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The Relationship Between Illness Representations, Avoidant Coping, and Health Outcomes in
People with Ongoing Symptoms of Chronic Illness

by

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A Thesis submitted to the Department of Psychology
in partial fulfillment of the requirements for the degree of

Master of Arts in General Psychology

UNIVERSITY OF NORTH FLORIDA

COLLEGE OF ARTS AND SCIENCES

July, 2015

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ACKNOWLEDGMENTS

I want to thank my parents for all of the love and support they have given me throughout the years. Their supporting and caring nature has encouraged me to work my absolute hardest and to never give up even when times get difficult. I am so unbelievably thankful for everything they have done and all the knowledge they have provided me.

I also want to thank my advisor Dr. Lori Lange for all of the time and effort she put in to making this thesis a reality. She has taught me so much over the past two years and I am very grateful for the opportunity to be a part of her research study. Her guidance and mentorship has helped mold me into a better student and researcher.

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ABSTRACT

Illness representations play an important role in the way people with chronic illness manage symptoms and view their overall health. Those suffering from functional somatic syndromes as well as conventional diagnoses seek information and meaning about their health threats in order to make appraisals concerning health outcomes. The primary interest of this study was to determine whether illness representations predict coping strategies which in turn influence general health outcomes. Data was collected from a series of four online surveys that measured an individual's illness representations (IPQ-R), coping responses (Brief COPE), and health outcomes (RAND-36). The sample included 204 participants (169 females and 30 males) all of whom experienced chronic illness symptoms and were classified as having a functional somatic syndrome (FSS) or conventional diagnosis (CD). As hypothesized, illness perceptions predicted avoidant coping strategies as well as general health. Specifically, illness beliefs of greater consequences and lower coherence were associated with greater reported use of self-blame, behavioral disengagement, and denial. Furthermore, these avoidant coping strategies were associated with poorer health. Self-blame emerged as a coping strategy most associated with illness representations and general health. Although a mediational model was proposed, self-blame did not mediate the relationship between illness consequence and general health. These findings suggest that viewing an illness as having more consequences is associated with more avoidant coping and has a negative impact on the overall general health in those suffering with chronic illness.

The Relationship Between Illness Representations, Avoidant Coping, and Health Outcomes in People with Ongoing Symptoms of Chronic Illness.

In modern society, there is an increase in the prevalence of chronic illness due to the fact that there is a larger aging population. Chronic illness is seen as a long-term medical condition that can potentially be permanent and has poor or limited recovery (Bury, 1991). The onset of a chronic illness can be very detrimental and not only affects an individual's physical self, but also impacts self-worth (Charmaz, 1983). According to Wagner and colleagues (2001), unlike acute illness, which is generally treated immediately, chronic illness is forcing people to develop self-management skills and play a more active role in their treatment. The disruptive nature of prolonged illness has people seeking more medical knowledge and treatment information in order to manage day-to-day symptoms.

Although there has been an improvement in chronic illness management over time, there is still a troubling subset of chronic illnesses that do not have a clear medical diagnosis. Functional somatic syndromes (FSS) are illnesses characterized by physical symptoms and impairments but are not attributed to any conventional disease or diagnosis (CD) (Christensen et al., 2015). Particular combinations of medically unexplained symptoms are used to diagnosis functional somatic syndromes even though no suitable explanation or etiology exists (Looper & Kirmayer, 2004). Patients suffering from FSS tend to feel as though their condition is dismissed as an emotional problem and believe that a medically explained diagnosis would help validate their condition. It is important to consider patients with CD and FSS in terms of the way they perceive their illness as well as their methods of coping and overall quality of life. Emotional distress and disorder is more common in those with FSS as well as debilitating symptoms that have a life-changing effect (Wessely, Nimnuan, & Sharpe, 1999).

A self-regulatory model by Leventhal et. al (1997) was created to help explain the way in which individuals with chronic illness tend to immediately attribute their symptoms to disease instead of another potentially explanatory factor. When trying to make sense of an illness, individuals develop a schema or representation of their illness that directly affects the way in which they cope. The schemas and coping attitudes ultimately perpetuate the extent of an individual's symptoms and disability (Moss-Morris & Wrapson, 2003). Chronic illnesses are generally viewed as having severe life consequences in those suffering from FSS than those with CD who have been given medically explained symptoms (Moss-Morris et. al., 2002).

Leventhal and colleagues (1980) created the Common-Sense Self-Regulation Model (CS-SRM) after conducting a series of fear communication studies which led to the understanding that representations of health threats and given action plans determines a person's coping actions. The idea behind the CS-SRM is that the individual is a problem solver who deals with the perceived reality of a health threat as well as emotional reactions to this threat (Diefenbach & Leventhal, 1996). The three central tenets of the model consists of describing the individual as an active problem solver seeking information and meaning about his or her health risks, using illness representations as a central cognitive construct that guides coping and the appraisal of outcomes, and stating representations are individualized and may not be in accord with medical facts.

According to the CS-SRM, two ways in which individuals specify the identity of symptoms and illness are through the symmetry rule and the stress-illness rule. The symmetry rule is a symptom-illness relationship in which individuals link symptoms or expected symptoms to a labeled diagnosis or expect specific symptoms to occur if already diagnosed. The stress-illness rule states that individuals attribute symptoms to illness when stressful events are not

present in their lives, but attribute symptoms to stress and away from medical conditions when a stressor is present. This rule states that social context is relevant when constructing an illness representation.

The CS-SRM model addresses illness representations and their role in how individuals match external or internal stimuli with schematic structures of prior health experiences. The five attributes of illness representation identified in the model include identity, timeline, causal, controllability, and consequences. The original assessment of illness representations, using the Illness Perception Questionnaire (IPQ), included the five attributes of illness representations beginning with “Identity”, which not only labels a condition but also seeks to find a relationship between symptom reporting and illness. The illness name can be broken down further and assess information such as the category of the disease, or whether or not it is infectious. The “Timeline” dimension addresses if an illness can be considered acute or chronic and how long an individual perceives his or her illness to be part of their lives. The attribute “Cause” consists of questions pertaining to the causal nature of an illness and what is hypothesized to be a contributing factor. The “Consequences” dimension defines an illness by the effect it has on an individual’s personal life. The last attribute “Control” assesses an individual’s beliefs about the extent to which they believe they can control or cure their illness.

The Common-Sense Self-Regulation Model also encompasses an emotional component in which health-relevant stimuli evokes emotional responses. An individual’s specific illness symptoms elicit different states of emotion. These emotions, in addition to the cognitive representations of a health threat, lead to the appraisal and performance of coping actions.

Mediation Model

The proposed relationships between illness representations, coping, and health outcomes in the CS-SRM represents a mediation model (Baron & Kenny, 1986), in which coping mediates the effect of illness representations on outcomes. Part of a mediation model involves being able to establish a relationship between the independent and dependent variables, in this case illness representations and health outcomes. The link between illness representations and outcomes has been supported empirically across a number of different illnesses. Multiple studies have established these associations in patients with chronic illnesses (Heijmans & de Ridder, 1998; Scharloo et. al., 1998). Individual's who perceived their illness as having a strong illness identity, chronic timeline, and more serious consequences had negative associations with health outcomes such as social role functioning.

Leventhal's model (1980) has been used to establish a mediational relationship in research studying conventional and functional illnesses. It has been found that illness representations and mood is mediated by coping responses in patients with gynecological cancer (Gould, Stephen, & Bramwell, 2010). Coping was found to mediate in a negative way, in that denial and disengagement were associated with negative health outcomes. In another study conducted on patients suffering from Irritable Bowel Syndrome (IBS), the coping strategies acceptance, venting emotions, and active coping formed paths mediating the relationship between illness representations and mood outcomes (Rutter & Rutter, 2002). Although rheumatoid arthritis, a chronic inflammatory disease, has been studied very little using the CS-SRM, evidence that avoidant/resigned coping partially mediated the relationship between illness representations and outcomes (Carlisle et. al., 2005).

Self-Regulation

The self-regulatory component of the model proposes that individuals develop beliefs about their physical symptoms in order to try and cope with potential health threats (Leventhal, Nerenz, and Steele, 1984). It portrays illness representations as influencing the selection and performance of coping strategies, which in turn influences an individual's health outcomes or appraisals (Leventhal, Meyer, & Nerenz, 1980). The model (See Figure 1) contains both cognitive and emotional representations of situational stimuli. The cognitive representations are associated with danger control while the emotional representations are associated with fear.

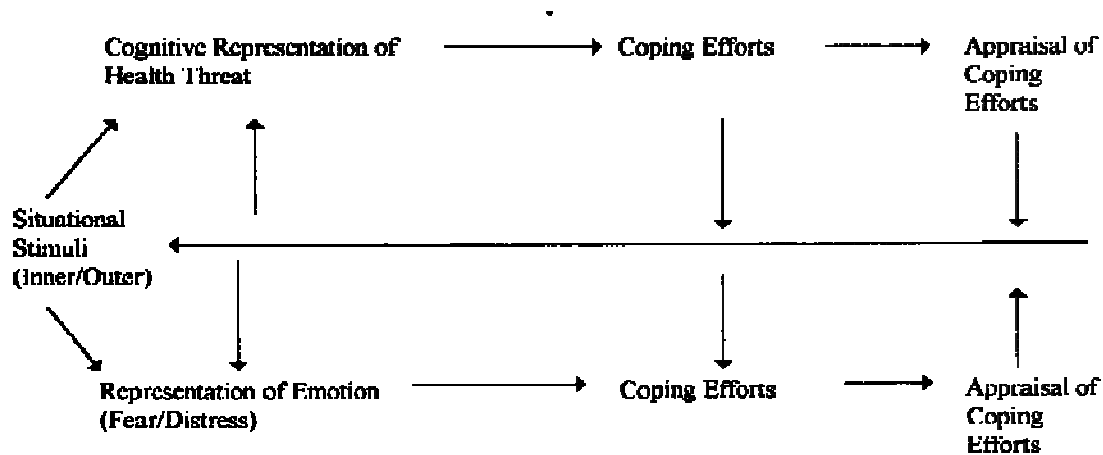


Figure 1. Common-Sense Self-Regulation Model

The IPQ was originally designed to investigate the cognitive components of illness representations without considering the emotional representations that appear in Leventhal's model (Moss-Morris et al., 2002). In order to more fully capture the emotional nature of representations, the questionnaire was modified to form the IPQ-R or Illness Perception Questionnaire Revised. The IPQ-R has seven attributes of illness representations including "Timeline Acute/Chronic", "Timeline Cyclical", "Consequences", "Personal Control",

“Treatment Control”, “Illness Coherence”, and “Emotional Representation”. The way in which a stimulus is decoded using these attributes plays a role in an individual’s coping decisions.

Self-Regulation and Coping

Coping behaviors and actions geared toward controlling and eliminating potential ongoing health threats are guided by the way in which an individual perceives his or her illness (Leventhal, Meyer, & Nerenz, 1980). Coping is defined as “a variety of cognitive and behavioral strategies individuals use to manage their stress” (Folkman & Moskowitz, 2004). Originally, coping was broken down into two main categories or styles: *problem-focused coping* and *emotion-focused coping*. Problem-focused coping involves dealing with the source of stress, such as planning and engaging in active coping, while emotion-focused concerns attempts to handle thoughts and feelings associated with the stressor such as positive reframing, acceptance, and turning to humor or religion (Litman, 2006). Although these two have been considered the two main subscales of coping, research has found that there is an overlap between the two and it appears individual’s tend to engage in both type of coping strategies (Tennen et. al., 2000). More recently, in order to truly define and differentiate coping strategies, two more subscales have been added: *avoidant coping* and *socially supported coping*. Avoidant coping can be defined as ignoring or withdrawing from a stressor or feeling, which involves behavioral disengagement, denial, substance use, distraction, and self-blame. Socially supported coping involves turning to others for help by seeking emotional and instrumental support as well as venting emotions (Litman, 2006).

Empirical evidence has established a relationship between illness representations and coping strategies.

IPQ-R Dimensions

Timeline cyclical. A study on psychological adjustment in patients with gynecological cancer found evidence for the relationship between the illness representation timeline cyclical and specific coping measures (Gould, Stephen, & Bramwell, 2010). Higher scores of denial and behavioral disengagement were related to patients feeling as though their illness is very unpredictable or comes and goes in cycles.

Timeline acute/chronic. It has been found that an individual's belief that his or her illness will only last for a short period of time is positively related to the coping strategy instrumental support (Rutter & Rutter, 2002), while the belief that an illness will have a longer duration is related to having less instrumental support (Arran, Craufurd, & Simpson, 2013). Instrumental support is defined as trying to, or getting advice from others about how to cope with an illness. The belief in a more acute timeline is also negatively related to the coping strategy acceptance. When an individual feels as though their illness is not considered chronic, he or she is less likely to believe in learning to live with the illness as well as accept the reality of it (Rutter & Rutter, 2002).

Consequences. Perceiving an illness as having more serious consequences is related to venting emotions and behavioral disengagement, while the belief in fewer consequences is related to acceptance (Rutter & Rutter, 2002). Venting is the act of allowing unpleasant feelings to escape or expressing negative feelings. Disengaging involves giving up trying to deal or cope with an illness. Studies done on chronic fatigue syndrome (CFS) have shown that patients attribute their illness to external biological and medical causes which in turn leads to higher level of impairment and poorer health outcomes. These patients avoid using active coping strategies,

which can be seen as partaking in disengagement (Paterson, Moss-Morris, & Butler, 1999; Sharpe, 1996)

Personal control/treatment control. Having little control over an illness, both personally and over the treatment, is positively related to active coping, planning, and reinterpretation, or reframing (Rutter & Rutter, 2002). Active coping strategies involve making efforts to change a situation or attempting to make it better, while planning is thinking about, or implementing a strategy on how to cope with an illness. The idea of positive reframing is to see an illness or situation in a different light or look for something good in what is happening. Both types of control are also associated with greater use of emotional and instrumental support, which involves receiving emotional support as well as actual help or advice (Arran, Craufurd, & Simpson, 2013).

Illness coherence. Although little evidence has been found to link the illness representation “coherence” with coping measures, a study on gynecological cancer linked low levels of illness coherence to the coping styles denial and disengagement (Gould, Stephen, & Bramwell, 2010).

Emotional representations. The way in which an illness causes an emotional reaction has a positive relationship with the emotion-focused coping strategy venting emotion (Rozema, Vollink & Lechner, 2009), as well as a relationship with acceptance coping (Searle et. al, 2007). Those who have more negative emotional representations are more likely to express their feelings, while accepting the reality of what has happened to them.

Emotional Representations

The elicitation of emotions in the CS-SRM is an important aspect in terms of health decisions. Leventhal’s (1980) fear studies in addition to breast cancer studies by Dean et al.

(1986) uncovered an underlying theme that people act to avoid threats. It was discovered that if an action can be used to avoid a threat, the stronger the threat the more likely the action would be taken. But, if a threat becomes uncontrollable, the stronger it is the less likely the action will be taken. These studies show how individuals engage in both health promotive and avoidant actions.

Illness Representations, Coping, and Health Outcomes

After reviewing many different studies involving acute and chronic illnesses such as chronic fatigue syndrome, Addison's disease, Huntington's disease, irritable bowel syndrome, and rheumatoid arthritis, research has shown that a moderate to strong relationship exists between illness representations, coping behaviors, and health outcomes (Hagger & Orbell, 2010). Scharloo et. al., (1998) found that individual's suffering from Huntington's disease and rheumatoid arthritis that believed in the controllability of their disease and used social support as a means of coping had better health outcomes and functioning. The illness perceptions "control", "timeline", and "consequences" have a large influence on whether people seek passive/avoidant coping styles or socially supported coping styles. Those who use more passive strategies tend to have worse health outcomes while those who seek social support have more positive or better outcomes. A study on IBS found that individual's who had strong feelings of control over their illness were more likely to engage in more active styles of coping which in turn had a relationship with a greater satisfaction of health (Rutter & Rutter, 2002). The same study concluded that those who perceived their illness as having less serious consequences were more likely to engage in acceptance as a coping strategy, leading to a greater quality of life.

It has been found that the effectiveness of coping strategies depends a great deal on the controllability of an individual's illness (Lazarus & DeLongis, 1983; Lazarus & Folkman, 1984).

People are more likely to use avoidant style coping when they believe that they are unable to control their illness. In women with diabetes, avoidance coping is used more frequently with those who perceive their illness as having more severe consequences (Awasthi & Mishra, 2011). Avoidant coping is associated with more negative health outcomes such as increased emotional distress, decreased functioning, poor physical health, poor psychological adjustment, and increased psychological distress (Culver et al. 2004; Kershaw et al. 2004). Additional evidence concerning poorer health outcomes has been found in patients with Huntington's disease. Those who believed their illness had more serious perceived consequences had more negative psychosocial functioning when adopting avoidant coping styles such as denial and behavioral disengagement (Kaptein et. al., 2006). In a study on women with diabetes, Awasthi & Mishra (2011) found that results of illness representations, coping, and outcomes has practical implications indicating that coping strategies used by patients with chronic illness may affect psychological and physical outcomes of illness.

Hypotheses

Based on the Common-Sense Self-Regulation Model of illness, it can be hypothesized that illness representations predict coping strategies, coping strategies predict health outcomes, and coping should mediate the relationship between illness representations and health outcomes (Figure 1).

Hypothesis 1. Illness representations predict coping strategies

Empirical evidence suggests that negative perceived illness representations will lead to more avoidant styles of coping, while positive illness representations will lead to more problem focused, emotion focused, and socially supported styles of coping. It is hypothesized that individuals who perceive their illnesses as having a cyclical or prolonged timeline, more severe

consequences, and having low levels of coherence or understanding of their illness will demonstrate more avoidant coping styles.

Hypothesis 2. Coping strategies predict health outcomes (general health)

Studies show that active coping strategies are linked to more positive health outcomes while passive coping strategies lead to negative health outcomes. Based on empirical evidence it is hypothesized avoidant coping will lead to poorer health outcomes.

Hypothesis 3. Coping will mediate the relationship between illness representations and health outcomes (general health)

The CS-SRM has been presented as a mediational model in which coping style mediates the relationship between illness representations and health outcomes (Leventhal, Meyer, & Nerenz, 1980). It is hypothesized that this relationship exists based on the mediational steps proposed by Baron and Kenny (1986). Empirical evidence has linked illness representations to outcome measures, illness representations to coping, and coping to outcome measures. The hypothesis will be tested based on hypotheses one and two.

Method

As part of the VOICE (Verification Of Illness, Coping, & Experience) study, data was gathered from participant responses to four surveys geared towards measuring personal experiences with chronic illness. The surveys, *The Impact of Illness on Your Life*, *Personal Views of Your Physical Symptoms*, *Relationships with Others and Support*, and *How You are Coping with Your Symptoms*, examined different aspects of illness experience including personal beliefs, coping/adjustment, and health outcomes. The surveys were administered online and open to any consenting adult. Participants had to be 18 years of age and currently experiencing persistent physical symptoms for at least three months. Data was not used from participants reporting physical symptoms for less than three months, those who had more than one primary

diagnosis, or had a primary diagnosis of a psychiatric or affective disorder. Also, data were not used from participants without a reported diagnosis, with medically unexplained symptoms, or from those who did not consent to completing the study. The overall participants included in the study reported having a consistent diagnosis, completed at least three of the four surveys, and had either a functional or conventional illness.

Participants

Chronic illness classification. Participants were categorized as having a functional somatic syndrome (FSS) or conventional diagnosis (CD) based upon their reported illness type and symptom conditions. As previously mentioned, a conventional diagnosis of an illness is based upon a medically explained symptoms with a clear etiology while functional somatic syndrome refers to an illness with medically unexplained symptoms with no clear explanation or etiology (Christensen et. al, 2015; Barsky & Borus, 1999). 64% of participants reported having a FSS (N=131) while the other 35.8% reported a CD (N=73). Participants represented 52 documented chronic illnesses (see Table 1 and 2). Of the illnesses represented, 99 participants were classified as CD and 67 were FSS. The cases labeled “other” consisted of people reporting multiple diagnoses or illness symptoms. The most prevalent illnesses among the participants were Fibromyalgia (N=49), Chronic Fatigue Syndrome (N=11), and restless leg syndrome (N=15).

Table 1

Participants Reporting Functional Somatic

Syndrome

<i>Illness Name</i>	<i>n</i>
Adrenal Fatigue	1
Atypical Facial Pain	1
CFIDS ^a	3
Chronic Fatigue Syndrome (CFS)	11
Chronic Low Back Pain	4
Delusional Parasitosis	1
Fibromyalgia	49
Food Sensitivities	1
Insomnia	1
Irritable Bowel Syndrome	3
Morgellon's Disease	5
Multiple Chemical Sensitivity	1
Myofascial Pain Syndrome	2
Restless Leg Syndrome	15
Tension Headache	1
Other	32

^aChronic Fatigue Immune Dysfunction Syndrome

Table 2

Participants Reporting Conventional Diagnosis

<i>Illness Name</i>	<i>n</i>	<i>Illness Name</i>	<i>n</i>
Addison's Disease	1	Interstitial Cystitis	1
Allergic Rhinitis	1	Lupus	1
Ankylosing Spondylitis	4	Lyme Disease	4
Arthritis	2	Meniere's Disease	6
Behcet's Disease	1	Pernicious Anemia	1
Celiac Disease	1	Postpolio Syndrome	1
COPD ^a	1	Pudendal Neuralgia	1
Chiari Malformation Type1	1	Rheumatoid Arthritis	5
Chronic Tonsillitis	1	Sarcoidosis	7
CRPS ^b	4	Scleroderma	1
Crohn's Disease	1	Sjorgren's Disease	1
Diabetes Insipidus	1	SOD ^d	1
Diabetes Mellitus	1	Spondylitis	4
Dysautonomia	1	Stiff Person Syndrome	2
Eczema/Dermatitis	1	TMJ ^c	1
Ehlers Danlos Syndrome	3	Other	6
Endometriosis	1		
Epstein Barr Virus (EBV)	1		
Generalized Anxiety Disorder	1		
Grave's Disease	1		

Hypothyroidism 1

^aChronic Obstructive Pulmonary Disease

^bComplex Regional Pain Syndrome

^cTemporomandibular Joint Dysfunction

^dSphincter of Oddi Dysfunction

Demographics

The sample consisted of 204 participants who were categorized based on their illness type as being a conventional diagnosis (CD) or a functional somatic syndrome (FSS) and had a consistent diagnosis throughout three or more surveys. As previously stated, the majority of the participants reported having an FSS (N=131) while the others reported having a CD (N=73). The average age of the participants was 43.61 years (SD=14.24), 82.8% being female and 14.7% male with 2.5% not identified. The majority (83.3%) of participants identified as White/Caucasian and 61% reported being in a committed relationship. In terms of symptom severity, 65.6% of participants experienced “a lot” or “extreme” persistent or intermittent physical symptoms. 79.4% had symptoms lasting a duration of more than one year, while 10.8% had symptoms lasting three months to one year and 9.8% were unidentified.

Participants were recruited through online postings to discussion boards and forums of illness support groups from websites based primarily in the United States. Online recruitment notices contained information describing the VOICE study and directed participants to the online surveys. In order to capture a representative sample, online notices were posted on discussion boards and forums for a wide range of chronic illnesses and conditions.

Measures

Illness representations. Emotional illness representations were measured using the Revised Illness Representations Questionnaire (IPQ-R). Revised from the Illness Perception Questionnaire (IPQ) developed by Weinman and colleagues (1996), the IPQ-R includes the

emotional representation component of illness representations. The IPQ was originally designed to investigate the cognitive components of illness representations without considering the emotional representations that appear in Leventhal's Common Sense Self-Regulation Model (Moss-Morris et al., 2002). In order to more fully capture the emotional nature of representations, the questionnaire was modified to form the IPQ-R or Illness Perception Questionnaire Revised. The IPQ-R has seven attributes of illness representations including "Timeline Acute/Chronic", "Timeline Cyclical", "Consequences", "Personal Control", "Treatment Control", "Illness Coherence", and "Emotional Representation". The way in which a stimulus is decoded using these attributes plays a role in an individual's coping decisions. Factor analyses of the emotional subscale of the IPQ-R indicated good internal reliability and validity, with a Cronbach $\alpha = .88$ (Moss-Morris, et al., 2002). Participants indicated their agreement with items (e.g. "My illness has major consequences on my life") on a 5-point Likert-type scale, ranging from *strongly disagree* to *strongly agree*. Scores from the 7 item scale ranged from 1 to 5, with higher scores suggesting higher degrees of emotional responses generated by the illness.

Health outcomes. Health outcomes were measured using the RAND-36 (SF-36) measure of health-related quality of life, which measures health using 36 items across eight dimensions (Hays & Morales, 2001). The eight dimensions include physical functioning, role limitations caused by physical health problems, role limitations caused by emotional problems, social functioning, emotional well being, energy/fatigue, pain, and general health perceptions. In a psychometric evaluation of the SF-36, McHorney and colleagues (1994) determined each health dimension scale to have strong validity and internal consistency reliability with a Cronbach α ranging from .78 to .93, which exceeds minimum reliability standards. The number of possible responses per item ranges from two to six. For example, for an item assessing physical

functioning, participants were asked to indicate the extent to which their health limited them from certain activities (e.g. lifting or carrying groceries) ranging from “*yes, a lot limited*” to “*no, not at all limited*”. Each dimension is scored on a scale of 0 to 100, with higher scores indicating better health.

Coping. Carver (1997) developed a measure for coping known as the Brief COPE, which was adopted from his previous measure the COPE inventory. The Brief COPE is a shortened version of the COPE inventory and is used to assess potentially dysfunctional coping responses, as well as adaptive coping responses. Coping behaviors and strategies were divided up into 14 different scales, each including two items. The scales, or ways in which coping is defined, are active coping, planning, positive reframing, acceptance, humor, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement, and self-blame. Each scale asks questions regarding coping style (e.g. “*I’ve been looking for something good in what is happening*”) and range from 0 (*I haven’t been doing this at all*) to 3 (*I’ve been doing this a lot*). Although the scales only contain two question items, each scale meets or exceeds a Cronbach’s $\alpha=.50$, which is minimally acceptable for analysis.

Results

Statistical analyses were conducted using multivariate tests, correlational coefficients, hierarchical linear regressions testing the relationship between illness representations, coping, and health outcomes, and meditational models. For the hierarchical linear regression analyses, scatterplots of residual values did not indicate violations in linearity or homoscedasticity. Alpha levels for all analyses were set at $\alpha = .05$. As a result of missing data, the number of participant responses for specific items is less than the total participant count in the sample (N=193).

Health Factors, Demographics, and Illness Representations

Analyses of Variance (ANOVA) were performed in order to test for relationships and compare group means for socio-demographic variables (ethnicity, education, household income, gender, committed relationship, employment status, and illness group) on illness representations. Those who reported their ethnicity as white perceived their illness to be chronic, $F(1,191)=16.141, p <.001$, and having more consequences, $F(1,191)=13.691, p <.001$, than those who reported having different or multiple ethnicities. More people who perceived an illness as being chronic and having more consequences were also in committed relationships $F(1,191)=10.398, p=.001$; $F(1,191)=4.733, p=.031$. Differences in employment status showed that individuals who identified their employment as “students” believed their illness timeline to be more acute in nature $F(4,184)=3.799, p=.005$. Students also perceived their illness to have fewer consequences than those who identified as employed, disabled, not working/unemployed due to health, and retired $F(4,184)=13.410, p <.001$. Employed individuals significantly differed from those who are disabled because they believe their illness has fewer consequences. There were significant differences between illness group in that those who suffered from a functional somatic syndrome reported less illness coherence than those who were diagnosed with a conventional illness $F(1,191)=5.985, p=.015$]. Because of these group differences, ethnicity, committed relationship, employment status, and illness group were held constant in the hierarchical linear regression. No other socio-demographic group differences were significant in reported illness representations ($p <.001$ to $p=.979$). All means and standard deviations are reported in Table 3.

Table 3

Analysis of Variance for Demographics and Illness Representations

Variable	n	Illness timeline acute/chronic		Illness timeline cyclical		Illness consequences		Illness coherence	
		M	SD	M	SD	M	SD	M	SD
Ethnicity		p<.001**		NS		p<.001**		NS	
White	171	24.36	5.60	15.09	3.94	25.55	4.53	15.32	5.45
Other/Multiple	22	18.90	8.56	14.18	3.71	21.55	6.48	15.29	5.36
Education		NS		NS		NS		NS	
High school or less	8	24.88	3.94	16.00	5.26	25.50	4.14	12.25	3.45
Some college	66	23.98	6.48	15.22	4.08	25.23	4.90	15.72	5.14
Associates degree	35	23.49	6.13	14.97	4.10	22.94	6.91	16.34	6.69
Bachelor's degree	37	25.11	4.21	15.16	4.14	26.16	3.58	14.26	4.57
Post college graduate	41	22.71	6.79	14.20	3.15	25.65	3.94	15.30	5.80
Household Income		NS		NS		NS		NS	
<\$20,000	52	23.89	5.47	15.40	3.96	25.13	5.08	15.27	5.26
\$20,000 - \$50,000	57	23.97	6.46	14.98	4.20	25.67	4.93	16.47	5.35
\$50,000 - \$100,000	49	24.82	4.75	15.59	3.12	25.81	3.66	14.35	5.40
>\$100,000	32	22.78	7.30	13.44	4.31	23.06	6.09	14.81	5.95
Gender		NS		NS		NS		NS	
Male	26	23.34	6.83	14.13	3.91	26.04	5.27	14.88	5.69
Female	163	23.84	6.17	15.16	3.84	25.04	4.83	15.30	5.39
Committed Relationship		p<.05*		NS		p<.05*		NS	
Yes	125	24.78	5.29	15.10	4.00	25.66	4.42	15.58	5.41
No	68	21.82	7.33	14.76	3.77	24.06	5.67	14.83	5.47
Employment Status		p<.05*		NS		p<.001**		NS	
Employed	58	24.69 ¹	5.77	14.47	4.06	24.70 ³	4.46	15.62	5.93
Disabled	50	24.48 ¹	5.73	15.02	4.17	27.44 ²	2.76	14.91	5.48
Not working/Unemployed due to health	49	23.55 ¹	6.39	15.48	3.48	25.63 ^{2,3}	4.56	15.10	4.75
Student	21	19.14 ²	7.06	15.05	3.57	19.33 ¹	6.45	16.08	5.28
Retired	11	25.53 ¹	5.57	15.85	3.69	26.45 ^{2,3}	3.78	13.73	5.93
Illness Group		NS		NS		NS		p<.05*	
Functional somatic syndrome	125	23.75	5.81	15.16	3.84	25.61	4.74	14.62	5.43
Conventional diagnosis	68	23.72	6.99	14.66	4.05	24.16	5.18	16.60	5.21

NS: Non-significant.

Means with different numbers were significantly different from each other.

Bivariate Relationships

Pearson's correlation coefficients (r) were calculated for variables of primary interest (i.e., illness representations, coping strategies, and general health) in order to test the strength of the associations between the variables (Table 4). The analysis revealed significant correlations of illness representations with coping strategies and general health outcomes. Illness consequences were significantly correlated with the coping strategies self-blame ($p < .001$), behavioral disengagement ($p = .048$), denial ($p = .028$), and self-distraction ($p = .013$). Illness coherence was significantly correlated with self-blame ($p = .004$), behavioral disengagement ($p < .001$), and denial ($p = .011$). Both illness consequences and coherence were significantly correlated with general health outcomes ($p < .001$, $p = .043$). The coping strategies self-blame and denial were significantly correlated with general health outcomes ($p < .001$, $p = .048$). The illness representation timeline acute/chronic was significantly correlated with general health outcomes ($p = .027$) and timeline-cyclical was significantly correlated with the coping strategy self-distraction ($p = .009$). As a result of only being correlated with only one other variable, timeline acute/chronic and timeline cyclical were not used in further analyses.

Table 4

Correlations Between Illness Representations, Coping, and General Health

	1	2	3	4	5	6	7	8	9	10
1. Timeline-acute/chronic		.052	.286**	.015	.109	.111	-.022	-.051	.021	-.161*
2. Timeline-cyclical			.115	.053	-.034	-.083	-.028	.188**	.005	-.133
3. Consequences				-.210**	.341**	.144*	.160*	.181*	.045	-.561**
4. Coherence					-.210**	-.266**	-.184*	-.096	-.111	.148*
5. Self-blame						.383**	.331**	.095	.245**	-.256**
6. Behavioral disengagement							.224**	-.052	.241**	-.139
7. Denial								-.001	.212**	-.142*
8. Self-distraction									.104	-.042
9. Substance use										.053
10. General health										

Note: $p < .05^*$, $p < .01^{**}$

Illness Representations and Coping Strategies

In order to test for relationships between illness representations and coping strategies, hierarchical linear regressions were performed. Four of the five coping strategies that make up avoidant coping were used as criterion variables (self-blame, behavioral disengagement, denial, and self-distraction). The coping strategy substance use was not used because bivariate analyses showed no correlations between any of the predictor variables. For each analysis, the demographic variables illness group, ethnicity, committed relationship, and employment status were entered into Step 1; illness consequences, and coherence were entered separately into Step 2 as predictor variables for each avoidant coping strategy (Table 5).

The first analysis used self-blame as the outcome variable and illness consequence as the predictor. The overall model was significant $F(5,179) = 4.96, p < .001$, accounting for 12.2% of the variance in self-blame. Illness consequence was the strongest independent predictor of self-blame accounting for a significant proportion of the variance in self-blame ($\Delta R^2 = 11.4\%, p < .001$). Higher levels of illness consequence were associated with increased self-blame. The next three analyses used the coping strategies behavioral disengagement, denial, and self-distraction as the outcome measures. For each analysis the overall model was not significant, however, when controlling for demographics illness consequence was a significant predictor of each outcome. Independently, the predictor variable significantly accounted for the variance in denial and self-distraction ($\Delta R^2 = 2.7\%, p = .025$; $\Delta R^2 = 3.0\%, p = .018$). Illness consequence was the least strongest predictor of behavioral disengagement but still accounted for a significant proportion of the variance in behavioral disengagement ($\Delta R^2 = 2.2\%, p = .046$). Higher levels of illness consequence were associated with greater denial, self-distraction, and behavioral disengagement.

Illness coherence was also used as a variable predicting the four coping outcome measures. The overall model predicting behavioral disengagement was significant $F(5,179) = 3.04, p = .012$, accounting for 7.8% of the variance. Illness coherence was the strongest independent predictor of behavioral disengagement accounting for a significant proportion of the variance in behavioral disengagement ($\Delta R^2 = 6.8\%, p < .001$). The overall models predicting self-blame, denial, and self-distraction were not significant, however, illness coherence significantly predicted self-blame and denial independently ($\Delta R^2 = 4.0\%, p = .007$; $\Delta R^2 = 3.5\%, p = .011$). Illness coherence did not significantly predict self-distraction and accounted for very little variance in the model ($\Delta R^2 = .9\%, p = .204$). Having less illness coherence was associated with greater self-blame, behavioral disengagement, and denial.

Table 5

Summary of Hierarchical Linear Regression of Illness Representations Predicting Coping Strategies

<i>Outcome Measures</i>	<i>Illness Consequence</i>				<i>Illness Coherence</i>			
	<i>B</i>	<i>SE</i>	β	ΔR^2	<i>B</i>	<i>SE</i>	β	ΔR^2
Self-Blame	.064	.013	.347***	.114	-.031	.011	-.202**	.040
Behavioral Disengagement	.024	.012	.152*	.022	-.035	.010	-.263***	.068
Denial	.023	.010	.170*	.027	-.021	.008	-.190*	.035
Self-Distraction	.033	.014	.179*	.030	-.015	.012	-.096	.009

Note: $p < .05^$, $p < .01^{**}$, $p < .001^{***}$*

Coping Strategies and General Health

In order to test for relationships between coping strategies and general health, hierarchical linear regressions were performed. For each analysis, the demographic variables illness group, ethnicity, committed relationship, and employment status were entered into Step 1; each avoidant coping strategy was entered separately into Step 2 as a predictor variable for outcome measure general health (Table 6).

The first analysis using self-blame as the predictor variable had a significant overall model $F(5,178) = 4.18, p = .001$, accounting for 10.5% of the variance in general health. Self-blame was the strongest independent predictor of general health ($\Delta R^2 = 9.3\%, p < .001$). Higher levels of self-blame were associated with poorer general health outcomes. The other three avoidant coping strategies did not produce significant overall models. Behavioral disengagement and denial were both significant independent predictors of general health ($\Delta R^2 = 2.5\%, p = .032$; $\Delta R^2 = 2.8\%, p = .024$). Self-distraction was not an independent predictor and accounted for very little variance in general health ($\Delta R^2 = .3\%, p = .493$).

Table 6

Summary of Hierarchical Linear Regression of Coping Strategies Predicting General Health

<i>Predictor Variable</i>	<i>B</i>	<i>SE</i>	β	ΔR^2
Self-Blame	-8.345	1.944	-.303***	.093
Behavioral Disengagement	-5.080	2.354	-.160*	.025
Denial	-6.280	2.765	-.167*	.028
Self-Distraction	-1.407	2.051	-.051	.003

Note: $p < .05^$, $p < .01^{**}$, $p < .001^{***}$*

Illness Representations and General Health

The final analysis to test the relationship between the variables of interest was a hierarchical linear regression to look for relationships between illness representations and general health outcomes. Just like the previous analyses, the demographic variables illness group, ethnicity, committed relationship, and employment status were entered into Step 1; illness consequences, and coherence were entered separately into Step 2 as predictor variables for the outcome measure general health (Table 7).

The overall model using illness consequence as a predictor was significant $F(5,182) = 17.43, p < .001$, accounting for 32.4% of the variance in general health. Illness consequence was the strongest independent predictor of general health accounting for a significant proportion of the variance in general health ($\Delta R^2 = 29.7\%, p < .001$). Greater levels of illness consequence were associated with poor general health.

When illness coherence was used as the predictor variable the overall model was not significant, but it was a significant independent predictor of general health ($\Delta R^2 = 2.7\%, p = .024$). Having more illness coherence was associated with greater general health.

Table 7

Summary of Hierarchical Linear Regression of Illness Representations Predicting General Health

<i>Predictor Variable</i>	<i>B</i>	<i>SE</i>	β	ΔR^2
Illness Consequence	-2.743	.307	-.570***	.297
Illness Coherence	.722	.317	.166*	.027

Note: $p < .05^$, $p < .01^{**}$, $p < .001^{***}$*

Mediational Analyses

After running the previous hierarchical linear regressions, the coping strategy self-blame was a strong proponent suggesting a mediation model between illness consequences and general health. All three steps of the mediation model were met according to Baron and Kenny (1986), in which the predictor illness consequence was associated with the outcome general health, (Figure 2) as well as the predicted mediator self-blame (Figure 3). Self-blame was also associated with the outcome general health (Figure 4).

Figure 2. Illness Consequence Predicting General Health

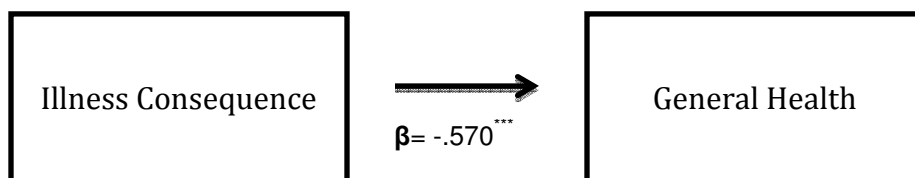


Figure 3. Illness Consequence Predicting Self-Blame

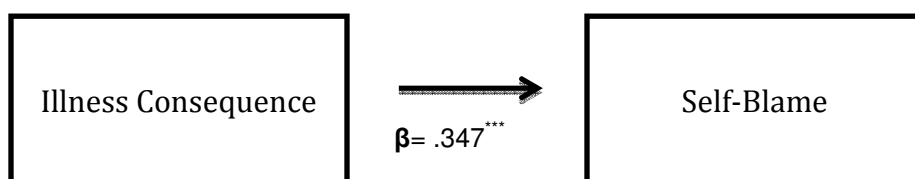
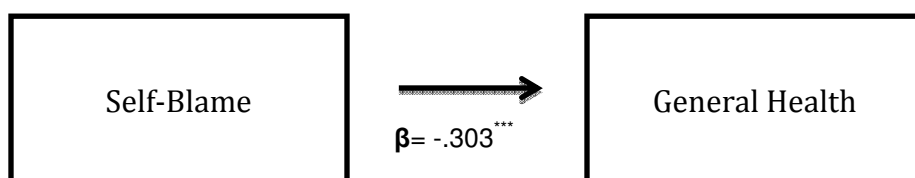


Figure 4. Self-Blame predicting General Health



In order to test the full model, the socio-demographics illness group, ethnicity, committed relationship, and employment status were entered into Step 1; illness consequence was entered into Step2; self-blame was entered into Step 3; and general health was entered as the outcome variable. In order for mediation to occur, the full model should no longer show that illness consequence is a significant predictor of general health. After running the analysis, illness consequence was still a significant predictor variable [$\beta = -.149, t = -7.171, p < .001$] and although the predictive power did decrease, the change was too small to support the model ($\Delta R^2 = 1.8\%, p = .032$).

Since the mediation model was disproven, an exploratory analysis using self-blame as a moderator variable was tested. The same first three steps were entered into the hierarchical linear regression and a fourth step was entered as an interaction variable comprised of multiplying illness consequence by self-blame. In order for the moderator variable to affect the direction and/or strength of the relationship between illness consequence and general health, the interaction variable should have been significant. After running the analysis, it was found that the interaction variable had no significant effect on the model ($\Delta R^2 = 0\%$, $p = .834$). Self-blame was neither a mediator nor a moderator, but overall it was proven that illness consequence and self-blame independently predict general health outcomes [$\beta = -.149$, $t = -7.171$, $p < .001$; $\beta = -.144$, $t = -2.156$, $p = .032$].

Discussion

The results of the study revealed that illness perceptions influence how people cope with their illnesses as well as how they view the general quality of their life. Although the pathway suggested by Leventhal (1980) was not fully supported, the research suggests that an individual's mindset and beliefs play an important role in the way people choose to go about dealing with severe health threats. Illness consequence, the strongest predictor of the avoidant coping strategy self-blame and general health, did not differ significantly based on illness classification. Literature suggests that those suffering from FSS view their illnesses as having more severe life consequences than those dealing with CD (Moss-Morris et. al., 2002) however, this study provides evidence that people living with any chronic illness are more likely to view their symptoms as severe.

Chronic Illness

Although the main focus of this study was to look at illness representations for all chronically ill participants, illness group did significantly differ in terms of illness coherence. Individuals with FSS reported having less illness coherence than those with CD. This finding coincides with research on chronic illness because not only are FSS medically unexplained but also the absence of an explanation leaves patients searching for validation behind their illness (Looper & Kirmayer, 2004). The participants in the sample tend to report having more obscure functional somatic syndromes and conventional diagnoses which implies that there may be a sub population within the chronic illness population who are more likely to be found in chat rooms designed to discuss their illnesses. It is possible that these individuals view their illnesses as more severe than those who do not spend time on discussion forums and are constantly seeing multiple healthcare providers in order to designate a label for their illness.

Illness Representations and Coping Strategies

The results associating illness representations and coping style found that negative perceived illness representations lead to more avoidant coping strategies. As hypothesized, illness consequence and coherence predict avoidant coping but timeline cyclical and chronic did not. Research suggests that perceiving an illness as unpredictable and more chronic in nature will result in negative behaviors and ways of dealing with the illness (Gould, Stephen, & Bramwell, 2010). However, timeline cyclical and chronic were not used in the regression analyses because neither of them shared a correlation with both coping and general health. It can be assumed, based on data quality and control, that every participant in the study was dealing with a chronic illness whether it was classified as FSS or CD, therefore, it is likely that very few would be living with optimal health.

Consequence and coherence illness representations significantly predicted avoidant coping, specifically self-blame and behavioral disengagement. This aligns with research by Rutter & Rutter (2002), which shows that believing an illness has more severe consequences prompts an individual to engage in more avoidant styles of coping. In this study, the perception that an illness has a serious effect of a person's life and strongly affects the way others view them leads to greater self-blame and criticism. The cognitive representation of the health threat leads to the appraisal and performance of coping actions, which in this case are all very negative ways to view chronic illness. If an individual were able to change their mindset concerning their FSS or CD and attribute less consequences to their illness, the act of performing more positive coping actions would take place.

In terms of illness coherence, there was evidence that understanding very little about an illness will lead to avoidant coping and most often behavioral engagement. Very little research has found connections using illness coherence and coping but empirical evidence has linked low levels of coherence to disengagement in cancer patients (Gould, Stephen, & Bramwell, 2010). The implications concerning this evidence is that individuals dealing with chronic illness, especially FSS, should be given as much information as possible about symptoms and treatments. Many times patients with FSS will attribute their symptoms to a disease before seeking medical help and can be very resistant to information that contradicts their own understand of the illness (Barsky & Borus, 1999).

Coping Strategies and General Health

Studies have shown that the use of avoidant coping strategies will lead an individual to have negative health outcomes including emotional distress, poor physical health, decreased functioning, and even increased psychological distress (Culver et. al.; Kershaw et. al., 2004).

There are many different subscales representing health outcomes from the RAND-36, but in order to get an overall idea of an individual's well being, the general health outcomes scale was used in the hierarchical linear regressions. General health evaluates the way a person views their overall health and whether or not they believe their health will improve or worsen with time.

The results associating avoidant coping and general health outcomes showed that increased self-blame, behavioral disengagement, and denial were all associated with negative general health. Hypothesis two was supported by this evidence and research by Scharloo et. al., (1998) confirms that the more an individual engages in avoidant coping, the worse they rate their overall general health. Self-blame most strongly predicted general health and has been shown to be a very salient coping strategy for understanding how people adjust with chronic illness. Engaging in self-criticism and blame is negatively related to self-compassion and if recognized, may be the key to redirecting the appraisal of outcomes (Sirois, Molnar, & Hirsch 2015). If individuals with chronic illness stopped turning to self-blame as a coping strategy and treated themselves with more kindness and less judgment, general health would increase. The analyses of this study are supported by evidence that individual coping efforts play a large role in the way people adapt to illnesses, implying that the way in which one chooses to cope will ultimately effect levels of overall well-being (Felton & Revenson, 1984).

Coping as a Mediator

The CS-SRM was originally proposed as a mediational model in which coping style influences the relationship between illness representations and health outcomes (Leventhal, Meyer, & Nerenz, 1980). Hypothesis three was tested based on the first two hypotheses, which established strong relationships between illness consequence and self-blame, as well as self-blame and general health outcomes. Before the mediation model could be tested, a third

relationship was established between illness consequence and general health as well as illness coherence and general health.

Illness consequence was the strongest predictor of general health indicating that believing an illness is more serious and has a greater effect a person's life will lead to poorer general health. Illness coherence was also a predictor of general health implying that the less an individual understands about their illness the worse their general health will be. Because the avoidant coping style self-blame had the strongest relationships with illness consequence and general health, the mediation model was tested using those three variables.

After running the analyses, it was discovered that self-blame did not affect the relationship between illness consequence and general health which failed to support the last hypothesis. Self-blame was also tested as a moderator during exploratory analyses, but did not play a role in the relationship between illness consequence and general health. The CS-SRM is seen as a mediation model; however, multiple studies have called into question this hypothesis based on using different variables for illness representations, coping, and outcomes (Hagger & Orbell, 2010). A moderating effect has not often been considered due to the overwhelming literature stating a mediational pathway exists (Rutter & Rutter, 2002). Because the mediator model was disproven based off of the strongest relationships between variables, other mediator models were not tested. Even though hypothesis three could not be proven, self-blame and illness consequence were found to independently predict general health which can still provide useful information regarding the way people view their illnesses and choose to cope.

Limitations and Future Directions

The data used for this study was conducted online and took approximately 10-15 minutes to complete each of the four surveys. Due to the amount of time needed, attrition is a standard limitation that takes place when using self-report measures, especially considering that these participants were dealing with ongoing symptoms of chronic illness. To maintain data integrity, 337 participants were not included in the study based on the fact that they completed less than three of the four surveys, were inconsistent with their diagnosis, or did not choose to categorize themselves as having a conventional diagnosis or functional somatic syndrome. Despite decreasing the sample size, the implementation of such criteria was necessary to maintain study integrity. However, it should be noted that the subset of participants who met study criteria may be distinct from those who did not meet study inclusion.

It is also important to note the validity of the participant's self-report measure considering that almost all of the chronic illnesses were less common diagnoses. Because the illnesses were so obscure, deciding which illnesses were FSS or CD based on specific criteria was not a clear-cut process. Those who use illness chat rooms and discussion forums may be considered their own sub population of people suffering with chronic illness and may not necessarily align with the majority of people with FSS and CD. Although it may be difficult to distinguish between the chronic illness classifications there are still strong implications that illness representations, coping, and general health are all associated with each other in people who are experiencing chronic illness symptoms.

Another limitation is the correlational design of the study. With this type of cohort design, causation could not be determined between the variables. Although specific confounds were controlled for each analysis, there appears to be an over representation of females within

the study which may suggest convenience sampling. The absence of a control group can potentially be a limitation because only those with chronic illnesses were used in the sample. Future studies may look at an acute illness group in order to establish a comparison between those with chronic illness and those with less threatening conditions.

Because illness consequences, self-blame, and general health were tested for both the meditational and moderator models future studies could test different variables to see if there are other relationships. Many previous studies simply use the term illness representations without specifically identifying which subscales are used in the model. Future studies could also look for ways to help chronically ill individuals experience less negative illness representations and guide them to engage in positive coping.

Overall, the common-sense self-regulation model (CS-SRM) stating that illness representations predict coping appraisals, which in turn predict health outcomes (Diefenbach & Leventhal, 1996), cannot be fully supported by the study. Although the overall model was not empirically proven, it was found that certain illness representations subscales do in fact predict specific avoidant coping behaviors as well as general health outcomes. This idea supports Leventhal's (1980) theory that illness representations act as a part of a regulatory system that guides coping efforts and sets goals to evaluate these efforts. By analyzing the variables within the model, we can still use the CS-SRM to understand how people formulate health related attitudes and construct lasting behavioral strategies for dealing with their health threats.

The findings are important for both individuals suffering from chronic illness and the healthcare professionals diagnosing and treating them. Knowing that negative illness views and coping are associated with poorer quality of life in patients, it is imperative that healthcare professionals educate patients to improve illness coherence as well as provide information

concerning the severity of their illness. Having more information about an illness will help patients use more positive coping strategies instead of turning to self-blame as a form of adapting. Simply understanding that mindset plays a significant role in the way chronically ill individuals assess and deal with their illness can potentially help people view the process with a more positive light which will increase their quality of life.

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Curriculum Vitae

EDUCATION

- 2013-2015 **Master of Arts, General Psychology**
University of North Florida, Jacksonville, FL
GPA 3.42
- 2009-2012 **Bachelor of Science, Psychology; Cognitive Sciences Minor**
University of Central Florida, Orlando, FL
GPA 3.73
- 2007-2009 **General Studies, Dual Enrollment Program**
Eastern Florida State College, Melbourne, FL
GPA 4.0

TEACHING EXPERIENCE

- 08/2014-07/2015 **Instructor of Record**
University of North Florida, Jacksonville, FL
Supervisor: Brian Fisak, Ph.D.
Class : Research Method Lab
- 08/2013-12/2013 **Teaching Assistant**
University of North Florida, Jacksonville, FL
Supervisor: Gabriel Ybarra, PhD.
Class : Psychology of Abnormal Behavior

RESEARCH EXPERIENCE

- 08/2014-05/2015 **Graduate Research Assistant/Intern**
The Mayo Clinic, Jacksonville, FL
Mentor: Steven C. Ames, PhD., ABPP
Project Involvement: Working with psychologists on clinical study:
The Role of Psychological and Health Behavior Factors in Quality of Life, Morbidity, and Mortality in Hematopoietic Stem Cell Transplant Patients. Assisting with data collection, data entry, and preparation for data analysis.
- 05/2013-06/2015 **Graduate Research Assistant**
University of North Florida, Jacksonville, FL
Verification Of Illness, Coping, and Experience (VOICE) Lab
Thesis Advisor: Lori Lange, PhD.
Project Involvement: Management of large data set involving ongoing online study investigating chronic and functional illness. Assisting with data quality and control, merging, synthesizing, and preparing data for analysis.
- 01/2012-04/2013 **Undergraduate Research Assistant**
University of Central Florida, Orlando, FL
Substance Use Research Group (SURG) Lab
Mentor: Michael Dunn, PhD.

Project Involvement: Funded under a Department of Education grant: *Models of Exemplary, Effective, and Promising Alcohol or Other Drug Abuse Prevention Programs on College Campuses*. Assisted with data collection, data entry, and experimental procedures. Administered experimental protocol through group implementation of a novel alcohol intervention and prevention program, geared toward college students.