arousal, cardiovascular changes, intrusive and ruminating thoughts) and poor coping predict health problems and psychological distress (Connor-Smith & Compas, 2004). Additional research has demonstrated the negative impact of chronic illness on mood, especially worsening depression and anxiety (Hansdottir, Malcarne, Furst, Weisman, & Clements, 2004). One of the primary reasons to study coping is to determine how individuals can effectively reduce the negative impact of stressful events on their well-being (Aldwin & Revenson, 1987).

Living with a chronic illness places great demands on an individual’s ability to adapt. Difficulties in adjustment to disease arise out of a dynamic interaction between the demands of an individual’s environment and the ability to cope (Fortune, Richards, Main, and Griffiths, 2002). Preserving a reasonable balance, sustaining relationships with family and friends, dealing with pain and other symptoms, and developing and maintaining adequate relationships with health care professionals are difficult tasks and patients must develop strategies for coping with this upheaval and use various resources to reorganize their lives.

The ability to adapt to the demands of a chronic illness depends on the individual’s evaluation of the difficulties and the coping behaviors that are subsequently initiated. Many
individuals with chronic illnesses feel forced to deal with the emotions resulting from their illness because they perceive no control over their actual illness and believe that coping strategies directed at specific problems will be ineffective. However, the nature of the disease, the available social support, and the individual’s degree of self-efficacy can be helpful in promoting problem-focused coping (de Ridder et al., 1997). Positive thinking is thought to promote and maintain well-being by facilitating the belief that obstacles can be successfully confronted and overcome. Conversely, if people’s expectations are unfavorable, they tend to reduce their efforts and disengage themselves from attaining their goals, especially in the face of impediments (Fontaine, Manstead, & Wagner, 1993). Maladaptive coping can adversely affect physical and mental health. According to Lazarus and Folkman (1984), when that which is at stake is substantial and coping resources are judged to be less than adequate for managing the demands of the situation, psychological distress is experienced. The greater the perceived imbalance, the greater the distress that results.

*Coping as an Individual Process*

Coping is a process that involves the cognitive selection and performance of a plan to deal with disease threats and to tolerate the effects of illness (Covic et al., 2004; O’Neill & Morrow, 2001). Effective coping is essential in achieving positive adaptation to chronic illness, demonstrated by improvements in the relationship between the environment and the individual (Yuet, Alexander, & Chun, 2002). Adjustment is an ongoing process, determined to a large extent by ways of coping with the disease and treatment (Cohen, 2002). Even with similar objective measures of health status, however, there are often vast differences in adjustment among patients and individuals vary greatly in their adaptation to the same chronic disease.
In cases of chronic illness, the physical, psychological, and psychosocial functioning of individuals with the same medical condition may vary widely. Medical factors alone do not account for the extent of the illness-related dysfunction (Heijmans, 1999). Subjective perceptions of health status contribute to the interpersonal variation in both physical and emotional outcomes, beyond the contribution of more objective indicators. A challenge to health professionals is to identify the factors that differ between those patients who do and who do not successfully adjust to their condition (Groarke, Curtis, Coughlan, & Gsel, 2004). Improved understanding of patients’ perceptions of and views regarding their illness may benefit patient care as these perceptions can influence the ways in which individuals cope with and adapt to their illness (Caress, Luker, and Owens, 2001).

Appraisal and coping processes are influenced by characteristics of the person and the environment and are likely to have both stable and variable characteristics. Stability is associated with personal characteristics such as temperament, personality, and history and with stable features of the environment. Variability is associated with situational demands and constraints (including the extent to which the situation is changeable and controllable), with resources available for coping, and with other goals and demands that may compete for the individual’s time and resources (Folkman & Greer, 2000).

When faced with stressful life events such as a chronic or life-threatening illness, the nature of coping responses and the buffering effect of social support are among the most significant moderators which may attenuate the disruptive effect of the stressors (Swindells et al., 1999). Psychosocial adaptation to chronic illness and disease depends on many factors, including sociodemographic factors (marital status, age at onset of disability); disability-related factors (level of functional limitations, duration of condition); psychological/personality factors
(self-concept, locus of control, perceived uncertainty, post-disablement and post-diagnosis level of activity); and social-environmental factors (perceived social support, existing architectural barriers) (Fleishman et al., 2003; Livneh & Wilson, 2003). Higher amounts of perceived or actual social support have a buffering effect on adaptive functioning in the sense that they often have beneficial effects on physical health and emotional well-being and fewer somatic complaints (Holahan & Moos, 1987; Leslie, Stein, & Rotheram-Borus, 2002; Swindells et al., 1999). Stress and inadequate social relationships diminish an individual’s adaptive functioning and are associated with negative health outcomes and depression.

Perceived control over the situation is a moderator of the association between coping and distress, and distress is lower when the type of coping is appropriate for the level of perceived control (Osowiecki & Compas, 1998). The perception of illness as controllable is related to active coping variables while perceiving an illness as being uncontrollable, chronic, and highly symptomatic is associated with avoidant and denial coping strategies (Hagger & Orbell, 2005). Persons with a more internal locus of control use more direct coping efforts (Fournier, de Ridder, & Bensing, 2002).

Age affects coping strategies and their effectiveness, although study results are somewhat conflicting. McRae (1982, as cited in Felton and Revenson, 1987) described the regression hypothesis which posits that advanced age brings about a reliance on more rigid, primitive, or otherwise less successful forms of coping. In a study by Quayhagen and Quayhagen (1982, as cited in Felton and Revenson), older adults were more likely to use emotion venting and less likely to seek help, mobilize social support resources, or problem solve. In Felton & Revenson’s study of the coping strategies of older adults, age was negatively correlated with emotional expression, self-blame, and information seeking.
Men and women perceive stressors differently and use different methods of coping. Women use more social support coping strategies in professional situations and more assertive coping strategies in interpersonal situations. Women are more likely to use confrontive coping strategies and less likely to use avoidance strategies, even in the face of serious and debilitating illness. Additionally, women are more likely to use emotion-focused coping (Endler & Parker, 1990). Men, however, use more aggressive and antisocial coping strategies and are more likely to respond directly to the stressor (Puhl and Brownell, 2003). Positive social support has a protective effect for both women and men while interpersonal conflict and dissention have a negative effect (O’Neill & Morrow, 2001).

**Definition of Coping**

Coping is most often viewed as the individual’s own behavioral and cognitive efforts to adapt to or reduce distress during stressful events. It is a stabilizing factor that may help individuals maintain psychosocial adaptation during periods of stress (Holahan & Moos, 1987). The process of coping involves cognitive appraisal of a threat followed by attempts to either remove or mitigate the effects of that threat (Fortune, Richards, Main, et al., 2002). The purpose of coping is to change a stressful situation, to reduce emotional tension, and to decrease the demands causing the subjective feeling of stress (Folkman, Chesney, Collette, Boccellari, & Cooke, 1986; Heszen-Niejodek, 1997; Kyngas et al., 2000; Parker, Endler, and Bagby, 1993). Coping may play a role in moderating involuntary arousal, with effective coping attenuating the relations between reactivity and poor outcomes, and ineffective coping amplifying the negative impact of involuntary reactivity (Connor-Smith & Compas, 2004). Stress results from continually changing person-situation transactions and arises when the person is unable to cope with the demands caused by the altered situation (Kyngas et al., 2000; Vollrath et al., 1995).
Conceptual Change over Time

Coping is a complex multidimensional phenomenon that must be assessed reliably in order to detect existing relationships between psychosocial factors and health to allow meaningful interpretation of the findings (Chan, 1994). Traditionally, coping had been viewed as a trait-based function that was relatively stable in a variety of situations. Coping as a trait-oriented behavior is performed in response to stressful stimuli across a broad range of situations. As evidence developed demonstrating that coping traits were poor predictors of behavioral and affective responses in certain contexts, the acceptance of a transactional-based theoretical view of coping developed with coping viewed as a dynamic process involving a continuous interaction between the person and the environment developed (Ahlstrom & Wenneberg, 2002; Sorlie & Sexton, 2001).

Currently, coping is most often viewed as cognitive processes and behaviors that are performed in response to specific stressful situations. Coping is a psychological process resulting from an individual’s interpretation of the situation and specific events; this interpretation involves affective, individual, situational, and cognitive determinants of coping and the influence of previous coping experiences on future attempts to manage stress (Coyle, Edwards, Hannigan, Burnard, & Fothergill, 2000; Livneh & Wilson, 2003; Pakenham, 1999; Puhl & Brownell, 2003). The coping model used in this study emphasizes situational coping based on a dynamic process involving evaluations and reevaluations of the interplay between the individual and the environment (Ben-Zur, 2005).

Coping as a Trait Activity

Coping strategies for an individual are the result of learning. In some individuals, a pattern of coping develops, referring to a person’s frequent use of some coping responses and
infrequent use of others (Fleishman et al., 2003). This concept of a coping style expresses the dispositions underlying individual stability in coping behavior; it does not, however, imply absolute stability of this type of behavior, nor does it ignore environmental demands. Coping style simply refers to the ways in which people usually manage demands that are appraised as taxing one’s resources. It describes and attempts to explain the individual factors underlying the differences in coping behaviors and may be defined as a repertoire of strategies available to cope with stressful encounters. Coping style refers to relatively stable, individual differences in coping with stress and is often conceptualized as a characteristic of personality.

This notion of coping style implies that if an individual has a free choice of coping strategies, that individual is more likely to cope according to personal preferences unless the stressful encounter clearly requires different coping strategies. People differ in the kinds and number of strategies available in their coping repertoires. As well, they differ in the degree to which their behavior is flexible and adaptable to the demands of a specific stressful situation (Heszen-Niejodek, 1997). Because one has a certain coping style does not mean that another form of coping cannot be used. In fact, individuals who cope most successfully demonstrate flexibility as part of their coping style.

Coping as a Situational Phenomenon

Process-oriented and transactional coping models conceptualize stress in terms of the relationship between a person and the environment, emphasizing the dynamic and interactive nature of stressful transactions. This approach emphasizes the specific stressful events and the way that the individual responds to them, rather than generalized perceptions of stress as the focus of interest (Parkes, 1986). Coping depends on the context of the situation, although stable coping styles do exist and are important. Situation-specific coping includes thoughts and actions
that are actually taking place, as opposed to the thoughts and actions in which the person usually engages. Process-oriented coping can only be studied when comparing what happened at one moment or in one context with what happened in another.

There are multiple influences affecting how individuals cope with problems (personality characteristics, situational or role demands, cognitive appraisal, age, education, past experiences and cultural practices) (Aldwin & Revenson, 1987; Mallosiotis, 1997; Parkes, 1986). Both situational and personal factors have been shown to influence coping strategies and their effectiveness (Fleishman et al., 2003; Puhl and Brownell, 2003). Thus, individual capacities and abilities as well as the nature of the environment in which the episode occurs are of potential interest in the study of coping processes (Parkes, 1986).

During the course of coping behavior, new forms of coping may appear and the specific actions used may vary over time depending on the situation and the available coping resources (Heszen-Niejodek, 1997; Shaw, 1999). Lazarus and Folkman proposed that coping responses change as the situation unfolds. This dynamic response results in coping strategies that are not particularly stable over time, even in response to similar situations (Fleishman et al., 2003). People vary their coping responses depending on the intensity of their emotional response and their ability to regulate it, the opportunities inherent in the situation for problem solving, and changes in the person-environment relationship. Coping does not cease in the event of an unsatisfactory outcome. In fact, the distress resulting from an unsatisfactory outcome is often the impetus for a third type of coping known as meaning-based coping. Meaning-based coping helps the individual to relinquish goals that are unattainable and to formulate new ones, making sense of what is happening, and appraising benefit where possible (Folkman & Greer, 2000).
In regards to looking at stress, emotion, and coping as a transactional phenomenon, these concepts cannot be understood strictly by looking at the person or the environment; the interaction between the person and the environment must be considered. Therefore, the terms transaction and relationship are often used interchangeably. However, the use of the term transaction emphasizes more of the dynamic interplay that exists between the variables (Lazarus & Folkman, 1987).

Lazarus and Folkman’s Model

The study of stress and coping from the transactional perspective was relatively uncommon when Lazarus & Folkman’s model was originally developed. Traditionally, stressful encounters and the subsequent coping mechanisms employed were looked at using two basic models: 1) the animal model and 2) the ego psychology model. The animal model viewed coping as a set of behavioral responses (primarily escape and avoidance) that controlled aversive environmental conditions resulting in lowered arousal or drive. The ego psychology model, however, involved making adaptational decisions as well as employing actions to manage impulses and deal with the environment. In the ego psychology model, the quality of the coping processes was important, with the spectrum ranging from pathological to healthy (Lazarus & Folkman, 1987).

People continuously appraise their environment. The stress process begins when the individual becomes aware of a real or threatened change in the status of current goals and concerns. Stress is a subconcept of the larger concept of emotion, which also includes positive relationships, appraisals, and emotions such as joy, happiness, pride, love, and relief. The stress process is comprised of relationships between the concepts of antecedent, mediating, and outcome variables. These variables are believed to be recursive, in that the flow between them is
not unidirectional; what was once one type of variable (i.e. an antecedent variable) will become another type of variable (i.e. a mediating variable). Stress concerns person-environment relationships, cognitive appraisals, and emotional response states that are primarily negative in nature and usually results in an appraisal of harm, threat, or challenge that subsequently leads to various coping strategies.

Lazarus’ Transactional Theory of Stress and Coping (depicted in Figure 2-2) defines stress as a “particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (as cited in Edwards & O’Neill, 1998). When a situation is appraised as stressful, coping processes are employed in an attempt to manage the difficult person-environment interaction. The quantity and quality of the resources available to the person experiencing a stressful situation are important to the coping process (Edwards & O’Neill, 1998; Watson, Willson, & Sinha, 1998). The process involves conceptual change over time and across situations. In regards to stress and negative emotions, individuals strive to change that which is undesirable or distressing. Social support can provide the necessary resources for the person to enhance understanding of the stressor, acceptance of the situation, and a more positive outlook (Mallosiotis, 1997).
Antecedents are situations that result in the development and utilization of appraisal and coping strategies. They can be divided into environmental antecedents (demands, constraints, resources, ambiguity, and imminence) and personal antecedents (goals, belief systems); mediating processes include primary and secondary appraisal and coping. Immediate effects (short-term outcomes) are experienced during and right after an encounter; long-term effects are those concepts such as subjective well-being, social functioning, and somatic health. In this model, coping is not static; it changes as an encounter unfolds (Lazarus & Folkman, 1987).

Cognitive appraisal and coping are mediating processes between stress and outcomes (O’Neill & Morrow, 2001).

**Appraisal**

According to Lazarus and Folkman, cognitive appraisal processes mediate the initial perception and subsequent experience of a potentially stressful situation. Specifically, cognitive
appraisals are thought to shape emotional, physiological, and behavioral responses to such events. Lazarus and Folkman define cognitive appraisal as the process of categorizing an encounter and its various facets with respect to its significance for well-being. It is an evaluative process that reflects the person’s subjective interpretation of the event. Cognitive appraisal is a dynamic process involving continual evaluations and alterations in both primary and secondary appraisals of situations. After one’s initial encounter with a stressor, subsequent cognitive appraisals are a function of the reevaluation of situational demands and coping resources in light of new information based on experience. In this way, appraisal influences emotion and subsequent coping. According to Lazarus, individuals will respond to events according to their perception and appraisal of that event and whether it is seen as stressful. The individual will perceive and respond according to the context of the situation and the perceived ability to react within it (Coyle et al., 2000). Cognitive appraisal addresses the implications of what a situation means for an individual. Essentially, the individual asks, “What does this situation mean for me?”

Cognitive appraisal occurs in two different but related steps: 1) primary appraisal, reflecting the individual’s perceptions of the nature and degree of risk that a situation presents and the specific emotions or meanings that are associated with that stressor; and 2) secondary appraisal, reflecting the extent to which situational demands are perceived as within or outside an individual’s resources or ability to cope. These processes do not occur in a linear manner; the outcome of one process may reinvolve a preceding process (Carver, Scheier, & Weintraub, 1989).

*Primary Appraisal*

Primary appraisal includes the appraisal of harm or loss that has already occurred, threatened harm or loss, or challenge. Primary appraisal is influenced by the person’s beliefs,
values, and commitments and is concerned with the motivational relevance of what is happening (i.e. is the well-being of the individual at risk). The primary appraisal process results in three outcomes: harm (already experienced), threat (anticipated harm), and challenge (having the potential for mastery or gain). Appraisals of threat are those in which the perception of danger exceeds the perception of abilities or resources to cope with the stressor. Appraisals of challenge are those in which the perception of danger does not exceed the perception of resources or abilities to cope. Challenge results in stress because the person must mobilize resources to cope with obstacles in order to produce a positive outcome. Also, there may be some element of risk involved in an appraisal of challenge. Threatened individuals perceive the potential for loss; challenged individuals perceive the potential for gain. Primary appraisals of threat are more strongly associated with negative emotional reactions as threatened individuals may be less task-focused to avoid exacerbating the situation whereas challenged individuals may be more task-focused and less distracted by negative emotions (Tomaka, Blascovich, Kelsey, & Leitten, 1993). The appraisal of an illness-related event as threatening or limiting opportunities for personal growth and/or as uncontrollable is likely to negatively influence adjustment to an illness (Pakenham, 1999).

Secondary Appraisal

Secondary appraisal assesses the extent to which the situation can be controlled or changed by the individual. It is the process of developing a potential response to the threat; coping is the process of executing that response. Secondary appraisal involves evaluative judgments and generalized beliefs about what actions may be taken to improve the person-environment relationship and about which coping options might be most effective. Secondary appraisal is essential because the outcomes of primary appraisal include how much an individual...
believes he or she can control the stressor (Lazarus & Folkman, 1987). Together, primary and secondary appraisals determine the intensity of the emotional response that accompanies these appraisals. Appraisal influences subsequent coping (Folkman & Greer, 2000).

Emotions depend on cognitive appraisals of the significance of the person-environment relationship for the individual’s well-being and the available options for coping. People use a variety of cognitive and behavioral strategies that have both problem-solving and emotion-regulating functions. The relationship between emotion and coping in stressful encounters is bidirectional, with each affecting the other. The behavioral flow begins with a transaction that is appraised as harmful, beneficial, threatening, or challenging. This appraisal process generates emotions and influences coping processes, which in turn change the person-environment relationship. The altered person-environment relationship is reappraised and this reappraisal leads to a change in the quality and intensity of the emotions. In this way, coping is a mediator of the emotional response (Folkman & Lazarus, 1988a).

Coping

There is a complex and dynamic interrelationship between the individual, the perception of the stressor, and the perceived ability to remove, change, live with, or avoid its effects. Coping is defined as “the cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual” (Folkman & Lazarus, p. 2, 1988b). This definition has four key features: 1) it is process-oriented; 2) it speaks of management rather than mastery; 3) it makes no a priori judgment about the quality of coping processes; and 4) it implies a stress-based distinction between coping and automatic adaptive behaviors (Folkman & Lazarus, 1988b). Coping is a dynamic process in response to a perceived internal or external stressor that changes over time in response to objective demands and the
individual’s subjective appraisal of the situation as testing or exceeding the resources of the person (Aldwin & Revenson, 1987; Stewart, Hirth, Klassen, Makrides, & Wolf, 1997). An individual may respond or cope in a changing way during the unfolding of the stressful event and may rely on different coping strategies within the same situation at different times (Coyle et al., 2000). Coping actions also affect the appraisal of the problem and subsequent coping strategies (Stone, Greenberg, Kennedy-Moore, & Newman, 1991; Terry, 1994). The goals of the implemented coping strategies are to change the troubled person-environment relationship, to manage the problem that is causing the distress (problem-focused coping), and to regulate emotional distress (emotion-focused coping) (Lazarus & Folkman, 1987).

Problem-focused coping strategies are used to deal with the stressor itself and focus on efforts to manage or alter the troubled person-environment relationship (Puhl & Brownell, 2003). Problem-focused coping tends to predominate when people feel that they have control over the situation and that something constructive can be done. Problem-focused coping strategies include seeking information, defining the problem, generating, evaluating and implementing potential solutions, following a plan of action, and attempting to cognitively reappraise the situation by shifting one’s aspiration level, reducing ego involvement, or finding alternative channels of gratification (Austenfeld & Stanton, 2004; Fleishman, et al., 2003). These strategies are directed toward the source of distress and require the individual to deal directly with the situation. Greater control, less distress, and improved quality of life are consistently associated with higher levels of problem-focused coping (Ben-Zur, 2005; Bouchard, Lussier, Wright, & Richer, 1998; Carver et al., 1989; Folkman & Greer, 2000; Swindells et al., 1999; Pakenham & Rinaldis, 2001; Terry, 1994).
Emotion-focused coping strategies are directed toward the emotions associated with the stressful situation; they are not actually meant to change the situation (Ahlstrom & Wenneberg, 2002). Emotion-focused coping predominates and is more effective in situations in which the individual has little control and feels that the stressor is something that must be endured (Carver et al., 1989; Terry, 1994). The individual may use emotion-focused coping strategies to regulate affective responses and minimize negative emotions associated with the situation (Puhl & Brownell, 2003). Although the use of emotion-focused coping strategies may be helpful in the short-term by regulating affective responses and minimizing negative emotions, their use in the long-term can be maladaptive and has been associated with higher levels of psychological symptoms (Austenfeld & Stanton, 2004; Bouchard et al., 1998). Emotion-focused coping strategies include cognitive reappraisal strategies such as minimization, positive comparisons, seeking good in negative events, accepting the situation, selective attention, distancing, avoidance, exercise, meditation, alcohol use, venting emotions, and seeking emotional support (Austenfeld & Stanton, 2004; Edwards & O’Neill, 1998). In general, a reliance on passive emotion-focused coping strategies is associated with higher levels of distress. Active-approach emotion-oriented coping strategies such as acceptance and positive reframing techniques that require mental engagement with a stressor are associated with enhanced adjustment (Pakenham & Rinaldis, 2001; Weaver et al., 2004).

Other researchers conceptualize coping as active (confrontational) or passive (avoidant) in nature (O’Neill & Morrow, 2001). Active coping strategies, much like problem-focused coping strategies, help the individual constructively handle the situation and deal with the problem; these strategies allow the person to express some of the distress associated with the situation, thereby lessening tension (Jalowiec, 1988 as cited in O’Neill & Morrow, 2001).
Active coping strategies are directed toward confronting the problem and are aimed at problem solving or actively attempting to resolve the stressor (Holahan & Moos, 1987; Soderstrom, Dolbier, Leiferman, & Steinhardt, 2000). Active coping strategies are associated with the personality characteristics of optimism, hardiness, Type A behavior, and with less depression, less overall distress, greater perceived social support, and fewer episodes of illness (Leslie et al., 2002; Puhl and Brownell, 2003; Soderstrom et al., 2000). In their study of parents with HIV infection, active coping mechanisms were associated with more health care satisfaction and less substance abuse (Leslie et al., 2002).

Passive coping strategies, much like emotion-oriented coping strategies, are aimed at reducing psychological distress by avoiding confronting the problem or reducing emotional tension associated with the stressor; they are exemplified by a fatalistic and submissive style of addressing problems (such as waiting and hoping the problem will go away) (Holahan & Moos, 1987; Soderstrom et al., 2000). In passive coping, disengagement responses (such as avoidance, denial, and withdrawal) involve orienting oneself away from the stressor and the related emotions and thoughts (Connor-Smith & Compas, 2004). Severe functional disability or frightening symptoms increase the use of passive coping strategies (Downe-Wamboldt, 1991 as cited in O’Neill & Morrow, 2001). Passive coping is associated with anxiety, depression, a greater number of somatic symptoms, higher levels of psychological distress, and with the inability to use interpersonal relationships to receive social support (Fleishman et al., 2003; Fortune, Richards, Main, et al., 2002; Murphy et al., 1999; Leslie et al., 2002; Soderstrom et al., 2000; Welch & Austin, 2001). Welch and Austin (2001) found that passive coping explained much of the relationship between psychosocial stressors and depression.
Coping Strategies with Chronic Illness

Coping strategies in the chronically ill are the behavioral and cognitive efforts used to deal with stressful encounters in the face of illness; they include not only steps to actively manage symptoms but also ways to mobilize resources and to minimize the disruption of the illness on relationships (O’Neill & Morrow, 2001). Coping strategies play a role in the way an individual responds and adapts to stressful situations and the chosen strategies may be adaptive or maladaptive, depending on the situation (Ben-Zur, 2005; Parker et al., 1993; Whitmarsh, Koutantji, & Sidell, 2003). Coping strategies also play a role in an individual’s physical and psychological well-being when confronted with negative or stressful life events and have been shown to influence health-related outcomes (Endler & Parker, 1990; Leslie et al., 2002).

Individuals react to an event that they perceive as stressful by adopting coping strategies directed at managing the demands that this event places on their resources. It is not the actual coping response that is used which is the key to reducing distress, but rather how well the coping strategy fits the perceived situation (Osowiecki & Compas, 1998). Thus, effective coping strategies may not be directed at mastering or solving the problem per se, but at managing the consequences for the individual (Helder et al., 2002). Effective coping strategies are those that eliminate the stressor, reduce physiological arousal and psychological distress, maintain social functioning, and preserve a sense of well-being (Ben-Zur, 2005).

People use both problem-focused and emotion-focused coping strategies in virtually every kind of stressful encounter. Problem-focused forms of coping are used more in encounters that are appraised as changeable; emotion-focused forms of coping were used more in encounters appraised as requiring acceptance. Lazarus and Folkman emphasize that both sets of coping strategies can be adaptive or maladaptive and that consideration of the context in which the
strategies are used is essential when evaluating the outcomes of the coping efforts (Austenfeld & Stanton, 2004). In fact, people often use multiple forms of coping to deal with a stressful situation (Fleishman et al., 2003). The coping strategy or strategies that an individual uses at a given time depend both on situational (changeability, controllability) and individual (self-confidence, perceived resources) factors (Penley, Tomaka, & Wiebe, 2002). The nature of the chronic illness, the amount of available social support, and a large sense of self-efficacy are factors that can be helpful in encouraging problem-focused coping. Although individuals do not always cope as well as they would like, beliefs regarding ideal ways of coping reveal a preference for active, approach-like ways of coping with chronic conditions (de Ridder et al., 1997).

Some forms of emotion-focused coping (denial, avoidance, venting of emotions, disengagement) are related to increased levels of depression, less perceived control, more distress and anxiety, and lower quality of life in chronically ill patients (Ben-zur, 2005; Burker, Evon, Loiselle, Finkel, & Mill, 2005; Folkman & Greer, 2000; Fortune, Richards, Main, et al., 2002; Swindells et al., 1999). Additionally, in chronically ill patients who use passive, emotion-focused coping strategies, greater physical disability and less psychological well-being have been noted (Heijmans, 1999). Passive coping strategies, such as mental and behavioral disengagement, are believed to have a negative influence on the well-being and adjustment of chronically ill patients in that they interfere with problem-focused coping (Heijmans, 1999; Helder et al., 2002). However, in some patients with chronic illness, emotion-focused coping strategies aimed directly at accepting the problems that accompany the disease are significantly related to overall well-being (Helder et al, 2002).
In addition to chronically ill individuals using certain types of coping strategies, there has been a small amount of research on the effect of specific components of Leventhal’s illness representations on coping strategies. Endler et al. (2001) and Heijmans (1999) found a higher perception of control over a situation was associated with greater use of more adaptive coping strategies as opposed to emotion-focused strategies. Similarly, Puhl and Brownell (2003) found that less perceived control over the stressor was related to more emotion-focused coping. Patients with more serious perceived consequences of their chronic illness were found to use more passive, emotion-focused coping strategies such as cognitive disengagement and venting of emotion whereas patients who experienced fewer perceived consequences of illness engaged in more active, problem-focused coping strategies such as planning and information seeking (Heijmans, 1999). In a meta-analysis by Hagger and Orbell (2005) a stronger sense of illness identity was positively correlated with more active coping, seeking social support, behavioral disengagement, avoidance, and wishful thinking. A sense of more perceived consequences was associated with denial, behavioral disengagement, avoidance behaviors, and wishful thinking. Similar to previous studies, more perceived control over the illness was correlated with active coping, seeking social support, and behavioral disengagement.

**Theoretical Basis for the Study**

Research combining Leventhal’s Common-Sense Model of Illness Representations with Folkman and Lazarus’ Transactional Theory of Stress and Coping in individuals with hepatitis C undergoing antiviral therapy has not been done. This research study combines the key elements of both theories. Illness representations will be analyzed using a validated questionnaire developed using the CSM as a framework. Coping processes will be analyzed using a validated questionnaire developed using Lazarus and Folkman’s coping model as a framework. Outcomes
for both theoretical models include quality of life as an important component. It is believed that the blending of the two theories will provide a holistic view of illness representations, coping, and quality of life in individuals with a chronic illness that are experiencing a variety of acute symptoms related to antiviral therapy.

**Conclusion**

In this chapter, an overview of Leventhal’s Common-Sense Model of Illness Representation and Lazarus and Folkman’s Transactional Theory of Stress and Coping was provided. Historical and current literature was reviewed as it relates to both theoretical models. Any given coping process may have favorable or unfavorable results depending on: 1) who uses it, 2) when it is used, 3) under which environmental and intrapsychic circumstances it is used, and 4) the adaptational outcomes. The difference between functional and dysfunctional coping may depend more on the fit between the person’s appraisal of what is happening and what is actually happening and the person’s appraisal of the options for coping and his or her coping activity (Lazarus & Folkman, 1987).

Patients with chronic hepatitis C who are undergoing treatment with antiviral therapy have complex illness representations, especially when the five dimensions of the overall illness representation are examined individually. Additionally, those individuals use different problem-focused and emotion-focused coping strategies to manage their subjective representation of illness. As both theoretical models can be applied when examining the impact of a chronic illness such as hepatitis C and quality of life is an outcome measure important to individuals with any illness, it was the goal of this study to evaluate the relationships between illness representations, coping strategies, and quality of life.
Chapter 3--Methods

Previously, the importance of illness representations and the role of coping with chronic illness were described. Additionally, the theoretical frameworks used to guide this research study were discussed. It is the purpose of this chapter to discuss preliminary work evaluating the Revised Illness Perception Questionnaire in a group of individuals with chronic illness. After a discussion of the preliminary research, the design and methods of the current research study are described.

Preliminary Study

Preliminary research assessing the reliability of the Revised Illness Perception Questionnaire (IPQ-R), an instrument developed to measure the components of an individual’s illness representation, was done in a group of patients with chronic kidney disease on maintenance hemodialysis (Fowler & Baas, 2006). The single-sample, correlational design involved a convenience sample of 42 dialysis patients. The study evaluated the overall perception of chronic kidney disease and determined significant correlations that exist between the specific dimensions of illness representations and overall well-being.

While the current study sample is not the same as that which was used in the preliminary work, similarities do exist. Both study samples suffer from a chronic illness that impacts the entire body and has personal, social, and financial consequences. Patients on chronic dialysis must attend dialysis sessions three times per week for approximately four hours per treatment. They must deal with a multitude of medical and personal problems related to their disease (e.g. pruritis, fatigue, volume overload, hypertension, increased susceptibility to infection, and early mortality). Patients with hepatitis C on antiviral therapy do not have the time commitment
required by patients on dialysis, but they must take oral medications twice daily and subcutaneous injections at least weekly. Additionally, hepatitis C patients on antiviral therapy must deal with the acute and chronic physical and emotional symptoms related to the antiviral therapy (e.g. flu-like symptoms, depression, fatigue, pruritis, and cognitive deficits). All of these medical and personal issues result in a diminished quality of life for both patient samples.

In the preliminary study, all subscales of the IPQ-R demonstrated adequate reliability (alpha levels ≥ .70) with the exception of the treatment control subscale of the IPQ-R, which had a reliability of only .46. The reliability of most of the IPQ-R subscales was adequate and represented a well-developed tool to measure illness perceptions in a sample of patients with a chronic illness. All items on the Timeline—Acute/Chronic subscale, Timeline—Cyclical subscale, Illness Coherence subscale, and Emotional Representation subscale had item-total correlations greater than .44. The researchers believed that the low reliability of the Treatment Control subscale may have been due to the vagueness of the instrument’s questions as they related to chronic renal failure and the different perspectives of the study participants. For example, some individuals may have believed that the questions were asking about their beliefs regarding the ability of health care providers and dialytic therapy to control the kidney disease while others may have believed that the questions were asking their beliefs regarding the ability of health care providers and dialytic therapy to control the symptoms of kidney disease. It is believed that participants in the current study will have less confusion about the questions as the goal of all patients receiving antiviral therapy is eradication of the virus.

Similar to the findings in the preliminary research, higher identity scores have been positively correlated with more consequences (Fowler & Baas, 2006; Griva et al., 2000; Petrie et al., 1996; Weinman et al., 1996). However, the positive correlation between the Identity
subscale and the Timeline—Cyclical subscale found in the chronic renal failure sample differed from the negative correlation found between the same two subscales in a study by Moss-Morris et al. (2002). The findings of a positive correlation between the Timeline—Acute/Chronic subscale and the Consequences subscale as well as the negative correlation between the Timeline—Acute/Chronic subscale and Personal Control subscale was consistent with the findings of Moss-Morris et al. (2002). Covic et al. (2004), however, found that personal control was positively correlated with a more chronic perception of illness in dialysis patients in Romania. Timeline—Cyclical scores in the chronic renal failure sample were positively correlated with the emotional representation and with perceived consequences, a finding consistent with Moss-Morris et al. (2002). Higher perceived consequences were correlated with more emotional representations consistent with the findings of Moss-Morris et al. (2002) and Covic et al. (2004).

The preliminary study was done to assess the reliability and validity of the Revised Illness Perception Questionnaire in a group of patients with a chronic illness. While most of the subscales performed adequately, further evaluation was needed in specific patient samples. Additionally, further study was needed to assess the entire theoretical framework described by Leventhal et al. These gaps in the literature prompted the framework for this research study.

Research Questions

The current study was done to evaluate illness representations, coping, and quality of life in a sample of patients with chronic hepatitis C undergoing treatment with antiviral therapy. Information evaluating the impact of illness representations on coping and quality of life was lacking and the results of this study will add to the body of literature and hopefully result in the
development of interventions that are useful in understanding and modifying illness representations and individual coping strategies, ultimately enhancing quality of life.

Specifically three research questions were posed:

1) Are problem-focused and emotion-focused coping strategies significantly correlated with physical and mental health in patients with chronic hepatitis C undergoing treatment with antiviral therapy?

2) Are the components of illness representations predictive of problem-focused and emotion-focused coping strategies in patients with chronic hepatitis C undergoing treatment with antiviral therapy?

3) Are the components of illness representations predictive of physical and emotional quality of life in patients with chronic hepatitis C undergoing treatment with antiviral therapy?

*Instruments*

*Demographic Information Form*

A demographic information form was developed by the researcher to gather general information about the research sample. Information gathered included gender, age, ethnicity, employment status, relationship status, educational level, and household income. Additionally, information was obtained regarding previous treatment with antiviral therapy, previous liver transplantation, and the presence of specific comorbid conditions. Finally, three questions were developed asking the participant to rate overall satisfaction with life as a whole, overall satisfaction with health, and beliefs in overall coping with antiviral therapy. These final three questions were included as measures against which the instruments that measure coping and quality of life could be correlated for validity.
Illness Representations

The original Illness Perception Questionnaire (IPQ) was developed by Weinman et al. (1996) to measure the five components of illness representations presented in Leventhal’s Common-Sense Model of Illness Representation. The IPQ has demonstrated reliability in a variety of samples with acute and chronic illnesses. Some researchers, however, have reported less than optimal reliability with some of the subscales. Shiloh, Rashuk-Rosenthal, and Benyamini (2002) reported an alpha of .52 on the Control/Cure subscale; Horne & Weinman (2002) reported an alpha of only 0.50 on the same subscale in patients with asthma. Heijmans and de Ridder (1998) reported an alpha of .49 and .64 for the Timeline subscale in patients with chronic fatigue syndrome and with Addison’s disease, respectively. Low alpha levels were also reported on the Control/Cure subscale (.40 and .63) and on the Consequences subscale (.62 and .69) in the same study sample. It is believed that the poor reliability of the subscales at least partially resulted from inconsistencies in the subjects’ interpretation of Control/Cure and Timeline subscales.

Based on the deficiencies identified in the original questionnaire, Moss-Morris et al. (2002) developed the Revised Illness Perception Questionnaire (IPQ-R). The revisions were based on data from previous studies that assessed the chronically ill individual’s cognitive and emotional representations of illness based on Leventhal’s Common-Sense Model. The psychometric properties of the revised tool have been assessed and are promising, but the tool had not yet been assessed in patients with chronic hepatitis C.

The Illness Coherence subscale was added to encompass beliefs that account for a person’s judgments as to the clarity of meaning of the illness to them and whether it made sense to them personally. The Control/Cure subscale was separated into Personal Control and
Treatment Control to account for beliefs about personal abilities to control the illness and the efficacy of treatment to cure or manage the illness. The chronicity of the illness and beliefs about the fluctuation in symptoms and temporal changeability of the illness are measured on subscales labeled Timeline—Acute/Chronic and Timeline—Cyclical. The Emotional Representation subscale was also added (Hagger & Orbell, 2005).

The instrument includes a set of 19 yes/no questions and 56 Likert-type items rated on a five point response system. These items form nine subscales including one that can be modified to include symptoms associated with specific illnesses. As suggested by the instrument’s authors, the identity subscale was modified to reflect symptoms frequently experienced by individuals with hepatitis C undergoing treatment with antiviral therapy. Scoring of the instrument involves summing the numerical responses on each subscale. The final instrument contained a total of 86 items which make up ten subscales, nine of which were included in the theoretically-derived model in this study. The subscales of the IPQ-R represent the five dimensions of cognitive illness representations theorized by Leventhal (identity, cause, timeline, consequences, and control/cure) as well as the emotional representation in response to the illness. The timeline dimension is further divided into acute/chronic (whether the patients see their illness as short-term or long-term) and cyclical (whether patients see their illness as recurring in nature with periods of waxing and waning of symptoms) subscales. The control dimension is divided into personal control (beliefs about one’s own ability to control symptoms) and treatment control (beliefs in the ability of health care provider interventions to control symptoms) subscales. A final subscale, illness coherence, measures the degree to which patients feel they understand their illness (Jopson & Moss-Morris, 2003). The psychometric properties of the tool have been tested in patients with a variety of illnesses including patients with myocardial
infarction, chronic fatigue syndrome, rheumatoid arthritis, diabetes, pain, kidney disease, and asthma (Covic et al., 2004; Fowler & Baas, 2006; Weinman et al., 1996). Internal reliability of the subscales of the instrument ranges from .79 to .89 (Moss-Morris et al., 2002). The version of the subscale used in this study was reviewed by two experts in the field of hepatitis C therapy, lending to its content validity. These individuals were doctorally-prepared (one in epidemiology and one in medicine) and have over 20 combined years of caring for patients with liver disease and treating acute and chronic hepatitis.

Theoretical and operational definitions related to the IPQ-R are as follows:

- “Identity” was theoretically defined as the symptoms the patient endorses as relating to antiviral therapy for hepatitis C. It was operationally defined as the sum of the number of items endorsed in column two of the symptom subscale. Possible scores ranged from 0-29.

- “Cause” was theoretically defined as the degree to which the patient endorses causal items as contributing to infection with the hepatitis C virus. This subscale is meant to be used after a factor analysis of the individual’s responses is done to determine underlying trends in beliefs about illness cause. This subscale was not used in this research study.

- “Timeline—Acute/Chronic” was theoretically defined as the degree to which the patient identified with statements related to the duration of their illness with lower values indicating a belief in a shorter illness duration and higher values indicating a belief in a more long-term illness duration. It was operationally defined as the sum of items # 1, 2, 3, 4, 5, & 18. Possible scores ranged from 6-30.
• “Timeline—Cyclical” was theoretically defined as the degree to which the patient identified with statements indicating a recurring nature of illness with waxing and waning of symptoms. It was operationally defined as the sum of items # 29, 30, 31, & 32. Possible scores ranged from 4-20.

• “Consequences” was theoretically defined as the number of items identified by the patient as being impacted by their illness. It was operationally defined as the sum of items # 6, 7, 8, 9, 10, & 11. Possible scores ranged from 6-30.

• “Control/Cure” was theoretically defined as the degree to which the patient believed that the hepatitis C virus can be controlled or cured. The control/cure subscale is further divided into “personal control” (the degree to which the patient believes in their own ability to control symptoms) and “treatment control” (the degree to which the patient believes in the ability of the healthcare provider to intervene and control symptoms). “Personal Control” was operationally defined as the sum of items # 12, 13, 14, 15, 16, & 17. “Treatment Control” was operationally defined as the sum of items # 19, 20, 21, 22, & 23. Possible scores on the “personal control” subscale ranged from 6-30; possible scores on the “treatment control” subscale ranged from 5-25.

• “Illness Coherence” was theoretically defined as the degree to which individuals identified with statements indicating that they understand their illness. It was operationally defined as the sum of items # 24, 25, 26, 27 & 28. Possible scores ranged from 5-25.
“Emotional Representation” was theoretically defined as subjective feelings of emotion related to illness and treatment. It was operationally defined as the sum of items # 33, 34, 35, 36, 37, & 38. Possible scores ranged from 6-30.

Coping

Specific instruments to measure coping strategies and appraisal processes based on the Common-Sense Model have not been developed. To measure coping strategies, researchers generally measure coping styles or specific coping strategies that have been specified by the researcher. The Ways of Coping Questionnaire (WCQ) was developed to provide researchers with a theoretically derived measure to explore the role of coping in the relationship between stress and adaptational outcomes (Folkman & Lazarus, 1988b). It was derived from the cognitive-phenomenological theory of stress and coping. The WCQ is used to assess cognitive, emotional, and behavioral strategies that individuals use to help them cope with stressful situations; it has been administered in a variety of disciplines and to diverse samples for the purpose of diagnosing and improving the ways individuals cope with situations and people (Kear-Colwell & Sawle, 2001; Scherer & Brodzinski, 1990). Researchers have used the WCQ to investigate the components and determinants of coping in a variety of studies. It is designed to identify the thoughts and actions an individual has used to cope with a specific stressful encounter. Coping in this study was theoretically defined using Folkman and Lazarus’ definition of coping as “the cognitive and behavioral efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual” (p. 2, 1988b).

An earlier version of the WCQ called the Ways of Coping Checklist was developed in the mid-1970s. Sixty-seven items were derived from the framework outlined by Lazarus and Folkman and from suggestions in the coping literature. The strategies included items from the
domains of defensive or palliative coping such as avoidance, magical or wishful thinking, intellectualization, isolation, and suppression, as well as items from the problem-solving domain such as information-seeking, inhibition of action, and direct action. Subjects responded to items on the Ways of Coping Checklist relative to a specific stressful event, indicating with an affirmative or negative response whether or not they had used that strategy to deal with the specific event. The revised version (the Ways of Coping Questionnaire) describes a broad range of cognitive and behavioral strategies that people often use to manage internal and/or external demands in a stressful encounter. Items that were redundant and unclear in the original version were deleted or reworded, and several items, such as prayer, were added based on the suggestions of research subjects. The response format was changed from a yes-no format to a 4-point Likert scale, allowing respondents to indicate the frequency with which they used each strategy (Folkman & Lazarus, 1988b).

The items on the earlier version of the instrument were classified on the basis of raters’ judgments as being “problem-focused” or “emotion-focused.” The two classifications were identified as inadequate in describing the wide range of coping behaviors. Subsequently, scores from three study samples were factor-analyzed. Eight subscales were ultimately derived from the data: 1) Confrontive Coping (aggressive efforts to alter the situation, suggesting some degree of hostility and risk-taking); 2) Distancing (cognitive efforts to detach oneself and to minimize the significance of the situation); 3) Self-Controlling (efforts to regulate one’s feelings and actions); 4) Seeking Social Support (efforts to seek informational support, tangible support, and emotional support); 5) Accepting Responsibility (acknowledging one’s own role in the problem with a concomitant theme of trying to put things right); 6) Escape-Avoidance (wishful thinking and behavioral efforts to escape or avoid the problem); 7) Planful Problem Solving (deliberate
problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem); and 8) Positive Reappraisal (efforts to create positive meaning by focusing on personal growth) (Folkman & Lazarus, 1988b). Planful problem solving and confrontive coping are described as efforts to alter the situation (problem-focused). Distancing, self-controlling, accepting responsibility, and escape-avoidance are described as ways of managing a stressful situation through cognitive and emotional efforts without changing the situation itself (emotion-focused). Seeking social support and positive reappraisal are more mixed in nature and can be seen as either problem-focused or emotion-focused, depending on the situation (Ahlstrom & Wenneberg, 2002). The delineation of a subscale as either problem-focused or emotion-focused is provisional; problem-focused coping can be used to regulate emotion and emotion-focused coping can have a problem-focused function. Thus, any act or thought can have more than one coping function depending on the psychological context in which it occurs (Folkman & Lazarus, 1988b).

A problem consistently identified with the WCQ is the lack of reproducibility of the proposed factors when a confirmatory factor analysis was performed in different studies. Recognizing that any coping function can serve as both a problem-focused and emotion-focused mechanism, the fact that many researchers performing factor analysis of the WCQ have come up with different factors is not surprising (Chan, 1994). As recommended by Parker et al. (1993), a factor analysis of the instrument in the proposed study sample was performed to determine which coping subscales described problem-focused or emotion-focused coping styles in this study sample.

Two methods of scoring the WCQ exist: raw and relative. Raw scores describe coping efforts for each of the eight types of coping, whereas relative scores describe the proportion of
effort represented by each type of coping. Raw scores are the sum of the subject’s responses to the items that comprise a given subscale. This method provides a summary of the extent to which each type of coping was used in a particular encounter. Relative scores describe the contribution of each coping subscale relative to all of the subscales combined. A relative score for each subscale is computed by calculating the average item score for the items on a given subscale by dividing the sum of the ratings on the subscale by the number of items on that subscale, b) calculating the sum of the average item scores across all eight subscales, and c) dividing the average item score for a given subscale by the sum of the average item scores across all eight subscales. The relative scoring technique controls for the unequal number of items within the subscales and for individual differences in response rates (Folkman & Lazarus, 1988b). The relative scoring method, however, reduces sensitivity to group differences and reduces effect size and patterns of prediction. As suggested by Lapp & Collins (1993), the raw scoring method was used in this study.

The authors of the WCQ assert that traditional test-retest reliability measurements are not appropriate because coping processes are variable. Therefore, the reliability of the WCQ is more often evaluated using Cronbach alpha. The alpha coefficients of the eight subscales of the WCQ averaged over five occasions are as follows: 1) Confrontive Coping = .70; 2) Distancing = .61; 3) Self-Controlling = .70; 4) Seeking Social Support = .76; 5) Accepting Responsibility = .66; 6) Escape-Avoidance = .72; 7) Planful Problem Solving = .68; and 8) Positive Reappraisal = .79 (Folkman & Lazarus, 1988b). Bouchard et al. (1998) found alpha levels for each of the subscales ranged from .58 to .82. Kroencke & Denney (1999) used the WCQ in a study of patients with multiple sclerosis, with alpha levels ranging from .61 to .82. In a study of patients with breast cancer, Cohen (2002) found internal reliabilities of .73 to .80. Blanchard-Fields and
Irion (1988) used the WCQ in a group of individuals and found reliabilities of each of the eight subscales ranging from .62 to .78. In patients with myocardial infarction, the reliability of the WCQ subscales ranged from .61 to .70 (Stewart et al., 1997).

Face validity of the WCQ is demonstrated as the strategies described in the questionnaire are those that individuals have reported using to cope with the demands of stressful situations. The items listed in the WCQ have been reviewed by multiple experts in the field of coping, supporting the content validity of the overall scale and subscales. Construct validity is demonstrated as the results of studies are consistent with the theoretical predictions that coping is a process consisting of both problem-focused and emotion-focused strategies (Folkman & Lazarus, 1988b).

Theoretical and operational definitions related to the WCQ are as follows:

- “Problem-Focused Coping” was theoretically defined as the degree to which the subject identified with coping efforts undertaken to manage or alter the troubled person-environment relationship that was the source of stress. “Problem-focused coping” was operationally defined as the sum of the subscale scores that fell into the factor entitled “Problem-focused Coping.” The range of possible scores was dependent on the results of the factor analysis.
- “Emotion-Focused Coping” was theoretically defined as the degree to which the subject identified with coping efforts undertaken to regulate stressful emotions. “Emotion-focused coping” was operationally defined as the sum of the subscale scores that fell into the factor entitled “Emotion-focused Coping.” The range of possible scores was dependent on the results of the factor analysis.
- “Confrontive Coping” was theoretically defined as efforts to alter the situation suggesting some degree of hostility and risk-taking. It was operationally defined as the sum of items 6, 7, 17, 28, 34, and 46. Possible scores ranged from 0-18.

- “Distancing” was theoretically defined as cognitive efforts to detach oneself and to minimize the significance of the situation. It was operationally defined as the sum of items 12, 13, 15, 21, 41, and 44. Possible scores ranged from 0-18.

- “Self-Controlling” was theoretically defined as efforts to regulate one’s feelings and actions. It was operationally defined as the sum of items 10, 14, 35, 43, 54, 62, and 63. Possible scores ranged from 0-21.

- “Seeking Social Support” was theoretically defined as efforts to seek informational support, tangible support, and emotional support. It was operationally defined as the sum of items 8, 18, 22, 31, 42, and 45. Possible scores ranged from 0-18.

- “Accepting Responsibility” was theoretically defined as acknowledging one’s own role in the problem with a concomitant theme of trying to make things right. It was operationally defined as the sum of items 9, 25, 29, and 51. Possible scores ranged from 0-12.

- “Escape-Avoidance” was theoretically defined as wishful thinking and behavioral efforts to escape or avoid the problem. It was operationally defined as the sum of items 11, 16, 33, 40, 47, 50, 58, and 59. Possible scores ranged from 0-24.

- “Planful Problem Solving” was theoretically defined as deliberate problem-focused efforts to alter the situation coupled with an analytic approach to solving
the problem. It was operationally defined as the sum of items 1, 26, 39, 48, 49, and 52. Possible scores ranged from 0-18.

- “Positive Reappraisal” was theoretically defined as efforts to create positive meaning by focusing on personal growth. It was operationally defined as the sum of items 20, 23, 30, 36, 38, 56, and 60. Possible scores ranged from 0-21.

Quality of Life

The Medical Outcomes Study Short Form-36 (SF-36) was originally developed for the Medical Outcomes Study and measures quality of life by investigating eight dimensions which contribute to the evaluation of overall physical and mental health (Covic et al., 2004). It is a generic measure of overall quality of life as opposed to an instrument that targets a specific population, disease, or age group. The instrument has been used in a variety of disease states. The earliest version of the SF-36 was released in 1988 and the current version (version 2) was released in 1996. Improvements in the second version of the tool include a shortened instrument and an increased number of response choices (as opposed to some dichotomous response choices in the original version).

The Physical Component Summary of the SF-36v2 is comprised of four subscales measuring Physical Functioning, Role-Functioning—Physical, Bodily Pain, and General Health perceptions. The Mental Component Summary is also comprised of four subscales that measure Social Functioning, Role-Functioning—Emotional, Mental Health, and Vitality (Covic et al., 2004; Swindells et al., 1999). Although there is some correlation among three of the subscales (vitality, social functioning, and general health) with both of the overall measures (physical and mental health), studies have confirmed that subscales loading highest on the physical health component are most responsive to interventions that alter physical health and subscales loading
highest on the mental component respond most to therapeutic interventions that target mental health (Ware, n.d.).

The SF-36 is a reliable measure of overall physical and mental health. The reliability coefficient for the subscales and overall instrument exceeds the minimum standard of .70 and usually exceeds .80. Overall reliability estimates for the two summary scores (physical and mental health) usually exceed .90 (Ware, n.d).

The SF-36v2 contains 36 items, most consisting of Likert-type responses. It is self-administered and usually requires 5-10 minutes for completion. Current recommendations involve a "norm-based" scoring system which standardizes each of the subscales, allows for easier interpretation, and makes comparisons of the subscales possible. Standardized scoring of the SF-36v2 as directed by the instrument’s developer was used. One item, a self-rating of current health status compared to one year ago is not included in the overall scoring.

Theoretical definitions, operational definitions, and the possible range of scores prior to any transformations are as follows:

- “Physical Functioning” was theoretically defined as the degree to which the individual’s health limits physical activities. It is operationally defined as the sum of items 3a, 3b, 3c, 3d, 3e, 3f, 3g, 3h, 3i, and 3j. Possible scores ranged from 10 to 30 with higher scores indicating better physical functioning.

- “Role-Physical” was theoretically defined as the degree to which limitations due to physical health occurred in the last four weeks. It was operationally defined as the sum of items 4a, 4b, 4c, and 4d. Possible scores ranged from 4 to 20 with higher scores indicating better role-physical functioning.
• “Bodily Pain” was theoretically defined as the degree to which pain interfered with daily activities. It was operationally defined as the sum of items 7 and 8 after recoding both items. Possible scores ranged from 2 to 12 with higher scores indicating lack of bodily pain.

• “General Health” was theoretically defined as the rating of current health, future health, and resistance to illness. It was operationally defined as the sum of items 1, 11a, 11b, 11c, and 11d after recoding three items. Possible scores ranged from 5 to 25 with higher scores indicating better general health perceptions.

• “Vitality” was theoretically defined as the amount of time in the past month that the individual felt full of pep, energetic, worn out, tired, or had enough energy to do the things that he/she desired. It was operationally defined as the sum of items 9a, 9e, 9g, and 9i after recoding two items. Possible scores ranged from 4 to 20 with higher scores indicating more vitality.

• “Social Functioning” was theoretically defined as the extent of limitations caused by physical health or emotional problems in normal social activities. It was operationally defined as the sum of items 6 and 10 after recoding one item. Possible scores ranged from 2 to 10 with higher scores indicating better social functioning.

• “Role-Emotional” was theoretically defined as the degree to which the individual experienced limitations in work or other regular daily activities during the past four weeks. It was operationally defined as the sum of items 5a, 5b, and 5c. Possible scores ranged from 3 to 15 with higher scores indicating better role-emotional functioning.
“Mental Health” was theoretically defined as the amount of time during the past month that the individual felt very nervous, downhearted, down in the dumps, happy, calm, or peaceful. It was operationally defined as the sum of items 9b, 9c, 9d, 9f, and 9h after recoding two items. Possible scores ranged from 5 to 25 with higher scores indicating better mental health.

After computing the sum of each of the subscales, scores were transformed to a 0-100 scale. The subscale scores were then transformed into z-scores and subsequently transformed into norm-based scores so that the results of one subscale could be compared with the results of the other subscales. The norms used for final scoring are based on 1998 data from the United States, with a mean of 50 and a standard deviation of 10 (Ware, Kosinski, & Dewey, 2002). As recommended by the instrument’s authors, missing scores were calculated by using the mean of the remaining items on that subscale if greater than 50% of that subscale’s items were completed (Ware et al., 2002).

**Study Design**

A non-experimental, cross-sectional design was used for this study. Because of the paucity of literature discussing the use of Leventhal’s theory in patients with HCV and the exploratory nature of the study, data were collected one time with the intention to study the phenomenon in more depth based on the findings of this research.

**Study Sample**

The proposed study took place at The Liver Institute at Methodist Dallas Medical Center in Dallas, Texas. Study participants were drawn from a convenience sample of those diagnosed with chronic hepatitis C who were undergoing antiviral therapy with ribavirin and/or interferon.
Many of these participants were also participating in clinical pharmaceutical trials for patients who had not previously responded to antiviral therapy. Other participants were undergoing treatment with different medication doses or for different durations of therapy than that which is currently approved by the Food & Drug Administration. Still others were receiving the current standard of care medication doses and durations of therapy for hepatitis C. All potential participants who met the inclusion criteria but did not meet the exclusion criteria were approached to participate in the study until the desired number of participants had been recruited. Potential participants were only asked to participate if participation in this research study would not conflict with participation in other research studies in which the potential participant was enrolled.

Sample Size Determination

A sample size of 80-125 participants was desired. This number would provide an adequate size to perform the statistical analyses. Two hundred participants were asked to complete the study packet to allow for missing information and to provide a sample for cross-validation of statistical analyses.

Inclusion Criteria

Inclusion criteria for the proposed study were:

1) Confirmed diagnosis of chronic hepatitis C with detectable hepatitis C virus RNA levels at the beginning of medical treatment

2) Undergoing antiviral therapy with interferon and/or ribavirin

3) Ability to read and speak English

4) Ability to complete the study instruments
Exclusion Criteria

Individuals meeting the exclusion criteria set for the proposed study were not approached for participation. No participants required removal from the study after their participation began. Exclusion criteria included:

1) Age <18 years

2) Psychiatric or medical disturbance that impaired the ability of the participant to complete the study instruments or to provide informed consent. A psychiatric disturbance that had not been cleared by a mental health professional would have eliminated the participant from receiving antiviral therapy. It was the judgment of the nurse practitioner or physician to determine if the potential participant was unable to complete the study instruments or provide informed consent.

3) Participation in another study that prohibited the subjects from being enrolled in more than one research study.

Protection of Human Subjects

There were no known risks or benefits to participants in this study. Permission to engage in the research was obtained by the participants’ health care providers. A copy of the permission letter is included in the appendix of this manuscript. Efforts were made to recruit adult participants of different age groups, equal numbers of men and women, and members of a variety of cultural groups. Approval was obtained from the Institutional Review Boards at both the University of Cincinnati and Methodist Dallas Medical Center. Approval documents are included in Appendix A. The principal investigator completed the CITI course in the protection of human research subjects prior to obtaining IRB approval. Potential research participants received a letter from the investigator listing information that is included in a standard research
consent form. As the only identifying information would be the signature on the consent form, written consent was not obtained. Research information obtained was exempt from the Health Insurance Portability and Accountability Act (HIPAA) as no personally identifying information was obtained and all information is reported as aggregate data. All information regarding the study participants remained confidential. Participants were identified solely by a coded number assigned by the researcher. Study packets were kept in a locked cabinet at the researcher’s place of employment.

Recruitment of Subjects

Potential study participants were identified by the treating physician and nurse practitioner. After a potential participant had been identified, that person was approached by the principal investigator or the treating clinician and a verbal description of the study was given. All questions were answered; any questions that were unable to be answered by the treating clinician were immediately referred to the principal investigator. Potential participants were informed that their healthcare would not be altered whether or not they decided to participate in the research study. Once the decision to participate had been made, a study packet containing the disclosure letter and the research instruments was provided in a self-addressed, stamped envelope. Participants were instructed to complete the research packet at their leisure and deposit the completed packet in the mailbox. No monetary incentive was provided for participation. However, the participant was informed that information learned from this research study may help others who undergo antiviral therapy in the future.
Research Packet

The research study packet included: 1) a letter to the potential research participant; 2) the demographic information form; 3) the Revised Illness Perception Questionnaire (IPQ-R); 4) the Ways of Coping Questionnaire (WCQ); and 5) the SF-36v2. Copies of all documents related to this research study packet (except for copyrighted material) are included in Appendix B. Permission to use copyrighted material is included in Appendix C.

Data Analysis

Study packets were coded numerically by the researcher and all data were entered into SPSS version 14.0 for descriptive and statistical analysis. To increase the number of participant responses that could be included in the data analysis, mean subscale scores for individual participants were substituted for missing data on each of the instruments’ subscales if less than 5% of the items were missing data and an analysis verified that the data were missing completely at random or missing at random. Missing completely at random (MCAR) data exists when missing data are randomly distributed throughout the sample across all observations and the missing data are not dependent upon another variable. Missing at random (MAR) data exists when missing data is not randomly distributed across all observations but are randomly distributed within one or more subsamples of the study participants (e.g. gender or income level). The testing for MCAR and MAR was done using t-tests to determine if differences in the mean subscale scores existed between those without missing responses and those with missing responses. Significant differences did not exist for any of the demographic subsets and the decision to substitute the mean subscale scores increased the number of participant responses available for analysis.
After performing demographic analyses on the study sample, the subscales of the Revised Illness Perception Questionnaire (IPQ-R), the Ways of Coping Questionnaire (WCQ), and the SF-36v2 were assessed in the study sample. Cronbach alpha measures were used to assess reliability of the subscales. As alpha levels are a function of test length, subscales which did not exceed ten items were deemed reliable if Cronbach alpha was $\geq .60$ (Loewenthal, 1996; Waltz, Strickland, & Lenz, 1991). However, all subscales with reliabilities of <.60 were further analyzed with changes made to improve subscale reliability. Ultimately, the cutoff value of .60 was used to determine subscale reliability in the study.

**Research Question #1**

Correlational analysis was used to answer research question #1. Correlation statistical techniques measure and describe a relationship between two variables. Variables are correlated if changes in one variable are associated with changes in the other variables (Hair, Anderson, Tatham, & Black, 1998). It was the goal of this research study to examine the relationships that exist between the variables in an exploratory approach to determine if the CSM described by Leventhal can be enhanced. Prior to analysis, the data were examined for outliers.

The most common measure of correlation is the Pearson product-moment correlation; it is represented by the correlation coefficient (r) (Gravetter & Wallnau, 1996). Specifically, the Pearson correlation measures the covariability of X and Y divided by the variability of X and Y separately. The strength of the relationship described using the principles described by Cohen (1988) defines a small relationship as having an r value of +/- .10-.29, a medium relationship as having an r value of +/- .30-.49, and a large relationship as having an r value of +/- .50-1.00.

To determine the degree of correlation between two variables, the coefficient of determination ($r^2$) was used, as recommended by Gravetter & Wallnau (1996). The coefficient
of determination measures the proportion of variability in one variable that can be determined from the relationship with the other variable (the percentage of explained variance) (Waltz et al., 1991).

Assumptions of Pearson’s Correlation

The primary assumption that must be met when performing Pearson’s correlation is that variables are continuous and normally distributed. All variables were continuous. Some of the study variables met the requirement of normality. Variables not meeting the normality requirement required correlational analysis using Spearman’s rho.

Research Questions #2 and #3

Multiple regression analysis was used to answer research questions #2 and #3. In predictive analyses based on probability theory, the independent variables cause variation in the value of the dependent variable. The goal is to determine how accurately one can predict the value of an outcome (dependent) variable based on the values of the predictor (independent) variables. The degree and character of the relationship between each of the independent variables (components of the illness representations) and the outcome measures (problem- and emotion-focused coping, physical and mental quality of life) was assessed using multiple regression. The contribution of each independent variable to the change in the dependent variable was measured. The final outcome of a regression analysis is a model from which values of the independent variables can be used to predict and explain values of the dependent variable in the sample (Burns & Grove, 2001). An alternative statistical approach would be to use canonical correlation. Interpretation, however, is more difficult, especially when attempting to develop a new model.
Power refers to the probability of detecting as statistically significant a specific level of $R^2$ or a regression coefficient at a specified significance level for a specific sample size. To increase the generalizability of the study results, the ratio of subjects to independent variables should not fall below 5:1; specifically, it is recommended to have 15 to 20 observations for each independent variable in the variate. However, a common sample size is 10 to 15 observations per independent variable. Eight independent variables were used in this study: 1) Emotional Representation; 2) Identity; 3) Timeline—Acute/Chronic; 4) Timeline—Cyclical; 5) Consequences; 6) Treatment Control; 7) Personal Control; and 8) Illness Coherence. Based upon the recommendations of Hair et al. (1998), for the most advanced regression equation possible in this study, the chosen sample size of 80-125 was adequate.

Regression coefficients are used to calculate the predicted values for each observation and to express the expected change in the dependent variable for each unit change in the independent variable (Hair et al., 1998). In this study, the standardized beta coefficients were used to eliminate the predicament of dealing with different units of measurement and to reflect the relative impact on the dependent variable of a change in one standard deviation of the independent variable.

**Model Specification**

Confirmatory and stepwise estimation procedures were used to estimate the regression equation. The confirmatory approach assumes that a theoretically proposed set of variables will be used to predict the dependent variable; it is the purpose of this type of analysis to test the validity of a theoretically proposed statement expressed as a regression equation (Burns & Grove, 2001). Using the confirmatory approach, all variables described in Leventhal’s model were entered into the equation to assess their influence on the dependent variables.
Using the stepwise estimation approach, each independent variable was considered for inclusion in the equation prior to developing the final equation and variables were successively added or deleted to maximize their predictive value with the independent variable having the greatest contribution added first. Independent variables were then selected for inclusion based on their incremental contribution over the variables already in the equation. A comparison of the equations developed using both confirmatory and stepwise specification techniques was done to assess the similarities and differences in the equations.

Eight subscales of the IPQ-R were used in the regression equation: emotional representation, identity, both timeline subscales (acute/chronic and cyclical), consequences, both of the control subscales (treatment control and personal control) and the illness coherence subscale. The cause subscale was not used because a score cannot be calculated from this subscale and it is meant to be further assessed using factor analysis. Both of the timeline subscales and both of the control subscales were used as these components of the overall illness representation can be different in the same individual.

Two regression equations were proposed to answer research questions two and three (a total of four regression equations). The basic regression equation was:

\[
Y = b_0 + b_1(\text{Emotional Representation}) + b_2(\text{Identity}) + b_3(\text{Timeline—Acute/Chronic}) + b_4(\text{Timeline—Cyclical}) + b_5(\text{Consequences}) + b_6(\text{Treatment Control}) + b_7(\text{Personal Control}) + b_8(\text{Illness Coherence})
\]

where \(Y\) = problem-focused coping strategies or emotion-focused coping strategies (research question #2) and physical or emotional health (research question #3), \(b_0\) = the intercept, and \(b_X\) = the change in the dependent variable associated with the change in the independent variable. As there were four regression analyses being performed using only one sample, the alpha level used
to assess for significance was .0125 rather than .05. This technique, called the Bonferroni
correction, is used to control for the Type I error inflation that can occur when multiple statistical
tests are performed on the same sample (Hair et al., 1998).

Assessing the Statistical Significance of the Model

The significance of the defined model was tested using the coefficient of determination
described by Hair et al. (1998). This tests that the amount of variation explained by the
regression model is more than the variation explained by the average ($R^2$ is greater than zero).
The F ratio obtained was compared to the tabled F statistic with the same degrees of freedom; if
the F ratio was higher than the table value, the hypothesis that the reduction in error was caused
by chance was rejected. A significant F value indicated that the regression equation was
effective in predicting variation in the dependent variable and that the $R^2$ value was not a random
variation from an $R^2$ value of zero (Burns & Grove, 2001).

Assumptions of Multiple Regression

Four assumptions must be met when performing multiple regression: 1) linearity of the
phenomenon measured; 2) constant variance of the error terms; 3) absence of multicollinearity;
and 4) normality of the error term distribution (Burns & Grove, 2001; Hair et al., 1998).

Linearity

Linearity refers to the relationship between the dependent and independent variables and
represents the degree to which the change in the dependent variable is associated with a change
in the independent variable. Assessing the assumption of linearity was done by examining the
partial regression plots which show the relationship of a single independent variable to the
dependent variable (Hair et al., 1998).

Constant Variance of the Error Term
Unequal variances (heteroscedasticity) are one of the most common assumption violations. Homoscedasticity was tested for by looking at a graphical analysis of the variance residuals and the predicted values of the dependent variable. Additionally, the Levene test for homogeneity of variance was used to test for unequal variances (Hair et al., 1998).

**Multicollinearity**

Each predictor value and their error terms should be independent (i.e. the predicted value is not related to any other prediction) (Hair et al., 1998). Multicollinearity implies that the independent variables are correlated not only with the dependent variable, but also with other independent variables. As multicollinearity increases, the variance explained by each independent variable decreases and the shared prediction of the two collinear independent variables increases (Burns & Grove, 2001; Hair et al., 1998). Multicollinearity does not affect predictive power but causes problems related to generalizability; the regression coefficients will not remain consistent across samples when cross-validation is performed. Most researchers consider multicollinearity to exist if a bivariate correlation is greater than .65; however, some researchers use a correlation of .80 or greater to indicate multicollinearity (Burns & Grove, 2001). Research in the preliminary study did reveal significant correlations between some of the components of Leventhal’s CSM; however, none of these correlations was greater than .60 (Fowler & Baas, 2006).

**Normality of the Error Term Distribution**

Normality of the error term distribution was assessed using the normal probability plots. In the normal probability plot, the standardized error residuals are compared with the normal distribution. The plotted residuals were closely compared with the diagonal line present in a normal distribution (Hair et al., 1998).
Summary

In this chapter, a description of the preliminary research evaluating the reliability of the IPQ-R in a chronically ill population was described. Additionally, the details of the current study including the research process, the research questions, tests to ensure the generalizability of results, and the analysis of data were presented. Study results are presented in Chapter 4.
Chapter 4--Results

Study results are reported in this chapter. Descriptive demographical data are presented first, followed by a discussion of the reliability of the research instruments and specific correlation and regression analysis results that answer the research questions.

Descriptive Statistics

Of the 200 research packets distributed, ninety-nine respondents returned the research packet for a response rate of 49.5%. Sixty (60.6%) of the respondents were male; 39 (39.4%) were female. The age of respondents ranged from 23 to 60 years (mean = 49.2, SD = 7.9). Nine participants did not list their age. None of the participants had undergone a previous liver transplant and none of the participants indicated that they were currently on a liver transplant waiting list. Treatment time with antiviral therapy ranged from 4 to 96 weeks (mean = 21.3, SD = 19.6). Fifty-four participants (54.5%) had previously received antiviral therapy for their hepatitis C. The average length of time that participants were aware of their diagnosis was 87.4 months (range = 2 to 384, SD = 87.9). Eighteen participants had diabetes. Thirty-three participants had hypertension. Three individuals were co-infected with HIV. None of the participants indicated that they had a history of heart disease or stroke. Ethnicity and relationship status are reported in Table 1. Employment status, education level, and annual household income of the group are reported in Table 2.

Table 1  Self-Reported Ethnicity and Relationship Status of Study Participants

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
</tr>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
</tbody>
</table>
African American 9 3 9% 3%
Caucasian 45 33 45% 33%
Hispanic 6 0 6% 0%
Biracial 0 3 0% 3%

Relationship Status
Single 6 6 6% 6%
Married 39 24 41% 25%
Divorced 6 3 6% 3%
Not married, but in a committed relationship 6 3 6% 3%

*Percentages may not add up to 100 because of multiple or missing responses

Table 2  Employment Status, Education, and Annual Household Income of Study Sample

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Participants</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Percent</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working Full-Time</td>
<td>33</td>
<td>21</td>
<td>33%</td>
</tr>
<tr>
<td>Working Part-Time</td>
<td>3</td>
<td>6</td>
<td>3%</td>
</tr>
<tr>
<td>Retired</td>
<td>3</td>
<td>0</td>
<td>3%</td>
</tr>
<tr>
<td>Disabled</td>
<td>21</td>
<td>3</td>
<td>21%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>0</td>
<td>6</td>
<td>0%</td>
</tr>
<tr>
<td>Education</td>
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<td></td>
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<tr>
<td>Not a High School Graduate</td>
<td>15</td>
<td>0</td>
<td>16%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>24</td>
<td>24</td>
<td>25%</td>
</tr>
<tr>
<td>Associate Degree/Certificate</td>
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<td>6</td>
<td>16%</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>3</td>
<td>9</td>
<td>3%</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $20,000</td>
<td>12</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>$20,000-$40,000</td>
<td>18</td>
<td>21</td>
<td>19%</td>
</tr>
<tr>
<td>$40,000-$60,000</td>
<td>9</td>
<td>6</td>
<td>10%</td>
</tr>
<tr>
<td>$60,000-$80,000</td>
<td>0</td>
<td>3</td>
<td>0%</td>
</tr>
<tr>
<td>$80,000-$100,000</td>
<td>12</td>
<td>3</td>
<td>13%</td>
</tr>
<tr>
<td>$100,000-$150,000</td>
<td>3</td>
<td>3</td>
<td>3%</td>
</tr>
</tbody>
</table>

*Percentages may not add up to 100 because of multiple or missing responses.

Normality

Data were assessed for normality using significance testing for the Kolmogorov-Smirnov test and tests for skewness. All of the subscales of the IPQ-R were normally distributed. A
factor analysis of the WCQ yielded two factors (Emotion-Focused Coping and Problem-Focused Coping) with normal distributions. As well, both the Physical Composite Scale and the Mental Composite Scale of the SF-36 revealed a normal distribution.

Subscale Reliability

The reliability of each of the instruments’ subscales is presented in Table 3. Cronbach alpha for the subscales ranged from .55 to .96. Standardized Cronbach alphas are reported for the SF-36 subscales because those subscales are standardized to have a uniform mean (50) and standard deviation (10) (Green, Salkind, & Akey, 2000). Non-standardized alphas are reported for the remaining subscales.

Table 3  Mean, Standard Deviation, and Reliability of the Revised Illness Perception Questionnaire (IPQ-R) Subscales, Ways of Coping Questionnaire (WCQ) Subscales, and Medical Outcomes Study Short Form-36 (SF-36) Subscales

<table>
<thead>
<tr>
<th>Subscale (Possible Score)</th>
<th>N</th>
<th># of Items</th>
<th>Mean</th>
<th>SD</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPQ-R</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity (0-29)</td>
<td>96</td>
<td>29</td>
<td>14.09</td>
<td>6.09</td>
<td>.86</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic (6-30)</td>
<td>99</td>
<td>6</td>
<td>17.94</td>
<td>5.71</td>
<td>.85</td>
</tr>
<tr>
<td>Consequences (6-30)</td>
<td>99</td>
<td>6</td>
<td>20.88</td>
<td>5.29</td>
<td>.84</td>
</tr>
<tr>
<td>Personal Control (6-30)</td>
<td>99</td>
<td>6</td>
<td>23.36</td>
<td>2.93</td>
<td>.59</td>
</tr>
<tr>
<td>Treatment Control (5-25)</td>
<td>99</td>
<td>5</td>
<td>19.61</td>
<td>3.76</td>
<td>.83</td>
</tr>
<tr>
<td>Illness Coherence (5-25)</td>
<td>99</td>
<td>5</td>
<td>11.67</td>
<td>4.16</td>
<td>.87</td>
</tr>
<tr>
<td>Timeline—Cyclical (4-20)</td>
<td>99</td>
<td>4</td>
<td>12.12</td>
<td>3.61</td>
<td>.86</td>
</tr>
<tr>
<td>Emotional Representation (6-30)</td>
<td>99</td>
<td>6</td>
<td>17.91</td>
<td>5.27</td>
<td>.89</td>
</tr>
<tr>
<td>WCQ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confrontive Coping (0-18)</td>
<td>99</td>
<td>6</td>
<td>3.67</td>
<td>2.96</td>
<td>.67</td>
</tr>
<tr>
<td>Distancing (0-18)</td>
<td>99</td>
<td>6</td>
<td>5.85</td>
<td>3.66</td>
<td>.71</td>
</tr>
<tr>
<td>Self-Controlling (0-21)</td>
<td>99</td>
<td>7</td>
<td>6.73</td>
<td>4.01</td>
<td>.64</td>
</tr>
<tr>
<td>Seeking Social Support (0-18)</td>
<td>99</td>
<td>6</td>
<td>9.27</td>
<td>5.62</td>
<td>.84</td>
</tr>
<tr>
<td>Accepting Responsibility (0-12)</td>
<td>99</td>
<td>4</td>
<td>2.70</td>
<td>2.50</td>
<td>.59</td>
</tr>
<tr>
<td>Escape-Avoidance (0-24)</td>
<td>99</td>
<td>8</td>
<td>6.91</td>
<td>4.91</td>
<td>.75</td>
</tr>
<tr>
<td>Planful Problem Solving (0-18)</td>
<td>99</td>
<td>6</td>
<td>7.91</td>
<td>4.27</td>
<td>.74</td>
</tr>
</tbody>
</table>
Revised Illness Perception Questionnaire

One subscale on the IPQ-R (Personal Control) did not meet the pre-determined criteria of .60 for reliability. After reviewing the questions of that subscale, it was noted that IPQ12 (“There is a lot which I can do to control my symptoms from Hepatitis C”) had an item-total correlation of only .140. This question was removed from the analysis and the alpha increased to .59, still below the minimal acceptable level of .60. Further review revealed that IPQ17 (“My actions will have no affect on the outcome of my Hepatitis C”) had an item-total correlation of only .126. This question was then removed from the analysis and the remaining four questions on the subscale had a reliability of .62. Although this alpha level is below the standard reliability of .70, it does meet the criteria established by Loewenthal as described in Chapter 3. The remaining four questions were used as the Personal Control subscale for the remainder of the study with a mean of 15.73 (SD = 2.28).

Ways of Coping Questionnaire

One subscale on the WCQ (Accepting Responsibility) did not meet the pre-determined criteria of .60 for reliability. After reviewing the item-total statistics for that subscale, it was determined that WCQ29 (“Realized I brought the problem on myself”) was poorly correlated
with the total subscale score (.292) and with the remaining questions on the subscale \( r = -.056 \) to .475). After deleting that question, the alpha level increased to .65. The decision was made to delete the poorly correlated question and to use sum of the remaining questions as the subscale score. The resulting subscale had a mean of 1.27 (SD = 1.81). In addition to the Accepting Responsibility subscale, two other scales (Self-Controlling and Confrontive Coping) did not meet the desired reliability of .70. Review of the both subscales did not demonstrate that an improvement in either alpha level was possible by deleting questions from the subscales. Both subscales were left unchanged for the remainder of the study. Although the Distancing subscale did demonstrate adequate reliability, it was noted that reliability could be further improved by deleting WCQ12 ("I went along with fate; sometimes I just have bad luck"), which had an item-total correlation of only .097. The item was deleted with reliability improving to .76 with a scale mean of 5.18 (SD = 3.46). The remaining five questions were used as the Distancing subscale for the remainder of the study.

*Medical Outcomes Study Short Form-36 Version 2*

All subscales on the SF-36 had reliability measures above .70. This tool was accepted as having adequate reliability and no changes were made.

*Factor Analysis*

After making the necessary changes to the Accepting Responsibility and Distancing subscales of the WCQ, a factor analysis was performed to determine which subscales represented problem-focused coping and which scales represented emotion-focused coping. All subscales of the WCQ were entered into the factor analysis. Data were analyzed and two factors had eigen values greater than or equal to 1. The first factor explained 58.94% of the variance of coping;
the addition of the second factor accounted for a total variance explanation of 71.11%. Varimax rotation of the factors was done to improve interpretation of the factors as these factors are theoretically correlated. The rotated component matrix is presented in Table 4.

Five subscales loaded most heavily on factor one (Seeking Social Support, Problem Solving, Positive Reappraisal, Confrontive Coping, and Distancing); the remaining three subscales loaded most heavily on factor 2 (Accepting Responsibility, Escape-Avoidance, and Self-Control). After reviewing the subscales and the dimensions of coping measured by those subscales, factor 1 was named “Problem-Focused Coping” and factor 2 was named “Emotion-Focused Coping.” The designated subscales of the WCQ were then summed to obtain a total score for each subject on the problem-focused and emotion-focused scales. Scores on the problem-focused coping scale ranged from 3 to 75 (mean = 36.97, SD = 18.14). The skewness score on this scale was -.112, indicating that the data distribution did not significantly deviate from normal. Scores on the emotion-focused coping scale ranged from 0 to 38 with a (mean = 14.91; SD = 9.50). The skewness score on this scale was .582, indicating that the data distribution did not significantly deviate from normal.

Table 4  Factor Loadings on the Varimax Rotated Component Matrix of the Ways of Coping Questionnaire Subscales

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Problem-Focused Coping</td>
<td>Emotion-Focused Coping</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>.850</td>
<td>.185</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>.810</td>
<td>.367</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>.763</td>
<td>.262</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>.697</td>
<td>.486</td>
</tr>
<tr>
<td>Distancing</td>
<td>.623</td>
<td>.139</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.085</td>
<td>.920</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>.503</td>
<td>.745</td>
</tr>
</tbody>
</table>
To assess the convergent validity of the proposed factors, the correlation of each of the subscales with the overall score for each coping dimension was performed. Spearman’s rho was used as not all of the subscales demonstrated a normal distribution. Although all subscales were correlated with both overall dimensions of coping, the correlation coefficients were higher on their respective coping scales (as shown in Table 5).

Table 5 Correlations Between Individual Coping Subscales and Problem-Focused and Emotion-Focused Coping Scores

<table>
<thead>
<tr>
<th></th>
<th>Problem-Focused Coping</th>
<th>Emotion-Focused Coping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking Social Support</td>
<td>.804**</td>
<td>.596**</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>.824**</td>
<td>.658**</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>.831**</td>
<td>.519**</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>.846**</td>
<td>.774**</td>
</tr>
<tr>
<td>Distancing</td>
<td>.572**</td>
<td>.440**</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.408**</td>
<td>.736**</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>.682**</td>
<td>.923**</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>.557**</td>
<td>.857**</td>
</tr>
</tbody>
</table>

**Correlation is significant at the .01 level (2-tailed).

Self-Report Measures (SRM)

Two questions instructed the respondents to indicate on a scale from 1 to 100 how satisfied they were with their life (Life Satisfaction SRM) and with their health (Health Satisfaction SRM) with 1 being least satisfied and 100 being most satisfied. Life satisfaction scores were skewed to the left (skewness = -1.911) with a mean of 76.39 (SD = 19.77, range = 1 to 100). Health satisfaction scores were slightly skewed to the left (skewness = -.755) with a mean of 66.18 (SD = 20.99, range = 1 to 100). A final question (Coping SRM) instructed the respondents to indicate how well they believed they were coping with their antiviral therapy with
1 indicating coping most poorly and 100 indicating coping very well. Coping scores had a mean of 75.00 (SD = 22.11, range = 1 to 100). The data were skewed to the left (skewness = -1.512). Attempts were made to transform the data and improve normality. However, all transformations resulted in a worsening of the normal distribution (as described in Table 6). Because the data were not normally distributed, Spearman’s rho was used to calculate the correlations among the three scales. The three self-report measure scores were strongly correlated as detailed in Table 7.

Table 6  Kolmogorov-Smirnov Test for Normality of Self-Report Measures Before and After Transformations

<table>
<thead>
<tr>
<th></th>
<th>Baseline Measure</th>
<th>Square Root Transformation</th>
<th>Log_{10} Transformation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>K-S</td>
<td>Sig.</td>
<td>K-S</td>
</tr>
<tr>
<td>Life Satisfaction SRM</td>
<td>1.773</td>
<td>.004</td>
<td>2.011</td>
</tr>
<tr>
<td>Health Satisfaction SRM</td>
<td>1.872</td>
<td>.002</td>
<td>1.839</td>
</tr>
<tr>
<td>Coping SRM</td>
<td>1.520</td>
<td>.020</td>
<td>1.864</td>
</tr>
</tbody>
</table>

Table 7  Intercorrelations Among Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Self-Report Measure Scores

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Life Satisfaction SRM</td>
<td>--</td>
<td>.603**</td>
<td>.597**</td>
</tr>
<tr>
<td>2. Health Satisfaction SRM</td>
<td>--</td>
<td>.517**</td>
<td></td>
</tr>
<tr>
<td>3. Coping SRM</td>
<td>--</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).

In addition to exploring the intercorrelations among the self-report measures, analysis was done to determine if problem-focused coping, emotion-focused coping, or any of the specific coping measures were correlated with scores on the SRMs. Data are presented in Table 8.
Table 8  Correlations Between Self-Report Measure Scores and Ways of Coping Questionnaire Scales and Subscales

<table>
<thead>
<tr>
<th></th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-Focused Coping</td>
<td>-.170</td>
<td>-.035</td>
<td>-.306**</td>
</tr>
<tr>
<td>Emotion-Focused Coping</td>
<td>-.354**</td>
<td>-.196</td>
<td>-.181</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>-.197</td>
<td>-.139</td>
<td>-.349**</td>
</tr>
<tr>
<td>Distancing</td>
<td>-.242*</td>
<td>.119</td>
<td>-.193</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>-.077</td>
<td>-.081</td>
<td>-.009</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>-.086</td>
<td>-.068</td>
<td>-.275**</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>-.372**</td>
<td>.011</td>
<td>-.186</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>-.449**</td>
<td>-.257*</td>
<td>-.304**</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-.165</td>
<td>-.066</td>
<td>-.331**</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>-.041</td>
<td>.184</td>
<td>-.021</td>
</tr>
</tbody>
</table>

**Correlation is significant at the .01 level (2-tailed).  
*Correlation is significant at the .05 level (2-tailed).

Finally, correlational analysis was performed to determine if the scores on any of the SRMs were associated with overall physical or mental health or with any of the health-related subscales. The results are listed in Table 9.

Table 9  Correlations Between Self-Report Measure Scores and SF36v2 Scales and Subscales

<table>
<thead>
<tr>
<th></th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Physical Health</td>
<td>.218*</td>
<td>.368**</td>
<td>.336**</td>
</tr>
<tr>
<td>Overall Mental Health</td>
<td>.557**</td>
<td>.439**</td>
<td>.467**</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>.281**</td>
<td>.378**</td>
<td>.363**</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>.321**</td>
<td>.372**</td>
<td>.459**</td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>.282**</td>
<td>.316**</td>
<td>.331**</td>
</tr>
<tr>
<td>General Health</td>
<td>.375**</td>
<td>.524**</td>
<td>.276**</td>
</tr>
<tr>
<td>Vitality</td>
<td>.154</td>
<td>.354**</td>
<td>.158</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>.437**</td>
<td>.335**</td>
<td>.380**</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>.522**</td>
<td>.475**</td>
<td>.474**</td>
</tr>
<tr>
<td>Mental Health</td>
<td>.557**</td>
<td>.451**</td>
<td>.450**</td>
</tr>
</tbody>
</table>

**Correlation is significant at the .01 level (2-tailed).  
*Correlation is significant at the .05 level (2-tailed).
Correlational analysis and analysis of variance was performed to determine if there were important associations or differences in the scores of any of the three self-report measures based on demographics. Employment status was recoded into “working” and “not working” for the Spearman rho analysis. Age and employment status were strongly correlated with all of the scores on the self-report measures as seen in Table 10. Income level was significantly associated only with Life Satisfaction ($r = -.300$, $p = .003$ and $r = .313$, $p = .002$ respectively). No other significant correlations existed. Significant differences in the mean Life Satisfaction SRM scores were noted by gender (men = 73.30, women = 81.15; $F(1, 97) = 3.840$, $p = .053$). Mean scores on the Health Satisfaction SRM and Coping SRM were almost equal. Differences on two of the SRMs (Satisfaction with Life and Coping with Antiviral Therapy) were also noted based on whether or not the patient had received previous antiviral therapy for their hepatitis C as presented in Table 11.

Table 10  Correlations Between Age and Employment Status with Self-Report Measure Scores

<table>
<thead>
<tr>
<th></th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.300**</td>
<td>.331**</td>
<td>.320**</td>
</tr>
<tr>
<td>Employment Status</td>
<td>-.341**</td>
<td>-.318**</td>
<td>-.320**</td>
</tr>
</tbody>
</table>

**Correlation is significant at the .01 level (2-tailed)**

Table 11  Differences in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Self-Report Measures Based on Previous Antiviral Therapy

<table>
<thead>
<tr>
<th></th>
<th>Mean Scale Score</th>
<th>F</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Previous Therapy (n=54)</td>
<td>No Previous Therapy (n=42)</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with Life</td>
<td>80.00</td>
<td>71.50</td>
<td>4.391</td>
</tr>
<tr>
<td>Satisfaction with Health</td>
<td>64.72</td>
<td>69.21</td>
<td>1.070</td>
</tr>
</tbody>
</table>
Because the variances of each of the remaining demographic variables were not equal, post hoc testing using Dennett’s C procedure was used to determine the origin of any significant differences as Dennett’s C does not assume equal variances among groups (Green et al., 2000). Except for individuals who described themselves as ‘single’ scoring higher than those individuals who were ‘not married, but in a committed relationship’ on the Life Satisfaction SRM, mean self-report measure scores did not differ by relationship status (mean of ‘single’ = 86.25 vs. mean of ‘not married, but in a committed relationship’ = 71.67; F(1, 4) = 2.667, p = .037). Some differences in the three self-report measures with regard to the remaining demographic variables were noted and are presented in Appendix D in Tables 22 to 27.

After reviewing the demographic information, statistical analyses were performed to answer the three research questions posed in the study. Each research question with a discussion of the statistical analyses is discussed separately.

Research Question #1

The first research question was “Are problem-focused and emotion-focused coping behaviors significantly correlated with physical and mental health in HCV patients undergoing antiviral therapy?” To answer this question, the scores on the physical and mental health composite subscales were correlated with the problem-focused and emotion-focused scales. Data are presented in Table 12.
Table 12  Correlations of Problem-Focused and Emotion-Focused Coping with Mental and Physical Health

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Problem-Focused Coping</td>
<td>--</td>
<td>.691**</td>
<td>-.356**</td>
<td>-.187</td>
</tr>
<tr>
<td>2. Emotion-Focused Coping</td>
<td>--</td>
<td>-.439**</td>
<td>-.134</td>
<td></td>
</tr>
<tr>
<td>3. Mental Health</td>
<td>--</td>
<td></td>
<td>.258**</td>
<td></td>
</tr>
<tr>
<td>4. Physical Health</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).

There was a significant negative correlation between overall mental health and the use of both problem-focused and emotion-focused coping strategies. Overall physical health, however, was not significantly correlated with either of the coping strategies. Interestingly, although the correlation was not statistically significant, both problem-focused and emotion-focused coping tended to correlate with poorer physical health. Higher mental health scores were significantly correlated with higher physical health scores. Additionally, individuals using problem-focused coping strategies tended to use more emotion-focused coping strategies as well.

A second analysis was performed to determine if any of the specific subscales of problem-focused or emotion-focused coping were correlated with overall mental or physical health. Data are presented in Table 13.

Table 13  Correlations of Problem-Focused and Emotion-Focused Coping Strategy Scores with Mental and Physical Health

<table>
<thead>
<tr>
<th>Problem-Focused Coping Strategies</th>
<th>Mental Health</th>
<th>Physical Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeking Social Support</td>
<td>-.448**</td>
<td>-.190</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>-.254*</td>
<td>.118</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>-.248*</td>
<td>-.145</td>
</tr>
<tr>
<td>Confrontive Coping</td>
<td>-.401**</td>
<td>-.062</td>
</tr>
<tr>
<td>Distancing</td>
<td>-.082</td>
<td>-.220*</td>
</tr>
</tbody>
</table>
Emotion-Focused Coping Strategies

<table>
<thead>
<tr>
<th>Description</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting Responsibility</td>
<td>-.342**</td>
<td>-.002</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>-.550**</td>
<td>-.150</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>-.206*</td>
<td>-.061</td>
</tr>
</tbody>
</table>

**Correlation is significant at the 0.01 level (2-tailed).**
*Correlation is significant at the 0.05 level (2-tailed).

Consistent with the trend of problem- and emotion-focused coping strategies being negatively correlated with physical health in the first analysis, higher scores on the Distancing subscale were negatively correlated with scores on the Physical Health Composite scale. Also consistent with the previous analysis, four of the five problem-focused coping strategies (seeking social support, problem solving, positive reappraisal, confrontive coping) and all of the emotion-focused coping strategies (accepting responsibility, escape-avoidance, self-controlling) were significantly negatively correlated with overall mental health in this study sample. Once again, most of the coping strategies tended to be negatively correlated with both mental and physical health, although the correlations were not always statistically significant.

**Research Question #2**

The second research question was, “Are the components of illness representations predictive of problem-focused and emotion-focused coping strategies in HCV patients undergoing antiviral therapy?” The proposed regression equation used to answer this research question was:

\[ Y = b_0 + b_1(\text{Emotional Representation}) + b_2(\text{Identity}) + b_3(\text{Timeline—Acute/Chronic}) + b_4(\text{Timeline—Cyclical}) + b_5(\text{Consequences}) + b_6(\text{Treatment Control}) + b_7(\text{Personal Control}) + b_8(\text{Illness Coherence}) \]
where $Y =$ problem-focused coping strategies or emotion-focused coping strategies, $b_0 =$ the intercept, and $b_X =$ the change in the dependent variable associated with the change in the independent variable.

The first regression equation using emotion-focused coping was confirmatory in nature and based on the assumption that all of the components of the overall illness representation described by Leventhal et al. influence an individual’s coping processes. Again, the “cause” dimension was not included in the equation as the IPQ-R does not allow the researcher to calculate a score for that dimension.

The regression equation was significant, $R^2 = .50$, adjusted $R^2 = .46$, $F(8, 90) = 11.44$, $p < .001$, indicating that the equation was effective in predicting variation in Emotion-Focused Coping and that the $R^2$ value was not a random variation. The theoretically-based model did account for 50% of the variance in emotion-focused coping. However, the sum of squares for the residual was approximately equal to the sum of squares for the regression equation, indicating that much of the change in emotion-focused coping was not explained by the proposed model. Changes in $R^2$ as each predictor variable was added to the regression equation are shown in Table 14. The final regression equation using all dimensions of illness perceptions based on the theoretical model was:

\[
\text{Emotion-Focused Coping} = -32.237 + .537(\text{Emotional Representation}) + .471(\text{Personal Control}) + .233(\text{Identity}) + .117(\text{Illness Coherence}) + .251(\text{Timeline—Cyclical}) + -.291(\text{Consequences}) + -.177(\text{Treatment Control}) + .079(\text{Timeline—Acute/Chronic}).
\]
A second analysis using the same dependent variable (Emotion-Focused Coping) was done using the stepwise regression technique. All variables present in the first analysis were included as potential predictors of emotion-focused coping. The predictor variable with the strongest correlation with the dependent variable was added to the model first. The stepwise regression technique allows individual variables to be removed from the regression equation as subsequent variables are added, improving model accuracy. As discussed in Chapter 3, the alpha level used to test for significance was .0125 rather than .05 to control for the Type I error inflation.

With the stepwise regression method, two predictor variables (Emotional Representation and Personal Control) were included in the final model. The regression equation was significant, $R^2 = .40$, adjusted $R^2 = .39$, $F(1, 96) = 8.195$, $p = .005$. A third predictor variable (Identity) was not included because of the more stringent significance levels. Changes in $R^2$ with the addition of each predictor variable in the stepwise equation are shown in Table 15. The final regression equation using the stepwise regression technique was:

Table 14  $R^2$ Change Produced with Each Variable of the IPQ-R Entered into Emotion-Focused Coping Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Representation</td>
<td>.346</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.397</td>
</tr>
<tr>
<td>Identity</td>
<td>.431</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.451</td>
</tr>
<tr>
<td>Timeline—Cyclical</td>
<td>.467</td>
</tr>
<tr>
<td>Consequences</td>
<td>.477</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>.501</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic</td>
<td>.504</td>
</tr>
</tbody>
</table>
Emotion-Focused Coping = -20.515 + .629(Emotional Representation) + .231(Personal Control).

With the resulting stepwise regression equation, the sum of squares for the residual was higher than the sum of squares for the regression equation (5336 vs. 3515), indicating that much of the change in emotion-focused coping was not explained by the proposed model.

Table 15  \( R^2 \) Change Produced with Each Significant Variable of the IPQ-R Entered into the Stepwise Emotion-Focused Coping Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>( R^2 ) After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Representation</td>
<td>.346</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.397</td>
</tr>
<tr>
<td>Identity*</td>
<td>.431</td>
</tr>
</tbody>
</table>

*Variable not entered into equation due to lower p-value used.

To answer the second part of research question #2, a regression equation including all of the components of illness representations was developed using problem-focused coping as the dependent variable. The regression equation was significant, \( R^2 = .38, \) adjusted \( R^2 = .32, \) \( F(8, 90) = 6.752, \) \( p < .001, \) indicating that the equation was effective in predicting the variation in Problem-Focused Coping. The theoretically-based model did account for 38\% of the variance in problem-focused coping. However, the sum of squares for the residual was much higher than the sum of squares for the regression equation (20144 vs. 12090), indicating that much of the change in problem-focused coping was not explained by the proposed model. Changes in \( R^2 \) with the addition of each predictor variable into the equation are shown in Table 16. The final regression equation using all dimensions of illness perceptions based on the theoretical model was:
Problem-Focused Coping = -45.878 + .434(Identity) + .426(Personal Control) + .124(Illness Coherence) + .252(Emotional Representation) + -.250(Consequences) + .188(Timeline—Cyclical) + -.051(Treatment Control) + .016(Timeline—Acute/Chronic).

Table 16  $R^2$ Change Produced with Each Variable of the IPQ-R Entered into the Problem-Focused Coping Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.205</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.281</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.320</td>
</tr>
<tr>
<td>Emotional Representation</td>
<td>.342</td>
</tr>
<tr>
<td>Consequences</td>
<td>.354</td>
</tr>
<tr>
<td>Timeline—Cyclical</td>
<td>.373</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>.375</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic</td>
<td>.375</td>
</tr>
</tbody>
</table>

A second analysis using the same dependent variable (Problem-Focused Coping) was done using the stepwise regression technique. All variables present in the first analysis were included as potential predictors of problem-focused coping. Again, the alpha level used to test for significance was .0125 rather than .05.

With the stepwise regression method, two predictor variables (Identity and Personal Control) were included in the model. The more stringent significance criteria used to answer this research question resulted in the elimination of Illness Coherence as a third predictor variable. The regression equation was significant, $R^2 = .28$, adjusted $R^2 = .27$, $F(1, 96) = 10.15, p = .002$. Changes in $R^2$ with the addition of each predictor variable in the stepwise equation are shown in Table 17. The final regression equation using the stepwise regression technique was:

Problem-Focused Coping = -19.353 + .507(Identity) + .281(Personal Control).
Again, the sum of squares for the residual was higher than the sum of squares for the regression equation (23171 vs. 9063), indicating that much of the change in problem-focused coping was not explained by the proposed model.

Table 17  \( R^2 \) Change Produced with Each Significant Variable of the IPQ-R Entered into the Stepwise Problem-Focused Coping Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>( R^2 ) After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.205</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.281</td>
</tr>
<tr>
<td>Illness Coherence*</td>
<td>.320</td>
</tr>
</tbody>
</table>

*Variable not entered into equation due to lower p-value used.

*Research Question #3*

The third research question was, “Are the components of illness representations predictive of physical and emotional quality of life in HCV patients undergoing antiviral therapy?” The proposed regression equation used to answer this research question was:

\[
Y = b_0 + b_1(\text{Emotion Representation}) + b_2(\text{Identity}) + b_3(\text{Timeline—Acute/Chronic}) + b_4(\text{Timeline—Cyclical}) + b_5(\text{Consequences}) + b_6(\text{Treatment Control}) + b_7(\text{Personal Control}) + b_8(\text{Illness Coherence})
\]

where \( Y \) = mental health or physical health, \( b_0 \) = the intercept, and \( b_X \) = the change in the dependent variable associated with the change in the independent variable.

The first regression equation developed was confirmatory in nature and based on the assumption that all of the components of the overall illness representation described by Leventhal et al. influence an individual’s overall mental health. Again, the “cause” dimension was not included in the equation as the IPQ-R does not allow the researcher to calculate a score for that dimension.
The regression equation was significant, $R^2 = .58$, adjusted $R^2 = .54$, $F(8, 90) = 15.365$, $p < .001$, indicating that the equation was effective in predicting the variation in overall mental health. The theoretically-based model did account for 58% of the variance in mental health. The sum of squares for the residual was lower than the sum of squares for the regression equation (6509 vs. 8891), indicating that most of the change in mental health was explained by the proposed model. Changes in $R^2$ with the addition of each predictor variable into the equation are shown in Table 18. The final regression equation using all dimensions of illness perceptions based on the theoretical model was:

\[
\text{Mental Health} = 81.605 + -.483(\text{Identity}) + -.381(\text{Consequences}) + -.253(\text{Timeline—Acute/Chronic}) + -.074(\text{Emotional Representation}) + .239(\text{Personal Control}) + .117(\text{Timeline—Cyclical}) + -.283(\text{Treatment Control}) + -.015(\text{Illness Coherence}).
\]

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.438</td>
</tr>
<tr>
<td>Consequences</td>
<td>.502</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic</td>
<td>.530</td>
</tr>
<tr>
<td>Emotional Representation</td>
<td>.540</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.547</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>.569</td>
</tr>
<tr>
<td>Timeline—Cyclical</td>
<td>.577</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.577</td>
</tr>
</tbody>
</table>

A second analysis with Mental Health as the dependent variable was done using the stepwise regression technique. All variables present in the first analysis were included as potential predictors of mental health. The alpha level used to test for significance was .0125 rather than .05 to control for the Type I error inflation.
With the stepwise regression method, only two predictor variables (Identity and Consequences) were included in the model. A third variable (Timeline—Acute/Chronic) was not included because of the more stringent significance criteria used to answer this research question (alpha = .0125 instead of alpha = .05). The regression equation was significant, $R^2 = .50$, adjusted $R^2 = .49$, $F(1, 96) = 12.440$, $p = .001$. Changes in $R^2$ with the addition of each predictor variable in the stepwise equation are shown in Table 19. The final regression equation using the stepwise regression technique was:

$$\text{Mental Health} = 71.665 + -.526(\text{Identity}) + -.288(\text{Consequences}).$$

The sum of squares for the regression equation and residual were almost equal.

### Table 19 $R^2$ Change Produced with Each Significant Variable of the IPQ-R Entered into the Stepwise Mental Health Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>.438</td>
</tr>
<tr>
<td>Consequences</td>
<td>.502</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic*</td>
<td>.530</td>
</tr>
</tbody>
</table>

*Variable not entered into equation due to lower p-value used.

To answer the second part of research question #3, a regression equation including all of the components of illness representations was developed using overall physical health as the dependent variable. The regression equation was significant, $R^2 = .46$, adjusted $R^2 = .41$, $F(8, 90) = 9.443$, $p < .001$, indicating that the equation was effective in predicting the variation in overall physical health. The theoretically-based model did account for 46% of the variance in physical health. However, in contrast to the theoretically-based model for mental health, the sum of squares for the residual was higher than the sum of squares for the regression equation (5096 vs. 4278), indicating that much of the change in physical health was not explained by the proposed
model. Changes in $R^2$ with the addition of each predictor variable into the equation are shown in Table 20. The final regression equation using all dimensions of illness perceptions based on the theoretical model was:

$$\text{Physical Health} = 40.544 + -.529(\text{Consequences}) + -.207(\text{Illness Coherence}) +$$

$$-.178(\text{Timeline—Cyclical}) + .163(\text{Personal Control}) + .294(\text{Timeline—Acute/Chronic}) +$$

$$ .218(\text{Identity}) + -.142(\text{Emotional Representation}) + .190(\text{Treatment Control}).$$

Table 20  $R^2$ Change Produced with Each Variable of the IPQ-R Entered into the Physical Health Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequences</td>
<td>.227</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.341</td>
</tr>
<tr>
<td>Timeline—Cyclical</td>
<td>.378</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.395</td>
</tr>
<tr>
<td>Timeline—Acute/Chronic</td>
<td>.422</td>
</tr>
<tr>
<td>Identity</td>
<td>.438</td>
</tr>
<tr>
<td>Emotional Representation</td>
<td>.446</td>
</tr>
<tr>
<td>Treatment Control</td>
<td>.456</td>
</tr>
</tbody>
</table>

A second analysis using the same dependent variable (Physical Health) was done using the stepwise regression technique. All variables present in the first analysis were included as potential predictors of physical health. The alpha level used to test for significance was .0125 rather than .05 to control for the Type I error inflation.

With the stepwise regression method, only two predictor variables (Consequences and Illness Coherence) were included in the model. One additional variable (Timeline—Cyclical) was not included because of the more stringent significance criteria used to answer this research question. The regression equation was significant, $R^2 = .34$, adjusted $R^2 = .33$, $F(1, 96) = 16.565$,.
p < .001. Changes in $R^2$ with the addition of each predictor variable in the stepwise equation are shown in Table 21. The final regression equation using the stepwise regression technique was:

$$\text{Physical Health} = 70.888 + -.586(\text{Consequences}) + -.355(\text{Illness Coherence}).$$

As in the theoretically derived model, the sum of squares for the residual was significantly higher than the sum of squares for the regression equation (6177 vs. 3197).

Table 21  $R^2$ Change Produced with Each Significant Variable of the IPQ-R Entered into the Stepwise Physical Health Regression Equation

<table>
<thead>
<tr>
<th>Variable</th>
<th>$R^2$ After Each Variable Entered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequences</td>
<td>.227</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.341</td>
</tr>
<tr>
<td>Timeline—Cyclical*</td>
<td>.378</td>
</tr>
</tbody>
</table>

*Variable not entered into equation due to lower p-value used.

Summary

The demographic make-up of the study sample was described in this chapter followed by a discussion of the reliability of the scales and subscales and the changes that were made to increase that reliability. Statistical analyses were presented to answer each of the three proposed research questions. A discussion of the study results as well as implications for future research is undertaken in the next chapter.
Chapter 5—Discussion

The purpose of this study was to assess the relationships among illness representations, coping processes, and quality of life. Additionally, the impact of each dimension of the overall illness representation was examined to determine its impact on problem-focused and emotion-focused coping and on overall physical and mental health. A general discussion of the research findings are presented in this chapter in relation to the demographic data and each of the three research questions. Limitations of the study are also presented. Finally, the impact of this study on nursing research, theory, and practice are discussed.

Demographic Data

The study sample provides insight into a population that has not previously been studied using Leventhal et al.’s CSM and Lazarus and Folkman’s Transactional Theory of Coping as a framework. The age of the respondents covered most of the adult age lifespan; however, few older adults participated in this study. One reason for this bias is that by the time an individual reaches older adulthood, many of their chronic conditions prohibit the use of antiviral therapy. As well, individuals at this age with chronic hepatitis C have most likely developed such extensive liver fibrosis, precluding them from being treated with antiviral therapy. This does limit the generalizability of the study results to individuals in older adulthood.

Fifty percent of participants in this research study had been aware of their positive hepatitis C status for five years or less; 25% had known that they were hepatitis C positive for 5-10 years, and the remaining 25% had been aware for more than 10 years. This covers a wide range of time frames and allows us to generalize this study to much of the hepatitis C positive population. None of the participants in the study, however, had ever had a liver transplant or
were on the waiting list to receive a liver transplant, which limits our ability to look at this subset of the chronic hepatitis C population. The illness criteria for being on a liver transplant waiting list and being treated with immunosuppressive drugs to prevent transplant rejection is accompanied by a variety of psychologic and physiologic symptoms which may have altered the outcomes of this study.

The majority of the study participants were Caucasian. Even though the clinic site used to recruit participants was located in an urban area with a significant population of African American and Hispanic individuals, these minorities accounted for only 18% of the study sample. This is consistent with previous research in which minorities have been reluctant to participate in research due to a history of unethical treatment against minority populations. Most of the participants had an annual income less than $40,000, but almost one-fourth of the participants had an annual income of $80,000 or more. Of the participants who had an annual income greater than $100,000, all were Caucasian. Most certainly, this limits the ability of the researcher to generalize the results to the non-Caucasian population.

Most of the study participants (55%) were still working full-time, although almost 25% of participants described themselves as disabled. Individuals who were disabled and working part-time scored lower on the Life Satisfaction SRM and Health Satisfaction SRM than did those participants in the other employment status categories. It may be that individuals who were able to continue working full-time had minimal symptoms that enabled them to continue dedicating 40 hours per week to employment. Additionally, those individuals who were able to continue working full-time may have felt some greater purpose in their life.

Half of the participants had a high school diploma and 35% had some college education. Only 13% of the study sample held a baccalaureate degree and none of the participants held a
graduate degree. Those individuals with a baccalaureate degree tended to be more satisfied both with their life and with their health and believed that they were coping better with antiviral therapy than did those with less education. It is possible that this increased satisfaction and more effective coping was related to more available resources because of their advanced education.

As this study was exploratory in nature, the lack of generalizability of many of the results is not surprising. Further study is needed with a larger sample size that is more representative and includes more minority populations.

**Scale Reliability**

In the preliminary study, the Treatment Control subscale of the IPQ-R had poor reliability. In this study, the Personal Control subscale had poor reliability but the Treatment Control subscale had an alpha of .83, significantly higher than in the chronic renal failure sample used in the preliminary study. Eliminating two of the six questions on the Personal Control subscale did improve its reliability, but only to an alpha level of .62. Both control subscales need further study and refinement in a variety of patient populations with chronic illness. The two questions from the Personal Control subscale that required elimination to achieve an adequate reliability were, “There is a lot which I can do to control my symptoms from Hepatitis C” and “My actions will have no affect on the outcome of my Hepatitis C”. It is possible that some individuals were more adept at others at controlling symptoms from their liver disease and the antiviral therapy resulting in the inconsistency in responses. Regarding the second question, some participants may have considered undergoing antiviral therapy as a personal action based on choice and the desire to eradicate the virus and some participants considered treatment to be a medical decision, lending to the ambiguity and poor reliability of that question.
Similarities in previous reliability measures on the WCQ subscales were noted in this study. Previously, the subscales with the highest reliability were Seeking Social Support and Positive Reappraisal. In the current study, the reliabilities for those subscales were .84 and .87, respectively, indicating strong internal consistency in the participants’ responses. The remaining subscales historically have been adequate in reliability measures.

The Accepting Responsibility subscale required the deletion of one question (“Realized I brought the problem on myself”) to improve its reliability from .59 to .65. While this item does indicate an acceptance of responsibility on the part of the participant, it also contains an element of self-blame. As the population of patients with hepatitis C is often marginalized from the rest of society, the element of self-blame in the question may not be appropriate for this group of people. Also, healthcare providers are often unable to identify the cause of hepatitis C exposure. These issues may have contributed to the poor reliability of this subscale in this sample. Two other subscales on the WCQ did not meet the standard reliability criteria of .70 (Self-Controlling and Confrontive Coping). No specific remedies were noted for these subscales based on the item-total correlations. A final subscale on the WCQ (Distancing) did demonstrate adequate reliability; however, it was noted that improvement in the alpha level (from .71 to .76) could be made by the deletion of one item, “I went along with fate; sometimes I just have bad luck.” It is unclear why this item was unreliable in this study sample.

With further study and some modifications, the subscales that historically score at the lower end of acceptable reliability could be improved. As this problem was noted in different populations in the literature, it does not appear to be an issue only with the hepatitis C population in the current study.
Illness Representations

Of the items listed in the identity subscale, the mean score was 14, indicating that almost one-half of the 29 symptoms listed was consistently chosen by the study participants. Participants in this study believed more that their illness was chronic in nature as opposed to acute or cyclical, with waxing and waning of symptoms. Beliefs in personal control and treatment control were almost equal after accounting for the range of possible scores on each subscale. Illness coherence scores were low. Perceived consequences of illness were strong as was the emotional component of the overall illness representation.

Coping

Most participants used seeking social support and positive reappraisal as their primary forms of coping. When patients are being treated with antiviral therapy for their hepatitis C, social situations are examined closely and reliance on a support person is frequently needed. Accepting responsibility and confrontive coping were rarely used. Interestingly, the coping subscales with the lowest scores also had the lowest measures of reliability.

A greater number of symptoms (higher scores on the identity subscale) and higher scores on the emotional representation subscale were significantly positively correlated with emotion-focused and problem-focused coping. This is partially consistent with Leslie et al.’s (2002) findings that a great number of somatic symptoms were correlated with passive (emotion-focused) coping. Although most of the participants did not identify strongly with their view of illness as having cyclical symptom exacerbations, those individuals with higher scores on the Timeline—Cyclical subscale did have higher scores on the Problem-Focused (p = .25) and Emotion-Focused (p=.005) coping scales.
Differences in the coping strategies used were noted between men and women in both Problem-Focused and Emotion-Focused coping and on many of the coping subscales. Women had higher mean scores on Confrontive Coping (p = .005), Self-Controlling (p = .024), Seeking Social Support (p < .001), Escape-Avoidance, (p = .002), Problem Solving (p < .001), and Positive Reappraisal (p < .001). This is consistent with Endler & Parker’s (1990) findings that women were more likely than men to use more emotion-focused coping strategies, especially social support coping strategies and confrontive coping strategies. However, the findings in this study are in contrast Endler & Parker’s findings, which revealed that men were more likely than women to use escape-avoidance coping strategies.

Review of the factor analysis of the WCQ, demonstrated that almost 75% of the variance in coping was explained by the two-factor model of global coping strategies (problem-focused and emotion-focused coping strategies). Even though the reliability of many of the WCQ subscales was not particularly strong, all of them correlated most highly with their overall coping scale, providing support for the two-factor model. Usually, Planful Problem Solving and Confrontive Coping fall into the problem-focused coping category. Distancing, self-controlling, accepting responsibility, and escape-avoidance usually fall onto the emotion-focused coping category. Similar results were noted in this study except for the fact that the Distancing subscale loaded more heavily on the problem-focused coping factor. Although confrontive coping did load highest on and was more strongly correlated with the Problem-Focused Coping factor, it loaded fairly high and was strongly correlated with emotion-focused coping as well. Each of the overall scales, however, demonstrated adequate reliability with alpha levels of at least .80 with individual item to total correlations exceeding .35.
Participants in this study used a significantly higher amount of problem-focused coping strategies. This may have something to do with the sample of participants in this study being focused on eradication of a virus that was destroying part of their body. Confirmatory testing is needed to determine if this finding is related solely to this sample or if the inconsistencies are related to other demographic variables as well.

Review of the Coping SRM revealed that the majority of participants believed they were coping fairly well with their antiviral therapy (mean score of 75). Interestingly, all of the coping subscales except Distancing, Accepting Responsibility, and Planful Problem Solving were negatively correlated with the Health Satisfaction SRM score, although this was usually not statistically significant. Further analysis is needed. Those who had previously undergone antiviral therapy scored significantly higher on the Coping SRM than did those who had not previously been treated. Perhaps individuals with previous experience knew what to expect from therapy. This phenomenon, described by Brownlee et al. (2000) in regards to previous illness experiences, does impact illness representations and coping strategies. Additionally, higher scores on the Coping SRM were significantly correlated with the age of the participant (r = .320, p = .002).

Individuals with higher scores on the Coping SRM (more perceived effective coping) were using significantly fewer problem-focused coping strategies (p = .01). No significant correlation was found between the Coping SRM scores and emotion-focused coping. However, two subscales of overall emotion-focused coping (Escape-Avoidance and Positive Reappraisal) were noted to be negatively correlated with perceived effective coping (p = .01).
Quality of Life

The physical functioning and mental health subscales of the SF-36 revealed the highest scores. Scores were lowest on the social functioning, bodily pain, and vitality subscales. In part, this is similar to study by Ware et al. (1999) which revealed that hepatitis most strongly impacted the role-physical, vitality, social functioning, and role-emotional components of overall mental and physical health.

Review of the self-report measures demonstrated that the average participant was more satisfied with their global quality of life than with their health-related quality of life. Women and those who had previously undergone antiviral therapy for their hepatitis C did score higher on the Life Satisfaction SRM. Life Satisfaction SRM scores and Health Satisfaction SRM scores were significantly correlated with both physical and mental health scores on the SF-36v2 (p ≤.001). An additional finding revealed that perceived effectiveness of coping was also correlated with physical and mental health (p < .001). Interestingly, life satisfaction, health satisfaction, and perceived effectiveness of coping were significantly correlated with all subscales on the SF36v2 except that the vitality subscale was only significantly correlated with health satisfaction. Perhaps vitality is more a function of health-related quality of life than of global quality of life. Scores on the Life Satisfaction SRM and Health Satisfaction SRM were significantly correlated with the self-reported age of the participant (p = .004 and p = .001, respectively).

Research Question #1

Individuals tended to simultaneously use problem-focused and emotion-focused coping strategies. Both forms of coping, however, were significantly negatively correlated with mental health and tended to be negatively correlated with physical health. This is not congruent with
previous research that found improved quality of life was associated with higher levels of problem-focused coping (Ben-Zur, 2005; Bouchard et al., 1998; Carver et al., 1989; Folkman & Greer, 2000; Swindells et al., 1999; Pakenham & Rinaldis, 2001; Terry, 1994). It is congruent, however, with the findings of Pakenham & Rinaldis (2001) and Weaver et al. (2004) in which mental health was negatively correlated with emotion-focused coping. Individuals with higher measures of overall physical health tended to have higher levels of overall mental health, indicating that although many professionals look at health using several subconcepts, there is evidence that health can be looked at as a single global phenomenon.

The coping subscales were reviewed to determine if their use was correlated with quality of life. All but one of the coping strategies tended to be negatively associated with physical health, although this was not statistically significant except for the Distancing subscale. This is not surprising as individuals using distancing measures as a coping strategy are consciously making decisions to detach oneself from and to minimize the significance of the situation. A further review of the IPQ-R subscales revealed three subscales that were significantly correlated with the Distancing subscale on the WCQ (Personal Control, Illness Coherence, and Emotional Representation). Individuals with higher scores on these three subscales may be purposely distancing themselves as a coping strategy.

It is important to remember that the presence of significant correlations between many of the theoretical concepts in this study does not indicate that one variable causes a change in another variable. Further research is needed using more advanced statistical techniques and a larger sample size to determine the specific impact of one variable on another.
Research Question #2

The regression equations developed to predict coping strategies based on all components of illness representations in Leventhal’s model explained between 38 percent (Problem-Focused) and 50 percent (Emotion-Focused) of the variance in coping. Overall, the dimensions of illness representations were better at predicting the use of emotion-focused coping strategies than they were at predicting problem-focused coping strategies. In both emotion-focused and problem-focused coping, the dimensions of Personal Control, Emotional Representation, Illness Coherence, Identity, Timeline—Cyclical, and Timeline—Acute/Chronic were all positive predictors of the dependent variable. Consequences and Treatment Control were negative predictors of the dependent variable.

Differences were noted depending on whether all variables were included in the model or if only those variables meeting a specific pre-determined significance level were included. The regression models that included all dimensions of illness representations were better at explaining the variance of both emotion-focused coping and problem-focused coping than were the stepwise regression models. The theoretically-based regression model explained 50% of the variance of emotion-focused coping; the stepwise regression model explained only 40% of the variance of emotion-focused coping. Similarly, the theoretically-based regression model explained 38% of the variance of problem-focused coping with the stepwise regression equation explaining only 28% of the variance in the same dependent variable. When looking at the theoretically-based regression model for problem-focused coping, the addition of Treatment Control and Timeline—Acute/Chronic resulted in no improvement in the variance explanation. This model, however, was still a better predictor of problem-focused coping than was the stepwise regression model.
When reviewing the stepwise regression model for emotion-focused coping, emotional representations and personal control were positive predictors of the dependent variable. Further research is needed to develop and test nursing interventions that foster change in these individual dimensions of the overall illness representation and subsequently alter the degree of emotion-focused coping required. Intuitively, the predictive ability of the emotional representation makes sense, as a strong emotional representation would lead to a high degree of emotion-focused coping. When reviewing the stepwise regression model for problem-focused coping, personal control was once again identified as a positive predictor variable. As this variable was identified in both coping strategy equations, it needs to be further analyzed to determine ways to optimize the degree of personal control (such as what days of the week to receive interferon injections). Illness identity (more perceived symptoms of illness) was also noted to be a positive predictor of problem-focused coping. This represents a further area of importance to nursing research by nurses interested in symptom-management techniques. Illness coherence was demonstrated to be a positive predictor of problem-focused coping. The concept, however, was not included in the final stepwise regression equation due to the strict significance level used in this study. Further research on a larger sample needs to be done to determine the impact of illness coherence on problem-focused coping. The significant predictors of emotion-focused and problem-focused coping are illustrated in Figure 3.

While the regression equations developed were significant predictors of both emotion-focused and problem-focused coping, a large amount of the variance was not explained by the overall illness representation in both the theoretically-driven and stepwise regression models. Further research needs to be done to explain the impact of other variables on the choice of
coping strategies (i.e. social support, knowledge) and to improve the variance explained by variables that did not significantly predict the dependent variables in this study sample.
Figure 3  Significant Positive Predictors of Emotion-Focused and Problem-Focused Coping Strategies in the Stepwise Regression Equations

Illness Coherence — Excluded from Model due to Significance Level

Identity

Personal Control

Emotional Representation

Problem-Focused Coping

Emotion-Focused Coping

*Treatment Control, Timeline—Acute/Chronic, Timeline—Cyclical, & Consequences were not significant predictor variables in either model.
Research Question #3

The regression equations developed to predict overall physical and mental health based on all components of illness representations in Leventhal’s model explained between 46 and 58 percent of the variance in the dependent variables. Overall, illness representations were better at predicting mental health than they were at predicting physical health. Contrary to the findings in the regression equations predicting emotion-focused and problem-focused coping, the only dimension of illness representations that was a consistent positive predictor of overall physical and mental health was the consequences dimension. The Timeline—Cyclical dimension was a positive predictor of mental health, but a negative predictor of physical health. The Timeline—Acute/Chronic, Identity, and Treatment Control dimensions were positive predictors of physical health but negative predictors of mental health.

Regarding mental health, the regression model developed including all dimensions of the overall illness representation explained 58% of the variance; this was slightly better than the stepwise regression model developed (explaining 50% of the variance in overall mental health). All of the dimensions of the overall illness representation were adequate predictors of overall mental health; however the addition of the Illness Coherence dimension to the other seven variables did not improve the predictive ability. With regard to physical health, including all variables of illness representation resulted in a better prediction of overall physical health (46%) than were the two variables included in the stepwise regression equation (34%). One variable in the stepwise regression models (Consequences) was a significant predictor of both mental and physical health.

In reviewing the stepwise regression model for Mental Health, illness identity and consequences were significant negative predictors of the dependent variable. Additionally, the
Timeline—Acute/Chronic dimension was a negative predictor variable of mental health but a positive predictor of physical health. It was, however, excluded from the final model due to the more restrictive significance level used in the study. Further research is needed to identify measures to alter the degree of symptoms experienced and to minimize the consequences of antiviral therapy and chronic HCV (e.g. the impact of therapy and other medical treatments on personal finances and social interaction). Individuals who had a more acute view of their illness and therapy did have higher mental health scores than those who viewed their illness as more chronic in nature.

In reviewing the stepwise regression model for Physical Health, more consequences were, once again, negative predictors of the dependent variable. Interestingly, illness coherence was negatively predictive of physical health. Further study is needed to determine the cause of this finding as it is incongruent with previous research demonstrating that understanding of illness and its manifestations results in better overall health. Although the Timeline—Cyclical dimensions of illness representation did appear to be a negative predictor of physical health, the variable was excluded due to the stricter significance level used.

While the regression equations developed were significant predictors of overall mental and physical health, a large amount of the variance was not explained by the overall illness representation in both the theoretically-driven and stepwise regression models. Further research needs to be done to explain the impact of other variables on the quality of life and to improve the variance explained by variables that were less significant in this study sample. Components of the illness representation that impact measures of health-related quality of life need to be further studied in a variety of patient populations to determine if this is related only to those undergoing
antiviral therapy for hepatitis C or if the model holds true for individuals with a variety of chronic illnesses.
Figure 4  Significant Negative Predictors of Mental Health and Physical Health in the Stepwise Regression Equations

*Emotional Representation, Personal Control, & Treatment Control were not significant predictor variables in either model.

Excluded from Model due to Significance Level
Implications for Nursing Practice

The implications of the study results to nursing practice are important. The sample in this study had a chronic illness, but the models are appropriate for a variety of acute and chronic conditions. It is clear that illness representations impact the chronically ill individuals coping strategies and overall physical and mental health. Personal control was a dimension of illness representation that was significantly important in predicting each of the dependent variables. Any intervention that alters the components of the illness representation may, in fact, alter the choice of coping strategies and the individual’s quality of life. This is particularly important for the patient’s perceived control over a variety of factors. Nursing practice should include a holistic assessment of the individual patient’s overall illness representation and the concepts that make up that illness representation. Nursing interventions to alter the overall perception of illness should be developed and tested as they may be effective in improving the outcomes of those with chronic illness.

Also, nurses should assess preferred coping strategies to determine if they are the most effective coping strategies for the patient’s situation. Some individuals do not have the resources available to use the most effective coping strategies; it is important for nurses to be aware of this deficit in encouraging and evaluating the effectiveness of patient coping. It is also important to remember that different stages of illness and different illness representations require different coping strategies to maintain positive outcomes such as quality of life. Individuals in this study that had undergone antiviral therapy before had significantly higher scores in life satisfaction and in perceived effectiveness of coping. Perhaps interactions with other individuals who have experienced the illness or treatment before would improve the quality of life of those experiencing the illness or treatment for the first time.
Implications for Nursing Education

Understanding individual beliefs about chronic illness are an important part in the understanding of the actions of the patient. Nursing education programs should include educational components that discuss illness representations, coping strategies, and quality of life. The models presented in this study are fairly easy to comprehend and provide a holistic view of illness.

Undergraduate nursing education should focus on differences in illness representations, coping strategies, and quality of life that are associated with specific diseases and responsive to nursing interventions. Graduate nursing education should focus on the assessment of illness representations and coping strategies and the development of theoretically-derived nursing interventions aimed at improving outcomes. The goal of education at the Master’s level should be to prepare individuals qualified to provide advanced nursing care to individuals with acute, chronic, and life-threatening illnesses. The goal of education at the doctoral level should be to prepare nurse scientists capable of developing models capable of predicting responses to nursing interventions aimed at specific points in the theoretical framework.

Implications for Nursing Research

This study provides evidence to better understand illness representations, coping, and quality of life in individuals with hepatitis C undergoing antiviral therapy. Much of the study results can be generalized to patient populations with other chronic illnesses. The study is limited, however, in that emotional illness representations were not analyzed separately from cognitive illness representations. According to the CSM, cognitive and emotional illness representations each result in different coping strategies being used and different outcomes. This parallel processing needs to be examined separately. Currently, however, specific components
of the emotional illness representation have not been identified; this concept should be more fully developed to determine the underlying dimensions inherent in emotional illness representations.

Folkman and Lazarus’ coping model includes personal resources as antecedents that impact the utilization of coping processes. Further research is needed in the chronic hepatitis C population to determine if perceived needs and resources are important predictors of coping strategy utilization. Also, coping strategies are expected to be used more when there is an appraisal of threat or when the perception of the individual’s abilities or resources to cope is exceeded. An instrument that looks at an individual’s perceived resources could be used to determine if those whose needs exceed their resources engage in more or different coping strategies.

People vary their use of coping strategies as the stressful situation changes. After categorizing this study sample into phases of antiviral therapy (<6 months, 6-11 months, 12-17 months, ≥18 months), significant differences were noted among the mean values of Problem-Focused coping (p=.002, F(3, 95) = 5.465) but not of Emotion-Focused coping (p=.135, F(3, 05) = 1.898). The sample size of this sample, however, was inadequate to make any recommendations or generalize based on this study. Future researchers need to investigate coping changes based on phases of treatment, especially using longitudinal studies to follow the same patient throughout the various phases of treatment; those studies can include the testing of specific interventions to improve effective coping.

Age differences noted in previous studies using the WCQ were not noted in this study sample. A review of this study sample revealed a mean age of 49 years; study participants were subsequently divided into two groups: 1) young (less than 49 years) and 2) old (older than 49
years). Although previous research by Folkman et al. (1987) revealed a preference in the younger age group for active, interpersonal problem-focused forms of coping (confrontive coping, seeking social support, and planful problem solving), significant differences in mean scores were not found in this study sample ($p = .530$, $F(2, 96) = .638$). Additionally, Folkman et al. found that the older population used more passive, intrapersonal emotion-focused forms of coping (distancing, accepting responsibility, and positive reappraisal). Conflicting findings were noted in this sample in so much as it was the younger population that revealed a preference for emotion-focused coping ($p = .004$, $F(2, 96) = 5.998$). Again, further research needs to be done with different study populations of acutely and chronically ill individuals to further assess the impact of age on problem-focused and emotion-focused coping.

The next step in this program of research involves developing and expanding the model of illness perception, coping, and quality of life. Zero-order correlation can be used to remove the influence of other variables in prediction. However, the ideal plan would be to use path analysis to combine the theoretical frameworks. Based upon the current study, important relationships were revealed to help develop the new model.

**Summary**

This study offers support for the use of the Revised Illness Perception Questionnaire, the Ways of Coping Questionnaire, and the Short Form-36 (version 2) in a chronically ill population of patients with chronic hepatitis C undergoing antiviral therapy. Further research is needed to refine the instruments and increase reliability of the subscales.

The study provides an overview of the predictive ability of illness representations on coping strategies and quality of life in this chronically ill population. The study also provides a rationale for developing interventions that alter the illness perceptions of chronically ill
individuals to promote the use of the most effective coping strategies that positively affect overall quality of life. The impact of illness representations and coping strategies on quality of life has been presented. Additionally, the implications of the study for nursing education, practice, and research have been discussed.

While much of the research using Leventhal’s CSM and Lazarus and Folkman’s coping model as a theoretical framework focuses on individuals with an acute illness, this study looked at individuals with a chronic illness that were experiencing acute symptoms related to treatment. This has added to the body of nursing knowledge and will impact patient assessment and nursing care in the future.
References


Retrieved December 15, 2003, from


The American Journal of Gastroenterology, 95, 2604.


Social Science and Medicine, 47, 93-102.


Appendix A—Institutional Review Board Documents
November 01, 2006
Christopher L Fowler, BSN, MSN
College of Nursing Admin
0038
2133 Weatherbee St.
Ft. Worth, TX 76110

RE: IRB #: 06-10-17-01-X Illness Representations, Coping, and Quality of Life in Patients with Hepatitis C Undergoing Antiviral Therapy

Dear Christopher Fowler,

The University of Cincinnati Institutional Review Board - Social and Behavioral Sciences (IRB-S) has reviewed and granted Exempt approval to your new research project.

Approval is effective 10/28/2006.

If your research requires signed consent, the approved consent version (with the IRB approval date and expiration date in the footer) is attached to this approval. This is the version that MUST be used with your participants.

The research MUST be conducted EXACTLY as approved. ANY modifications to the approved project must be reviewed and approved by the IRB-S BEFORE being implemented.

Also attached to this approval are Investigator Responsibilities, which are expected of all human subjects researchers at the University of Cincinnati.

Sincerely,

Julie W. Gerlach, B.S.N., M.P.H., C.I.P.
Chair, UC IRB-S

JWG.cn

cc: Linda Baas, PhD (m.c.s.)
November 10, 2006

Illness representations, coping, and quality of life in patients with hepatitis C undergoing treatment with antiviral therapy.

PI: Christopher Fowler, RN, MSN, ACNP - Methodist Investigator Initiated study
Re: IRB Approval
2006.00.368. A

Your above study was approved on November 10, 2006 by expedited initial review, along with the modified informed consent script. The next continuing review is due on or before November 10, 2007. Please send your continuing review form to the IRB office at least 21 days before your study expires.

The above study was submitted for expedited review. I found it did meet the expedited review criteria of minimal risk and fit into the following research category:

- #7 Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

The approval decision for the study is based on minimizing risk¹, acceptable risk-benefit ratio for subjects, equitable selection of subjects, and confidentiality in the use of data².

¹ “Minimal Risk” means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

² Confidentiality in the use of data requires at a minimum: (a) not abstracting personal identifiers such as names, addresses, telephone numbers, e-mail addresses, or social security numbers except when essential to an approved study protocol; (b) removing coded personal identifiers such as clinic or hospital numbers at the earliest stage of the research compatible with the study goals, such as after linking data from various sources together; (c) If coded personal identifiers must remain to combine with future data, these should be encrypted and not be the plain clinic or hospital numbers; and (d) the data files should be kept in a secure environment such as a locked cabinet or a properly secured computer file with password protection.

³ 45 CFR 46.116(d) requires the following for waiver of informed consent: (a) a minimal risk study, (b) the waiver will not adversely affect the rights and welfare of subjects, (c) The research could not practicably be carried out without the waiver or alternation, (d) whenever appropriate or feasible, subjects will be provided with additional pertinent information after participation.
The informed consent was not waived, but was modified (in accordance with 45 CFR 46.116(d) 3.) along with it’s documentation (in accord with 45 CFR 46.117(f)(2)) to allow for the approved modified consent to be used.

You must document that the patient agreed to participate. These should be kept in your research files the same as an informed consent document would be. Federal regulations for a modified informed consent also require “whenever appropriate, subjects will be provided with additional pertinent information after participation” (45 CFR 46.116(d)(4)). If you believe your study generates pertinent information for patients, please send a letter to participating patients with this information after the study is concluded.

These studies can involve risks to patients that investigators must be aware of. Harms that can be done by are psychological and financial risks resulting from improper disclosure of personally identifiable health information. These include potential denial of health insurance coverage, difficulty obtaining employment, embarrassment, loss of reputation, legal liability, or anxiety about what the recipient of an unauthorized disclosure of information might do with it. Because of these risks, confidentiality in the use of data as detailed in the footnote 2 is important.

Expedited review approvals are submitted to the next IRB board meeting to keep "all members advised of research proposals which have been approved under the procedure." There is always the possibility the full board may make a change in the expedited review approvals that are submitted, and we will notify you if that occurs.

You must fulfill all requirements of the IRB written procedures including but not limited to the following:

1. Conduct the research as required by the Protocol.
2. Use only the Consent Form approved by the Board.
3. If you provide Non-English speaking patients with a translation of the Consent Form in the patient’s first language it must be approved by the IRB. The Board must approve the translated version.
4. Obtain pre-approval from the Board of any changes in the research activity (except when necessary to protect human subjects; (HHS 45 CFR & 46.103(b)(4); FDA 21 CFR & 56.108(a)(3)); immediately report to the Board any such emergency changes for the protection of human subjects.
5. Within 5 days, report in writing to the Board the death, hospitalization, or serious

1 “Minimal Risk” means that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.

2 Confidentiality in the use of data requires at least minimum: (a) not abstracting personal identifiers such as names, addresses, telephone numbers, e-mail addresses, or social security numbers except when essential to an approved study protocol; (b) removing coded personal identifiers such as clinic or hospital numbers at the earliest stage of the research compatible with the study goals, such as after linking data from various sources together; (c) if coded personal identifiers must remain to combine with future data, these should be encrypted and not the plain clinic or hospital numbers; and (d) the data files should be kept in a secure environment such as a locked cabinet or a properly secured computer file with password protection.

3 45 CFR 46.116(d) requires the following for waiver of informed consent: (a) a minimal risk study, (b) the waiver will not adversely affect the rights and welfare of subjects, (c) The research could not practically be carried out without the waiver or alternation, (d) whenever appropriate or feasible, subjects will be provided with additional pertinent information after participation.
Illness of any study subject enrolled in a Methodist IRB approved protocol that is
or may be related to your study.

6. Within (5) days, promptly report to the Board any new information that might
adversely affect the safety of the subjects or the conduct of the trial.

7. Provide reports to the Board concerning the progress of the research, when
requested.

8. Obtain pre-approval of study advertisements from the Board before use.

9. Conduct the informed consent process, without coercion or undue influence and
provide the potential subject sufficient opportunity to consider whether or not to
participate.

If you have any questions or need additional information please contact the IRB office at
(214) 947-2542.

Sincerely,

Jerry C. McGill, Ph.D., F.A.B.M.P.
Methodist Institutional Review Board Chairman

---

1 "Minimal Risk" means that the probability and magnitude of harm or discomfort anticipated in the
research are not greater in and of themselves than those ordinarily encountered in daily life or during the
performance of routine physical or psychological examinations or tests.

2 Confidentiality in the use of data requires at a minimum: (a) not abstracting personal identifiers such as
names, addresses, telephone numbers, e-mail addresses, or social security numbers except when essential to
an approved study protocol; (b) removing coded personal identifiers such as clinic or hospital numbers at
the earliest stage of the research compatible with the study goals, such as after linking data from various
sources together; (c) if coded personal identifiers must remain to combine with future data, these should be
encrypted and not be the plain clinic or hospital numbers; and (d) the data files should be kept in a secure
environment such as a locked cabinet or a properly secured computer file with password protection.

3 45 CFR 46.116(d) requires the following for waiver of informed consent: (a) a minimal risk study, (b) the
waiver will not adversely affect the rights and welfare of subjects, (c) The research could not practically be
carried out without the waiver or alternation, (d) whenever appropriate or feasible, subjects will be
provided with additional pertinent information after participation.
October 20, 2006

To Whom It May Concern:

As referring physicians to Cheryl Levine, PhD, RN, FNP, and Kathleen Tully, RN, MSN, ANP, we agree that Christopher Fowler, RN, MSN, ACNP, may recruit our patients to complete a research study focusing on illness representations, coping, and quality of life in patients who are undergoing antiviral therapy for hepatitis C.

We understand that an individual’s perception of their illness and the coping processes utilized during treatment can positively or negatively affect quality of life. The information learned in this research study will provide valuable information that may be of benefit to future patients undergoing treatment for a variety of chronic and life-threatening illnesses.

Sincerely,

Reem Ghalib, MD
Medical Director of Liver Transplant
Director of Hepatology and Research
THE LIVER INSTITUTE at Methodist Dallas

Jeffrey S. Weinstein, MD
Medical Director, Liver Transplantation
And Hepatobiliary Services
THE LIVER INSTITUTE at Methodist Dallas
Appendix B—Research Packet
Title of Study: “Illness Representations, Coping, and Quality of Life in Patients with Hepatitis C Undergoing Treatment with Antiviral Therapy”

I am a student at the University of Cincinnati and am conducting research on how individuals cope with their illness and treatment. You are one of approximately 200 people being asked to participate in this research study because you have been diagnosed with Hepatitis C and are being treated with antiviral therapy. Permission to conduct this research has been obtained from your health care provider.

Before agreeing to participate in this study, it is important that the following explanation of the proposed procedures be read and understood. It describes the purpose, procedures, risks, and benefits of the proposed study. It describes the right to withdraw from the study at any time. It is important to understand that no guarantee or assurance can be made as to the results of the study.

If you choose to participate in this study you will be asked to complete a form about you (sex, age, etc.) and surveys that include questions about the way you view your illness and how you cope. Participation in this study may pose a slight inconvenience to your usual schedule as you take the time to complete the forms. You will not be paid for your participation in this research study and you will not incur any costs as a participant. While it is rare, recalling events and feelings may bring up some unpleasant memories that are bothersome. If this occurs, you may contact me and I will make a referral to a counselor or pastoral care professional at your expense. No other known risks are associated with this research study. If you agree to take part in this research study, there may not be a direct medical benefit to you. I hope the information learned from this research study will help others.

No information that is obtained in connection with this study can be identified with you. The questionnaires will be marked with a code number and your identity will remain anonymous. The health care providers who are treating you will not see your responses. Choosing to participate or not to participate will not influence your medical treatment or care. All data will be reported as group information only. The results from the study may be published; however, you will not be identified. The original forms that you complete will be kept in a locked file cabinet for two years and then destroyed.

If you decide to take part in this research study, you will be asked to complete 6 questionnaires. It is estimated that it will take approximately 30-45 minutes to complete the forms. If you complete the forms at home, a stamped, self-addressed envelope will be provided for you to return your questionnaires to me. You may decide not to participate. Choosing not to participate in the study will not result in any penalty or loss of benefits to you.

If you have questions about the study, you will have a chance to talk to me or your health care provider. Do not participate in this study unless you have had the chance to ask questions and have received satisfactory answers. If you have questions about this research study or to report a research-related injury, you can contact me at 214-947-4417. My research adviser is Linda S. Baas, PhD, RN, professor at the University of Cincinnati College of Nursing. You may contact her at 513-558-5718. You may also contact Cheryl Levine, PhD, RN, FNP, at The Liver Institute at 214-947-4450.

By completing the questionnaires, you indicate your consent to participate in the study. You may keep this letter for future reference.

Sincerely,

Christopher L. Fowler, RN, MSN, ACNP
By completing this survey, I indicate my consent to participate in this study.

DEMOGRAPHIC INFORMATION

Gender: M _____ F _____ Age _____

Select what best describes you (you may select two if you consider yourself bi-racial):

_____ African American   _____ Asian American
_____ Caucasian          _____ Hispanic
_____ Native American    _____ Other:

Are you currently:

_____ Working full-time   _____ Working part-time   _____ Retired
_____ Disabled            _____ Unemployed        _____ Homemaker by choice

What is your current relationship status?

_____ Single             _____ Married           _____ Divorced
_____ Widowed            _____ Other committed relationship, but not married

What is the highest educational level you have completed?

_____ Not a high school graduate   _____ High School Graduate
_____ Associate Degree/Certificate  _____ Bachelor’s Degree
_____ Master’s Degree           _____ Doctoral Degree
_____ Other: __________________________

What is your current household yearly income before taxes?

_____ Less than $20,000      _____ $20,000 to $40,000
_____ $40,000 to $60,000     _____ $60,000 to $80,000
_____ $80,000 to $100,000    _____ $100,000 to $150,000
_____ More than $150,000     _____

Have you ever had a liver transplant? _____ Are you currently on a liver transplant waiting list? _____

How many months have you been on antiviral therapy for your Hepatitis C? __________________________

Have you received antiviral therapy for your Hepatitis C before your current treatment regimen? ________________

How long have you known that you have Hepatitis C? ________ Years ________ Months

On a scale from 1 to 100 (with 1 being the worst and 100 being the best), how would you rate your overall satisfaction with your life as a whole? ________________

On a scale from 1 to 100 (with 1 being the worst and 100 being the best), how would you rate your overall satisfaction with your health? ________________

On a scale from 1 to 100 (with 1 being the worst and 100 being the best), how well do you believe you are coping with your antiviral therapy for Hepatitis C? ________________

Please check any of the following conditions if you have them now or have had them in the past:

_____ Diabetes   _____ Heart Disease   _____ Stroke   _____ High Blood Pressure   _____ HIV
Revised Illness Perception Questionnaire (IPQ-R)

Listed below are a number of symptoms that you may or may not have experienced since you began antiviral therapy for your hepatitis C. Please indicate by circling Yes or No whether you have experienced any of these symptoms since beginning antiviral therapy, and whether you believe that these symptoms are related to your antiviral therapy.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>I have experienced this symptom since starting antiviral therapy</th>
<th>This symptom is related to my antiviral therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fevers or chills</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Headache</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Weakness or fatigue</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Muscle aches</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Joint pain</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Numbness or tingling</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nausea or vomiting</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Constipation</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Taste changes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Increased gas</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Decreased appetite</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Weight loss</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Increased urination</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Inability to sleep</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Chest pain</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Coughing or sneezing</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nose bleeds</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Depression</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Poor concentration</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Rash</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Itching or Dry Skin</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Hair loss</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sore eyes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Changes in vision</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
By completing this survey, I indicate my consent to participate in this study.

We are interested in your own personal views of how you see your Hepatitis C. Please indicate how much you agree or disagree with the following statements about your Hepatitis C by placing a check in the appropriate box.

<table>
<thead>
<tr>
<th></th>
<th>Views About Your Hepatitis C</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree Nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP1</td>
<td>My Hepatitis C will last a short time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP2</td>
<td>My Hepatitis C is likely to be permanent rather than temporary.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP3</td>
<td>My Hepatitis C will last for a long time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP4</td>
<td>My Hepatitis C will pass quickly.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP5</td>
<td>I expect to have Hepatitis C for the rest of my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP6</td>
<td>My Hepatitis C is a serious condition.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP7</td>
<td>My Hepatitis C has major consequences on my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP8</td>
<td>My Hepatitis C does not have much effect on my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP9</td>
<td>My Hepatitis C strongly affects the way others see me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP10</td>
<td>My Hepatitis C has serious financial consequences.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP11</td>
<td>My Hepatitis C causes difficulties for those who are close to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP12</td>
<td>There is a lot which I can do to control my symptoms from Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP13</td>
<td>What I do can determine whether my Hepatitis C gets better or worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP14</td>
<td>The course of my Hepatitis C depends on me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP15</td>
<td>Nothing I do will affect my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP16</td>
<td>I have the power to influence my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP17</td>
<td>My actions will have no effect on the outcome of my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP18</td>
<td>My Hepatitis C will improve in time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP19</td>
<td>There is very little that can be done to improve my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP20</td>
<td>My treatment will be effective in curing my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP21</td>
<td>The negative effects of my Hepatitis C can be prevented by my treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP22</td>
<td>My treatment can control my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP23</td>
<td>There is nothing which can help my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
By completing this survey, I indicate my consent to participate in this study.

<table>
<thead>
<tr>
<th>Views About Your Hepatitis C</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree Nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP24 The symptoms of my Hepatitis C are puzzling to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP25 My Hepatitis C is a mystery to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP26 I don’t understand my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP27 My Hepatitis C doesn’t make any sense to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP28 I have a clear picture or understanding of my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP29 The symptoms of my Hepatitis C change a great deal from day to day.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP30 My symptoms come and go in cycles.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP31 My Hepatitis C is very unpredictable.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP32 I go through cycles in which my Hepatitis C gets better and worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP33 I get depressed when I think about my Hepatitis C.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP34 When I think about my Hepatitis C I get upset.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP35 My Hepatitis C makes me feel angry.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP36 My Hepatitis C doesn’t worry me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP37 Having Hepatitis C makes me feel anxious.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IP38 My Hepatitis C makes me feel afraid.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
We are interested in what you consider may have been the cause or causes of your Hepatitis C. As people are very different, there are no correct answers for these questions. We are most interested in your own views about the factors that caused your Hepatitis C rather than what others, including doctors or family members, may have suggested to you. Below is a list of possible causes for your Hepatitis C. Please indicate how much you agree or disagree that they were causes for you by checking the appropriate box.

<table>
<thead>
<tr>
<th>Possible Causes</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree Nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1 Stress or Worry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C2 Hereditary—It runs in my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C3 A germ or virus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C4 Diet or eating habits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C5 Chance or bad luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C6 Poor medical care in my past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C7 Pollution in the environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C8 My own behavior</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C9 My mental attitude (e.g. thinking about my life negatively)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C10 Family problems or worries caused my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C11 Overwork</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C12 My emotional state (e.g. feeling down, lonely, anxious, empty)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C13 Aging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C14 Alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C15 Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C16 Accident or injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C17 My personality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C18 Overactive or underactive immunity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C19 Illegal drug use</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
By completing this survey, I indicate my consent to participate in this study.

In the spaces below, please list in order (most important to least important) the three most important factors that you now believe caused YOUR Hepatitis C. You may use any of the items listed on the previous page, or you may have additional ideas of your own.

The most important causes for me:

1. 

2. 

3. 
Ways of Coping Questionnaire

The Ways of Coping Questionnaire is copyrighted material and is, therefore, not included in this appendix. If you would like further information on the instrument, the website address is www.mindgarden.com. The publisher is Mind Garden, Inc., 1690 Woodside Road, Suite #202, Redwood City, CA 94061, 650-261-3500.
Medical Outcomes Study Short Form 36 (Version 2)

The Medical Outcomes Study Short Form 36 (Version 2) is copyrighted material and is, therefore, not included in this appendix. If you would like further information on the instrument, the website address is [www.sf-36.org](http://www.sf-36.org). The contact address is SF-36.org, 640 George Washington Highway, Lincoln, RI 02865, 401 334-8800.
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Author(s): Susan Folkman, Ph.D.; Richard Lazarus, Ph.D.
Source: Ways of Coping Questionnaire Review Set, October 2000
Price: $25.00 (USD)
Christopher Fowler

From: Michelle Koch [mkoch@qualitymetric.com]
Sent: Thursday, March 11, 2004 8:30 AM
To: fowler@uta.edu
Subject: QualityMetric18274

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2. Please sign and date the last page of the license agreement
3. Please return the signed agreement to my attention.

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Please fax back to my attention all of the pages to the license agreement with your initials and date initialed on every page.

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Thank you,

Michelle Koch
Research Analyst
QualityMetric, Inc
Phone: 401-334-8800 x258
Fax: 401-334-8770
mkoch@qualitymetric.com

3/11/2004
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Christopher Fowler
2412 Jefferson Court Lane
Apt. #1620
Arlington, TX 76005

Signature: [Signature]
Name: Christopher Fowler
Title: Doctoral Student
Date: 3/1/2004
# Appendix D—Additional Statistical Analyses

Table 22  Differences Among Age Groups in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Age Group (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) 20-29 (3)</td>
<td>85.00</td>
<td>50.00</td>
<td>50.00</td>
</tr>
<tr>
<td>(B) 30-39 (6)</td>
<td>60.00</td>
<td>65.00</td>
<td>65.00</td>
</tr>
<tr>
<td>(C) 40-49 (27)</td>
<td>81.11</td>
<td>68.00</td>
<td>68.00</td>
</tr>
<tr>
<td>(D) 50-59 (51)</td>
<td>79.12</td>
<td>69.18</td>
<td>69.18</td>
</tr>
<tr>
<td>(E) 60-69 (3)</td>
<td>90.00</td>
<td>90.00</td>
<td>90.00</td>
</tr>
</tbody>
</table>

Significant Group Differences*  
C & D with E  
A with B, C & D; E with B, C & D  
A & C with D

*p<.05.

Table 23  Differences Among Education Level in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Education Level (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) Not a High School Graduate (15)</td>
<td>66.20</td>
<td>60.00</td>
<td>70.20</td>
</tr>
<tr>
<td>(B) High School Graduate (48)</td>
<td>78.44</td>
<td>67.94</td>
<td>76.50</td>
</tr>
<tr>
<td>(C) Associate Degree/Certificate (21)</td>
<td>73.57</td>
<td>61.00</td>
<td>71.43</td>
</tr>
<tr>
<td>(D) Bachelor’s Degree (12)</td>
<td>86.25</td>
<td>76.25</td>
<td>77.50</td>
</tr>
</tbody>
</table>

Significant Group Differences*  
B & C with D  
None  
None

*p<.05.
Table 24  Differences Among Employment Status in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Employment Status (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) Working Full-time (54)</td>
<td>83.06</td>
<td>72.33</td>
<td>84.11</td>
</tr>
<tr>
<td>(B) Working Part-Time (9)</td>
<td>70.00</td>
<td>66.67</td>
<td>66.67</td>
</tr>
<tr>
<td>(C) Retired (3)</td>
<td>100.00</td>
<td>90.00</td>
<td>100.00</td>
</tr>
<tr>
<td>(D) Disabled (24)</td>
<td>59.50</td>
<td>49.62</td>
<td>56.37</td>
</tr>
<tr>
<td>(E) Unemployed (6)</td>
<td>77.50</td>
<td>82.50</td>
<td>55.00</td>
</tr>
</tbody>
</table>

Significant Group Differences* A with C & D; B, D & E with C; A & C with D; B, D & E with C; A with B, C & D; B & D with C

*p<.05.

Table 25  Differences Among Annual Income in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Annual Income (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) Less than $20,000 (15)</td>
<td>60.20</td>
<td>60.20</td>
<td>66.20</td>
</tr>
<tr>
<td>(B) $20,000-$40,000 (39)</td>
<td>75.77</td>
<td>63.54</td>
<td>76.08</td>
</tr>
<tr>
<td>(C) $40,000-$60,000 (15)</td>
<td>80.00</td>
<td>64.00</td>
<td>74.00</td>
</tr>
<tr>
<td>(D) $60,000-$80,000 (3)</td>
<td>80.00</td>
<td>80.00</td>
<td>90.00</td>
</tr>
<tr>
<td>(E) $80,000-$100,000 (15)</td>
<td>78.00</td>
<td>69.40</td>
<td>76.00</td>
</tr>
<tr>
<td>(F) $100,000-$150,000 (6)</td>
<td>87.50</td>
<td>72.50</td>
<td>62.50</td>
</tr>
</tbody>
</table>

Significant Group Differences* None B & C with D B & F with D

*p<.05.
Table 26  Differences Among Treatment Time in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Months on Therapy (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) 1 (15)</td>
<td>71.20</td>
<td>69.60</td>
<td>71.00</td>
</tr>
<tr>
<td>(B) 2 (9)</td>
<td>75.00</td>
<td>63.33</td>
<td>56.67</td>
</tr>
<tr>
<td>(C) 3 (21)</td>
<td>76.43</td>
<td>67.14</td>
<td>72.86</td>
</tr>
<tr>
<td>(D) 4 (12)</td>
<td>81.25</td>
<td>63.75</td>
<td>91.25</td>
</tr>
<tr>
<td>(E) 5 (3)</td>
<td>100.00</td>
<td>90.00</td>
<td>100.00</td>
</tr>
<tr>
<td>(F) 6 (10)</td>
<td>77.00</td>
<td>78.60</td>
<td>72.50</td>
</tr>
<tr>
<td>(G) 7 (3)</td>
<td>80.00</td>
<td>50.00</td>
<td>70.00</td>
</tr>
<tr>
<td>(H) 8 (9)</td>
<td>70.00</td>
<td>49.67</td>
<td>65.00</td>
</tr>
<tr>
<td>(I) 9 (5)</td>
<td>86.00</td>
<td>78.00</td>
<td>92.00</td>
</tr>
<tr>
<td>(J) 10 (3)</td>
<td>75.00</td>
<td>65.00</td>
<td>90.00</td>
</tr>
<tr>
<td>(K) 18 (3)</td>
<td>75.00</td>
<td>50.00</td>
<td>80.00</td>
</tr>
<tr>
<td>(L) 24 (3)</td>
<td>90.00</td>
<td>75.00</td>
<td>75.00</td>
</tr>
</tbody>
</table>

Significant Group Differences* B, C, D & H with E; H with L; E, G, H & K with C; C, D & H with E; C, E, J & L with H; D, E & J with B & C; D with B, C E, G, H, K & L; E with B, C, D, F & H; H with J

*p<.05.

Table 27  Differences Among Ethnicity in Mean Scores for Satisfaction with Life, Satisfaction with Health, and Coping with Antiviral Therapy Scales

<table>
<thead>
<tr>
<th>Ethnicity (N)</th>
<th>Satisfaction with Life</th>
<th>Satisfaction with Health</th>
<th>Coping with Antiviral Therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean Score</td>
<td>Mean Score</td>
<td>Mean Score</td>
</tr>
<tr>
<td>(A) African American (12)</td>
<td>90.00</td>
<td>75.00</td>
<td>85.00</td>
</tr>
<tr>
<td>(B) Caucasian (78)</td>
<td>73.31</td>
<td>62.27</td>
<td>72.31</td>
</tr>
<tr>
<td>(C) Hispanic (6)</td>
<td>87.50</td>
<td>87.50</td>
<td>87.50</td>
</tr>
<tr>
<td>(D) Biracial (3)</td>
<td>80.00</td>
<td>90.00</td>
<td>80.00</td>
</tr>
</tbody>
</table>

Significant Group Differences* B & D with A; B with C & D with B with D

*p < .05.