

## **Title of the article:**

Participatory Decision Making for Cancer Care in a High-Risk Sample of Low Income Mexican-American Breast Cancer Survivors: The Role of Acculturation

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## **Abstract:**

**Background:** Despite declining cancer incidence and mortality rates, Latina patients continue to have lower 5-year survival rates compared to their non-Hispanic white counterparts. Much of this difference has been attributed to lack of access and poorer quality of care. Research, however, has not considered the unique healthcare experiences of Latina patients.

**Methods:** Latina women with a prior diagnosis of stage 0-III breast cancer were asked to complete a cross-sectional survey assessing several socio-demographic factors along with their experiences as cancer patients. Using a series of linear regression models in a sample of 68 Mexican-American breast cancer survivors, we examined the extent to which patient ratings' of provider interpersonal quality of care were associated with patients' overall healthcare quality, and how these associations varied by acculturation status.

**Results:** Findings for Latina women indicated that participatory decision-making (PDM) ( $\beta=0.62$ ,  $p<0.0001$ ) and trust ( $\beta=0.53$ ,  $p=0.02$ ) were both significantly associated with patients' ratings of healthcare quality. The interaction between acculturation and PDM further suggested that participating in the decision-making process mattered more for less acculturated than for more acculturated patients ( $\beta=-0.51$ ,  $p<0.01$ ).

**Conclusions:** The variation across low and high acculturated Latinas in their decision-making process introduces a unique challenge to health care providers. Further understanding the relationship between provider-patient experiences and ratings of overall healthcare quality is critical for ultimately improving health outcomes.

## **Key Words:**

quality of care, interpersonal quality of care, participatory decision-making, trust, Latina, breast cancer survivor

## 1. Introduction

In the United States alone, approximately 276,480 new cases of invasive breast cancer are expected to be diagnosed in 2020 along with 48,530 new cases of non-invasive (in situ) breast cancer.<sup>[1]</sup> Furthermore, a projected total of 42,170 U.S. women are expected to die from breast cancer in the same year, reflecting the highest cancer death rate after lung cancer.<sup>[1]</sup> Although breast cancer continues to be major source of disease, early detection and advancement in treatment have resulted in higher survival rates. As of January 2020, there are more than 3.5 million women with a history of breast cancer living in the United States.<sup>[1]</sup> It is, therefore, crucial to consider the experiences of breast cancer survivors during their treatment process.

Within the past few decades, patients have become increasingly active in their own medical care. Recently diagnosed cancer patients are not only faced with the complexities of coping with the emotional stress of their diagnosis, but are also expected to comprehend extensive information about treatment procedures immediately after diagnosis in order to participate in the decision-making process with their provider. Although the initial diagnosis may be challenging, many patients tend to seek additional information and later return to their healthcare providers as informed patients rather than as passive recipients of advice and treatment.<sup>[2]</sup>

As the availability and complexity of treatment options has increased, studies have shown that patients who have a higher quality provider-patient relationship and are concurrently guided through the treatment process, are more satisfied with their care.<sup>[3,4]</sup> The model in which providers actively engage patients with their own medical care has been termed ‘shared’ or ‘participatory decision-making’ (PDM).<sup>[5,6]</sup> Ideally, a PDM style approach involves a provider-patient relationship in which patients are presented with the best available information. Patients’ values, goals, capabilities and care preferences are then assessed, and together with their healthcare team, providers and patients arrive at mutually agreed-upon treatment plans. The perception that the provider involves them in the treatment decision-making process has been associated with improved health outcomes, better self-management, and higher levels of patient satisfaction.<sup>[7,8]</sup> In turn, satisfaction with care in the area of breast cancer has been associated with better illness-management and health behaviors, including improved adherence to recommended therapy,<sup>[9]</sup> leading to potentially improved health outcomes and quality of life.<sup>[10-12]</sup>

Recent studies, however, have reported a disparity in PDM among Latina patient populations, as they have the lowest rates of PDM and poorest provider-patient communication compared to their non-Hispanic white counterparts.<sup>[13]</sup> Latinas with breast cancer, and in particular low acculturated Latinas, are less likely to report high clinical communication quality for both surgeons and medical oncologists,<sup>[13]</sup> less informed about their diagnosis and less likely to seek or receive information about their treatment options compared to other racially/ethnically diverse women.<sup>[14]</sup> Surprisingly, a large population-based cohort study examining satisfaction with care that included low-income Latina women suggested that most women (nearly 75%) reported being extremely satisfied with the breast cancer care they had received, and that less acculturated Latinas had nearly five times the odds of being extremely satisfied compared to non-Hispanic white women.<sup>[15]</sup> However, these studies have been descriptive in nature, and have not taken further steps toward understanding how patient-ratings’ of their provider experience contribute to ratings of their healthcare quality.

Furthermore, the paradoxical finding noted may arise, in part, from the limited consideration of acculturation factors, which may influence not only expectations around provider-patient communication and the patient’s confidence in participating throughout the treatment decision-making process, but also expectations of received care from the medical system.<sup>[15,16]</sup> Studies examining racial/ethnic differences in patient perspectives when it comes to their cancer treatment experiences have found that lower acculturated Latinas are less likely to report high communication quality with their clinicians and that Spanish-speaking Latinas had the highest odds of low satisfaction with their surgical

treatment decisions.<sup>[13,17,18]</sup> However, there is growing evidence that first generation Hispanic immigrants have higher levels of satisfaction with care than second or later generation Hispanic patients.<sup>[19]</sup> Given the evidence that lower health literacy and language barriers are often associated with lower ratings of participatory decision making, lower satisfaction with the treatment decision making process,<sup>[20,21]</sup> and more treatment regret, it is difficult to disentangle the potentially opposing influence of factors related to acculturation and immigration-related barriers to care.

This raises the question as to whether the strong association between participatory decision making and satisfaction with care generalizes to Latina women or is limited to those of a certain acculturation level, and more importantly whether there are other components of the provider-patient relationship that warrant examination. Therefore, this study was designed to examine (1) associations between patient ratings of the interpersonal qualities of the provider-patient relationship and their overall healthcare quality, and (2) the extent to which patient acculturation levels affected these associations in a sample of Mexican-American breast cancer survivors.

## **2. Methods**

### **2.1 [Study Design and Participants]**

Latina breast cancer survivors were recruited through an academic medical center and were asked to complete a survey assessing several socio-demographic factors along with their experiences as cancer patients. Inclusion criteria comprised the following: 1) identifying as Mexican-American, 2) at least 18 years of age, 3) prior diagnosis of stage 0-III breast cancer, 4) have completed active treatment 6 months prior to recruitment, 5) have a body mass index >25 kg/m<sup>2</sup> and <43, and 6) English or Spanish speaking. Reasons for exclusion included the following: 1) Stage IV (e.g., metastatic disease), 2) recurrent cancer, 3) contraindications for moderate physical activity (i.e., walking), 4) visual or hearing impairment, or 5) any major psychiatric and/or life-threatening illness that impeded the ability to consent to or complete the study. Approximately 77 women were approached, and 70 consented to complete a survey in their preferred language (either English or Spanish) containing measures that assessed their level of acculturation and other socio-demographic characteristics, patient- perceived quality of care, and satisfaction with care. In order to accommodate language preferences within this sample, all study materials were made available in either Spanish or English to avoid any inclusion bias based on language. Study procedures were approved by the University of California, Irvine Institutional Review Board.

### **2.2 [Measures]**

#### **2.2.1 [Outcome Measures]**

Evaluation of overall quality of care was assessed using a single item that asked patients to rate the quality of care they received over the course of their cancer treatment. The item used a 5-point Likert scale, in which a higher score indicated better quality of care (1=Poor, 5=Excellent).

#### **2.2.2 [Provider-patient relationship measures]**

Level of patient involvement in decision-making related to their breast cancer treatment was assessed using a 4-item measure of participatory decision making (PDM-4).<sup>[22,23]</sup> Participatory decision making scales have consistently been used across all racial/ethnic groups, with some studies specifically focusing on minority groups.<sup>[22,24-25]</sup> A sample item included “How often did the doctors that took care of you during your cancer treatment offer you choices in your medical care?” Ratings were made on a 5-point Likert scale (1=never/none of the time, 5=very often/all of the time).

Items were averaged to create a composite variable (Cronbach's alpha was adequate = 0.89). To assess patient perceptions of being treated as an equal partner, we used a single item question rated on a 5-point scale (1=definitely yes, 5=definitely no). A total of five questions were used to assess patients' trust in their provider.<sup>[26]</sup> A sample item included "How often do you feel that you trust your doctor's judgments about your medical care?" Ratings were made on a 5-point scale (1=never, 5=always). Items were averaged to form a composite measure (Cronbach's alpha=0.84).

### 2.2.3 [Acculturation Status]

Acculturation status was assessed using a combination of information from three content areas: 1) whether or not the participant was born in the U.S. (0=no, 1=yes); 2) length of time in the U.S. (those who had lived in the U.S. for less than 10 years, between 10 and 20 years, and 20 or more years); and 3) primary language spoken (1=English-speaking only or English better than Spanish, 2=equal proficiency in both English and Spanish, and 3=Spanish-speaking only or Spanish better than English).

Data was combined to create a point scale from 0 to 3 (0=born outside the U.S. and lived in the U.S. for less than 10 years, 1=born outside the U.S. and lived in the U.S. for 10–20 years, 2=born outside the U.S. and lived in the U.S. for 20 or more years, 3=born in the U.S.). The categories applied to language spoken were assigned a point scale from 0 to 2 (0=Spanish-speaking, 1=both equally, 2=English-speaking).

Scores were then added together to create a composite acculturation score, which ranged from 0 (least acculturated) to 5 (most acculturated). Participants were dichotomized into a less acculturated group (scores=0–2) and a more acculturated group (scores=3–5). This scoring system was modeled after a study on Hispanic and Chinese populations, reflecting a more accurate representation of acculturation compared to separate analyses of each variable as these variables tend to cluster within individuals.<sup>[27]</sup>

### 2.2.4 [Covariates]

Covariates in the analysis included standard demographic characteristics, such as age and years of education. Participants also reported their date of diagnosis, as well as the time passed since their last chemotherapy or radiation treatment. Participants were asked about the length of relationship with their doctor (1=less than one month, 2=more than 1 month but less than a year, 3=1-2 years, 4=more than two but less than five years, 5=5 or more years). Health insurance status was reported (0=no insurance, 1=insurance), as well as insurance type (1=insurance provided by job or employer, 2=Medi-Cal, 3=Cal-Optima, 4=MSI, 5=Medicare, etc.).

## 2.3 [Statistical Analysis]

All data were analyzed using SPSS release 17.0 (SPSS Inc., Chicago) and SAS/STAT software version 9.4 (SAS Institute Inc., Cary, NC, USA.). All derived multi-item measures were tested for reliability using Cronbach's alpha. We first describe the sociodemographic and health characteristics of the patient sample. A linear regression model using full information maximum likelihood (FIML) was created to examine the effect of acculturation on the association between components of the interpersonal quality of the provider–patient relationship and overall patient ratings of quality of care. Interactions of acculturation were made with each interpersonal component of the provider–patient relationship to test if quality of care was moderated by acculturation. To allow for ease of interpretation and to help account for the small sample size, acculturation was dichotomized into low acculturation (score of  $\leq 2$ ) and high acculturation (scores of  $\geq 3$ ).

## 3. Results

### 3.1 [Sample Description]

**Table 1.** Socio-demographic Characteristics by Acculturation, (N=63)

	Acculturation		p-value
	Low (n=42)	High (n=21)	
	%	%	
Preferred Language, % Spanish	100	0.0	<0.0001
Education, % high school graduate or more	31.0	57.1	0.05
Born outside of the U.S., % Yes	100	61.9	
Married or living with partner, % Yes	47.6	39.1	0.47
Income, % \$14,999 or less	59.5	57.1	0.86
Insurance – Government Sponsored (e.g., MediCal), %	85.7	76.2	0.35
Medical provider speaks Spanish, % Yes	9.5	9.5	1.0
Time since last treatment, % 5 or more years	38.1	28.6	0.45
	Mean (SD)	Mean (SD)	p-value
Average age, years	57.1 (10.1)	52.2 (12.0)	0.12
Time since diagnosis, years	5.8 (3.8)	5.7 (4.0)	0.94
Time in the US, years [only born outside US]	28.2 (9.9)	34.3 (8.6)	0.05
<i>Components of Provider-Patient Relationship</i>			
Participatory Decision-Making (PDM)	4.5 (0.7)	4.1 (1.0)	0.12
Trust	4.8 (0.4)	4.7 (0.5)	0.44
Treated as an Equal Partner	4.8 (0.5)	5.0 (0.2)	0.15
<i>Dependent Variable</i>			
Quality of Care	4.7 (0.7)	5.0 (0.2)	0.14

A total of 70 Latina breast cancer survivors responded to the survey with 68 respondents having a non-missing quality of care value. Of the 68 respondents, **Table 1** describes the 63 participants that had complete data from which level of acculturation could be calculated; of these, 42 were categorized as having lower acculturation, and 21 were categorized as having higher acculturation. Overall, the sample generally consisted of women with low socioeconomic status, as the majority of the sample is on government sponsored insurance (e.g. MediCal/CalOptima,) and 64.5% of the sample had a total annual household income less than \$14,999. Few significant differences were found when assessing sociodemographic characteristics in lower versus higher acculturated respondents in this sample. Respondents who were of lower acculturation were older (Means= 57.1 years old vs 52.2 years old,  $p=0.12$ ) and in the U.S. for less time than their higher acculturated counterparts (Means=28.2 years in U.S. vs 34.3 years in US,  $p=0.05$ ). Furthermore, respondents who were of lower acculturation were also less likely to have graduated from high school (Percents=31.0% high school graduate or more vs 57.1% high school graduate or more,  $p=0.05$ ) compared to higher acculturated respondents.

### 3.2 [Patient-Perceived Quality of Care and Satisfaction with Care]

**Table 2.** Means and Correlations for Components of the Patient-Provider Relationship and the Outcome, Quality of Care (N=68)

	Mean (SD)	1	2	3	4
1. Participatory Decision-Making (PDM)	4.3 (0.9)	--			
2. Trust in Provider	4.7 (0.5)	0.38*	--		
3. Treated as an Equal Partner	4.8 (0.5)	0.51**	0.49**	--	
4. Quality of Care	4.7 (0.8)	0.53**	0.55**	0.41*	--

\* $p < 0.002$  \*\* $p < 0.0001$

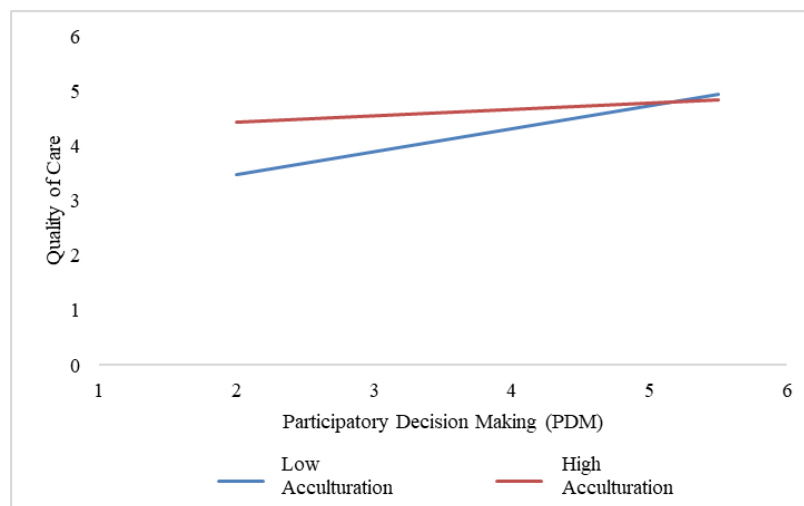
Means and standard deviations for all patient-centered care variables as well as their bivariate correlation analysis are displayed in **Table 2**. All three components of patient-provider interpersonal qualities [participatory decision making (PDM) style, being treated as an equal partner, and feelings of trust] were associated with patients' ratings of overall healthcare quality.

**Table 3.** Association between Provider-Patient Relationship and Patient-Reported Quality of Care for High versus Low Acculturated Patients (N=68)

Variables:	Quality of Care		
	$\beta$ (SE)	t	p-value
Main Effects:			
Acculturation	-0.57 (3.49)	-0.16	0.87
Participatory decision making (PDM)	0.62 (0.14)	4.36	<0.0001
Trust in provider	0.53 (0.22)	2.43	0.02
Treated as an equal partner	-0.27 (0.22)	-1.26	0.21
Interactions:			
PDM x Acculturation	-0.51 (0.20)	-2.60	<0.01
Trust in provider x Acculturation	0.18 (0.34)	0.54	0.59
Treated as an equal partner x Acculturation	0.42 (0.63)	0.67	0.50

**Note.** Analyses also included age and level of education as covariates.

The results of the linear regression model testing the interaction of acculturation by each interpersonal component of the provider-patient relationship on patient-reported quality of care are shown in **Table 3**. Significant main effects were observed for PDM ( $\beta=0.62$ ,  $p < 0.0001$ ) and trust in provider ( $\beta=0.53$ ,  $p=0.02$ ) with an  $\alpha < 0.05$ . When assessing the moderating effect of acculturation, the only significant interaction was observed between PDM style and acculturation level ( $\beta=-0.51$ ,  $p < 0.01$ ).



**Figure 1.** Crude Linear Association of PDM and Quality of Care by Low and High Acculturation

As shown in **Figure 1**, the association between PDM ratings' and ratings of overall quality of care were less strong among higher acculturated patients and more strong among lower acculturated patients.

## 4. Discussion

The field of healthcare is becoming increasingly sensitive to the importance of high-quality provider-patient relationships and its role in improving patient satisfaction with care and health outcomes. The growing literature has shown that patient ratings of overall quality of care, as well as the importance of the various components of the provider-patient relationship, vary between individuals from different racial/ethnic groups.<sup>[13,15,28-31]</sup> This study specifically set out to examine the extent to which each of three provider-patient relationship components were associated with patients' rating of their satisfaction with care. Additionally, our study investigated whether the importance of each component varied by acculturation level.

Although all components of the patient-provider relationship were correlated with one another, not all were significantly associated to ratings of quality of care in the regression analysis. Specifically, our study found that PDM was significantly associated with quality of care, such that increased levels of PDM were independently associated with higher patient ratings in quality of care. Similarly, a study reported that interventions designed to increase participatory/shared decision making within a group of Hispanic and other racially diverse individuals by encouraging patients to voice their concerns were associated with increased perceptions in quality of care.<sup>[32]</sup> Study results buttress these patterns suggesting that, for minority women in particular, it is uniquely important to engage patients in opportunities to voice their concerns and ask questions during their treatment process. By doing so, both patients and providers are given the opportunity to address cultural differences around expectations for participating in treatment decision and poor provider-patient communication prominent among some Latinas. In the context of receiving medical care, strong trust in health care providers has consistently been shown to guide patients' follow up care experiences,<sup>[33]</sup> such that increased trust has been associated with higher satisfaction with treatment and quality of care.<sup>[34]</sup> These findings hold true in non-Hispanic<sup>[35-37]</sup> and Hispanic<sup>[38]</sup> population alike. Our findings are consistent with the literature<sup>[36]</sup> in that those who had high trust in their providers reported significantly better quality of care ratings than

those who had low trust in their providers, irrespective of acculturation status. Here, patient-provider relationships high in trust may facilitate communication and decrease patient fear, resulting in higher ratings of quality of care.<sup>[33,37]</sup> Additionally, this association may be explained, in part, by a patient's need to feel trust, especially after being confronted with a serious diagnosis, that their provider is doing everything possible in order to obtain the best treatment outcome.<sup>[33]</sup>

Furthermore, results indicated a significant interaction for participatory decision-making and acculturation level, indicating that the association between PDM ratings' and ratings of overall quality of care was less strong among higher acculturated patients and more strong among lower acculturated patients. Our findings add to the literature by showing that variations exist in the provider-patient relationship within a single ethnic group, and that a patients' acculturation level may differentially impact the association of participatory decision-making with patient ratings of satisfaction with care.

Paradoxical findings in previous studies showing that low income and low acculturated Latinas are more likely to report higher satisfaction with care<sup>[15]</sup> even though Latina patient populations report the lowest rates of PDM and poorest provider-patient communication compared to their non-Hispanic white counterparts<sup>[14]</sup> highlights the importance of disentangling the role of acculturation. Growing literature continues to indicate that higher acculturated Latina patients are generally less satisfied with care than their lower acculturated counterparts.<sup>[8,15]</sup> Our study similarly shows that, when it comes to the modifying effect of acculturation, associations between PDM and overall quality of care are strong among lower acculturated patients and weaker among higher acculturated patients. An explanation may be that individuals of different acculturation levels may have different perceptions of what PDM means in the context of their care. A study assessing doctor-patient relationships in the public and private health care contexts within the Mexican health care system bring attention to existing differences in expectations for these relationships. Study findings indicated that the type of medical care subsystem, public versus private, shaped different relationships between patients and doctors.<sup>[39]</sup> Encounters between patients and physicians within public medical settings, which typically care for lower-income patients, appear to be more doctor-centered, while these encounters become more complex in the private sector, which typically care for more affluent patients, shifting to a model where a patient-centered approach coexists with the traditional physician-centered approach.<sup>[39]</sup> Within Mexican culture, access to public versus private health care shapes patient experiences and may play a role in expectations upon transition to the US health care system. The patients included in this study were all recruited from a medical clinic that provides care to the underserved, and thus our low-acculturated patients seen in this setting may have lower expectations for engagement with their providers in comparison to what they could expect in their country of origin. Thus, upon immigration to the US, it is likely that as women have the opportunity to become increasingly involved in the decision-making process, these experiences have a strong impact on their ratings of quality of care.

On the other hand, it is also possible that Latina women who are less acculturated may be more grateful for any type of care they receive, resulting in higher ratings in quality of care as they become increasingly involved with their medical care. This conceptual framework, emphasizing deference toward providers among lower acculturated individuals,<sup>[38]</sup> likely explains the impact of acculturation seen across our results. The idea that individuals who have not had an opportunity to extensively acculturate into the US and its health care system, especially with its emphasis on patient autonomy, are more likely to regard providers with greater respect and esteem than those who have had more opportunity to acculturate.<sup>[38]</sup> Perhaps individuals with lower acculturation scores have not always had the same access to care and are appreciative of these providers for providing necessary care after their cancer diagnosis while higher acculturated individuals maintain high expectations for the amount of care and quality of care they receive.



This study finds strength in its ability to add to a small but growing literature suggesting that patient preferences may be contingent on expectations driven by cultural and sociodemographic factors.<sup>[13]</sup> Nonetheless, this study also has a few limitations. First, our sample size was relatively small and predominately comprised of low-income Mexican-American women, which may not be generalizable to other breast cancer survivor populations, Latina or otherwise. Nonetheless, this study offers a unique and interesting perspective given that recruited participants were predominantly low income, held lower education levels, and the majority were born outside the US. Second, the descriptive nature of this study prevents any assumptions of causality between the variables. Although the relationship between the provider and patient has been shown to influence patients' satisfaction with care ratings, there may be other factors, such as their impression of other health care staff and their ability to work together, receptionists, ease of navigating the healthcare system, etc., that are unaccounted for in our study and also likely influence reports of quality of care.<sup>[40,41]</sup> It is also important to note that respondents were not asked about language or ethnic concordance with their providers, factors likely to improve communication and influence feelings of participation and trust.

Final limitations concern the measurement of quality of care and acculturation.<sup>[42,43]</sup> Quality of care was measured using a single question and may have resulted in a crude assessment. Acculturation, on the other hand, was assessed using a combination of information from three content areas. Whereas language and nativity are commonly used as proxy measures,<sup>[44]</sup> in recent years a more comprehensive understanding of acculturation has evolved that has called for greater attention to the socio-cultural context that affect the experience of migration – including the environments from which people emigrate and to which they immigrate.<sup>[45]</sup> For example, Allen and colleagues highlight how immigration can be accompanied by a disruption in social ties, increased stress, and experiences of discrimination.<sup>[46]</sup> Our goal was to evaluate the extent to which acculturation influences the association between ratings of provider-patient interpersonal quality on and ratings of healthcare quality, as opposed to understanding the indirect influence of these other socio-contextual factors.

Based on the findings from our study, we demonstrated the importance of the provider-patient relationship in Mexican-American breast cancer survivors' satisfaction with care and aim to bring attention to the acculturation differences in the various components of these relationships. In order to improve satisfaction in health care among ethnic minority patients, there may be a need for a more tailored relationship between the provider and patient. Our findings indicate that providers should, to the best of their ability, prioritize participatory decision-making in their interactions with patients in order to improve ratings in quality of care which could have beneficial downstream and longer-term effects for patient health. Future research should continue to focus on larger populations and include additional minority groups in order to investigate whether these finding are generalizable. Furthermore, future studies should also investigate additional factors involved in the provider-patient relationship that may additionally be affected by acculturation levels. Ultimately, this study provides results that would inform the creation of an intervention to establish a causal relationship between the provider-patient interactions and satisfaction with care.

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