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Psychosocial factors in fibromyalgia: a phenomenological understanding of the experiences of Latinas

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Pepperdine University
Graduate School of Education and Psychology

PSYCHOSOCIAL FACTORS IN FIBROMYALGIA: A PHENOMENOLOGICAL
UNDERSTANDING OF THE EXPERIENCES OF LATINAS

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by

Elisenda Rodes

July, 2022

Carrie Castañeda-Sound, Ph.D., Dissertation Chairperson

This clinical dissertation, written by

Elisenda Rodes

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

Doctoral Committee:

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DEDICATION

To all my teamwork: Jaros, Carla, and Ainhoa. This has been hard, and I am so proud of us. To my family, for inspiring me every day and supporting me in my dreams.

ACKNOWLEDGEMENTS

I am very grateful for my dissertation chair, Dr. Carrie Castañeda-Sound, who has been supporting me patiently along this long journey. Special thanks to my dissertation committee: Dr. Amy Tuttle and Dr. Anne Cohen for all your inputs and feedback, and Dr. Joan Rosenberg for joining me in the last run of this dissertation. My deepest thanks to all participants, who shared their time and experiences with me. It was a privilege for me to get to listen to you, and I admire your strength and resilience.

VITA

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EDUCATION**Candidate for Doctorate in Clinical Psychology.**

- Pepperdine University, Graduate School of Education and Psychology
- APA – Accredited
- Dissertation Title: *Psychosocial Factors in Fibromyalgia: A phenomenological Understanding of the Experiences of Latinas.*
- Advisor: Dr. Carrie Castañeda-Sound, Ph.D.
- Clinical Competency Examination: Pass with Distinction
- Treatment Approaches: Cognitive-Behavioral Therapy, Humanistic Existential

Master in Neuropsychology,

- Autonomous University of Barcelona (UAB), Barcelona, Spain
- Master's Thesis: *The Pyramids and Palm Trees Test: Pilot Normalizing Study in a Spanish Sample of Young Adults (20 to 49 years)*
- Advisor: Dr. Peña-Casanova, MD, Ph.D.

Bachelor's in psychology,

- University of Barcelona (UB), Barcelona, Spain

AWARDS:

- Undergraduate tuition scholarship for a psychology program at Norwegian Technical University NTNU Trondheim, Norway (2002)
- Student Poster Award on Diversity. National Academy of Neuropsychology (2019)

LANGUAGES

Spanish: Fluent in Spanish

Catalan: As a mother language

English: Advanced level, written and spoken

CLINICAL TRAINING EXPERIENCE**Neuropsychology Intern**

July 2020-June 2021

UCLA Semel Institute for Neuroscience and Human Behavior

Hispanic Neuropsychiatric Center of Excellence (HNCE)

Los Angeles, California

Mentor: Dr. Paola Suarez

- Responsibilities:
 - Conducting bilingual (English/Spanish) outpatient and inpatient neuropsychological assessments. This includes performing clinical interviews, scoring and interpretation of test results, integrated report writing, and imparting feedback sessions.
 - Conducting weekly psychotherapy as part of the STAR clinic
 - Training includes attending didactic seminars, other didactics courses.
 - As part of group supervision, presenting cases monthly.
- Population:
 - From 6-year-old to advanced elderly
 - Monolingual Spanish and bilingual (English/Spanish) speakers

- Referrals from neurology, psychiatry, organ transplant, and other medical center clinics and community at large, including referrals from the Los Angeles County Department of Mental Health.

Neuropsychology Extern

July 2018-June 2020

UCLA Semel Institute for Neuroscience and Human Behavior

Cultural Neuropsychology Program (CNP)

Los Angeles, California

Supervisors: Dr. Paola Suarez & Dr. Xavier Cagigas

- Responsibilities:
 - Conducting bilingual (English/Spanish) outpatient comprehensive neuropsychological and psychodiagnostic assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, and feedback sessions)
 - Participating in the process of the WADA test
 - Training includes attending didactic seminars and neuropathology brain cuttings
- Population:
 - From 6-year-old to advanced elderly
 - Monolingual Spanish and bilingual (English/Spanish) speakers
 - Referrals from neurology, psychiatry, organ transplant, Operation Mend cases, and other medical center clinics and community at large, including referrals from the Los Angeles County Department of Mental Health

Neuropsychology Extern

July 2017-June 2018

Children's Hospital Los Angeles

Los Angeles, California

Supervisors: Dr. Sharon O'Neil

- Responsibilities:
 - Conducted bilingual (English/Spanish) outpatient comprehensive neuropsychological and psychodiagnostic assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, and feedback sessions)
 - Group therapy participation (8-9 members) for social-skills training in children with craniofacial abnormalities
 - Training included attending didactic seminars and neuropathology brain cuttings
 - Observed the administration of Autism Diagnostic Observation Schedule- 2 (ADOS-2)
- Population:
 - From nine-month-old to adults up to 65 years old
 - Monolingual Spanish and bilingual English-Spanish patients and their families
 - Referrals from different medical divisions: hematology-oncology, neurology, cardiology, and neurosurgery

Neuropsychology Extern

September 2016-July

2017

Olive View Medical Center

Los Angeles, California

Supervisors: Dr. Brandon Birath & Dr. Xavier Salazar

- Responsibilities:
 - Conducted bilingual (English/Spanish) outpatient comprehensive neuropsychological and psychodiagnostic assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, feedback sessions, and communicating and consulting with the interdisciplinary team)
 - Co-led outpatient individual psychotherapy sessions under supervision of Psychiatric Department

- Developed and executed behavioral interventions for inpatients with behavioral disturbance as part of an interdisciplinary team
- Population:
 - Adults and elderly
 - Monolingual Spanish and bilingual English-Spanish speakers
 - Outpatients and Inpatients
 - Referrals from different medical divisions: neurology, psychiatry, HIV clinic, from other medical center clinics, and the community at large. Major work with low-income and underserved population

Clinical Psychology Extern

September 2015-

Present

**Pepperdine University Graduate School of Education and Psychology
Los Angeles, California**

Supervisors: Dr. Aaron Aviera & Dr. Shelly Harrell

- Responsibilities:
 - Performed individual psychotherapy, phone intakes, and in-person intake interviews, psycho-diagnostic evaluations, and writing intake reports as well as case notes
- Population:
 - Young adults, adults, and older adults. English and Spanish-speaking clients

MASTERS CLINICAL TRAINING EXPERIENCE

Neuropsychology Extern

September 2000- July

2002

**Hospital del Mar
Barcelona, Spain**

Supervisor: Dr. Peña-Casanova

- Responsibilities:
 - Conducted outpatient comprehensive neuropsychological assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, and feedback sessions)
 - Collaborated in the differential diagnosis as part of interdisciplinary coordination meetings
- Population:
 - Young adults, adults, and older adults
 - Major work with underserved and low-income population
 - Inpatients referred from different hospital departments (cardiology, internal medicine, neurology, nephrology or psychiatry)
 - Reasons for referral included cerebrovascular pathology, chronic renal insufficiency, infectious and inflammatory processes such as HIV and encephalitis, traumatic brain injury, and toxic concomitant conditions such as alcoholism, Wernicke-Korsakoff, or drug abuse
 - Outpatients referred from other health institutions or from their primary physician

All work in this site was in Spanish.

Neuropsychology Extern

September 2000- July

2002

**Municipal Geriatric Center (IMAS)
Barcelona, Spain**

Supervisor: Dr. Peña-Casanova

- Responsibilities:
 - Conducted outpatient comprehensive neuropsychological assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, and feedback sessions)

- Collaborated in the differential diagnosis as part of interdisciplinary coordination meetings
 - Designed and led individual cognitive rehabilitation programs
- Population:
 - Young adults, adults, and elderly population
 - Major work with underserved and low-income population
 - Inpatients referrals from different hospital departments (cardiology, internal medicine, neurology, nephrology or psychiatry.) Reasons for referral included cerebrovascular pathology, chronic renal insufficiency, infectious and inflammatory processes such as HIV and encephalitis, toxic concomitant conditions such as alcoholism, Wernicke-Korsakoff, or drug abuse, and traumatic brain injury

All work in this site was in Spanish.

CLINICAL WORK EXPERIENCE

Job Title: Clinical Neuropsychologist
2009

June 2007-November

**Hospital of Mental Health (psychiatric) “Germanes
Hospitalàries de Benito Menni”
St Boi, Spain**

- Responsibilities:
 - Conducted outpatient comprehensive neuropsychological assessments and inpatient brief neuropsychological batteries (including clinical interviews, scoring and interpretation of results, integrated report writing, and feedback sessions)
 - Collaborated in the differential diagnosis as part of interdisciplinary coordination meetings
 - Coordination with the interdisciplinary team to plan and supervise cognitive rehabilitation programs
 - Provided support and psychoeducation to families
 - Trained clinical psychology internship students in conducting clinical interviews, administering and scoring neuropsychological tests, and case conceptualization
 - Imparted lectures to inform other professionals
- Population:
 - Older adults with comorbid psychiatric conditions (psychosis, substance abuse, mood disorders), and diverse neurodegenerative diseases
 - Patients from rural and underserved areas

All work in this site was in Spanish.

Job Title: Clinical Neuropsychologist
2007

October 2004- June

**St. Jordi Hospital
Cornella, Spain**

- Responsibilities:
 - Conducted psychological and neuropsychological assessments (establishing baselines and doing follow up) of psychogeriatric patients with neurodegenerative diseases
 - Design and supervision of cognitive rehabilitation programs for outpatients and inpatients
 - Taught other professionals how to implement rehabilitation interventions
 - Worked with patient’s families: conducting intake interviews, providing support and psychoeducation
 - Imparted lectures to other professionals
- Population:
 - Inpatients and outpatients in different stages of dementia and their families
 - Patients from rural and underserved areas

All work in this site was in Spanish.

Job Title: Clinical Psychologist
2004

September 2003-December

**Various centers for elderly
Barcelona area, Spain**

- Responsibilities:
 - Conducted cognitive rehabilitation and cognitive-enhancing programs
 - Led brief- behavioral interventions
- Population:
 - Inpatients at different stages of dementia
 - Normal aging older adults and geriatric population
 - Patients from rural and underserved areas

All work in this site was in Spanish.

Job Title: Clinical Psychologist
2004

September 2002-July

**Cognitive Rehabilitation Center (“Psychostimulation Alois”)
Cornella, Spain**

- Responsibilities:
 - Conducted psychological assessments and neuropsychological screening assessments
 - Designed and imparted cognitive rehabilitation programs
 - Led brief- behavioral interventions
 - Provided support and psychoeducation about neurodegenerative diseases to families
- Population:
 - People at different stages of dementia
 - Patients from rural and underserved areas

All work in this site was in Spanish.

Clinical Psychology Extern
1999

September 1998-July

**Children’s Center for Autism
Barcelona, Spain**

- Responsibilities:
 - Assisted children with autism and other psychotic diagnosis in their daily school classes
Guided them through their school homework, daily activities, and relationships

Clinical Psychology Extern
1999

September 1998-July

**Children’s House for Autism
Sabadell, Spain**

- Responsibilities:
 - Coached children with autism and other psychotic diagnosis in their daily living at the
Children’s House for Autism throughout the week

RESEARCH EXPERIENCE

Project of the European Reminiscence Network: *Making Memories Matter*
2005

June

**Sponsorship: Foundation Pere Tarrés
Barcelona, Spain**

- Responsibilities:

- Recollection of patients. Conducted interviews to patients and families to collect autobiographical information. Guided reminiscence therapy sessions, including building “life boxes” project. Coordination with artists

Epidemiologic study about the Incidence of the Alzheimer’s disease

February

2002

El Prat de Llobregat, Spain

- Responsibilities:
 - Conducted neuropsychological screening test to residents of the area

Thesis of Masters Studies:

The Pyramids and Palm Trees Test: Pilot Normalizing Study in a Spanish Sample of Young Adults (20 to 49 years)

September 2000-July

2002

Barcelona, Spain

- Responsibilities:
 - Research Assistant, as part of the Neuropsychology Master’s Program
 - Recollection of patients, conducting screening measures and other neuropsychological tests and scoring and interpreting results to obtain norms for that specific population

Projects: *Neuro-Cog*, *Neuronorma*, and *Integration Program of Neuropsychologic Assessment (PIEN)-Test Barcelona*. (Peña-Casanova)

September 2000-July

2002

- Responsibilities:
 - Research Assistant as part of the Neuropsychology Master’s Program,
 - Conducted screening measures and other neuropsychological tests (including scoring and interpretation of results) to obtain normative data for international test in Spanish-speaking population

PUBLICATIONS

1. Gudayol-Ferré, E., Lara, J. P., Herrera-Guzman, I., Böhm, P., **Rodés, E.**, Ansaldo, A. I., & Peña-Casanova, J. (2008). Semantic memory as assessed by the Pyramids and Palm Trees Test: The impact of sociodemographic factors in a Spanish-speaking population. *Journal Of The International Neuropsychological Society*, 14(1). 148-151.
2. Buriel, Y., Gramunt, N., Bohm, P., **Rodes, E.**, Peña-Casanova, J. (2004). Verbal Fluency: preliminary normative data in a Spanish sample of young adults (20-49 years of age). *Neurologia*, 19(4). 153-159.

ORAL PRESENTATIONS

1. **Rodes-Sendros, E.**, (2009, September). *Non-Pharmacological Therapeutic Interventions*. Oral presentation at the Annual Convention for Alzheimer’s Dementia, at the “Bennito Menni” psychiatric, St. Boi de Llobregat, Spain.
2. **Rodes-Sendros, E.**, Malla, LL. & Valverde, C. (2009, March). *Behavioral Disturbances in Dementia*. Oral presentation at the Professional Series Workshops, at the “Bennito Menni” psychiatric, St. Boi de Llobregat, Spain.
3. **Rodes-Sendros, E.**, (2008, June). *What is Dementia?*. Oral presentation at the Annual Convention for Alzheimer’s Dementia, at the “Bennito Menni” psychiatric, St. Boi de Llobregat, Spain.
4. **Rodes-Sendros, E.**, Casado, X., Azpiazu, P., Almenar, C. (2007, September). *Living with Dementia. Get in their skin*. Oral presentation at Annual Convention for Alzheimer’s Dementia, at the “Bennito Menni” psychiatric, St. Boi de Llobregat, Spain.

5. **Rodes-Sendros, E.**, (2006, April). *Dementia and Behavioral Disturbances*. Oral presentation at the St. Jordi's Nursing home conferences, at Cornellà, Spain.

6. **Rodes-Sendros, E.**, (2005, June). *Non-Pharmacological Interventions*. Oral presentation at the Annual Convention for Alzheimer's Dementia, at Cornellà, Spain)

POSTER PRESENTATIONS

1. **Rodes, E.**, Malla, LL. & Valverde, C. (2005). Psychogeriatric Residents Description in Cornellà. Presentation of 4 cases with pharmacologic and non-pharmacologic treatment. Poster presentation at the 1st International Meeting of the Non Pharmacologic Therapies for Alzheimer's disease: Madrid, Spain.

2. Buriel, Y., **Rodes, E.**, Gramunt, N., Bohm, P. & Peña-Casanova, J. (2002). Verbal Fluency. Pilot Normalizing Study in a Spanish Sample of Young Adults (20 to 49 years). Poster Presentation at the 54th Annual Meeting of the Spanish Neurology Society: Barcelona, Spain.

3. Yañez J. Janet, **Rodes, E.**, Díaz-Santos, M., Cavanagh, L., Miranda A. Alberto., Cagigas E. Xavier & Suarez A. Paola. (2019). Socially Responsible Neuropsychology (SRN) in Action: Assessment of a highly educated bilingual Latina older adult. *National Academy of Neuropsychology*, San Diego, CA.

4. Yañez J. Janet, Díaz-Santos, M., **Rodes, E.**, Cavanagh, L., Miranda A. Alberto., Cagigas E. Xavier & Suarez A. Paola. (2019). Socially Responsible Neuropsychology in Action: Bilingual Alzheimer's disease in two highly educated bilingual Latina women. *International Neuropsychology Society*, Denver, CO.

CONFERENCES AND ADDITIONAL TRAINING

- Assistance to the presentation ***Chronic Pain: A Mindbody Disorder***
New Center for Psychoanalysis Los Angeles (October 2019)
- Certificate for online training for the administration of the ***Columbia Suicide Severity Rating Scale. (CSSFR)*** (March 2017)
- Certificate on ***Trauma-Focused Cognitive-Behavioral Therapy***
Online Training Course (October 2016)
- Assistance at ***The Annual Meeting of the Dementia's Diagnosis and Treatment Units***
Santa Maria's Hospital. (May 29th 2009)
- Assistance at ***The Annual Meeting of the Dementia's Diagnosis and Treatment Units***
St. Caterina's Hospital. (May 30th 2008)
- Assistance at ***The 4th Barcelona-Pittsburgh Biennial Conference of Alzheimer***
ACE Foundation (May 21-23rd 2008)
- Assistance at ***The Clinical and Research Neuropsychology Conference: the 1st Congress of the Spanish Neuropsychology Associations (FANPSE)***
Catalan Neuropsychology Society (May 9-10th 2008)
- Assistance at ***The 12th Congress in Psychogeriatric Actualization***
Hospital "Germanes Hospitalaries del Sagrat Cor de Jesús" (May 10-11th 2007)
- Certificate for the assistance at the International Congress: ***Clinical Neuropsychology Advances***
(15h.)
Mapfre Foundation (October 2006)

- Assistance at the IV Neuroforum for Dementias: ***Aging and Memory***
Health Assistance Institute (October 6th, 2006)
- Certificate for the assistance at ***The Death and Mourning Concept Actualization*** (9h.)
Catalan Official Psychology College (COPC) (May 2006)
- Certificate for the assistance at ***The Multidisciplinary Treatment in Psychogeriatric Behavior Disorders*** (9h.)
Catalan Official Psychology College (COPC) (March 2006)
- Assistance at the ***4th Congress of the Spanish Psychogeriatric Society*** (November 2005)
- Certificate for the assistance at the ***1st Congress for the Geriatric Residences and Day Care Professionals.***
Catalan Official Psychology College (COPC) (May 2005)
- Certificate for the assistance at the ***1st International Congress of Non-Pharmacological Therapies for the Alzheimer's Disease.*** (20h) (May 2005)
- Certificate for the assistance at ***Culture and Personality. An intercultural psychological perspective*** (15 hours) (April 2004)
- Assistance at the ***54th Annual Neurological Spanish Society Meeting*** (December 2002)
- Assistance at the ***53rd Annual Neurological Spanish Society Meeting*** (December 2001)

PROFESSIONAL AFFILIATIONS

- Hispanic Neuropsychological Society, Student member
- National Academy of Neuropsychology, Student member
- International Neuropsychology Society, Student member
- American Psychological Association, Student member
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ALL REFERENCES AND TRANSCRIPTS ARE AVAILABLE UPON REQUEST

ABSTRACT

Fibromyalgia (FM) is a syndrome characterized by chronic, widespread musculoskeletal pain. Its prevalence is estimated to be about 2% to 5% of the adults in the United States (Arnold et al., 2019). However, significant variations exist in this respect, due to a lack of consensus about the guidelines for FM diagnosis by physicians. FM symptoms are not restricted to pain, and often include fatigue, anxiety, depression, somatic and cognitive symptoms, and poor quality of life. Although its etiological causes are still not clear, important psychological, social, and cultural factors have been linked to the onset, maintenance, and to the ways to respond to the condition, raising questions that remain unanswered to clinicians (Arnold et al., 2010, 2019; DeLuca et al., 2011; Yunus, 2012). The aim of this study was to understand the psychosocial characteristics of fibromyalgia in Latinas, precipitating factors as well as particular experiences, and ways to cope with it. Biopsychosocial theory was used to explore past and present social dynamics of people with FM, cultural influences, and psychological traits and mechanisms to deal with it. Semi-structured interviews were conducted with four patients, and after an interpretative phenomenological analysis, the major themes are presented. These results aim to help better understand this condition in Latinas, to guide clinicians to develop culturally responsive treatments for this population, and to ultimately decrease the stigma that persists around it.

Keywords: Fibromyalgia, interpretative phenomenological analysis, Latina, psychosocial factor

Chapter I: Introduction

Fibromyalgia (FM) is a complex chronic pain condition that presents with other physical symptoms and psychological distress and causes remarkable disruption on quality of life and function. It is estimated to affect between 2% and 5% of the adult general population in the United States, with women aged 50 and up more vulnerable to the condition (Arnold et al., 2010). Unlike nociceptive and neuropathic pain, FM does not present with structural changes that can explain its symptoms; thus, is usually classified as “unexplained illnesses” and often called “psychosomatic” disorder (DeLuca et al., 2011, pp 246, 254). The medical field started to address this debilitating and painful condition, but if there are no physiological causes for symptoms, physicians often believe that they do not exist; therefore, patients often feel dissatisfied with their clinicians’ responses and feel rejected (Armentor, 2017; Johnson, 2008; Upshur et al., 2010). Indeed, FM is considered a central sensitivity chronic pain syndrome, and chronic pain conditions with centralized phenomena are less well understood (Arnold et al., 2016; Yunus, 2009). Central sensitization (CS), which involves hyperexcitement of the central nervous system neurons, has been objectivated in fibromyalgia and has been proposed as one of the mechanisms causing hyperalgesia and allodynia symptoms. At the same time, CS is influenced by biological factors and psychosocial distress, and it can be well understood by the biopsychosocial model, where psychological risk factors may be mediated through interaction with biology (Yunus, 2009). For this reason, in all conditions involving central sensitization, an evaluation of psychosocial variables should be done to optimize treatment (Yunus, 2009). Currently, factors contributing to FM are considered to be multifactorial, involving not only physiological reasons, but also psychosocial elements (Bazzichi et al., 2020; DeLuca et al., 2011; Turk et al., 2016).

Although there has been significant progress in understanding FM, there is a lack of agreement for international criteria that hinders the diagnosis of the condition, and patients with FM can visit an average of 3.7 different physicians and spend more than two years before being diagnosed. As a result, it has been observed that after the diagnosis is given, patient's satisfaction increases and healthcare utilization decreases (Choy et al., 2010). Recently, the ACTION-APS Pain Taxonomy (AAPT) has made an international FM working group to establish revised diagnostic guidelines of FM using a multidimensional diagnostic framework that responds to the multifactorial condition (Edwards et al., 2016). The increasing emphasis on the psychosocial variables to understand and diagnose FM encourages future research to use the AAPT classification pain system to assess a set of key psychosocial and behavioral factors involved in FM (Edwards et al., 2016).

Certainly, psychosocial factors such as past traumatic events, cognitive processes, coping style, or interpersonal relationships have been documented to contribute to the onset of FM and/or are also the consequence of sustained pain. They are involved in the mediation of pain sensation as well as the maintenance of it. At the same time, they are also influencing the magnitude of the consequences of living with FM and determining how people cope with its symptoms (DeLuca et al., 2011). For these reasons, understanding of psychosocial variables surrounding the life of sufferers may be crucial to understand their unique pain experience and develop proper treatments. Further, early literature pointed to the importance of culture in determining and shaping the response to pain (Zatzick & Dimsdale, 1990). In the same line, more recent research uncovered ethnic differences that mediate and modulate the experience of pain (Jarrett, 2011; Rahim-Williams et al., 2012). However, few studies (e.g., De León-Menjivar, 2021; Torres et al., 2017) explore the particular experiences of Latinos/as (the fastest growing

population in the United States) with FM, and more research involving this community is critical. The following study aimed to provide a deeper understanding of important psychological and sociocultural factors that may influence the experience of pain for Latinas as well as the way they cope with it.

Overview of the Disorder

Description

The main characteristic of fibromyalgia is the chronic generalized musculoskeletal pain of unclear origin. However, most patients with FM also suffer from severe fatigue, unrefreshed sleep, cognitive difficulties involving mostly memory and executive functioning, emotional disturbances, and hypersensitivity to light, noise, and tactile stimuli. All these symptoms can reduce drastically their quality of life, and result in disability (DeLuca et al., 2011; López-Solà, 2014; Wolfe et al., 2010). FM includes symptoms like allodynia (pain due to a stimulus that does not usually provoke pain) hyperalgesia (increased pain from a stimulus that usually provokes pain; Arnold et al., 2016) and multisensory hypersensitivity (López-Solà, 2014). Individuals with FM can also have allergic reactions such as drug and environmental sensitivities. FM is frequently comorbid with psychiatric conditions, and anxiety and depression are the most common ones, but also can course with medical conditions such as headaches, irritable bowel syndrome, rheumatic diseases, infections, endocrine disorders, chronic fatigue syndrome, temporomandibular disorder, interstitial cystitis, chronic pelvic pain, or multiple chemical sensitivities (Arnold, 2010; DeLuca et al., 2011; Wolfe et al., 2010). With that said, is not clear if these comorbidities had their onset before or after the onset of FM.

Etiology

Although factors contributing to FM are still uncertain, in the last 40 years there have been huge advances in understanding the nature of pain, and numerous studies support the idea that central sensitization phenomenon is a factor contributing to allodynia and hyperalgesia in FM (Yunus, 2009). At the same time, CS is not purely biological phenomenon and is influenced by a number of psychosocial variables (e.g., distress, cognitive bias, adverse childhood); thus, increasingly, many authors point to a combination of biological and psychosocial factors contributing to the development and the maintenance of this condition (Arnold et al., 2010; see also Arnold et al., 2019; Bazzichi et al., 2020; Henningen, et al., 2018; Theoharides et al., 2015; Yunus, 2009). Moreover, it has been documented that contributing to the onset and maintenance of pain might be genetic factors, stress and disturbances in the stress-response system, as well as hormonal imbalances and neurotransmitters (Arnold, 2010).

Diagnosis

Several classifications and diagnostic criteria for FM have been developed and changed over the years. However, FM is still underdiagnosed and undertreated, and physicians are still unsure which diagnostic criteria to use and the options for its treatment (Arnold et al., 2019). The core diagnostic criteria for FM are based on the American College of Rheumatology (ACR) classification, which was first presented in 1990 (Wolfe et al., 1990) and revised in 2010 (Wolfe et al., 2010). Criteria defined in 1990 focused exclusively on chronic widespread pain (CWP) and included a review of patient's history of widespread pain of at least three months affecting both sides of the body as well as upper and lower parts. These criteria also required pain in at least 11 of 18 tender points sites on digital palpation (Wolfe et al., 1990). These criteria stemmed from a multi-center research study that found widespread pain and mild to greater tenderness in

at least 11 of 18 specified tender points on digital palpation in patients with fibromyalgia compared to patients with other chronic musculoskeletal diseases, with a sensitivity of 88% and a specificity of 81% (DeLuca et al., 2011; Wolfe et al., 1990). New diagnostic criteria were developed in 2010 by the ACR. In these revised criteria, the tender point examination was replaced with a continuous widespread pain index scale that provided much more information about the characteristics of pain, and a better understanding of the extent of the fatigue, waking unrefreshed, cognitive and somatic symptoms. Then, in 2011, a modified version of the 2010 criteria was proposed and was based on the patient's self-report of pain and a simplified list of somatic symptoms (Arnold et al., 2016; Jones et al., 2015) reflecting the increasing attention to the subjective perception component of the illness. These last criteria have been referred to as the modified 2010 criteria but was not formally endorsed by the ACR. In 2016, new-revised criteria required that patients had pain in 4 of 5 regions, with no specific requirement for its localization, and moving from the "widespread pain" to the "generalized pain." As Arnold et al. (2019) stated, "there is no gold standard for FM diagnosis" (para. 620), and diagnosis will have to rely on patients' report and clinical assessment until the pathophysiology is better understood and biomarkers identified.

Consequently, currently, there is a lack of international consensus on which criteria should be used, and a lot of effort is being put in understanding the characteristics of FM and in gaining consensus on diagnostic guidelines (Arnold et al., 2016).

More recently, in 2018, the ACTION-APS Pain Taxonomy (AAPT) developed an evidenced-based, multidimensional, chronic pain classification system in which psychosocial concepts and processes were crucial to understanding how chronic pain develops as well as its consequences. The AAPT chronic pain classification system included five dimensions, and

dimensions four and five explore psychosocial factors contributing to the experience of FM. Dimension 1 proposed core set of diagnostic symptoms for FM (pain, and severe sleep problems or fatigue); dimension 2 included common features (tenderness, cognitive problems, musculoskeletal stiffness, and environmental sensitivity or hypervigilance) and epidemiology; dimension 3 incorporated common medical and psychiatric comorbidities; dimension 4 embraced neurobiological, psychosocial, and functional consequences of FM, and dimension 5 comprised recognized neurobiological and psychosocial mechanisms, risk factors, and protective factors for FM (Arnold et al., 2019; Edwards et al., 2016).

The current criteria for the diagnosis of FM are independent of the presence of other disorders (including rheumatological illnesses) and tests (i.e., laboratory, imaging). However, the differential diagnoses for FM can be challenging, since many of its symptoms overlap with other medical conditions that present with widespread musculoskeletal pain, such as chronic pain disorder, chronic fatigue syndrome (CFS), irritable bowel syndrome, chronic pelvic pain, or chronic headaches and migraine disorders. Also, many rheumatic conditions, both inflammatory and degenerative, can trigger peripheral pain and be comorbid with FM, which has been called “secondary FM” (Arnold, 2010; Arnold et al., 2019; Wolfe et al., 1990).

In this respect, Yunus (2009, 2012) emphasized the mutual association among central sensitivity syndromes and observed that FM is highly prevalent within other chronic pain conditions such as rheumatoid arthritis, systemic lupus, ankylosing spondylitis, osteoarthritis, diabetes mellitus, and inflammatory bowel disease. Recognizing FM among these diseases is essential so that the symptoms are not confused, and patients overmedicated (Arnold, 2010; Arnold et al., 2019; Yunus, 2012).

Course

It is estimated that the average onset of the condition is 30-50 years. Although the course of the condition is chronic, symptoms of FM often come and go, and many sufferers report difficulties identifying a pattern to their symptoms. Also, there is some evidence that patients adapt to the symptoms and improve their functioning over time (Arnold, 2010).

Prevalence

The prevalence of FM has been estimated to be between 2% and 5% in the general adult population in the United States, with women being more susceptible to the condition even when using diagnostic criteria that eliminates tender points (Arnold et al., 2019). Prevalence is higher at ages between 50 and 59, with women aged 50 and up more frequently diagnosed with this condition. However, there exist significant discrepancies on prevalence and female/male ratios depending on which criteria are used for the diagnosis. A study comparing these differences between the 1990, 2010, and modified 2010 criteria found that prevalence was 1.7%, 1.2%, and 5.4% respectively. Importantly, prevalence is not only higher with the modified 2010 criteria, but also a larger proportion of men were identified: 13.7:1, 4.8:1 and 2.3:1, respectively (Jones et al., 2015).

Consequences

FM has multiple psychosocial and functional consequences in the physical, cognitive, social, occupational, emotional, and economic areas, causing a significant decrease in the quality of life of those affected. Furthermore, since chronic pain persists over time, psychosocial variables will not only be influenced by the chronic pain, but also will impact the experience of pain and its related symptoms. Additionally, pain occurs in a person living in a particular social context, including social support, responses to communication of pain (overt expressions),

distress, and pain behaviors related to suffering that will in turn influence the outcomes of pain experience and the ability to adapt to it (Turk et al., 2016). In the same line, Pincus and Morley (2001) observed how sustained pain might lead to changes in the contextual and subjective phenomena involved in the perception of pain (such as loss of functionality and social roles, uncertainty of the diagnosis, etiology, or stigma), which in turn, created cognitive bias when processing information (i.e., interpretation and memory bias).

Arnold et al. (2008) conducted a qualitative study to identify FM symptom's domains and to understand their impact on the daily life of patients. Across all the focus groups that they conducted, the symptom domains that were most consistently reported were pain, fatigue, sleep disturbance, cognitive impairment, depression, anxiety, and decreased functionality and quality of life. Specifically, fatigue was the area of most concern and significantly incapacitating. In this study, patients described constant general pain as "achiness" and "hurt all over" (Arnold et al., 2008, pp. 117). Some explained their initial sensation as "skin sensitivity" (Arnold et al., 2008, pp. 117) that led to a "burning sensation." Most patients reported their pain would not cease for more than one day. This constant pain occurred in the context of constant fatigue, impaired sleep, and cognitive problems. Most participants presented depressive and anxious symptoms and expressed feelings of embarrassment, frustration, guilt, isolation, and shame. Further, the same authors described cognitive problems in FM, which have been often called "FibroFog," and have been reported across domains. Although increasing interest has been put on the study of cognitive symptoms in fibromyalgia, results are still controversial. In a recent meta-analysis of cognitive performance in fibromyalgia, results were negatively associated with struggles on all cognitive functions. Specifically, the study evidenced significantly worse performance by the fibromyalgia group on inhibitory control (including selective attention and inhibition capacity),

followed by short and long-term memory and processing speed, with the smallest differences for other executive functions (set shifting and accessing). The authors concluded that these findings appeared to be in congruence with the hypothesis that consumption of attentional resources for constant pain perception can impair activation of inhibitory systems in fibromyalgia (Bell et al., 2018). Importantly, the cognitive deficits encountered in fibromyalgia appear to be independent of depressive symptoms (Tesio et al., 2015). To capture these cognitive difficulties, the proposed AAPT multidimensional diagnostic system for FM included a section called *dyscognition* as a common feature in FM (within dimension 2), characterized by trouble concentrating, forgetfulness, and disorganized or slow thinking.

FM symptoms also impact the social and occupational function of those who suffer it. The unpredictability of symptoms impedes patients to participate in social activities, and the fatigue and cognitive symptoms make it difficult to maintain their jobs and responsibilities. Patients report losing friends and jobs while feeling guilty for not being able to take care of their loved ones or to carry on their daily house chores. Consequently, FM also impacts family and economic situation (Arnold et al., 2008). Moreover, Porter-Moffitt et al. (2006) compared biopsychosocial characteristics of seven chronic pain syndromes and found that the FM group was distinguished by the highest psychosocial difficulties. Specifically, they found that people with FM were more physically/functionally impaired, and presented higher elevations in the scales of hypochondriasis, depression, hysteria, and psychasthenia relatively to other pain groups. Also, according to these authors the FM group had a higher percentage of individuals with a “Neurotic Triad” profile in the Minnesota Multiphasic Personality Inventory (MMPI), and had more impaired coping abilities, higher levels of self-reported disability and anxiety, and showed poorer quality of life. The study revealed that the FM group was the most bio-

psychosocially disabled and highlighted the need for comprehensive treatment programs that focus on physical/functional disability issues, and on reducing affective distress.

In their study, Turk et al. (2016) reviewed and described several cognitive, behavioral, and affective constructs, as well as biomedical factors involved in the experience of pain and its consequences (i.e., beliefs, appraisals, thought processes such as catastrophizing, sense of control, or self-efficacy, mood/affect, coping resources, expectations, sleep quality, physical function, pain-related interference with daily activities), and the interaction of these elements with the socioenvironmental context in which they occur. The authors emphasized the importance to assess all these elements to gauge the impact of chronic pain in the sufferers. To this end, the authors also reviewed and proposed a set of measures and procedures to explore the above-mentioned aspects. Importantly, in this study, the authors underscored the overlap between psychosocial constructs and processes as “causal” agents of pain, and psychosocial constructs and processes as a consequence of sustained pain. For example, specific beliefs may lead to behaviors such as avoidance and deactivation, which may in turn increase pain, and promote more negative thoughts and beliefs about the pain.

Stigma. Additionally, people with chronic pain have expressed feeling dissatisfied with their care (Upshur et al., 2010). Cedraschi et al. (2015) pointed that the relationship between FM patients and physicians is often complicated, with discordance, lack of understanding, and feelings of uncertainty. In their study, the authors highlighted the importance of understanding patient experiences, perceptions, and causal attributions to find a treatment that responds to the individual’s needs. Another study, in which patients with FM described their experiences with the illness found that often, doctors feel clueless and do not know how to treat the condition. Often, they push their patients to take medication that most patients refuse. Consequently, some

physicians had reportedly been rude to patients. Similarly, numerous people with FM reported a lack of understanding and being treated unsympathetically by their coworkers (Dennis et al., 2013).

Chapter II: Literature Review

An electronic search of the literature was performed using popular engines from the fields of health/medicine and psychology, available to the researcher from Pepperdine University and UCLA. Engines included: PubMed, Medline, PsycInfo, and Scopus. Also, searches through UCLA library involved exploring articles across multiple databases.

Most common search terms included: Fibromyalgia, Fibromyalgia and Latinos, FM and Hispanics, Pain and Latinos, and Pain and Hispanics. Only peer reviewed articles were included. Because of important discoveries, definitions, and diagnosing criteria were made in the early century, and to have a better understanding of the evolution of FM, the year of publication of the articles ranged from 1940 up to 2021. However, this range was restricted when searching for specific topics related to FM's current status quo (e.g., etiology, treatments). Part of the included literature was chosen from the references and citations from studies found through the engines mentioned above. Occasionally, if a potentially interesting article was not found through the mentioned searching engines, the researcher used Google Scholar (<https://scholar.google.com/>)

When searching for peer-reviewed literature regarding Fibromyalgia, very little research used qualitative methods. Beyond that, qualitative research exploring Latinos/as with Fibromyalgia was almost non-existent. Although there were more studies done on FM using quantitative methods, these often did not specify ethnicity of participants, or included non-Latinos/Hispanics.

The Biopsychosocial Model

The biopsychosocial model (Campbell & Rohrbaugh, 2006) moves from a model that emphasized the pathophysiology involved in the pain, to the involvement of the person's cognitive and emotional states, and helps to understand the multidimensional construct of FM.

The model is derived from the general systems theory, which proposes a bidirectional relationship between the biological, the psychological, and the social systems. The biological system includes the anatomical, structural, and molecular substrates and their effects on the patient's biological functioning. The psychological system entails how the developmental factors, motivation, and personality guide the patient's experiences and reactions to illness. The social system explores how cultural, environmental, and familial factors impact the appearance of the illness and experience of the person. Although under the umbrella of the biopsychosocial model exist several different models, all of them propose that affect, cognition, and behavior interact with neurobiological pathways to determine long-term pain outcomes. Specifically, the biopsychosocial model of pain defines pain and disability as a multidimensional, dynamic interaction between physiological, psychological, and social variables that determine the pain condition, and not merely a response to tissue damage (DeLuca et al., 2011).

Guided by the biopsychosocial model, in 2017, the Addiction Clinical Trial Translations, Innovations, Opportunities, and Networks (ACTION)-American Pain Society (APS) Pain Taxonomy (AAPT) proposed an evidence-based, multidimensional, chronic pain classification system to capture and understand the different psychosocial constructs contributing to chronic pain and its outcomes. Upon this classification system, Edwards et al. (2016) highlighted the role of psychosocial factors in the development and adjustment to chronic pain, as well as in modulating treatment outcomes.

Under the umbrella of the biopsychosocial approach, other models have proposed a less multidimensional view. For example, Vlaeyen and Linton (2000) and Hadjistavropoulos (2017) described a model in which two mechanisms guided the pain experience. The first one was the Fear Avoidance Model (FAM), which proposes that we can deal with pain fear either by

“confronting” or “avoiding” our experience. The former might facilitate reduction of pain, and the second one, leads to maintenance or amplification of pain fear, and results in disability. The model predicts that fear impedes recovery and highlights an inter-relationship between catastrophizing, fear, depression, and pain-related disability. The second mechanism determining pain experience is the avoidance-endurance model (AEM), which highlights the interaction between psychosocial processes and behavior. While some patients will become activity-avoidant and fearful of pain, others will show an “endurance” response. This response in turn, can be maladaptive (characterized by high anxiety and suppression of thoughts) or adaptive (high levels of positive affect and tendency to minimize pain threats). However, this model has been questioned for the different assumptions about the proposed sequential and cyclical relationships among psychological risk factors. Instead, Wideman et al. (2013) proposed a multidimensional framework to address the broad range of processes contributing to pain-related disability, and that includes not only resilience, physiological, and behavioral processes, but also the influence of social, cultural, and environmental factors in the shaping pain and disability. Additionally, the authors added the importance of taking into consideration the cumulative impact of multidimensional risk factors to predict pain outcomes.

Currently, the biopsychosocial model has been the most accepted and used when exploring pain and its related conditions (Arnold et al., 2016; Edwards et al., 2016; Orhan et al., 2018; Preece et al., 2005; Turk et al., 2016; Yunus, 2009).

Biological Formulation

The biological-descriptive database includes the etiology of the illness and its impact to the human body. It assesses patients' biological predispositions and how their demographics match the known epidemiology of a disorder. Although in FM there is no evidence of underlying

structural changes to support its symptoms, numerous studies have observed biological differences in patients with this condition. In this respect, Arnold (2010) supported that contributing to the expression of FM are genetic factors, stress and disturbances in the stress-response system, hormonal influences, and/or an aberrant central nervous system processing of pain contributing to the condition. In his study, he documented that it is very common for FM patients to have a family history of chronic pain, and first-degree relatives of FM patients, are eight times more prone to suffer from this illness (Arnold et al., 2010). In the same line, other studies observed that positive familial history of pain was significantly associated with lower pain threshold and pain tolerance, while absence of family history appeared linked to higher pain threshold and tolerance (Fillingim et al., 2000; Racine et al., 2012b), suggesting that biological factors involving genes may be in part determining the experience of pain (Arnold et al., 2019). Regarding stress and its response system, Arnold (2010) pointed out the alteration of the stress-response system as a result of chronic stress and suggested that people with FM might have decreased hypothalamic corticotropin -releasing hormone (CRH) secretion, that could contribute to FM features. The author also observed the relationship between level of estrogens and responsiveness of the CRH gene expression. Since the CRH hormone helps to decrease pain perception, alterations in estrogens have been linked to decreased responsiveness to CRH, stress, and potentially to FM. Further, although different neurotransmitters have been found to be higher in FM patients, results are still controversial (Arnold et al., 2019). Lastly, in his study, Arnold (2010) suggested a dysfunction of the nervous system processing of pain contributing to FM symptoms. Importantly, robust research considers central sensitization as a physiological hallmark of FM that leads to increase central pain processing (Arnold et al., 2019; Geisser et al., 2008; Gracely et al., 2002; Henriksson, 2003; Yunus, 2009). In this regard, patients with FM

might have decreased activity of the descending analgesic pathways and diffused increased processing of all sensory stimuli (not just pain). Specifically, the mechanisms underlying central sensitization may lead to hyperexcitability of postsynaptic neurons in the nociceptive pathways reducing pain threshold, increasing the magnitude and duration of responses to noxious inputs, and causing dysfunction of descending pathways for inhibition of pain, all in all, leading to amplification of pain (Yunus, 2009).

There also exists strong evidence for the relationship between elevated levels of Substance P (SP) and pain. SP is a neuropeptide and acts as neurotransmitter of pain. It has been associated with the hypothalamic-pituitary-adrenal (HPA) axis, which regulates stress. Lyon et al. (2011) discussed the relationship between central sensitization of nociception and the activation of the stress response and pointed to the role of neuropeptide Substance P in the development of central sensitization. The authors suggested that elevated levels of SP and its preferred receptor, neurokinin 1 (NK 1R), could be a result of a prolonged stress response and would be critical to the pathogenesis of FM. Thus, these authors hypothesize that SP could serve as a biomarker for chronic activation of the stress response. Importantly, they also point out that cognition can trigger and maintain the stress response and the release of SP, leading to a higher perception of pain.

Psychological Formulation

The psychological system includes patients' psychological world. For example, the subjective patients' experiences of growing up, influences from others, personal descriptions of oneself, or ways to react to problems. This part includes how the patient developed psychological vulnerabilities (predisposing factors), current psychosocial stressors (possible precipitants),

consequences of current psychosocial stressors (emotions and cognitions), and ways of dealing with stress (adaptive and maladaptive behaviors).

Stress, Childhood Adversities, and Posttraumatic Stress Disorder. Contributing to the development of FM are various types of stressors (Arnold et al., 2010; Edwards et al., 2016). Abundant research has demonstrated the idea that having suffered traumatic events, or childhood adversity can predispose individuals to FM. Varinen et al. (2017) provided significant information about the possible background contributors to the onset of FM. The authors found statistically significant associations between fibromyalgia and six family childhood adversities (parental divorce, long-lasting financial difficulties, serious conflicts, being afraid of a family member, serious or chronic illnesses, and alcohol problems). Moreover, this association appeared not related to gender, age, educational level, marital status, and presence of depression.

In the same line, in his multicentric study, Häuser et al. (2013) found that the prevalence of PTSD in patients with FM was at 45%. In 66% of cases, the traumatic events and PTSD symptoms preceded their pain. In 30% of patients, traumatic events and PTSD symptoms followed the onset of the pain. In 4% of patients, the traumatic events and PTSD symptoms happened within the same year. Notably, they observed that patients with FM and PTSD reported more pain, more somatic and psychological distress and disability than patients with FM without PTSD. The authors concluded that patients with FM had experienced more traumatic life events than controls, and also, FM patients were more prone to experience major life events as traumatic, evidencing an overlapping between triggers and consequences of FM. Other authors have identified disruptive circumstances, psychological distress, and hopelessness surrounding FM symptoms onset, supporting the idea that emotional and physical trauma may contribute to the development of FM (Cedraschi et al., 2015).

Cognitive Processes. Multiple cognitive processes have been documented to influence favorably or adversely our experience of pain and our way to cope with it. Some studies have linked positive psychological factors to resilience against chronic pain and related suffering (Edwards et al., 2016). Among these factors are engaging in positive thinking (including positive self-efficacy and perceived control of pain), making encouraging self-statements, distracting one's attention from pain, undertaking as much physical activity as possible, and/or using relaxation exercises and stretching. Furthermore, acceptance, psychological flexibility, and values-based action exhibit improved responses to pain. Specifically, acceptance has shown to mediate the pain experience. Also, providing education about the biological processes underlying pain has been observed to reduce catastrophizing and pain-related negative affect, while reducing the intensity of pain. The underlying mechanism for that has been hypothesized to be a change in the conceptualization of pain (Edwards et al., 2016). Conversely, cognitive processes such as catastrophizing, negative cognitive bias, beliefs, and perception of low self-efficacy can worsen or perpetuate the pain.

Catastrophizing. Catastrophizing is a cognitive process in which one assumes the worst consequence from a situation, and a vast volume of evidence suggests its crucial role in determining the experience of pain (Lazaridou et al. 2017). Catastrophizing has been distinguished from beliefs and coping strategies, and independently associated with different outcomes, and different studies point out the importance to ponder catastrophizing separately from other cognitions and coping strategies in individuals with chronic pain (Turner et al., 2000). Lazaridou et al. (2017) linked hyperalgesia in FM to catastrophizing processes due to dysfunctional cognitive-emotional patterns. Although it is not clear if the tendency to catastrophize is a trigger or a consequence of the pain suffered, it has been stated that

catastrophizing contributes to perpetuate and/or exacerbate the different symptoms of the condition (Day et al., 2012; Turk et al., 2016). Specifically, catastrophizing has been linked to negative affect such as depression, anxiety, and fear of pain, and it can impair treatment outcomes; therefore, teaching patients with chronic pain to modify catastrophic thoughts might help prevent negative affect, increase effectivity of treatments, and decrease disability (Edwards et al., 2016; Turner et al., 2000).

Cognitive Bias. Pincus and Morley (2001) were interested on the impact of chronic pain on the self and developed a model explaining the relationship between cognition, affect, and chronic pain. According to their model, population with chronic pain display biases in the way they process pain-related information. For example, in an ambiguous context, individuals with chronic pain tend to interpret information by generating responses related to pain, health and illness. Similarly, individuals with chronic pain tended to remember material congruent with they mood state. The authors hypothesized that these biases emerged as a consequence of the interrelation of three schemes: the self, the pain, and the illness, and the context in which they overlapped. When the three schemes completely overlap, this might maintain and intensify distress. This can happen when sustained pain causes repeated interruption and interference with performing tasks to the point where it can impact the person's self-schema. On the contrary, if pain has no implications for one's general physical well-being and has little self-relevance, the overlap between the schemas will not be substantial, and will not cause significant distress.

Beliefs. A broad range of psychological variables can impact the experience of pain (Edwards et al., 2016). Although beliefs, catastrophizing, and coping strategies influence each other, different studies have looked into how they independently can influence the experience of pain and its consequences (i.e., physical disability and depression). Beliefs are assumptions about

reality that are used to interpret events. The influence of pain-related beliefs is powerful, and modification of maladaptive beliefs about pain has demonstrated changes in pain, response to treatment (Turk et al., 2016), and also, may predict physical disability and depression (Turner et al., 2000). In their literature review, Stella and Schofield (2010) evidenced how different cultures hold different beliefs about pain, and how beliefs about the underlying causes of pain and its meaning determine the suffering of the individual. Additionally, beliefs influence individual's sense of self-efficacy and his or her coping responses.

Self-Efficacy. Self-efficacy has been defined as the individual's belief in his or her own ability to perform a certain behavior to achieve a desired outcome (Keefe & Somers, 2010). As Edwards et al. (2016) pointed out, according to Bandura's social-cognitive theory, self-efficacy might be key in shaping individual's thoughts, feelings, and behaviors in stressful situations; thus, it can determine the efficiency of coping with adversity. Further, pain-related self-efficacy beliefs have been observed to impact pain experience and grade of disability (Edwards et al., 2016). Specifically, lower perception of self-efficacy and self-control has been linked to greater clinical pain rates and disability (Sardá et al., 2009; Turk et al., 2016), and the conviction of not being able of controlling a situation or to overcome obstacles has been associated with chronic pain (Jarrett, 2011); therefore, assessing beliefs around self-efficacy could help on the prognosis of chronic pain (Martinez-Calderon et al., 2018). Additionally, Edwards et al. (2016) advised that the perception of self-efficacy, among other psychosocial factors, can emerge from the experience of pain, and poor sense of self-efficacy can be a risk factor for developing chronic pain, and ultimately, disability.

Coping Strategies. It has been observed that maladaptive coping strategies for stress (e.g., internalizing or suppressing anger) leads to depressive and anxiety symptoms in people suffering

from FM; thus, it has been recommended that interventions for FM include teaching adaptive strategies to cope with pain (e.g., increase positive emotions, modify catastrophic thoughts, reinforce internal locus of control, or increase self-efficacy; Amutio et al., 2015). In their study, Turner et al. (2000) suggested that this variable contributed independently to physical disability. Turk et al. (2016) concluded that coping strategies might predict pain perception, levels of emotional distress, adaptation, and functional disability. With that said, successful coping strategies might not be universal, and they may depend on unique factors of the individual, such as goals, family situation, and other environmental variables (Turner et al., 2000).

Perception of Control/Helplessness. How patients perceive their ability to control pain and associated stress influences the way they cope with the pain, and a higher sense of control has been associated with greater functionality. Consequently, low perception of pain control and helplessness has been related to a worsening of pain and poorer physical and psychological adjustment to chronic pain (Keefe & Somers, 2010; Turk et al., 2016). Relatedly, an external locus of control has been correlated with high levels of anxiety and depression in FM patients, and it has been observed that women with FM appear to present higher external locus of control, lower levels of adaptive cognitive bias, less perceived family support, and lower mood (Amutio et al., 2015; Shuster et al., 2009).

Finding Meaning. In their review, Stella and Schofield (2010) highlighted the importance of finding a meaning for pain to help accept and reduce the suffering. Particularly, they observed that understanding the underlying cause of pain determined interpretation of pain and coping behaviors of those who suffered from it. However, they found that different cultures interpreted pain in a different way; thus, the authors advocated for an understanding of the

individual's culture/ethnicity and race, to guide which particular factors could help individuals give meaning to their pain and alleviate their suffering.

Emotional Distress. Research supports an interrelation between mood disorders and persistent pain, and a large number of FM patients have a history of psychiatric care, with depression and anxiety being the most common ones. People with chronic pain have shown elevations in indices of depression, anxiety, and high emotional distress in general (Edwards et al., 2016; Hadlandsmyth et al., 2020); yet, it remains unclear if these psychiatric entities are triggers for pain or a reaction to it. Exploring this question, Geisser et al. (2008) observed a significant association between sensory amplification and higher clinical pain and greater number of comorbid somatic symptoms in people with FM; however, this measure was not associated with depressive symptoms, showing that sensory amplification in people with FM is not a consequence of depression or depressive symptoms. Similarly, Hadlandsmyth et al. (2020) observed significant associations between depression and multiple somatic and cognitive variables, that were not associated with anxiety. Consequently, they suggested that central sensitization or systemic inflammation could be underlying solely symptoms of depression and specific somatic variables, but not other mood disturbances, indicating that depression was less likely to be a consequence of pain. On the contrary, Hirsch et al. (2020) found that the greater the impact of fibromyalgia was on sufferers, the more depressive symptoms were encountered; besides, finding a silver lining appeared to be a protective factor against mood disturbances, including depression. These results showed that depressive symptoms seemed to arise from suffering FM. Additionally, Turk et al. (2016) observed that depressed patients with pain reported more pain than non-depressed patients with pain. In light of this literature then, the presence of depressive symptoms in FM may not necessary be a consequence of pain, and

identifying and understanding several other variables associated with depression (e.g., catastrophizing, quality of sleep, fears) may facilitate to understand, identify, and target specific contributors to the symptoms of FM.

Alexithymia/Communication of Emotions. Several studies have documented that emotional functioning plays a significant role in fibromyalgia. Specifically, alexithymia has been associated as a characteristic of patients with FM (Di Tella et al., 2015; Montoro et al., 2016; Vallejo et al., 2014). However, studies in this area do not explore the origin of alexithymia, thus, it is unclear if the incapacity to connect to emotions could be a preexistent factor or a consequence of FM. In this regard, Cedraschi et al. (2015) found that FM patients had difficulties coping with pain problems associated with significant distressing emotions and with conveying these emotions to clinicians. The authors suggested that patients with FM and other psychosomatic pain conditions might have learned to use emotional avoidance and to not verbally process their traumatic events.

Social Formulation

The social system includes social life, which involves family, friends/significant others, social environment, education, work, housing, income, access to healthcare services, or legal problems. In this regard, numerous studies have looked into different psychosocial variables influencing the experience of pain and also emerging from the experience of pain. In their review, Edwards et al. (2016) documented the role social factors not only in the risk for developing pain, but also in shaping long-term adjustment to pain, and in modulating pain treatment outcomes. The authors pointed out that interactions between chronic pain sufferers and their significant others (i.e., parents and/or spouses) could either ease or worsen adjustment to pain. For example, they found that social support improved outcomes in people with different

medical conditions, and solicitousness predicted higher pain-related disability. Similarly, parental pain catastrophizing was linked to children's persistent pain following major surgery. Furthermore, high levels of depressive symptoms in the spouse, predicted worsening of symptoms and disability in people with rheumatoid pain. Also, partners with avoidant attachment styles and anxious attachment styles were more likely to experience more pain and less well-being. Besides, lack of social support at work appeared to be a strong predictor for work disability related to pain.

Bergman (2005) found socio-demographic, psychosocial, and lifestyle factors relevant to populations with FM. Belonging to a lower socio-economic group, being an immigrant, living in a compromised housing area, having a lower educational level, experiencing lower social support, and having a family history of chronic pain, appeared to modulate the experience of pain in patients with chronic pain and FM. In addition, occupational stress, including high workload, low decision authority, and experiences of being bullied, have been thought to increase the risk of FM diagnosis, with the perception of being bullied as the strongest predictor (Kivimäki et al., 2004). Likewise, work stress could play a significant role in the incidence of depression in the chronic pain population (Munce et al., 2006).

Social comparison was explored by Cabrera-Perona et al. (2017), who suggested that this process could serve as a modulator and mediator of illness adjustment. The authors added the Identification-Contrast Model to the upward and downward processes for comparison and described how the higher the perception of pain was in people with fibromyalgia, the more they used negative-interpretation comparison strategies (upward contrast and downward identification). They also had more catastrophizing thoughts and perceived more impact from the

illness and psychological distress. For that reason, considering how people with FM compare to others may be helpful when designing treatments for this population.

Interestingly, Stella and Schofield (2010) found that the involvement of the family and friends was a crucial component to help alleviate suffering in specific ethnicities such as Hispanics and African Americans and played a less determinant role in non-Hispanic whites. With that said, it has been observed how family structures, behaviors, capabilities, and burden determine how much the family can alleviate pain. For example, marital conflict or family stress might contribute to worsen health outcomes, while family support and resilience to a better health (Preece & Sandberg, 2005). These studies support the importance to consider the involvement of family in treatments for pain.

The biopsychosocial model provides a useful framework to understand pain, facilitate diagnosis, and tailor treatments for a multidimensional entity such as FM. The recognition of the role of these specific biopsychosocial factors in the experience of pain suggests the importance to target all those variables in treatment (Turner et al., 2000).

Gender and Experience of Pain

Various studies have explored sex/gender differences in pain. Racine et al. (2012a,b) did a two-part systematic review of literature about sex/gender differences in experimental pain perception from 1998-2008. The authors observed a lack of consistency across studies and significant differences depending on the modality of induced pain (e.g., thermal, ischemic, or pressure pain). Furthermore, they pointed out that the vast majority of the articles reviewed, included a healthy population of students, and did not include populations that suffer from different chronic pain conditions (Racine et al., 2012a). In a second part of this study, analyzing the same literature, the authors investigated the biopsychosocial factors that could mediate sex-

differences in the perception of pain. In this review, the authors found inconsistent, insufficient, or mixed evidence supporting the role of biological factors in determining sex/gender differences in pain, and if any evidence was found, this did not apply to all pain modalities. However, psychosocial factors such as catastrophizing, coping style, and interpersonal relationships could mediate sex differences in pain experiences. For example, the authors found that females tended to cope better with pain through using pain attentional focus or reinterpretation, whereas men tended to use more distraction. Likewise, gender role expectations were suggested to explain some differences in pain perception between men and women. Lastly, the authors found few studies showing that when the sex of the experimenter was the opposite of the participant, this seemed to increase pain tolerance and threshold in participants, regardless of their sex (Racine et al., 2012b).

Ethnicity and Experience of Pain

Pioneer work by Zatzick and Dimsdale (1990) and Zborowski (1952), pointed to ethnic, racial, and sociocultural differences in the experience of pain. Specifically, Zborowski (1952) observed ethnic/racial differences in the attitudes, behavioral aspects generated after the pain, impact of the disease, and in how different each ethnicity coped with pain. Zatzick and Dimsdale (1990) emphasized the difference between pain tolerance and pain threshold, the first one being more loaded toward psychological variables such as culture. Also important, they noted significant differences in the vocabulary of pain used by different ethnicities. The mechanisms underlying the observed differences are still unclear. More recent studies (Gagnon et al., 2014; Jarrett, 2011; Kim et al., 2017; Orhan et al., 2018; Rahim-Williams et al., 2012; Stella & Schofield, 2010) supported the idea that a combination of psychological and socio-cultural aspects determine such differences. In their literature review, Rahim-Williams et al. (2012)

found potentially important ethnic/racial group differences in experimental pain perception, that were attributed to a number of sociocultural, psychological, and biological factors. As sociocultural aspects, the authors included beliefs, attitudes, language and expressiveness, medication practices, spirituality, social roles and expectations, cultural group membership, socialization of pain expression, perceived discrimination, socioeconomic status, or acculturation. As psychological influences, the authors included pain coping strategies, mood, or hypervigilance. However, this literature review included mostly African American and non-Hispanic whites. In another literature review, Kim et al. (2017) included Hispanic population to describe ethnic and racial experimental pain sensitivity, and found that African American, Asian, and Hispanic participants presented higher pain sensitivity to experimental pain compared with Non-Hispanic-Whites (NHWs). These differences in pain perception were detected across multiple stimulus modalities (mechanical pressure, ischemic stimuli, electrical, and thermal). Also, they were greater when using suprathreshold than with threshold stimuli, which indicates a difference not only in pain perception but also in pain tolerance (Kim et al., 2017; Rahim-Williams et al., 2007, 2012). Additionally, Rahim-Williams et al. (2007) used ethnic identity as an index to measure the degree to which the individual identifies with his/her ethnic identity and associated values, and to which grade these factors were influencing his/her responses to pain. The authors found that more identification with one's ethnicity predicted greater pain responses in African-Americans and Hispanics, compared to non-Hispanic and white Americans, indicating that ethnicity contributes at least in part, in shaping our perception of pain.

Similarly, several studies have stressed that differences in reactions and expressions of pain have no neurosensory origin, but are founded on the different meanings, language, emotional and cognitive aspects of pain, which at the same time, are molded by culture (Rahim-

Williams et al., 2012; Stella & Schofield, 2010). In their study, Stella and Schofield (2010) explained the subjective and multifactorial nature of the pain experience and described particular cultural differences in experiencing, interpreting, and expressing pain. Additionally, there exists some evidence that culture and/or ethnicity determine at the same time, illness perception, sense of self-efficacy, and fear avoidance beliefs regarding physical activities and work (Orhan et al., 2018).

Further, Gagnon et al. (2014) used data from medical records of patients evaluated and treated in a pain management program to identify ethnic differences also in treatment outcomes. They observed that Latinos/as endorsed higher levels of pain-related anxiety, pain severity, and pain catastrophizing than Caucasians at pretreatment and post-treatment. Also, Latinos/as showed greater use of prayer than Caucasians at both pre- and post-treatment. The authors suggested that there were ethnic group differences in the initial reporting of pain as well as in the pain treatment outcomes.

Latinos and Management of Pain

Besides psychosocial factors influencing the differences in the experience of pain, the way we cope with it, and the effectiveness of pain treatments, other research has found sociocultural factors underlying differences in the management of pain. In their qualitative study, Torres et al. (2017) explored the pain management needs and perceived barriers to medical pain care in Hispanic patients and identified traditional Hispanic cultural values impacting patient's perspectives and expectations around their pain and treatment. The authors found that foreign-born Hispanics living in the United States shared their responsibility and desire to provide for their families. This value motivated them to endure their pain, and in case of being helped, made them feel guilty not being able to do things on their own. Other values they found consistent with

previous literature were their preference for natural alternatives and noninvasive medical treatments, and the use of medication just when the pain became unbearable. Also common, was their limited knowledge about their treatment options. Further, the authors found that most of participants felt their encounters with health providers short and impersonal, and believed that physicians did not care about them. Although medication was not preferred, they reported concern for not being offered medication treatment, and often, they seek care and advice in their country of birth or borrow medication from others. Other studies have observed that Hispanics used prayer more than non-Hispanic Whites when facing pain (Gagnon et al., 2014).

An additional issue are the significant ethnic/racial disparities in how pain is recognized and managed by health institutions in different countries, and multiple psychosocial factors have been associated with them. Ethnic minorities could have restricted access to health care and to appropriate medication, have more problems communicating, or have attitudes and beliefs influencing their acceptance, understanding, and need for treatment (Shavers et al., 2010; Torres et al., 2017), what may also contribute to significant differences in pain treatment outcome (Kim et al., 2017). Studies that have focused on ethnic differences on perceptions of pain treatment have pointed that dissatisfaction with treatment is often related to a lack of physician cultural competence. For example, Meyer and Zane (2013) evidenced how issues related to race and ethnicity were crucial themes that ethnic minorities valued when reporting their satisfaction with treatment. Specifically, racial match, provider knowledge of prejudices/discrimination, and discussions of race and ethnicity were the most valued elements. The authors concluded that cultural aspects of mental health services determine how ethnic minorities respond to treatment. Clark et al. (2013) investigated differences in the management of FM, and social and occupational aspects of FM between Latin America and Europe, countries with different cultures

and economies. Through surveys given to patients and physicians, the authors objectivated that participants from Latin America reported having FM symptoms for a significantly longer time, taking significantly longer to be diagnosed, and seeing more physicians to receive a diagnosis compared to European participants. Also, participants from Latin America rated their pain higher and reported more often that FM had impacted their ability to work and to earn income.

Although fewer patients from Latin America had been unemployed, they more often reported missing more than 40 days of work due to FM. Lastly, participants from Latin America also described more often that FM had impacted aspects of their daily living strongly or very strongly (including physical mobility, motivation, and their overall quality of life). This study shows how not only differences in the perception of pain exist, but also differences in the management of FM as well as in its social and occupational consequences.

Latino Cultures

It is estimated that 18.1% of the population in the United States is Hispanic (U.S. Census Bureau, 2017). The United States Bureau uses the term “Hispanic” to refer to people whose origin is Mexican, Puerto Rican, Cuban, Spanish-speaking Central or South American countries, or other Hispanic/Latino, regardless of race. This category term also includes Dominicans and people who responded "Hispanic," "Latino," or provided other general terms. However, the term “Hispanic” was used by the U.S Census Bureau to include people from white European colonial heritage while excluding the indigenous, slave, mestizo, and non-European and non-Spanish-speaking heritages, and not everyone agrees with the choice. The term Latino/a has also been used to include all of the other groups not embraced by the term “Hispanic.” Also, many Latinos/as prefer identifying with a more regional term such as Cuban, Puerto Rican, Colombian

or Chicano/a. Many Latinos/as have also identified with the term “La Raza” (Gallardo, 2012). In this study, we will use the term Latino/a to refer to all these different groups.

Although the Latino culture is very diverse, there are fundamental core values that transcend all groups, especially regarding family structure and interpersonal relationships (Antshel, 2002; Gallardo, 2012). Values such as familismo, simpatía, or respeto have been suggested to contribute to social integration, social support, and cohesion, which have been associated with better mental and physical health (Campos & Kim, 2017; Ruiz et al., 2016). However, the unique situation of an individual (specific health condition, multiple psychosocial and cultural factors; Perez & Cruess, 2014) and the characteristics of the family (Preece & Sandberg, 2005) may determine how much the value of familism contributes to resilience and a better health.

In their review of current knowledge on key aspects of Latino health, Ruiz et al. (2016) described how although Latinos/as experience significant physical health risks factors and health care access issues, they experience better health and live longer than non-Hispanic Whites, which has been called the *Hispanic or Latino health paradox*. This phenomenon has brought to light the influence of sociocultural factors as moderators of Latino health resilience. In this regard, cultural values such as social support, simpatía, familismo, respeto, and social integration have been considered to promote better mental and physical health and resilience in Latinos/as. Additionally, spirituality and religiosity appear to be a vital component of health for Latinos/as (Jurkowski et al., 2010).

With that said, not all groups of Latinos/as share the same cultural features, characteristics, psychosocial experiences, socioeconomic positions, immigration status, or level of acculturation. Understanding the unique psychosocial experiences of Latinas with FM may

include taking into consideration these variables and its multiple intersections. The following section reviews potentially relevant cultural constructs impacting their experience of pain.

The Role of Sociocultural Constructs in Latinas' Health

Familismo (Familism)

Familismo or familism is a cultural value that goes beyond the family members sharing tasks (Gallardo, 2012) and includes respect for authority, generosity, and loyalty towards the family, as well as responsibility, sacrifice, and hard work to provide for them. Latinos/as may prioritize family as a group over personal interests. The family usually is very concerned in the care of its members. For example, family is involved in the medical treatment and decision-making of the members. Several studies have explored the relationship between familism and health outcomes (Campos & Kim, 2017; Perez & Cruess, 2014; Preece & Sanders, 2005; Ruiz et al., 2016; Valdivieso-Mora et al., 2016) and results have been controversial. A systematic review of the relationship between familismo and mental health in Latinos/as found that familismo had a positive impact on depression, suicide, and internalizing behaviors, but only accounted for a small effect on these variables (Valdivieso-Mora et al., 2016). In the same line, it has been observed that family is crucial in lessening the pain agony by being “together” in numerous cultures, including Hispanic families (Stella & Schofield, 2010). In their study, Preece and Sanderg (2005) found that high levels of family stress was associated with self-reported health problems and increased experience of pain, while familial social support and hardiness were linked to decrease in reported health problems and functional disability.

Collectivism

This term describes the emphasis on the needs and objectives of the in-group instead of individualistic needs and values (Marín & Marín, 1991, as cited in Gallardo, 2012). Relationship

processes have been suggested as crucial in shaping psychological and physical health. Specifically, social integration, positive interaction, and social support are believed to be essential aspects of the relationships linked with good health (Campos & Kim, 2017). A key element among these aspects appears to be social integration, which is thought to foster health through a series of social mechanisms such as stress buffering, tangible support, and communal coping (Ruiz et al., 2016). The same authors conceptualized Latinos/as' health resilience as an interaction between cultural processes (values, traditions, or social behaviors), and social networks (social resources such as family, friends, acquaintances as well as neighborhood and community). Moreover, relationships (with family and close friends) have been associated with better health (Campos & Kim, 2017). To support this idea, these authors documented that nurturing relationships allow individuals to grow to be secure, socially skilled, and to attain a higher socioeconomic status. On the other hand, lacking nurturance leads to health-harming behavior and dysregulated stress-responsive biological systems contributing to long-term poorer psychological and physical health across one's life span. For their role in health, experiences of connectedness with others were relevant to this study.

Personalismo and Simpatía

In the context of collectivism, interdependent relationships are nurtured via personalismo and simpatía. Whereas personalismo refers to the tendency to prefer personal relationships rather than impersonal or institutional ones, simpatía is the trend to express emotional positivity, and avoid negativity, including conflict and confrontation, to foster enjoyable social interactions (Antshel, 2002). In this respect, simpatía can contribute to positive social interactions, but it has also been related to values of marianismo (self-sacrificing) and the silencing of women to avoid confrontation (Sanchez et al., 2018); since this could have a negative impact on health and the

experience of pain (see Alexithymia and Communication of Emotions), it may be worth exploring when adapting pain treatments for Latinas.

Respeto

The term characterizes the deferential ways to relate to others based on age, gender and authority (Arrendondo et al., 1996, as cited in Antshel, 2002) to preserve honor and dignity of others. To this end, it involves avoiding topics that might cause discomfort to others (Campos & Kim, 2017). Respeto can be shown as avoiding eye contact (Antshel, 2002) or as not expressing your point of view even when you disagree with authority. For women with FM, this term could also relate to the role of avoiding conflict and not expressing their uncomfortable emotions, which could have a negative impact on health (see Alexithymia and Communication of Emotions). Respeto can also be found in the relationship between healthcare providers and Latinas, where provider's ideas and knowledge is unquestionable, preventing them from advocating for themselves (De León Menjívar, 2021); thus, might be considered when diagnosing and treating Latinas with FM.

Machismo and Caballerismo

This term describes how men are expected to assume the responsibility of providing for the family while maintaining dignity and honor (Gallardo, 2012). While machismo encompasses male control and dominance (often called “traditional machismo”) caballerismo is associated with caretaking, chivalry, and family caretaking; it embodies positive male images of the nurturing provider who is respectful, defends the weak, and lives by an ethical code (Arciniega et al., 2008; Herrera, 2013). Traditional aspects of machismo related to dominance, sexism, and emotional restrictiveness have been associated with anxiety, interpersonal hostility, and mistrust of others (Nuñez et al., 2016). At the same time, machismo might facilitate values of

marianismo, the weak and passive role of women, which has been associated with poor health outcomes and will be relevant for this study.

Marianismo

This term emphasizes the centrality of family such as being home-centered or assisting in caretaking duties, and being submissive, pure, and dependent. It also implies that Latinas should maintain harmony and avoid confrontation and discomfort within their interpersonal relationships, and the belief that Latinas should be the spiritual leader of the family. According to the study by Nuñez et al. (2016), while family and spiritual aspects of *marianismo* have been linked to academic motivation and achievement, the subordinate role and avoidance of confrontation have been related to cognitive-emotional factors such as depression, increased anxiety, and hostility among Latinas. With that said, the authors pointed out that *marianismo* is a multidimensional construct and its different components may relate differently to these cognitive-emotional factors. Specifically, the authors found that aspects such as family responsibilities and being the spiritual guide appeared to contribute to psychological burden in Hispanics. Also, the expectation that women should be obedient, silence their needs, and be forgiving to maintain harmony was associated with a negative view of others (i.e., hostility). Given the impact of traditional gender roles in cognitive-emotional well-being, these roles might be explored in Latinas with FM to lessen their suffering.

Religion and Spirituality

Religion and spirituality are important aspects of culture that can influence health through a series of beliefs, values, and behaviors. In the context of the Latino community, religion and spirituality are regarded as an important protective factor when Latinos/as face hardships, and a source of guidance to answer their life dilemmas (Comas-Díaz, 2006; Mc Neill & Cervantes,

2008, as cited in Gallardo, 2012; Gonzalez, 1997). This statement has frequently been misinterpreted as Latinos/as' sense of lack of control over their lives. However, it should not be mistaken as not having any control over one's life, but as knowing one's capabilities as well as limitations, which can serve as a safeguard factor. For some Latinos/as Divine power gives them a sense of trust that no matter what occurs, life will follow the course that it needs to (Gallardo, 2012). In this regard, Jurkowski et al. (2010) highlighted the importance of distinguishing between an active and passive relationship with God and equated it with an internal and external locus of control. The active role was more positive when coping with pain and illness in general. Also, the authors observed that all Latinas in their study recognized the connection between spirituality and health, although they had different beliefs about the way this happened. Importantly, Latinas had a holistic view of their health, which included spiritual, psychological, and physical components.

Current Treatments for FM

Non-Pharmacological Interventions

FM is complex and a good example of the dynamic interrelationship between numerous biopsychosocial aspects involved in the pain experience (Arnold et al., 2016; Edwards et al., 2016; Orhan et al., 2018; Preece et al., 2005; Turk et al., 2016; Yunus, 2009). The biopsychosocial model has been used to guide research and intervention in chronic pain, and literature advocates for a multidisciplinary approach to address fibromyalgia, integrating medication, physician (neurologist, psychiatrist, or rheumatologist), and psychotherapy (Anderson & Winkler, 2007; Spaeth & Briley, 2009). Current psychotherapy interventions for chronic pain focus on improvements in the physical, emotional, social, and occupational functioning, rather than trying to eradicate the pain itself. As Sturgeon (2014) states in her study,

therapies that have demonstrated some degree of efficiency for management of chronic pain can be classified into operant-behavioral therapy, cognitive-behavioral therapy (CBT), acceptance and commitment therapy (ACT), and mindfulness-based therapy, by targeting different domains such as physical functioning, pain medication use, mood, cognitive patterns, and quality of life. However, Sturgeon (2014) observed different treatment responses after CBT interventions across different pain populations, and for example, the effectivity of CBT interventions for pain was not as robust in populations with FM. The authors encouraged researchers to investigate the mechanisms contributing to the different treatment responses, and cautioned that demographic, psychological, and medical differences among patients may play a role in treatment outcomes. In the same line, to determine the efficacy and safety of the different psychological interventions for chronic pain (excluding headache and cancer pain), Williams et al. (2020) conducted a literature review and compared CBT, behavioral therapy (BT), and ACT with controls and treatment as usual (TAU). The review, which included numerous fibromyalgia participants, concluded that CBT provided a small or very small benefit in reducing pain, disability, and distress. For BT and ACT, the quality of the evidence had low quality to draw conclusions about their benefits. Looking into the specific necessary components of effective psychological treatment in pain management, Sharpe et al. (2020) conducted a Delphi study in which they identified seven approaches that could be incorporated in the intervention to optimize efficacy. Of those, three were considered to be the most necessary, and included psycho-education (specifically, about pain mechanisms and the role of thoughts in maintaining pain), increasing activities (with an emphasis in reducing avoidance), and cognitive approaches (mostly CBT programs involving cognitive restructuring with behavioral approaches).

Although the observed variability in treatment outcomes, CBTs are currently the dominant psychological treatment used for chronic pain by targeting cognitive and behavioral processes (e.g., negative thoughts, catastrophizing, increasing activities) and using behavioral modification to improve functioning and provide skills for coping with pain (Day et al., 2012; Karlsson et al., 2015). Researchers have identified negative cognitive distortions that may play a role in the development and perpetuation of numerous symptoms of FM like distress, or depressive symptoms. For example, catastrophizing has been highly associated with FM patients (Day et al., 2012; Edwards et al., 2016; Lazaridou et al. 2017; Montoro & Reyes del Paso, 2015; Turk et al., 2016). The cognitive-behavioral model postulates that cognitive processes like catastrophizing can influence and exacerbate the pain experience (Day et al., 2012); therefore, promoting more positive and realistic reappraisal of situations (e.g., changing negative automatic thoughts for more adaptive ones) may help prevent intensification of pain.

Cognitive restructuring is used to address and replace negative and dysfunctional thoughts and to modify the appraisal of pain (Kohl et al., 2014). Techniques to facilitate emotional expression have proven to be efficient when combined with psychoeducational classes (Anderson & Winkler, 2007). Also, the use of CBT in group psychotherapy has been observed to effectively teach skills to control pain and to manage fatigue/sleep and stress. Other techniques that have been effective in group psychotherapy have been stress management strategies, assertiveness training, identification and improved use of social support systems or normalization of experiences. Furthermore, when combined with exercise, CBT techniques were found to be more effective (Anderson & Winkler, 2007). Additionally, teaching acceptance strategies can also help patients to increase their pain tolerance instead of using distraction or suppression.

Relatedly, more recent literature conveys mindfulness is an effective intervention to ameliorate fibromyalgia symptoms. Particularly, Parra-Delgado and Latorre-Postigo (2013) demonstrated the effectiveness of Mindfulness-Based Cognitive Therapy (MBCT) as a group intervention in decreasing depressive symptoms and intensity of pain in patients with fibromyalgia. In the study, the main goal was to teach patients mindfulness exercises to relate their experiences of pain and the thoughts/feelings aroused in a compassionate and non-judgmental way. This goal was complemented with psycho-educational activities. With that said, in his study, when comparing the effectivity of four psychological therapies for chronic pain (operant-behavioral therapy, cognitive-behavioral therapy, mindfulness-based therapy, and acceptance and commitment therapy), Sturgeon (2014) found that while MBSR demonstrated to be effective for back and neck pain, it appeared to be less effective in cases of FM, chronic migraine, or headache.

A systematic online database review indicated that first generation of mindfulness-based programs (FG-MBI) are efficient in reducing physical symptoms and psychological distress in patients with FM (Henke & Chur-Hansen, 2014). Second generation of mindfulness-based interventions (SG-MBI) add concepts of impermanence, interconnectedness, non-self or emptiness, and non-attachment principle to the FG-MBI. Compared to FG-MBI, SG-MBI emphasize the spiritual aspect of mindfulness and support that spirituality might play an important role in the manifestation of FM. In their study, Van Gordon et al. (2016) observed an improvement in psychosomatic well-being (i.e., improved ability to cope with pain and improved quality of life), spiritual growth, increased awareness of impermanence, and increased sense of citizenship, after participation in a SG-MBI intervention. In a different study using the same SG-MBI, the same authors saw an improvement on FM symptomatology, pain perception,

psychological distress, sleep quality, non-attachment, and civic engagement in participants with FM, that had been previously observed when using FG-MBI. However, the authors highlighted that compared to FG-MBI, SG-MBI added a spiritual aspect to mindfulness that might play an important role in the manifestation of FM symptoms, by increasing social connectedness and prosocial behavior (Van Gordon et al., 2017).

Brief Note about Pharmacological Interventions

Pharmacological treatments for FM have not shown efficacy for all sufferers, and effective outcomes remain disputed. While a small number of patients may report a decrease of symptoms, many patients discontinue treatment due to a lack of relief and/or adverse effects (Haüser et al., 2012; Nüesch et al., 2013). Furthermore, a study conducted in Italy highlighted a prominent reluctance to use medication and poor results of drug therapy, and found that 98% of fibromyalgia patients seek complementary therapies such as spiritual healing, massage therapy, specific exercise, melatonin, magnesium, green tea, and fish oil (Bazzichi et al., 2020). Also, several studies have found that many Latinos choose self-management practices before seeking health care and do choose pain medication as one of the last resources to treat their pain (Torres et al., 2017).

Purpose of the Study

There is robust evidence of the multidimensional aspects that determine the experience of pain in fibromyalgia. Biopsychosocial factors play a significant role in the development and adjustment to pain, as well as in modulating pain treatment outcomes. At the same time, psychosocial factors, such as attitudes, beliefs, values, or ways to cope with pain, are strongly influenced by culture; therefore, it is not surprising that research has demonstrated that perception and interpretation of pain is highly mediated and modulated by ethnicity. Importantly,

particular values, beliefs, customs, and traditions influence not only our pain experiences but also our way to cope with them. For this reason, treating pain effectively implies taking into consideration the various psychosocial factors that come interwoven with it, including the culture from where they have emerged. Latinas/os with FM might have particular pain experiences and ways to cope with the pain that might differ from other ethnicities. They might as well have meaningful values that can help them decrease or worsen FM symptoms; thus, more research needs to include Latinas/os when understanding their experiences with fibromyalgia and when designing efficient, responsive, and meaningful treatments for them.

Most of the current available literature exploring FM have been quantitative, and with European Americans. Fewer studies have focused on describing the condition qualitatively; the research with Latinos/as living with FM is almost non-existent.

The purpose of this study is to explore and provide a phenomenological description of Latinas with FM by identifying common themes in their experiences. A better understanding of the different topics surrounding the life of Latinas with FM will help to develop culturally responsive treatments, to choose the most suitable psychotherapy approach and components, and ultimately, to decrease the stigma that exists around this condition.

The research questions guiding this study included the following:

1. What are Latinas' phenomenological experiences with FM?
 - a. How do family and friends fit into this experience? Are there other people who are important in their experience?
 - b. What has been their experience with the mental healthcare system and other treatments (both pharmacological and non-pharmacological)?
2. What are psychosocial factors that are helping Latinas cope with FM?

3. What psychosocial factors may be exacerbating the symptoms of FM?
4. How do Latinas make meaning of their pain?

Chapter III: Methodology

The researcher chose qualitative research methods as the best approach to understand the particular experiences and the social context of Latinas diagnosed with fibromyalgia. Data was collected through semi-structured interviews, and analyzed using an Interpretative Phenomenological Analysis, under the phenomenological approach. This methodology was selected according to recommendations by Levitt et al. (2018) and Smith & Osborn (2003) for three main reasons. First, because qualitative methods allow for an open-ended discovery, and the researcher aims to explore what is most relevant to this population, minimizing assumptions. Second, because it attempts to explore personal experiences of a historically understudied population, whose experiences may not be well-represented in the research literature. Third, because it involves an examination of the participant's life. Additionally, the biopsychosocial model was used to frame and understand the multidimensional construct of FM.

Participants

There is no necessary, correct number of participants for a qualitative study; however, Smith & Osborn (2003) recommended analyzing three cases for IPA newcomers. For the purposes of this study and given the lack of experience that the researcher had with this method before this study, the researcher recruited four participants.

The participants were a homogeneous, criterion sample that were chosen to represent Latinas with fibromyalgia, and the criteria for participation included: (a) having a diagnosis of Fibromyalgia, (b) identifying as Latina (or from specific Latin American countries), (c) being over the age of 18, and (d) speaking either English or Spanish.

All of the participants identified as Latinas suffering from Fibromyalgia and had a romantic partner at the time of the interviews. The ages of the participants ranged from age 44 to

52, and the years since their diagnosis of FM ranged from 2 to 20 years (see Table 1); however, they all had struggled with pain since an earlier time. Two participants stopped their paid job due to their pain, one had recently finished a 1-year-job-leave, and the other participant was struggling to get disability status while working full time in a paid-job. Names were substituted by pseudonyms to protect confidentiality.

Table 1.

Participant Demographics

<i>Pseudonym</i>	<i>Age</i>	<i>Years since diagnosis</i>	<i>Ethnicity</i>	<i>Relationship Status</i>	<i>Education</i>
Jennifer	44	15	Latina	Married	Master's degree
Claudia	49	20	Puerto Rican	Married	Master's degree
Lily	49	2	Latina	Partner	Doctoral degree
Diomaris	52	3	Latina	Married	High School diploma

Materials

The materials required for this study included informed consent forms in English and Spanish that were approved by Pepperdine's IRB (see Appendix A). Although it was initially planned to recruit participants through flyers, in the end, these were not needed. All participants had access to a computer and internet, thus, the researcher conducted all interviews via computer using the Zoom platform. In one of the cases, because the participant expressed difficulties finding a Spanish-speaking psychologist, the researcher provided her with a list of psychotherapy referrals in the community (see Appendix B). In addition, the researcher developed a protocol of eight semi-structured interview questions in English and Spanish to help understand their experience of fibromyalgia (see Appendix C and D). The written materials for this study were in both English and Spanish, so the participant could choose their preferred language. As a result, two of the participants preferred to read and speak in English, and two preferred to communicate

in Spanish. The primary researcher was born and educated in a Spanish-speaking country through her graduate training and was prepared to conduct the interviews in both languages. On a couple of occasions during the interviews, the researcher asked the participant for clarification of the meaning of particular words (i.e., AVP).

Procedure

Approval was secured by the IRB committee at Pepperdine University. Appropriate consent forms were given to the participants before the interviews and are provided in Appendix E and F. Recruitment started by word of mouth, and after interviewing the two first participants, the final two participants were recruited using snowball sampling. Once potential participants were identified, the researcher called them by phone to provide more information about the study, explain briefly the consent forms, and the process of interviews. If participants accepted to collaborate, they would agree on a date for the interview with the researcher. The researcher then emailed consent forms in the language that participants preferred, and they were asked to email back the forms with their signature. The researcher answered all the questions the participants had. Once recruited and due to circumstances that prevent in-person visits during the COVID-19 pandemic, the interview was conducted via a HIPAA-compliant Zoom video conference. Before the start of the interviews, the researcher reviewed consent forms with the participants and answered any questions they had. Additionally, on one occasion, after translating the first interview, the researcher chose to follow up with an interesting topic that had been brought up by the participant and set up a second day of interview with that participant. Due to the fatigue often associated with FM, the researcher tried to interview participants for no more than 1 hour. In the cases where the participant exceeded an hour, the researcher offered either a break, or continuing another day, which was not necessary for any of the cases.

The researcher assigned a number to each participant when recording the interview. Each number was linked to the participant initials in a separate password-protected electronic document saved in the researcher's password-protected computer. After the interpretative analysis was completed, and using the same document, the researcher assigned a pseudonym to each of the numbers of the participants.

The researcher collected data using semi-structured interviews. This type of interview was chosen to facilitate rapport while engaging in a dialogue where the initial questions could be modified depending on participants' responses. The participants were asked about particular perceptions of themselves, and their experiences within a social context. Depending on the participants' preference, the interviews were conducted in Spanish, English, or both. Verbatim transcripts of the semi-structured interviews represented the raw data for the study. In the case of interviews conducted in Spanish, the data was not translated into English until presentation of the results to aim for a more accurate interpretation. Paragraphs and excerpts in Spanish were translated first by the main researcher, and then reviewed by the dissertation chair.

Data Analysis

The data was analyzed using Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003). Other articles were also consulted to make sure that the study met quality standards and to help unfold the narrative (Levitt et al., 2018; Morrow, 2005; Nizza et al., 2021; Smith & Osborn, 2003).

Steps

Interviews were transcribed respecting the original language of the participant. Notes, comments, and initial ideas were made in the left margin of the transcripts, and some of them were numbered to facilitate later grouping of similar ideas. Initial coding of the responses was

grouped and converted into themes, which were recorded in the right margin of the transcripts. The themes intended to bring the previous notes, comments, and ideas into a higher level of abstraction (including psychological terminology if needed). During this process, the researcher ensured that each emerging theme was supported by excerpts in the narrative, which were highlighted to facilitate final quotations. At this point, the researcher noted in a new document all the themes for each participant, and several initial ideas were included as sub-themes. Coding involved an ideographic approach by focusing on the unique experiences of each participant before moving on to analyze the other narratives. The process of writing themes down for each participant, involved an iterative process, where incoming data would trigger new questions that prompted to look back into previous participants narratives. Once all four transcripts were coded, the researcher looked for patterns and connections across participants that were documented as superordinate themes and served to unfold the narrative account. Verbatim extracts from each participant during the interview were interwoven in the narrative to provide evidence for each interpretation. Following the article by Nizza et al. (2021), the following tenets served as a general guide to unfold the narrative: attending to convergences and divergences, close analytic reading of participant/s words, developing a vigorous experiential and existential account, and constructing a compelling, unfolding narrative.

The process of choosing the superordinate themes across participants, involved self-reflection and consultation with the dissertation chair. In the end, we agreed to include the themes repeated across all participants, or that were present in at least three of the narratives. Themes brought up for two participants were included to point a divergence within a theme or as a continuation of a previous one. Lastly, themes unique to a single participant were included only in the Discussion section.

Additionally, during coding, the researcher wrote in a separate document a memo with first impressions (i.e., themes, sense of the participant's emotions while narrating, convergences with other participants, convergences with literature, divergences, links/associations between different problems...) that was consulted when developing the Results section.

Quality and Rigor

In qualitative research, the researcher is the instrument to acquire information from participants, with the danger to bring her expectations and assumptions to the research process. To ensure that the lived experiences of participants were accurate and trustworthy, and to minimize subjectivity, the researcher monitored her biases and assumptions during the IPA process using self-reflection and debriefs (Morrow, 2005) with the dissertation chair. For example, this process was followed when choosing which themes to include into the master theme table.

Researcher's Perspective

The current study has been inspired by my encounters with people with FM and from my experiences growing up immersed in several common Latino values such as machismo, marianismo, familismo, and religion. I observed how every woman responded different to these values. I observed how numerous women seemingly adopt a role of submission, even if it implies suffering. While from my perspective, this suffering is incongruent with their needs, I also wonder what their experiences and thoughts are and how this impacts their quality of life and their resilience. I want to understand how much our beliefs, attitudes, and values can normalize our life of suffering, in some cases, to the point where our bodies have to "scream" for justice. I want to look into how our different beliefs, attitudes, and values mediate and modulate our experiences of pain and the impact they have on our way to cope with it; this will involve

exploring possible protective factors that can ameliorate the suffering of living with Fibromyalgia, as well as the challenges that make it harder. I am curious about the different meanings that pain might have for Latinas, and how this can impact their experience.

Chapter IV: Results

The analysis of the transcripts resulted in 14 superordinate themes. These superordinate themes were classified into four major categories: External Factors that make it hard living with FM; Internal Factors that make it hard living with FM; External Factors that make it easier living with FM; and Internal Factors that make it easier living with FM. Within these categories, the superordinate themes led into fourteen subordinate themes, and three of them, had their own sub-subordinate themes (See Figure 1).

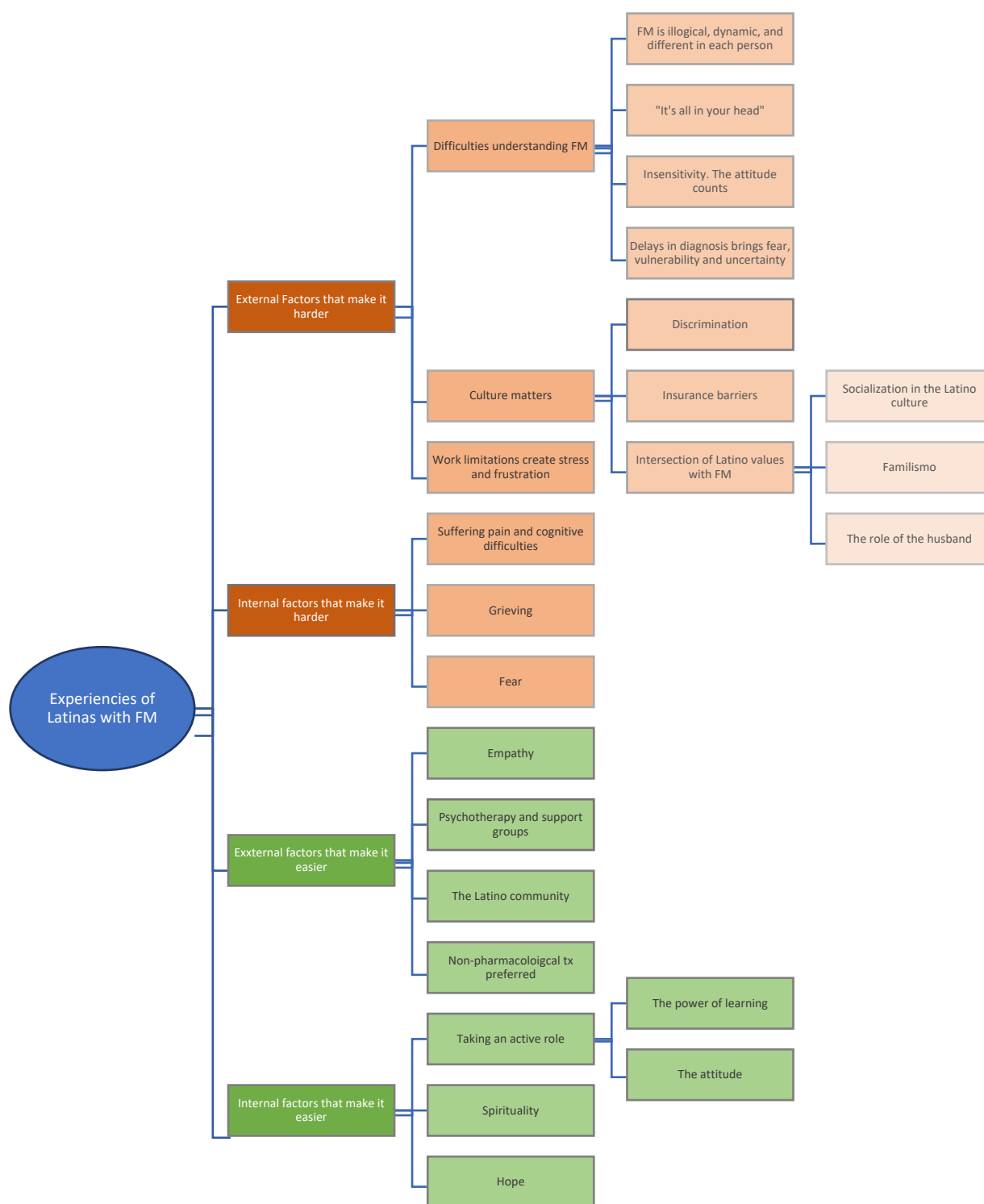
The following narrative represents a summary of what was selected as being the most repeated and relevant topics expressed by the participants. The different topics are presented as themes, and most of the themes, include sub-themes, to reflect different ideas that emerged within that topic. First, a general summary presents the main superordinate themes that were found across participants that make their lives harder, and that rely primarily on environmental factors. Second, the themes and sub-themes are unfolded, interweaving quotes from participants to exemplify the idea and to provide evidence. If the subordinate theme included numerous sub-subordinate themes, this is introduced by a brief summary of all the sub-themes that emerged within that topic. The same process is done to unfold the Internal Factors that make it harder to live with FM. Lastly, the same structure is repeated to unfold the environmental and the internal factors that make it easier to live with FM.

External Factors that Make it Hard

By external factors that make it hard, the researcher includes the environmental variables adversely impacting the lives of the participants.

Summary

Participants expressed several environmental factors that make it harder to live with FM. All participants agreed that FM remains mostly unknown. Sufferers noticed a lack of knowledge by healthcare professionals and colleagues, and they struggled to make sense of it. At the same time, this situation triggered feelings of uncertainty and vulnerability. All of them agreed that they felt misunderstood and mistreated, and two reported needing more support. Three other participants were impacted by feelings of discrimination on top of their pain suffering, and three communicated that Latino values such as *matriarcado* and *machismo* made it more difficult to deal with FM. Also, the experience of FM was aggravated in three participants by their lack of insurance coverage. Lastly, all of them had suffered important changes in their paid jobs that added to their stress.

Figure 1.*Categories and Superordinate Themes*

Difficulties Understanding Fibromyalgia

All four participants expressed difficulties understanding fibromyalgia, not just by themselves, but also by health providers and colleagues. They all agreed, with their own idiosyncrasies, that the condition is illogical, dynamic, and different in each person. The lack of knowledge about FM may contribute to delays in the diagnosis and thus, in the implementation of treatments. Together with poor understanding, it also leads to a lack of empathy and insensitivity by others that triggers feelings of fear, vulnerability, and uncertainty for the participants, and that can challenge trust and connection with their physicians. Lastly, the lack of cultural diversity in the healthcare system was an added factor brought up by most participants that was also making it difficult to feel comfortable with their healthcare providers.

Fibromyalgia is Illogical, Dynamic, and Different in Each Person. The following excerpts exemplify the struggles that all participants have understanding the “logic” of FM: Jennifer expressed the changing nature of FM, and her frustration trying to understand the logic of this condition as well finding an efficient treatment that works for a longtime:

I’ve noticed that some things help and then they stop helping so I have to kind of find something new, because the symptoms change [...] it’s illogical because it’s like, right, it’s not defined, like you know, there is no like... ok, you have a tumor, and this is of it, and this is what you can do, you know, and there is no plan, so you ah, that is what I meant it, illogical, like...I am very logical and it’s like ok, $A=B$ equals C . This is not $A+B$ equals C , so [...] I am constantly having to adjust and try something different [...] I’ve probably tried five different medications because they will work for six months and then I need to try something else.

Also Claudia expresses her frustration with the lack of logic: “Si yo pudiese decir que solamente tengo dolor cuando tengo estrés, cuando tengo situaciones....no pero, en momentos que yo entiendo que estoy en paz, feliz y satisfecha también me duele, así que” (English translation: If I could say that I only have pain when I have stress, when I am in situations.....but no, during moments that I understand that I am in peace, happy and satisfied, it also hurts, so...)”

Moreover, Lily added that FM can manifest differently in each person, what makes it even more complicated to define and treat: “[...] I think everybody gets pain you know in different parts of their body but for me a lot of it was digestive [...]”

“It’s All In Your Head.” Indeed, participants are not the only ones not understanding what is going on with them, and still, all the participants have encountered health providers and friends who told them “It’s all in your head,” or that don’t believe in FM, what makes them feel misunderstood, and unsupported: “ Aquí no hay muchos médicos que crean en la FM [...] lo ven como psicossomático [...]. Y mucho doctor que no cree literalmente de lo que tu le hablas [...] que es un disparate, que eso no existe!” (Claudia) (English translation: Here there are barely physicians that believe in FM [...] they see it as something psychosomatic [...]. And a lot of physicians that do not believe literally what you are talking about [...] that this is folly, that this does not exist!) Diomaris experiences a similar situation with some of her friends from church, where she volunteers:

Pero cuando yo me siento mis dolores muy fuertes yo no voy al servicio, entonces es como por ejemplo compañeras que me dicen es como... como es que ‘todo esta en tu mente’, ‘es que no tienes’, ‘es que tienes que ocuparte para que no estés pensando en eso.’ Entonces es ahí cuando yo no me siento como comprendida, pero, pero es. (English translation: But when I feel my pain intensely I do not go to the service, then it’s like my

friends tell me....‘everything it’s in my head’, like ‘you don’t have’, ‘you have to get busy so that you are not thinking about this.’ Then it’s there when I do not feel understood, but, but is this.)

Insensitivity. The Attitude Counts! Besides the lack of understanding, all participants complained about the attitude that some healthcare providers and friends adopted with them. In this excerpt, Claudia expresses how the attitude is even more important than getting right answers: “Si yo tengo dolor aunque tu no ...pienses que...que ese es el diagnóstico y yo voy a donde ti a buscar una ayuda, pues por lo menos vale la actitud, me entiendes?... pero la actitud es muy fea... no creen y se comportan rudos.” (English translation: “If I have pain, even if you don’t...think that...that this is the diagnosis and I come to you to ask for help, then at least the attitude counts, you know?...but the attitude is very nasty...they don’t believe and behave rude.) As a consequence, all participants expressed feeling mistreated: “I’ve had doctors that said very insensitive things, like I already know there are certain neurologists that don’t believe [...] I guess a neurologist once was like....(long sigh) you are just depressed, like and I was like Whhh...and I remember going in my car and bawling because I was like..... it was almost like he didn’t believe me..... (Jennifer). Also, Lily expressed how hard it is to feel misunderstood and dismissed by others:

I’ll tell you that my partner.... I had a really hard time because one of the things that he used to tell me is that all of these [sic] was in my head. And... doctors too... and so the hardest part was just people not believing me...and so I think this is the hardest part is being dismissed [...] I went to this doctor [...] she would have an attitude with me [...] like now what do you want? [...] I am like, I am already in pain, I don’t need to add to

this because I was feeling like I was feeling dismissed, I was not really listened to and the person was having an attitude with me and it was just too much to deal with [...]

Delays in Diagnosis Brings Fear, Vulnerability, and Uncertainty. The lack of understanding about FM may not just lead to insensitivity when treating this population, but also delays in their diagnosis and treatment, which prolongs their suffering beyond pain. With the expression “scared little kid”, Lily communicated how vulnerable she felt while waiting to find out a diagnosis to her symptoms: “I think it was like July or August of 2020, so that is when I didn’t... so for the first year I was like this scared little kid you know going to the doctors left and right because I didn’t know what was going on with my body, what was happening.”

Similarly, delays in diagnosis facilitated the appearance of psychiatric symptoms for Diomaris:

Al principio era de ponerme a llorar en los consultorios, en el consultorio del doctor. Y solamen..., estuve visitando varios consultorios al principio porque era muy frustrante para mi ir y que me hacían análisis a mi de varias cosas, de muchísimas cosas y gracias a Diós todo estaba bien, pero yo no me sentía bien. Entonces esto para mi también ha traído mucha ansiedad y depresión. Ansiedad y depresión. Entonces eso es he estado a mi... lidiando con eso por tantos años por tanto tiempo, como siete años mas o menos con mi depresión y ansiedad y mas o menos como así tres años ya que fue el doctor que me dijo que lo que ‘tu presentas todos los síntomas de FM.’ (English translation: “At the beginning I would cry in the doctors’ offices, in the doctor’s office. And only..., I was consulting different offices at the beginning because it was very frustrating for me to go there and that they performed blood draws for different things, for a lot of things and thank God everything was okay, but I was not feeling well. Then, for me, this brought a lot of anxiety and depression. Anxiety and depression. Then, this is how I have been

coping with it for so many years, like seven years approximately with my depression and anxiety and approximately like three years already that the doctor told me that ‘you present all the symptoms of FM.’”)

Delays in diagnosis also holds up options for treatment. In the following quotation Lily expressed the difficulty to find the right treatment and the drawbacks to delay it:

At first... cause I didn’t understand what was happening to me, I didn’t know. Once I went to that group, I stopped going to the doctor. And so I was like [...]I did not go to this group until this year which is two years later, you know, this past year. ... and so if they’d sent me in 2019, I would have avoided them a lot of money from going to I don’t know how many doctors and specialists.

Claudia communicated the scary and disrespectful messages she was given while trying to understand her symptoms, and how she overcame her fears about them:

Lo que pasa es que lo primeros mensajes que a mi me dieron fue ‘tienes cáncer o en los huesos o en la sangre te voy a poner a convalecer tres meses en una cama en lo que vas a.... A la clínica para el cáncer y te tratan.’ Este....después fui a otro doctor heee ‘cambia tu estilo de vida porque en menos de un año vas a estar en una silla de ruedas’. Fui a otro doctor y me dijo ‘de todas las pacientes que yo tengo tu eres la peor, tu vas a tener problemas hasta con tu esposo, porque no vas a poder realizar ni tan siquiera las relaciones con tu esposo. Vas a tener que dejar de trabajar.’ Todo era bien negativo y yo como que me programé otra cosa [...] (English translation: “What happened is that the first messages that they gave me were ‘you have cancer either in your bones or in your blood I am going to put you to convalesce for three months in bed in which you are going to...to a clinic for cancer and they will treat you. So...after, I went to another doctor heee ‘you have to change

your life style because in less than a year you will be on a wheelchair.’ I went to another doctor and told me ‘of all the patients I have you are the worst, you will even have problems with your husband. You will have to quit your job.’ Everything was so negative and I was like I programmed myself for different thing” [...])

Culture Matters

These difficulties understanding FM, including the lack of knowledge, empathy, and insensitivity, made it sometimes difficult for all participants to feel comfortable with their physicians. On the top of that, Jennifer added encountering a lack of cultural diversity in the medical field that is also making it difficult to connect and trust some of her healthcare providers:

About the nutritionist, I also would love her to be a person of color, right? So last night, I just googled nutritionist, dietitian, FM. And 10 people came up and they were all like....everybody was whiiiiite. So then I am like ok they are white but let me read the bios to see if there’s something culturally bla bla bla, something something something. There was nothing. And I am like let me look at their pictures to see if they look friendly (laughs)...yes! Like the cultural stuff reeeeaally helps.... So, if there was a...I’ve never seen a Latina/Latino.... in pain management.

Certainly, across the interview, Jennifer expressed that doctors of the same culture, or those attuned to different cultures, would facilitate her trust, safety, and implicit understanding. Specifically with the sentence “let me look at their pictures to see if they look friendly,” Jennifer expresses that friendliness with doctors it’s important for her because it may facilitate trust and connection, and this is easier when doctors share her same culture or when they are attuned to different cultures. Similarly, Diomaris encountered a lack of cultural diversity as an obstacle for

her care: “ha sido difícil llegar con un buen psicólogo, ha sido difícil he, y a parte del costo ha sido para mi muy difícil llegar a un psicólogo porque ..a...muy pocos muy pocos ofrecen sus servicios en español.” (English translation: It has been difficult to reach a good psychologist, it has been difficult, and besides the cost, it has been for me very difficult to reach a psychologist because...a... there are very few very few who offer their services in Spanish.”)

Discrimination. Jennifer continued expressing how poor cultural diversity not only challenges her trust and connection with healthcare providers but also triggers fear of discrimination:

Because historically black women, brown women, especially with pain, they are not taken seriously and I’ve got a, an experience where it’s downplayed you know, I ‘ve been....I know it, I’ve read it, I know the facts, I...read the news, I know. So why am I going to put myself through that? Like, I already have enough to deal with. So race, and class, and culture it’s just another obstacle that hopefully in some years probable in our lifetime we don’t need to think about...but right now we do.

Likewise, being a Latina and the status of immigrant was an added stress in the life of the participants, and most of them expressed a sense of discrimination at some point of the interview contributing to her overall stress.* Within the work area, Lily communicated how feelings of discrimination have been part of her stress: “I guess the AVP, which was above me and above my boss ... wasn’t interested in having me in that position... and I think I personalized that as like you know he wasn’t interested in a Latina running the place... so even if it wasn’t what it was, this is how I felt.”

Insurance Barriers. For Diomaris, being a Latina and also an immigrant challenged her access to medical care: “la desventaja como Latina es vuelvo y hago como muy importante la la

la falta de oportunidades de mejores trabajos donde ofrezcan un servicio médico para nosotros como inmigrantes.” (English translation: “the disadvantage as Latina, and I come back to it and make it very important, is the the the lack of opportunities for better jobs that can offer a medical service for us as immigrants”). This situation also interfered with her FM treatments, which either she could not afford or were ineffective: “y pienso que he necesitado como un tratamiento mas mas profundo y yo solamente he estado visitando como como lugares de de, de.... Lugares am... de servicio comunitario que son de bajo costo pero no no tienen, no son tan profesionales en pocas palabras, sí.” (English translation: "and I think that I have needed like a deeper deeper treatment, and I only have been visiting like places of of.....places ahm.....of community services, which are low cost but they do not have, they are not as professional in few words, yes.”). Jennifer was also encountering barriers to access to treatments for FM: “I said ok TMS, so I look it up and I was like great, let’s do it... So I went, and my insurance right now is terrible, I am getting better insurance now but I’ve been trying to get approved by my insurance since July and it hasn’t been approved, ahm, because it’s super expensive, you know”

*Pt. 2 was the only participant who did not express discrimination as a result of being Latina; however, she was the only one living in Puerto Rico.

Intersection of Latino Values with FM. While all participants described several Latino values impacting her life with FM, just the ones that were more repeated across participants’ accounts were selected for the following narrative. Likewise, participants identified values that made it easier to cope with FM; however, the following section summarizes just the values that were making it harder.

Socialization in the Latino Culture. As part of their socialization, most participants described how they had adopted roles as caretakers that had interfered with self-care. In the case of Lily, she adopted the role of caretaker while growing up, as the oldest sibling: “I learned from my mother like, how to take care of everybody and she was always last... and I couldn’t say you know what? I can’t cook, or you know what? I can’t wash the dishes, or you know I can’t clean, this is how I function...so being socialized to always take care of others before you.” Claudia chose the concept of *matriarcado* to describe her role within society and how it was impacting her experience with FM: “Acá la cultura es bien matriarcal. Ahá. La madre es la fuerte aquí verdad? Entonces pues yo tengo la fama de ser la fuerte así que cuando yo estoy descompensada pues es vaga, es vagancia (laughs)”. (English translation: “Here the culture is sure very matriarch. Aha. The mother is the strong one here, right? Then, so I have the reputation of being the strong one so that when I am decompensated then it’s lazy, it’s laziness (laughs)”). Similarly, Jennifer pointed at the importance to show strength and hide weaknesses within the Latino family:

it’s not helping in that culturally you don’t talk about really personal things, you know, you might pretend things are great, so most of the people think oh! Ms. XX is this...she has got it altogether... most people don’t know, don’t ask, they just assume that I don’t work cause maybe we are rich, I don’t know (laughs)...

Familismo. Indeed, Jennifer preferred not to share personal issues with many in her family. She added, that it would be complicated for many in her family to understand her condition, and she feared being judged, and that they would spread information about her that is not true and could be detrimental to her: “you know, they don’t know... and I’ve never felt comfortable talking about it... like it will be a total gossip like I would be like (susto

expression)...like el bochinche! [...] I don't think the majority don't have even heard about FM, I don't feel safe a...sharing it..." With that said, most participants expressed the double-sided aspect of familismo, and while it appeared to be less helpful for Jennifer and Claudia, it was of vital importance for Lily and Diomaris. This is how Diomaris conveyed the solidarity and bond with her family and how they support each other: "...mi familia directa que son mi esposo y mis hijos, entonces ellos me me... siempre están buscando como algo, una actividad para mantenernos unidos como en familia, salir, convivir, visitar, entonces de esa manera yo me siento como, me siento como bendecida de tener a mi familia..." Diomaris. (English translation: "my direct family who are my husband and my children, then they ...they are always looking for like something , an activity to keep us together as a family, go out, live together, visit, then, this way, I feel like, I feel like blessed to have my family...")

The Role of the Husband. All participants highlighted how crucial their partner's support was when coping with FM. However, while Claudia and Lily had some complaints about the lack of support by their romantic partners, Jennifer and Diomaris described how critical their husband's help was to help them cope with FM. Specifically, participants described this support as understanding, flexibility, and taking over roles if needed: "I couldn't imagine going through this with a husband that was like...I don't know, some of the things you hear from other people like I am like you know, like he is not a model of a macho man you know" (Jennifer). Conversely, Lily regretted not having this support, which would help her so much in coping with her stress and pain:

On top of that you know I was managing like I would say maybe about 20 boss people and would come home and would still like cook, and clean, and you know my partner

would just sit there and kind of be on the phone rolling his am... scrolling through his phone while... he waited for me to finish dinner...

Work Limitations Create Stress and Frustration

Although all participants appreciated having more help from their husbands, they all coincided in the vital importance to keep working. In this regard, all participants described challenges maintaining their previous workloads, to the extreme that two of the participants had to quit their paid jobs against their will: “los días que tenía que trabajar cuando yo me sentía así, era frustrante para mí era muy difícil, porque no podía, no podía levantarme en las mañanas de cómo yo me sentía. [...] tuve que dejar de trabajar...” (Diomaris). (English translation: “on the days that I had to work, and I was feeling like this, it was frustrating for me, it was very difficult, because I could not, I could not wake up in the morning because of how I felt [...] I had to quit my job...”)

Jennifer needed a lot of support to accept that she could not endure a paid job: “...it was hard to... I mean... to accept. I was hoping it was temporary and kept waiting [...] it just was hard to realize that I was limited you know like I couldn't do the same things I've always done. I've never imagined that would not be able to work aaa....[...] it involved a lot of therapy and a lot of tears like, realizing I couldn't work.” Beyond her health limitations, she added that all the time she spent on her FM healthcare was also an impediment to maintain even a part time job: “9 to 3 three days a week like I couldn't have this schedule because the stress but also because of the time is needed to take care of my body you know like all the appointments, so so many doctors' appointments, sooo many other things that I need to do that it's just a lot of time.”

Claudia felt eager to continue working, and even when rest could ease her symptoms, being inactive made her feel even worse: “El descanso me ayuda pero como trabajo, cuando...si veo acumular todo lo que tengo que hacer del trabajo y de mis cosas pues entonces o mejoro porque el cuerpo puede descansar pero mi mente no descansa porque estoy con la preocupación de todo lo que tengo que hacer” (laughs). (English translation: “Rest helps me, but since I work, when...if I see to accumulate all what I have to do regarding my job and my things, then I feel better because my body can rest but my mind is not resting because I am so worried about all the things that I have to do” (laughs).

Similar to Claudia, Lily continued to work in a paid job, but she was struggling to keep up the pace, and felt frustrated: “I have been so used to being such a high functioning person that that is one of the most frustrating things that I haven’t been able to like, lead my life in the way that I was used to, like before this...”

Internal Factors that Make it Hard

By internal factors that make it hard, the researcher includes the variables within the individual that are making it harder to deal with FM.

Summary

Participants described their hardest symptoms of living with FM that depended on internal aspects. Participants described severe pain and cognitive difficulties impacting their level of functioning that made it difficult to keep their previous level of functioning. As a result, they all recognized a challenging but necessary process of grieving their old self and life in order to move on. They communicated several fears surrounding FM, some of them, stemming from a general sense of lacking control over symptoms and of becoming addicted to medication, that made living with FM emotionally demanding.

Suffering Pain and Cognitive Difficulties

Although severe pain is the primary symptom of FM, most participants also described cognitive difficulties that interfered with their activities of daily living. Specifically, they described most struggles with concentration and memory, what has been also defined as “brain fog.” Jennifer explained what it is for her: “...sometimes I am not available for like my kids like you know like I am on fire like it’s the brain fog that kicks in right? and I am like I can’t think right now...” Besides memory problems, Claudia mentioned experiencing slower processing speed that impacted her verbal comprehension: “por ejemplo para leer, yo tengo que leer mucho, lo mismo, porque de repente no lo comprendí, cosa que normalmente pues yo las leía y te las podía cantar el otro día, me toma mucho tiempo.” (English translation: “for example, for reading, I have to read a lot, the same thing, because suddenly I did not understand, which usually I was able to read and I could explain it to you next day; it takes me a lot of time.” Definitely, pain and cognitive difficulties, made it harder to keep their previous level of functioning, and it has been hard for all participants to accept their acquired limitations.

Grieving

In order to move on in their lives, all participants expressed the need to accept their new condition, with the limitations it entailed; however, they were all struggling in the process of accepting their new life, and their new self.

... and in this new way and kind of accept this way of being and I think many of us just don’t want to, accept this new way of being [...] and really, in order to move forward you just have to accept... That this is who you are, this is where you are at right now, and how can you move forward [...] and how you can be in life with those limitations, how can you function with those limitations. (Lily)

[...] Le digo a la directora, adelanto las clases, me tengo que ir a las dos porque tengo cita [...] y a las tres y media voy para el carro y digo se me olvidó la cita. Literal. Se me olvidó [...] sí sí. Entonces... este... pues esa parte es la que se me hecho mas difícil manejar, porque yo siempre he sido multitasking. Claudia. (English translation: [...] I tell the director, before the classes, I have to go at 2 pm because I have an appointment [...] and at 3.30 pm I go to my car and I say I forgot about the appointment. Literally. I forgot about it. [...] yes yes. Then...so...so this is the part that has been the most difficult to manage, because I have been always multitasking. (Claudia)

[...] for somebody like me with a master's degree who was always really productive you know, the hard thing is like coming to terms with like this diagnosis [...] so I think that is why it took me so long [...] for me to accept it, accept my limitations, and then figure out what I needed it...(Jennifer)

Fear

Accepting their new life and self was one aspect that brought fear into participants' lives, but it was not the only one. There were different fears surrounding the life of all participants as a result of living with FM. In their narratives, they expressed fear of losing control over their symptoms, to become useless and less functional, and to become dependent on pain medication. With the following paragraph, Claudia expressed her fear of being inactive and less functional, as well as her fear of becoming dependent on medication:

Yo no tiendo a encerrarme, no me gusta, heee, tengo que estar bien mal, bajo medicamentos, para acostarme, porque yo entiendo que el cuerpo se va a habituar, y yo misma me voy a tirar a una cama [...] descansar me ayuda pero no me quiero sentir que estoy inútil en una cama. Porque bueno con gente que literalmente le diagnostican y se

tiran a la cama. (English translation: “I don’t tend to stay inside home, I don’t like, heee, I have to feel really bad, under the effect of medication, to lie down in bed, because I understand that the body will get used to it, and I am going to remain in bed [...] to rest helps but I don’t want to feel useless while lying in bed. Because well, there are people that literally, after being diagnosed they are bedridden.”

Likewise, Lily communicated her fear to become an addict to pain medication:

I wasn’t sleeping, I couldn’t sit, I couldn’t stand, I couldn’t sleep, I couldn’t do anything cause the pain was just soo excruciating, and they had me on...(“ts” sound) on muscle relaxers, they had me on sleeping meds, they had me on pain medication, all the stuff that had I taken all of it, initially I did take it and I was like a walking zombie, but had I continued to take it I could see myself as an addict.

External Factors that Make it Easier

By external factors that make it easier, the researcher includes the environmental variables that help the participants deal with FM.

Summary

All participants emphasized the importance of feeling understood by others and appreciated having support from their friends, partners, and family. All narratives included some aspects from the Latino community that made it easier for participants to cope with FM, including some values and traditions. Additionally, it was noticed a preference for a non-pharmacological approach to healing. Although family appeared to benefit Lily and Diomaris, this factor, for its controversial effects, also has been developed in familismo, within the Factors that make it hard to live with FM.

Empathy

All participants emphasized how they missed being understood by physicians and friends, and how important it was as a healing agent itself. That is what Claudia answered when she was asked what was the most difficult thing about living with FM:

Que te entiendan! Porque como la gente no ve moratones, no ve sangre, heee, a veces dicen a ‘Diós pero si tu estabas lo más bien y ahora te duele’ o... este... ‘y como es eso?’ Este... o que eso es mental, eso es mental, ponte en tu cabeza que eso es mental.... y te lo digo, si es mental mental karaoke que no es mental porque me duele a mi me duele!”
(Claudia). (English translation: “That they understand you! Because since people don’t see bruises, don’t see blood, heee, at times they say ‘God but if you were doing very well and now it hurts you’ or...so...and ‘how is this possible?’” so...oh that this is mental, this is mental, make up your mind that this is mental... and I tell you, if this is mental karaoke that this is not mental because it hurts, it hurts to me!”)

As mentioned previously, Claudia also expressed what she would need in response: [...] Si yo tengo dolor aunque tu no ...pienses que...que ese es el diagnóstico y yo voy a donde ti a buscar una ayuda, pues por lo menos vale la actitud, me entiendes?... pero la actitud es muy fea... no creen y se comportan rudos” (English translation: “If I have pain, even if you don’t...think that...that this is the diagnosis and I come to you to ask for help, then at least the attitude counts, you know?...but the attitude is very nasty...they don’t believe and behave rude.)”

To this end, this is what another participant expressed when she was asked what she would expect/like to see in the future in regard to FM: “Que encuentren una...una... algún tratamiento, y sentirme, sentirme como mas comprendida médicamente hablando, porque...es difícil lidiar con FM.”(Diomaris) (English translation: “That they find a...a...any treatment, and

to feel, to feel like more understood medically speaking, because...it is difficult to cope with FM.”

Psychotherapy and Support Groups

Similarly, most participants expressed benefiting from some type of psychological intervention. Specifically, psychotherapy, and support groups including cognitive-behavioral interventions appeared to help participants to feel understood, to accept change, to grieve their old self, and to move forward. For Jennifer, individual psychotherapy had been key to feel understood and supported, to accept her limitations, to remind her of her limitations, and to work on past trauma. The next paragraph exemplifies one of the aspects that Jennifer finds beneficial from therapy:

I know I need like coaches, right? So already I read so much, I read the books, so...I kind of know, have a lot of information but I need reminders (snaps her fingers) to keep motivating me so I feel like this support system, these doctors, are kind of like my coaches, ahm, so like my therapist, she listens, tadada, she like but then she will remind me like hey! Why are you so hard on yourself?

To a lesser degree, Claudia also appeared to benefit from individual psychotherapy. Here is what she said about her psychologist: “Es muy buena. Sí me ayuda mucho, me ayuda muchísimo. Heee.... es.... también me da nalgaditas de vez en cuando (laughs) porque yo tengo mi carácter este...” (English translation: She is very good, she helps me a lot. Heee... she is... she also scolds me every now and then (laughs) because I have my character...” For Lily, support groups for chronic pain, which included cognitive-behavioral interventions had been vital to remind her about the mind-body connection and its implications. Lily explained what was it about: “So that chronic pain group [...] half of it, it’s taught by a psychologist and then the other half by a physical

therapist, and it's the most wonderful thing ever because you finally figure out how these two things connect, cause otherwise you just think you are going crazy (laughs)."

The Latino Community

Being on the same page with healthcare providers, family, and friends was important for all participants. Similarly, participants appeared to benefit from being part of the Latino community for several reasons. For Diomaris, belonging to the Latino community gave her a shared goal and a meaning to live her life with pain:

Tengo días débiles, tengo días mas buenos, tengo temporadas buenas, otras no tan buenas, pero pero en las que no son tan buenas siempre estoy luchando para encontrar esa fuerza, que mi mamá, mi mamá, en en en la... en nuestra cultura, no? de de de Latinos que venimos a este país a a salir a delante, y a a luchar para tener un futuro mejor. Eso es lo que a mi me, me motiva, me impulsa mucho a a estar trabajando cada día por levantarme. (English translation: "I have weak days, I have days that are better, I have periods of time that are good, and others no so good, but but during the ones that are not so good, I am always fighting to find this force, which my mom, my mom, in in ...in our culture, right? Of of of Latinos who come to this country to get through, and to fight to have a better future. This is what motivates me, it motivates me, it really drives me to wake up everyday.")

For Claudia, music and the way that people from her country express affect brought her optimism and happiness: "Pues la música, la gente de acá es bien alegre y afectuosa, los Puerto Riqueños son bien afectuosos, y aunque no te entiendan, porque generalmente no te entienden pero pues un abrazo que se yo [...] pues si tienden a ser afectuosos, a abrazar a uno, aa... a tratar de... 'a pues tu lo manejas bien.'" (English translation: So music, people from here are very

happy and affectionate, Puerto Ricans are surely very affectionate, and even if they don't understand you, because generally, they don't understand you, so a hug, I don't know [...] so they do tend to be affectionate, to hug, aa...so they try to...."oh so you are managing well"))

Similarly, after sharing her medical condition with members of her family, Lily was encouraged to undergo a Latino ritual "*limpia*" to help her heal, after which she felt pain relief and less fatigue:

[...] and so my aunt said and my mom were like 'no ella tiene mal de ojo, ella tiene, tienes que rezarle' you know, you have to, you have to pray and am... you have to do a *limpia* with the huevo... whatever it is that is negative I guess energy that I have absorbed needs to kind of be removed. [...] I felt so much better after that. And... you know, I don't know if it's just like, you know, faith, like believing in something, or...am... yeah I mean it did. (see Appendix G for translation and explanation).

Moreover, Lily expressed her interest in pursuing more ways to heal through traditional Latino methods: "[...] the other thing I wanted to do is I wanted to go to a.... a... *curandera* as well, and my friend and I tried to am... you know do that but COVID kicked in [...]" (See Appendix G for description of *curandera*).

Non-Pharmacological Options Preferred

Actually, Claudia, Lily, and Diomaris expressed their strong preference for alternative treatments, and to heal without or with minimal medication; Jennifer appeared open to both. This is how Claudia expressed her preference: "Me gustan las cosas tópicas, este...ponerme hielo, ponerme pads, té, crema...Sí, Sí. Me siento mas cómoda. Como que lo controlas mas porque si llegué a usar medicamentos que me adormecían la lengua y me sentía muy fuera de control." (English translation: "I like topical things, this...to apply ice, pads, teas, cream...yes yes. I feel

more comfortable. It's like you can control it better because I did use medications that numbed my tongue and I was feeling a lot out of control." Lily shared the same philosophy and expressed her preference for non-pharmacological options to cope with pain:

[...] I feel they don't really teach you like skills about how to manage it [...] would be a lot more helpful than somebody you know developing this addiction where they can't even function anymore.

When choosing non-pharmacologic treatments, it seemed that it was important for all participants to have an active role when facing their FM, such as learning about the condition, having cognitive and behavioral tools to deal with it, or relying on spirituality.

Internal Factors that Make it Easier

Summary

Most participants appreciated being involved in their treatments, putting from their part instead of solely relying on medication, and they all had adopted an active role in their care as a way to cope with FM. Specifically, most of participants articulated the need to learn about FM, about the mind-body connection, and about learning non-pharmacological tools to face their pain, what also facilitated their acceptance to live with the condition. As part of this toolbox, spirituality appeared to be a powerful resource for all participants.

Taking an Active Role

The Power to Understand. In the mist of the lack of the knowledge about FM and being dismissed even by healthcare professionals, most participants conveyed a need to make sense of their experience and appreciated learning about possible causes contributing to their pain, as well as cognitive and behavioral resources to cope with it. Specifically, for all participants, learning

about the mind-body connection was crucial to make sense of their experiences and thus, how stress and anxiety can exacerbate pain, and relaxing the mind can help ease it:

I am aware that anxiety and depression can manifest physically, right? am... but I wasn't yeah, I don't know, I think what it happened to me I wasn't making that connection, I think it was cause I was in so much pain myself...physically, that I couldn't make that connection then, am... literally somebody had to... spell it out for me![...] and I think I wasn't really making that connection of the... emotional with the physical, because I think I couldn't fathom that emotional things could cause like such an extreme physical pain. (Lily)

Similarly, once she understood this connection, it was easier for Diomaris to take control of her symptoms:

Hacer ejercicio. Caminar. Me ayuda mucho a relajar y a estar un poco mas a...mas tranquila, porque de no hacerlo, mi cuerpo me duele, me duele mucho. [...]Dormir, descansar. Descansar. [...] Ah... meditar, orar, orar mucho y y eso me ayuda porque eso me me me ayuda como a estar un poco mas tranquila porque al principio era que yo me desesperaba mucho de lo que yo sentía. (English translation: Exercise. Walk. It helps me a lot to relax and to stay a little bit more a...more tranquil, because if I don't do it, my body hurts, it hurts me a lot. [...] Sleep, rest. Rest. [...] Ah... meditate, pray a lot and this helps me because this helps me be more tranquil because at the beginning was like I would become very desperate about what I was feeling.”

Besides learning about mind-body connection, most participants expressed benefiting from learning other aspects of FM. For example, Jennifer and Lily communicated learning to read her body has been useful to set limitations: “[...] if it's too much then it's like next day...you know,

there is like a balance, and I kind of figured out like... you know, I kind of know how much I can take or not. [...] So it's been five years kind of understanding mentally what I can handle but also physically what my body can handle.” (Jennifer)

Likewise, the following excerpt exemplifies how information helped Diomaris to ease her fear: “ha sido muy frustrante porque comencé teniendo ataques de pánico, ansiedad con ataques de pánico muy fuertes que yo los vivía y yo me asustaba al sentir eso porque nadie me explicaba que era. Yo tenía muy poco conocimiento de lo que era y... y poco a poco yo fui buscando ayuda” (English translation: “It has been very frustrating because I started suffering panic attacks, anxiety with very strong panic attacks, which I experienced and when I felt like that, I was scared because nobody would explain to me what it was. I had very little knowledge about what this was and... and slowly I looked for help.”)

Moreover, understanding helped participants to make more sense of their experiences and facilitated the process of accepting their condition. In this process, it seemed important for most participants to understand the connection between past adversity and current pain. In this regard, all participants expressed some type of hardship in their past, and three of them, believed that these adversities had contributed to trigger their pain. Jennifer expressed it like that:

I think with me...the pain has to do with trauma and anxiety, I think it's still by brain and body are wired. Like...the way my body responds to stress and anxiety, aaa.....based on...kind of my upbringing, my experiences, and...so the way my body reacts, like stress, anxiety here, is like (hhhh) it kind of contracts, I feel like my pain, if I could let go...

Lily came out with the same connection:

[...] there is a lot of stuff that am... I I think emotionally I've been carrying for a long time, there's a lot of actually trauma, a lot of traumatic events, a... in my life, and my guess is that has also contributed to probably me developing fibromyalgia is that I think my body at some point said this is it I can't deal anymore, I can't you know, I can't do this anymore am... and that my body just crushed.

Additionally, it was noticed that Claudia was given inaccurate information about some aspects of FM that was contributing to her stress. For example, she was told that FM is a degenerative condition: “Bueeeno, he, si yo se que es degenerativo, estoy consciente, de que es degenerativo así que estoy buscando otras cosas para entretenerme y aprender nuevas cosas para cuando ese momento llegue, verdad?” (English translation: “Well, he, if I know that this is degenerative, I am aware, that this is degenerative so I am looking for things to entertain myself and to learn new things for when this moment arrives, right?”). Besides, she was not under any type of formal treatment.

The Attitude. As part of their process of healing, all participants learned that their attitude was one of the most important pieces to overcome FM symptoms. Diomaris explained her process:

Al principio era que yo me desesperaba mucho de lo que yo sentía. Entonces he ido aprendiendo he ido aprendiendo mucho poco a poco he ido aprendiendo y sobretodo poco a poco he ido aceptando (lentamente y enfatizando “aceptando”), sí? En en en que es una condición que yo puedo.....depende mucho mi mi mi como mi actitud. Si tengo una actitud buena, he... me ayuda a... a buscar maneras para que me ayuden a lidiar con esto. (English translation: “At the beginning I would become desperate about what I was feeling. Then, I have been learning, I've been learning a lot, slowly I've been learning

and mostly, slowly, I've been accepting (slowly and emphasizing the word "accepting"), right? That this is a condition in which I can... it depends a lot on my my my like my attitude. If I adopt a positive attitude, he... this helps me to...to find ways to cope with it.")

Particularly, Claudia appeared to react to her FM with involvement in all type of activities, almost challenging her condition. She was a big supporter of maintaining herself as active and positive as possible:

[...]yo le digo esa es la actitud que tiene que tener una... tienes que poner de tu parte. Porque si dices te vas a tirar a una cama pues te vas a tirar a una cama. Si dices este... no voy a poder hacer esto, pues así mismo te vas a quedar. [...] lo manejo de esta manera, heee...[...] Trato de buscar gente que sea activa, que sea positiva, trato de involucrarme en cosas, en iglesias, en... en trabajos, en mi casa, con mi familia, he, y pon de tu parte eso es lo que les digo. (English translation: "I say, this is the attitude that one has to have...you have to do your part. Because if you say that you are going to be bedridden then you will be bedridden. If you say ...I am not going to be able to do this, then this way will be. [...] I manage it this way, heee...[...]. I try to look for active people, who are positive, I try to get involved in things, in church, in...in different work, in my house, with my family, he, and do your part is what I say.")

As part of this attitude, looking at the positive side had been very helpful, and most participants had found that FM also brought positive aspects in their lives. For example, since her diagnosis, Claudia tried new activities and found the strength to study a new career:

[...] y esto han sido como... como las cosas que yo he tenido que usar de escalones para... para progresar, para superarme. Entonces yo digo después de la FM yo he hecho mas cosas

locas que antes de la FM. Yo me he montado en banche que no lo hacía [...] Me he metido por chorreras de agua con los estudiantes cosa que yo no hacía, heee...[...] me he puesto a estudiar la maestría que yo no me había atrevido, este... cosas que se supone que yo me iba a limitar pues... he decidido que no, que yo voy a pasar de eso, que me han dicho que. (English translation: [...] and this has been like...like the things that I have had to use as steps to...to progress, to surpass myself. Then, I say that after having FM I have done more crazy things than before having FM. I have ridden a horse, which I had never done [...] I have gone into water ruffles with my students, which I had never done, heeee [...] I studied my master's degree, which I never dared before... things that were supposed to limit me so... I decided that no, that I will ignore that.”)

Jennifer pointed her increased empathy and connection with others as a result of her condition: “I am super empathetic and I think it has had its positive things like it's not all terrible. I know that because of my experiences I am able to connect with people more.” Also, together with Lily, they valued being more involved in their spirituality. This is how Lily explained how her relationship with God had changed after struggling with FM: “My relationship with God. I mean that was the only thing in the end that was left. There was nothing else you know, a... [...] so I became a lot more spiritually connected because prior to that I would tell you that I considered myself a cafeteria catholic.”

Spirituality

In addition, most participants expressed how helpful had been spirituality to cope with FM. Diomaris explained: “me ayudan el... el ser fuerte, no? El el el encontrar dentro de mi ese poder esa fuerza, la fe [...] la fe principalmente en Diós, en en pedir a él esa fuerza y eso me me me ayuda [...]. (English translation: “it helps to...to be strong, right? To find within me this

power, this strength, the faith [...] faith mainly in God, to ask him for this power, and this helps me [...].”) Even Jennifer appeared confused on why it is not yet part of FM treatments or even is not usually recommended by healthcare professionals:

[...] I feel like my faith has really also been very helpful, and I think that is the key, it’s something that you know, obviously not in the medical profession like your doctor is not gonna say like you should pray more ah, but I wished that would be something that I would see, like I haven’t seen a book about, you know I’ve seen FM books about the importance of like gut’s health and the importance of this, and therapy, and stress management, and trauma, and bla bla bla bla bla, but I am like, what about spirituality, and prayers, and faith, and hope [...]

Hope

Fortunately, in the narratives of all participants there were expressions of hope toward their futures. Here is how Jennifer envisioned the future of FM:

I am just hoping for more research and knowledge about it so that more can be studied to find better...treatments? And also to better understand the source of it [...] my hope is that in the next 20 years there will be more advances, so like “here take this magic pill or this vitamin”, or “eat the supplement”, or “let’s do this minor surgery to like take out your whole bladder cause that’s what is messing everything up, you know, something like that. That’s my hope!

For Claudia, the idea of impermanence helped her to accept her present: “Es como yo diría como un impedimento, lo veo como un obstáculo que yo tengo que sobrepasar, que aunque dicen que eso me va a limitar completamente, yo lo sigo viendo como un catarro que me dió y que en un momento no lo voy a tener. Se va a ir.” (English translation: “It is like I would say an impediment,

I see it as an obstacle that I have to get over, which, although they say that this is going to completely limit me, I continue to see it as a cold that I caught and that suddenly I am not going to have it. It will go away.”)

Hope and faith fostered optimism in Lily, who also appeared strongly connected to her current healthcare provider:

I do believe that I can be cured from it... I think that part of what helps me is that I have faith but I will be curious even if they tell you that there's no cure for it, am... this naturopath she [...] it took her 30 years to do that. She cured herself out of her own chronic illness [...] and she is the only one who is really I felt she has listened to me out of all the doctors [...]

As stated before, Diomaris hoped that in the future, someone finds an efficient treatment, and also wishes that she can be better understood by the medical field. Besides, when asked how she imagined an efficient treatment, here is what she imagined: “Yo me lo imagino como... masajes en todo el cuerpo (laughs softly) así que que... (continues laughing) sí, como una pastillita ahí, que un masaje que ayude a... a sentirte relajado el cuerpo y a no sentirte molestias, dolores, ni ni ni este, molestias porque hasta para tocar mis codos, todo así me duele.” (English translation: “I imagine it like...massages all over the body (laughs softly) like...(continues laughing) yes, like a little pill, a massage that helps to...to feel your body relax, and to not feel trouble because even to touch my elbows, everything hurts.”)

Chapter V: Discussion

This study explored the experiences of Latinas with fibromyalgia, including aspects that make living with the condition more challenging, and aspects that make it easier. To this end, the researcher formulated five main questions: (a) How do family, friends, or any other people contribute to the experience of Latinas living with FM? (b) What has been their experience with FM treatments (including mental health, pharmacological, and non-pharmacological interventions)? (c) What are psychosocial factors that are helping Latinas cope with FM? (d) What psychosocial factors may be exacerbating symptoms of FM? And (e) How can Latinas find meaning in their pain?

The results of this small study provide some insight to these questions. Due to the interconnectedness of these questions, there is a of overlap between the questions when discussing the results. In these cases, the researched points out this overlap. Overall, the results were consistent with current available research, but also identified important themes specific to Latinas, who have little mention in the literature on FM. Also, there were idiosyncratic themes that were included and discussed for the significance of the topic. These themes will be discussed in this section.

Regarding question (a) there were three different themes identified that provided information surrounding this matter: Familism, The Role of the Husband, and the Latino Community. First, the construct of familism appeared to influence participants' well-being in different directions, and while all participants expressed benefiting from the support provided by family members, two participants expressed difficulties finding this support within the family (immediate and/or extended), and one participant even expressed that communicating her condition to her extended family made her feel unsafe. Numerous studies have shown the

positive effect of familism values in physical and psychological health outcomes and a growing body of research is looking into the mechanisms by which this association occurs. For example, Ruiz et al. (2016) noted that although there are a lack of studies showing direct evidence between the association between specific cultural values and objective health indicators, several proxies of Latino culture have been used and linked to better health outcomes. Specifically, the authors highlighted the importance of examining social support, social integration, and cohesion as proxies to understand how Latino culture can modulate health outcomes. Interestingly, familism appeared to contribute to greater social integration and cohesion. Likewise, Campos and Kim (2017) described how social support and relationships are key instruments mediating and modulating psychological and physical health in collectivist cultures, and familism appeared to offer a context where Latinos could perceive, obtain, and benefit from social support, which in turn benefited relationships and health outcomes. Significantly, they added that the link between relationships and health was influenced at the same time by cultural representations of the relationships, which are distinctive across cultures (i.e., how different cultures define and practice positive relationships). Consequently, a particular culture might benefit from familism in a different way. Although most research indicates that Latinos' culture appears to benefit significantly from familism values, in their literature review, Perez and Cruess (2014) found that familism generated different health outcomes in Hispanics depending on their medical condition, the demographic characteristics (individual's age, gender, or generation), and their context. While the authors observed that values such as family cohesion and family support increased proactive self-care behaviors of Hispanics with certain chronic medical conditions (i.e., diabetes) they also observed that when self-care routines involved putting themselves as a priority (violating a central principle of familism) they preferred to please their family. In the case of FM,

which very often entails a decrease in the previous level of functioning and plenty of self-care, would be reasonable that participants felt conflicted to transgress this rule, and put their needs before the family ones. In fact, results of this preliminary study showed how most participants adopted roles as caretakers that had interfered with their self-care. In line with our results then, because of the multiple facets that compose familism values, and the unique situation of an individual (multiple psychosocial and cultural factors), its benefits may not be for everyone. Regarding the second theme informing question (a), The Role of the Husband, all participants pointed the importance of having the support of their partners, and most of them expressed that values related to machismo were unhelpful for their care. Specifically, the participants who had to assume all tasks at home were struggling because of the pain and the stress (also providing light to question d). Concerning the third theme surrounding question (a), belonging to the Latino community appeared to be a powerful positive psychosocial factor in the experience of FM (providing light to question c as well). Although the role of community in health has been less studied, it might be a useful proxy to measure the relationship between Latino values and health outcomes. The little research in this regard indicated that social connectedness is a common and pivotal feature of Latino families and communities, and that cultural practices in these communities serve as pathways for bringing families and friends together, reinforcing social ties and cohesion, and contributing to health (Mendez-Luck et al., 2015). Similarly, most participants in the present study benefited from participating in activities tied to the Latino community (i.e., religion/spirituality, Latino rituals, festivities, and music). Further, for one of the participants, the Latino Community contributed to give meaning to her pain (also answering our question number e). Considering these findings, the role of communities in wellbeing should be further explored and contemplated when choosing treatments for Latinas in pain.

Regarding treatments, and providing information related to question (b), a common experience present in the life of all participants, was the fear stemming from becoming dependent on medication and for not controlling its effects. This finding is related to previous research on Latinos' preference for non-pharmacological treatments or the use of medication as a last resource (Shavers et al., 2010; Torres et al., 2017; Turner et al., 2020), but the participant's experience adds the dimensions of fear and lack of control. In line with the previously mentioned studies, most of our participants preferred non-pharmacological interventions for pain and chose to minimize medication if needed. Importantly, one of our participants, who maintained a good and close relationship with her Latino family, chose and benefited from engaging in traditional non-pharmacological Latino remedies, and expressed her willingness to continue trying these practices. Besides the effects of the practice itself, this finding is consistent with previous speculations noting that individuals with higher acculturation to Latino culture present better mental and physical health (Ruiz et al., 2016), and should be taken into consideration when exploring treatments with Latinas. Relatedly, and providing information for questions (c) and (d), all participants agreed in the benefits of receiving psychotherapy from a person of a similar culture or attuned to different cultures, what appeared to facilitate connection, trust, and adherence to treatment. This finding is also consistent with existing literature in the field of psychology, which postulates that individuals tend to prefer therapists of their own race-ethnicity, but therapy can be same effective if the therapist applies multicultural competencies (Cabral & Smith, 2011).

As part of the non-pharmacological preference for treatments, and informing questions (b) and (c), the participants expressed the need to take an active role in their treatments, and specifically, they appeared to benefit from educating themselves, and engaging in spirituality and

religion within the context of their traditional Latino practices. First, learning about mind-body interconnection appeared to help all participants to make more sense of their experiences; thus, it also helped them to guide their responses to pain (e.g., relaxing, changing activities, or asking for help), and for three of them, contributed to their process of acceptance. Second, although not everyone benefited from participating in support groups, they all did benefit from social support, found often in traditional Latino practices. In this regard, spirituality, religion, and the Latino community appeared to be crucial to find the energy to continue managing their pain, and to maintain a positive attitude and hope. Indeed, spirituality and religiosity can be important aspects of human life and have been positively associated with several aspects of physical and psychological well-being in people with chronic pain and FM (Baetz & Owen, 2008; Ferreira-Valente et al., 2020; Moreira-Almeida et al., 2006, 2008; Rippentrop, 2005). Although a direct association between spirituality/religious variables and health outcomes or level of pain has not been found, spirituality and religious practices have been linked indirectly to a better quality of life through other mechanisms such as health practices, social support, cognitive resources, or psycho-neuro-immuno-endocrinology (Moreira-Almeida & Koenig, 2008), and through promoting pain-coping skills, other problem-focused coping, and by social support seeking, in people with FM (Biccheri et al., 2016; Ferreira-Valente et al., 2020). Not surprisingly, there is growing research pointing out the importance of incorporating spirituality in pain treatments (Ferreira-Valente et al., 2020; Garschagen et al., 2015). With that said, spirituality has been left out in most interventions for chronic pain populations and it is critical to start including it in well-designed treatments.

Responding to question (c), there were various psychosocial factors that appeared to help Latinas cope with FM, which have been mentioned above. They included Taking an Active Role

in the treatment through engaging in psychoeducation, in Latino practices, in the Latino community, and in spirituality. Besides that, all participants agreed about the importance to find a culturally attuned psychotherapist to facilitate connection, trust, and continuity of care.

On the other hand, all participants expressed numerous psychosocial factors that worsened their experience of living with FM and responded to the (d) question. First, and in line with previous research that has been done (mostly with non-Latinas or heterogenous samples, but also with Latinas) all participants felt dismissed and treated unfairly. They all agreed that the lack of knowledge about the condition, that is often believed to be either psychosomatic or nonexistent, made it hard to make sense of what was happening to them. This confusion, also present in the healthcare field, led to delays in diagnosis, and triggered feelings of uncertainty and vulnerability. Probably as a result of this gap of knowledge, and specifically because of the unknown structural changes underlying FM, all participants also reported experiences of insensitivity and lack of empathy by their healthcare providers and friends, that made them feel misunderstood and mistreated. In this regard, Armentor (2017) described two types of stigmatizations in the lives of women with FM. The first stems from the invisibility of the illness that often leads to reputational stigmatization (e.g., sufferers' symptoms are called into a question). The second is the further skepticism and stigmatization as a consequence of receiving the diagnosis. Participants in the current study encountered both. Despite the advances made toward understanding FM, these results confirm the stigma that still persists around FM and how this attitude is detrimental to the ones who suffer from it, to the extreme where all the participants in this study expressed that feeling understood in itself, would improve their quality of life (informing question c as well). Also consistent with these findings, De Ruddere et al. (2012) found how in their sample (5% of which were healthcare providers and 10% were

pursuing education in a health-related field), participants attributed lower pain, felt less sympathy for the patient, were less distressed while observing the patient, and were less inclined to help the patient, in the absence of a medical explanation for their pain, compared to when medical evidence was present. As part of this insensitivity and lack of empathy, all participants in the present study reported being told the statement “it’s all in your head,” what made them feel once more, misunderstood, confused, and unsupported, and challenged their rapport with healthcare providers. Similar results were presented in a very unique study by De León-Menjivar (2021), who explored how Puerto Rican women with fibromyalgia navigated their communication about their condition with medical professionals. The author found that all women experienced dismissal by healthcare providers, often were prescribed antidepressants and told “it’s all in your head.” Importantly, this same study further uncovered that ethnic background appeared to exacerbate this situation and put Latina women at a disadvantage for their pain management (because the intersectionality with Latino values such as respeto, and for the belief that women of color exaggerate their pain). This was also found in the present study, within the theme Culture Matters, providing insight for our questions one, two, and four. Indeed, most participants in the present study felt more comfortable with healthcare providers with the same or a similar culture, yet they encountered a lack of cultural diversity, more evident in the medical field, that challenged their connection and trust, and threatened their continuity of care. Beyond that, being Latina appeared to be an added source of stress for most participants, who expressed feelings of discrimination and fear of being treated unfairly because of their ethnicity. Besides being Latina, being an immigrant with no access to healthcare further complicated access to proper pain management. These findings have been scarcely explored in the available literature and reflect the particular challenges in the lives of Latinas with FM that may differ from other dominant

cultures that have been researched; thus, it is important to expand literature in this direction, and to look at the experiences of minoritized communities to incorporate cultural responsiveness in their treatments.

Also, the Latino value of matriarcado (matriarchy) appeared to negatively influence the participants in the present study. This was an interesting outcome from the study, since Marianismo (marianism) was first hypothesized to complicate FM coping, but the construct of matriarchy was not considered. Moreover, no research was found looking into the relationship between matriarchy and health, and little research explored this construct in relation to other issues non-relevant to this study. For our participant, matriarchy involved the strong role of women, who are supposed to lead, morally guide, support, and nurture the family. Not surprisingly, this is a hard role to maintain while suffering FM. Likewise, some participants described how they had been taught to be caretakers within the Latino family, and how this role contributed to putting themselves last. Additionally, some of the participants discussed benefits about sharing housework with their husbands, and how values of machismo would worsen their pain (informing questions c and d).

Also in line with previous work, the participants described severe pain and cognitive difficulties (i.e., mostly concentration and memory problems) that made it hard to keep up with their previous workload. They all tried to maintain their jobs at all costs, which appeared to be an ongoing effort for all. Numerous studies have documented that one of the hardest consequences of living with FM is not keeping up with previous workloads, to the extreme that a significant number of sufferers must quit their paid jobs against their will (Arnold et al., 2008; Crooks, 2007). As a result, and in line with this literature, all our participants expressed feeling stressed and frustrated, and tried to engage in jobs/activities to maintain their productivity; however, they

needed help to adjust and to accept their new level of functioning and current needs. In this regard, some participants emphasized the hard but necessary process of grieving their old self in order to move on. Certainly, previous research found that FM caused work disability and loss of paid jobs (DeLuca et al., 2011; López-Solà, 2014; Turk et al., 2016), and revealed the benefits to offer transition strategies toward adaptation for people with chronic pain (Furnes et al., 2015), to help in the process of grieving the old self (Smith & Osborn, 2007), and to work on acceptance (Du et al., 2021; McCracken et al., 2004; Sturgeon 2014) to move on in their lives.

Regarding question (e), most participants associated their pain with their psychological history, but struggled to find a meaning in it. However, they all shared some insight related to the question. One participant explained how she could find meaning in her pain through a shared goal with the Latino community (i.e., their drive to find a better life in the United States). Also, all participants encountered positive aspects that their condition brought into their lives, such as increased empathy, improvement of oneself, or a reunion with their spirituality.

Looking at the overall results, it appears that participants expressed a lot of information related to positive and negative psychosocial factors influencing their experience of living with FM. Secondly, they also brought up substantial matters related to their experiences with FM treatments. Although in less amount, participants also mentioned several themes related to Latinos/as cultural values impacting their experiences with FM that appeared very unique to this culture and less represented in the current literature. Lastly, compared to the rest of the questions, the researcher did not gather much information regarding question number five, and reasons for that are suggested at the end of this section as well as in the Limitations' chapter.

Besides the answers to the research questions, and in line with numerous studies, all the participants shared a history of hardships during their lives, and two of them, used the words

“trauma” or “traumatic events” to refer to these occurrences. Although it was not one of the goals of this research, these narratives support previous literature linking past psychological trauma to suffering fibromyalgia and should be taken into consideration when treating people with FM.

Moreover, the results of this study also provided support for hypothesized Latino sociocultural constructs that could have an impact to the lives of Latinas living with FM (see page 32). In this regard, the roles of familism, machismo, and spirituality have been already described above, and information related to the constructs of collectivism, and marianismo can be also extracted from the results. First, it could be inferred that collectivism could impact the lives of Latinas living with FM in a similar way as familism, since they both rely on a value system that prioritize in-group goals over personal goals, and they just differ in that collectivism includes not just family as an in-group but also other in-groups (Greenfield & Quiroz, 2013), and this hypothesis has been also supported in literature (Schwartz et al., 2010). Further, it has been documented that they both can be associated with increased well-being because it facilitates social ties, but also with higher psychological distress for the obligations it involves (Schwartz et al., 2010). Second, marianism (described on page 34) is a multidimensional construct involving taking care of family responsibilities and being obedient and silencing one’s own needs. From the narratives of the participants, it could be concluded that all of them benefited from sharing family responsibilities and from adopting behaviors not related to obedience or silence: for example, they explained how helpful it was to adopt an active role to cope with FM, to participate either in psychotherapy or support groups, and to have social support; all in all, making marianism a construct that could negatively impact Latinas with FM. Conclusions regarding the impact of the constructs of personalismo and simpatía (see definitions on page 32)

and respeto (described on page 33) on Latinas living with FM could not be made from the information provided by the participants, and drawing conclusions would involve too many assumptions, thus, they were not included in this study's results.

Furthermore, looking at the convergencies and divergencies across narratives, it also could be noted that there were important differences in the understanding of FM and recommended treatments between the United States and Puerto Rico. In this respect, the only participant living in Puerto Rico appeared to believe that FM was a degenerative process, and that she may finish on a wheelchair, information that was given by her healthcare providers. She also seemed to have not received any type of psychoeducation and had made up her own treatments, prioritizing her mind over her body. For example, she adopted a very active role as a way to control her fear of becoming inactive. Besides, and probably as a consequence, she also seemed to be struggling the most when accepting her new self. With that said, this was just one case, compared with 3 in the United States, and it is not representative of the Puerto Rican population; thus, conclusions should not be drawn from this observation. In addition, the denial of the existence of FM, appeared to impact all participants, and mostly, the participant living in Puerto Rico, who encountered a doctor who gave her the diagnosis while others wouldn't. Besides the consequent confusion and vulnerability, this situation exemplifies the powerful role that healthcare providers play in the impact and experience of FM.

Additionally, the limited responses on the question number five might also be because giving meaning to pain involves believing that pain exists, what was often denied in the life of the participants. Further, pain can be interpreted in different ways, which makes the question vague and more challenging to respond to. The following section adds discussion in this regard.

Few Notes About the Meaning of Pain

Following the biopsychosocial model, pain is a multifaceted construct in which contextual aspects contribute to how we can understand, accept, and give meaning to it. In the case of FM, and as part of the social context, most people don't believe in the condition, and deny that it exists, and all participants had encountered this situation and had been told that "all was in their heads." Relatedly, the participant responses appeared related to the level of acceptance and endurance of their FM. For example, the participant who was most impacted by the denial of her diagnosis appeared to struggle the most with the acceptance of her new self and adopted behaviors that ignored her pain to keep active in life. She saw it as something transitory, which would go away in the future. On the other hand, the other participants appeared to be further in the process of accepting their condition, and for example, had a stronger understanding about the mind-body connection, and seemed to have started the process of grieving their old self and to accept their limitations. These observations exemplify how the social context has an impact on the understanding of FM, and how it can contribute to give meaning to it. Therefore, if the social context of people living with FM would accept the existence of FM, would the participants be able to understand it differently and give it another meaning? Are their limited responses influenced by this lack of understanding/acceptance by others? The fact that one of the participants imagined part of the cure of FM as others understanding and admitting that this condition exists says a lot about all the work we, as healthcare workers, have to do. Certainly, the first step we should take is listen to what our patients have to say about their condition, and to keep in mind that regardless of the cause, FM exists.

Limitations and Strengths

This study included a very small sample size, and the results might not be representative of all populations of Latinas living with FM. As such, the results serve solely as a base for future research to develop. Also, for the nature of a qualitative study, the results are dependent on the experience, interpretation, and criterion of the researcher involved, and might contain subjectivity. Although different methods of bracketing were used, these do not guarantee the absence of bias. Lastly, the researcher did not obtain robust information about the meaning of pain for Latinas with FM, and this, besides the reasons given above, could be explained in part because the question was difficult to answer and also because it was not further explored.

On the other hand, this study provides unique information about how Latino values can influence the experience of pain. It promotes further research in this direction, contributing at the same time, to increasing literature surrounding the experience of FM in Latinas, which is currently very limited. The participants of the study expressed appreciation, and were grateful to be “seen” and considered.

Conclusion and Implications for Treatment

Results from this study noted several aspects in the experiences of Latinas living with FM that are similar to what has been observed in previous work with non-Latinas and heterogeneous populations with FM. For example, the participants in the present study recognized a lack of knowledge about FM by healthcare providers and people in general, which contributed to stigmatization and delays in diagnosis. Consequently, the participants felt dismissed and treated unfairly, which together with delays in their diagnostic process, triggered confusion, vulnerability, and uncertainty. Also, in line with previous research with non-Latinas, the participants experienced cognitive difficulties that interfered with their daily activities and

caused frustration. Cognitive difficulties and pain appeared to prompt functional decrease, and in some cases, loss of paid jobs. Indeed, loss or interference with work appeared to be one of the most detrimental consequences of living with FM, and participants expressed benefiting from practices to help process the loss of work, and the change of identity that comes with it. In the process of rediscovering their new self, it was observed that sociocultural background (including cultural roles, language, and specific fears) should be explored within the context of being Latina, for differences from other non-Latino populations, and connotations that this involves.

Besides the above commented common experiences, the results identified other experiences that were specific to Latinas living with FM. First, being Latina seemed to exacerbate the fear of stigmatization due to a lack of cultural diversity in the healthcare field that challenged connection, trust, and continuity of care. Second, fear of discrimination was also an added stress beyond pain that Latinas experienced. The immigration status of participants further complicated access to proper pain management; therefore, matters of discrimination and cultural diversity must be guaranteed in interventions with Latinas.

Latino values appeared to impact the participants' lives in different ways. The construct of familism should be explored in therapy to gauge the positive or negative impacts on the particular individual, since according to previous work and current results, the role of the family in health outcomes might depend on medical condition, demographic characteristics and context (Perez & Cruess, 2014; Preece et al., 2005). Contrarily, there is robust research supporting the positive impact of social support in health in non-Latinos and Latinos. In this regard, different traditional Latino practices and values have been speculated to foster and facilitate social support and have been hypothesized to contribute to the "Latino health paradox" phenomenon. Subsequently, it's important to examine which sources of social support can Latinas benefit

better from, including their nuclear and extended families, spirituality, and possible communities. To this end, exploring the degree of acculturation may be crucial when choosing interventions. Similarly, other Latino values related to traditions, customs, music, or language appeared to play a role in the FM treatment experience and may be assessed to choose interventions and optimize treatment outcomes.

Taking into consideration the pivotal role of social support in health outcomes, it is urgent to offer support groups for Latinas with FM, since they are currently non-existent, and could be a powerful choice for many Latinas lacking strong social networks (e.g., immigrants who live separated from their families and communities). At the same time, this would also facilitate access to learning about FM, the mind-body relationship, and other tools for coping with FM, that appeared to be life-changing for most of our participants.

Additionally, all of the participants explained visiting multiple doctors from different disciplines before being diagnosed with FM, and the multiple healthcare providers that they currently visit to keep their treatment going and effective. One of our participants articulated her emotional exhaustion caused by her constant search for the right treatment, the right healthcare provider, and for managing all her appointments. Because of the multifactorial nature of FM, the gaps of knowledge that still exist, the involvement of different services in treatment, and the changing nature of it, sufferers may benefit specially from the collaboration, coordination, and communication of the interdisciplinary care. At the same time, working together with social workers, might facilitate access to resources, especially for Latinas with an immigrant status.

In summary, it appears that evidence-based psychological treatments that facilitate learning, acceptance, and social support, such as ACT, could be a good choice to cope with FM in Latinas. However, as part of the intervention, they could also benefit from taking into

consideration the following aspects: 1) an assessment of the degree of acculturation 2) the status of immigrant and access to care 3) exploring matters of discrimination 4) exploring Latino values and practices and their meaning for the individual 5) assessing the involvement in some type of spirituality 6) exploring sources of social support and possible participation in support groups and 7) aim for an interdisciplinary team approach to care. Expansion of these small preliminary findings might have the potential to help Latinas with FM and people in their lives to understand better this condition and to choose optimum intervention options for this minoritized group.

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APPENDIX A

Institutional Review Board Approval Letter

Pepperdine University
24255 Pacific Coast Highway
Malibu, CA 90263
TEL: 310-506-4000

NOTICE OF APPROVAL FOR HUMAN RESEARCH

Date: October 01, 2021

Protocol Investigator Name: Elisenda Rodes Sendros

Protocol #: 21-03-1560

Project Title: Psychosocial Factors in Fibromyalgia: A Phenomenological Understanding of the Experiences of Latinas

School: Graduate School of Education and Psychology

Dear Rodes Sendros:

Thank you for submitting your amended exempt application to Pepperdine University's Institutional Review Board (IRB). We appreciate the work you have done on your proposal. The IRB has reviewed your submitted IRB application and all ancillary materials. Upon review, the IRB has determined that the above entitled project meets the requirements for exemption under the federal regulations 45 CFR 46.101 that govern the protections of human subjects.

Your research must be conducted according to the proposal that was submitted to the IRB. If changes to the approved protocol occur, a revised protocol must be reviewed and approved by the IRB before implementation. For any proposed changes in your research protocol, please submit an amendment to the IRB. Since your study falls under exemption, there is no requirement for continuing IRB review of your project. Please be aware that changes to your protocol may prevent the research from qualifying for exemption from 45 CFR 46.101 and require submission of a new IRB application or other materials to the IRB.

A goal of the IRB is to prevent negative occurrences during any research study. However, despite the best intent, unforeseen circumstances or events may arise during the research. If an unexpected situation or adverse event happens during your investigation, please notify the IRB as soon as possible. We will ask for a complete written explanation of the event and your written response. Other actions also may be required depending on the nature of the event. Details regarding the timeframe in which adverse events must be reported to the IRB and documenting the adverse event can be found in the ***Pepperdine University Protection of Human Participants in Research: Policies and Procedures Manual*** at community.pepperdine.edu/irb.

Please refer to the protocol number denoted above in all communication or correspondence related to your application and this approval. Should you have additional questions or require clarification of the contents of this letter, please contact the IRB Office. On behalf of the IRB, I wish you success in this scholarly pursuit.

Sincerely,

Judy Ho, IRB Chairperson

cc: Dr. Lee Kats, Vice Provost for Research and Strategic Initiatives

Mr. Brett Leach, Regulatory Affairs Specialist

APPENDIX B

Resources

Clinics with Spanish-speaking services:

Lancaster/Palmdale area referrals

Child & Family Guidance Center

40005 10th Street West
Palmdale, CA 93551
(661) 265-8627

Penny Lane Centers - Lancaster

43423 Division St., Suite 102
Lancaster, CA 93535
(661) 274-0770

Hathaway-Sycamores Child & Family Services

44738 Sierra Highway
Lancaster, CA 93534
(661) 942-5749

Other Areas (*all operate on a sliding scale fee*)

Open Paths Counseling

5731 W. Slauson Ave., Suite 175
Culver City, CA 90230
Administration: 310-258-9737
Counseling Services: 310-258-9677

Airport Marina Counseling Center

La Tijera Blvd., Los Angeles, CA 90045
(310) 670-1410

GSEP West Los Angeles Community Counseling Center

6100 Center Dr., Los Angeles, CA 90045
(Availability of Spanish-speaking cases depending on current students)
(310) 568-5600

Pepperdine University Counseling Center, Irvine

Lake Shore Towers III; 18111 Von Karman Ave, Irvine, CA 92612
(949) 223-2570

Psychology Praxis (Los Angeles – West Side)

(310) 620-3106

USC Telehealth

Online therapy in English and Spanish – connect via computer, laptop, tablet, or
smartphone
(866) 740-6502

APPENDIX C

Interview Questions

Demographics:**Age:****Gender:****Education:****Ethnicity/Culture****Employment:****Marital Status:****Years since dx:****Living with Fibromyalgia**

1. What helps you cope with FM?
2. What makes it difficult to cope with FM?
3. Who are the people that support you in coping with FM? (Prompt: Family, friends, other people)

Culture and Fibromyalgia

4. How do you think being a Latina affects your experience with FM? (Prompt: What do you value most in your culture that helps you cope with FM? Are there any values/traditions that make it difficult to cope with FM?)

Treatments Experiences

5. What are your experiences with the mental health care system and treatments?
6. What experiences do you have with alternative treatments (e.g. alternative or traditional forms) or other ways of healing?

Cognitions

7. What are your expectations around FM?
8. What is/are your believe/s about pain?

APPENDIX D

Preguntas de la Entrevista

Información demográfica:**Edad:****Género:****Educación:****Etnicidad/Cultura:****Empleo:****Estado civil:****Años desde que tiene el diagnóstico de fibromialgia:**

1. **¿Qué le ayuda a lidiar con la fibromialgia?**
2. **¿Qué es lo más difícil de vivir con fibromialgia?**
3. **¿Quién es la gente que le ayuda y le apoya a vivir con fibromialgia?** (Pista: familia, amigos, otra gente)
4. **¿Cómo piensa que el hecho de ser Latina afectar a su experiencia de vivir con fibromialgia?** (Pista: ¿Qué es lo que valora más en su cultura que le ayuda a luchar contra la fibromialgia? Hay algunos valores/tradiciones que le hacen más difícil manejar la fibromialgia?)
5. **¿Cuáles son sus experiencias con el sistema de salud mental y con los tratamientos para la fibromialgia?**
6. **¿Cuáles son sus experiencias con tratamientos alternativos o con otras maneras no convencionales de sanarse?**
7. **¿Cuáles son sus expectativas respecto a la fibromialgia?** (Pista: como cree que evolucionará)
8. **Cuál/es es/son su/s creencia/s sobre el dolor?**

APPENDIX E

Consent Form English

PEPPERDINE UNIVERSITY**INFORMED CONSENT FOR PARTICIPATION IN RESEARCH ACTIVITIES****Title of Project: Psychosocial Factors in Fibromyalgia: A Phenomenological Understanding of the Experiences of Latinas**

You are invited to participate in a research study conducted by Elisenda Rodes, M.A. who is under the supervision of Dr. Carrie Castañeda-Sound, PhD., Associate Professor of Psychology at Pepperdine University, because you identify as an adult Latina and/or Hispanic with the diagnosis of Fibromyalgia. Your participation is voluntary. You should read the information below and ask questions about anything that you do not understand, before deciding whether to participate. Please, take as much time as you need to read this form. You might also decide to discuss participation with your family and friends. If you decide to participate, you will be asked to sign this form.

PURPOSE OF THE STUDY

The purpose of this study is to identify and to understand better the various psychological and social factors intersecting with Fibromyalgia and influencing the experience of pain and the ways to cope with it. This knowledge will help to develop effective and culturally responsive treatments.

STUDY PROCEDURES

If you volunteer to participate in this study, you will be asked to provide basic demographic information (e.g., age, education, occupation, etc.), and a face-to-face semi- structured interview. Volunteers are required to be audio recorded in order for accuracy of data being collected, and further analysis. The interview consists on eight questions, and last about 30 minutes, depending on the answers provided. The interview will be conducted via zoom link.

Interview

The interview will include eight questions about your experiences living with fibromyalgia. You may request to stop the interview any time.

POTENTIAL RISKS AND DISCOMFORTS

Participation in the study is no more than minimal, and might include discomfort when reporting personal events. If feelings of discomfort or distress are triggered by participating in the study, the researcher might implement relaxation techniques if appropriate, and a referral list of community mental health resources will be provided for both (English and Spanish-speaking participants).

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR SOCIETY

While the study may not provide direct benefits to all participants, it is hopeful that the data collected will contribute to the field of psychology gaining greater understanding of the experiences of fibromyalgia in Latinas, and the factors that exacerbate or ameliorate their pain. Also, it will provide information to psychologists and physicians to help them understand better

people who suffer fibromyalgia and to choose the best treatment for them as well as topics for therapy that are meaningful for them.

PAYMENT/COMPENSATION FOR PARTICIPATION

All participants will be compensated with a \$10 visa gift card. If participants choose to prematurely withdrawal from the study prior to the interview being complete, the gift card is forfeited. Discontinuation of the study once started will not affect eligibility for this compensation. This gift card will be sent by email, and by mail, if the participant does not have access to email.

CONFIDENTIALITY

The records collected for this study will be confidential as far as permitted by law. However, if required to do so by law, it may be necessary to disclose information collected about you. Examples of the types of issues that would require me to break confidentiality are if disclosed any instances of child abuse and elder abuse. Pepperdine's University's Human Subjects Protection Program (HSPP) may also access the data collected. The HSPP occasionally reviews and monitors research studies to protect the rights and welfare of research subjects.

The data will be stored on the audio recorder used for the interviews, in the principal investigator's place of residence. The emails with consent forms, questionnaires, and transcriptions of the interview will be stored electronically in a pass-protected computer, in the principal investigator's place of residence. All electronic data will be stored for a minimum of three years after the study has been completed and will then be deleted permanently. Addresses collected to send the gift card will be deleted the same day that the cards are sent.

Any identifiable information obtained in connection with this study will remain confidential. All participants will be assigned a random number that will correspond to their name, questionnaires, and interview (i.e., audio recording, verbatim transcription). The audio recordings from the interview will be transcribed verbatim by the principal investigator. The transcription will be coded by both the principal investigator and a second coder for data analysis and will then be reviewed by an auditor (i.e., dissertation chair member). Questionnaires, audio recordings, and verbatim transcriptions will only be shared with the research team (i.e., dissertation chair member, coder, auditor, transcriber) and will only be used for the purpose of this study.

PARTICIPATION AND WITHDRAWAL

Your participation is voluntary. You may withdraw your consent at any time and discontinue participation without penalty. However, the gift card will only be provided upon you completing the interview that is part of the study. Furthermore, you are not waiving any legal claims, rights or remedies because of your participation in this research study.

ALTERNATIVES TO FULL PARTICIPATION

The alternative to participation in the study is not participating or completing only items that you feel comfortable.

INVESTIGATOR'S CONTACT INFORMATION

You understand that the investigator is willing to answer any inquiries you may have concerning

the research herein described. You understand that you may contact Elisenda Rodes, M.A., who is under the supervision of Dr. Carrie Castañeda-Sound, Ph.D. if you have any other questions or concerns about this research. Elisenda Rodes, M.A. can be reached by email at or by phone. Dr. Carrie Castañeda-Sound, Ph.D. can be reached by email or by phone.

EMERGENCY CONTACT INFORMATION: In the event of a research-related emergency, you may contact: Research Chair Carrie Castañeda-Sound, Ph.D. by email or by phone. You may also contact IRB Chair Judy Ho, Ph.D.

RIGHTS OF RESEARCH PARTICIPANT – IRB CONTACT INFORMATION

If you have questions, concerns or complaints about your rights as a research participant or research in general please contact Dr. Judy Ho, Chairperson of the Graduate & Professional Schools Institutional Review Board at Pepperdine University 6100 Center Drive Suite 500 Los Angeles, CA 90045, 310-568-5753 and gpsirb@pepperdine.edu.

I understand to my satisfaction the information regarding participation in the research study. All my questions have been answered to my satisfaction. I have received a copy of this informed consent form, which I have read and understand. I hereby consent to participate in the research described above.

Participant's Signature

Date

I have explained and defined in detail the research procedure in which the subject has consented to participate. Having explained this and answered any questions, I am cosigning this form and accepting this person's consent.

Elisenda Rodes, M.A.
Principal Investigator

Date

APPENDIX F

Consent Form Spanish

PEPPERDINE UNIVERSITY

CONSENTIMIENTO INFORMADO PARA LA PARTICIPACION EN ACTIVIDADES DE INVESTIGACION

Título del Proyecto: Factores psicosociales en Fibromyalgia: Entendimiento Fenomenológico de las experiencias en Latinas.

Usted esta invitada a participar en la investigación que realiza Elisenda Rodes, M.A., quién esta bajo la supervisión de la Dra. Carrie-Castañeda-Sound, Professora Asociada de la Universidad de Psicología de Pepperdine, porque usted se identifica como una adulta Latina y/o Hispana con el diagnóstico de Fibromialgia. Su participación es voluntaria. Usted debería leer la información presentada en esta hoja, y hacer cualquier pregunta sobre lo que no entienda, antes de decidir si quiere participar o no. Por favor, tómese todo el tiempo que necesite para leer este papel. Quizás quiera también hablarlo con su familia o amigos. Si decide participar, se le pedirá que firme este consentimiento.

PROPOSITO DE ESTE ESTUDIO

El objetivo de este estudio es identificar y comprender mejor los diversos factores psicológicos y sociales que coexisten con la enfermedad de fibromialgia y pueden estar influenciando su experiencia del dolor y la manera de afrontarlo. La información que obtengamos nos ayudara a desarrollar tratamientos para la fibromialgia que sean más efectivos, y al mismo tiempo, congruentes culturalmente.

PROCESO DEL ESTUDIO

Si usted participa voluntariamente en este estudio, se le pedirá información demográfica básica (ej., edad, educación, trabajo...), y contestar una entrevista con 8 preguntas, a través de la plataforma de zoom). El audio de la entrevista se grabará por motivos de corrección y precisión de los datos, así como para el posterior análisis. La entrevista se realizará a través del programa zoom, por lo que usted deberá disponer de algún medio para poder conectarse (e.j., iPhone, ordenador, iPad, Tablet....). Una vez realizada la entrevista, se le enviará una tarjeta visa con 10\$ por email o por correo ordinario.

ENTREVISTA

La entrevista consta de 8 preguntas sobre sus experiencias viviendo con fibromyalgia, y dura aproximadamente media hora, dependiendo de las respuestas dadas. Usted puede discontinuar la entrevista en cualquier momento. La entrevista se efectuará vía enlace de zoom.

RIESGOS Y MOLESTIAS POTENCIALES

La participación en este estudio puede comportar no más que molestias mínimas o leves, relacionadas con malestar al narrar hechos relacionados con la condición de fibromialgia. En caso de que la participación en el estudio comportara cualquier malestar, se proveerían referencias a recursos de salud mental en la comunidad.

BENEFICIOS POTENCIALES PARA USTED Y PARA LA SOCIEDAD

Aunque este estudio puede no proveer beneficios directos a todos los participantes, se espera que los datos obtenidos contribuyan al campo de la psicología mejorando el entendimiento de las experiencias de las Latinas con fibromialgia, y de los factores que pueden empeorar o disminuir su dolor. También contribuirá a proveer información a psicólogos y médicos para ayudarles a entender mejor a la gente que sufre de fibromialgia y a escoger el mejor tratamiento para ellos.

COMPENSACIÓN POR SU PARTICIPACIÓN

Todos los participantes serán compensados con una tarjeta visa con 10 \$. Si los participantes escogen retirarse antes de haber completado la entrevista, no se les concederá la tarjeta. La discontinuación de la entrevista una vez empezada, no afectará la compensación.

CONFIDENCIALIDAD

Los datos obtenidos de este estudio serán confidenciales tal y como lo establece la ley. Sin embargo, si la ley lo requiere, será necesario dar esta información. Ejemplos de estas situaciones en que se requeriría romper la confidencialidad serían si me informa de que hay un menor o una persona mayor que están siendo abusados. El Programa de Protección de Sujetos Humanos de la Universidad de Pepperdine (HSPP) también puede acceder a los datos obtenidos. El HSPP revisa y controla de vez en cuando estudios de investigación para proteger los derechos y el bienestar de los sujetos que participan en los estudios.

Los datos de la entrevista serán guardados en el ordenador protegido con contraseña o en una grabadora. Las hojas de consentimiento, cuestionario, y traducciones de la entrevista se guardarán electrónicamente en un ordenador protegido con contraseña, en el lugar de residencia del principal investigador. Todos los datos guardados en la computadora se eliminarán permanentemente después de un mínimo de tres días después de que el estudio haya sido completado. Las direcciones postales y de email de los participantes serán borradas en el mismo día en el que se envíen las tarjetas de regalo.

Cualquier información identificable obtenida que esté relacionada con este estudio se mantendrá confidencial. A todos los participantes se les asignará un número al azar que corresponderá a su nombre, cuestionario, y entrevista (ej., audio grabado y traducción literal). Los audios grabados de la entrevista serán traducidos a un documento por el investigador principal y un segundo traductor de análisis de los datos, y después, serán revisados por el supervisor de la tesis. Los cuestionarios, grabaciones audio, y traducciones literales solo serán compartidas con el equipo de investigación (ej., supervisor de la tesis, analizador de datos, y traductor), y sólo serán usados con la finalidad de realizar este estudio.

PARTICIPACION Y RETIRADA

Su participación es voluntaria, y usted puede retirar su consentimiento de participación en cualquier momento. La tarjeta de regalo pero, será entregada solamente después de su participación en la entrevista. Además, por participar en este estudio, no se le ignoran sus derechos legales.

ALTERNATIVAS A SU ENTERA PARTICIPACION

La alternativa a participar en este estudio es no participar, o completar solamente las preguntas con las que se sienta mas confortable.

DATOS DE CONTACTO DEL INVESTIGADOR

Usted entiende de que el investigador puede contestar cualquier duda que usted tenga relacionada con la presente investigación. Usted entiende de que puede contactar el principal investigador, Elisenda Rodes, M.A., bajo la supervisión de Dra. Carrie Castañeda-Sound, Ph.D. en caso de que tenga preguntas sobre el estudio. Puede contactar a Elisenda Rodes, M.A. La Dra. Carrie Castañeda-Sound, Ph.D. puede ser contactada al correo electrónico o por teléfono.

CONTACTO DE EMERGENCIA: En caso de que surja alguna emergencia relacionada con su participación en el estudio, puede contactar a la supervisora encargada de la investigación: Carrie Castañeda-Sound, Ph.D. por correo electrónico o por teléfono. También tiene la opción de contactar la responsable de la junta de revisión institucional (IRB en ingles), Judy Ho, Ph.D.

DERECHOS DEL PARTICIPANTE EN LA INVESTIGACION - INFORMACION DE CONTACTO DEL IRB:

Si tiene preguntas, preocupaciones, o quejas sobre sus derechos como participante en este estudio, por favor, contacte la Dra. Judy Ho, de la escuela “Graduate & Professional Schools Institutional Review Board”, en Pepperdine University 6100 Center Drive Suite 500 Los Angeles, CA 90045, 310-568-5753 y gpsirb@pepperdine.edu.

Entiendo la información proveída en relación a mi participación en este estudio. Todas mis preguntas han sido contestadas a mi satisfacción. He recibido una copia de este consentimiento, el cual he leído y entiendo. Aquí consiento mi participación en el estudio descrito.

Signatura del Participante

Fecha

Yo expliqué y definí en detalle el procedimiento de este estudio en el cual el sujeto ha consentido su participación. Habiendo explicado el estudio, y contestado las preguntas, aquí signo este documento conjuntamente con el participante y acepto su consentimiento.

Elisenda Rodes, M.A.
Investigador Principal

Fecha

APPENDIX G

Paragraph Explanations

“Ella tiene mal de ojo”: She has “mal de ojo.” “Mal de ojo,” what can be literally translated as “evil of the eye,” is a situation when someone has been cursed.

“Tienes que rezarle”: You have to pray for her.

“Limpia”: The literal translation means “to clean.” In this context, is the name of the ceremony

“Huevo”: Egg, which is used to practice this ritual.

Curanderos/as: They are practitioners who heal individuals through specialized knowledge of herbs, massage, bone setting, counseling, spirituality, and midwifery. In Latino/a communities, curanderos/as are a significant source of alternative health care services (Hoskins and Padrón, 2018).