

PERCEIVED STIGMA, ILLNESS INVALIDATION, SLEEP DIFFICULTIES, AND
PSYCHOLOGICAL DISTRESS IN EMERGING ADULTS IN
COLLEGE WITH PERSISTENT PAIN

by

SHWETA KAPOOR

BEVERLY E. THORN, COMMITTEE CHAIR
REBECCA S. ALLEN
NATALIE DAUTOVICH
JASON DeCARO
STEVEN PRENTICE-DUNN

A DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in the Department of Psychology
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2015

Copyright Shweta Kapoor 2015

ALL RIGHTS RESERVED

ABSTRACT

Persistent pain is traditionally associated with middle-aged to older adults and most of the pain literature is focused on this age group. However, recent research indicates a high prevalence of pain in children and adolescents as well. These studies have indicated significant differences in the variables affecting pain experience of children and adolescents as compared to older adults. One of the least studied groups of individuals with pain is emerging adults, individuals between the ages of 18-29 years. The limited number of epidemiological surveys focused on this age group has suggested a surprisingly high prevalence of pain in this age group. A lack of understanding and acknowledgement of pain experience in emerging adults may lead to problems of inadequate pain relief and delay in treatment, potentially worsening long-term health outcomes. Preliminary analyses of a qualitative study of college students with chronic or recurrent pain (Kapoor, Thorn, & Eyer, *forthcoming*) suggest a perception of stigmatization because of their pain as well as perceived invalidation of their pain experience. These factors seemed to be additionally influenced by college students' perception of experiencing persistent pain as an off-time life event. The current study aimed to examine pain experience of college students with chronic or recurrent pain and compare them to peers who do not experience pain on a regular basis. It was hypothesized that participants with pain, apart from endorsing higher depressive symptomatology, would report lower satisfaction with life as well as lower physical quality of health. In addition, the association of sociocultural contextual factors such as perceived pain-related stigma and illness invalidation with pain-related variables and psychological variables was analyzed. The results revealed that greater perceived invalidation of pain was

associated with a higher perceived pain-related stigma, lower satisfaction with life, heightened pain perception and catastrophizing, impaired quality of life, as well as greater self-reported depression. Finally, sleep difficulties of the participants with pain as compared to their same age peers were investigated. The results indicated that those with pain reported poorer quality as well as quantity of sleep. Furthermore, for participants with pain, higher self-reported depression was associated with a lower quality of sleep. Clinical implications are discussed.

DEDICATION

To Veer. Through your eyes I am reliving the wonder of ladybugs, Mickey Mouse, and the sweet security that Spiderman has our back. To Mom. Thank you for supporting me through each and every one of my endeavors. Your abiding optimism, sunny outlook, and eternal hopefulness has carried me through my darkest hours. To Papa. I hope that someday I can be as skilled a physician, as compassionate an individual, and as loving a parent as you. Thanks for being there unconditionally, no matter what, why, where, or when. To Prince. Your unwavering belief in my insane ideas is deeply appreciated. So is your humor and sarcasm. It keeps me on my toes. To the memory of my grandparents. I hope to continue your legacy of knowledge, wisdom, and kindness. To Bev. Thank you for being you. I could not have accomplished so much without your constant support, the much needed nuggets of wisdom and cheer, and the ready supply of Kleenex!

To Nitin. You are the best “*Sarathy*” ever, cajoling and occasionally bullying me into keeping my focus on the bird’s eye! Thank you for being my cheerleader as I broke convention, pursued my dreams, and stepped, sometimes apprehensively, on this uncharted path. This would not have been possible without you. Indeed, this would be meaningless without you.

“Every story has an ending. However, in life, every ending is a new beginning” ~Somebody wise

To new beginnings.

LIST OF ABBREVIATIONS AND SYMBOLS

df	Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data
F	Fisher's F ratio: A ratio of two variances
M	Mean: the sum of a set of measurements divided by the number of measurements in the set
p	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
r	Pearson product-moment correlation
<	Less than
=	Equal to
≤	Less than or equal to

ACKNOWLEDGEMENTS

The successful completion of this project was not possible without the generous logistical and intellectual contributions of a number of people. First and foremost, I am grateful to my advisor and Committee Chair, Dr. Beverly E. Thorn, who put in an incredible amount of time and effort to help me develop, execute, and understand this study. I could not have completed this without her guidance, encouragement, and consistent support. I would also like to extend my gratitude to the members of my committee, Drs. Rebecca Allen, Jason DeCaro, Steve Prentice-Dunn, and Natalie Dautovich for their invaluable suggestions, encouraging words, and overall enthusiasm for this study. I always came away with renewed confidence, intellectual invigoration, and happiness after each committee meeting.

I would also like to thank the undergraduate research assistants who cheerfully donated their time and intellectual resources to help collect data for this study and brainstorm with me: Alec Owens, Matthew Anderson, Jane Smith, and Clare Newman. Last, but not at all the least, a big thank you to all those who participated in this study. This would not have been possible without your help and willingness to share your experiences. I hope a future free of pain for you.

CONTENTS

ABSTRACT.....	i
DEDICATION.....	iii
LIST OF ABBREVIATIONS AND SYMBOLS.....	iv
ACKNOWLEDGEMENTS.....	v
LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
INTRODUCTION.....	1
CHAPTER 2: STUDY 1.....	14
CHAPTER 3: STUDY 2.....	32
CHAPTER 4: STUDY 3.....	48
CHAPTER 5: CONCLUSION.....	61
REFERENCES.....	63
APPENDIX A	89
APPENDIX B	115

LIST OF TABLES

1. Demographics, Pain, Psychological Variables, and Emerging Adulthood Dimensions.....	72
2. Correlations between pain variables, psychological variables, and Emerging Adulthood Dimensions.....	73
3. Pain Characteristics of the Pain Group.....	74
4. Multivariate Differences between pain and non-pain groups in terms of psychological well-being.....	75
5. Multivariate Differences between pain and non-pain groups in terms of self-reported quality of life.....	76
6. Multivariate Differences between pain and non-pain groups in terms of the dimensions of emerging adulthood.....	77
7. Demographic, Pain, and Psychological Variables.....	78
8. Correlations between the demographic, pain, and psychological variables.....	79
9. The unstandardized and standardized estimates of the Structural Paths.....	80
10. Squared Multiple Correlations for Dependent Latent Variables in Final Model.....	81
11. Demographics, Pain, Sleep, and Psychological Variables.....	82
12. Multivariate group differences controlling for sex and depressive symptomatology.....	83
13. Bivariate analyses (Pain Group Only).....	84
14. Hierarchical Regression Model Examining Predictors of the Quality of Sleep.....	85

LIST OF FIGURES

1. Initial Measurement Model [Only indicates significant paths ($p < 0.05$)].	86
2. Hypothesized Latent Model.	87
3. Final Latent Regression Model [Only indicates significant paths ($p < 0.05$)].	88

CHAPTER 1

INTRODUCTION

Persistent pain is commonly associated with the aging process, both empirically as well as anecdotally. A plethora of clinical trials and studies have contributed towards identifying and providing efficacious psychosocial therapies for chronic pain in older adults and to some extent, in children and adolescents (Youssef & van Tilburg, 2013; Palermo & Holley, 2013). A recent report by the Institute of Medicine identified children and adolescents as vulnerable populations in regard to pain conditions (Board on Health Sciences Policy, 2011). It was suggested that this younger age group faces disparities due to the lack of acknowledgement and understanding of their pain experience. Indeed, it is likely that the robust association of persistent pain with older adults adds to such disparities. Although it is certainly a positive trend that pain in the very young is being recognized, it is concerning that persistent pain in individuals who are neither adolescents nor full adults, referred to as emerging adults, remains unaddressed.

Emerging adults are people between the ages of 18 and 29 who are transitioning from adolescence to young adulthood. This concept was introduced by Jeffrey Arnett in his landmark paper in the *American Psychologist* (Arnett, 2000). According to the paradigm proposed by Arnett, emerging adulthood is a time of exploration and change gradually leading towards the point where a majority of these young individuals have formed stable and richer self-views as well as world views, and have identified their life goals. Recent research suggests that emerging adults experience subjective feelings of ambiguity, of being in-between adolescence and adulthood (Arnett, 2013). It is plausible then that relative to the

other age groups, these individuals struggle with heightened stress and psychosocial distress due to the major changes happening in their lives.

Emerging adults are the most overlooked and understudied age group in regard to pain conditions. They are typically presumed to be in good health and consequently overlooked as individuals who may experience persistent pain. It is logical to expect that pain catastrophizing, depression, and poor satisfaction with life would be associated with pain experience in emerging adults given their influence on older adults with pain. However, given the distinctness of emerging adulthood in terms of life and health conditions from full adults, it is likely that additional factors affect their pain experience. Due to the paucity of research examining pain in emerging adults, there is a lack of clarity as to the most important variables affecting their pain experience. As a consequence, providing efficacious interventions for emerging adults with persistent pain is lacking. The present study is specifically focused on this age group utilizing them as a purposive sample. It is important to note that, although the proposed recruitment for the study was from a college population, it is not being used as typical convenience sample of college students. Instead, it is being utilized as a purposive sample and being studied precisely because there is virtually no research on persistent pain in emerging adults.

Persistent Pain. According to the International Association for the Study of Pain (IASP), pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (International Association for the Study of Pain, 2012). According to the most widely used pain classifications, pain can be classified as transient, acute, chronic, or recurrent pain (Turk & Okifuji, 2001). Transient pain is possibly the shortest and the least alarming type of pain. It includes the occasional pain one experiences in daily life, for instance, hitting your elbow on

the wall. It rarely needs medical care. Acute pain is generally considered to be alarming, more often than not has a clear organic pathology, is usually temporary, and is often the result of trauma. For example, post-surgical pain, pain due to injuries, and pain due to burns are often classified as acute pains. The person is often able to recover completely in the expected time-frame of recovery. Chronic pain, such as arthritis and fibromyalgia, is considered to be of longer duration than acute pain with less defined underlying pathologies. Acute and chronic pains are sometimes difficult to distinguish because there are no fixed standards on how long pain must continue before it is considered chronic. Some suggest that the criteria for defining chronic pain is any pain that lasts beyond 3-6 months; others suggest that the criteria should be any pain lasting beyond what would be expected given the injury, condition, or disease (Turk & Okifuji, 2001). Most commonly, pain lasting for more than 3 months that causes interference in daily activities is defined as chronic pain. This is used for categorizing chronic pain clinically as well as for research purposes (Turk & Okifuji, 2001; Thorn, 2004). Recurrent pain often shares features of both acute and chronic pain. It is characterized by episodes of pain that is either interfering or disabling alternating with pain-free periods. It is usually defined as episodic pain lasting for a few days in a month and which causes significant interference in daily activities when the person is in pain. Patients who suffer from migraines often report experiencing acute-like pain intermittently or episodically over a lengthy time period (Goadsby, Lipton, & Ferrari, 2002). Recurrent pain often causes psychological distress and cognitive responses similar to those with chronic or constant pain. Indeed, two of the most commonly studied pain types in pain literature (headaches and lower back pain) are generally experienced as recurrent pains. Persistent pain is often used to denote both chronic and recurrent pain.

Persistent pain presents an enormous public health problem with an estimated 100 million American adults experiencing persistent pain. This translates into \$635 billion annual

expenditure in health care, disability, and lost productivity (Board on Health Sciences Policy, 2011). There is a robust association of persistent pain with psychosocial distress, with individuals with pain reporting increased depression, greater catastrophizing, poorer sleep, and lower quality of life (Banks & Kerns, 1996; Sullivan, Thorn, Haythornthwaite, Keefe, Martin, Bradley, & Lefebvre, 2001). Typically, empirical research focused on chronic pain has examined older adults unless the disorders are particularly prevalent during childhood or adolescence.

Psychosocial variables and pain. Pain experience is complex and each person's response to pain differs tremendously based on a variety of psychosocial factors, including cognitions, emotions, social and cultural context, the meaning of pain to the individual, beliefs about pain, as well as biological factors (Turk & Okifuji, 2002). Persistent pain influences all aspects of a person's functioning and lifestyle, including, emotions, interpersonal relationships, work, and physical health. The widely recognized biopsychosocial model of pain supports the assimilative role of biological, social, and psychological in shaping how an individual responds to pain (Turk & Okifuji, 2002). In this regard, empirical inquiry has indicated the importance of pain catastrophizing, depression, and quality of life as some of the variables especially important.

Pain catastrophizing is one of the most studied variables that affect a person's pain experience. Pain catastrophizing involves exaggerated maladaptive cognitions or emotions in response to present or a past pain experience. It is an important pain-influencing construct and is extensively studied in pain literature. Research has shown a robust association of pain catastrophizing with not only greater pain intensity, but also with depression, anxiety, negative affect, activity interference, pain-related disability, employment status, and psychological distress in patients with pain (Cheng & Leung, 2000; Severeijns et al., 2001;

Sullivan et al., 1995; Sullivan, Stanish, Waite, Sullivan, Tripp, 1998; Turner, Dworkin, Mancl, Huggins, Truelove, 2001; Turner, Jensen, Warms, Cardenas, 2002).

The comorbidity of depression and persistent pain is shown to be high although there are no definite estimates of the co-prevalence of these two. Due to methodological variability, the estimates vary largely from 10% to 100% (Pilowsky, Chapman, & Bonica, 1977; Romano & Turner, 1985). Research has shown that depressed patients with pain are often younger, have poorer pain-related outcomes, higher medical costs, and higher disability than those who are not depressed (Arnold et al., 2009; Haythornthwaite, Sieber, & Kerns, 1991; Rudy, Kerns, Turk, 1988). The detrimental role of depression holds true in case of children with evidence indicating that children and adolescents with persistent pain as well as depression report more intense pain and poorer adjustment (King et al., 2011; Piquart & Shen, 2011). In a study examining pain and depression in adolescents, the latter reported higher levels of depression and disability, as well as anxiety (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004). Furthermore, it is not surprising that there is a significant association between pain catastrophizing and depression (Edwards, Cahalan, Mensing, Smith, & Haythornthwaite, 2011). In the study focused on adolescents mentioned above, the emotional distress and depression in the adolescent participants was significantly predicted by pain catastrophizing (Eccleston et al., 2004).

Another important construct in relation to persistent pain is quality of life (QoL). QoL is defined as an individual's appraisal of his or her well-being and functioning in different areas of their life (Niv & Kreitler, 2001). It is described as a subjective, phenomenological, multidimensional, dynamic, and evaluative construct. There is empirical evidence that pain affects most domains of QoL, especially physical and emotional functioning (Gormsen, Rosenberg, Bach, & Jensen, 2010; Huijnen, Kindermans, Seelen, Peters, Smeets, Serroyen, & Verbunt, 2011). QoL is utilized extensively in pain studies as an outcome measure, including

studies evaluating pain in children (Moore, Straube, Paine, Phillips, Derry, & McQuay, 2010; Mullady, Yadav, Amann, O'Connell, Barmada, Elta, & Anderson, 2011; Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). It is believed to be a modifiable variable that is responsive to various treatment modalities, thus, useful in assessing the efficacy of interventions. A related, widely studied construct is satisfaction with life. Satisfaction with life refers to a global feeling of well-being. It is not restricted to just physical or psychological health-related quality of life but is conceptualized as a cognitive judgment of how well one's life is going and how close it is to his or her ideal (Pavot & Diener, 2008). Satisfaction with life has been shown to be a robust indicator of psychological distress in patients across different types of chronic illnesses, for example, cancer, diabetes, and chronic pain (Boonstra, Reneman, Stewart, Post, & Preuper, 2013; Dunn, Ng, Breitbart, Aitken, Youl, Baade, & Chambers, 2013; von Humboldt, Leal, Santos, & Niculescu, 2013; Bjordal, Mastekaasa, & Kaasa, 1995). In addition, research focused on individuals with chronic illnesses has indicated that a person's assessment of his or her satisfaction with life predicted multiple other domains of their life, including psychological, social, and physical well-being (Strine, Chapman, Balluz, Moriarty, & Mokdad, 2008).

Empirical evidence emphasizes the important role of these psychosocial factors in older adult's pain experience. Although it is logical to expect that these are influential across age groups, there may be other factors that are unique to each age group and may have been overlooked. For instance, with increasing focus on pain in children and adolescents, unique factors have been identified that influence a child or adolescent's persistent pain. These include parental experience of pain, maternal catastrophizing, and parents' responses to their child's pain. All these affect a child's pain experience and health care utilization which is quite distinct from an older adult's pain experience. This has helped inform interventions for children and adolescents addressing specific parental variables in addition to other modifiable

pain-related variables (DeGarmo, Reid, Fetrow, Fisher, & Antoine, 2013; Scholten, Willemen, Last, Maurice-Stam, van Dijk, Ensink, E., & Grootenhuis, 2013). Similarly, it is possible that emerging adults' pain experience is influenced by specific factors unique to their stage of life in addition to the usual psychosocial variables.

There is robust evidence that sleep impacts the quality of life and perceived pain and psychological distress in middle-aged and older adults. There is a high comorbidity between sleep difficulties and persistent pain leading to heightened deleterious effects. Given that both sleep problems and persistent pain have been shown to benefit from specifically developed but similar psychosocial interventions, for example, cognitive-behavioral therapy, it may be immensely beneficial to incorporate some parts of sleep interventions while delivering psychosocial pain interventions.

Emerging Adulthood. Individuals between the ages of 18 and 29 years are referred to as emerging adults. Emerging adulthood is conceptualized as a distinct transition phase of life from late teens until adulthood occurs (Arnett, 2001). Arnett (2000), who coined this term, argues that this life stage is distinct from both adolescence and adulthood in terms of subjective experiences, demographics, and most importantly, identity exploration. Although the distinction from adolescence is clearer, emerging adulthood is often confused with young adulthood. Arnett suggests that "young adulthood" is a term more appropriate for people in their thirties. He argues that "young adulthood" suggests that adulthood has already been reached. However, according to empirical evidence, most people in their twenties believe they have not yet reached adulthood (Arnett, 2014). Instead, they believe they are gradually progressing towards adulthood (Arnett, 2013; Arnett & Schwab, 2012). Furthermore, while emerging adults are in the process of obtaining an education and are mostly unmarried, most people in their thirties see themselves as adults and have typically settled on a career (Arnett, 2000, 2001).

Emerging adults and chronic illness. The struggles and changes that occur during emerging adulthood can be immensely challenging and may affect the individual cognitively, behaviorally, and emotionally (Arnett, 2000; Arnett & Tanner, 2006; Nelson & Barry, 2005; Schwartz, Côté, & Arnett, 2005). The emotional and social development during this life stage may, thus, be greatly influenced by the emerging adult's physical and mental abilities. As with any other age group or life stage, it is logical to expect that emerging adults with chronic illnesses are vulnerable to heightened stress (Arnett, 2000; Packman et al., 2012). There is preliminary empirical evidence that emerging adults struggle with unique mental and physical health problems, especially those suffering from chronic illnesses (Richardson, et al., 2012; Bruce & Harper, 2012; Widome, Littman, Laska, & Fu, 2012; Hanna et al., 2013). McCloughen, Foster, Huws-Thomas, & Delgado (2012) conducted a systematic review of literature focused on mental and physical health of individuals between the ages of 16 and 25. They found that there is a high co-morbidity of mental-physical conditions in this age group, including persistent pain, anxiety, depression, psychosis, and respiratory disorders. Additionally, they identified the presence of lifestyle risk factors and poor health behaviors in this age group that will likely lead to cardiovascular and other serious disorders later in life (McCloughen et al., 2012).

Luyckx et al. (2008) provided evidence that there is a positive association between a strong self-identity and decreased diabetes-related problems as well as less depressive symptoms in emerging adults with Type 1 Diabetes Mellitus. Those with a stronger self-concept reported having better coping resources as well as better management of their chronic illness.

There are an extremely limited number of studies examining persistent pain in emerging adults leading to a lack of awareness and knowledge about the extent of the problem in this particular age group. Mallen, Peat, Thomas, & Croft (2005) conducted an

epidemiological survey investigating the prevalence of pain in adults between the ages of 18 and 25. Notably, the prevalence of any pain in the last six months was 66.9% with persistent pain being reported by 14.3% of those surveyed and severely disabling pain being reported by 3.0%. In another survey looking at persistent pain in presumably healthy college students, approximately 25% of the students endorsed experiencing pain of 3 months' duration or more (Thomas, Roy, Cook, & Marykuca, 1992). There is also some empirical evidence suggesting that, similar to older adults, there is a high degree of comorbidity of pain and depression in emerging adults and the negative influence of pain and depression on the coping skills of emerging adults with pain (Ruehlman, Karoly, & Pugliese, 2010). In addition, there is a greater incidence of pain in emerging adults with a positive family history of pain (Hoftun, Romundstad, & Rygg, 2013).

Perceived Stigma, Emerging adults, and Persistent Pain. Persistent pain often does not have a well-defined etiology. Stigma in persistent pain may be related to the attribution of pain to psychosomatic causes, which are thought of as being at least partly under the control of the individual (Marbach, Lennon, Link, & Dohrenwend, 1990). It is, thus, reasonable to expect that individuals with persistent pain will be vulnerable to stigma and the negative psychological and social consequences related to stigmatization. Jackson (2005) describes the experience of persistent pain as a “between or betwixt” state where the patient is neither healthy nor completely sick. They are almost in an ambiguous state. This ambiguity is perceived as a threat to society and its order, giving rise to stigma and alienation (Jackson, 2005). Osborn & Smith (2011) conducted an interpretative phenomenological analysis based on interviews with nine patients with chronic low back pain. The interviewees were adult females over the age of 50. One of the main themes that emerged was “not being believed”. The participants expressed their confusion and frustration at being unable to justify their persistent pain condition and a perceived inability to convey the legitimacy of their pain

experience to family, friends, and health care professionals. This, combined with the internalized stigma for their own pain, led to fear and uncertainty about future and loss of self-identity. Werner & Malterud (2003) interviewed 10 older adult women with chronic musculoskeletal pain about their interactions with their physicians. A majority of them described having negative experiences with their medical providers. They reported modifying their behavior and interaction style so as to convince the doctors' of their symptoms and attract the doctor's attention and interest, and were anxious to not come across as whiners or complainers and have their illness invalidated. They described this as being extremely stressful and anxiety-provoking, threatening their self-esteem and self-concept (Werner & Malterud, 2003). A series of focus groups were conducted with college-attending emerging adults who experienced persistent pain (Kapoor, Thorn, & Eyer, *forthcoming*). It was interesting that perceived stigma emerged as a primary theme and a majority of the participants expressed the hesitation to talk about their pain in the fear of losing friends or being seen as complainers or worriers. This was accompanied by intense feelings of sadness, isolation, and loss of a positive self-concept as well as the inability to live their life as they would like (Kapoor, Thorn, & Eyer, *forthcoming*).

Pain and invalidation. In addition to stigma, emerging adults are likely to experience invalidation. Persistent pain is strongly associated with advanced age and there is a common belief that it is uncommon for people in their twenties to experience pain on a regular basis. It is believed that social norms dictate the timing of major life events in an individual's life (Neugarten, 1976). Research suggests that the events that break these norms and occur out-of-turn or "off-time" are much more stressful than if the same events occur in the expected time frame, in other words, "on-time" events (Rook, Catalano, & Dooley, 1989). Experiencing life events at atypical times compared to same-age peers, can lead to low self-esteem, lower personal competency, psychological distress, as well as loneliness (Rook,

Catalano, & Dooley, 1989). The strong association of pain and advanced age may lead to invalidation of pain in emerging adults leading to persistent pain at this age being strongly perceived as an “off-time” life event. For instance, early loss of one’s spouse, childbirth at an advanced age, or chronic illnesses at a young age, especially if not commonly encountered in that period of life are all considered off-time events. Patients with any kind of chronic illnesses may receive both supporting and rejecting social responses that can influence their physical and mental well-being (Coty and Wallston, 2010; Newsom et al., 2008). Positive social support is linked with better health among patients with pain (Demange et al., 2004; Neugebauer and Katz, 2004; Treharne et al., 2005). Conversely, negative social responses, like discounting and lack of understanding, are related to poorer health among patients with persistent pain (Kool et al., 2010). Such negative and rejecting responses can be referred to as ‘illness invalidation’. Illness invalidation can deplete the individual’s skills in coping with life’s challenges. These challenges can be managing work-related problems, communication problems, and dealing with interpersonal and emotional difficulties. Furthermore, the invalidation of a person’s pain experience and insinuations of malingering and secondary gain can foster intense feelings of guilt, shame and embarrassment. The perceived invalidation or skepticism related to their pain experience may be seen as having their credibility questioned as well as being judged on their moral values. Research has indicated that patients with mental illness had poorer satisfaction and higher psychological distress when they perceived invalidating interactions with their health care providers. In context of persistent pain, such patients may be at greater risk for invalidation due to the relative invisibility of pain. In a study looking at illness invalidation perceived by patients with fibromyalgia and rheumatoid arthritis, higher perception of discounting and lack of understanding was associated with higher psychological distress and impaired social functioning. In addition, discounting was associated with higher physical disability and pain

intensity (Kool, Van Middendorp, Lumley, Schenk, Jacobs, Bijlsma, & Geenen, 2010).

Appropriate and optimal social support can be a key in ensuring the well-being of people with chronic illnesses and invalidation can become a hindrance in this. It is, thus, extremely important to examine the extent of invalidation perceived by emerging adults associated with their pain and how it affects their mental and physical health.

Statement of the problem. Emerging adulthood is an important period of life during which an individual is believed to attain financial and emotional independence, develop a richer self-concept, and establish long-term relationships. Experiencing a chronic illness at this time can become a major barrier in attaining these goals. Persistent pain in emerging adults is an overlooked and understudied area of empirical inquiry. It is logical to expect that psychosocial factors affecting the pain experience in older adults such as depression and pain catastrophizing will play a similar role in emerging adults. Additionally, it is likely that factors like illness invalidation and pain-related stigma influence the pain experience in both older adults and emerging adults. However, it is also likely that they do so to a greater extent in emerging adults and are more relevant for them than older adults but very little is empirically known about their role. In addition, there is a lack of clarity as to how the stress of a chronic illness affects self-identity, depression, physical quality of life, and satisfaction with life in emerging adults when compared to same age peers who do not experience pain regularly. In the future, this information would aid in designing relevant psychosocial interventions for individuals experiencing persistent pain in this developmental stage.

The present project aimed to examine the role of stigma and illness invalidation on the pain experience of emerging adults with persistent pain above and beyond that of established pain-influencing variables such as pain catastrophizing and depression, which have been previously shown to affect the pain experience in older populations. Second, the project aimed to analyze the differences between emerging adults with pain to same-age

peers who do not experience regular pain in terms of identity formation, depression, and health-related quality of life. Third, the association of sleep disturbances, psychological distress, and persistent pain in emerging adults was examined.

CHAPTER 2

STUDY 1

Persistent pain is a major public health problem (Blyth, March, Brnabic, & al., 2006). Pain chronicity accounts for significant disability as well as complex psychological, physical, and socioeconomic losses (Turk & Okifuji, 2002). Given the strong clinical and anecdotal association of pain with aging, persistent pain has been historically studied and discussed in context of older adults. Emerging research, however, indicates that persistent pain is a major health challenge in pediatric populations as well (Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). A report by the Institute of Medicine identified children and adolescents as vulnerable populations in relation to pain conditions (Board on Health Sciences Policy, 2011). It was emphasized that these younger age groups face disparities due to a lack of understanding, and perhaps acknowledgment, of their pain experience.

Such administrative efforts and increasing attention by policy makers have helped spur empirical inquiry into the pain experience of children and adolescents. However, very few studies have included or focused on emerging adults (individuals between the ages of 18 and 29). Consequently, there is a lack of awareness about the extent of pain-related problems in this population. It is important to note that the limited number of studies examining persistent pain in emerging adults have found a considerable prevalence of persistent pain in this population. Mallen, Peat, Thomas, & Croft (2005) conducted an epidemiological survey investigating the prevalence of pain in emerging adults between the ages of 18 and 25. Persistent pain was reported by 14.3% while 3.0% reported severely disabling pain. In another survey investigating persistent pain in presumably healthy college students,

approximately 25% of the participants endorsed experiencing pain for 3 months or more (Thomas, Roy, Cook, & Marykuca, 1992). The limited number of studies examining specific pain conditions in young adults, such as, sickle cell disorder related pain and functional abdominal pain have indicated compromised psychosocial and physical functioning, disability, as well as heightened distress akin to older adults (Paananen et al., 2011).

Emerging adulthood is a critical period of life during which an individual is believed to attain financial and emotional independence, develop a richer self-concept, and establish long-term relationships (Arnett, 2001). Experiencing persistent pain during this period is a potential barrier in attaining these life goals and the salient developmental features of emerging adulthood, namely, formation of a sound self-identity, having a range of possibilities for the future, and seeking stability in life. Struggling with a chronic illness at this time, including persistent pain, potentially leads to a hindrance in the development of a stable self-concept, which is critical for coping with and self-managing chronic illness (Luckyx, 2011). Moreover, persistent pain can also limit the perception of future possibilities and increase the feelings of instability.

The widely recognized biopsychosocial model of pain supports the assimilative role of the above-discussed biological, social, and psychological variables in shaping how an individual responds to pain (Turk & Okifuji, 2002). A body of evidence has corroborated the significance of pain catastrophizing, depression, and quality of life associated with pain experience across a variety of clinical settings and populations (Cheng & Leung, 2000; Severeijns et al., 2001; Sullivan et al., 1995; Sullivan, Stanish, Waite, Sullivan, Tripp, 1998). Pain catastrophizing refers to exaggerated maladaptive cognitions or emotions in response to a present, past, or anticipated pain experience. Research has corroborated a robust association of pain catastrophizing with greater pain intensity, depression, negative affect, activity interference, and pain-related disability (Cheng & Leung, 2000; Severeijns et al., 2001;

Sullivan et al., 1995; Sullivan, Stanish, Waite, Sullivan, Tripp, 1998; Turner, Dworkin, Mancl, Huggins, Truelove, 2001; Turner, Jensen, Warms, Cardenas, 2002). Pediatric research has suggested that children and adolescents with persistent pain are more likely to report greater depressed mood, more intense pain rating, higher disability, and poorer adjustment (King et al., 2011; Piquart & Shen, 2011). Furthermore, akin to older adults, emotional distress and depression in adolescents is significantly predicted by pain catastrophizing (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004).

The present study was focused on emerging adults experiencing persistent pain. The study included a comparison with same-age peers who did not report persistent pain, in relation to self-reported depression, dispositional pain catastrophizing, satisfaction with life, quality of life, and the different dimensions of emerging adulthood. It was hypothesized that emerging adults with pain would report greater depression and catastrophizing. In addition, it was hypothesized that emerging adults with pain would report lower satisfaction with life as well as lower quality of life. Lastly, those with persistent pain would struggle more with forming a stable self-identity, reporting a greater perception of instability and decreased sense of potential future possibilities. It is important to note here that even though the recruitment for the study was done from within a college population, they were not utilized as a typical convenience sample. Instead, they were utilized as a quasi-purposive sample given the focus population for the study.

Method

Participants

Data were obtained from 301 emerging adults in college. This included emerging adults with persistent pain (N=185) and those without pain (N=116). They were recruited from the Introductory Psychology classes and received credit towards their course requirements for participation. Participants with and without self-reported pain were recruited

for the study. Additionally, in keeping with the age range of emerging adulthood, participants between the ages of 18 to 29 years were included in the study. A participant pool of 301 provides sufficient power (0.90) to find a medium effect size with $p = .05$ (Cohen, 1988). It is important to note that this data was collected as part of a larger study examining pain in emerging adults. As such, the two groups do not reflect the actual proportion of participants experiencing persistent pain in the population from which they were drawn. To fulfill the aims of the larger study, differential recruiting was done to recruit a higher number of emerging adults with pain. The study was approved by the University of Alabama Institutional Review Board.

Procedure

The study was listed and open to participation on the University of Alabama Introductory Psychology Subject Pool website. The students taking the Introductory Psychology classes were required to either complete papers or participate in research studies to receive credit in their course. The students had the choice to sign up for any of the available studies. Thus, they self-selected to participate in this study. Once they signed up, they were administered the questionnaire packet on the designated time and day. At the beginning of the study, the researchers explained the requirements of the study and obtained a signed informed consent from the participants. Once the participant had provided consent, he or she was asked to complete the measures described below. Upon completion of the questionnaires, a debriefing was conducted to respond to any questions the participants may have had.

Measures

Demographics and Pain Survey. A demographics and pain survey designed for the study was used to obtain sex, age, race/ethnicity, relationship status, employment status, and year of study in college. In addition, the participants completed questions pertaining to the

intensity of their pain in the last 7 days as well as duration, type, and interference of pain over the past one week.

Pain Catastrophizing Scale (PCS). The PCS was used to measure pain catastrophizing (Sullivan et al., 1995). Pain catastrophizing involves exaggerated maladaptive cognitions or emotions in response to present or a past pain experience. It is a significant construct studied extensively in pain literature and has been found to be associated with not only greater pain intensity, but also to depression, anxiety, negative affect, activity interference, pain-related disability, employment status, and psychological distress in patients with chronic pain (Cheng & Leung, 2000; Severeijns et al., 2001; Sullivan et al., 1995; Sullivan, Stanish, Waite, Sullivan, Tripp, 1998; Turner, Dworkin, Mancl, Huggins, Truelove, 2001; Turner, Jensen, Warm, Cardenas, 2002). There is robust empirical evidence that pain catastrophizing predicts negative pain-related outcomes, both in clinical and non-clinical study populations (Edwards, Cahalan, Mensing, Smith, & Haythornthwaite, 2011; Westman, Boersma, Leppert, & Linton, 2011; Tsao, Allen, Evans, Lu, Myers, & Zeltzer, 2009). The PCS is a 13-item measure asking respondents to rate the extent to which they have particular thoughts and emotions when they experience pain. The PCS measures catastrophizing on three dimensions, namely, magnification, rumination and helplessness and the total score for catastrophizing is the sum of the raw scores. Higher scores indicate greater catastrophic thinking related to pain. This scale was shown to have a high internal consistency of .87 in clinical and non-clinical populations in the original validation study (Sullivan et al., 1995). The total scores on this scale were used in the first MANOVA to ascertain group differences in cognitive and psychological well-being. The Cronbach's alpha for the present sample was excellent (0.92).

The Center for Epidemiological Studies Depression Scale (CES-D). The CES-D was used to assess depressive symptomatology in the participants. There is a robust

association of coexisting depression and persistent pain and the association between the two is well-established (Fishbain et al., 1997). Indeed, it is found that depression is more common among pain patients than the general population but notably many pain patients are not treated for the depression they experience (Sullivan et al., 1992). In addition, the patients with persistent pain who report concurrent depression have poorer clinical outcomes than those who do not. It is possible that depression compromises a person's coping resources, thus worsening the pain experience. This is a 20-item questionnaire where the respondents rate the frequency with which each item occurred over the previous week. The total score is obtained by summing up the scores on each item with 4 items being reverse scored. Higher scores indicate greater depression. The CES-D has high internal consistency, adequate test-retest reliability, and convergent as well as discriminant validity (Radloff, 1977).

Furthermore, CES-D has been validated for use in patients with persistent pain (Turk & Okifuji, 1994). The scores on this scale were used in the first MANOVA to ascertain group differences in the cognitive and psychological well-being. The Cronbach's alpha for the present sample was high (0.88).

Satisfaction with Life Scale (SWLS). The SWLS is a 5-item scale designed to measure global life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985). Satisfaction with life is conceptualized as a cognitive judgment of well-being (Diener, 1985). It is an overall impression of a person's perceived well-being and satisfaction with where he or she is in life. It is widely used to measure general well-being, including individuals with persistent pain, and validated in patients with persistent pain (Jensen et al., 1991). The total score is obtained by summing the scores on the 5 items. Higher scores indicate greater satisfaction with life. In the original scale development and validation study, the SWLS demonstrated good test-retest reliability over a 2-month period (.82) and excellent internal consistency (.87). SWLS has demonstrated good internal consistency ($r=0.8$) in a persistent pain sample. The scores on this

scale were used in the first MANOVA to ascertain group differences in the cognitive and psychological well-being. The Cronbach's alpha for the present sample was high (0.87).

Inventory of the Dimensions of Emerging Adulthood (IDEA). IDEA measures the 5 dimensions of emerging adulthood. Psychometric analyses suggested 5 primary dimensions (identity explorations, experimentation/possibilities, negativity/instability, self-focus, and feeling in-between) and one counterpart (other-focus). It encompasses themes of transition-to-adulthood (Reifman, Arnett, & Colwell, 2007). Internal consistency was between 0.80 and 0.85 across 5 validation studies. Adequate test-retest reliability has also been demonstrated. In the original validation study, people across all age groups, from adolescence to older adults, completed the IDEA scale. Not surprisingly, it was found that the emerging adulthood dimensions were overwhelmingly endorsed by people in the ages between 18 and 29. Except for a difference in marital status, with non-college attending emerging adults more likely to be married, college and non-college respondents were largely similar in demographics. Across the 5 validation studies, no differences were found across sex, race, and class in the emerging adults' sample. In addition, it was found that the emerging adults who scored higher on identity exploration reported greater satisfaction with life. The scores on the Self-Focus, Possibilities, Self-Identity, and Negativity were used in the third MANOVA to ascertain group differences. The Cronbach's alphas for the different dimensions ranged from 0.86-0.87 for the present sample.

World Health Organization Quality of Life-Brief (WHOQOL-BREF). The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100 quality of life assessment (World Health Organization, 1996; Skevington, Lotfy, & O'Connell, 2004). It was developed to be used for field work by the WHO field workers. It provides scores for four domains of quality of life, namely, physical health, psychological health, social relationships and environment. Additionally, it includes one item on overall quality of life

and one on overall health. Higher scores indicate greater satisfaction with life or health and higher quality of life. For the validation studies, cross-sectional data was collected from adults from 23 countries. Both sick and well respondents were included in the study. This included patients with primary and secondary complaints of pain and patients with physical and mental disorders. WHOQOL-BREF domains have demonstrated good internal consistency ($\alpha > 0.80$) and good test-retest reliability. The domains from this scale were used in the second MANOVA to examine differences in the two groups for Quality of Life. The Cronbach's alpha for the present sample for the four domains of quality of life was high (0.87-0.90).

Data Analysis

Basic descriptive analyses were examined and reported in Table 1. Frequencies with corresponding percentages were analyzed for categorical variables while means and standard deviations were used for continuous variables. In addition, for the participants with pain, means were calculated for pain intensity over the past week, number of days with pain over the past month, and perceived pain interference. Also as part of the preliminary analyses, for each of the MANOVAs, the correlations between the variables of interest were investigated to ensure that they were in the medium range. To examine group differences (pain group versus non-pain group), a series of multivariate analyses of variance (MANOVAs) were conducted. In the first MANOVA, group differences between cognitive and psychological well-being, namely, self-reported pain catastrophizing, depression, and satisfaction with life, were examined. The second MANOVA examined group differences in self-reported quality of life utilizing the four domains of the WHOQOL-BREF scale (physical, psychological, social, and environmental). Lastly, the third MANOVA analyzed the dimensions of emerging adulthood comparing the pain group to the non-pain group. As part of the analyses, it was confirmed that the assumptions of sample size, normality, outliers, linearity, homogeneity of

regression, and multicollinearity were not violated. The Box's M Test of Equality of Covariance Matrices were above 0.001 for the three MANOVAs.

Results

Descriptive Analyses

The demographic characteristics, psychological variables, quality of life, and data pertaining to the dimensions of emerging adulthood for the study sample are presented in Table 1. For the overall study (N=301), the sample was primarily female (N=230; 76.4%) and Non-Hispanic Whites (N=253; 84.1%). Comparisons between the pain group (N=185) and the non-pain group (N=116) indicated no statistically significant differences in age and sex. See Table 1. A preliminary bivariate analysis confirmed that the dependent variables in each of the three MANOVAs were correlated at a medium level, appropriate for employing them in the multivariate analyses. See Table 2. Also see Table 3 for a description of pain-related variables of those with self-reported persistent pain.

MANOVA 1: Group differences in psychological well-being.

MANOVA analysis (Wilk's Lambda) demonstrated a significant effect of the group (pain versus non-pain group) in relation to self-reported depression, pain catastrophizing, and satisfaction with life, Wilk's lambda=0.829, $F(3,288)=19.882$, $p<0.001$, $\eta^2=0.171$. The results revealed that emerging adults with self-reported persistent pain had significantly higher pain catastrophizing [$F(1,292)=30.221$, $p<0.001$, $\eta^2=0.094$]; greater depressive symptomatology [$F(1,292)=39.275$, $p<0.001$; $\eta^2=0.119$]; and lower satisfaction with life [$F(1,292)=14.48$, $p<0.001$, $\eta^2=0.05$]. The effect size was large. See Table 4.

MANOVA 2: Group Differences in Quality of Life

MANOVA analysis (Wilk's Lambda) demonstrated a significant effect of the group (pain versus non-pain group) for the four different domains on the WHOQOL scale, namely, physical health, psychological health, social, and environmental quality of life, $F(4,288)=5.756, p<0.001, \eta^2=0.074$. The pain group reported a poorer perception of quality of life across all the four domains, including, physical health [$F(1,291)=4.177, p=0.042, \eta^2=0.014$]; psychological health [$F(1,291)=11.642, p=0.001, \eta^2=0.038$]; social [$F(1,291)=6.701, p<0.001, \eta^2=0.023$]; and environmental quality of life [$F(1,291)=19.192, p<0.001, \eta^2=0.062$]. The effect size was in the small (0.02) to medium range (0.06). See Table 5.

MANOVA 3: Group Differences in the Dimensions of Emerging Adulthood

MANOVA analysis (Wilk's Lambda) demonstrated a significant effect of the group (pain versus non-pain group) on the four dimensions of emerging adulthood, Wilk's Lambda=0.954, $F(4,283)=3.374, p=0.01, \eta^2=0.05$. Furthermore, the results indicated that emerging adults with self-reported persistent pain had significantly higher perception of instability in their life [$F(1,286)=5.081, p=0.025, \eta^2=0.02$] as well as a heightened focus on self [$F(1,286)=6.199, p=0.013, \eta^2=0.021$]. There were no significant differences in the development of self-identity [$F(1,286)=1.118, p=0.291, \eta^2=0.004$] and perception of possibilities [$F(1,286)=2.809, p=0.095, \eta^2=0.01$] between the two groups. The effect size was small (<0.02). See Table 6.

Discussion

The results of the present study provide insight into the pain experience of emerging adults, a subset of population that is largely unstudied in relation to persistent pain. The findings revealed that persistent pain was associated with multifaceted and wide-ranging detrimental psychosocial and emotional development outcomes. Emerging adults with pain

reported impaired quality of life, greater depression, and higher catastrophic cognitions in relation to pain. Additionally, they reported perceiving greater instability and negativity in life while simultaneously perceiving themselves as having taken on more responsibilities and being more autonomous. The study thus presents findings consistent with the adult and older adult pain psychology literature in terms of psychosocial impairment and extends the current literature by examining the impact of persistent pain on the psychological developmental aspects emerging adulthood (Turk & Okifuji, 2002).

Furthermore, the findings of the present study are consistent with the evolving empirical evidence suggesting that, similar to older adults, there is an association between pain, depression, and quality of life in emerging adults (Ruehlman, Karoly, & Pugliese, 2010). Based on the results, it is evident that the psychosocial impact of pain is broadly equivalent irrespective of the age of the patient with pain. Given that emerging adults in general are vulnerable to heightened psychological distress and mental health problems (increased suicidality, psychotic breaks, and depression) during these years, experiencing persistent pain is a significant additional stressor likely worsening the outcomes. Also, individuals who report pain during childhood or early adulthood but fail to receive adequate treatment during that time, experience pervasive pain problems into their adulthood (Brattberg, 2004). Indeed, it has been found that emerging adults with chronic illnesses endure negative trajectories in terms of depressive symptomatology and quality of life as compared to healthy same-age peers (Ferro, 2014). Raposa, Hammen, Brennan, O'Callaghan, & Najman (2014) found that childhood adversity, including childhood and adolescence chronic illness, predicted long-term detrimental physical and mental health outcomes extending into emerging adulthood. The authors also noted that such individuals were more likely to have interpersonal problems and suboptimal living conditions due to poor social support, poor mental health as well as reduced access to care (Raposa et al. 2014).

There is an increasing interest in examining the salient characteristics of emerging adulthood pertaining to interpersonal and romantic relationships, religiosity, and social media use (Abo-Zena & Ahmed, 2014; Bond & Drogos, 2014). It is interesting to note that the emerging adulthood literature pertaining to health is primarily focused on more readily apparent issues, including, substance use, high risk behaviors, and sexual health behaviors (Bersamin et al., 2014; Mashhoon et al., 2014). This is perhaps, in part, due to the higher prevalence and also in part attributable to the widely prevalent stereotypes pertaining to individuals in this age group (Arnett, 2006; Twenge, 2013). Although there is a very gradual shift towards examining the impact of chronic health conditions such as diabetes, sickle cell disease, and cardiovascular health, persistent pain in this population has not garnered much attention. This is not surprising given that emerging adults are typically presumed to be in good health and as a result overlooked as individuals with disabling long-term pain.

Despite the similarities between the experience of pain in emerging adults and other clinical populations, there are unique aspects associated with health and well-being in this young population. According to Arnett, emerging adults experience negative aspects of the transition given that change and the necessity to make multiple decisions can be overwhelming (Robbins & Wilner, 2001). Consistent with the initial hypothesis of the study, the results indicated that the participants with persistent pain reported significantly greater perception of instability and negativity. A number of factors may contribute to this feeling of negativity, such as, stress of coping with pain on a regular basis, navigating the adult health care system, and interference of pain in achieving life goals. It is interesting though that emerging adults with pain perceived themselves to possess a greater self-focus. Self-focus refers to becoming more independent and taking on responsibility for oneself as the transition is made from adolescence into adulthood. It is also described as a time when an individual develops the knowledge, skills, and self-understanding that leads to greater self-reliance. It is

plausible that those with persistent pain develop self-focus quicker than his or her peers to maintain his or her health despite the pain.

It is noteworthy that there were no significant group differences in relation to self-identity and perception of possibilities and optimism. Although it is too preliminary to deduce definite conclusions through a single study, the findings are encouraging such that the emerging adults with persistent pain appeared to be resilient in terms of developing a stable self-concept. Moreover, it has been shown that a stable sense of self provides protection against the detrimental effects of chronic illnesses in this age group. Luyckx et al. (2008) provided evidence that there is a positive association between a strong self-identity and decreased diabetes-related problems as well as less depressive symptoms in emerging adults with Type 1 Diabetes Mellitus. It was indicated that those with a stronger self-concept reported having better coping resources as well as better management of their chronic illness. However, the results of the present study revealed that for emerging adults with pain, there was no link between a strong self-concept and catastrophizing or depressive symptomatology. Further studies should further explore this link to better understand the trajectory of persistent pain in relation to the emotional development during emerging adulthood.

In comparison to the normative data obtained in other studies focused on US college students, the healthy participants in the present study presented as less depressed ($M=16.70$ vs $M=11.37$) while those with pain in the present sample reported higher depression ($M=16.70$ vs $M=17.99$) (Daughtry & Kunkel, 1993). It is also noteworthy that the emerging adults with pain reported poorer quality of life on three domains, namely, physical, psychological, and social corroborating the psychological distress associated with long-standing pain (Hawthorne, 2006; Skevington, 2010). In respect to satisfaction with life, for the present study sample, both the groups obtained slightly higher scores than the normative

scores of US college students (Diener, 1993). One of the problems in interpreting and understanding this disparity is the datedness of the normative data. It was obtained in the 1990s and may not be truly comparable to the data obtained recently.

In conclusion, the present study aims to acknowledge, encourage, and facilitate empirical inquiry into the pain experience of emerging adults. It is critical to fully understand the complex, chronic, and perhaps irreversible repercussions associated with the undertreatment of pain in emerging adulthood. There is robust evidence suggesting a significant deterioration of health and decreased access to services in the early to mid-twenties compared to adolescence. A report by the Centers for Disease Control has highlighted that more than any other age group, including adults older than 75 years, emerging adults are most likely to be uninsured as well as being the highest utilizers of emergency department services and report the lowest number of contacts with primary care physicians (Fact Sheet-Health Care Disparities and Inequalities Report-US 2011). This was attributed to losing parental insurance coverage, inability to successfully navigate the adult health care system, as well as a variety of sociocultural factors. Indeed, except the Affordable Care Act (2010) that extends health insurance coverage for emerging adults aged 25 on their parents' policies, most of the health care initiatives are primarily geared towards improving health care for children and adolescents (Fact Sheet-Health Care Disparities and Inequalities Report-US 2011). Given that the presence of persistent pain necessitates consistent quality health care, these trends are indeed worrisome.

Limitations and future studies: The present study has limitations that necessitate consideration. This is a cross-sectional study thus it is difficult to establish causality. In addition, as is common, the study was limited by the number of variables examined. It is possible that there are additional factors that affect pain experience in this population and need to be examined in future studies. Furthermore, the sample was obtained from a college

population, which may limit its generalizability to emerging adults who do not attend college or may have dropped out. Future studies should include community samples of emerging adults to better understand the relationship between pain and psychosocial variables.

Conclusion

The struggles and changes that occur during emerging adulthood can be immensely challenging and affect the individual cognitively, behaviorally, and emotionally (Arnett, 2000; Arnett & Tanner, 2006; Nelson & Barry, 2005; Schwartz, Côté, & Arnett, 2005). Experiencing persistent pain during this critical developmental phase of life further augments the psychological distress and impairment in perceived quality of life. It is vital to empirically and clinically understand the pain experience of this population to provide quality treatment and help them achieve their potential despite the presence of such chronic illnesses. According to WHO, interventions should be accessible and acceptable to the patient. In relation to young adults with chronic illnesses, such as persistent pain, providing interventions that are sensitive and acceptable is of utmost importance. There is an increasing emphasis on recognizing the health needs of emerging adults and indeed a recent report by the Institute of Medicine (IOM) and Healthy People 2000 proposed the need to study emerging adults as a distinct group. In a health care system heavily geared towards treating and interacting with older patients or the very young, young adults are heavily underserved. Thus, it is important to engage emerging adults with chronic illnesses in the health care system and provide timely interventions to promote positive long-term health outcomes. Towards this end, group psychosocial interventions provide a valuable avenue to engage this population in treatment. In addition to providing cognitive skills to cope with long-standing pain, the social support such interventions offer would be particularly useful for emerging adults and help in reducing isolation and withdrawal.

The present examination brought to light the substantial detrimental impact of persistent pain in emerging adulthood. The results indicate the emotional suffering endured by emerging adults while coping with their pain and at the same time potentially trying to keep up with their healthy same-age peers. During this early phase of life, being able to lead a socially productive life is an important part of an individual's development. This issue logically leads to the second study, which examined the contextual sociocultural factors that affect the well-being of emerging adults with persistent pain. In the context of pain, there can be a wide range of social responses which can be both positive and negative. Although, pain literature focused on older adults' has indicated the role of spousal and physician responses in the older adults' lived experience of pain, not much is known about the social needs of emerging adults. It is important to understand the influence of social processes such as illness invalidation and stigmatization to better understand and address the needs of this population.

Table 6. Multivariate Differences between pain and non-pain groups in terms of the dimensions of emerging adulthood

Dependent variable	df	df Error	Mean Square	F	Mean	p	Partial Eta Squared	
Identity	1	291	5.142	.913	Pain	3.64	.340	.003
					Non-Pain	3.68		
Possibilities	1	291	8.082	2.045	Pain	3.58	.154	.007
					Non-Pain	8.65		
Instability	1	291	56.218	4.802	Pain	2.91	.029	.016
					Non-Pain	2.78		
Self-focus	1	291	21.045	5.410	Pain	3.55	.021	.018
					Non-Pain	3.65		

df: Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data ; F: Fisher's F ratio; Identity: Identity dimension of emerging adulthood; Poss: Possibilities dimension of emerging adulthood; Instability: Instability dimension of emerging adulthood; Self: Self-focus dimension of emerging adulthood.

CHAPTER 3

STUDY 2

Sociocultural factors exert a significant impact on the lived experience of an individual with chronic illness (Joachim & Acorn, 2000; Earnshaw & Quinn, 2012). Contextual social variables such as stigma and illness invalidation, perpetuate detrimental outcomes in individuals or social groups anticipating, experiencing, or internalizing such responses (Earnshaw & Quinn, 2012; Wahl, 2012). Extant literature links stigmatization with suboptimal life opportunities, chronic stress, and social disqualification (Katz, 2014; Becker & Arnold, 1986). Certain illnesses invoke stigma as well and health-related stigma acts as a substantial barrier to help-seeking and treatment adherence, potentially worsening clinical course and outcomes (Vanable, Carey, Blair, & Littlewood, 2006; Link & Phelan, 2006). Persistent pain is increasingly being recognized as a stigmatizing health condition (Jackson, 2005). Pain lasting beyond the expected time of healing and without an obvious etiology leads to disbelief and suspicion from health care providers as well as family and friends (Kool et al., 2011). Furthermore, persistent pain is often attributed to psychosomatic causes believed to be partly under the control of the individual (Marbach, Lennon, Link, & Dohrenwend, 1990).

Phenomenological inquiries have provided rich empirical support indicating the deleterious impact of negative social responses on an individual's experience with pain. Illness invalidation or "not being believed" and stigmatization have emerged as critical themes from the patients' narratives of lived experience with long-standing pain. Werner & Malterud (2003) interviewed 10 older adult women with chronic musculoskeletal pain. A majority of them described having negative experiences with their medical providers and the

need to modify their pain behaviors and interaction style so as to convince the doctors' of their symptoms. The patients discussed their anxiety of coming across as "complainers" and consequently suffering unhelpful and invalidating responses. The participants also expressed their confusion and frustration at having to justify their persistent pain condition and a perceived inability to convey the legitimacy of their pain experience to family, friends, and health care professionals.

It is believed that social norms influence the timing of major life events in an individual's life (Neugarten, 1976). Research suggests that the events that occur out-of-turn or "off-time" are much more stressful than those occurring in the expected time frame or "on-time" (Rook, Catalano, & Dooley, 1989). As a life event, persistent pain is strongly associated with advanced age. Emerging adults are believed to be in the prime of their health and expected to fulfill a variety of roles at home, school, and work. Furthermore, this period of life is strongly associated with the ability to recover quickly from acute illnesses and is not commonly associated with chronic health conditions such as persistent pain. Thus, experiencing persistent pain in emerging adulthood, a period where an individual is expected to be at their prime, can lead to accentuated stigmatization and invalidation and is linked to low self-esteem, lower personal competency, psychological distress, and loneliness (Rook, Catalano, & Dooley, 1989).

Patients with persistent pain may receive both supporting and rejecting social responses that can influence their physical and mental well-being (Coty and Wallston, 2010; Newsom et al., 2008). Positive social support is linked with better health among patients with pain (Demange et al., 2004; Neugebauer and Katz, 2004; Treharne et al., 2005). In context of persistent pain, patients are at a greater risk for invalidation due to the relative invisibility of pain. Appropriate and optimal social support can be a key in ensuring the well-being of such individuals. Conversely, negative social responses, like discounting and lack of

understanding, are related to poorer health among patients with persistent pain (Kool et al., 2010). Such negative and rejecting responses are referred to as 'illness invalidation'. Illness invalidation can dwindle the individual's skills in coping with life's challenges. The perceived invalidation or skepticism related to their pain experience may be seen as having their credibility questioned as well as being judged on their moral values (Blom et al., 2012). A combination of illness invalidation from the work environment and helplessness is associated with embitterment in patients with FM. *Rheumatology*, 51(2), 347-353.). In a study looking at illness invalidation perceived by patients with fibromyalgia and rheumatoid arthritis, higher perception of discounting and lack of understanding was associated with higher psychological distress and impaired social functioning. In addition, discounting was associated with higher physical disability and pain intensity (Kool, Van Middendorp, Lumley, Schenk, Jacobs, Bijlsma, & Geenen, 2010). Appropriate and optimal social support can be a key in ensuring the well-being of people with chronic illnesses and invalidation can be a significant hindrance. It is, thus, extremely important to examine the extent of invalidation perceived by emerging adults associated with their pain and its impact on their mental and physical health.

The present study aimed to examine the association of perceived stigmatization and illness invalidation on emerging adults' emotional well-being as well as quality of life. It was hypothesized that perceived stigma and pain invalidation would be associated with lower emotional well-being (lower satisfaction with life and greater depressive symptomatology), higher perceived pain intensity and catastrophizing, and an impaired quality of life (physical, social, and environmental). It is important to note that, although the proposed recruitment for the study was from a college population, they were not being used as a typical convenience sample of college students. Instead, they were utilized as a quasi-purposive sample and were the population of interest for the study.

Method

Participants

The study included 185 emerging adults in college with self-reported persistent pain. The participants were drawn from the Introductory Psychology classes. The present study is part of a larger study that enrolled participants irrespective of the presence or absence of self-reported pain. For the present study, the inclusion criteria included the self-report of persistent pain. The latter referred to pain experienced on most days in a month over the past three months or pain on more than 4 days in a month over the past three months severe enough to cause interference in daily activities. The participants received credit towards their course for completing the study. The participants self-opted to participate in the study and had other options available to them if they chose not to participate in this study. Inclusion criteria included the presence of pain on most days in a month over the past three months or pain on more than 4 days in a month over the past three months severe enough to cause interference in daily activities. In keeping with the age range of emerging adulthood, participants between the ages of 18 to 29 years were recruited and included.

Procedure

The study was included in the studies available on the University of Alabama Introductory Psychology Subject Pool website. The students taking the Introductory Psychology classes were required to either complete papers or participate in research studies to receive credit towards their course. The students had the choice to sign up for any of the available studies. Thus, they self-selected to participate in this study. Once they signed up, they were administered the questionnaire packet on the chosen time and day. At the beginning of the study, the researchers explained the requirements of the study and obtained a

signed informed consent from the participants. Once the participant had provided consent, he or she was asked to complete the measures described above. Upon completion of the questionnaires, a debriefing was conducted to respond to any questions the participants may have had.

Measures

Demographics and Pain Survey. A demographics survey designed for the study was used to obtain sex, age, race/ethnicity, year of study in college, and relationship status of the participants. In addition, the participants completed questions pertaining to the intensity of their pain in the last 7 days and number of days that pain was experienced over the past 90 days.

Pain Catastrophizing Scale (PCS). The PCS was used to measure pain catastrophizing (Sullivan et al., 1995). Pain catastrophizing involves exaggerated maladaptive cognitions or emotions in response to present or a past pain experience. There is robust empirical evidence that pain catastrophizing predicts negative pain-related outcomes, both in clinical and non-clinical study populations (Edwards, Cahalan, Mensing, Smith, & Haythornthwaite, 2011; Westman, Boersma, Leppert, & Linton, 2011; Tsao, Allen, Evans, Lu, Myers, & Zeltzer, 2009). The PCS is a 13-item measure asking respondents to rate the extent to which they have particular thoughts and emotions when they experience pain. The PCS measures catastrophizing on three dimensions, namely, magnification, rumination and helplessness and the total score for catastrophizing is the sum of the raw scores. Higher scores indicate greater catastrophic thinking related to pain. This scale was shown to have a high internal consistency of .87 in clinical and non-clinical populations in the original validation study (Sullivan et al., 1995). It is the most widely used and well-validated measure of pain catastrophizing. The Cronbach's alpha for the study population indicated excellent reliability ($r=0.90$).

The Center for Epidemiological Studies Depression Scale (CES-D). The CES-D was used to assess depressive symptomatology. There is robust evidence supporting the substantial comorbidity of depression and persistent pain (Fishbain et al., 1997). Indeed, it is found that depression is more common among pain patients than the general population (Sullivan et al., 1992). The patients with persistent pain who report concurrent depression have poorer clinical outcomes than those who do not. The CES-D is a 20-item questionnaire where the respondents rate the frequency with which each item occurred over the previous week. The total score is the sum of the item scores. Higher scores indicate greater depression. The CES-D has high internal consistency, adequate test-retest reliability, and convergent as well as discriminant validity (Radloff, 1977) and the CES-D has been validated for use in patients with persistent pain (Turk & Okifuji, 1994). CES-D has been used in college populations with good results, and can successfully diagnose clinical depression in accordance with the Diagnostic and Statistical Manual-IV (DSM-IV) (Sprinkle, Lurie, Insko, Atkinson, Jones, Logan, & Bissada, 2002). The Cronbach's alpha for the study population was excellent ($r=0.89$).

Satisfaction with Life Scale (SWLS). The SWLS is a 5-item scale designed to measure global life satisfaction (Diener, Emmons, Larsen, & Griffin, 1985). Satisfaction with life is conceptualized as a cognitive judgment of well-being (Diener, 1985). It is an overall impression of a person's perceived well-being and satisfaction with where he or she is in life. The SWLS is not used for the measurement of specific satisfaction domains (e.g. health, energy) but a person's global satisfaction with life conditions. Among the various components of subjective well-being, SWLS is narrowly focused to assess global life satisfaction and does not tap related constructs such as positive affect or loneliness. It is widely used to measure general well-being, including individuals with persistent pain, and validated in both clinical and non-clinical populations (Jensen et al., 1991). For the purpose

of the study, it was important to assess the participant's satisfaction with life and how that relates to their experience of pain. The total score is obtained by summing the scores on the 5 items. Higher scores indicate greater satisfaction with life. In the original scale development and validation study, the SWLS demonstrated good test-retest reliability over a 2-month period (.82) and excellent internal consistency (.87). Jensen et al., (1991) have used it to measure quality of life of patients with pain. SWLS demonstrated good internal consistency of .80 in a persistent pain sample. The Cronbach's alpha for the study population indicated good reliability ($r=0.86$).

World Health Organization Quality of Life-Brief (WHOQOL-BREF). The WHOQOL-BREF is an abbreviated 26-item version of the WHOQOL-100 quality of life assessment (World Health Organization, 1996; Skevington, Lotfy, & O'Connell, 2004). It was developed to be used by WHO field workers. It provides scores for four domains of quality of life, namely, physical health, psychological health, social relationships and environment. Additionally, it includes one item on overall quality of life and one on overall health. Higher scores indicate greater satisfaction with life or health and higher quality of life. For the validation studies, cross-sectional data were collected from adults from 23 countries. Both sick and well respondents were included in the study. This included patients with primary and secondary complaints of pain and patients with physical and mental disorders. WHOQOL-BREF domains have demonstrated good internal consistency ($\alpha>0.80$) and good test-retest reliability. The Cronbach's alpha for the four different domains indicated good reliability ($r=0.85-0.88$).

Chronic Pain Stigma Scale (CPSS). The Chronic Pain Stigma Scale is a 30-item Likert-type instrument measuring an individual's perception of stigma from three sources (general public, physicians, family) across several hypothesized dimensions of stigma related to pain, including, estrangement, attribution to psychological cause,

malingering, bias against opioid analgesics, and general negative attitudes (Reed, 2006). CPSS is designed to assess the level of stigma a person with pain perceives from family, physicians, and general public. The authors suggest that total scores on each of the three sections can be analyzed separately or a mean of the three total scores can be used to assess an overall level of stigmatization. The higher the scores on CPSS, higher is the perceived stigma related to pain. CPSS scale has been validated with a pain population, including sickle cell anemia and indicated a high level of perceived stigma and was shown to be associated with greater depression and psychological distress as well as higher pain levels (Jenerette, Brewer, Edwards, Mishel, & Gil, 2014; Reed, 2006). The original validation study indicated excellent internal consistency of 0.91 for the scale and its three subscales and so does the present sample.

Illness Invalidation Inventory (3*I). The 3*I is a measure for assessing patients' perceptions of invalidation related to their illness (Kool et al. 2010). The construct of invalidation is a relatively new one in pain literature. It has been shown that greater perceived invalidation of pain conditions leads to heightened psychological distress as well as decreased quality of life, increased bitterness, and negative effect on work performance (Kool et al., 2010). The participants indicate on a 5-point Likert scale how often people in each category respond to them in a particular way in the past 12 months. The participants can skip a category that is not relevant or does not apply to them. This measure is composed of two factors: discounting and lack of understanding. Higher scores indicate greater perceived invalidation. The scale has been validated in clinical samples of patients with persistent pain, including rheumatic diseases as well as fibromyalgia and has demonstrated good internal consistency, $\alpha > 0.70$ (Kool, 2012). For the present sample, the reliability was adequate ($r = 0.88$).

Data Analysis

First, basic descriptive analyses were conducted. Frequencies with corresponding percentages were analyzed for categorical variables, including, sex, race, year in college, type of primary pain, and whether the participants were first-generation college students. Means along with standard deviations are reported for age, the level of self-reported difficulty in meeting one's financial needs, quality of sleep, and sleep and awake time. In addition, for the participants with pain, means for the pain intensity over the past week and past three months are reported. Preliminary bivariate correlations of all the variables of interest were also conducted.

Using SPSS 21.0, all the variables were checked for accuracy of data entry, missing values, multivariate outliers, normality, linearity, and homoscedasticity. It was confirmed that all skewness and kurtosis of each variable was below the critical value. Structural equation modeling was employed to test the hypothesized model. The maximum likelihood estimations were calculated using MPlus 7.0 (Muthen & Muthen, 1998-2012). The model fit was evaluated using the chi-square goodness-of-fit statistic, Comparative Fit Index (CFI), and the Root Mean Square Error of Approximation (RMSEA). These indices helped ascertain adequate representation of the sample covariance matrix by the estimated covariance matrix. Acceptable fit includes a non-significant chi-square value (Bollen, 1989). In the presence of a significant chi-square value (common in larger data sets), alternate or additional estimates are recommended: CFI values greater than .90, and RMSEA values less than .05 (Tabachnick & Fidell, 2001). Furthermore, CFI values greater than 0.95 is considered an excellent fit.

Latent variables included in the model were as follows: Illness Invalidation with three manifest variables (illness invalidation inventory-family, illness invalidation inventory-physicians, illness invalidation inventory-partner); Pain-related Stigma (CPSS-family, CPSS-physicians, CPSS-public); Quality of Life (WHOQoL-Physical, WHOQoL-Social,

WHOQoL-Environment); and Pain (pain intensity over the past week, number of days of pain experienced in the past 90 days, and pain catastrophizing). In addition, the scores on CES-D and SWLS were added single indicator variables. Drawing from previous quantitative and qualitative research, it was hypothesized that illness invalidation and perceived pain-related stigma would be associated with increased psychological distress, decreased satisfaction with life, impaired quality of life, and heightened pain perception. In addition, illness invalidation and stigma would be significantly correlated with each other. Furthermore, depression would be negatively correlated with satisfaction with life and quality of life whereas it would be associated with a heightened pain experience.

In the first step, the fit of the measurement model was examined. A measurement model refers to the preliminary model where the indicator variables used to specify the latent variables are examined for fit. Once an acceptable fit was obtained, a latent regression model was run to examine the relationship between the different latent and single indicator variables. The modification indices guided the pruning of the model to obtain the model best fitting the data as the final model.

Results

Descriptive Statistics

The means/frequencies of the demographic, pain, and psychological variables are summarized in Table 7. The participants were primarily females (N=145, 78.4%), Caucasians (N=160, 86.5%), with a mean age of 18.96 years (SD=1.17). The majority of the participants reported being in a relationship (N=123, 66.5%). The mean pain intensity over the past week was 4.61 (SD=1.93) and the average days of pain experienced over the past 90 days was reported to be 42.66 (SD=23.42). The mean depression score was 17.99. Radloff and colleagues have suggested 16 as a cut-off score for clinical levels of depression. Bivariate correlations between the study variables are detailed in Table 8. As none of the correlations

were above 0.80, an overlap of constructs was not a concern while running the structural equation models.

Confirmatory Factor Analysis of the Measurement Model.

Confirmatory factor analysis of the proposed measurement model indicated that the latter had an acceptable fit. Latent variables were allowed to covary in the absence of any structural relations specification. The manifest variables were restricted to load onto the corresponding latent variables. Based on the modification indices, the model fit was improved by allowing the manifest variable illness invalidation by partners to covary with the social quality of life. In addition, the psychological quality of life as a manifest variable for the latent variable of quality of life was creating a problem of multicollinearity with the manifest variable depression and hence removed from the analysis. The final measurement model demonstrated acceptable fit, $\chi^2=91.99$, $df=63$, CFI=0.95, TLI=0.92, and RMSEA=0.05 with CI(90%)=0.025-0.071 indicating that the latent variables were adequately measured by their respective manifest variables. See Figure 1 for the illustrative depiction of the measurement model.

Latent Regression Model

The model representing the hypothesized model for the relationships between the latent variables (perceived illness invalidation, perceived pain-related stigma, pain variables, and the quality of life) is depicted by Figure 2. The hypothesized model for testing the latent regressions was tested using the maximum likelihood method utilizing MPlus 7.0 statistical software program (Muthen & Muthen, 1998-2012). The model revealed a less than acceptable fit, $\chi^2=119.27$, $df=64$, $p<0.001$; CFI=0.89; TLI=0.85; RMSEA=0.07 with CI(90%)=0.049-0.087. Based on the modification indices, instead of correlating the latent variables of Pain-related Stigma and Illness Invalidation, the indices suggested regressing the

former on the latter. Thus, Pain-related Stigma was regressed onto Illness Invalidation. The model demonstrated an acceptable fit with the following statistics: $\chi^2=91.99$, $df=63$, $p=0.01$; CFI=0.95; RMSEA=0.05 with CI(90%)=0.025-0.071. The model was modified further by pruning of the non-significant structural paths. There were no significant changes in the model fit and there were no further changes suggested in the modification indices, thus, this model was retained. The standardized estimates are presented in Table 9. Furthermore, with the present model, 44.2% of the variability in Stigma, 25.6% variability in Pain, and 25.8% variability in Quality of Life could be explained by the model. See Table 10 for the squared multiple correlation coefficients for the endogenous variables in the model.

According to the model, Illness Invalidation directly influenced the latent variables of Pain-related Stigma ($\beta=0.521$), Quality of Life ($\beta= -0.533$), Pain ($\beta=0.521$), two indicator variables of depression ($\beta= -0.66$) and satisfaction with life ($\beta= -0.413$). The parentheses here indicate the structural path coefficients for the latent variables. Latent variables of Perceived Stigma as well as Pain were not directly associated with any other latent or indicator variables. Depression was negatively correlated with both Quality of Life ($\beta=-0.372$) and Satisfaction with Life ($\beta=-0.307$). Satisfaction with Life and Quality of Life were correlated in the positive direction ($\beta=0.555$). Furthermore, the manifest variable of illness invalidation attributed to partners was negatively correlated with quality of life in the social domain ($\beta= -0.66$). See Figure 3.

Discussion

The results were consistent with the overarching general study hypothesis that illness invalidation and perception of stigma related to the pain condition would emerge as important variables affecting the lived experience of emerging adults with pain across multiple domains. However, in relation to the nature of the association between the two, the results

revealed that it is in fact the perception of illness invalidation, in other words, not being believed, that drove the perception of pain-related stigma. In addition, not feeling like one is believed also drove the individual's pain perception, emotional well-being, and quality of life. The results of the present study suggest the substantial impact of illness invalidation as opposed to perceived pain-related stigma, on self-reported pain experience, emotional well-being as well as the quality of life of emerging adults with persistent pain. It was surprising that perceived stigma did not appear to directly impact these psychosocial variables.

To the best of the authors' knowledge, this is the first study to examine the impact and association of perceived stigma and invalidation on an individual's pain experience. There is phenomenological evidence supporting the concurrence or overlap of invalidation and stigmatization in the lived experience of patients with pain. However, despite their increasing prominence in the recent body of pain literature, they have only been investigated separately and their association had remained unaddressed. In addition, the present study adds to the very limited literature focused on the experience of emerging adults with persistent pain. A number of experimental pain studies have examined college students utilizing them as a presumably healthy convenience sample. The results of the present study indicate that it is necessary to focus on this often overlooked population and identifying their unique health care needs in relation to their pain condition.

Illness invalidation emerged as a primary variable negatively affecting a multitude of emotional and social variables in the present study. It was associated with a heightened perception of stigmatization, greater depression, lower satisfaction with life, greater impairment in perceived quality of life, as well as worse pain experience in terms of intensity, frequency, and catastrophizing. These results are consistent with the findings of previous studies focused primarily on older adults. Illness invalidation is shown to negatively impact an individual's skills in managing work-related problems and dealing with interpersonal and

emotional difficulties (Kool et al., 2010). In a study looking at illness invalidation perceived by patients with fibromyalgia and rheumatoid arthritis, higher perception of discounting and lack of understanding was associated with higher psychological distress and greater impairment in social functioning (Kool, 2010). In addition, discounting was associated with higher physical disability and pain intensity (Kool, Van Middendorp, Lumley, Schenk, Jacobs, Bijlsma, & Geenen, 2010). Furthermore, the invalidation of a person's pain experience and insinuations of malingering can foster intense feelings of guilt, shame and embarrassment. Indeed, this may consequently foster stigma consistent with the results of this study. Similarly, perceived stigma is germane to any illness where there is a lack of a clear organic cause for chronic pain with the tendency to ascribe psychological causes for such illnesses, for example, persistent pain and mental illnesses (Shaver, 1985; Weiner, 1993; Wright, 1983). Chronic pain often does not have a well-defined etiology and it is, thus, reasonable to expect that individuals with chronic pain will be vulnerable to stigma and the negative psychological and social consequences related to invalidation and stigmatization.

In context of emerging adulthood, perceived invalidation and stigmatization act as incremental barriers in conjunction with the commonly prevailing stereotypes related to this stage of life (Trzesniewski & Donnellan, 2014). The association of "drug-seeking" behaviors and disproportionately high rates of substance abuse linked to this age group potentially complicate interactions with health care providers, specifically for emerging adults presenting for persistent pain management (Jenerette, Brewer, & Ataga, 2014). Thus, invalidation and perceived disbelief of the health care providers has serious implications in terms of disengagement of this vulnerable age group from the health care system.

According to the World Health Organization, an intervention should be accessible and acceptable to the patient. Thus, in relation to young adults with concealable stigmatizing

chronic illnesses such as pain, providing interventions that are sensitive and acceptable is of utmost importance. In a health care system heavily geared towards treating and interacting with older patients or the very young, it is becoming imperative that the unique needs of young adults are understood and addressed. More efforts are needed to engage them in the health care system and providing timely interventions for better long-term health outcomes. Better training and fostering cultural competence in health care providers working with this population would be beneficial. Utilizing validating attitudes, displaying empathy and understanding, discussing any perceived stigma related to pain provides avenues of interventions that are easy and practical to implement. Indeed, designing behavioral interventions that directly target maladaptive cognitions such as perceived illness invalidation and stigma for emerging adults may yield beneficial results by alleviating the associated psychological distress, enhance the quality of life, and improve overall pain-related outcomes.

Another distinctive finding of the study is the clinically meaningful levels of depression endorsed by the participants. The mean depression scores was 17.99. Radloff and colleagues have suggested a cut-off score of 16 as indicative of clinical levels of depression. Given the robust evidence corroborating the link between depression and persistent pain, this finding is not surprising (Robinson et al., 2009). More importantly, the link between illness invalidation and depression is noteworthy such that it further suggests the potential of targeting perceived invalidation during psychosocial treatments to lessen the psychological distress. In order to effectively help individuals reframe or modify their perception of not being believed, Cognitive Behavioral Therapy (CBT) provides particularly useful strategies. CBT generally teaches assertive communication which can be helpful for emerging adults to express their pain-related experience and needs (Hollon & Beck, 1994). In addition, CBT often teaches about pain behavior or pain expression and how family members or health care

providers may misunderstand the individuals' pain behavior cues leading to invalidating responses (Eyer & Thorn, 2015). Helping emerging adults learn how to effectively communicate with their health care providers, friends, and family can be beneficial. In an ongoing PCORI trial examining pain in patients living in rural United States, communication with health care providers is being approached as a skill and targeted as a skill building intervention (Eyer & Thorn, 2015).

Limitations and future studies: The present study has limitations that warrant consideration. This is a cross-sectional study thus it is difficult to establish causality. In addition, as is common, the study was limited by the number of variables examined. It is probable that there are additional factors that affect pain experience in this population and need to be examined in future studies. Furthermore, the sample was obtained from a college population which may limit its generalizability to emerging adults who do not attend college or may have dropped out. Future studies should include community samples of emerging adults to better understand the relationship between pain and psychosocial variables.

The results of this study revealed the social variables affecting the psychological well-being of emerging adults with pain. Extant literature suggests the detrimental effect of pain on sleep and vice-versa. In addition, sleep disturbances have been shown to exert a negative influence on the overall physical and emotional functioning on individuals across the life-span. Sleep disturbances are amongst the most common complaints in an emerging adult population. In context of emerging adults with persistent pain, it thus becomes particularly important to examine if and how the pain experience is impacting sleep. Thus, the final study aimed to examine the additional pain-related detrimental effect on sleep and well-being of the participants with pain as compared to their healthy same-age peers.

CHAPTER 4

STUDY 3

The Association of Sleep and Persistent Pain in Emerging Adults

Difficulties with sleep and persistent pain are among the two most commonly reported health problems in adults across a variety of clinical settings (Ohayon, 2002; Punjabi, 2008; Blyth, 2006). This has been consistently corroborated by epidemiological surveys focused on the general population as well (Klink, Quan, Kaltenborn, & Lebowitz, 1992). The estimates, though wide-ranging, indicate a significantly high prevalence of sleep problems in patients who experience persistent pain (Moldofsky 2001; Okifuji & Hare, 2014; Okifuji & Turk, 2014). In relation to clinically significant insomnia, the estimates range from 50% comorbidity in those with non-specific chronic pain to approximately 99% in patients with fibromyalgia (Okifuji & Hare, 2014). The findings from these studies suggest a higher degree of compromised social, physical, and emotional functioning (Moldofsky 2001; Okifuji & Hare, 2014). In fact, both animal and human studies have corroborated the analgesic role of sleep (Smith & Haythornthwaite, 2004). Moreover, robust empirical evidence underscores the vital link between maladaptive cognitions, including excessive anxiety, worry, and depression in those with a persistent pain condition and coexisting sleep disturbances (Parmelee, Tighe, & Dautovich, 2014).

Extant literature suggests a bidirectional or reciprocal relationship between sleep difficulties and persistent pain (Moldofsky, 2001, Smith & Haythornthwaite, 2004). It has been shown that sleep pathologies such as insomnia lead to heightened stress, fatigue, and chronic pain (Owens, 2014). Conversely, pain likely exerts a negative impact on sleep duration and quality with its sleep-interfering nature. To deduce a temporal link between these two conditions, sequential studies have been performed. Long-term studies consistently suggest that chronic pain is a significant predictor of development of sleep problems in the future (Bohra, 2014). There is additional evidence that poor sleep leads to increased perception of pain in individuals both with and without persistent pain, including children and adolescents (Lautenbacher, Kundermann, & Krieg, 2006; Harrison, Wilson, & Munafò, 2014).

Amongst the various mechanisms examined or postulated to explain this relationship, behavioral and psychosocial factors constitute an important avenue for clinical research and interventions. In particular, maladaptive thoughts including worry, anxiety, and catastrophic cognitions related to sleep have been shown to impact sleep in youth with chronic pain (Palermo 2011). Emerging evidence suggests a significant discrepancy between the subjective and objective reports of sleep while depressive symptomatology and sleep-related catastrophic cognitions are shown to be better predictors of the objectively measured sleep variables (Orff, Drummond, Nowakowski, & Perlis, 2007; Varkevisser & Kerkhof, 2005). Surprisingly, it has been consistently found that sleep disturbance in individuals with chronic pain is not proportional to the reported pain intensity (Zarrabian, Johnson, & Kriellaars, 2014). Thus, it is highly likely that other factors, including psychosocial factors, influence this relationship. A biopsychosocial approach to understand the link between sleep and pain is thus warranted.

Empirical inquiry on comorbid sleep and pain conditions has so far primarily focused on middle-aged to older adults. More recently, the pain experience of children and adolescents has gained empirical scrutiny and this burgeoning research focused on the pediatric population reveals that approximately 50% of youth with chronic pain report sleep difficulties as compared to only 15% of same age peers who do not experience pain (Palermo 2011). Epidemiological surveys have suggested an association between chronic sleep problems in youth with adverse mental health outcomes, such as, depression, anxiety, difficulties in concentrating, feelings of irritability, and fatigue (Owens, 2014). There is emerging evidence that sleep problems are robust predictors of academic performance, depression, and suicidal behavior in young adults (Ribeiro 2012). In a study focused on adolescents with persistent pain, comorbid insomnia was shown to be associated with poorer self-reported quality of life and compromised physical functioning (Moldofsky 2001). However, there is very limited information and understanding available in relation to the pain experience of young adults with comorbid sleep problems. Additionally, there is robust evidence that individuals in their twenties experience more sleep disturbances than other age groups (Petrov, Lichstein, & Baldwin, 2014). Thus, considering that emerging adulthood is a period of a number of substantial life changes, experiencing persistent pain, which if further compounded by sleep difficulties, would potentially lead to much worse outcomes and far-reaching pervasive deleterious effects over the life-span.

The goal of the present study was two-fold. First, the study aimed to compare self-reported sleep quality, total sleep duration at night, and total awake time at night in emerging adults with and without persistent pain while controlling for sex and depressive symptomatology. Second, the cognitive and pain-related predictors (namely, duration of pain, pain intensity, pain catastrophizing, and depression) of sleep variables in individuals

experiencing persistent pain were examined. The results are discussed in context of clinical and research implications.

Method

Participants

Participants were recruited from the University of Alabama Psychology Subject Pool. Overall, 301 participants between the ages of 18 and 29 were recruited. Of these, 185 participants were recruited with self-reported chronic pain and while 116 participants did not report pain. Chronic pain was defined as experiencing pain on most days in a month for the last 3 months severe enough to cause interference in daily activities while recurrent pain was defined as episodic pain (at least 4 days in a 30-day period over the past 3 months) severe enough to cause interference in daily activities with intermittent periods of pain-free periods. Participants with chronic or recurrent pain are being referred to collectively as experiencing persistent pain (Turk & Okifuji, 2001). Each participant was administered the questionnaire packet by the researcher individually.

Measures

Demographics, Sleep, and Pain Questionnaire. A demographics questionnaire designed for the study was used to obtain sex, age, race/ethnicity, and year of study in college. In addition, this questionnaire inquired whether the participant experienced persistent pain. If they responded yes, the participants were further queried about the intensity of pain over the past week and information pertaining to the duration, type, and location of their pain condition. The demographic questionnaire also included questions in relation to sleep quality (measured on a Likert scale of 0-5 with zero being very poor sleep and five being very good sleep), total sleep time (in hours), and cumulative awake time (in minutes) during the night over the past two weeks.

Pain Catastrophizing Scale (PCS). The PCS was used to measure pain catastrophizing (Sullivan et al., 1995). Pain catastrophizing involves exaggerated maladaptive cognitions or emotions in response to present or a past pain experience. It is a significant construct extensively studied in the pain literature and has been found to be associated with not only greater pain intensity, but also to depression, anxiety, negative affect, activity interference, pain-related disability, employment status, and psychological distress in patients with chronic pain (Cheng & Leung, 2000; Severeijns et al., 2001; Sullivan et al., 1995; Sullivan, Stanish, Waite, Sullivan, Tripp, 1998; Turner, Dworkin, Mancl, Huggins, Truelove, 2001; Turner, Jensen, Warm, Cardenas, 2002). The PCS is a 13-item measure asking respondents to rate the extent to which they have particular thoughts and emotions when they experience pain. The PCS measures catastrophizing on three dimensions, namely, magnification, rumination and helplessness and the total score for catastrophizing is the sum of the raw scores. Higher scores indicate greater catastrophic thinking related to pain. The PCS is shown to have a high internal consistency of .87 in clinical and non-clinical populations in the original validation study (Sullivan et al., 1995). There is robust empirical evidence that pain catastrophizing predicts negative pain-related outcomes, both in clinical and non-clinical study populations (Edwards, Cahalan, Mensing, Smith, & Haythornthwaite, 2011; Westman, Boersma, Leppert, & Linton, 2011; Tsao, Allen, Evans, Lu, Myers, & Zeltzer, 2009). The Cronbach's alpha for the present sample was excellent (0.92).

The Center for Epidemiological Studies Depression Scale (CES-D). The CES-D is a 20-item questionnaire where the respondents rate the frequency with which each item occurred over the previous week. Higher scores indicate greater depression. There is a robust association of coexisting depression and persistent pain and the association between the two is well established (Fishbain et al., 1997). Indeed, it is found that depression is more common among patients with pain than the general population but notably patients with pain are not

treated for the depression they experience (Sullivan et al., 1992). In addition, patients with persistent pain who report concurrent depression have poorer clinical outcomes than those who do not. It is possible that depression compromises a person's coping resources, thus worsening the pain experience. The CES-D has high internal consistency, adequate test-retest reliability, and convergent as well as discriminant validity (Radloff, 1977) and the CES-D has been validated for use in patients with persistent pain (Turk & Okifuji, 1994). The Cronbach's alpha for the present sample was excellent (0.88).

Procedure

The study was listed and open to participation on the University of Alabama Subject Pool website. The students taking the Introductory Psychology classes are required to either complete papers or participate in research studies to receive credit in their course. The students had the choice to sign up for any of the available studies. Thus, they self-selected to participate in this study. Once they signed up, informed consent was obtained and the questionnaire packet was completed by the participants. Upon completion of the study, a debriefing was conducted to clarify the purpose of the study and to respond to any questions the participants had. It is important to note that this data was collected as part of a larger study examining pain in emerging adults. As such, the two groups do not reflect the actual proportion of participants experiencing persistent pain overall from the population that they were drawn. To fulfill the aims of the larger study, differential recruiting was done to recruit a higher number of emerging adults with pain than would be normally distributed in this population. The study was approved by the Institutional Review Board of the university prior to the beginning of the study.

Data Analysis

Descriptive analyses pertaining to demographic, pain, sleep, and psychological variables were conducted as part of the preliminary analyses. Frequencies with corresponding

percentages for categorical variables (sex, race, year in college, and type of primary pain) and means along with standard deviations (age, quality of sleep, and sleep and awake time) are presented. In addition, for the participants with pain, means for the pain intensity over the past week and past three months are reported. Bivariate correlations of all the variables of interest were also conducted. A multivariate analysis of covariance (MANCOVA) was conducted on the overall sample to examine group differences (pain versus non-pain) in total sleep time, total awake time, and sleep quality. These multivariate statistical approaches are useful in analyzing relationships between predictors and multiple inter-related dependent variables. MANCOVA tests whether groups differ on a combination of outcome variables, and thus provides protection against inflating the false positive rate in testing multiple dependent variables. Given the significant association of depression and sex with both sleep as well as pain, scores on CES-D and sex were entered as covariates. Next, for those participants who reported experiencing persistent pain, two separate multiple hierarchical regression analyses were conducted to examine the predictors of sleep quality and total awake time. The pain intensity over the past week and number of days with pain in the past 30 days was entered on the second step, and on the last step, pain catastrophizing and depression scores were entered. Prior to conducting the hierarchical multiple regression analyses, the data were examined for multicollinearity, outliers, normality, and homoscedasticity.

Results

Descriptive analysis

The results for demographic characteristics, pain, sleep, and data pertaining to psychological variables is presented in Table 11. For the overall study (N=301), the sample was primarily female (N=230; 76.4%) and Non-Hispanic Whites (N=253; 84.1%). This corresponds closely with the demographics of the institution where the study was conducted.

Comparisons between the pain group (N=185) and the non-pain group (N=118) indicated no statistically significant differences in age or sex. Please see Table 11.

Multivariate Group Differences in Sleep Variables (Pain group versus non-pain group)

A multivariate analysis of covariance (MANCOVA) was conducted to compare group differences between the pain and non-pain groups. Dependent variables consisted of sleep quality, total sleep time, and total awake time. The sex and depression scores were employed as covariates in this analysis. Preliminary checks confirmed that there were no violation of the assumptions of normality, linearity, homogeneity of variances, and homogeneity of regression slopes. After adjusting for depression and participant sex, the MANCOVA revealed significant group differences in terms of sleep quality [$F(3,285)= 7.172, p= .008$], total sleep time [$F(3,285)= 6.431, p< .012$], and cumulative awake time [$F(3,285)=7.185, p=0.008$]. This result indicates that participants with persistent pain reported a lower quality of sleep ($M=2.94, SD=0.85$ vs $M=3.37, SD=0.81$), lesser hours of sleep per night ($M=6.57, SD=1.37$ vs $M=7.00, SD=1.17$), and greater number of minutes spent awake each night ($M=67.83, SD=75.74$ vs $M=37.15, SD=29.57$) over the past two weeks. The effect sizes were medium. See Table 12.

Predictors of sleep variables in participants with persistent pain (N=185)

Bivariate analyses were conducted to examine the correlations between age, sex, pain intensity over the past week, total number of days pain was experienced in the past three months, pain catastrophizing, depression scores, quality of sleep, total sleep time, and cumulative awake time at night over the past two weeks. The results revealed that quality of sleep was significantly correlated with the pain intensity, number of days of pain in the past 3 months, catastrophizing, and depression scores. Demographic variables were not associated with the quality of sleep. Total awake time was significantly correlated with depression

scores. However, total sleep time was not associated with any of the independent variables of interest hence further regression analyses were not conducted for this variable. See Table 13. The bivariate analyses were followed up with multiple hierarchical regression analyses. The first regression analysis examined the predictors of the quality of sleep. In preliminary analyses, age and sex were not significantly related to sleep quality and hence were not included in the regression model. For examining the variables influencing the self-reported quality of sleep, the predictors were entered on two different steps (first step: pain intensity over the past one week and number of days pain was experienced over the past month, second step: pain catastrophizing and depression scores). The results revealed that the model significantly explained the variance in the quality of sleep [$F=(4,172)=6.131, p<0.001$]. Only depression emerged as a significant predictor of the quality of sleep ($B=-0.241, t(172)=-3.255, p=0.001$). Depressive symptomatology explained 24.1% of the variance in the perceived quality of sleep. A linear regression model was conducted to examine whether depression scores influenced the total awake time in a significant manner. Results revealed that there was a significant influence of depression with greater depression scores indicating more time spent awake in bed after initial onset of sleep, $F(1,178)=9.71, p=0.002, B=0.228$. Pain intensity, number of days pain was experienced over the past 30 days, and pain catastrophizing did not significantly influence the quality of sleep. See Table 14.

Discussion

Research on the impact of comorbid sleep difficulties and persistent pain, so far, has been primarily focused on middle-aged and older adults and as of recently on children and adolescents. To the authors' knowledge this is the first study to examine sleep difficulties and its psychosocial correlates in a sample of emerging adults with persistent pain. Thus, this study contributes to the still nascent area of pain research focused on emerging adults. The results of the study suggest significant sleep difficulties experienced by emerging adults with

persistent pain as compared to their same-age peers, even after controlling for depression and sex. These results extend the results obtained in previous studies focused on older adult and pediatric populations.

The results of the present study indicated that the emerging adults with persistent pain reported fewer hours of sleep per night, more minutes spent awake at night after the initial onset of sleep, and poorer quality of sleep. Lund, Reider, Whiting, & Pritchard (2010), in a large study evaluating sleep in emerging adults in college, found a mean sleep duration of 7.02 hours. Thus, the participants with self-reported persistent pain in the present study reported lower sleep duration [6.54 hours] than the normative data (Lund, Reider, Whiting, & Prichard, 2010) as well as the study non-pain group (7.00 hours). These results are vital considering the importance of optimal sleep for positive health outcomes across the lifespan. Indeed, Steptoe and colleagues examined sleep durations and health outcomes in university-attending emerging adults. The results revealed that short sleepers (individuals sleeping less than seven hours per night) reported a significantly greater risk of poorer self-reported health (Steptoe, Peacey, & Wardle, 2006).

Sleep disturbance exerts a multifaceted impact on an individual's health and overall well-being. Emerging research has suggested that healthy sleep in youth promotes better health, reduces coronary heart disease, decreases the incidence of chronic illnesses, and reduces mortality (Petrov et al., 2013). Petrov et al (2014) have further suggested a link between sleep difficulties in cognitive as well as physical functioning in emerging adults between the ages of 18 and 30 years. Epidemiological surveys have suggested an association between chronic sleep problems in youth and adverse mental health outcomes, such as, depression, anxiety, difficulties in concentrating, feelings of irritability, and fatigue. Deficits in sleep are significantly more deleterious when sleep duration is fewer than 5 hours (Meldrum, 2014). Given that emerging adulthood is a defining developmental life stage and

health during this time impacts long-term health outcomes, understanding the influence of chronic illnesses as well as designing efficacious interventions is vital. Importantly, in adolescents with chronic pain, insomnia has been associated with lower quality of life and increased functional limitations, suggesting that the consequences of insomnia may be far reaching in this population (Roberts, Roberts, & Duong, 2009; Fernández-Mendoza et al., 2009).

The significant influence of cognitive variables, specifically, depression on the self-reported quality of sleep is not surprising as evidenced in the existing literature (Tsunoo, Besset, & Ritchie, 2005; Slaughter, 2005). Moreover, the quality of sleep was not impacted by self-reported pain intensity over the past 1 week. This is consistent with previous studies where self-reported pain intensity is shown not to be predictive of sleep duration or sleep efficiency in patients with persistent pain (Zarrabian, Johnson, & Kriellaars, 2014). The findings highlight the substantial impact of psychological distress and maladaptive cognitions on sleep in those who experience pain on a regular basis instead of the actual level of pain itself. Considering the high incidence of coexisting persistent pain and depression, it is logical to expect that emerging adults with pain and depressive symptomatology are at a greater risk of sleep difficulties further perpetuating the cycle of adverse outcomes. It becomes critical to fundamentally understand this relationship as both of these persistent pain and chronic sleep problems have been found to be independently associated with adverse mental health outcomes such as severe mood disturbance, depression, and even suicidal ideation. (Palermo 2011).

Increasingly, clinical trials evaluating psychosocial interventions for chronic pain have found that concurrently addressing sleep difficulties are proving efficacious (Vitiello, Rybarczyk, Von Korff, & Stepanski, 2009). Given the potential negative consequences of sleep disturbances on the individual's ability to cope with persistent pain, it is of utmost

importance to develop, examine, and implement sleep interventions in those with pain. Interventions aimed at reducing sleep problems may lead to substantial improvements in pain and other health-related outcomes in emerging adults with persistent pain. There have been encouraging results in this direction in adult intervention literature. Vitiello and colleagues found that older adults with osteoarthritis pain and insomnia who were delivered cognitive-behavioral therapy for insomnia reported clinically meaningful improvement in sleep as well as reduction in pain after treatment and the gains were maintained at long-term follow-up compared to an attention control group (Vitiello, Rybarczyk, Von Korff, & Stepanski, 2009). Moreover, recent studies have also demonstrated that insomnia-focused interventions were able to reduce anxiety and depression in patients with chronic back pain due to a spinal pathology (Zarabbain et al., 2014). Thus, although it is not clear at this time whether the pain limits sleep or sleep impacts pain, or both, this relationship provides avenues for interventions into sleep disturbance as a therapeutic approach that is currently underutilized and not stressed on optimally.

Limitations and future studies: The present study has limitations that necessitate consideration. This is a cross-sectional study thus it is difficult to establish causality or temporal sequence of the occurrence of persistent pain and sleep difficulties. The sample is obtained from a college population which may limit its generalizability to emerging adults who do not attend college or may have dropped. Future studies should include community samples of emerging adults to better understand the relationship between pain and sleep.

In conclusion, the present study underscores the important association between persistent pain, depression, and sleep difficulties in emerging adults. It provides preliminary evidence that this young population is as vulnerable to the deleterious effects of pain conditions as their older and younger counterparts. Furthermore, the results highlight the adverse impact of experiencing persistent pain at this stage of life in terms of poorer

perceived quality of sleep as well as sleep duration as compared to same-age peers. This highlights the necessity to encourage more empirical inquiry into the health outcomes and psychosocial interventions specifically developed for this population.

CHAPTER 5

CONCLUSION

Emerging adulthood is an important period of life during which an individual is believed to attain financial and emotional independence, develop a richer self-concept, and establish long-term relationships (Arnett, 2006). Experiencing a chronic illness at this time is a major barrier in attaining these goals. Persistent pain in emerging adults is an overlooked and understudied area of empirical inquiry. The results of the present study indicate that persistent pain affects the psychosocial well-being of emerging adults. It is important that psychosocial interventions are specifically designed for individuals experiencing persistent pain in this developmental stage emphasizing their unique needs and requirements.

The present study was divided into three smaller studies to address its three-fold aim. The first study evaluated the differences between emerging adults with pain and same-age peers who do not experience regular pain in context of cognitive and psychological well-being (depression, satisfaction with life), identity development during this stage of life, as well as perceived quality of life. As expected, those with pain reported a poorer cognitive well-being, impaired quality of life, and a greater perceived negativity and instability in their life. The second study focused exclusively on emerging adults with persistent pain. It was revealed that illness invalidation was a primary variable that perpetuated psychological distress, impaired quality of life, heightened pain perception as well as a perception of stigmatization in emerging adults with pain. Thus, the important role of contextual sociocultural variables was brought to light. Finally, the third study examined sleep in the study population. The results indicated the detrimental effect of pain on sleep in emerging

adults. The latter who self-reported experiencing regular pain reported greater sleep disturbance, in terms of quality as well as quantity. The sleep quality was also shown to be affected by psychosocial variables, most particularly depression..

Thus, the results were consistent with the overarching hypothesis of the study such that persistent pain influenced a variety of psychosocial and health-related variables in emerging adults with pain. This study provides preliminary data highlighting the extent and nature of pain problem in emerging adults. In the future, more advanced longitudinal studies should examine the impact of pain over the course of emerging adulthood into the young adulthood to obtain a more comprehensive understanding of the developmental effects of pain on this population.

References

- Abo-Zena, M. M., & Ahmed, S. (2014). Religion, Spirituality, and Emerging Adults: Processing Meaning Through Culture, Context, and Social Position. *Emerging Adults' Religiousness and Spirituality: Meaning-Making in an Age of Transition*, 220.
- Arnett, J.J. (2000). Emerging Adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, 55(5), 469-480.
- Arnett, J. J., & Tanner, J. L. (Eds.). (2006). Emerging Adults in America: Coming of age in the 21st century. *American Psychological Association*: Washington, DC.
- Arnett, J. J. (2007), Emerging Adulthood: What Is It and What Is It Good For? *Child Development Perspectives*, 1, 68–73.
- Arnett, J.J. (2011). "Emerging adulthood(s): The Cultural Psychology of a New Life Stage." In L.A. Jensen (Ed.), "Bridging cultural and developmental approaches to psychology: *New Synthesis in theory, research, and policy*," (pp. 255-275). New York: Oxford University Press.
- Arnett, J. J., & Schwab, J. (2012). The Clark University Poll of Emerging Adults, 2012: Thriving, struggling, and hopeful. Worcester, MA: *Clark University*.
- Arnett, J. J. (2013). The Evidence for Generation We and Against Generation Me. *Emerging Adulthood*, 1(1), 5-10.
- Arnett, J. J., Trzesniewski, K. H., & Donnellan, M. B. (2013). The Dangers of Generational Myth-Making Rejoinder to Twenge. *Emerging Adulthood*, 1(1), 17-20.
- Banks, S. M., & Kerns, R. D. (1996). Explaining high rates of depression in chronic pain: a diathesis-stress framework. *Psychological Bulletin*, 119(1), 95.
- Becker, G., & Arnold, R. (1986). Stigma as a social and cultural construct. In *The dilemma of difference* (pp. 39-57). Springer US.
- Bersamin, M. M., Zamboanga, B. L., Schwartz, S. J., Donnellan, M. B., Hudson, M., Weisskirch, R. S., ... & Caraway, S. J. (2014). Risky business: Is there an association between casual sex and mental health among emerging adults? *Journal of sex research*, 51(1), 43-51.
- Bjordal, K., Mastekaasa, A., & Kaasa, S. (1995). Self-reported satisfaction with life and physical health in long-term cancer survivors and a matched control group. *European Journal of Cancer. Part B: Oral Oncology*, 31(5), 340-345.
- Blom, D., Thomaes, S., Kool, M. B., van Middendorp, H., Lumley, M. A., Bijlsma, J. W., & Geenen, R. (2012). A combination of illness invalidation from the work environment and helplessness is associated with embitterment in patients with FM. *Rheumatology*, 51(2), 347-353.
- Board on Health Sciences Policy. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Released: June 29, 2011
<http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-transforming-Prevention-Care-Education-Research.aspx>, retrieved on 8-26-2013.

- Bohra, M. H., Kaushik, C., Temple, D., Chung, S. A., & Shapiro, C. M. (2014). Weighing the balance: how analgesics used in chronic pain influence sleep? *British Journal of Pain*, doi:2049463714525355.
- Bollen, K. A. (1989). A new incremental fit index for general structural equation models. *Sociological Methods & Research*, 17(3), 303-316.
- Bond, B. J., & Drogos, K. L. (2014). Sex on the Shore: Wishful Identification and Parasocial Relationships as Mediators in the Relationship Between Jersey Shore Exposure and Emerging Adults' Sexual Attitudes and Behaviors. *Media Psychology*, 17(1), 102-126.
- Boonstra, A. M., Reneman, M. F., Stewart, R. E., Post, M. W., & Preuper, H. R. S. (2013). Life satisfaction in patients with chronic musculoskeletal pain and its predictors. *Quality of Life Research*, 22(1), 93-101.
- Brattberg, G. (2004). Do pain problems in young school children persist into early adulthood? A 13-year follow-up. *European Journal of Pain*, 8(3), 187-199].
- Bruce, D., & Harper, G. W. (2012). Future Life Goals of HIV-Positive Gay and Bisexual Male Emerging Adults. *Journal of adolescent research*, 27(4), 449-470.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Daughtry, D., & Kunkel, M. A. (1993). Experience of depression in college students: A concept map. *Journal of Counseling Psychology*, 40(3), 316.
- DeGarmo, D. S., Reid, J. B., Fetrow, B. A., Fisher, P. A., & Antoine, K. D. (2013). Preventing Child Behavior Problems and Substance Use: The Pathways Home Foster Care Reunification Intervention. *Journal of child & adolescent substance abuse*, 22(5), 388-406.
- Diener, E. D., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of personality assessment*, 49(1), 71-75.
- Dunn, J., Ng, S. K., Breitbart, W., Aitken, J., Youl, P., Baade, P. D., & Chambers, S. K. (2013). Health-related quality of life and life satisfaction in colorectal cancer survivors: trajectories of adjustment. *Health and quality of life outcomes*, 11(1), 46.
- Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of health psychology*, 17(2), 157-168.
- Eccleston, C., Crombez, G., Scotford, A., Clinch, J., & Connell, H. (2004). Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain*, 108(3), 221-229.
- Edwards, R. R., Cahalan, C., Mensing, G., Smith, M., & Haythornthwaite, J. A. (2011). Pain, catastrophizing, and depression in the rheumatic diseases. *Nature Reviews Rheumatology*, 7(4), 216-224.
- Eyer, J. C., & Thorn, B. E. (2015). The Learning About My Pain study protocol: Reducing disparities with literacy-adapted psychosocial treatments for chronic pain, a comparative behavioral trial. *Journal of health psychology*, 1359105315570985.

- Fact Sheet-Health Care Disparities and Inequalities Report-US 2011; <http://www.cdc.gov/minorityhealth/CHDIR/2011/FactSheet.pdf>; Retrieved on 2-11-2015.
- Fernández-Mendoza, J., Vela-Bueno, A., Vgontzas, A. N., Olavarrieta-Bernardino, S., Ramos-Platón, M. J., Bixler, E. O., & De la Cruz-Troca, J. J. (2009). Nighttime sleep and daytime functioning correlates of the insomnia complaint in young adults. *Journal of adolescence*, 32(5), 1059-1074.
- Ferro, M. A. (2014). Adolescents and young adults with physical illness: a comparative study of psychological distress. *Acta Paediatrica*, 103(1), e32-e37.
- Fishbain, D. A., Cutler, R., Rosomoff, H. L., & Rosomoff, R. S. (1997). Chronic pain-associated depression: antecedent or consequence of chronic pain? A review. *The Clinical journal of pain*, 13(2), 116-137.
- Goadsby, P. J., Lipton, R. B., & Ferrari, M. D. (2002). Migraine—current understanding and treatment. *New England Journal of Medicine*, 346(4), 257-270.
- Gormsen, L., Rosenberg, R., Bach, F. W., & Jensen, T. S. (2010). Depression, anxiety, health-related quality of life and pain in patients with chronic fibromyalgia and neuropathic pain. *European Journal of Pain*, 14(2), 127-e1.
- Hanna, K. M., Weaver, M. T., Stump, T. E., Slaven, J. E., Fortenberry, J. D., & DiMeglio, L. A. (2013). Readiness for living independently among emerging adults with type 1 diabetes. *The Diabetes Educator*, 39(1), 92-99.
- Harrison, L., Wilson, S., & Munafò, M. R. (2014). Exploring the associations between sleep problems and chronic musculoskeletal pain in adolescents: A prospective cohort study. *Pain Research & Management: The Journal of the Canadian Pain Society*, 19(5), e139.
- Haythornthwaite, J. A., Sieber, W. J., & Kerns, R. D. (1991). Depression and the chronic pain experience. *Pain*, 46(2), 177-184.
- Hoftun, G. B., Romundstad, P. R., & Rygg, M. (2013). Association of Parental Chronic Pain With Chronic Pain in the Adolescent and Young Adult Family Linkage Data From the HUNT Study Parental Chronic Pain and Pain in Offspring. *Journal of American Medical Association Pediatrics*, 167(1), 61-69.
- Hollon, S. D., & Beck, A. T. (1994). Cognitive and cognitive-behavioral therapies.
- Huijnen, I. P., Kindermans, H. P., Seelen, H. A., Peters, M. L., Smeets, R. J., Serroyen, J., & Verbunt, J. A. (2011). Effects of self-discrepancies on activity-related behaviour: Explaining disability and quality of life in patients with chronic low back pain. *Pain*, 152(9), 2165-2172.
- Jackson, J. E. (2005). Stigma, liminality, and chronic pain: Mind–body borderlands. *American Ethnologist*, 32(3), 332-353.
- Jenerette, C. M., Brewer, C. A., & Ataga, K. I. (2014). Care seeking for pain in young adults with sickle cell disease. *Pain Management Nursing*, 15(1), 324-330.
- Jenerette, C. M., Brewer, C. A., Edwards, L. J., Mishel, M. H., & Gil, K. M. (2014). An intervention to decrease stigma in young adults with sickle cell disease. *Western journal of nursing research*, 36(5), 599-619.

- Jensen, M. P., & Karoly, P. (1991). Control beliefs, coping efforts, and adjustment to chronic pain. *Journal of Consulting and Clinical Psychology, 59*(3), 431.
- Joachim, G., & Acorn, S. (2000). Living with chronic illness: the interface of stigma and normalization. *The Canadian journal of nursing research, 32*(3), 37-48.
- Kapoor, K., Thorn, B.E., & Eyer, J. (2013). *Focus groups with Emerging Adults experiencing chronic or recurrent pain: A phenomenological analysis*. Unpublished manuscript.
- Katz, I. (2014). *Stigma: A social psychological analysis*. Psychology Press.
- King, S., Chambers, C. T., Huguet, A., MacNevin, R. C., McGrath, P. J., Parker, L., & MacDonald, A. J. (2011). The epidemiology of chronic pain in children and adolescents revisited: A systematic review. *Pain, 152*(12), 2729-2738.
- Klink, M. E., Quan, S. F., Kaltenborn, W. T., & Lebowitz, M. D. (1992). Risk factors associated with complaints of insomnia in a general adult population: influence of previous complaints of insomnia. *Archives of Internal Medicine, 152*(8), 1634-1637.
- Kool, M. B., van Middendorp, H., Boeije, H. R., & Geenen, R. (2009). Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. *Arthritis Care & Research, 61*(12), 1650-1656.
- Kool, M. B., Van Middendorp, H., Lumley, M. A., Schenk, Y., Jacobs, J. W. G., Bijlsma, J. W. J., & Geenen, R. (2010). Lack of understanding in fibromyalgia and rheumatoid arthritis: the Illness Invalidation Inventory (3* I). *Annals of the Rheumatic Diseases, 69*(11), 1990-1995.
- Lautenbacher, S., Kundermann, B., & Krieg, J. C. (2006). Sleep deprivation and pain perception. *Sleep medicine reviews, 10*(5), 357-369.
- Link, B. G., & Phelan, J. C. (2006). Stigma and its public health implications. *The Lancet, 367*(9509), 528-529.
- Luyckx, K., Seiffge-Krenke, I., Schwartz, S. J., Goossens, L., Weets, I., Hendrieckx, C., & Groven, C. (2008). Identity development, coping, and adjustment in emerging adults with a chronic illness: The sample case of type 1 diabetes. *Journal of Adolescent Health, 43*(5), 451-458.
- Lund, H. G., Reider, B. D., Whiting, A. B., & Prichard, J. R. (2010). Sleep patterns and predictors of disturbed sleep in a large population of college students. *Journal of adolescent health, 46*(2), 124-132.
- Mallen, C., Peat, G., Thomas, E., & Croft, P. (2005). Severely disabling chronic pain in young adults: prevalence from a population-based postal survey in North Staffordshire. *BMC Musculoskeletal Disorders, 6*(1), 42.
- McCloughen, A., Foster, K., Huws-Thomas, M., & Delgado, C. (2012). Physical health and wellbeing of emerging and young adults with mental illness: An integrative review of international literature. *International Journal of Mental Health Nursing, 21*(3), 274-288.
- Mashhoon, Y., Czerkawski, C., Crowley, D. J., Cohen-Gilbert, J. E., Sneider, J. T., & Silveri, M. M. (2014). Binge alcohol consumption in emerging adults: Altered anterior cingulate cortical thickness is associated with alcohol use consequences. *Drug & Alcohol Dependence, 140*, e135-e136.

- Meldrum, R. C., & Restivo, E. (2014). The behavioral and health consequences of sleep deprivation among US high school students: Relative deprivation matters. *Preventive medicine*, 63, 24-28.
- Moldofsky, H. (2001). Sleep and Pain. *Sleep Medicine Reviews*, 5(5), 385-396.
- Moore, R. A., Straube, S., Paine, J., Phillips, C. J., Derry, S., & McQuay, H. J. (2010). Fibromyalgia: Moderate and substantial pain intensity reduction predicts improvement in other outcomes and substantial quality of life gain. *Pain*, 149(2), 360-364.
- Mullady, D. K., Yadav, D., Amann, S. T., O'Connell, M. R., Barmada, M. M., Elta, G. H., & Anderson, M. A. (2011). Type of pain, pain-associated complications, quality of life, disability and resource utilisation in chronic pancreatitis: a prospective cohort study. *Gut*, 60(1), 77-84.
- Muthén, L.K. and Muthén, B.O. (1998-2012). Mplus User's Guide. Seventh Edition.
Los Angeles, CA: Muthén & Muthén.
- Nelson, L. J., & Barry, C. M. (2005). Distinguishing features of emerging adulthood the role of self-classification as an adult. *Journal of Adolescent Research*, 20(2), 242-262.
- Neugarten, B. L. (1976). Adaptation and the life cycle. *The Counseling Psychologist*, 6(1), 16-20.
- Niv, D., & Kreitler, S. (2001). Pain and quality of life. *Pain Practice*, 1(2), 150-161.
- Ohayon, M. M. (2002). Epidemiology of insomnia: what we know and what we still need to learn. *Sleep medicine reviews*, 6(2), 97-111.
- Okifuji, A., & Turk, D. C. (2014). Assessment of Patients with Chronic Pain with or Without Comorbid Mental Health Problems. In *Mental Health and Pain* (pp. 227-259). Springer Paris, Chicago.
- Okifuji, A., & Hare, B. D. (2014). Chronic Widespread Pain and Fibromyalgia Syndrome. In *Handbook of Musculoskeletal Pain and Disability Disorders in the Workplace* (pp. 101-120). Springer New York.
- Orff, H. J., Drummond, S. P., Nowakowski, S., & Perlis, M. L. (2007). Discrepancy between subjective symptomatology and objective neuropsychological performance in insomnia. *Sleep*, 30(9), 1205e1211.
- Osborn, M., & Smith, J. A. (2011). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology*, 3(1), 65-83.
- Paananen, M., Taimela, S., Auvinen, J., Tammelin, T., Zitting, P., & Karppinen, J. (2011). Impact of Self-Reported Musculoskeletal Pain on Health-Related Quality of Life among Young Adults. *Pain Medicine*, 12(1), 9-17.
- Packman, W., Mehta, I., Rafie, S., Mehta, J., Naldi, M., & Mooney, K. H. (2012). Young Adults with MSUD and Their Transition to Adulthood: Psychosocial Issues. *Journal of genetic counseling*, 1-12.
- Palermo, T. M., Eccleston, C., Lewandowski, A. S., Williams, A. C. D. C., & Morley, S. (2010). Randomized controlled trials of psychological therapies for management of

- chronic pain in children and adolescents: an updated meta-analytic review. *Pain*, 148(3), 387-397.
- Palermo, T. M., & Holley, A. L. (2013). The Importance of the Family Environment in Pediatric Chronic Pain The Family Environment in Pediatric Chronic Pain. *Journal of American Medical Association Pediatrics*, 167(1), 93-94.
- Parmelee, P. A., Tighe, C. A., & Dautovich, N. D. (2014). Sleep disturbance in osteoarthritis: linkages with pain, disability and depressive symptoms. *Arthritis care & research*.
- Pavot, W., & Diener, E. (2008). The satisfaction with life scale and the emerging construct of life satisfaction. *The Journal of Positive Psychology*, 3(2), 137-152.
- Petrov, M. E., Lichstein, K. L., & Baldwin, C. M. (2014). Prevalence of sleep disorders by sex and ethnicity among older adolescents and emerging adults: Relations to daytime functioning, working memory and mental health. *Journal of adolescence*, 37(5), 587-597.
- Pinquart, M., & Shen, Y. (2011). Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *Journal of pediatric psychology*, 36(4), 375-384.
- Punjabi, N. M. (2008). The epidemiology of adult obstructive sleep apnea. *Proceedings of the American Thoracic Society*, 5(2), 136-143.
- Radloff, L. S. (1977). The CES-D scale A self-report depression scale for research in the general population. *Applied psychological measurement*, 1(3), 385-401.
- Raposa, E. B., Hammen, C. L., Brennan, P. A., O'Callaghan, F., & Najman, J. M. (2014). Early adversity and health outcomes in young adulthood: The role of ongoing stress. *Health Psychology*, 33(5), 410.
- Reed, P. (2006). Chronic pain stigma: Development of the chronic pain stigma scale. Alliant International University, San Francisco Bay). ProQuest Dissertations and Theses, 112-112 p. Retrieved from <http://search.proquest.com/docview/304911598?accountid=14472>
- Reifman, A., Arnett, J.J., & Colwell, M.J. (2007, Summer). Emerging adulthood: Theory, assessment, and application. *Journal of Youth Development*, 2(1). <http://www.nae4ha.org/directory/jyd/index.html>
- Richardson, J.T.E. (2011). Eta squared and partial eta squared as measurements of effect size in educational research. *Educational Research Review*, 6, 135-147.
- Richardson, L. P., Russo, J. E., Katon, W., McCarty, C. A., DeVries, A., Edlund, M. J., ... & Sullivan, M. (2012). Mental health disorders and long-term opioid use among adolescents and young adults with chronic pain. *Journal of Adolescent Health*, 50(6), 553-558.
- Roberts, R. E., Roberts, C. R., & Duong, H. T. (2009). Sleepless in adolescence: prospective data on sleep deprivation, health and functioning. *Journal of adolescence*, 32(5), 1045-1057.
- Robinson, M. J., Edwards, S. E., Iyengar, S., Bymaster, F., Clark, M., & Katon, W. (2009). Depression and pain. *Front Biosci*, 14(503), 1-5051.

- Rook, K. S., Catalano, R., & Dooley, D. (1989). The timing of major life events: Effects of departing from the social clock. *American Journal of Community Psychology, 17*(2), 233-258.
- Rudy, T. E., Kerns, R. D., & Turk, D. C. (1988). Chronic pain and depression: toward a cognitive-behavioral mediation model. *Pain, 35*(2), 129-140.
- Ruehlman, L. S., Karoly, P., & Pugliese, J. (2010). Psychosocial Correlates of Chronic Pain and Depression in Young Adults: Further Evidence of the Utility of the Profile of Chronic Pain: Screen (PCP: S) and the Profile of Chronic Pain: Extended Assessment (PCP: EA) Battery. *Pain Medicine, 11*(10), 1546-1553.
- Scholten, L., Willemen, A. M., Last, B. F., Maurice-Stam, H., van Dijk, E. M., Ensink, E., & Grootenhuis, M. A. (2013). Efficacy of Psychosocial Group Intervention for Children With Chronic Illness and Their Parents. *Pediatrics, 131*(4), e1196-e1203.
- Schwartz, S. J., Côté, J. E., & Arnett, J. J. (2005). Identity and Agency in Emerging Adulthood Two Developmental Routes in the Individualization Process. *Youth & Society, 37*(2), 201-229.
- Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. *A report from the WHOQOL group. Quality of Life Research, 13*(2), 299-310.
- Slade, S. C., Molloy, E., & Keating, J. L. (2009). Stigma experienced by people with nonspecific chronic low back pain: a qualitative study. *Pain Medicine, 10*(1), 143-154.
- Slaughter, J. R. (2005). Sleep and depression. *Missouri medicine, 103*(5), 526-528.
- Smith, M.T., & Haythornthwaite, J.A. (2004). How do sleep disturbance and chronic pain inter-relate? Insights from the longitudinal and cognitive-behavioral clinical trials literature, *Sleep Medicine Reviews, 8*, 119–132.
- Sprinkle, S. D., Lurie, D., Insko, S. L., Atkinson, G., Jones, G. L., Logan, A. R., & Bissada, N. N. (2002). Criterion validity, severity cut scores, and test-retest reliability of the Beck Depression Inventory-II in a university counseling center sample. *Journal of counseling psychology, 49*(3), 381.
- Steptoe, A., Peacey, V., & Wardle, J. (2006). Sleep duration and health in young adults. *Archives of Internal Medicine, 166*(16), 1689-1692.
- Strine, T. W., Chapman, D. P., Balluz, L. S., Moriarty, D. G., & Mokdad, A. H. (2008). The associations between life satisfaction and health-related quality of life, chronic illness, and health behaviors among US community-dwelling adults. *Journal of Community Health, 33*(1), 40-50.
- Sullivan, M. J., Bishop, S. R., & Pivik, J. (1995). The pain catastrophizing scale. Development and Validation. *Psychological Assessment, 7*(4), 524-532.
- Sullivan, M. J., Thorn, B., Haythornthwaite, J. A., Keefe, F., Martin, M., Bradley, L. A., & Lefebvre, J. C. (2001). Theoretical perspectives on the relation between catastrophizing and pain. *The Clinical journal of pain, 17*(1), 52-64.

- Syed, M., & Mitchell, L. L. (2013). Race, Ethnicity, and Emerging Adulthood Retrospect and Prospects. *Emerging Adulthood, 1*(2), 83-95.
- Tabachnick, B. G., Fidell, L. S., & Osterlind, S. J. (2001). Using multivariate statistics.
- Thomas, M., Roy, R., Cook, A., & Marykuca, S. 1992. Chronic Pain in College Students: Issues of management. *Canadian Family Physician, 38*, 2597–2601.
- Trzesniewski, K. H., & Donnellan, M. B. (2014). “Young People These Days...” Evidence for Negative Perceptions of Emerging Adults. *Emerging Adulthood*, doi: 2167696814522620.
- Tsao, J. C., Allen, L. B., Evans, S., Lu, Q., Myers, C. D., & Zeltzer, L. K. (2009). Anxiety sensitivity and catastrophizing associations with pain and somatization in non-clinical children. *Journal of health psychology, 14*(8), 1085-1094.
- Tsuno, N., Besset, A., & Ritchie, K. (2005). Sleep and depression. *Journal of Clinical Psychiatry*.
- Turk, D. C., & Okifuji, A. (1994). Detecting depression in chronic pain patients: adequacy of self-reports. *Behaviour research and therapy, 32*(1), 9-16.
- Turk, D. C., & Okifuji, A. (2002). Psychological factors in chronic pain: Evolution and revolution. *Journal of consulting and clinical psychology, 70*(3), 678.
- Twenge, J. M. (2013). The Evidence for Generation Me and Against Generation We. *Emerging Adulthood, 1*(1), 11-16.
- Vanable, P. A., Carey, M. P., Blair, D. C., & Littlewood, R. A. (2006). Impact of HIV-related stigma on health behaviors and psychological adjustment among HIV-positive men and women. *AIDS and Behavior, 10*(5), 473-482.
- Varkevisser, M., & Kerkhof, G. A. (2005). Chronic insomnia and performance in a 24-h constant routine study. *Journal of Sleep Research, 14*(1), 49-59.
- Vitiello, M. V., Rybarczyk, B., Von Korff, M., & Stepanski, E. J. (2009). Cognitive behavioral therapy for insomnia improves sleep and decreases pain in older adults with co-morbid insomnia and osteoarthritis. *Journal of clinical sleep medicine: JCSM: official publication of the American Academy of Sleep Medicine, 5*(4), 355.
- Wahl, O. F. (2012). Stigma as a barrier to recovery from mental illness. *Trends in cognitive sciences, 16*(1), 9-10.
- Werner, A., & Malterud, K. (2003). It is hard work behaving as a credible patient: encounters between women with chronic pain and their doctors. *Social Science & Medicine, 57*(8), 1409-1419.
- Westman, A. E., Boersma, K., Leppert, J., & Linton, S. J. (2011). Fear-avoidance beliefs, catastrophizing, and distress: a longitudinal subgroup analysis on patients with musculoskeletal pain. *The Clinical journal of pain, 27*(7), 567-577.
- Widome, R., Littman, A. J., Laska, M. N., & Fu, S. S. (2012). Preventing chronic illness in young veterans by promoting healthful behaviors. *Preventing Chronic Disease, 9*.
- World Health Organization. (1996). *WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment*. Geneva: WHO.

- Youssef, N. N., & van Tilburg, M. A. (2013). Cognitive Behavioral Therapy for Children with Functional Abdominal Pain. *In Pediatric Neurogastroenterology* (pp. 471-479). Humana Press.
- Zarrabian, M. M., Johnson, M., & Kriellaars, D. (2014). Relationship Between Sleep, Pain, and Disability in Patients With Spinal Pathology. *Archives of physical medicine and rehabilitation*, 95(8), 1504-1509.

Table 1. Demographics, Pain, Psychological Variables, and Emerging Adulthood Dimensions

	Overall Sample (N=301)	Pain Group (N=185)	Healthy Group	p-value	Normative Sores (Mean in college populations)
Sex					
Male	71 (23.6%)	40 (21.6%)	31 (26.7%)	<i>ns</i>	
Female	230 (76.4%)	145 (78.4%)	85 (73.3%)		
Age	18.92 (1.18)	18.96 (1.17)	18.89 (1.12)	<i>ns</i>	
Race					
Non-Hispanic White	253 (84.1%)	160 (86.5%)	93 (80.2%)	<i>ns</i>	
Black	42 (13.9%)	1 (0.5%)	5 (4.4%)		
Other	6 (2.0%)				
Relationship Status					
Single	203 (67.4%)	123 (66.5%)	80 (69.0%)	<i>ns</i>	
In a relationship	98 (22.6%)	62 (33.5%)	36 (31.0%)		
Pain Catastrophizing	13.97 (10.92)	16.67 (10.62)	9.63 (10.03)	<0.001	
Depression	15.43 (9.36)	17.99 (9.61)	11.37 (7.34)	<0.001	16.70
Satisfaction with life	26.32 (5.17)	25.39 (5.34)	27.81 (4.54)	<0.001	25.20
WHOQOL-Physical	56.70 (10.19)	55.65 (10.37)	58.35 (9.72)	<0.001	85.41
WHOQOL-Psychological	66.26 (12.12)	64.30 (12.42)	69.34 (10.99)	<0.05	71.40
WHOQOL-Social	70.94 (18.72)	68.61 (19.45)	74.62 (16.93)	<0.05	72.90
WHOQOL-Environmental	77.38 (13.51)	74.66 (13.79)	81.60 (11.92)	<0.05	74.30
IDEA-Identity	3.66 (0.34)	3.64 (0.36)	3.68 (0.30)	<0.05	3.35
IDEA-Possibilities	3.60 (0.40)	3.58 (0.40)	3.65 (0.39)	<0.05	3.37
IDEA-Instability	2.86 (0.49)	2.91 (0.48)	2.78 (0.50)	<0.05	2.93
IDEA-Self focus	3.59 (0.33)	3.55 (0.35)	3.65 (0.28)	<0.05	3.23

Table 2. Correlations between pain variables, psychological variables, and Emerging Adulthood Dimensions

	Dep	SWL	QOL-Phys	QOL-Psych	QOL Social	QOL-Env	Identity	Poss	Instabilit	Self
CAT	0.28** *	-0.23***	-0.11	-0.13*	-0.06	-0.21***	-0.001	0.009	0.12*	-0.004
Dep	-	-0.41***	-0.40***	-0.41***	-0.32***	-0.04	0.03	-0.04	0.30***	-0.15*
SWL		-	0.38***	0.50***	0.34***	0.49***	0.04	0.04	-0.26***	0.24***
QOL-Phys			-	0.52***	0.34***	0.51***	0.08	0.03	-0.20**	0.11
QOL-Psych				-	0.45***	0.45***	0.07	0.13*	-0.27***	0.29***
QOL-Social					-	0.31***	0.05	0.002	-0.18**	-0.13
QOL-Env						-	0.04	0.06	-0.17**	0.12
Identity							-	0.44***	0.13*	0.58***
Poss								-	0.19***	0.52***
Instability									-	0.08
Self										-

*: $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; CAT: Pain catastrophizing; Dep: Depression; SWL: Satisfaction with Life; QOL-Phys: Physical quality of life; QOL-Psych: psychological quality of life; QOL-Social: Social quality of life; QOL-env: Environmental quality of life; Identity: Identity dimension of emerging adulthood; Poss: Possibilities dimension of emerging adulthood; Instabilit: Instability dimension of emerging adulthood; Self: Self-focus dimension of emerging adulthood.

Table 3. Pain Characteristics of the Pain Group

Pain Variable	Mean (Standard Deviation)
Days pain experienced in the past 90 days	42.66 (23.42)
Pain intensity in the past 7 days (on a scale of 0 to 10 with 10 being the worst pain)	4.61 *(1.93)
Pain interference	5.36 (3.82)

*Considered “moderate” on an 11-point Likert scale.

Table 4. Multivariate Differences between pain and non-pain groups in terms of psychological well-being

Dependent Variable	Df	df Error	Mean Square	F	Means	P	Partial Eta Squared
Catastrophizing	1	290	3266.933	30.221	Pain	16.67	.000 .094
					Non-Pain	9.63	
Depression	1	290	3060.924	39.275	Pain	17.99	.000 .119
					Non-Pain	11.37	
Satisfaction with Life	1	290	356.769	14.480	Pain	25.39	.000 .048
					Non-Pain	27.81	

df: Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data ; F: Fisher's F ratio

Table 5. Multivariate Differences between pain and non-pain groups in terms of self-reported quality of life

Dependent Variable	df	Df Error	Mean Square	F		Means	P	Partial Eta Squared
QoL_Physical	1	291	415.567	4.177	Pain	55.65	.042	.014
					Non-Pain	58.35		
QoL_Psychological	1	291	1621.792	11.642	Pain	64.30	.001	.038
					Non-Pain	69.34		
QoL_Social	1	291	2196.057	6.701	Pain	68.61	.010	.023
					Non-Pain	74.62		
QoL_Environmental	1	291	3118.727	19.192	Pain	74.66	.000	.062
					Non-Pain	81.60		

df: Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data ; F: Fisher's F ratio; QOL-Phys: Physical quality of life; QOL-Psych: psychological quality of life; QOL-Social: Social quality of life; QOL-env: Environmental quality of life.

Table 6. Multivariate Differences between pain and non-pain groups in terms of the dimensions of emerging adulthood

Dependent variable	df	df Error	Mean Square	F	Mean	p	Partial Eta Squared	
Identity	1	291	5.142	.913	Pain	3.64	.340	.003
					Non-Pain	3.68		
Possibilities	1	291	8.082	2.045	Pain	3.58	.154	.007
					Non-Pain	8.65		
Instability	1	291	56.218	4.802	Pain	2.91	.029	.016
					Non-Pain	2.78		
Self-focus	1	291	21.045	5.410	Pain	3.55	.021	.018
					Non-Pain	3.65		

df: Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data ; F: Fisher's F ratio; Identity: Identity dimension of emerging adulthood; Poss: Possibilities dimension of emerging adulthood; Instability: Instability dimension of emerging adulthood; Self: Self-focus dimension of emerging adulthood.

Table 7. Demographic, Pain, and Psychological Variables

Variable	Frequency (%) or Mean (SD)
Sex	
Male	40 (21.6%)
Female	145 (78.4%)
Age	18.96 (1.17)
Race	
Non-Hispanic White	160 (86.5%)
Black	24 (12.9%)
Other	1 (0.5%)
Relationship Status	
Single	123 (66.5%)
In a relationship	62 (33.5%)
Days pain experienced in past 90 days	42.66 (23.42)
Pain intensity (past 7 days)	4.61 (1.93)
Pain Catastrophizing	16.67 (10.62)
Depression	17.99 (9.61)
Satisfaction with life	25.39 (5.34)
WHOQOL-Physical	55.65 (10.37)
WHOQOL-Psychological	64.30 (12.42)
WHOQOL-Social	68.61 (19.45)
WHOQOL-Environmental	74.66 (13.79)
CPSS-P	36.04 (4.80)
CPSS-D	31.44 (5.97)
CPSS-F	30.82 (7.01)
III-P	8.22 (3.12)
III-F	8.90 (2.86)
III-D	7.78 (2.55)

N=185; WHOQoL: World Health Organization Quality of Life Scale; CPSS-P: Public; CPSS-D: Doctors; CPSS-F: Family; III-P: Partner; III-F: Family; III-D: Doctors.

Table 8. Correlations between the demographic, pain, and psychological variables

	Days90	CAT	CESD	SWLS	Phys	Social	Env	CPSS-P	CPSS-D	CPSS-F	IIP	IIIF	IIID
PI	0.31***	0.31***	0.07	-0.12	-0.06	0.04	-0.93	0.12	0.17	0.14	0.15	0.11	0.2*
Days90	-	0.25***	-0.01	-0.91**	-0.10	-0.11	-0.17*	0.11	0.11	0.09	0.15	0.09	0.22**
CAT		-	0.27**	-0.19*	-0.11	0.002	-0.15*	0.10	0.21**	0.09	0.23	0.22**	0.32***
CESD			-	-0.38***	-0.37**	-	-0.21**	0.13	0.20	0.17	-	0.24**	0.20***
SWLS				-	0.35**	0.34**	0.44***	-0.06	-0.01	-0.29**	-0.32*	-0.32***	-
Phys					-	0.27**	0.47***	-0.11	.01	-0.07	-0.16	-0.19*	0.17*
Social						-	0.25***	-0.11	-0.06	-0.11	-	-0.28***	0.18*
Env							-	0.17**	-0.17	-0.25**	-0.12	0.33***	0.13
CPSSP								-	0.48***	0.48	0.06	-0.28***	0.35***
CPSSD									-	0.61***	0.34**	0.33***	0.38***
CPSSF										-	0.26	0.45***	0.32**
IIP											-	0.43**	0.36***
IIIF												-	0.50***
IIID													-

N=185; *: p<0.05; **: p<0.01; ***: p<0.001.

PI: Pain intensity in the past 7 days; Days90: Number of days pain experienced in the past 90 days; CAT: Pain catastrophizing; CESD-Scores on the Center for Epidemiological Scale-Depression; SWLS: Satisfaction with Life Scale; Phys: WHO Quality of Life-Physical health domain; Social: WHO Quality of Life-Social domain; Env: WHO Quality of Life-Environment domain; CPSSP: Chronic Pain Stigma Scale-Public; CPSSD: Chronic Pain Stigma Scale-Doctors; CPSSF: Chronic Pain Stigma Scale-Family; IIP: Illness Invalidation Inventory-Partner; IIIF: Illness Invalidation Inventory-Family; IIID: Illness Invalidation Inventory-Doctors.

Table 9. The unstandardized and standardized estimates of the Structural Paths

Path	Standardized Estimates	Standard Errors	Significance (p-value)
Illness Invalidation → Quality of Life	-0.533	0.169	0.000
Illness Invalidation → Pain-related Stigma	0.665	0.075	0.000
Illness Invalidation → Pain	0.521	0.196	0.008
Illness Invalidation → Depression	0.305	0.143	0.033
Illness Invalidation → Satisfaction with Life	-0.413	0.146	0.005
Pain-related Stigma → Quality of Life	0.039	0.168	0.816
Pain-related Stigma → Pain	-0.023	0.186	0.903
Pain-related Stigma → Depression	0.042	0.138	0.759
Pain-related Stigma → Satisfaction with Life	0.078	0.140	0.577

N=185

Table 10. Squared Multiple Correlations for the Dependent Latent Variables in the Final Model

Latent Variable	Squared Multiple Correlations
Pain-related Stigma	44.2%
Quality of Life	25.8%
Pain	25.6%

Table 11. Demographics, Pain, Sleep, and Psychological Variables

	Overall Sample (N=301)	Pain Group (N=185)	Healthy Group (N=116)	p-value	Normative Data on College Students
Sex					
Male	71 (23.6%)	40 (21.6%)	31 (26.7%)	<i>ns</i>	
Female	230 (76.4%)	145 (78.4%)	85 (73.3%)		
Age	18.92 (1.18)	18.96 (1.17)	18.89 (1.12)	<i>ns</i>	
Race					
Non-Hispanic White	253 (84.1%)	160 (86.5%)	93 (80.2%)	<i>ns</i>	
Black	42 (13.9%)	24 (12.9%)	5 (4.4%)		
Other	6 (2.0%)	1 (0.5%)			
Relationship Status					
Single	203 (67.4%)	123 (66.5%)	80 (69.0%)	<i>ns</i>	
In a relationship	98 (22.6%)	62 (33.5%)	36 (31.0%)		
Pain intensity		4.61 (1.93)			
Days of pain in past month		14.40 (7.57)			
Pain interference		5.36 (3.82)			
Sleep time (hours)	6.71 (1.33)	6.54 (1.39)	7.00 (1.17)	<0.05	7.02 (1.15)
Awake time (minutes)	56.00 (63.50)	67.91 (75.07)	37.14 (29.57)	<0.05	
Sleep quality	3.10 (0.87)	2.93 (0.84)	3.36 (0.81)	<0.001	
Pain Catastrophizing	13.97 (10.92)	16.67 (10.62)	9.63 (10.03)	<0.001	
Depression	15.43 (9.36)	17.99 (9.61)	11.37 (7.34)	<0.001	16.70

ns: not significant, p>0.05.

Table 12. Multivariate group differences controlling for sex and depressive symptomatology

Dependent Variable	Sum of Squares	df	Mean Square	F	p-value	Partial Eta Squared
Total sleep time	10.903	1	10.903	6.431	.012	.022
Total awake time	26712.99	1	26712.992	7.185	.008	.025
Sleep quality	4.685	1	4.685	7.172	.008	.025

Table 13. Bivariate analyses (Pain Group Only)

	Age	Sex	Race	Intensity	Interference	Pain (30 days)	PCS	CES-D	SQ	ST	AT
Age	-										
Sex	0.285	-									
Race	-0.03	-	-								
Intensity	0.075	0.066	0.02	-							
Interference	0.059	0.131	0.041	0.577***	-						
Pain (30 days)	0.007	0.182	0.003	0.337***	0.288***	-					
PCS	0.004	0.037	0.057	0.314***	0.506***	0.232**	-				
CES-D	0.006	0.189	0.156	0.073	0.139	-0.008	0.267**	-			
SQ	0.058	0.105	0.049	-0.182	-0.102	-0.141	-	-	-		
ST	0.11	0.059	-	0.006	0.053	-0.074	0.217**	0.266***	0.335	-	
AT	-	0.039	-	0.107	0.096	0.026	0.077	0.228**	-	-	-
	0.002	0.046	0.076						0.283**	0.192**	

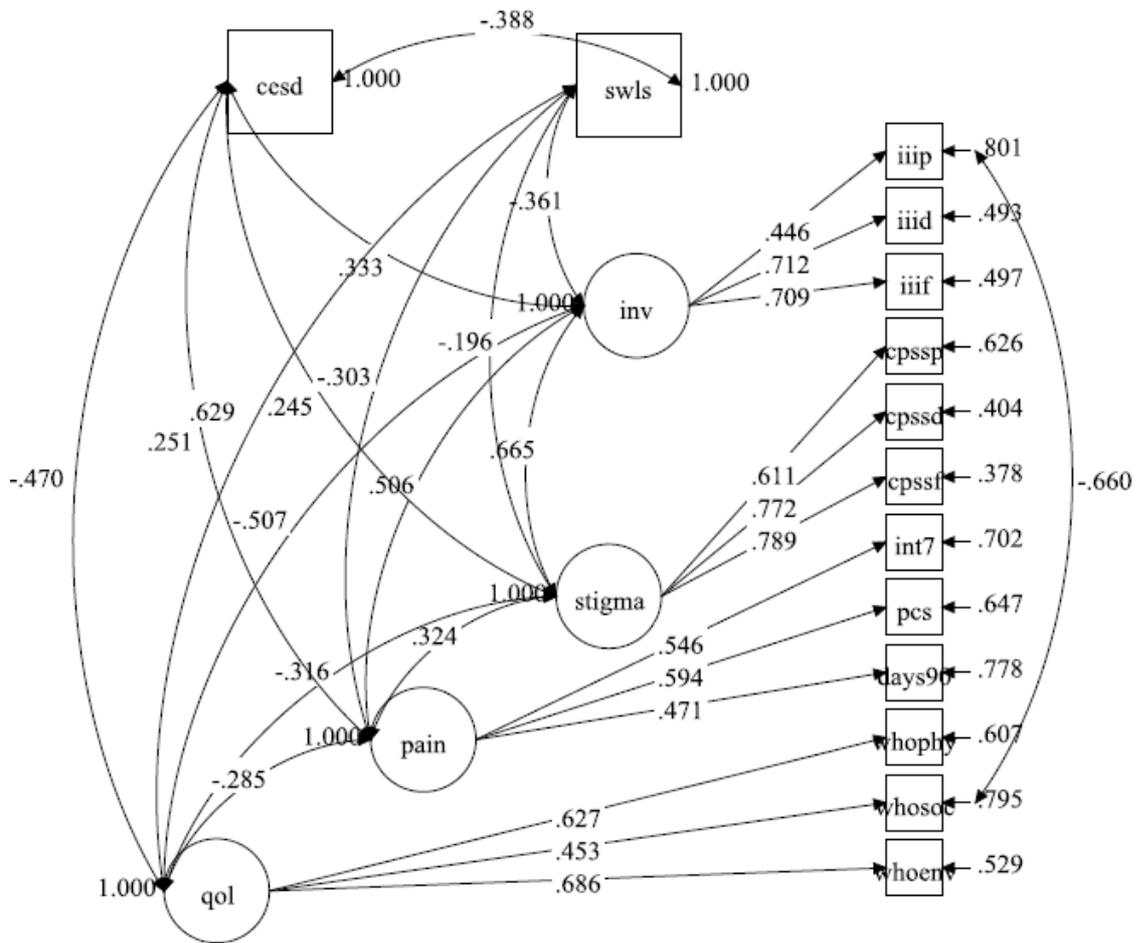
*: <0.05; **: <0.01; ***: <0.001. PCS: Pain Catastrophizing Scale; CES-D: Center for Epidemiological Scale-Depression; SQ: Sleep Quality; ST: Sleep Time; AT: Awake Time.

Table 14. Hierarchical Regression Model Examining Predictors of the Quality of Sleep

	Variable	B	SE(B)	<i>B</i>	R^2	ΔR^2	<i>F</i>	<i>p-value</i>
Step 1					0.028		3.702	0.027
	Pain Intensity	-0.052	0.178	-0.117				
	Days of pain	-0.015	0.035	-0.129				
Step 2					0.113	0.085	6.131	<0.001
	Pain Intensity	-0.026	0.035	-0.059				
	Days of Pain	-0.018	0.009	-0.126				
	Catastrophizing	-0.009	0.006	-0.119				
	Depression	-0.021	0.007	-0.241				

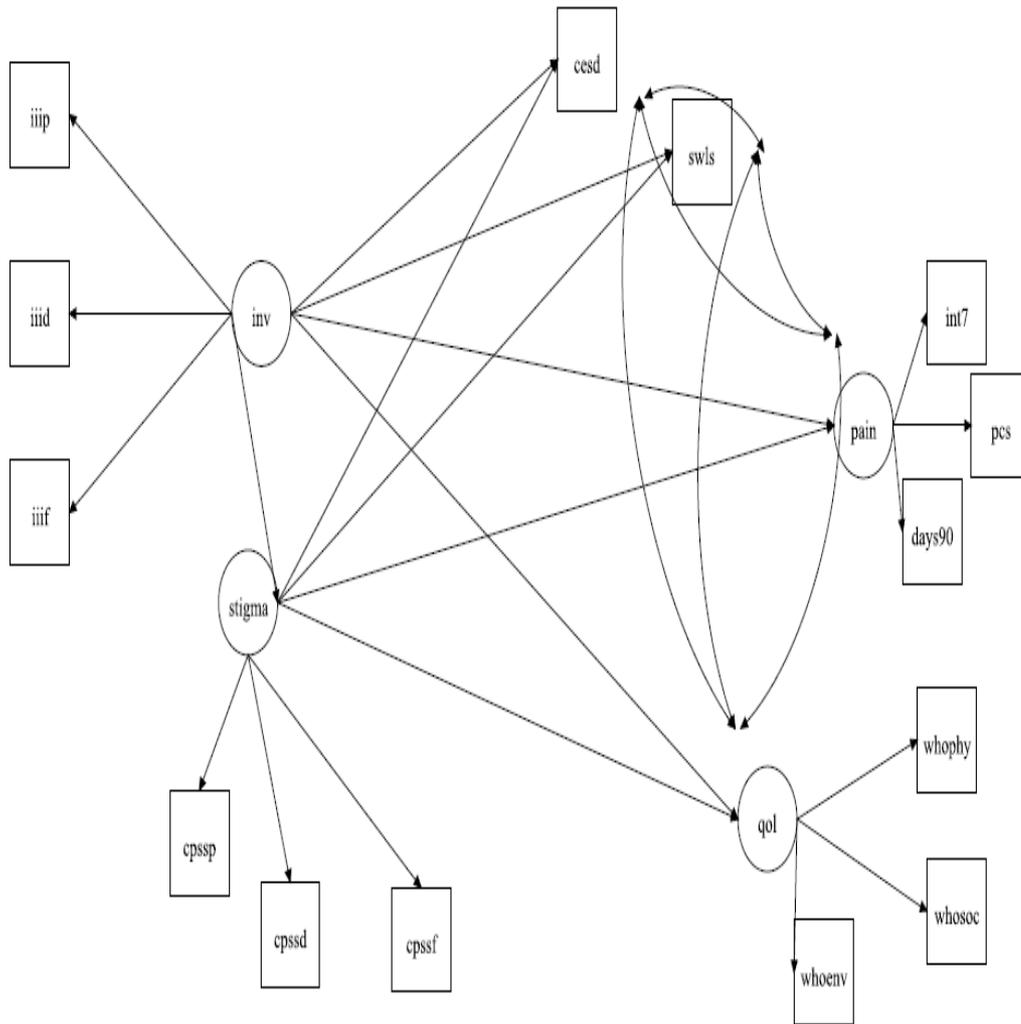
N=185. Pain Intensity: pain intensity in the past 7 days; Days of pain: number of days pain experienced in the past 90 days. .

Figure 1. Initial Measurement Model [Only indicates significant paths ($p < 0.05$)]



Inv: Illness Invalidiation; iiip: illness invalidation-partner; iiif: illness invalidation-family; iiid: illness invalidation-doctors; Stigma: Pain-related Stigma; cpssp: perceived stigma-people; cpssd: perceived stigma-doctors; cpssf: perceived stigma-family; qol: quality of life; whoenv: quality of life-environmental; whosoc: quality of life-social; whophys: quality of life-physical; cesd: depression; swls: satisfaction with life; pain: Perceived Pain; int7: pain intensity over the past week; pcs: pain catastrophizing; days90: number of days pain experienced over the past 90 days.

Figure 2. Hypothesized Latent Model

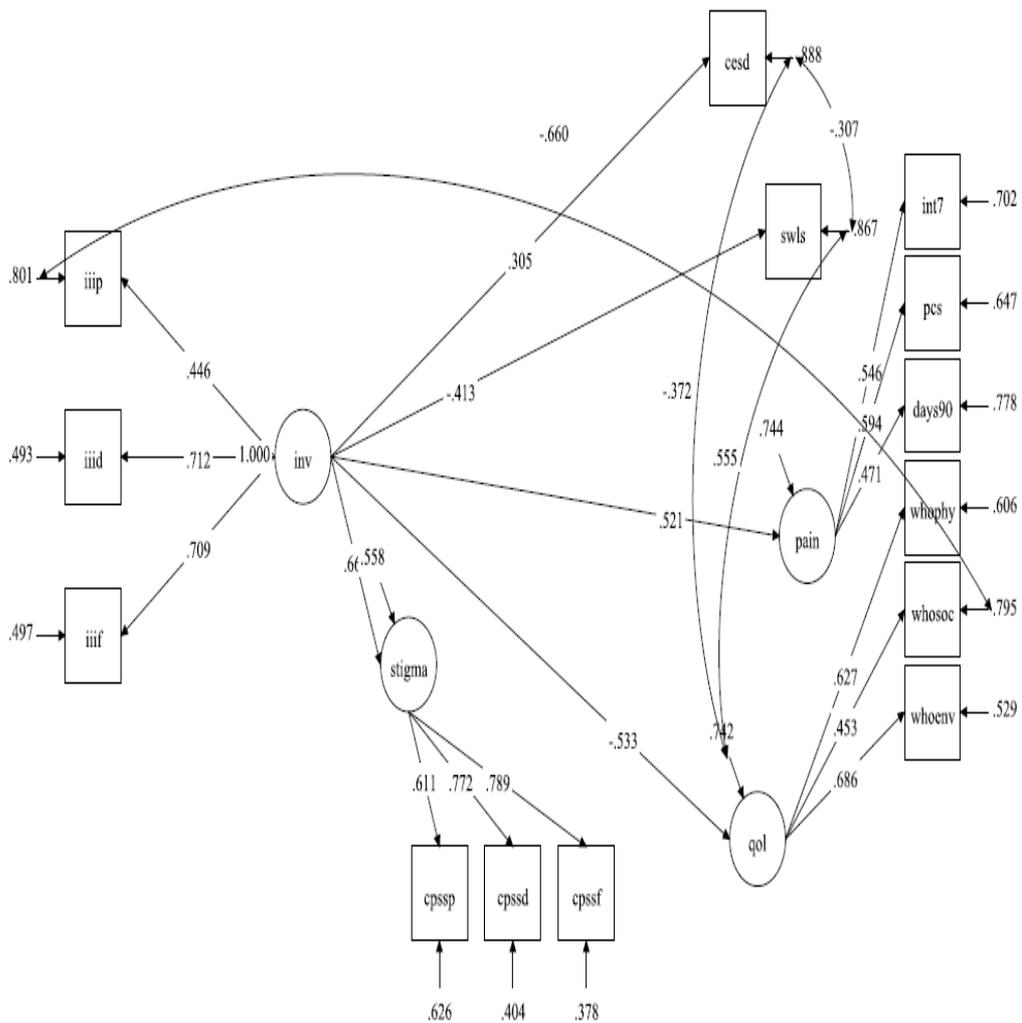


O

Inv:

Illness Invalidation; iiip:illness invalidation-partner; iiif: illness invalidation-family; iiid: illness invalidation-doctors; Stigma: Pain-related Stigma; cpssp: perceived stigma-people; cpssd: perceived stigma-doctors; cpssf: perceived stigma-family; qol: quality of life; whoenv: quality of life-environmental; whosoc: quality of life-social; whophy: quality of life-physical; cesd: depression; swls: satisfaction with life; pain: Perceived Pain; int7: pain intensity over the past week; pcs: pain catastrophizing; days90: number of days pain experienced over the past 90 days.

Figure 3: Final Latent Regression Model [Only indicates significant paths (p<0.05)]



Inv: Illness Invalidation; iiip:illness invalidation-partner; iiif: illness invalidation-family; iiid: illness invalidation-doctors; Stigma: Pain-related Stigma; cpssp: perceived stigma-people; cpssd: perceived stigma-doctors; cpssf: perceived stigma-family; qol: quality of life; whoenv: quality of life-environmental; whosoc: quality of life-social; whophys: quality of life-physical; cesd: depression; swls: satisfaction with life; pain: Perceived Pain; int7: pain intensity over the past week; pcs: pain catastrophizing; days90: number of days pain experienced over the past 90 days.

APPENDIX A

Emerging Adults Pain Study: Demographic and Pain Questionnaire

1. Age: _____
2. Gender: Male Female
3. **Year** in college:

 Freshman Sophomore Junior Senior
 Other: _____
4. Racial/ethnic group:

 White (non-Hispanic) White (Hispanic) Black (non-Hispanic)
Black (Hispanic) Asian/Indian Asian or Pacific Islander
 Native American Other: _____
5. Relationship status:

 Single In a relationship Married Divorced
 Separated
6. Employment status:

 Not working Employed full-time Employed Part-time
Looking for work
7. Do you have any children? Yes No

If yes, how many? _____
8. Do you live with:

 Parents Alone With a partner
 With a friend/room-mate
9. Are you a first-generation college student? Yes No
10. How hard is it for you to pay for the very basics like food, housing, medical care, and heating?

|-----|-----|-----|

0	1	2	3
Not difficult at all	Somewhat difficult	Difficult	Extremely difficult

11. Where are you from? Country: _____ State _____

12. Which state did you grow up in? _____

13. Do you have any close family member(s) who experience(s) persistent pain?

Yes No

If yes, what is your relationship to them? _____

14. At what age approximately do you think it is most common for people to experience or start experiencing chronic or persistent pain? _____ years

15. Do you have any chronic illness (more than 3 months' duration)? Yes No

If yes, what is it? _____ Duration: _____

Sleep:

a. Over the past two weeks:

i. On average how many hours did you spend asleep per night? _____

ii. On average, how many minutes did you spend awake per night (including time to fall asleep, time awake during the night, and time awake in the morning before getting out of bed)? _____

b. How would you rate the quality of your sleep in the last week? (Please circle the relevant number)

----- ----- ----- -----				
1	2	3	4	5
Very poor	Poor	Fair	Good	Very good

PAIN QUESTIONNAIRE:

1. A. Do you experience chronic pain regularly (pain most days in the last 3 months severe enough to interfere in your activities)?

Yes No

OR

B. Do you experience recurrent pain (periods of pain severe enough to interfere in your activities separated by times with no pain)?

If yes, please list it. _____

PAIN INTENSITY

1. For the past **90 days (3 months)**, on average, how intense has your pain been?

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible

2. For the **past 7 days**, on average, how intense has your pain been?

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible

3. How intense is your pain **right now**?

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible

PAIN INTERFERENCE:

Please respond to each question or statement below by marking one box per row.
In the **past 7 days**...

	Not at all	A little bit	Somewhat	Quite a bit	Very much
1. How much did pain interfere with your day to day activities?	<input type="checkbox"/>				
2. How much did pain interfere with work around the home?	<input type="checkbox"/>				

3. How much did pain interfere with your ability to participate in social activities?
4. How much did pain interfere with your household chores?

Pain Catastrophizing Scale

Everyone experiences painful situations at some point in their lives. Such experiences may include headaches, tooth pain, joint or muscle pain. People are often exposed to situations that may cause pain such as illness, injury, dental procedures or surgery.

We are interested in the types of thoughts and feeling that you have when you are in pain. Listed below are thirteen statements describing different thoughts and feelings that may be associated with pain. Using the scale, please indicate the degree to which you have these thoughts and feelings when you are experiencing pain.

	Not at all	To a slight degree	To a moderate degree	To a great degree	All the time
I worry all the time about whether the pain will end	0	1	2	3	4
I feel I can't go on	0	1	2	3	4
It's terrible and I think it's never going to get any better	0	1	2	3	4
It's awful and I feel that it overwhelms me	0	1	2	3	4
I feel I can't stand it anymore	0	1	2	3	4
I become afraid that the pain will get worse	0	1	2	3	4
I keep thinking of other painful events	0	1	2	3	4
I anxiously want the pain to go away	0	1	2	3	4
I can't seem to keep it out of my mind	0	1	2	3	4
I keep thinking about how much it hurts	0	1	2	3	4
I keep thinking about how badly I want the pain to stop	0	1	2	3	4
There's nothing I can do to reduce the intensity of the pain	0	1	2	3	4

CENTER FOR EPIDEMIOLOGIC STUDIES—DEPRESSION SCALE

Circle the number of each statement which best describes how often you felt or behaved this way – DURING THE PAST WEEK.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
During the past week:	0	1	2	3
1) I was bothered by things that usually don't bother me	0	1	2	3
2) I did not feel like eating; my appetite was poor	0	1	2	3
3) I felt that I could not shake off the blues even with help from my family and friends	0	1	2	3
4) I felt that I was just as good as other people	0	1	2	3
5) I had trouble keeping my mind on what I was doing	0	1	2	3
6) I felt depressed	0	1	2	3
7) I felt that everything I did was an effort	0	1	2	3
8) I felt hopeful about the future	0	1	2	3
9) I thought my life had been a failure	0	1	2	3
10) I felt fearful	0	1	2	3
11) My sleep was restless	0	1	2	3
12) I was happy	0	1	2	3
13) I talked less than usual	0	1	2	3
14) I felt lonely	0	1	2	3
15) People were unfriendly	0	1	2	3
16) I enjoyed life	0	1	2	3
17) I had crying spells	0	1	2	3
18) I felt sad	0	1	2	3
19) I felt that people disliked me	0	1	2	3
20) I could not get "going"	0	1	2	3

SWLS

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item **by placing the appropriate number on the line preceding that item.** Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

____ In most ways my life is close to my ideal.

____ The conditions of my life are excellent.

____ I am satisfied with my life.

____ So far I have gotten the important things I want in life.

____ If I could live my life over, I would change almost nothing.

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last four weeks**.

		Very poor	Poor	Neither poor nor	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four (4) weeks.

		Not at all	A little	A moderate	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7.	How well are you able to concentrate?	1	2	3	4	5

8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your means of transportation?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

IDEA Survey

- First, please think about this time in your life. By “time in your life,” we are referring to the present time, plus the last few years that have gone by, and the next few years to come, as you see them. In short, you should think about a roughly five-year period, with the present time right in the middle.
- For each phrase shown below, please place a check mark in one of the columns to indicate the degree to which you agree or disagree that the phrase describes this time in your life. For example, if you “Somewhat Agree” that this is a “time of exploration,” then on the same line as the phrase, you would put a check mark in the column headed by “Somewhat Agree” (3).
- Be sure to put only one check mark per line.

Is this period of your life a...	Strongly Disagree (1)	Somewhat Disagree (2)	Somewhat Agree (3)	Strongly Agree (4)
1. time of many possibilities?				
2. time of exploration?				
3. time of confusion?				
4. time of experimentation?				
5. time of personal freedom?				
6. time of feeling restricted?				
7. time of responsibility for yourself?				
8. time of feeling stressed out?				
9. time of instability?				
10. time of optimism?				
11. time of high pressure?				

12. time of finding out who you are?				
13. time of settling down?				
Is this period of your life a...	Strongly Disagree (1)	Somewhat Disagree (2)	Somewhat Agree (3)	Strongly Agree (4)
14. time of responsibility for others?				
15. time of independence?				
16. time of open choices?				
17. time of unpredictability?				
18. time of commitments to others?				
19. time of self-sufficiency?				
20. time of many worries?				
21. time of trying out new things?				
22. time of focusing on yourself?				
23. time of separating from parents?				
24. time of defining yourself?				
25. time of planning for the future?				

26. time of seeking a sense of meaning?				
27. time of deciding on your own beliefs and values?				
28. time of learning to think for yourself?				
29. time of feeling adult in some ways but not others?				
30. time of gradually becoming an adult?				
31. time of being not sure whether you have reached full adulthood?				

Illness Invalidation Inventory (3*1)

© 2008, Kool, van Middendorp & Geenen

We are interested in how others react to people who have health problems or an illness. Each of the sections below refers to different people in your life. We would like you to rate how often during the past year each person or category of people reacted toward you in the way described. After each statement, circle the number between 1 (never) and 5 (very often) to indicate how often they reacted toward you that way.

The questionnaire has five sections, and you will rate the same reactions a number of times, but referring to different people. If a particular section does not apply to you, you may skip that part of the questionnaire and go on to the next section. Remember, rate the items with respect to how others reacted toward you **as a person who has health problems or an illness**.

Section 1: Spouse or partner

If you are single (not married, a widow/widower, or without a steady partner) then skip Section 1 and go directly to Section 2.

My spouse or partner.....	Never	Seldom	Some- times	Often	Very often
1.1finds it odd that I can do much more on some days than on other days.	1	2	3	4	5
1.2thinks I should be tougher.	1	2	3	4	5
1.3takes me seriously.	1	2	3	4	5
1.4gives me unhelpful advice.	1	2	3	4	5
1.5understands the consequences of my health problems or illness.	1	2	3	4	5
1.6makes me feel like I am an exaggerator.	1	2	3	4	5
1.7thinks I can work more than I do.	1	2	3	4	5
1.8gives me the chance to talk about what is on my mind.	1	2	3	4	5

Section 2: Family

For example, children, parents, brothers, sisters, uncles, aunts, grandparents, in-laws.

My family.....	Never	Seldom	Some- times	Often	Very often
2.1finds it odd that I can do much more on some days than on other days.	1	2	3	4	5
2.2thinks I should be tougher.	1	2	3	4	5
2.3takes me seriously.	1	2	3	4	5
2.4gives me unhelpful advice.	1	2	3	4	5
2.5understands the consequences of my health problems or illness.	1	2	3	4	5
2.6makes me feel like I am an exaggerator.	1	2	3	4	5
2.7thinks I can work more than I do.	1	2	3	4	5
2.8gives me the chance to talk about what is on my mind.	1	2	3	4	5

Section 3: Medical professionals

For example, your primary care physician, medical specialist, physical therapist, and other medical professionals. (Do not include your employer's company physician).

Medical professionals	Never	Seldom	Some- times	Often	Very often
3.1find it odd that I can do much more on some days than on other days.	1	2	3	4	5
3.2think I should be tougher.	1	2	3	4	5
3.3take me seriously.	1	2	3	4	5

3.4give me unhelpful advice.	1	2	3	4	5
3.5understand the consequences of my health problems or illness.	1	2	3	4	5
3.6make me feel like I am an exaggerator.	1	2	3	4	5
3.7think I can work more than I do.	1	2	3	4	5
3.8give me the chance to talk about what is on my mind.	1	2	3	4	5

Section 4: Work environment

For example, your co-workers and boss. (Do not include your employer's company physician).

If you did not have paid or unpaid employment in the past year, then skip this Section and go directly to Section 5.

People at work.....		Never	Seldom	Some-times	Often	Very often
4.1find it odd that I can do much more on some days than on other days.	1	2	3	4	5
4.2think I should be tougher.	1	2	3	4	5
4.3take me seriously.	1	2	3	4	5
4.4give me unhelpful advice.	1	2	3	4	5
4.5understand the consequences of my health problems or illness.	1	2	3	4	5
4.6make me feel like I am an exaggerator.	1	2	3	4	5
4.7think I can work more than I do.	1	2	3	4	5
4.8give me the chance to talk about what is on my mind.	1	2	3	4	5

Section 5 : Social services

For example, your employer's company physician, work-reintegration or vocational rehabilitation staff, unemployment and other government agencies, organizations for care at home, general government workers and health insurance companies.

If you did not have any interactions with these providers, you may skip this Section.

People in social services.....	Never	Seldom	Some- times	Often	Very often
5.1find it odd that I can do much more on some days than on other days.	1	2	3	4	5
5.2think I should be tougher.	1	2	3	4	5
5.3take me seriously.	1	2	3	4	5
5.4give me unhelpful advice.	1	2	3	4	5
5.5understand the consequences of my health problems or illness.	1	2	3	4	5
5.6make me feel like I am an exaggerator.	1	2	3	4	5
5.7think I can work more than I do.	1	2	3	4	5
5.8give me the chance to talk about what is on my mind.	1	2	3	4	5

CPSS

Instructions: Each of the following statements describes attitudes that some people may express about chronic pain. Read each statement carefully. Then circle the response that best fits how you feel about the statement. Do not think too much about your answers, just circle the first response that feels right to you.

Please note: In the following 10 statements the word **people** refers to people in general, not to members of your family.

1. People believe that someone with chronic pain is as mentally and emotionally healthy as the average person.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

2. People believe that it is mostly the patient's fault when his/her pain does not get better.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

3. People are sympathetic when they hear about someone with a pain condition.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

4. People believe that chronic pain is used as an excuse to get pain medication.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

5. People understand the suffering experienced by someone with chronic pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

6. People may feel embarrassed to tell other people that they cannot do something because of their pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

7. People think less of someone who is unable to work because of chronic pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

8. People believe that having chronic pain is a sign of personal weakness.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

9. People think that someone taking prescription pain medication on a regular basis is a "drug addict."

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

10. When people hear that someone has chronic pain they think that person is also likely to have a mental or emotional problem.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

Please note: In the following 10 statements, the word **doctor** refers to doctors in general.

1. Most doctors believe that there is a real physical cause for chronic pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

2. Doctors think that people with chronic pain exaggerate their pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

3. Many doctors think that people with chronic pain want more pain medication than is necessary for their physical pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

4. Doctors think that chronic pain is mostly a mental or emotional problem.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

5. Most doctors think that people with chronic pain use pain medication appropriately.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

6. Most doctors think that people with chronic pain complain about their illness about as much as people with other medical conditions.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

7. Many doctors believe that people with chronic pain could be more physically active if they wanted.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

8. Many doctors think that people with chronic pain are less emotionally stable than people with other medical problems.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

9. Many doctors think that people with chronic pain are "drug addicts."

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

10. Most doctors would prefer not to treat people with chronic pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

Please note: In the following 10 statements the word family refers to the people most important to a person.

1. Family members of a person with pain understands that he/she has physical pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

2. Family members of a person with pain think that he/she needs less pain medication than they actually take.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

3. Family members of a person with pain feel that he/she exaggerates how much he/she hurts in order to get out of doing things that he/she doesn't want to do.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

4. Family members of a person with pain understand that he/she uses only as much pain medication as is medically necessary.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

5. Family members of a person with pain think that he/she could be more physically active if he/she wanted.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

6. Family members of a person with pain think that by taking pain medication on a regular basis he/she has become a "drug addict."

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

7. Family members understand that chronic pain is a real medical condition.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

8. Family members may have less respect for the person with pain since he/she developed chronic pain.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

9. Family members of a person with pain may think that chronic pain is more of a mental or emotional problem than a physical problem.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

10. Family members may feel embarrassed to tell people that a person in their family has a chronic pain condition.

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

APPENDIX B

Office for Research
Institutional Review Board for the
Protection of Human Subjects



June 14, 2013

Beverly Thorn, Ph.D.
Department of Psychology
College of Arts & Sciences
The University of Alabama

Re: IRB Protocol # 13-020-ME
"Emerging Adults with Chronic or Recurrent Pain: Relationships
between Pain Experience, Perceived Invalidation and Stress,
and Physiological Cytomegalovirus (CMV) Stress Response"

Dr. Thorn:

The University of Alabama Medical IRB has granted initial approval of the above application for a one-year period. Please be advised that your protocol will expire one year from the date of approval, 6/13/13.

If your research will continue beyond this date, complete the Renewal Application Form. If you need to modify the study, please submit the Modification of An Approved Protocol Form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure Form.

Should you need to submit any further correspondence regarding this proposal, please include the assigned IRB application number. Please use reproductions of the IRB approved stamped consent/assent forms to obtain consent from your participants.

Good luck with your research.

Sincerely,



358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
(205) 348-8461
FAX (205) 348-7189
TOLL FREE (877) 820-3066

John C. Higginbotham, Ph.D., MPH
Medical IRB Chair
The University of Alabama