

A CULTURAL FRAMEWORK FOR PAIN MANAGEMENT: UNDERSTANDING
TRADITIONAL CULTURAL VALUES IN HISPANIC PATIENTS WITH CHRONIC PAIN
AND LIMITED ENGLISH PROFICIENCY

by

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ABSTRACT

In the United States, Hispanics face additional barriers to accurate pain management due to language and cultural differences. The aim of this study was to obtain patients' perspectives and deepen our understanding of the cultural beliefs influencing the pain management decisions of Hispanics with low acculturation and limited English proficiency who turn to Federally Health Qualified Centers (FQHCs) for healthcare services. The sample included 24 (17 females and 7 males) Spanish-speaking patients with chronic pain. Participants participated in a focus group or key-informant interview and shared about their pain management needs and factors influencing how they experience, report, and treat their chronic pain. Descriptive data on pain and mood variables were also collected to inform how this unique population compares to the original norms reported in the pain literature. This study highlights the emphasis of family needs over individual needs and how this prioritization prevented participants from expressing pain behaviors and seeking care. Satisfaction with healthcare providers was highly influenced by patients' expectations and preference for personal, warm, and friendly interactions. Across all interviews, patients' reported preference for self-care practices, non-invasive medical treatments and reported negative attitudes towards pain medications. Beliefs about pain relief and finding the cure for chronic pain significantly affected their expectations about medical visits. The implications of our findings suggest that patients' unfamiliarity with mainstream treatment options for chronic pain may shape their expectations and satisfaction with medical care.

DEDICATION

This thesis is dedicated to my parents, brother, and family members who have supported me all the way since the beginning of my studies. To all my friends, thank you for your understanding and emotional support from afar, especially Laura Wandner. I am where I am today thanks to your encouragement and guidance. I would also like to thank my good friend and roommate Ana Rondon for always listening and helping me clarify my thoughts and ideas as I put this manuscript together. Finally, this work is dedicated to my mentor Beverly Thorn, who believed in me and supported my ideas.

LIST OF ABBREVIATIONS AND SYMBOLS

<i>a</i>	Cronbach's Alpha: an index of internal consistency
Atlas.ti	Qualitative Data Analysis Software
Cohen's <i>d</i>	A measure of effect size that describes the difference between two means in terms of standard deviations
FQHC	Federally Health Qualified Center
IRB	Institutional Review Board
<i>M</i>	Mean: the sum of a set of measurements divided by the number of measurements in the set
MPAC	Memorial Pain Assessment Card
<i>N</i>	Sample size: The total number of participants in the sample
PAS	Psychological Acculturation Scale
PCS	Pain Catastrophizing Scale
PANAS	Positive and Negative Affect Scale
<i>r</i>	Pearson product-moment correlation
SD	Standard deviation: the square root of variance
SPSS	Statistical Package for Social Sciences,
<i>t</i>	Computed value of <i>t</i> test
U.S.	United States of America
WHS	Whatley Health Services
=	Equal to
%	Percentage: The number of occurrences per 100

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CHAPTER 1

INTRODUCTION

Chronic pain is a significant public health problem affecting over 100 million Americans; it is one of the top causes of disability and the leading contributor to healthcare cost (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). The burden of chronic pain on everyday life impacts individuals physically, emotionally, and financially (Gatchel et al., 2007). Despite its high prevalence and impact, chronic pain remains poorly understood and treated. Although the majority of patients affected by chronic pain report inadequate pain management, ethnic and racial minorities have been substantially more affected than whites by disparities in the assessment and treatment of chronic pain (Edwards, Fillingim; Mossey, 2011; Torres et al., 2013; Wandner et al., 2014).

Contributing factors to disparities in pain management exist at the patient, provider, organizational, and societal level (IOM,2011). As expected, these sources of pain disparities are complex and difficult to isolate. The management of pain is multifaceted, and lack of understanding of patients' cultural beliefs about pain could provide additional challenges for health professionals who attempt to make accurate pain assessment and treatment recommendations (Torres et al., 2013; Weech-Maldonado et al., 2012). Unfamiliarity with patients' cultural background and limited cultural competency could significantly reduce the quality of the patient-provider relationship and contribute to poor outcomes

(Burgess et al., 2008; Im, Guevara, & Chee, 2007; Rahim-Williams, Riley, Williams, & Fillingim, 2012; Weech-Maldonado et al., 2012).

In fact, non-adherence with treatment recommendations is often the consequence of incongruence in views and beliefs about treatment preferences between the provider and patient (Butow & Sharpe, 2013; Monsivais & Engebretson, 2012; Sleath, Roter, Chewing, & Svarstad, 1999). These differences likely increase the chances of miscommunication and may very likely make Hispanic patients to feel unwelcomed, interpret interactions as impersonal, and ultimately result in a lack of trust of their providers. Although studies done with Hispanics remain limited in number, these reports illustrate the qualitative interface of cultural beliefs, language differences and pain management (Monsivais & Engebretson, 2012; Rutledge, Cantero, & Ruiz, 2013; Upshur, Bacigalupe, & Luckmann, 2010).

In pain research, patient-centered approaches, including focus groups, have been shown to be a good technique to obtain reliable information from patients and improve our understanding of the factors contributing to pain disparities (Day et al., 2011; Kuhajda et al., 2011; Thorn et al., 2011). Qualitative studies done with Hispanics have allowed researchers to further illustrate the influence and interface of the cultural values and beliefs on pain management (Katz et al., 2011; Monsivais & Engebretson, 2012; Rutledge et al., 2013; Upshur et al., 2010). Some researchers and agencies have suggested reaching out to other subgroup of Hispanics, in order to report more precise and meaningful demographic (e.g., country of origin) and cultural characteristics (e.g., acculturation) to help with the interpretation of the diversity within the Hispanic population (Campbell et al., 2009; Jimenez, Dansie, Buchwald, & Goldberg, 2013). To our knowledge, the perspectives from patients of low-income, limited English-

proficiency, with low acculturation levels, and seeking care at Federally Health Qualified Centers (FQHCs) have not been included.

FQHCs serve patients who are predominately of low socio-economic status (SES) and are uninsured or covered by public programs, such as Medicaid. FQHCs scale their fees based on patients' ability to pay (Hennessy, 2013). FQHC's have played a significant role at reducing disparities caused by access barriers faced by underserved populations (Almufleh et al., 2015; Epstein, 2001; Hennessy, 2013; Smith-Campbell, 2005). Although all racial/ethnic minorities are more likely than White non-Hispanics to be uninsured, Hispanics represent the highest uninsured rate among minorities (Hargraves & Hadley, 2003). Even with the advent of the Affordable Care Act, particularly in states such as Alabama where Medicaid expansion has not taken place, a large number of poor individuals remain uninsured. Given the growing size of the Hispanic population in the U.S. and lack of insurance coverage, it is likely that Hispanics turn to FQHCs for their healthcare needs. Therefore, obtaining patients' perspectives about pain management from these settings will expand our knowledge about the needs of Hispanic patients with chronic pain and facilitate our understanding of their experiences with FQHCs.

Even though patient-centered approaches, including focus groups, have been successfully used to obtain reliable information from patients, few have used mixed methods to capture the pain experience and needs of Hispanics. For example, a study conducted in southern California employed validated questionnaires to describe the typology of chronic pain among overweight Hispanics and also conducted focus groups to inquire about pain management strategies (Rutledge et al., 2013; Zettel-Watson et al., 2011). As seen here and in other pain studies, the integration of qualitative and quantitative findings allows for a more comprehensive analysis and enhances the interpretation of the pain experience (Hollingshead, Matthias, Bair, & Hirsh, 2014;

Rowell & Polipnick, 2008). Combining these two methods helps describe and quantify patients' pain experience of Hispanic-speaking patients with chronic pain seeking care at FQHCs. Given the number of stressors faced by low-SES patients, it could be especially beneficial to implement culturally validated measures to assess the psychological functioning as well as physical impairment of Hispanics with chronic pain. Doing so could add to our knowledge about other potential barriers in pain management faced by Hispanics at FQHCs.

Although efforts have been made to translate and validate standardized measures for Hispanics, for the most part these studies describe the adaptation process and fail to report detailed descriptive data about the sample involved in the adaptation process (Escobar, Domine, Contreras, & Valcárcel, 2009; García Campayo et al., 2008b; Robles & Páez, 2003). Therefore, it is difficult to generalize how Hispanics as a whole perform on these measures, and how different subgroups compare to the norms available for Hispanics and other chronic pain patients. In this study, we used a number of language- and culturally-validated measures, such as the Pain Catastrophizing Scale (PCS). The PCS is a measure used to describe maladaptive cognitive thinking about pain, which has been linked to negative pain outcomes, including pain anxiety, fear of pain, helplessness, and disability (García Campayo et al., 2008a; Sullivan, Bishop, & Pivik, 1995). Although the linguistic and culturally validated version of the PCS exists, limited efforts have been made to administer the PCS and other pain-related questionnaires to understand the influence of pain catastrophizing and psychological functioning on the pain experience of Hispanic patients (Campbell et al., 2009; García Campayo et al., 2008a). While there are also norms available for Hispanics on the PCS, little is known about how other subgroups of Hispanics respond to this questionnaire (García Campayo et al., 2008a). Making comparisons to the available norms may provide additional evidence for the cultural

acceptability of the PCS among patients of low SES, limited English proficiency, seeking care at FQHCs, and improve our understandings of other factors contributing to the inequalities in pain management of Hispanics.

Aim of the Study

To apply previous knowledge and extend the generalizability of the cultural values and beliefs that contribute to the disparities in pain management among Hispanics, the current study included perspectives from 24 Hispanic patients at FQHCs with limited English proficiency and low acculturation. This paper presents the pain management needs and barriers to optimal pain care of a population that to our knowledge has not yet been considered. Furthermore, participants' responses pre-and post interview on pain-related variables provided additional evidence for the acceptability and reliability of quantitative measures used among patients with chronic pain, as well as how this population compared to the available norms.

CHAPTER 2

METHODOLOGY

Participants and Recruitment

The study was approved by the Institutional Review Board (IRB) of The University of Alabama. Participants were recruited from Whatley Health Services (WHS), a community health center devoted to serving medically underserved patients in West Alabama. Participants were referred by medical providers or approached directly in the waiting room by a Spanish-speaking researcher. Inclusion criteria were age greater than 19 years, persistent pain for over 3-months, use Spanish as their primary language, and patient of WHS. Eligible participants were invited to attend a one-time 2-hour focus group. We recruited patients on an on-going basis, and for every 5-9 interested participants, a focus group was scheduled. To account for no-shows, we decided to conduct key-informant interviews when less than 4 participants showed up to each scheduled focus group. We determined the number of participants based on previous qualitative studies that used focus groups to support findings about the Hispanic culture (Monsivais & Engebretson, 2012; Rutledge et al., 2013). At arrival, written informed consent was obtained from all study participants and questionnaires were administered before and after the interviews. Upon completion of the study, participants were compensated with \$20.

Measures

In addition to providing socio demographic data and information related to their pain condition, subjects completed the following standardized measures.

The Brief Acculturation Scale for Hispanics

The Spanish validated version of the Brief Acculturation Scale was used to capture acculturation levels based on language use (Norris, Ford, & Bova, 1996). Acculturation is described as the degree of which immigrants adapt their attitudes and behaviors as they come in contact with a new group, nation or culture (Rogler, Cortes, & Malgady, 1991). Participants were asked to indicate their preference of spoken language, as well as language preference for communicating with family, friends, and language typically used for thinking. Participants indicated their preferences with a likert-type scale with endpoint ranging from 0=“*Only Spanish*” to 4= “*Only English,*” and anywhere in between. The Brief Acculturation Scale for Hispanics has been shown to have high reliability ($\alpha=0.92$) and validity among different subgroups of Hispanics, suggesting that this brief 4-item measure is an accurate instrument to measure acculturation (Norris et al., 1996; Wallen, Feldman, & Anliker, 2002). In our sample, The Brief acculturation Scale for Hispanic was also found to be a reliable measure with good internal consistency ($\alpha=. 86$).

Psychological Acculturation Scale (PAS)

The Spanish validated version of the PAS was used to examine psychological aspects of acculturation, such as feelings of belonging and emotional attachment to the Anglo American and Latino/Hispanic culture(Tropp, Erkut, Coll, Alarcón, & Vázquez García, 1999). The PAS is a 10-item self-report measure that captures cultural orientation on 9-point Likert-type scale with endpoints ranging from 1=“*only Hispanic/Latino*” to 9=“*only Anglo/American*” and anywhere in between. The midpoint indicates bicultural orientation, suggesting equally psychological acculturation to both cultures. Regarding reliability, the alpha coefficient of our sample ($\alpha=.90$)

was found to be comparable and similar to the alpha coefficients reported in the the Spanish ($\alpha=.83$) and English ($\alpha=.85$) versions of the PAS.

Pain Catastrophizing Scale (PCS)

The Spanish validated version of the PCS was included to measure pain catastrophizing based on three domains, magnification, rumination and helplessness (García Campayo et al., 2008b). Pain catastrophizing is described as the tendency to exaggerate and negatively evaluate one's ability to deal with pain. There is robust evidence that pain catastrophizing is associated with negative pain outcomes, higher levels of disability, increased pain medication usage, increased avoidance and fear of pain (García Campayo et al., 2008a; Quartana, Campbell, & Edwards, 2009; Sullivan et al., 1995). The PCS is a widely used 13-item self report measure that captures participants' responses to statement about thoughts and emotions experienced when they were in pain (Sullivan et al., 1995). Participants used a 5-point likert-type scale that ranges from 0="not at all" to 4="all the time," to indicate the degree to which they have certain thoughts and feelings when they experience pain. The Spanish version of the PCS has adequate internal consistency ($\alpha = .79$), high test-retest reliability over a six-week period ($r=.84$), and similar psychometric properties to those found in the original English scale. The Spanish version of the PCS was originally validated with a Hispanic sample from Spain, to our knowledge this is the first time this version is administered at a FQHC in the U.S. In the current sample, the Spanish version of the PCS had good internal reliability ($\alpha=.88$).

Positive and Negative Affect Schedule (PANAS)

The Spanish validated version of the PANAS was used to measure mood states, in terms of positive affect (PA) and negative affect (NA) (Sandin et. al,1999). PA and NA have been reported to influence pain-related outcomes. Higher levels of NA are linked to higher levels of

pain and worse pain-related outcomes compared to lower levels of NA (Hassett et al., 2008). Higher levels of PA are found among patients with lower pain intensity and fatigue than among patients with higher levels of pain and fatigue (Franklin, Lee, Hanna, & Prinstein, 2013). Given the clinical implications of PA and NA, more efforts are being made to continue using the PANAS to understand the affect balance relationship of PA and NA on pain outcomes (Hassett et al., 2008; Sibille et al., 2012). The PANAS is a self-report measure that captures participants positive affect based on a 10-item list (active, alert, attention, determined, enthusiastic, excited, inspired, interested, proud and strong), and a 10-item list for negative affect (afraid, ashamed, distressed, guilty, hostile, irritable, jittery, nervous, scared, and upset). Participants were asked to indicate how they were feeling “*at the present moment,*” and used a 5-point likert-type scale with endpoints ranging from 1=“none at all” to “extremely”. Compared to the original English version, the Spanish-validated version of the PANAS has been shown to have strong internal consistency for PA ($\alpha=.85$) and NA ($\alpha=.81$). To our knowledge, the Spanish version of the PANAS has yet to be used with a clinical sample (e.g., patients with chronic pain). Adequate internal consistency for PA ($\alpha=.74$) and NA ($\alpha=.74$) were found in the current sample.

Memorial Pain Assessment Card (MPAC)

The Spanish validated version of the MPAC was used to assess pain (Escobar et al., 2009). The MPAC is a quick and convenient tool widely used in the U.S. to capture a multidimensional overview of the current state of patients with cancer pain who are in treatment (Contreras, Valcárcel, Dómine, & Escobar, 2008; Escobar et al., 2009; Fishman et al., 1987). A visual analog scale (VAS) is used to indicate the degree of pain intensity, pain relief, and overall mood. In addition, the MPAC also includes adjectives to describe pain, such as: *moderate,*

strong, excruciating, mild, weak, just noticeable, no pain, or severe. Only the pain intensity VAS was used in the current study. The MPAC has been shown to have convergent validity with longer measures that are typically used in pain research such as the McGill Pain Questionnaire (MPQ), Profiles of Mood Scales (POMS), Hamilton Depression Scales (HDRS), and Zung Anxiety Scale (ZAS) (Contreras et al., 2008; Escobar et al., 2009; Fishman et al., 1987). The Spanish version of the MPAC has an internal consistency of ($\alpha=72$). Overall, the Spanish version of the MPAC is a valid and reliable instrument for pain assessment that contains psychometric properties similar its English counterpart(Contreras et al., 2008; Escobar et al., 2009). To our knowledge, this is the first time that the MPAC is used with non-cancer patients.

Study Design

This study used a mixed method design (quantitative embedded into qualitative) that included focus groups and key-informant interviews, and a quantitative component that required participants to complete questionnaires before and after the qualitative interview. The objective of the qualitative component of this study was to investigate and describe the pain experience and pain management needs of Hispanics with chronic pain. The interview guide was developed by members of the research team to identify potential barriers and facilitators to pain management. The interview guide consisted of open-ended questions about the participants' pain experience, interference, coping mechanisms, past and current treatment experiences, attitudes towards medications and willingness to try other pain treatments (See Appendix A). All interviews were done at WHS, moderated by the primary author and audio recorded for transcription purposes. The PCS, PANAS and MPAC were administered at beginning and at the end of the qualitative interview. The researcher was available to read questions out loud and clarify as need

Data Analysis

Qualitative Data

Audio recordings were transcribed verbatim by a transcriptionist and translated into English by two members of the research team. Translations were checked by a bilingual researcher, who also conducted a back-translation of the English version into Spanish to check for accuracy in translation and cultural interpretation of the text. All transcripts were imported into the qualitative data management software Atlas-ti version 6.2. We conducted an inductive thematic analysis, and followed the guidelines described by Braun and Clark (2006), that have also been used in other qualitative pain studies to examine physicians, medical trainees, and patients' perspectives about chronic pain (Bair et al., 2009; Hollingshead et al., 2014; Matthias et al., 2010). Coding and memo writing strategies were used to analyze and understand the relationships observed throughout data collection. Doing so allowed us to check, refine our understanding, and improve our interpretation at all phases of data collection and data analysis.

For the first focus group and first key informant interview, three members of the research team read the transcripts multiple times in order to identify overall impressions and develop a coding scheme. The researchers met to discuss similarities and discrepancies until a final coding scheme and overall theme impressions were agreed upon. The same coding scheme was then applied to the remaining transcripts. Using the coding scheme, the first author searched for patterns and variations among all interviews, compared across key-informant interviews and focus groups until saturation was reached. Constant comparisons enabled us to shape codes and categories until central components of the themes were observed across all participants.

Quantitative Component

All quantitative analyses were conducted using the Statistical Package for Social Sciences, SPSS version 21. Descriptive statistics were used to describe the socio demographic, acculturation factors, pain history, psychological functioning, and other characteristics of our sample. As part of an exploratory analysis to examine change in responses to the Spanish-validated versions of the PCS, MPAC (pain intensity only), and PANAS, participants' responses were submitted to a paired simple t-test and compared for differences between pre-and-post interviews. Since we did not have a control group, these analyses were exploratory in nature and done to facilitate our understanding of the changes that might have occurred due to sharing and talking with others about pain. Participants' responses pre-and-post interviews were also analyzed for reliability in responses across the Spanish versions of the questionnaires. A one-sample t-test was conducted to determine how the mean scores of our sample compared to the norm groups from the original studies done in Spanish. These comparisons were done for the MPAC-pain intensity, PCS, and PCS.

CHAPTER 3

RESULTS

Seventy-five patients expressed interest in the study and 24 completed the study. Primary reasons given declining participation were work-related conflicts, lack of transportation, and childcare. In total, there were 3 focus groups and 4 key informant interviews conducted.

Descriptive Statistics

Demographics

Refer to Table 3.1 for a summary of the demographics and pain characteristics of our sample. A total of 17 (70.8%) females and 7 (29.2%) males participated in the study. The mean age of our participants was 41.9 years (SD=8.6) with a range of 27 to 55 years old. All of our participants were Hispanic, half of our participants selected white (50.0%) and the other half selected “other” (50.0%) for their race. Most of our participants were married (88.0%), non-insured (83.0%), educated below high school (77.0%), worked full-time or part-time (54.0%) in housekeeping (58.0%) and reported an annual household income below \$15,510 (71.0%).

Acculturation

All of our participants were born out of the continental US. (two reported being born in the US. territory of Puerto Rico). From the 24 participants, 19 (80%) were born in Mexico, 3 in Honduras (12 %), and 2 in Puerto Rico (2 %). The mean number of years living in U.S. contiguous or non-contiguous states was 13.5 years (SD=5.2) with a range of 6-28 years. In terms of acculturation levels, our sample is characterized as “less acculturated” as measured by the Brief Acculturation Scale (scores below 2.99) and the PAS (scores below 4.99). All of our

participants preferred and used Spanish to communicate with others. In terms of acculturation attitudes and sense of attachment to the Anglo-American or Latino/Hispanic culture, most our participants preferred and identified with the Latino/Hispanic culture, with the exception of two participants, who preferred the Latino/Hispanic and Anglo/American culture equally and therefore were considered “bicultural,” as suggested by the PAS.

Pain Typology

The most frequent location of pain cited by participants was low back (25%), followed by head (16.7%) and knee (16.7%) pain. Most reported the cause of their pain as unknown (58.3%). Under the unknown category, some participants also listed poor nutrition, stress, weak cartilage, and heat as the potential source of pain. Participants reported moderate levels of pain intensity ($M=4.8$, $SD=3.1$), and mean pain duration was 4.5 years ($SD=5.3$).

Table 3.1: Summary of Patients' Characteristics

Characteristic	Total Sample	Frequency (%)
Sex		
Female	17	70.8
Male	7	29.2
Race		
White	12	50.0
Other	12	50.0
Occupation/Industry		
Unemployed	9	37.5
Housekeeping	6	25.0
Construction	5	20.8
Restaurant	4	16.7
Country of Origin		
Mexico	19	79.2
Honduras	3	12.5
Puerto Rico ^a	2	8.3
Pain Location (Primary)		
Low Back	6	25.0
Head	4	16.7
Knee	4	16.7
Shoulder	3	12.5
Pelvic	3	12.5
Feet	2	8.3
Hands	2	8.3
Source of Pain		
Unknown	14	58.3
Arthritis	5	20.8
Accident	4	16.7
Migraine	1	4.2

Note: ^a U.S. territory

Qualitative Findings

The results revealed the significant and multilevel impact of traditional Hispanic's cultural values and beliefs on patients' perspectives and expectations about pain and its treatment. Six main themes were identified.

Theme 1: Keep on Going Despite the Pain

Numerous statements across interviews indicated that participants were likely to push themselves and continue doing their normal work both outside and inside the home despite the pain. Many participants felt that their desire to provide for their families motivated them to endure the pain and continue working. Across all interviews, participants pressured themselves to serve as mothers, fathers, wives, and husbands and often ignored their pain to meet the needs of their families. Doing things for others, such as cleaning and cooking were prioritized and completed regardless of the individual's pain. The majority of our participants had jobs that required physical labor (e.g., housekeeping), and many admitted that self-talk and reminders that the pain will be over soon were widely used continue with normal work activities despite the pain.

“The pain is always there, and one just tries to forget about it because one has a lot of things to do. One has to work, clean, cook, and if one centers on the pain then one cannot get anything done.”

“And you know the pain is there but you have to continue. Sometimes I've done some chores, but I still need to cook but I don't stop cooking because I am in pain because I just have to keep going, there is no other option you have to keep moving.”

In terms of pain behaviors, some of our participants reported refraining from overt pain behaviors to prevent family, especially young children, from worrying about them. Some participants referred to complainers as weak, and believed that pain endurance was a sign of strength. We also had one participant who reported withholding from talking about or expressing pain behaviors because of a lack of validation from her partner and fear of not being able to fulfill her role as a wife. In particular, she feared that her husband would leave her if she did not have sex with him, regardless of her pain level. At work, many participants were hesitant about showing pain and being labeled as complainers or getting fired. Many indicated acting like the

pain was not there and continuing with their work activities. Getting fired or losing workdays was a significant factor preventing them from expressing or talking about their pain at work.

“With my arm half moving I am not cleaning well, imagine if I don’t move my arm at all I will get fired. I just have to keep working because at work they might think that I am going to sue them.”

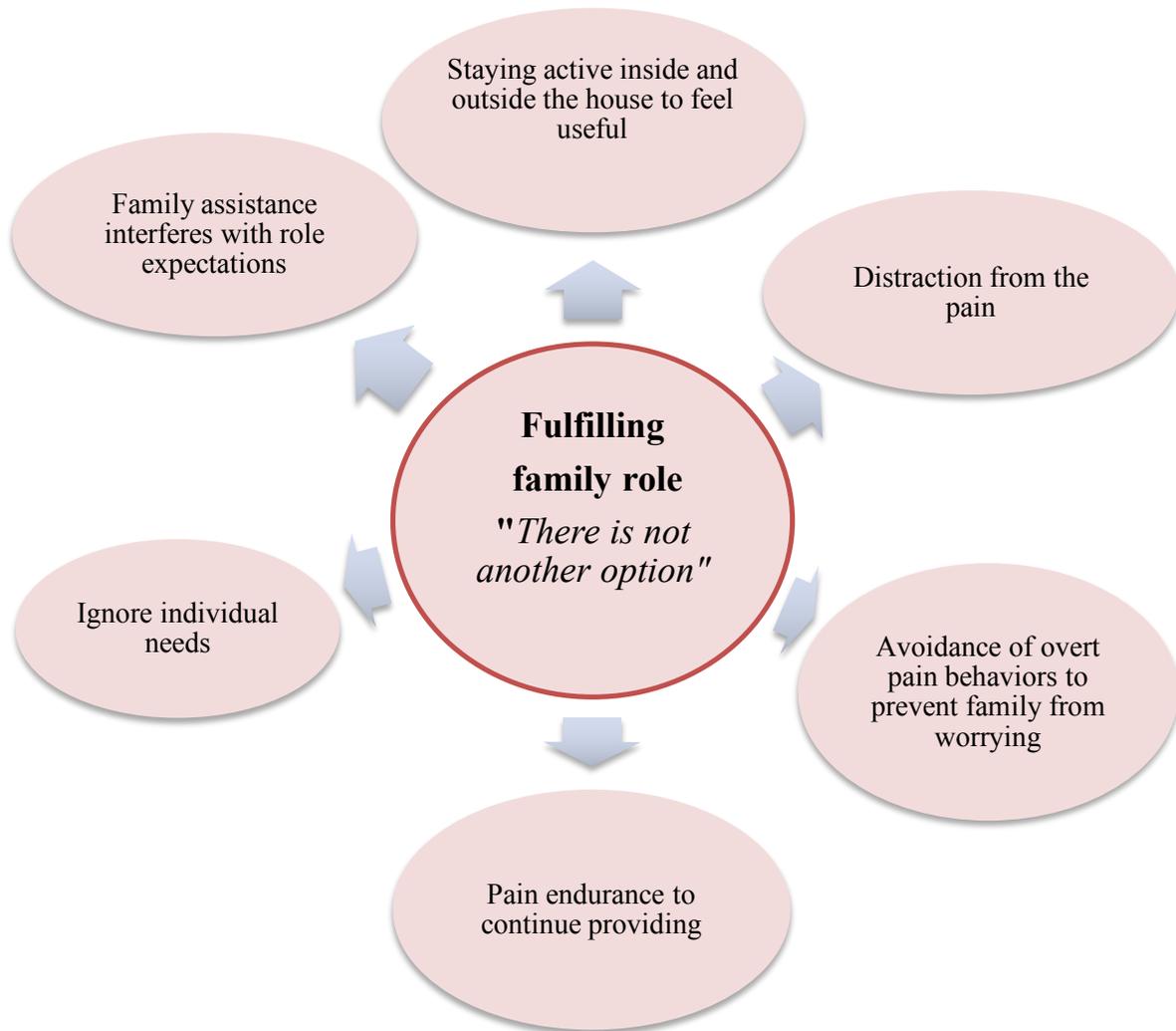
Theme 2: Attitudes Towards Family Assistance

Participants described their family relationships as cohesive and expected family members to care for each other. Relying on family members for assistance with chores and child rearing were mentioned across all interviews. Assistance and support from extended family members was also common and accepted. For the most part, participants appreciated the help and were glad that their families cared about their condition and limitations. Despite this help, some participants expressed dislike and sadness about not being able to do things on their own (which relates to the first theme) and feeling like a failure to their families. One common rationale for feeling disturbed about receiving help was not being able to fulfill their family role. This was especially bothersome for stay-at-home moms who felt useless for not being able to do chores. Figure 3.1 illustrates the influence of family on the pain experience of our participants.

“I can do the cooking and cleaning but they don’t let me do them. They are already doing my chores and they are taking away my job at home.”

“My husband helps me and tells me to lie down, rest and don't work, but I get stressed. I stress a lot when I am not doing much. However, chores are small so I do them, I do them fast and then I do not have nothing to do and that is when I feel more the bad. I need to maintain busy so I can forget about the pain.”

Figure 3.1: The Role of Family on the Pain experience of Hispanics



Theme 3: Beliefs About Medication and its Effectiveness

Across all interviews, the majority of the participants expressed negative attitudes and beliefs about medication, but with some ambivalence. The primary reason for rejecting medication was fear of becoming an addict. Some participants also indicated fearing side effects and questioned the effectiveness of medication. For example, one participant asked others if they knew of a medication that worked and did not have side effects. Many participants expressed

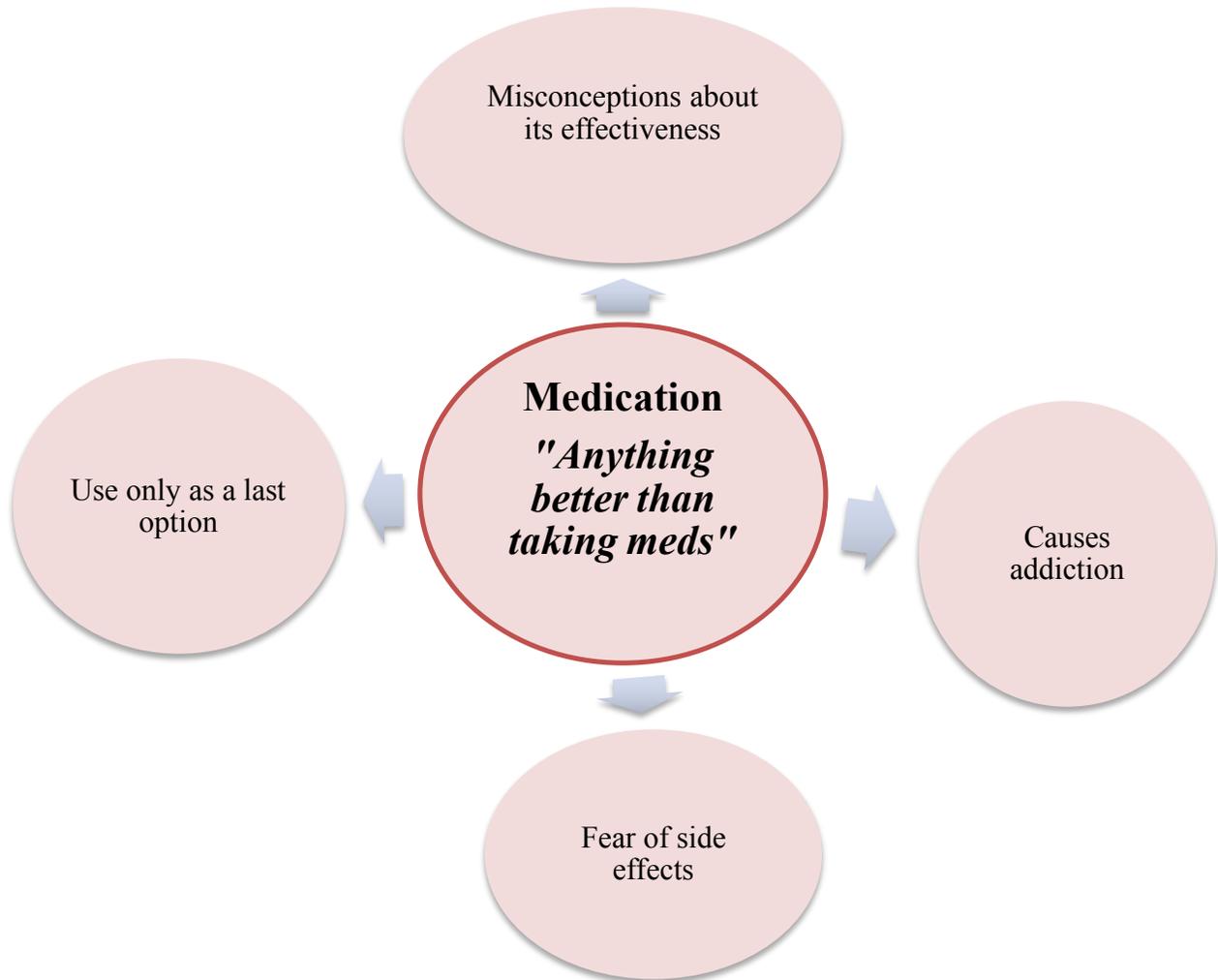
worry about what others would think of them if they did take medication. Participants justified using medication by noting that medication was never their first choice and it was only used when the pain was no longer tolerable. It is interesting to note that those who used pain medication more frequently than other respondents reported feeling weak for relying on medication to relieve the pain. We also had some participants who had neutral or even positive attitudes towards medication and pain relief. The following quotes as well as figure 3.2 illustrate the mix of attitudes towards medication for pain management.

“In my case I stand as much as possible, I try to not to pay attention to the pain until the pain is already very strong, then I go for the medicine.”

“I don't want to take anything for the pain, I tried to get rid of the pain without taking anything. I don't want to be dependent on medicine.”

“I take medication only for pain when I need it, or for conditions or when actually the body says-You are passing the limit that you can tolerate-that's when I take medication for the pain.

Figure 3.2: Attitudes and Beliefs About Pain Medication



Theme 4: Self-management Strategies and Knowledge About Pain Treatments

Participants preferred natural alternatives and non-invasive medical treatments, such as over-the-counter (OTC) pain relief creams, electric blankets, chiropractic, and yoga. Participants also reported using folk remedies, such as homemade ointments, teas, and/or consulting with a natural healer. During the interviews, it was common for participants to share about homemade remedies and suggest to each other what else to try as an alternative to medication. As previously mentioned, the majority of our participants turned to self-distraction strategies to cope with the

pain. Some turned to house-related chores to distract themselves from the pain but also reported pain relief after engaging in other activities. Others mentioned social activities with family as fun distractions from pain, such as dancing and playing with kids in the park. The following quote is from a participant who has been prescribed medication but also turns to distraction to cope with the pain.

“Well, apart from the medicine that we already know, pills and all that, what has worked for me is to distract myself. The pain does not stop, but at least I make something that I like to forget a little of what hurts, the head and such, and suddenly I am surprised because I do not hurt anymore, I am ready, let’s go. So it is something that is not medicine but it helps.”

Some participants reported relying on homemade remedies and self-distraction techniques because they did not know what else to do for the pain and believed that the pain will go away on its own. They also believed that medication was the only option that they would receive if they sought medical care. Limited knowledge about other treatment options was also common. None of the participants had been offered surgery for their pain. Across all interviews, participants voiced their desire to learn more about different types of pain management treatments. When asked about any previous attendance at or possible interest in a pain management group (defined as a group teaching information about chronic pain and coping skills to help self-manage chronic pain), participants reported to not knowing much about them but were open to trying them. Some liked the idea that it was an alternative to medication, *“Anything better than medicine.”* The following quotes illustrate participants’ willingness to try psychosocial treatments for chronic pain.

“I will experiment and see and if it is expensive I will see and get my budget and if I can do a payment plan or any opportunities they offer and see the options. I mean I will pay; even if is 10 dollars I will pay. I would do and try anything as long as I see that it is working.”

“Like she said, if there are possibilities to pay and do payment plans and work out a budget I will. And if it benefits me and my health I would do it.”

Theme 5: Satisfaction with Medical Visit

Satisfaction with medical visits was highly influenced by patients’ expectations about pain relief, amount of time providers spent with them, and the perceived friendliness of the healthcare interactions. Participants expressed frustration and disappointment for feelings of not being taken seriously by their providers and not finding a cure for their pain. Patient-provider interactions were described as rushed and impersonal. Most participants were unsatisfied with the (small) amount of time providers spent in the examination room. Some participants indicated being dissatisfied with how little the provider knew about them, and the lack of follow-up questions. Many participants mentioned going to the doctor multiple times for the same problem and not finding a cure for their pain. It was especially frustrating for those who had to take off work and made time to go to the doctor, and for those that dependent on others for rides to their appointments. Many listed difficulties surrounding verbal communication, especially for describing their pain and asking follow-up questions to understand what the provider was saying. Given the language barrier, some participants felt that providers were not taking their pain seriously. These quotes show participants’ disappointment for not getting what they felt was optimal treatment for their pain.

“So I feel that sometimes the doctors do not take you seriously or they are in a hurry. They are in a hurry, because they see and treat you for two or three minutes and they leave. I stayed sincerely disillusioned and mad, because it is the specialist, for the love of God.”

“One is holding the pain and when one already decides to go to the doctor it is because you need treatment, because you want them to see you. It costs you much work to make the decision to go, because you know that you are going to lose time, that you are going to spend money, and when you are already there you want them to treat you.”

Participants were also concerned about not being offered medication as a treatment option because they perceived that their providers assumed they were exaggerating their pain and/or seeking medication. Although medication was not preferred, participants indicated using medication as a last resource for the pain and wanted to have access if needed. As a result, some participants reported seeking care elsewhere, like consulting with doctors from their country of birth, or borrowing medication from others. Participants also believed that they were not being offered medication because providers assumed that they could not afford them. Despite their low income, some participants indicated that they would have followed up with medication treatment and found ways to cover it, if their provider offered it.

“That is, they assume that you cannot buy the medicine. But they do not know if you are going to make an effort to buy it, so I ask him ‘how much is very expensive, how much does it cost?’ He did not tell me. That is why I say they suddenly judge you”

“Many times they think that one is not going to pay, they do not give you sufficient medicine or attend you well.”

Theme 6: Patients’ Expectations and Preference for Warm and Personal Interactions

Across all interviews, participants commented on how they would like their providers to treat them. Participants emphasized their preference for more personal interactions with their healthcare providers. Most participants felt that providers were unfriendly and did not pay attention to them. One participant described her experiences as *“here is all business and they don’t care about you.”* In terms of culture and country of origin, patients indicated that providers often assume that all Hispanics are the same, and fail to ask where patients are from:

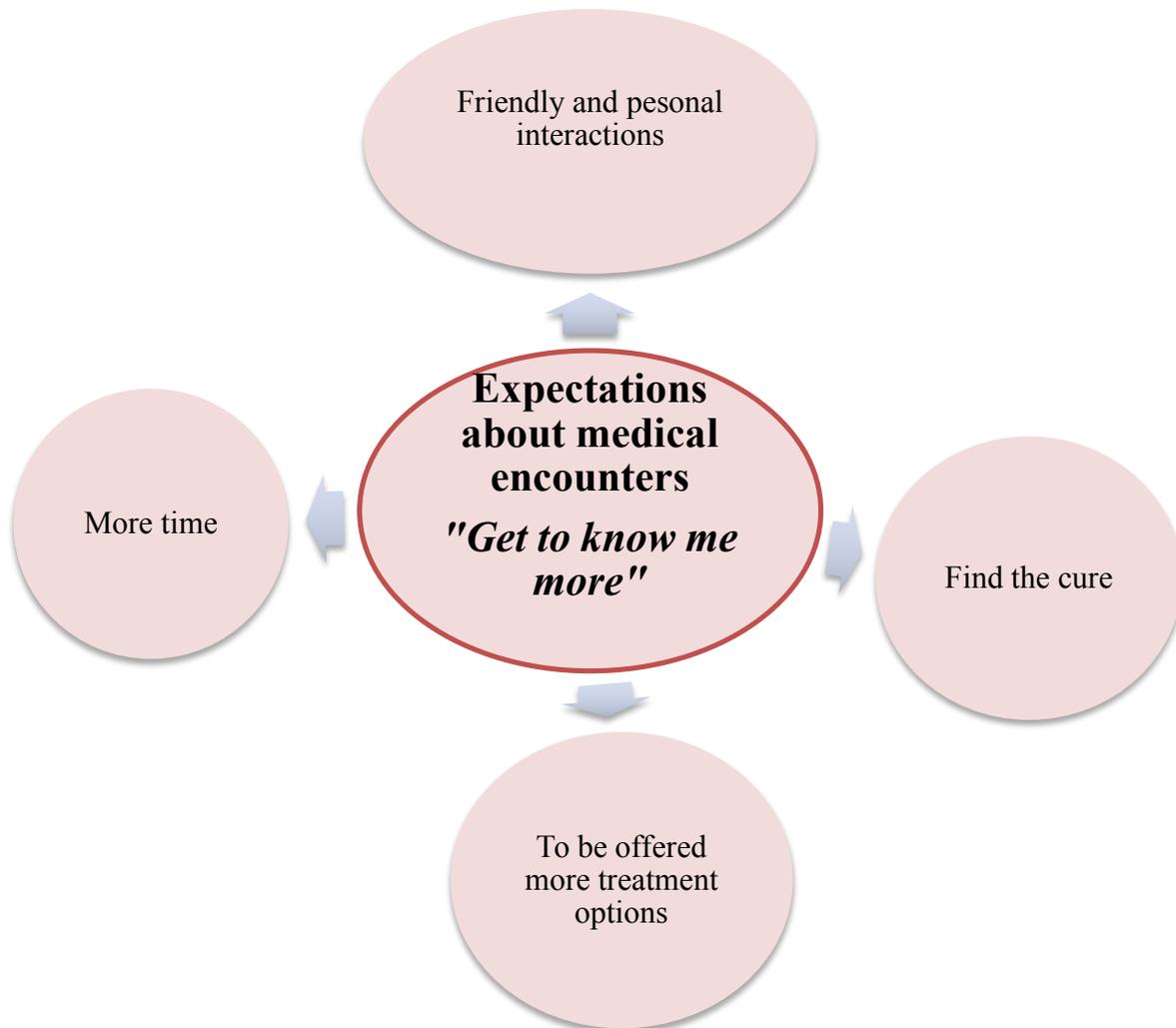
“We are all not the same.” Even if people are from the same country, participants highlighted the importance of acknowledging regional differences, since there might be variations in dialects, customs, and ways of treating pain. As a whole, participants would like their providers to listen

to them and ask questions that are more personal. Figure 3.3 shows various expectations that shape patients' beliefs about medical encounters.

"I was very disillusioned, I said well, as far as I know I paid for the doctor to look at me and to pay attention to me."

"I know that I cannot change the medical system here, but I would like more attention, because in our countries the doctor stays for up to an hour with you if possible, here he comes and goes and ends, sometimes you are there two minutes and then he leaves, you say What do I have, What do I do?, but nothing. Like I said, I am not going to change all of the methods of the system here but I would like attention."

Figure 3.3: Patients' Expectations About Healthcare Providers and Medical Visits



Quantitative Findings

Pain Catastrophizing

When comparing the PCS pre-interview scores from our sample to the validation sample, we found that the scores in our sample before the interview ($M=23.9$, $SD=11.5$) were comparable to those found in the original validation study with Spanish fibromyalgia patients ($M=24.4$, $SD=11.8$), $t(23)=-.194$, $p=.85$, (García Campayo et al., 2008b). Table 3.2 shows how our participants' responses compared to the normative sample employed during the validation studies for all measures administered pre-and-post interview.

Our participants' post-interview scores on the PCS ($M=24.4$, $SD=12.5$) remained comparable, $t(23)=-.00$, $p=.99$, to the validation study. We also compared our participants' PCS scores with the scores reported on the original English version, and found that our participants' scores remained comparable to the sample used in the English speaking samples of patients with chronic pain (de Boer, Steinhagen, Versteegen, Struys, & Sanderman, 2014; García Campayo et al., 2008b; Sanchez, Martinez, Miro, & Medina, 2013; Sullivan et al., 1995). In terms of change, our analyses revealed that there were no statistically significant differences on PCS scores between pre-and-post interview responses in our current sample, $t(23)=-.29$, $p=.79$.

Positive Affect

The PANAS scores of our sample on positive affect (PA) before the interview were lower ($M=27.2$, $SD=5.8$) than those found in the original validation study with healthy Hispanics, ($M=33.5$, $SD=7.4$), $t(23)=-2.5$, $p=.02$, (Sandin et al., 1999). When participants completed the PANAS for a second time at the end of the interview, PA scores ($M=30.5$, $SD=5.3$) were found comparable to those obtained with healthy Hispanics from the original study ($M=33.5$, $SD=7.4$) (Sandin et al., 1999). We also found that our participants' PANAS post-interview scores on PA

were comparable to previous research done with the English language version of the PANAS on patients with chronic pain in clinical and healthy participants experimental settings (Hassett et al., 2008; Sibille et al., 2012). There was a significant increase in PA scores from pre- to post-interview, indicating that our participants reported an improvement in PA, $t(23)=-2.8$, $p=.01$.

Negative Affect

When NA pre-interview scores were compared to the norms available for Hispanics, we found that our participants' scores on NA were significantly lower ($M=17.6$, $SD=6.2$) than those than those found in the original validation study with healthy Hispanics, (Sandin et. al,1999) in the original sample, $t(23)=-2.4$, $p=.03$. Participants' scores at the end of the interview remained lower ($M=14.5$, $SD=4.7$) than the original Hispanic validation sample reported, ($M=22.7$, $SD=6.8$) (Sandin et. al,1999). When our scores were compared to previous research done with the English language version of the PANAS among patients with chronic pain, we found that our participants reported lower NA scores than those found with fibromyalgia patients ($M=18.1$, $SD=5.9$) (Hassett et al., 2008). We also compared participants' responses on the NA domain of the PANAS during pre-and-post interview and found a significant decrease in NA scores from $M=17.6$, $SD=6.2$, to $M=14.5$, $SD=4.7$, $t(23)=3.3$, $p=.00$.

MPAC

MPAC scores on the pain intensity subscale were significantly different from the original validation study with Hispanic cancer patients. The sample mean of 4.8 ($SD=3.1$) in pain intensity was significantly lower than 7.1 ($SD=2.1$), $t(23)=6.5$, $p=.00$ in the original validation study with Hispanics cancer patients (Escobar et al., 2009). Participants' scores remained significantly lower in comparison to the available norms. The sample mean of 3.5 ($SD=2.5$) in pain intensity at end of the interview was significantly lower than those found in previous study

with Hispanics and cancer pain, $t(24)= 5.4, p=.00$ and $t(24)=5.8, p=.00$ (Contreras et al., 2008; Escobar et al., 2009). Finally, when participants' scores were compared pre-and-post interview, we found a significant difference for the pain intensity subscale of the MPAC, suggesting a reduction in reported pain intensity following the interview (Mean of 4.8 vs. 3.5), $t(23)=3.0, p=.01$

Table 3.2: Mean comparison between responses on the PCS, MPAC, PANAS and available norms

Variable	Normative Sample		Current Sample				t(23)	p	Cohen's d
	M	SD	Pre-Interview		Post-Interview				
	M	SD	M	SD	M	SD			
PCS									
Total	24.4	11.2	23.9	11.5	24.4	12.5	-2.9	.78	-.04
MPAC									
Pain Intensity	7.1	2.1	4.8	3.1	3.5	2.5	3.0	.01*	.46
Mood	4.7	1.9	6.1	2.4	6.1	2.2	-.09	.93	.00
PANAS									
Positive	33.05	7.4	27.2	5.8	30.5	14.5	-2.8	.01*	-.59
Negative	22.7	6.8	17.6	6.2	5.3	4.7	3.3	.00**	.56

Note: **= $p<.01$; *= $p<.05$

CHAPTER 4

DISCUSSION

This is the first study to capture the pain management needs and coping strategies of Hispanic patients with limited English proficiency and low-acculturation who are seeking medical care at FQHCs. By directly engaging patients directly in their native language (Spanish), the current study adds to the existing literature about Hispanics and the influence of cultural beliefs and attitudes towards pain management from a subgroup of Hispanics who may be underrepresented in research due to the language barrier, availability of Spanish-speaking researchers, and availability of culturally-validated standardized measures. By bringing together patients with shared common experiences (e.g., foreign born) and cultural characteristics, we provided a comfortable environment for patients to voice their needs about the perceived barriers and factors influencing their medical decisions about chronic pain as they adapt and assimilate to the U.S. culture.

Overall, our findings illustrate the multilevel influence of family values throughout various aspects of the pain experience. Due to the emphasizes of family, Hispanics patients in our sample turned to self-distraction strategies and physical activities (e.g., household chores) to continue enduring the pain while also fulfilling family roles (Theme 1 and 4). Interestingly, many of our participants felt dismay about receiving assistance from family members with daily activities and house-related tasks, especially when this help came from children (Theme 2). This disappointment may be due to the belief that receiving help from family is in some way interfering with the family structure and parental responsibility toward children. In fact, Eunk

and colleagues (2007) listed traditional gender roles and women's perceived obligation to their families as explanations for inadequate pain management among Hispanic women with cancer. Given the prioritization of family needs over individuals needs, family responsibilities prevented some patients from seeking care, which could unintentionally cause more complications as care is delayed and perhaps even elicit pain crisis, or force patients to seek emergency care.

Patients preferred non-medical treatments and reported self-management strategies as their main coping approach. Self-management strategies mentioned across focus groups and key-informant interviews were reflective of what has been previously found with Hispanic patients, such as folk-remedies, including herbs and other home remedies (Campbell et al., 2009; Rutledge et al., 2013). Some studies have reported that Latinos preference for folk-remedies is sometimes due to the financial costs associated with medical visits and lack of insurance (Campbell et al., 2009). However, in this study our participants preferred folk-remedies because they are non-invasive, natural, and convenient. Although studies have reported that folk-remedy practices are more common among older and low-aculturated adults, it is unclear if these practices would become less popular if individuals were offered accessible and culturally appropriate non-biomedical pain treatments (Campbell et al., 2009; Jimenez et al., 2013). Across all interviews, participants voiced their desire for non-medical treatment options, such as psychosocial treatments, even if they had to arrange payments (Theme 4). This suggests that while financial difficulties are common among low SES patients, their willingness to manage their pain with a non-invasive treatment might help reduce pain suffering for those who oppose medication for pain relief.

As previously found with other subgroups of Hispanics, our participants also voiced reluctance about using medication for pain relief (Campbell et al., 2009; Monsivais & Engebretson, 2012; Upshur et al., 2010). Figure 3.2 illustrates the influence of cultural beliefs about medication and how these shape patients' understanding of pain medications. These findings suggest that our patients may not understand the role of medication for treating acute pain vs. chronic pain, and reveal potential factors contributing to their misconceptions. Campbell (2009), found that pain medication use among Latino patients might be highly influenced by their familiarity and access to such. Because of all of our participants had limited English proficiency, it highly likely that for some participants part of their hesitation to trying medications in the U.S. may also be caused by their unfamiliarity with names/brands and costs related to these medications.

Combined, these findings may explain reluctance to consider medication as a treatment option and highlights the need to educate and make resources available to patients about pain management treatment options. Patients need to be informed that chronic pain cannot be cured but managed, and healthcare providers need to offer a variety of treatment options that might match the patients' cultural preferences. Improving accessibility, availability, and understanding of safe pain management treatments might also facilitate the acculturation process, as patients become familiar and consider mainstream practices. Making information available in Spanish can help patients learn about pain management and influence medical decision making among Latino patients with limited English proficiency and help address one the reasons (access) contributing to pain disparities (Riley et al., 2008).

These findings emphasize the need for personal attention and rapport building among patients who highly value these qualities. Interestingly, these requests mirror core concepts

described in the patient-centered care model, which have been associated with improvements in patient satisfaction and health (Bechel, Myers, & Smith, 2000; Epstein, 2001). Therefore, we believe that patient populations like this may gain additional benefits from patient-centered care. Doing so could help prioritize patients' needs and values and contribute to integration and acknowledgment of cultural differences in pain management care. One way to do so, is by inquiring about self-management practices, since it will create a sense of personal interest and help establish relationship with patients.

For our patients the ability to seek care without health insurance at FQHCs allowed the opportunity to address health needs at an affordable cost. Despite the access to medical care, our patients' satisfaction with medical care were mostly described as dissatisfactory. Since medical systems differ from one country to the next, patients' expectations about how much time providers spend with them as well as satisfaction with medical visit could be the result of patients' previous encounters with their medical providers in their home country. Given the short time of medical encounters, some patients may interpret their providers as as rude and think that providers are disinterested in establishing trusting relationships with their patients. It is therefore important to consider how patients' perceptions of pain management as well as experiences with healthcare providers in the U.S. medical system inform their willingness to seek care in the future.

In addition to our qualitative findings, our exploratory analyses on the quantitative portion of the study provided an initial look at how participants respond to standardized measures such as the PCS, PANAS, and MPAC, which have been validated into Spanish but have not been administered to Hispanics with chronic pain in the United States and low acculturation. The PCS was validated in Spain with fibromyalgia patients, the PANAS was also

validated in Spain with healthy individuals, and the MPAC was originated validated with Hispanics with cancer pain living in the U.S. Since our participants' scores were comparable to those found with the normative sample during the validation of the PCS and PANAS, it could be assumed that the Spanish version of these questionnaires are capturing catastrophic thoughts related to pain to a similar degree among this subgroup of Hispanics. As expected, our participants' scores on the pain intensity scale of the MPAC were not found to be comparable to the normative sample of cancer patients. Given that the MPAC was designed as an assessment instrument for cancer pain, we were not surprise to find that our results are much lower than those reported in the validation study.

Regarding pre- to post-interview changes, although our participants showed an improvement in affect and pain intensity after their participation in the interview, we cannot determine if these improvements were solely caused by their participation. Since we did not include a control group, our findings only demonstrate how our participants' scores stand in relation to what has been previously reported with the MPAC, PANAS, and PCS (Table 3.2).

Limitations

Because this sample included Spanish-speaking patients of mostly Mexican-descent, the experiences and interpretations of our findings are exclusively applicable to the 24 patients included in our study. These are perspectives of “low-acculturated” patients and should be interpreted with caution, since these themes may not reflect the pain experience of “high acculturated” Hispanics. Given the nature of qualitative inquiry, transferability of findings is limited due to the depth of information and understanding obtained from a particular sample(Golafshani, 2003). In terms of qualitative themes, we combined information captured through focus groups and key-informant interviews. While saturation was obtained across our

sample, it is possible that a higher distribution between the two types of interviews could of reveal additional themes. Lastly, the nature of our study (quantitative embedded into qualitative) and our small sample for generalizability of quantitative data, the results on the standardized Spanish version of the PCS and PANAS should only be interpreted as descriptive and serve as additional evidence for the use objective measures to assess the pain experience of Spanish-speaking patients.

Conclusion and Future Directions

The multi-method embedded design employed in this study captured the pain experience of foreign born Hispanics with low acculturation while also expanding our understanding of the perceived barriers to pain management faced by this population as they navigate the US. medical system and seek care at FQHCs. It is especially evident that patients who immigrate to the U.S. face a number of roadblocks as they learn, adapt, and assimilate to how healthcare settings and health policies may differ from their country of origin. As a result, patient preference for self-care practices and folk remedies *may* be partially due to patients' unfamiliarity with available treatment options for pain. The implications of our findings illustrate that even when some access barriers are removed via providing options for care to medically underserved patients, pain disparities remain a problem influenced by cultural differences on expectations about medical visits and pain management treatment. We conclude that pain disparities could be partially driven by patients' acculturation level (language) and knowledge about mainstream practices.

These findings help illustrate some contextual factors that are potential targets for action to reduce pain disparities. Future studies should examine the influence of low linguistic acculturation on satisfaction with pain management treatments and medical providers. Efforts are

needed to evaluate the impact that culturally appropriate and easy-to-understand education regarding pain (in Spanish and English) may have on patients' ability learn about and consider mainstream practices (such physical therapy, pain medication, surgery) for pain management. More efforts are needed to evaluate if patients' experiences turn out to be similar and unsatisfactory as they come into contact with medical providers that provide personable and trusting relationships as part of patient-centered model of care. Doing so would add to our understanding of the predisposed attitudes Hispanics patients may have due to their exposure to different healthcare systems and acculturation levels.

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APPENDIX

Appendix A: Topic guide

1. Would you like to share briefly about your pain?
Prompts: Type of pain, location, source, how did it start, duration of pain
2. In what ways, if any, does it interfere in your life?
Prompts: Job/work, social life, relationships, family, and your ability to enjoy life?
Do you have any interference in physical activity? Do you avoid doing certain things?
3. How does your pain affect your mood, stress levels, self-confidence?
4. What has your experience been with medications or other substances you have used to cope with your pain or lessen your pain?
5. What are some of the things that you do to cope with pain? What works best?
What is not helpful?
6. How do your spirituality, religion and beliefs influence how you cope with your chronic pain?
7. What do your employer(s), family and friends tell you or feel regarding your chronic pain?
8. Does anybody in your family have chronic pain? How has that affected you?
9. What is your greatest concern when it comes to your pain?
10. How do you decide when to seek treatment? How do you decide what kinds of treatments to seek?
11. How do you determine when to accept or decline a treatment recommendation? What influences your decision?
12. Can you describe your experiences with healthcare providers who have treated your pain? How would you describe the communication between them as health care provider and you as a patient?
13. In what ways do you think being a primarily Spanish-speaking patient has influenced your treatment for chronic pain? How about in other settings outside of WHS?
14. If you could have a frank conversation with your doctor or other healthcare provider to help them better treat your pain, what would you like to tell him or her?
15. At present, what are your needs regarding your pain? Are there any areas where help might be beneficial?
Prompts: At work, psychological and medical needs

16. Have you ever attended a pain management group? Pain management groups teach you information about chronic pain and teach you coping skills to help you better manage your chronic pain. They generally run once per week for about 10 weeks. What do you think about joining a group like this?

Appendix B: IRB Approval



May 27, 2014

Beverly E. Thorn, Ph.D.
Professor and Chair of Psychology
College of Arts & Sciences
The University of Alabama

Re: IRB # 13-OR-251-ME-R1 "Focus Groups to Explore the Experience and Perceived Needs of Spanish-Speaking Patients with Chronic Pain"

Dear Dr. Thorn:

The University of Alabama Institutional Review Board has granted approval for your renewal application.

Your renewal application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review category 7 as outlined below:

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

Your application will expire on May 26, 2015. If the study continues beyond that date, you must complete the IRB Renewal Application. If you modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure form.

Please use reproductions of the IRB approved informed consent form to obtain consent from your participants.

Should you need to submit any further correspondence regarding this proposal, please include the above application number.

Good luck with your research.



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