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Erica Crosley Date

Understanding Illness Perceptions and Self-Efficacy to Manage Chronic Disease among Latinos with Lupus through the *Hablemos de Lupus* Facebook Page

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Master of Public Health

Global Epidemiology

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An abstract of
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Abstract

Understanding Illness Perceptions and Self-Efficacy to Manage Chronic Disease among Latinos with Lupus through the *Hablemos de Lupus* Facebook Page

By: Erica Crosley

Background: Latinos are disproportionately affected by the chronic autoimmune disease systemic lupus erythematosus (SLE), and they also have worse outcomes. Self-efficacy (SE) to manage chronic disease correlates with outcomes. Illness perception (IP) affects SE, but little is known about SLE patients' IP and SE. **Objectives:** This cross-sectional study aimed to: (1) Understand SLE IP and SE in Latinos (2) Examine IP by sociodemographic and disease characteristics (3) Test whether an increased emotional distress IP associates with low symptom management SE. **Methods:** Self-reported survey data was collected anonymously through the educational Facebook page *Hablemos de Lupus* (followed by 74,000 Spanish-speakers). *Ad-hoc* questions assessed sociodemographics and disease characteristics, the Brief Illness Perception Questionnaire assessed IP, PROMIS measures assessed SE, and the Stanford Evaluation Measure assessed communication with physicians. Programming in SAS calculated mean scores, tested IP by subgroups, and used multivariate logistic regression to examine the association of emotional distress IP and symptom management SE. **Results:** 1401 patients responded from 19 countries; ages 18-80; 95% females; 33% diagnosed in past three years; 46% with severe SLE. Mean total BIPQ score representing perceived illness threat was 45.1 (SD 10.1), emotional distress was 7.8 (SD 2.1), and illness comprehension was 8.2 (SD 1.9). Emotional distress and illness threat were significantly ($p<0.05$) higher if recently diagnosed or low SES. Illness comprehension was higher for those with severe SLE or diagnosis > 5 years. All SE T-scores were lower than the reference population's (ranging between 42.5 for managing emotions to 46.3 for treatment and symptom management). The mean provider communication score was 2.5 (SD 1.1). The adjusted OR was 1.44 [95% CI 1.29-1.61] for low symptom management SE (defined as PROMIS T score ≤40) per one unit increased emotional distress. Lack of social support and recent diagnosis were independently associated with low SE. **Conclusion:** Latino lupus patients have high illness threat and emotional distress levels along with low SLE management SE despite feeling they understand lupus. Emotional distress IP is associated with low symptom management SE. Education that impacts emotional distress may improve SE. Recently diagnosed patients and those lacking social support need extra provider support.

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Table of Contents:

Background

I. A Note on Terminology

This paper recognizes that the concepts of race and ethnicity are ever changing. We noticed the ongoing academic dialogue regarding the use of 'race' and 'ethnicity' in research and how these terms should be used moving forward (1). This study gathered information from Spanish-speakers in North, South and Central America. We are referring to our participants as 'Latino' given the common use of this term in the United States to refer to those with ancestral roots in Latin America (2). Occasionally we use the term 'Spanish-speakers,' but few other studies use this language. We recognize that there is genetic, racial and cultural heterogeneity among Latino persons and that we are not including certain non-Spanish-speaking Latino persons in our study. Many papers cited in this thesis refer to either 'Latino' or 'Hispanic' groups, and we are assuming that studies are relevant for our heterogeneous and multi-country study population. We use the term 'Hispanic' or 'Latino' when our source uses that term, even if we are unsure if they applied the term correctly. We refer to patients who are primarily non-Caucasian as 'minorities' based on research language used in the United States academic community and the language used in lupus papers on health disparities.

II. Overview of Systemic Lupus Erythematosus:

Epidemiology and Risk Factors:

Systemic Lupus Erythematosus (SLE) is a complex and chronic autoimmune illness that may damage any organ system and affects over five million people worldwide (3). SLE prevalence is 20 to 150 cases per 100,000 people and varies between countries and ethnic groups (4). Certain ethnicities have a higher prevalence and more severe disease manifestations (5). In particular, those that are of predominantly non-white ethnicity and are of African, Hispanic and Asian descents have higher risk for SLE development and less favorable outcomes (5-10). SLE occurs most commonly in adult women, but it may appear in men and children as well. This is

likely from hormonal influence on the immune system (11). Incidence and prevalence of SLE among women are nine to ten times that among men. Several studies show peak incidence rate of SLE occurring after age 40 in women, but African-American and Hispanics tend to develop SLE earlier and during childbearing years (4, 7-10). Mortality has decreased compared to several decades ago, partly from improved detection of mild and early cases (4). The five-year survival rate for a newly diagnosed patient is about 90%, and the 15-20 year survival rate is about 80% (4). However, mortality is substantially higher in ethnic minorities compared to Caucasians (4, 12)

Etiology and Pathogenesis:

SLE is an auto-immune condition in which the body's immune system erroneously damages its own tissues (particularly connective tissues such as cartilages and lining of blood vessels) (13). The cause is not completely understood, and genetic, hormonal and environmental factors all contribute (14). As a disease of the immune system, the production of autoantibodies is a hallmark, and multiple immune and inflammatory pathways are linked to SLE pathogenesis and clinical manifestations. Certain environmental triggers are associated with development and flares, with the most common being ultraviolet light exposure. Cigarette smoking, infections, and certain medications are also common triggers (11).

Much of the organ damage from SLE comes from injury to the tissues after antibodies bind and form immune complexes. These immune complexes are thought to cause many manifestations of SLE, especially renal damage from lupus nephritis. One difficulty in lupus research and treatment is that various parts of the immune system are abnormal. T cells, B cells, monocytes, and multiple cytokines are all implicated in SLE presentation and progression (14).

Clinical Presentation and Course:

SLE initial presentation and clinical course varies between individuals. Some patients experience abrupt disease onset and/or severe multi-organ damage. Others experience a more insidious onset and mild complications. SLE usually follows a relapsing-remitting pattern where

patients experience times of 'flares' when there is a higher production of autoantibodies and the disease is more active on laboratory tests or symptomatically (15).

SLE may affect any organ system including dermatologic, hematologic, renal, gastrointestinal, cardiovascular, pulmonary, musculoskeletal, and central nervous systems. Organ damage may be accrued over a long period of time or may happen quickly without warning (16). The classic textbook-taught presentation of the butterfly ('malar') rash with inflammatory arthritis is not that common, and only 20-40% of patients have the malar rash at presentation (15, 17, 18). More often, patients present with nonspecific symptoms such as fatigue, fevers, photosensitive rashes that come and go, lymphadenopathy, chest pain, mouth ulcers, arthralgias or malaise. This often results in delayed diagnoses (15).

The most common life-threatening organ complication is lupus nephritis. This occurs in anywhere between 15 to 50% of patients depending on genetic and ethnic background, and it may result in renal failure requiring dialysis (6). Patients with SLE are at a high risk for cardiovascular disease and myocardial infarctions (11). They also have higher risk for cancers of the blood, breast, lung and cervix (19). Mental health diagnoses such as anxiety and depression are frequent among patients with SLE (20). The most common causes of mortality are infections, atherosclerosis, and organ failure from active SLE (21).

III. Living with Lupus

Medical Management of SLE and Balancing Goals of Care:

SLE medical treatment may include glucocorticoids, nonsteroidal anti-inflammatories, antimalarials, immunosuppressants or biologics that target various aspects of the immune system (14). Treatment differs based on the organ involved and active flare versus maintenance therapy. Medication side effects are a concern. Immunosuppressant medications increase the risk for recurrent or life-threatening infections. Glucocorticoids can cause low bone density, psychiatric

disturbances, weight gain, cardiovascular disease, and secondary diabetes. Many patients struggle with body image because of glucocorticoid-associated weight gain, and extensive glucocorticoid use predicts decreased quality of life in lupus patients (19).

It is important to conceptualize SLE as a chronic illness in order to appreciate the multi-factorial nature of managing and living with lupus. Optimal SLE management requires early diagnosis and close follow-up every two to six months with a primary care doctor and rheumatologist to track disease activity and early signs of organ damage(19). Three concepts are central to the care of patients with SLE- improving patient quality of life, minimizing damage from disease activity and preventing long-term morbidity. Usually all three cannot be achieved simultaneously, and a physician and patient must work together to set priorities (19). Unfortunately, there is no easy way to predict who will develop severe complications or when a new flare will occur, leading to a high level of uncertainty for patients and their providers (15).

The Complexity of Lupus Self-Management and Impact on Quality of Life:

Like in many chronic conditions, self-management is key for SLE patients, as they must manage multiple appointments, multiple medications, current symptoms, prevention of flares, and the emotional impact of living with a chronic illness (22). Access to reliable and quality healthcare impacts long-term SLE outcomes (6). Lower socioeconomic status (SES) is associated with less favorable outcomes related to quality of life, disease activity and organ damage (6). Lower SES is also associated with higher mortality from SLE, and this is thought to stem from the need for patients to navigate and access complex specialty care to live successfully with lupus (6). A low SES often means a lack of adequate social support, quality healthcare access, illness understanding, and reliable transportation, which in turn create barriers for successful management (6).

In recent years, a focus developed on studying health-related quality of life (HRQoL) in patients with chronic diseases and also in SLE patients. HRQoL is seen as an important outcome for chronic disease patients, and SLE greatly affects several areas of HRQoL like physical

functioning, psychological/emotional status, and social interactions. The physical function decline is particularly impactful. A progressive functional decline in many SLE patients often results in disability and an inability to participate in the workforce, which decreases HRQoL (23). Disability and functional decline is more common in minority or impoverished populations (6). This emphasis on HRQoL is an example of a improved focus in SLE research on patient-centered outcomes rather than clinical or physiologic ones alone (24).

'Invisible Symptoms' of Lupus: Neuropsychiatric Disorders, Fatigue and Pain:

SLE patients express that 'invisible symptoms' (those that are not easily apparent to others) such as fatigue and pain are often the most distressing. They also report difficulty in communicating these with their social circle and physicians. In particular, neuropsychiatric symptoms, pain and fatigue are common and impact HRQoL (25-27).

SLE-related neuropsychiatric (NP) problems occur in 70% of patients (28). Headaches, cognitive dysfunction and psychiatric disorders like anxiety or depression are the most common (28). Strokes and seizures are serious but less prevalent (28). The cause of the common NP complications is multifactorial and related to both physiologic and non-physiologic processes (28). Rheumatologists are encouraged to screen for anxiety and depression in patients with SLE given its prevalence and association with decreased HRQoL and suicidal ideation (29, 30). Depression is common, with one study of Caucasian patients showing 65% having a diagnosis of major depression or anxiety disorder (31). In some populations, the rates of suicidal ideation are astounding. Depending on time since diagnosis and country lived in, rates of current suicidal ideation among SLE patients range from 8-10% in North America to 35% in China (30, 31).

Among the many signs and symptoms associated with lupus, fatigue and pain deserve particular attention given their prevalence and impact on HRQoL (32). Fatigue is present in up to 80% of SLE patients, is difficult to treat, and is not always associated with disease activity or severity of organ damage (25, 33). Pain may come in the form of widespread and non-localizable pain typical of fibromyalgia, or it may be acute and restricted to one organ system (34). Like

fatigue, it is not always associated with other signs of disease activity (34). Joint and muscle pain are frequent and may often be one of the first presenting symptoms (34). Treatment of SLE fatigue and pain involves non-pharmacological strategies such as aerobic exercise or cognitive behavioral therapy, which have proved somewhat effective (34).

Emotional Distress and Mitigation by Social Support

The term 'emotional' or 'psychological' distress is a broad term used in academics to encompass a range of emotional states that negatively impact an individual. These states may or may not be part of a psychiatric medical diagnosis (35). The term 'emotional distress' encapsulates an important aspect of the SLE- it covers feelings other than anxiety or depression and includes the complex network of psychological states that a patient with SLE may experience. There is a high risk of SLE patients having significant emotional distress during their illness, and the SLE literature uses the term to describe emotional changes that may be part of a NP diagnosis or may reflect any emotional state related to living with lupus (36). Examples of emotional distress components other than depressed mood and anxiety include emotional lability, worrying, uncertainty, guilt, and self-blame (36-38).

There are many causes of a SLE emotional distress, some stemming from coping with pain and fatigue (27, 39). Other sources come from non-physical stimuli. For example, patients report distress over symptoms being invisible to others, that their beliefs compared to those of healthcare providers differ, that they struggle with the uncertainty of prognosis, and that family, friends and providers do not understand the gravity or impact of their disease (27). While emotional distress is a known consequence of chronic illness (especially inflammatory ones like lupus), SLE patients have higher levels of distress compared to patients with other rheumatologic conditions like rheumatoid arthritis (36).

Social support is quite important in an individual's SLE experience and may mitigate emotional distress. Social support from friends, family, support groups and healthcare providers all have a positive impact on HRQoL and coping skills (26, 40, 41). Several SLE researchers

call on providers to consider social support when assessing a patient because poor support can have a negative impact on emotions, HRQoL, self-efficacy, and coping skills, and it can even increase the risk of mortality (26, 40, 41).

Living with lupus can have a profound psychological impact on patients, and many struggle no matter their level of disease activity or organ damage. Having better outcomes relies on a combination of healthcare resources, family/friend interactions and support, SES, self-efficacy and self-management practices, emotional coping and individual genetics.

IV. SLE Disparities and Lupus in Latino Populations

The negative impacts of lupus are more extreme in vulnerable and minority populations (42). The disparities between non-white SLE patients and their Caucasian counterparts are multifactorial, with genetic, socioeconomic and healthcare-access factors contributing (4, 43-45). Genetics are thought to play a role early in disease development, whereas socioeconomics and healthcare access contribute substantially to long-term outcome disparities(6). When SES in SLE patients is separated from ethnicity, its influence on poor outcomes and higher mortality is clear. However, there are varying opinions on how much the influence of SES is to blame for SLE health disparities (4, 6). It is not just the physiologic disparities that are concerning. Apart from more severe disease course and higher mortality, there are levels of unmet psychosocial needs and higher rates of depression and anxiety among minorities with SLE (42).

The academic focus on lupus ethno-racial disparities began in African-American populations. In recent years the lupus scientific community performed the first major Hispanic/Latino studies. These demonstrated higher lupus prevalence and outcome disparities like the results from African-American lupus studies (43). There are two cohorts that formed to study SLE in Latinos- The 'Grupo Latino Americano de Estudio del Lupus' (GLADEL) study cohort and the 'Lupus in Minorities: Nature vs. Nurture' (LUMINA) cohort (46). The GLADEL

study included 1214 patients from nine Latin-American countries within the first two years after diagnosis (47). The LUMINA cohort includes over 600 patients in the Southern U.S. and Puerto Rico (48). While these cohorts have been important for advancing the understanding of lupus in Latino patients, there are still major research gaps. There are no rigorous population-based epidemiological SLE studies in Latinos (49). Despite these gaps, the GLADEL and LUMINA studies along with other research into similar populations resulted in a general consensus that SLE in Hispanics/Latinos presents more frequently, at a younger age, and more acutely (6, 50). There is also a higher rate of relapse, higher disease activity, more damaging manifestations and a higher rate of mortality (6). The first clinical practice guidelines for the treatment of SLE in Latin-American patients was published in 2018 (50). This demonstrates that unique needs exist for Latinos with SLE. The guidelines also call for more research regarding Latino SLE in order to improve patient care and outcomes (50, 51).

V. Addressing Latino SLE: The *Hablemos de Lupus* Facebook Page

One theme that the SLE provider community has discussed in relationship to poor Latino SLE outcomes is the lack of educational and culturally appropriate resources for this community. The thesis advisor for this paper, Dr. Cristina Drenkard, and her colleagues noticed that the information available for Spanish-speaking patients with SLE was often directly translated from English materials and was rarely culturally appropriate (51). Among Latino patients in the U.S., a language barrier may complicate patient care and patient SLE understanding. Many providers felt that an increase in culturally relevant Spanish-language SLE materials for Latino patients would positively impact them (6, 45).

The Facebook page *Hablemos de Lupus* (*HdL*), translated as "Let's talk about lupus," was created in 2017 to address the gap in culturally appropriate lupus education resources in Spanish (52, 53). With over 80,000 followers from all over the world, *HdL* is now the largest

social media-based lupus education campaign for Latinos living with lupus (54). Dr. Drenkard and her colleagues from the Pan-American League of Rheumatology Associations (PANLAR) and the Group for the Study of Lupus (GLADEL) started the Facebook page primarily for patient education. It now has hundreds of posts, ranging from educational animated videos to live chats with experts to motivational stories. The *HdL* community provides a unique opportunity to recruit a large number of Spanish-speaking SLE patients from a variety of cultural backgrounds to provide information on their life with lupus. Because of the existence of this group, we may now fill a gap in lupus research and improve understanding of the Latino lupus population needs both abroad and in the U.S.

VI. Concepts and Quantitative Measurement Tools in Behavioral Health

Some of the terms we have used above like 'self-efficacy,' 'self-management,' 'emotional distress,' and 'perception' are part of decades of behavioral-health theories and research on living with chronic illness. The sections below outline important concepts in behavioral health that contribute to the framework for this thesis' central questions.

Leventhal's Common Sense Model (CSM):

The Common-Sense Model of Self-Regulation (CSM) by Leventhal and colleagues is a framework from behavioral health theory and used for over half a century. The CSM framework describes a patient's conceptualization of and reaction to a health condition. It is based on the idea that illness is an inherently stressful experience. The novel aspect of the CSM is the specification of two parallel pathways- the cognitive and emotional representations of the illness (55). The two paths are mostly independent and cause response behavior. The CSM also describes a feedback loop. What occurs after a regulatory behavior may change the patient's emotional or cognitive illness pathway. The patient appraises their behavior's effect on their

emotional state or illness outcome, and this information gets re-incorporated into the illness conceptualization (55, 56).

In summary, the CSM suggests that a person has mental representations of their condition and that these mental representations affect behavior. It also suggests that the patient monitors the perceived success or failure of the behavior. The CSM has an emotional and cognitive pathway following this pattern. CSM application is variable and broad given that it describes perception, behavior and cognitive representations (57, 58).

Illness Perception as Part of the CSM:

The CSM model is often used in studies of chronic diseases to understand patient illness representation and illness behavior (59). Original work for the CSM suggested five mental representation categories that have an effect on patient behavior: 1) identity- what a person may think the disease is, 2) timeline- what a person believes happens with the disease over time and how long the disease will last, 3) cause- what a person believes is the reason for developing the disease, 4) control/cure- whether a person believes certain things may be done to improve or change the disease course, 5) consequences- what outcomes a person believes their illness caused(59, 60). Mental representations are flexible and change through education or psychotherapy (59, 60).

The CSM mental representations were grouped into one term known as 'illness perception' (IP). IP research is becoming increasingly popular given the demonstrated link between IP and outcomes like recovery and disability, survival, and treatment-related behavior (61, 62). Generally, a less threatening IP is associated with better health outcomes (61, 62). Furthermore, IP is found to differ greatly between patient groups with the same illness, so studying it in various patient populations and demographics is informative (63, 64).

Understanding a patient's IP better informs interventions, and IP-based self-management education interventions have successfully developed for several conditions like renal and heart disease (63). These interventions changed IP through education, and they resulted in better

outcomes (better treatment adherence, faster return to the workforce, etc.) (63). Some studies on IP even suggest incorporating an IP tool into routine care and having providers target a negative IP (63, 64). IP has been studied quantitatively in various rheumatologic patient populations, including a few studies in patients with SLE. However, these studies were limited to small homogenous countries (New Zealand, the Netherlands, Poland) and did not report on all domains of IP (65). To our knowledge there are no studies specifically focusing on IP in Latinos with lupus.

Assessing Illness Perceptions- Brief Illness Perception Questionnaire ('BIPQ')

IP was originally studied qualitatively through open-ended questions and interviews. Eventually the Illness Perception Questionnaire (IPQ) was developed in the 1990's to assess the 5 mental representations (identity, timeline, consequences, control/cure and cause). This tool was revised to the Illness Perception Questionnaire-Revised (IPQ-R) in the early 2000s to add emotional representation and coherence (understanding) of illness. However, lengthiness of administration was a problem. As a response, Broadbent and colleagues created the Brief Illness Perception Questionnaire (BIPQ)- a 9-item IP scale for clinical or research settings (56, 63). The IPQ and BIPQ attempt to translate a patient's illness perception on an emotional and cognitive level into structured data. The BIPQ in particular has been used in over 36 countries, in 26 languages, and in over 180 studies of mental and physical illnesses (56, 65). The IPQ and BIPQ have been used in rheumatologic research, including in lupus patients (66-68). The BIPQ has also been translated and validated in a subset of Spanish-speakers (69).

The BIPQ has 9 questions related to individuals' perceptions about the illness, one for consequences, one for timeline, one for personal control, one for treatment control, one for identity (experience of symptoms), one for illness understanding/coherence, one for emotional representation and one for illness

concern (which is described as a combination of emotional and cognitive representations). There is one causal question that is free-response and asks the patient to list the top three causes of their illness. All responses (except for the causal question responses) are in the form of a Likert scale from 0 to 10, with 0 being the least extreme answer and 10 being the most extreme answer (65). For example, for the question of 'How much does your illness affect you emotionally?' , a score of 0 would represent 'not at all,' but a score of 10 would represent 'affects me a lot.'

Scoring of the BIPQ can be done on an individual question level or by calculating an entire score without the causality (as the causal answers must be grouped into categories and then undergo categorical analysis). Taking the scores for questions one, two, five, six and eight together and then adding the reverse scores for question three, four and seven calculates the total score. A high score represents a more threatening view of the illness and is known as the 'total score' or the 'illness threat score' (70). There is also a score that represents emotional distress, which is calculated by scoring question six (illness concern) and question eight (emotional representation), adding these scores together, and then dividing that number by two (70). See appendix A for a diagram explaining the structure and scoring of the BIPQ.

Self-Efficacy: Definition, History and Correlation with Self-Management Behaviors

Self-efficacy (SE) is central to chronic disease management. The concept originated in the latter half of the 20th century and was explored by Albert Bandura as part of Social Cognitive Theory (the theory which aims to predict and explain human behavior) (71-73). According to Bandura, SE is the belief in oneself to perform a specific behavior in an effort to achieve a goal. SE has two major characteristics- (1) SE is part of a behavior-determining process and (2) SE may be specific to certain behaviors (i.e. someone might have a high level of self-efficacy for one task or area of behavior like taking medications but not another like managing symptoms) (71, 72, 74, 75). SE also may precede a behavior or it may result from a behavior. In other words, SE

may either predict behavior or you may augment it through interventions (75). SE has also been accepted as its own conceptual framework among chronic illness researchers outside of Bandura's theory, demonstrating it's central role in chronic illness (76, 77)

SE has a close relationship with self-management (SM) (78). SM refers to a set of behaviors that an individual does in order to change, improve or maintain their physical and/or mental wellness and typically refers to those with chronic conditions. SM behaviors fall into the categories of medical and behavior management (i.e. taking a prescribed medicine or doing more exercise), role management (i.e. changing the way or amount of time in which one does a hobby or activity like knitting), and emotional management (i.e. learning how to cope with the anger felt at having pain or chronic symptoms from a disease) (79). It is helpful to think about self-management as certain actions or behaviors and self-efficacy as how confident someone feels in their ability to perform certain actions or behaviors.

SM behavior and SE are intrinsically tied, and SE is an important predictor of successful patient SM behavior (78, 80). Better SM behaviors in chronic illnesses relate to better health outcomes (79). The SM behaviors necessary to achieve a change in outcomes vary based on the illness and the population. The mechanism by which self-management prevents poor outcomes is multifactorial (79). The fact that SE is an important part of SM skills is evidenced by the multitude of interventions that claim to target SM behavior which are actually teaching a combination of the SM skill with how to increase SE (75, 78, 79, 81). The association of SE with SM and health outcomes is now widely accepted in behavioral health, and there are many tools to measure SE (81, 82).

Self-management and Self-efficacy in Patients with SLE

SM and SE have been recognized as an integral part of SLE care for several decades now (83). One tangible example is how SM behaviors such as medication adherence decrease SLE activity and risk of flares (84-86). Interventions that address SM/ SE for SLE patients demonstrate improvements in cognitive function, global physical function, global mental health

status, fatigue and pain (86-88). Observational studies demonstrate an association between SE in SLE patients and improved medication adherence, physical function, mental health status, disease activity, and health-related quality of life (89-91). While interventional SE/SM studies show promising results, there are fewer studies examining SE/SM in SLE patients and it's important to grow our understanding of SE/SM in certain SLE patient subsets (92, 93). Given that differences in SM/SE may be seen based on demographic/socioeconomic characteristics of patients, it is important to examine SM/SE amongst minority patients (94). To our knowledge there are no studies specifically focusing on SE in Latinos with lupus.

Measuring Self-Efficacy: Patient Reported Outcomes Measurement Information System (PROMIS) and Stanford Physician Communication Tool

Multiple tools exist to examine SE. Many chronic disease studies examine SE as an outcome given its correlation with self-management behavior and other positive outcomes (95). Two tools are described below that relate to patient SE.

PROMIS: Background and Scoring

Patient Reported Outcome Measurement Information System (PROMIS®) was created by the National Institute of Health in order to develop standardized, validated tools for measuring patient-reported outcomes (95). One such construct is SE to manage chronic conditions, and the definition of this as per PROMIS is "An individual's confidence in his/her ability to successfully perform specific tasks or behaviors related to one's health in a variety of situations" (95). The PROMIS tools are generalizable to a multitude of chronic conditions and are available for use among non English-speaking populations (96). The lupus research community supports patient-reported outcome measures like PROMIS (24).

Our study measures four domains of SE with PROMIS tools (rather than measuring general SE). These domains are chronic disease symptom, emotion, social interaction, and medication/treatment management. PROMIS has a validated

translation system for use in Spanish-speaking populations (96). PROMIS results are reported as T scores, which are calculated by the PROMIS Health Measure Scoring System. This scoring system uses response pattern scoring rather than just using a raw score conversion table (97). A higher PROMIS SE score represents better SE for that domain. The T score is the reference population standardized PROMIS score where the mean is 50 and the standard deviation (SD) is 10. The raw score determining the mean T score is determined by a large clinical sample of U.S. patients with various chronic diseases (aka the 'centering sample') (98). The PROMIS website suggests a cutoff of 40 (one SD below the population mean) as the point where SE to manage chronic disease is considered low (99). Although PROMIS tools are available in several languages, we should note that they were developed with a U.S. clinical sample for T score calibration and centering. They have not been rigorously tested and validated for use in different cultures, but they are used by many international researchers (97). Appendix B includes a copy of the four PROMIS short forms used in this study.

Communication with Physicians Evaluation Tool

Originally developed by chronic disease self-management researchers and Stanford University, the 'Communication with Physicians' evaluation tool asks three questions regarding a patient's communication behavior with a physician. It is asking about behavior frequency, so it falls under the category of a SM measurement tool, but, as described above, SM has a large overlap with SE so it may be seen as a SE proxy also. On the measurement tool's website it is listed as a SE measurement tool (100). The answers are on a 6-point Likert scale with 0 being 'never' and 5 being 'always,' and the final score is determined by taking the mean of all three numerical answers. The higher this overall score, the higher the patient's communication with their physician (100). This tool was used and evaluated for 550

Spanish-speakers as part of the 'Tomando Control de su Salud' through Stanford and is publically available in Spanish (100, 101). Appendix B contains a copy of the Communication with Physicians Evaluation Tool.

Illness Perception and Self-Efficacy:

In the early 2000s, Lau Walker suggested that SE be considered in relation to Leventhal's CSM concept of IP (102-104). Lau Walker argued that SE and IP both influence SM behaviors and are not exclusive. They examined this hypothesis in patients with heart disease, first looking at the relationship between general SE and the 'consequences' domain of IP. As hypothesized, there was a significant relationship (102). In another study, they examined self-efficacy for exercise over time in relation to certain IP domains, and they found that control, identity and timeline domains of IP were associated with SE for exercise (104). A later study by Lau Walker looked at the whether certain IP domains could predict general, diet and exercise SE; they found that symptoms and control/cure IPs could predict SE (105). Breland's review article in 2010 regarding the relationship between IP and SE argued in favor of Lau Walker's view that they are not exclusive given their strong correlations with SM behavior and various other patient outcomes (62). Another author, Bonsaken in Scandinavia, examined the relationship between IP and SE among obese patients and those with COPD, and they argued for the examination of IP as a modifiable influencer of SE (76). These studies demonstrate the minimal amount of research (to our knowledge) on IP's association with SE and a need for continued studies on these two concepts in specific disease populations. At the same time, they demonstrate theoretical and experimental support for a connection between IP and SE, and that modifying IP as a way to enhance SE. To our knowledge, there is no research into the relationship between IP and SE for SLE patients.

VII. Bringing it all together: A novel project to understand Latinos with SLE and make patient education recommendations

Patient education (PE) is a broad term that encompasses different domains depending on the disease, the educator's professional role in relationship to the patient, and desired outcome of the education. More recently the conversation around PE has focused on what types of knowledge may impact behavior. For example, impacting self-management behaviors and self-efficacy for a particular patient are now accepted targets for education efforts, rather than transmitting pure factual information (78). In 2015, the European League Against Rheumatism published an overview of patient education for conditions of inflammatory arthritis like SLE. They recommended that PE and PE research be individualized for certain subgroups of patients (e.g. men vs. women, varying cultural backgrounds). They also called for PE to be rooted in behavioral health theory to impact factors such as SE (106). This is similar to recommendations for education in other chronic diseases (78, 107, 108). Targeted PE has the potential to reduce ethno-racial disparities in chronic illnesses like lupus.

This study aims to contribute to the effort for better PE focused on SE in the Spanish-speaking population, a population historically underrepresented in lupus research. The goal of this project is to quantitatively evaluate IP and SE/SM in Latinos with SLE from South, Central and North America through an online survey and using a cross-sectional study design. The *HdL* page provides a unique and large pool of potential participants from various countries, which can be leveraged to provide this information. Furthermore, we want to test a relationship between IP and SE in order to make an educated conclusion about whether IP is a modifiable factor for SE outcomes and a future target for Latino SLE education programs.

Methods

Study Description and Sampling Methods:

This was an observational quantitative study using an online cross-sectional survey of Latino lupus patients through the *HdL* Facebook page. The study was designed for two phases: (1) To explore IP, SE, and communication with physicians, and (2) To test a hypothesis related to one IP domain and one SE domain based on initial exploration. The final hypothesis tested was that a higher emotional distress was associated with increased odds for low SE to manage symptoms. The study's goal was to gain new understanding about Latinos with SLE in order to make recommendations regarding patient education, hence the multifaceted nature of design and analysis.

The sampling method was voluntary responses. Those that accessed the public *HdL* Facebook page could take the survey through a link within a Facebook post. There are large numbers of followers of the *HdL* Facebook page (>84,000), and we desired responses from participants in multiple countries on a topic with little previous research even though convenient sampling may introduce bias. We attempted to control for this bias in our analysis.

Inclusion/Exclusion Criteria and IRB Considerations:

The Emory University Institutional Review Board approved the study and any promotional materials. Inclusion criteria were being at least 18 years old, speaking Spanish, and receiving a lupus diagnosis by a physician. Exclusion criteria were being located in any country in the European Union. Those located in the EU were not eligible to respond at the request of our Institutional Review Board given new legislation regarding data transmission outside of the EU. We collected data carefully so that no identifiable information was requested. All study participants provided anonymous online consent before starting the survey.

Recruitment Techniques:

The researchers' anecdotal experiences suggested that many patients are unfamiliar with the culture and steps of scientific research. Given that *HdL* is a patient education page, we used the recruitment phase as an opportunity to inform the Latino SLE community about scientific research. An animated video posted on the *HdL* page describing the purpose of research and informed consent on September 24th, 2019. The survey was posted on September 25th, 2019, and a reminder video was posted on September 30th, 2019. On October 8th, 2019, a live educational video chat occurred with the primary investigator regarding SLE research. The survey collected ~1000 responses in the first week and continued until December 20th, 2019. This extended collection minimized possible selection bias from inclusion of only early responders.

Hablemos de Lupus User Participation and Demographics:

Some terms relating to Facebook statistics are followers, engagement and reach. These are defined in Facebook's glossary (109). Followers are those that click on a Facebook page's 'follow' button and receive updates from that page on their personal Facebook feed. Engagement and reach are terms that Facebook uses to report statistics on a whole page or an individual post within the page to the page's administrators. Engagement is counted if a person shares a post with another user, reacts with a 'like' or other emotion on the post, comments on the post, or clicks a link or picture embedded in the post. Reach is the amount of people exposed to a post. This number may be increased or decreased by external factors such as the Facebook algorithm that results in suggesting a specific *HdL* post for a user in their main feed. Administrators of a page may also pay Facebook to promote their material and increase reach. *HdL* does not pay for Facebook to promote materials.

The *HdL* Facebook page had 77,331 followers on September 24, 2019, which was the day before starting data collection and the day that the lupus research education video posted. The three-and-a-half-minute research education video had a reach of over 30,000. There were over 1,200 one-minute views and 3,798 engagements. The initial study recruitment link posted on September 25, 2019 had over 40,000 reaches, 6692 engagements, 5288 clicks on anywhere in

the post, and 1032 clicks on the embedded survey link in the post. The reminder to participate nine-second video posted on September 30th, 2019 had a reach of over 5,200 users with 157 engagements and 490 views. The live video chat on lupus and research on October 8, 2019 had a reach of over 13,500, with 2,377 people viewing one minute or more and 1,318 engagements. The survey software Typeform was the online program used for data collection, and Typeform showed that there were 2095 unique survey visits. Of those visits there were 1401 eligible participants.

The *HdL* Facebook page currently (as of April 17, 2020) has 83,153 followers. Facebook reports demographics for *HdL* followers to better understand who is viewing the page. Eighty-nine percent are female and 11% are male. Most are 25-34 years old or 35 to 44 years old (33% and 29% respectively). The next highest age group representation is 45-54 years old at 17%. Age groups 18-24 and over 55 each represent 9% and 11% respectively. Less than 1% are younger than 18 years old. Followers live in 45 countries, with the top countries represented being Mexico (32%), Argentina (14%), Peru (7%), Colombia (7%), and the U.S. (7%). All Latin-American countries are represented by *HdL* followers.

Study Measures:

The survey contained 68 required questions and took 15-20 minutes to complete. It collected variety of data, including sociodemographics, disease characteristics, most worrying SLE complications, illness perceptions, self-efficacy to manage chronic illness, and communication with physicians. See Figure 2 for a concise list of measures grouped by outcomes, exposures and covariates.

Outcomes:

The outcome explored by univariate and multivariate logistic regression was SE to manage symptoms as measured by PROMIS Short Form v1.0 – Self-Efficacy for Managing Symptoms (4a). This tool has four questions regarding confidence in one's ability to manage symptoms. Answers are given on a Likert scale of one to five, where

one represents 'not confident at all' and five represents 'very confident.' The results are sent to the Health Assessment Scoring Service for conversion to a standardized T score created from a chronic illness population in the U.S. The mean T score for PROMIS SE measures is 50 with a SD of 10. A score cutoff of 40 or lower defined our outcome of a low SE to manage SLE symptoms.

Other outcomes were collected but not evaluated in a final univariate and multivariate logistic regression models. Three other SE to manage chronic disease domain measures were collected using the following: PROMIS Short Form v1.0- Self-Efficacy for Managing Emotions 4a, v1.0- Self-Efficacy for Managing Social interactions 4a, and v1.0- Self-Efficacy for Managing Medications and Treatments 4a (95). Communication with physicians was measured by the 'Communication with Physicians' evaluation tool originally created by Stanford University (110). It includes three questions about the frequency of communication behavior. Responses are in the form of Likert scales from zero to five, with zero being 'never' and five being 'always.' The total score is the average of all three individual question scores.

Exposures:

Illness Perception was the exposure, as measured by the Brief Illness Perception Questionnaire (BIPQ) (56). The main illness perception domain included in the multivariate model was emotional distress. The BIPQ has eight quantitative questions with responses on a Likert scale of zero to ten (zero being the least extreme answer to the question and ten being the most). Emotional distress represents a combination of two questions representing illness concern and emotional response.

Each individual BIPQ question's mean score was calculated and reported. The total BIPQ score (illness threat score) was calculated by reverse scoring questions 3,4, and 7 and adding with the values of the non-reverse-scored questions. Emotional

distress, illness comprehension (question 7), and illness threat were examined by certain covariates.

Covariates and potential confounders:

Sex, age, education level, financial strain, insurance type, employment, certain disease characteristics, past *HdL* use, and lack of social support were collected as potential covariates. Socioeconomic status covariates were collected in a broad way aimed at capturing the variety in a multi country study. For example, rather than asking monthly income, which has different implications depending on the country of the participant, we asked if someone has money left over at the end of the month (111).

There were some variables collected not as covariates but as population descriptors. These were country (as a written-in text response), general health rating (Likert scale of one to 5), most worrying SLE complications or symptoms (users were asked to choose four), and whether someone had a rheumatologist providing most of their SLE care.

Age was collected as categorical five-year groups and later grouped into three broader categories (18-35, 36-55, 56 and over). Education, insurance type, employment and financial strain were all collected as categorical variables. Education was collected as three categories: primary school education, secondary school education or technical school, and university or higher. It was later dichotomized for the final model to having a university degree or not. Insurance categories were public insurance, private insurance or no insurance/disability. Financial strain was originally collected as five categories but was dichotomized based on whether someone had any money left at the end of the month.

The disease characteristic covariates included time since diagnosis and history of severe lupus manifestations (central nervous system, vascular, pulmonary or renal). Time since diagnosis was collected as <1 year, 1-3 years, 3-5 years, 5-10 years and < 10 years. It was later grouped as <1 year, 1-5 years and >10 years. History of severe complications

was dichotomized into whether someone had any of the complications we asked about or not.

Other covariates collected were *HdL* use and social support. *HdL* use was first collected as number of videos seen (none, 1-5, >5) and later dichotomized into having seen five or less and more than five videos. Social support was collected as a binary variable and asked whether a participant felt supported by family and friends.

Approval to use the BIPQ was obtained directly from the author, along with the scoring instructions. PROMIS measures and the Physician Communication tool are available online for public use. Permission was granted to reprint PROMIS and Physician Communication in this thesis' appendices. All materials were available in Spanish online, and the PROMIS translation service provided the short form questions in Spanish.

Data Export, Cleaning and Analysis:

The survey was created on the web platform 'Typeform' and was designed in Spanish by the primary and supervising author, who is a native speaker. Five Spanish-speaking volunteers with lupus from different SES and Latin American countries piloted the survey before data collection began. Once collection completed, the results were exported into a spreadsheet. Data collected through PROMIS were submitted to the Health Assessments Scoring Service, which provided raw and standardized T scores for each PROMIS SE measures. These scores were incorporated into the larger spreadsheet, which was then converted into a Statistical Analysis System (SAS) data file. The primary author performed all the data cleaning in SAS. Country text-response answers had to be cleaned extensively into consistent character responses. Binary character variables were converted to numerical 0 or 1. Indicator variables were created for certain categorical data to be used in the final model. All Likert-scale variables were converted to numerical format. Variables were created for the calculated values of BIPQ total score,

emotional distress score, and total communication with physician score. A binary variable for low SE to manage symptoms was created using the cutoff of 40 (99). This cutoff, recommended by the PROMIS website, is similar to the cutoff for the bottom quartile (41.9) of our study participants' SE scores. No changes to the original dataset were made, and all data cleaning occurred via SAS coding.

Descriptive statistics were calculated on the cleaned dataset for demographics and disease characteristics. Normality was examined for the BIPQ scores. Non-parametric tests of association amongst various sociodemographic and disease characteristic groups were performed for emotional distress, illness comprehension and total BIPQ (illness threat) scores. These tests were the Kruskal-Wallis test and the Mann Whitney/Wilcoxon rank sums tests. These three BIPQ domains were chosen for analysis given the high mean score for emotional distress, the fact that illness threat represents all the BIPQ domains, and that illness comprehension scores may allow us to add context to any potential conclusions about future SLE Latino education interventions. SE and communication with physician score descriptive analysis consisted of calculating mean, median, range and SD for each measure among all participants.

Based on our initial data exploration and analysis, we chose to examine the relationship between emotional distress BIPQ score and SE for symptom management. The hypothesis was that higher emotional distress was associated with increased odds for low SE to manage symptoms (an odds ratio greater than 1). These two variables were chosen for several reasons. The mean emotional distress score was one of the highest (worst) individual BIPQ scores. Furthermore, emotional distress was a composite of two BIPQ questions that address the emotional representation path of the CSM. We favored a variable that encompassed multiple parts of the emotional representation of illness rather than just 'illness concern' or just 'emotional response.' We chose SE to manage symptoms as our dependent variable rather than other SE domains because it encompasses a clinical and psychological outcome of living with lupus. We felt exploring this variable would apply to the widest audience of fellow SLE researchers.

Modeling started with simple logistic regression to get an unadjusted odds ratio (OR) for an increase in all BIPQ domains and having a low SE to manage symptoms. This confirmed that increase in emotional distress had one of the highest unadjusted measures of association with our dependent variable. We then built a multivariate logistic regression model, first considering potential confounders using theoretical and statistical criteria. We included some potential confounders (e.g. sex, age, history of severe lupus manifestations) in our final model that did not have a statistically significant association with our exposure and outcome because these are factors consistently associated with SLE susceptibility and disease outcomes. We included whether a participant was a high user of the *HdL* page as a confounder even though *HdL* usage was not statistically significantly associated with emotional distress because we felt strongly about the theoretical possibility of confounding. We included the variable of low social support as a confounder because of its strong association with our independent and dependent variables and its emphasis in many other studies of SLE emotional and clinical outcomes. We assessed all covariates for collinearity using a Pearson correlation test and subsequently removed employment because of a weak but present collinearity with health insurance status and monthly financial strain. We then ran our final logistic regression model and outputted an adjusted odds ratio. We finally examined for any interaction between not having social support and emotional distress using an interaction term in the model.

Results

Sociodemographics of Participants

Table 1 summarizes participant sociodemographics. There were 1,401 eligible Latino patients with SLE who took the online survey, and 100% completed it. The vast majority (94.8%) was female. Most were younger than 56, with 752 (53.7%) being between 18 and 35 years old and 576 (41.1%) being between 36 and 55 years old. Participants represented 19 countries throughout North, South and Central America, the most common being Mexico (456, 32.6%), Argentina (274, 19.6%) and Colombia (156, 11.1%). Almost half (49.3%) completed university or post-graduate schooling, and only 41 (2.9%) attained less than a primary school education. One hundred and fifty (10.7%) were unemployed or disabled and the rest were either employed at least part-time (752, 53.7%) or out of the labor force as students, retirees or homemakers (499, 35.6%). Only a third (32.1%) had private medical insurance, and the rest had no insurance (21.8%) or relied on federal or public insurance (46.2%). Over two-thirds (78.4%) reported to experience monthly financial strain.

Participant Health Characteristics:

Disease-related and general health characteristics are depicted in Table 2. About half (50.8%) were diagnosed over five years ago, 531 (37.9%) one to five years ago, and 159 (11.4%) within the past year. Most participants (1107, 79.0%) had a rheumatologist providing the majority of their SLE care. Six hundred thirty-nine participants (45.6%) had a history of a severe SLE. Over half (53.5%) viewed their health as 'good' or better. When asked which four SLE symptoms or complications worried the participants the most, kidney involvement (529, 37.8%), joint inflammation (501, 35.8%), fatigue (491, 35.1%) and musculoskeletal pain (442, 31.6%) were the most frequent choices. Four hundred ninety-eight participants were high users of *HdL* (35.5%), 631 were low users (45.0%), and there was a significant number who had never seen a *HdL* video (272, 19.4%).

BIPQ Score Results:

Table 3 shows BIPQ results for all participants. Out of the eight individual BIPQ questions, those with the highest mean scores were illness timeline (8.9; SD 2.2), illness concern (8.2; SD 2.4), illness understanding (8.2; SD 1.9), and illness emotional response (7.4; SD 2.6). The calculated mean emotional distress score (average of illness concern and illness emotional response) was 7.8 (SD 2.1). The mean total BIPQ score (illness threat score) was 45.1 (SD 10.1; range 0-80).

Illness comprehension, emotional distress and illness threat scores were associated with various sociodemographic, disease characteristic and *HdL* usage factors. Results are shown in tables 4.1, 4.2, and 4.3. The emotional distress and illness threat scores showed similar results for association with sociodemographic factors. Factors that were statistically significant ($p<0.05$) for association with emotional distress and illness threat were education ($p=0.01$, $p=0.003$), employment status ($p=0.0003$, $p<.0001$), medical insurance status ($p=0.01$, $p<.0001$), and monthly financial strain ($p<.0001$, $p<.0001$).

Participants with higher education levels reported lower emotional distress and illness threat. Mean emotional distress scores decreased from 8.4 (SD 1.7) for those who attained primary school to 7.9 (SD 2.1) for secondary/technical school to 7.7 (SD 2.2) for university. A similar trend was observed for the illness threat score as education improved (primary school 46.7 (SD 9.3) versus 46.1 (SD 10.1) for secondary/technical school versus 44.1 (SD 10.2) for university). Employed participants had lower emotional distress and illness threat. Emotional distress among the employed was 7.6 (SD 2.2) compared to those that were out of the labor force (7.9 (SD 2.1)) or unemployed/disabled (8.3 (SD 1.8)). The same trend for illness threat showed a score of 44.2 (SD 10.5) for the employed, 45.3 (SD 9.7) for students/retirees/homemakers and 49.3 (SD 8.7) for the unemployed/disabled. Participants with private insurance seemed to have lower emotional distress and illness threat. The mean emotional distress score was 7.6 (SD 2.1) for private insurance holders compared to 7.9 (SD 2.1) for public holders and 7.9 (SD 2.2) for

uninsured/disabled persons. Private insurance holders had a mean illness threat score of 44.1 (SD 10.4) compared with 45.5 (SD 9.8) and 45.9 (SD 10.3) among public insurance holders and disabled or uninsured persons. Those with financial strain also perceived higher emotional distress and illness threat. They had an emotional distress score of 7.9 (SD 2.1) compared to 7.3 (SD 2.1) among those without financial strain. Their mean illness threat score was 45.9 (SD 10.0) compared with 42.5 (SD 10.2) amongst those without financial strain.

The disease characteristic that was associated with higher emotional distress and illness threat was time since diagnosis. Those who had been diagnosed more than five years ago had a lower emotional distress score of 7.5 (SD 2.2) compared to 8.0 (SD 2.1) and 8.1 (SD 1.9) for the <1 year ago and 1-5 years ago groups, respectively ($p<.0001$). Those with a diagnosis >5 years ago had better/lower scores (44.1; SD 10.2) of illness threat, compared to 45.8 (SD 10.2) amongst those diagnosed <1 year ago and 46.3 (SD 9.9) amongst those diagnosed 1-5 years ago ($p=0.001$).

The BIPQ illness comprehension score did not show the same variation based on socioeconomic factors that illness threat scores and emotional distress scores did, except for one sociodemographic category. Education level was significantly associated ($p=0.01$) with illness comprehension like it was for emotional distress and illness threat. Those with primary school education or lower and university school or higher had better illness comprehension (8.3 (SD 1.9) and 8.4 (SD 1.8)) compared to secondary/technical school graduates (8.0 (SD 2.0)). Illness comprehension also differed by age ($p=0.05$), with those 18-35 and 36-55 having lower illness comprehension (8.3 (SD 1.8) and 8.1 (SD 1.8)) than those who were older (8.7 (SD 1.8)). Occupation, insurance status and presence of financial strain did not have an association with illness comprehension, but time since diagnosis ($p<.0001$) and severe SLE history ($p=0.0001$) did. Those with a very recent diagnosis had a worse illness comprehension (7.6 (SD 2.2)) than those with longer-term diagnoses (7.9 (SD 2.0) in those 1-5 years since diagnosis and 8.6 (SD 1.6) in those >5 years since diagnoses). Those with no history of severe SLE reported a worse

illness comprehension (8.0 (SD 2.0)) compared with those who have a history of severe SLE (8.4 (SD 1.8)).

Self-Efficacy PROMIS scores and Communication with Physician Scores:

The PROMIS self-efficacy mean T-scores in our participants were below the mean for the centering population of those with other chronic disease (score of 50). The results were 46.3 (SD 6.5) for SE to manage symptoms, 42.5 (SD 7.9) for SE to manage emotions, 46.3 (SD 8.9) for SE to manage medications and treatments, and 43.3 (SD 8.5) to manage social interactions. The mean score of the communication with physicians measure was 2.5 (SD 1.1) (on a scale of 0 to 5) for the total sample. Tables 5 and 6 summarize these results.

Univariate Logistic Regression of BIPQ Categories and SE Symptom Management:

Univariate logistic regression showed unadjusted ORs for increase in BIPQ scores and low SE to manage symptoms, as summarized by Table 7. Out of the BIPQ scores, all but illness timeline had a statistically significant relationship with low SE to manage symptoms. The most extreme results were an OR of 1.6 (95% CI 1.4-1.7) for emotional distress and an OR of 2.9 (95% CI 2.5-3.5) for illness threat score. Units of eight for the total BIPQ illness threat score (range of 0-80) were used in order to compare with the individual domain categories (range of 0-10).

Final Multivariate Logistic Regression Model:

The final multivariate logistic regression model is represented in Table 8 and Figure 3. The model controlled for the following covariates: age (18-35 and 56+ with 36-55 as reference), female sex, lower education (not having a university degree), insurance status (none/disability or public insurance with private insurance as reference), having monthly financial strain, time since diagnosis (<1 year, 1-5 years and >5 years as reference), no social support, having a history of severe lupus, and being a low user of the *HdL* group. The parameter estimate for emotional distress BIPQ score in the multivariate logistic regression was 0.37 with a standard error of 0.06 and a Wald Chi Square value of 42.62 (p=<0.0001). The adjusted OR of having a low SE to manage symptoms given an increase in emotional distress score of one unit was 1.44 (95% CI,

1.29-1.61). Therefore, we can say there is a significantly higher odds of having the outcome of low SE to manage symptoms with an emotional distress score increase after controlling for age, sex, education level, medical insurance, financial strain, time since diagnosis, having social support and being a low *HdL* user. The covariates that had a significant relationship in our final model with low SE to manage symptoms were financial strain (OR 1.58, 95% CI 1.01-2.47), less than 1 year since diagnosis (OR 2.03, 95% CI 1.26-3.27), low or no history of *HdL* use (OR 0.66, 95% CI 0.48-0.90), and lack of social support from family/friends (OR 2.75, 95% CI 1.95-3.87). Exploration of potential interaction between not having family/friend social support with emotional distress on low SE to manage symptoms showed results that were not statistically significant (parameter estimate= -0.04, p = 0.77).

Discussion

This study examined a large Spanish-speaking Latin American population with SLE to quantitatively explore participant perceptions about the illness and self-efficacy to manage symptoms, manage medications/treatments, manage social interactions and manage emotions. It also explored self-reported communication with providers. It then tested the hypothesis that one element of IP, emotional distress, is associated with low SE to manage symptoms. Prior research suggests that Latino SLE patients have unique needs compared to their non-Latino counterparts that deserve particular attention in education and provider interactions, and our findings in general support this (50).

Illness Perception Results:

Out of all the BIPQ questions, illness timeline, concern, emotional response and coherence had the most extreme results. Illness timeline was expected to have an extreme score given that SLE is a lifelong condition without definitive cure. The results for illness concern and emotional response were, to our knowledge, amongst the highest ever reported. Illness concern and emotional response are the questions representing the emotional pathway of the BIPQ and are also used in calculating emotional distress score. While the topic of emotional impact of SLE is often discussed in the literature, the few studies that measured IP through BIPQ in SLE patients did not find as high of values as our study of Latino SLE patients (65, 112-115). Those other studies describe BIPQ scores in SLE or other rheumatic conditions, but they all use participants from non-Latin-American countries and have fairly small participant groups (the largest having 80 patients) (65, 112-115). For illness concern, the range in non-Latinos was 5.8 to 6.9 (SD 1.6-2.8), and our study had a mean score of 8.2 (SD 2.4). For emotional response, the other populations had means from 5.3 to 6.4 (SD 1.4-3.0), and ours had a mean of 7.4 (SD 2.6) (65, 112-115). Although we did not statistically compare Latinos with other populations as part of our study methods, our findings suggest a higher emotional burden among Latinos than those in

non-Latino SLE individuals. Given the possible increased emotional burden in minority populations of living with lupus, it should not be a surprise that concern and emotional response categories resulted in extreme values.

This increased emotional burden may result from minorities being more likely to have low socioeconomic status and related consequences, such as a lack of social support, difficulty with affording basic needs, or lack of quality and consistent healthcare (116, 117). It could also be related to SLE minority populations having higher disability and functional decline (6), the assumption being that those with disability have higher emotional consequences of living with SLE.

Other societal or cultural factors could play a role. These factors may vary between countries and may be especially prominent in certain cultural contexts. In the U.S., one study on SLE psychosocial burdens found Hispanic patients to have the highest level of unmet psychosocial needs and anxiety/depression compared to other minority and non-minority ethnic groups (42). In a non-SLE study of dialysis patients in California, Hispanic patients were found to have high levels of emotional response measured by the illness perception questionnaire revised (IPQ-R); this was in comparison to other minority groups like African Americans (118). While these studies were in the U.S. and we can't compare these populations with our multi-country study, they show that there is evidence of other minority groups in the U.S. (who are often socioeconomically disadvantaged like Latinos in the U.S.) not being as emotionally burdened by their chronic illness as Latinos. This suggests a potential sociocultural reason for the worse emotional aspect of chronic illness in Latino patients.

Literature describing Latino cultural values emphasizes that mental health struggles are often seen as weakness and stigmatized; mental health struggles are contradictory to the concepts of 'marianismo' and 'machismo' (terms that refer to the need for a woman and man to be emotionally strong) (119). Perhaps this stigmatization creates a higher emotional burden for a Latino patient who attempts to overcome the mental health consequences of their illness without

external resources. This theory on a potential connection between emotional distress in Latinos with chronic illness and cultural stigmatization of mental health has not been formally researched to our knowledge. Whether Latino patients have a more threatening emotional illness perception than non-Latino counterparts and the potential pathways for these findings warrants further research.

The reasons why there are heightened emotional components of illness perceptions in Latinos with SLE could be explained with further qualitative studies. The *HdL* group provides a rich source of material given the large amount of organic patient comments, some of them being quite long and narrative in form. The comments, although not analyzed qualitatively yet, anecdotally support our survey's quantitative IP findings of a high emotional impact of SLE in Latinos.

Another interesting difference between our study and the few other IP SLE studies lies in the coherence IP domain. Our mean score was actually quite high (8.2), reflecting that participants feel they understand their lupus well. Compared to this score in the non-Latino SLE studies, our population had a much higher average score. The next highest was 7.0 (SD 2.5) among patients in Poland (65, 112-115). Our result could reflect recruitment methods more so than Latino patients feeling they understand their SLE better than other populations. Despite our participants reporting higher illness understanding, the emotional distress scores were still high. This supports the existing suggestion that patient education not solely be factual transmission because that does not necessarily change a patient's emotional experience of illness; and the emotional experience of illness is a large component of the patient-centered outcomes like HRQoL (19, 24, 43, 78, 107, 120, 121).

The mean total BIPQ score representing illness threat was 45.1 (SD 10.1) among our participants and is above the range's midpoint of 40. It's difficult to compare our illness threat score to other SLE populations because the only other study that calculated this score occurred in Poland among 80 patients where the mean was 43.1 (SD 11.6) (112). However, there are a few

IP studies in other chronic illnesses where threat scores were calculated. Out of these, which were compiled in a recent systematic review by Broadbent et al, the handful that calculated illness threat found average scores below 40 with the exception of one study of COPD patients with an average of 45 (65). Patients with SLE may view their illness as more threatening compared to other chronic illness populations. More research needs to be done to make a generalization.

Analysis of certain BIPQ domains among subsets of participants showed that illness threat and emotional distress varied by the same sociodemographic subgroups. Perhaps this reflects that a large part of the total illness threat score for our participants was determined by emotional distress, given that emotional distress had of the most extreme scores in comparison with most other domains that had scores closer to the mid-point of five. The fact that illness threat and emotional distress scores varied based on multiple socioeconomic categories suggests a strong role of these factors in the emotional impact of SLE. This mirrors conclusions of other studies on SES and SLE (4, 41, 90, 120, 122, 123). Interestingly, time since diagnosis was associated with illness threat and emotional distress, but a history of severe SLE was not. This means that past SLE physiologic outcomes were less important for overall emotional distress and illness threat perception and demonstrates that we should not assume that patients with mild SLE manifestations are emotionally well or perceive SLE as benign. Latinos diagnosed over five years ago had lower illness threat and emotional distress scores, suggesting that positive coping mechanisms require time to be incorporated. As patients with recent diagnosis perceive the disease as more threatening and are more likely to be emotionally impacted, they deserve extra care and attention from providers. Having no social support was strongly associated with higher scores for illness threat and emotional distress, which is expected given other SLE research showing the strong contribution of social support to HRQoL and better SLE outcomes (26, 36, 41, 45, 90, 91, 120).

The analysis of BIPQ illness comprehension scores demonstrated a relationship between age and illness comprehension, with those who are 56-80 years old having better illness

comprehension. This likely reflects time since diagnosis rather than an effect of age alone given that those with longer diagnoses are older. A history of severe SLE was also associated with better illness comprehension, suggesting that those with severe complications feel they understand their SLE best. This is expected given that they likely had more exposure to SLE-related healthcare and are more motivated or prompted to seeking more information.

Education level exhibited unexpected illness comprehension results. Those with very low or very high education reported better comprehension than those in the middle (with secondary or technical school education). This could be due to those with very low education levels being older and having longer diagnoses. The results for illness comprehension and being a low or high *HdL* user shows that high *HdL* users reported worse illness comprehension. This could be due to those who are seeking extra amounts of education on SLE already feeling they have little understanding of their lupus rather than an effect of *HdL* on illness understanding. The unexpected result supports the need to control for this variable in our final multivariate model.

Self-Efficacy for Managing Chronic Disease and Communicating with Physicians Results:

In all four SE categories, the Latino SLE average score was below the mean T score of 50 for the PROMIS comparison population of U.S. adults with chronic illnesses. SE to manage emotions had the lowest score, with the next lowest being SE to manage social interactions. SE to manage symptoms and medications/treatments had similar low scores. The fact that SE to manage emotions was so low fits with the IP data showing high levels of emotional distress among SLE Latino patients and further supports how emotional aspects of living with SLE is a particular area of need in Latinos. The fact that all the SE scores had averages below the comparison population's mean of 50 suggests that SLE Latino patients have low SE across multiple behavioral domains of disease management.

There are just a handful of data reporting PROMIS SE data for SLE patients, although there is significant external support and enthusiasm for using the PROMIS tools in SLE (124). One abstract reported a self-efficacy for managing medications score of 50 and 52 for non-

Caucasian and Caucasian patients in a tertiary lupus clinic in the US (125). Another abstract reported PROMIS SE for managing chronic disease scores among 60 Peruvian patients ranging from a mean of 43.1 to 48.6 (126). Our results echo those found in the Peruvian study, further suggesting that SE in various domains for Latino SLE patients is low. Interestingly, other research on SE in SLE patients using non-PROMIS tools concluded that SLE patients have low SE scores for pain management and general chronic disease management compared to non-SLE patients (39, 127). Perhaps SLE patients in general have a lower SE to manage chronic illness no matter their ethnicity/race.

The Chronic Disease Self Efficacy for Communication with Physicians tool results in our SLE population showed an overall mean score of 2.5 in a range of 0 to 5, with 5 being a high level of provider communication SE. This is in comparison to 1130 subjects with chronic disease in the U.S. who had a mean score of 3.1 (100, 110, 128). The tool was also tested in 550 Spanish-speakers in the U.S. who had a mean of 1.64, although it's unclear if these patients were seeing Spanish-speaking providers or not (100). The combination of our results with this low communication score from Spanish-speakers in the U.S. suggests that there is room for improvement in the Latino communication with providers. Out of the three individual SE communication questions, the one with the lowest mean was frequency of preparing a list of questions, the next lowest was the frequency of talking about personal problems related to SLE, and the highest was the frequency of asking questions one feels unsure about. This suggests that it's not that patients feel they can't ask physicians questions but rather that they don't prepare them ahead of time and don't talk about specific question types (related to their personal life). When targeting improvement in SLE Latino patient communication with physicians, giving concrete behavior examples like how to prepare a list of questions could be especially helpful. It may also help to encouraging physicians to ask patients about their personal problems related to SLE in order to normalize that illness' affect on personal life is important.

<u>Low SE to Manage Symptoms and all Illness Perception Domains:</u>

Univariate logistical regression examined the OR for having a low SE to manage symptoms for an increase in illness perception scores. Almost every category except for illness timeline showed a statistically significant OR for the outcome of low symptom management SE. This supports our initial suggestion based on work by Lau-Walker that IP and SE are tied and IP may affect SE. The simple logistic regression results suggest that potential areas for intervention in order to improve SE may be almost any IP domain, emotional or cognitive.

Low SE to Manage Symptoms and Emotional Distress:

The final model showed increased odds of low SE to manage symptoms with increase in emotional distress illness perception after controlling for all potential confounders, which supported our initial hypothesis. Even with the control for socioeconomic factors, social support and disease characteristics, there is a significant relationship between higher levels of emotional distress and low SE to manage symptoms. This has important implications for the future care of Latino SLE patients, showing that emotional distress is important to address for patient-centered outcome improvement. The final model supports the importance of providers paying particular attention to Latino SLE patients diagnosed within the past year given that their OR for low SE to manage symptoms remained significant. Monthly financial strain was also independently associated with low SE in the model, which is consistent with other SLE research indicating that SES affects outcomes (4, 6). Lack of social support from family and friends was strongly associated with low SE to manage symptoms. This is in agreement with the literature on social support in SLE (26, 40, 41). Our study did not find that social support mitigated the effect of emotional distress on low SE to manage symptoms; however, longitudinal studies are warranted to better understand the pathways involved in the relationship of these various constructs.

Strengths and Weaknesses:

The strengths of this study stem from the novel question and unique recruitment methods within a historically understudied high-risk population. Furthermore, it's a multi-country study that resulted in a large number of responses on a topic which little is known. For the methods, the

tools used to measure SE and IP were rigorously created and are commonly used in psychosocial studies. The fact that we recruited via social media allowed us to capture a more diverse participant pool that may have varying exposure in terms of quantity and quality to SLE healthcare.

Weaknesses include recruiting a sample of convenience. Our participants may not represent all Latinos with SLE, but rather Latinos who use social media extensively. These participants may also be seeking information from the *HdL* group so they could be patients who are struggling more than other Latinos with lupus. The fact that our population had a relatively high education level suggests a lack of generalizability. Furthermore, the inability to include participants from the EU means that the data does not reflect Latinos living in EU countries. While our measurements for SE and IP were rigorously created, they have not been validated in a multi-country Latino population.

The cross-sectional nature of our survey does not allow for a definitive conclusion regarding exposure of emotional distress causing a low symptom management SE. The relationship could potentially occur in the other direction or concurrently. The fact that most of our study population had exposure to the *HdL* page in the past also introduces a potential for the *HdL* past educational material having an impact on their illness perception or SE, but we did control for past HdL use in our final model because of this potential confounder.

Final Conclusions and Suggestions for Patient Education for Latinos with SLE:

Latinos with SLE have a high degree of emotional distress and perceived illness threat overall. Those with low SES and lack of social support have especially poor illness perceptions. Those who were recently diagnosed in the past year are also are especially vulnerable. Latinos with SLE feel they understand their illness well, especially if they have had their diagnosis for several years or if they have a history of severe lupus. Despite feeling SLE is understood fairly well, they still experience high levels of perceived illness threat and emotional distress.

All measures of SE were low for Latino SLE patients. Whether this reflects that SLE SE is low for most patients or just for Latinos is yet to be determined given lack of rigorous SE lupus research. Based on how multiple SE domains resulted in low scores, increasing SE is an important aim for future efforts.

Our results from the univariate and multivariate logistical regression suggest that IP is a modifiable contributor to SE to manage symptoms in Latinos with lupus. Almost all domains of IP are associated with SE to manage symptoms. When controlling for confounders, high levels of emotional distress are associated with increased odds of low SE to manage symptoms. Therefore, targeting dysfunctional aspects of IP, particularly emotional distress, may have important implications for improving SE in Latino patients with SLE.

IP may be an important target of SLE Latino education. Educational and behavioral interventions aiming at reducing emotional distress illness perception in particular can contribute to improved SE for chronic disease management. The *HdL* platform remains a useful medium to provide patient education to a large number of Latino SLE patients, and emotional distress education could be amplified and improved on the page. If new tailored education efforts improve Latino SLE SE, they may positively impact SLE outcome disparities. IP varied in our population compared with other populations, supporting previous research that IP may vary based on cultural and clinical contexts (65, 121). It may be useful for providers to use the BIPQ in individual care to determine which areas an individual patient is particularly high or low in.

Future Directions:

There are several future studies that could contribute to the SLE research community. Measurements of SE and BIPQ in a large non-Latino population would allow comparison to our Latino SLE patient group. It would also be useful to design an interventional patient-education study to reduce emotional distress illness perception in Latino SLE patients and examine its

potential impact on SE. This would further support our hypothesis that IP is a modifiable risk factor for low SE.

There were two specific groups in our Latino SLE populations that had low SE to manage symptoms in our multivariate model- those without social support and those diagnosed less than one year ago. The extreme results for those who lack social support echoes other studies in non-Latino populations, and our results about recently diagnosed patients is a new addition to SLE research. Education efforts or research on these two subgroups could have positive implications for Latino SLE patients. Educating providers to consider Latino patients without social support or newly diagnosed as particularly vulnerable may have a positive impact on outcomes. It could also be helpful to examine the patient-provider relationship amongst Latinos with SLE to better understand how providers can best impact patients on an individual level.

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Tables

Table 1. Sociodemographics of Participants

	N (=1401)	%
Age		
18-35	752	53.7
36-55	576	41.1
56-80	73	5.2
Female	1328	94.8
Male	73	5.2
Country (top 5 represented, then grouped by location)		
Mexico	456	32.6
Argentina	274	19.6
Colombia	156	11.1
Chile	117	8.4
Peru	86	6.1
Other North America (U.S.)	33	2.4
Other Central America (Costa Rica, o, Dom. Rep., El Salvador, Guatemala, Honduras, Nicaragua, Panama, Puerto Rico)	132	9.4
Other South America (Bolivia, Brazil, Paraguay, Uruguay, Venezuela)	147	10.5
Education		
Primary or lower	41	2.9
Secondary or technical school	670	47.8
University or graduate school	690	49.3
Employment Status		
Unemployed or Disabled	150	10.7
Student/Retired/Homemaker	499	35.6
Employed full or part-time	752	53.7
Insurance Type		
None/Disabled	305	21.8
Public (from state or country)	647	46.2
Private	449	32.1
Financial strain	1099	78.4
No financial strain	302	21.6

Table 2. Health and SLE Characteristics of Participants

	N (=1401)	%
Lupus treated by Rheumatologist	1107	79.0
History of Severe SLE*	639	45.6
General Health Rating		
Poor	102	7.3
Fair	549	39.2
Good	504	36.0
Very Good	198	14.1
Excellent	48	3.4
Time since diagnosis		
<1 year	159	11.4
1-5 years	531	37.9
>5 years	711	50.8

SLE symptoms or complications that participants are most worried about**		
Kidney involvement	529	37.8
Joint inflammation	501	35.8
Fatigue	491	35.1
Muscle and bone pain	442	31.6
HdL past use		
Never seen an *HdL* video before	272	19.4
Low user (1 to 5 videos seen)	631	45.0
High user (>5 videos seen)	498	35.5

*Severe SLE= history of renal, central nervous system, vascular or pulmonary complications from lupus
**Participants chose up to four answers so the percentages do not sum to 100%
Abbreviations: SLE= Systemic Lupus Erythematosus, *HdL*= Hablemos de Lupus Facebook Page

Table 3. BIPQ among Latinos with SLE by Illness Perception Domains

BIPQ Category * [range]	Mean (n=1401)	Median	SD
Question 1: Consequences [0-10]	6.4	7.0	2.3
Question 2: Timeline [0-10]	8.9	10.0	2.2
Question 3: Personal Control [0-10]	6.1	6.0	2.3
Question 4: Treatment Control [0-10]	7.8	8.0	2.2
Question 5: Identity [0-10]	6.4	7.0	2.3
Question 6: Concern [0-10]	8.2	9.0	2.4
Question 7: Understanding [0-10]	8.2	9.0	1.9
Question 8: Emotional Response [0-10]	7.4	8.0	2.6
Emotional Distress** [0-10]	7.8	8.5	2.1
Total score*** [0-80]	45.1	46	10.1

Abbreviations: BIPQ= Brief Illness Perception Questionnaire, SLE= Systemic Lupus Erythematosus
*A higher value indicates a more extreme perception for each category
**Emotional Distress Score = Sum of question 6 (concern) and question 8 (emotional response) divided by 2
***Total Score= Sum of questions 1,2,5, 6 and 8 added to the to the reverse score. Represents perceived illness threat
Abbreviations: SLE= Systemic Lupus Erythematosus

	N	Mean [range 0-80]	SD	p value
Age				
18-35	752	45.2	10.0	0.94 §
36-55	576	45.0	10.5	
56-80	73	45.7	9.3	
Female	1328	45.1	10.1	0.31 ¶
Male	73	46.5	10.1	
Education				
Primary or lower	41	46.7	9.3	0.003 § *
Secondary or technical	670	46.1	10.1	
University or graduate	690	44.1	10.2	
Occupation				
Unemployed or disabled	150	49.3	8.7	<.0001 § *
Student/Retired/Homemaker	499	45.3	9.7	
Employed full or part-time	752	44.2	10.5	
Insurance Status	305	45.9	10.3	<.0001 § *
None/disabled	647	45.5	9.8	
Public	449	44.1	10.4	

Private				
Financial Strain	1099	45.9	10.0	<.0001 ¶ *
No Financial Strain	302	42.5	10.2	
Time since diagnosis				
<1 year	159	45.8	10.2	0.001 § *
1-5 years	531	46.3	9.9	
>5 years	711	44.1	10.2	
History of severe SLE**	639	45.3	10.3	0.26 ¶
No history of severe SLE	762	45.0	10.0	
No social support	249	50.4	9.2	<.0001 ¶ *
Has social support	1152	44.0	10.0	
Low *HdL* user (<5 videos seen)	498	44.5	10.4	0.07 ¶
High *HdL* user	903	45.5	10.0	

Abbreviations: BIPQ= Brief Illness Perception Questionnaire, SLE= Systemic Lupus Erythematosus, *HdL*= Hablemos de Lupus Facebook Page

1 Total score reflects illness threat perceived by patient and is calculated by reverse scoring questions ,3,4 and 7 and adding those to questions 1,2,5,6, and 8.

§ Kruskal Wallis test, ¶ Wilcoxon-Mann-Whitney test

*Statistically significant difference (p<= 0.05)

**Severe SLE= history of renal, central nervous system, vascular or pulmonary complications from lupus

Table 4.2. BIPQ Emotional Distress Score[1] by Sociodemographics and Illness Characteristics

	N	Mean [range 0-10]	SD	p value
Age				
18-35	752	7.9	2.0	0.20 §
36-55	576	7.7	2.3	
56-80	73	7.7	2.1	
Female	1328	7.8	2.1	0.75 ¶
Male	73	7.9	1.9	
Education				
Primary or lower	41	8.4	1.7	0.01 § *
Secondary or technical	670	7.9	2.1	
University or graduate	690	7.7	2.2	
Occupation				
Unemployed or disabled	150	8.3	1.8	0.0003 § *
Student/Retired/Homemaker	499	7.9	2.1	
Employed full or part-time	752	7.6	2.2	
Insurance Status				
None/disabled	305	7.9	2.2	0.01 § *
Public	647	7.9	2.1	
Private	449	7.6	2.1	
Financial Strain	1099	7.9	2.1	<.0001 ¶ *
No Financial Strain	302	7.3	2.1	
Time since diagnosis				
<1 year	159	8.0	2.1	<.0001 § *
1-5 years	531	8.1	1.9	
>5 years	711	7.5	2.2	
History of severe SLE**	639	7.8	2.2	0.90 ¶
No history of severe SLE	762	7.8	2.1	
No social support	249	8.4	2.0	<.0001 ¶*

Has social support	1152	7.7	2.1	
Low *HdL* user (<5 videos seen)	498	7.7	2.2	0.90 ¶
High *HdL* user	903	7.8	2.1	

Abbreviations: BIPQ= Brief Illness Perception Questionnaire, SLE= Systemic Lupus Erythematosus, *HdL*= Hablemos de Lupus Facebook Page
1 Emotional distress score calculated by taking the average of question 6 (illness concern) and question 8 (emotional response) of the Brief Illness Perception Questionnaire
§ Kruskal Wallis test, ¶ Wilcoxon-Mann-Whitney test
*Statistically significant difference ($p \leq 0.05$)
**Severe SLE= history of renal, central nervous system vascular or pulmonary complications from lupus

Table 4.3. BIPQ Illness Comprehension Score[1] by Sociodemographics and Illness Characteristics

	N	Mean [range 0-10]	SD	p value
Age				
18-35	752	8.3	1.8	0.05 §*
36-55	576	8.1	1.8	
56-80	73	8.7	1.8	
Female	1328	8.2	1.9	0.67 ¶
Male	73	8.2	2.0	
Education				
Primary or lower	41	8.3	1.9	0.01 §*
Secondary or technical	670	8.0	2.0	
University or graduate	690	8.4	1.8	
Occupation				
Unemployed or disabled	150	8.4	1.8	0.44 §
Student/Retired/Homemaker	499	8.3	1.9	
Employed full or part-time	752	8.2	1.9	
Insurance Status				
None/disabled	305	8.2	2.0	0.10 §
Public	647	8.2	1.8	
Private	449	8.3	1.9	
Financial Strain	1099	8.2	1.9	0.97 ¶
No Financial Strain	302	8.3	1.8	
Time since diagnosis				
<1 year	159	7.6	2.2	<.0001 § *
1-5 years	531	7.9	2.0	
>5 years	711	8.6	1.6	
History of severe SLE**	639	8.4	1.8	0.0001 ¶*
No history of severe SLE	762	8.0	2.0	
No social support	249	8.0	2.1	0.08 ¶
Has social support	1152	8.3	1.8	
Low *HdL* user (<5 videos seen)	498	8.5	1.7	0.0004 ¶*
High *HdL* user	903	8.1	1.9	

Abbreviations: BIPQ= Brief Illness Perception Questionnaire, SLE= Systemic Lupus Erythematosus, *HdL*= Hablemos de Lupus Facebook Page
1 Question number seven of the Brief Illness Perception Questionnaire
§ Kruskal Wallis test, ¶ Wilcoxon-Mann-Whitney test
*Statistically significant difference ($p <= 0.05$)
**Severe SLE= history of renal, central nervous system, vascular or pulmonary complications from lupus

Table 5. Self-Efficacy for Managing Chronic Disease among Latinos with SLE

PROMIS SE Measurement*	Mean T score ** (n=1401)	Median	Range	SD
SE to manage symptoms	46.3	46.3	25.4-61.8	6.5
SE to manage emotions	42.5	42.2	25.1-63.1	7.9
SE to manage medications and treatment	46.3	45.3	21.7-57.9	8.9
SE to manage social interactions	43.3	42.8	23.2-58.2	8.5

Abbreviations: SE=Self-Efficacy, SLE=Systemic Lupus Erythematosus
*Measured with PROMIS item bank v1.0 self efficacy for managing chronic disease short forms 4a
**The mean T score for the comparison population with chronic conditions is 50. Stddev is 10. Lower scores mean worse SE

Table 6. Communication with Physicians among Latinos with SLE

Communication with Physicians Question*	Mean score** (n=1401)	Median	SD
1) Frequency of preparing list of questions	1.9	2	1.5
2) Frequency of asking questions you feel unsure about	3.1	3	1.4
3) Frequency of discussing SLE-related personal problems with provider	2.4	2	1.5
Total communication with physicians score***	2.5$^{\alpha}$	2.3	1.1

Abbreviations: SLE=Systemic Lupus Erythematosus
*Measured by the Self Management Resource Center's Communication with Physicians Questionnaire
**Range 0-5 where 0 indicates 'never' and 5 indicated 'always'
***Total score for each participant calculated by taking the average of questions 1, 2, and 3
α Mean for comparison population of chronic disease patients in U.S. was 3.1

Table 7. Univariate Logistic Regression for Brief Illness Perception Questionnaire Domains and Low Self-Efficacy to Manage Symptoms* among Latinos with SLE

BIPQ Category *	Units	Parameter Estimate	P value	Unadjusted Odds Ratio	95% CI (LL-UL)
Question 1: Consequences	1	0.39	<.0001	1.48	1.36-1.60
Question 2: Timeline	1	0.04	0.29	1.04	0.97-1.12
Question 3: Personal Control	1	-0.29	<.0001	0.75	0.70-0.8
Question 4: Treatment Control	1	-0.24	<.0001	0.79	0.75-0.84
Question 5: Identity	1	0.26	<.0001	1.29	1.20-1.39
Question 6: Concern	1	0.22	<.0001	1.25	1.15-1.36
Question 7: Understanding	1	-0.22	<.0001	0.81	0.75-0.86
Question 8: Emotional Response	1	0.36	<.0001	1.44	1.32-1.57
Emotional Distress**	1	0.44	<.0001	1.55	1.39-1.73
Total score*** [0-80]	8	0.13	<.0001	2.94	2.46-3.51

Abbreviations: BIPQ=Brief Illness Perception Questionnaire, SLE=Systemic Lupus Erythematosus, LL=lower limit, UL=upper limit
*low self-efficacy is defined as a PROMIS T-score <= 40
**Emotional Distress Score = Sum of question 6 (concern) and question 8 (emotional response) divided by 2
***Total Score= Sum of questions 1,2,5, 6 and 8 added to the to the reverse score. Represents perceived illness threat

Table 8. Multivariate Logistic Regression Model: Adjusted Odds Ratio for Low Self Efficacy to Manage Symptoms* for a One Point Increase in Perceived Emotional Distress among Latinos with SLE

Variable/Intercept	Estimate (B)	SE	Wald Chi Square	Pr >Chi Sq	OR	95% CI LL	95% CI UL
Intercept	-5.91	0.66	79.2	<.0001	n/a	n/a	n/a
Emotional distress**	0.37	0.06	42.62	<.0001	**1.44**	**1.29**	**1.61**
Female sex	0.19	0.37	0.26	0.61	1.21	0.58	2.51
Age (ref 36-55)							
18-35	0.2	0.17	1.39	0.24	1.22	0.88	1.69
56 and older	0.29	0.37	0.63	0.43	1.34	0.65	2.73
No college degree (ref college or higher)	0.23	0.16	2.16	0.14	1.26	0.93	1.73
Insurance (ref private)							
Uninsured or disabled	0.22	0.22	0.97	0.32	1.25	0.81	1.93
Public insurance	0.32	0.19	2.83	0.09	1.38	0.95	2
Monthly financial strain	0.46	0.23	4.05	0.04	1.58	1.01	2.47
Time since diagnosis (ref >5 years)							
<=1 year ago	0.71	0.24	8.44	0.004	2.03	1.26	3.27
1-5 years ago	0.27	0.18	2.39	0.12	1.31	0.93	1.85
Lack of social support	1.01	0.17	33.6	<.0001	2.75	1.95	3.87
Severe SLE***	-0.08	0.16	0.27	0.61	0.92	0.67	1.27
Low *HdL* user (<5 videos seen)	-0.42	0.16	6.88	0.01	0.66	0.48	0.9

Abbreviations: SLE=Systemic Lupus Erythematosus, HdL=Hablemos de Lupus Facebook Page, SE=Standard error, OR=odds ratio, LL=lower limit, UL=upper limit

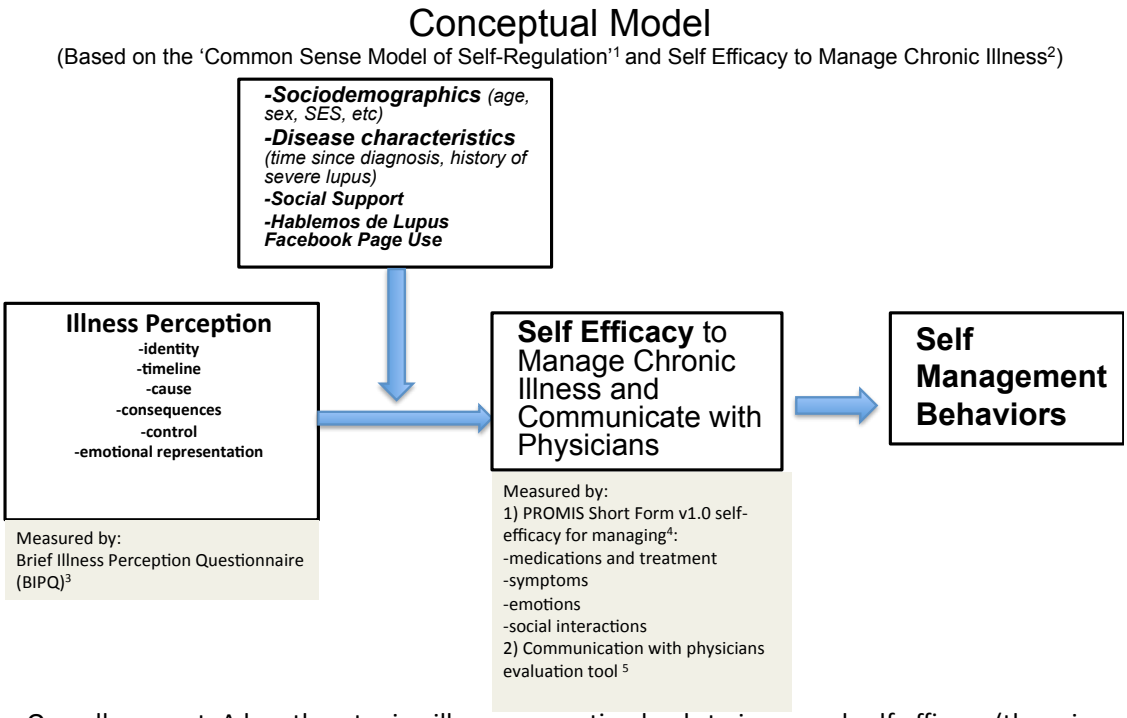
*Low self-efficacy defined as a PROMIS self-efficacy to manage symptoms T-score <= 40

**Emotional distress score is 0 to 10, with 0 being little emotional distress from lupus and 10 being extreme emotional distress

***Severe SLE is having central nervous system, renal, pulmonary or vascular complication

Figures

Figure 1: Conceptual Model of Thesis

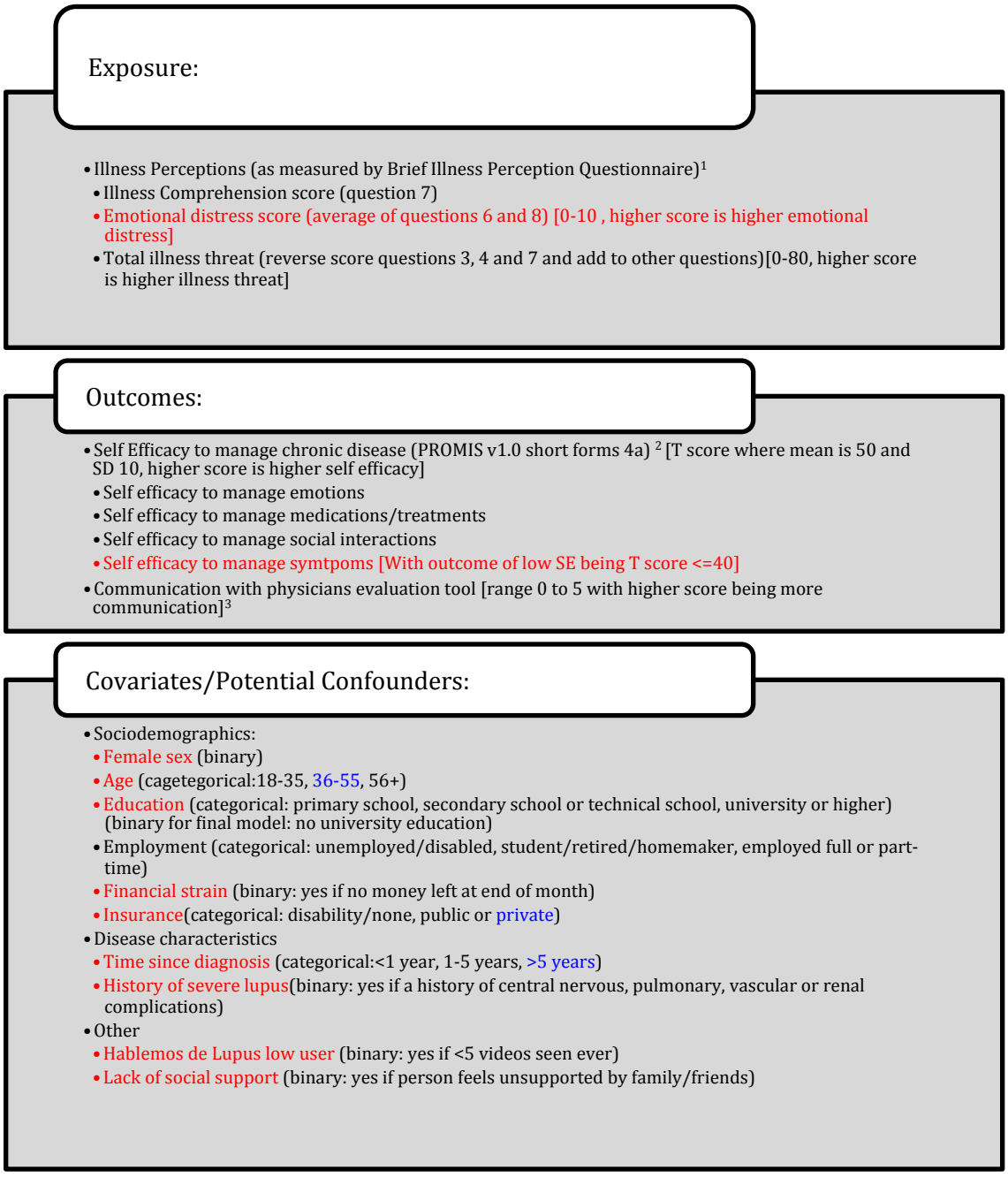


Overall concept: A less threatening illness perception leads to improved self efficacy (there is an inverse relationship). Sociodemographics and disease characteristics may augment this relationship. Better self-efficacy translates to better self-management of lupus.

1- Leventhal, H., L.A. Phillips, and E. Burns, *The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management*. J Behav Med, 2016. **39**(6): p. 935-946.
2- Bandura, A., Self-efficacy mechanism in human agency. American psychologist, 1982. **37**(2): p. 122.
3- Broadbent, E., et al., *The brief illness perception questionnaire*. J Psychosom Res, 2006. **60**(6): p. 631-7.
4-Gruber-Baldini, A.L., et al., *Validation of the PROMIS(®) measures of self-efficacy for managing chronic conditions*. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 2017. **26**(7): p. 1915-1924.
5- Lorig K, S.A., Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and Other Health Care Interventions*. 1996, Sage Publications: Thousand Oaks, California. p. 22,40.

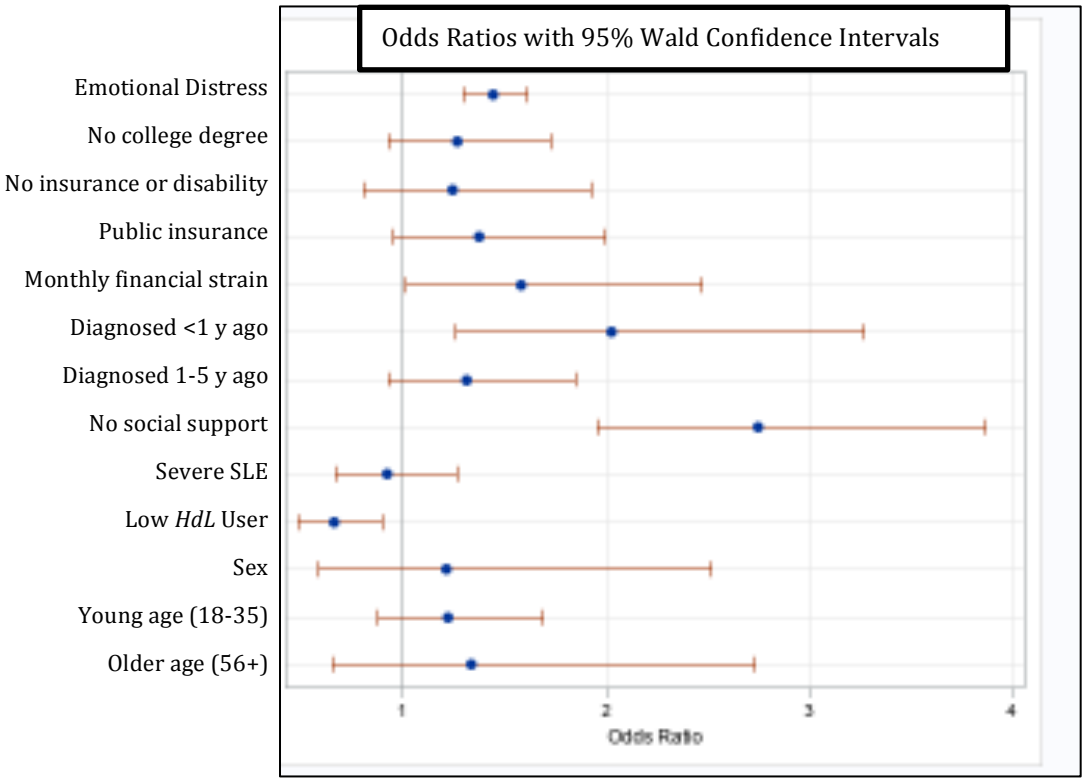
Figure 2: Figure of Methods

Figure Legend:
Red font=included in final logistic regression multivariate model
Blue font=reference category in final logistic regression multivariate model



1- Broadbent, E., et al., *The brief illness perception questionnaire*. J Psychosom Res, 2006. **60**(6): p. 631-7.
2-Gruber-Baldini, A.L., et al., *Validation of the PROMIS(®) measures of self-efficacy for managing chronic conditions*. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation, 2017. **26**(7): p. 1915-1924.
3-Lorig K, S.A., Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and Other Health Care Interventions*. 1996, Sage Publications: Thousand Oaks, California. p. 22,40.

Figure 3: Graphical Representation of Odds Ratios from Multivariate Logistic Regression for Emotional Distress Illness Perception and Low Self Efficacy to Manage Symptoms in Latinos with SLE



Abbreviations: HdL=Hablemos de Lupus Facebook Page, SLE=Systemic Lupus Erythematosus

Appendices

Appendix A: Overview of Brief Illness Perception and Scoring

BIPQ Question Descriptions and Domains[1]

Question Number	Question Domain	Basics of what each BIPQ question asks	Response Type	Emotional or Cognitive Pathway of Common Sense Model Represented?
1	Consequences	Extent of illness affecting life	Quantitative (0 to 10)	Cognitive
2	Timeline (duration)	How long illness lasts	Quantitative (0 to 10)	Cognitive
3	Personal Control	Amount of control one has over illness	Quantitative (0 to 10)	Cognitive
4	Treatment Control	Amount treatment helps	Quantitative (0 to 10)	Cognitive
5	Identity	Symptom frequency	Quantitative (0 to 10)	Cognitive
6	Concern	Amount of concern about illness	Quantitative (0 to 10)	Emotional
7	Understanding (aka coherence)	How much understanding one has of illness	Quantitative (0 to 10)	n/a
8	Emotional Response	Amount illness affects emotionally	Quantitative (0 to 10)	Emotional
9	Cause	Top three causes of illness	Qualitative	n/a

Composite Score Methods[2]

Total Illness Distress [Range 0-80]= Reverse score of questions 3,4, and 7. Add to questions 1, 2, 5, 6, 8.

Emotional Distress : $\frac{(Q6 + Q8)}{2}$

1- Broadbent, E., et al., *The brief illness perception questionnaire*. J Psychosom Res, 2006. **60**(6): p. 631-7.
2- Broadbent, E. The Brief Illness Perception Questionnaire Scoring Instructions. [cited 2019 November 1]; Available from: https://www.uib.no/ipq/files/Brief-IPQ.doc.

Appendix B: Self Efficacy Measures: PROMIS v1.0 Short Forms 4a and Communication with Physicians

The PROMIS Self-Efficacy Measures

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Chronic Conditions - Managing Symptoms – Short Form 4a

Self-Efficacy for Managing Chronic Conditions - Managing Symptoms – Short Form 4a

Please respond to each question or statement by marking one box per row.

	CURRENT level of confidence…	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMSX010	I can manage my symptoms during my daily activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSX014	I can keep my symptoms from interfering with relationships with friends and family	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSX009	I can manage my symptoms in a public place	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSX011	I can work with my doctor to manage my symptoms	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Chronic Conditions – Managing Emotions – Short Form 4a

Self-Efficacy for Managing Chronic Conditions – Managing Emotions – Short Form 4a

Please respond to each question or statement by marking one box per row.

	CURRENT level of confidence…	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMEM015	I can handle negative feelings.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMEM016	I can find ways to manage stress.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMEM012	I can avoid feeling discouraged.....	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMEM010	I can bounce back from disappointment	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Chronic Conditions - Managing Medications and Treatment– Short Form 4a

Self-Efficacy for Managing Chronic Conditions - Managing Medications and Treatment – Short Form 4a

Please respond to each question or statement by marking one box per row.

	CURRENT level of confidence…	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMMT005	I can follow directions when my doctor changes my medications	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMMT023	I can take my medication when there is a change in my usual day (unexpected things happen)	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMMT006	I can manage my medication without help.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMMT010	I can list my medications, including the doses and schedule	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

PROMIS Item Bank v1.0 - Self-Efficacy for Managing Chronic Conditions - Managing Social Interactions – Short Form 4a

Self-Efficacy for Managing Chronic Conditions - Managing Social Interactions – Short Form 4a

Please respond to each question or statement by marking one box per row.

	CURRENT level of confidence…	I am not at all confident	I am a little confident	I am somewhat confident	I am quite confident	I am very confident
SEMSS014	I can talk about my health problems with someone	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSS024	If I need help, I can find someone to take me to the doctor's office	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSS013	I can get emotional support when I need it	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
SEMSS012	I can ask for help when I don't understand something	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Self-Management Resource Center's Communication with Physicians Evaluation Tool

When you **visit your doctor**, how often do you do the following *(please circle **one** number for each question):*

	Never	Almost never	Some-times	Fairly often	Very often	Always
1. Prepare a list of questions for your doctor	0	1	2	3	4	5
2. Ask questions about the things you want to know and things you don't understand about your treatment	0	1	2	3	4	5
3. Discuss any personal problems that may be related to your illness	0	1	2	3	4	5