

Social Support: a Key Variable for Health Promotion and Chronic Disease Management in Hispanic Patients with Rheumatic Diseases

Alyssa T. Brooks, Regina E. Andrade, Kimberly R. Middleton and Gwenyth R. Wallen

National Institutes of Health Clinical Center, Bethesda, Maryland.

ABSTRACT: Chronic diseases, including rheumatic diseases, can cause immense physical and psychosocial burden for patients. Many Hispanics suffering with arthritis face activity limitations. Social support, or the functional content of relationships, may be important to consider when examining treatment and outcomes for Hispanic individuals. Participants were recruited from an urban community health center (CHC) as part of a larger health behavior study. A cross-sectional, descriptive, mixed methods analysis was conducted to explore the role of social support in the sample. Only Hispanic/Latino patients ($n = 46$) were included in this analysis. Interviews were conducted in both English and Spanish. The majority of the sample (87%) perceived some presence of social support in their lives. The two most commonly cited types of social support were emotional and instrumental. The two most common sources of social support were family members other than spouses (52.2%) and spouses (32.6%). Body mass index (BMI) was significantly correlated with the number of perceived sources of support. The presence or absence and the role of social support in supporting optimal health outcomes should be considered for Hispanics with chronic rheumatic diseases. Involving family members and spouses in the plan of care for this population could facilitate health promotion and chronic disease management.

KEYWORDS: social support, arthritis, rheumatic disease, Hispanic, Latino, chronic disease

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CORRESPONDENCE: gwallen@cc.nih.gov

Background

Hispanics/Latinos are the largest ethnic minority group in the United States, representing 16.3% of the US population in 2010 and expected to account for up to 35% of the population by 2050. More than 40% of Hispanics living in the US are immigrants.¹ Hispanics currently make up 25% of the nation's uninsured and are three times less likely to have a consistent source of medical care compared to those of non-Hispanic Whites.² There are unique culture-specific health protective factors and structural risk factors in Hispanic populations with the potential to affect health outcomes.^{3,4} Hispanic populations may differ from the US population in general with regard to their disease burden and symptom management strategies.⁵

More than three million Hispanic adults in the US have arthritis, which is the leading cause of disability in the United States. Out of them, more than 1.4 million Hispanics suffer activity limitations because of arthritis, making it the most common arthritis disability across Hispanic groups.⁶ Ultimately, the impact of arthritis and other rheumatic diseases depends on both environmental factors such as access to treatment and individual factors such as coping mechanisms and social networks.

Social support among patients with rheumatic disease. Given the immense physical and psychosocial burden that patients with rheumatic disease must bear, social support or the “functional content of relationships”⁷ may be important to consider when examining health promotion strategies



and chronic disease management for these individuals. Social support can affect functionality and pain,⁸ mental health,⁹ and feelings of isolation.¹⁰ Family and friends providing a positive support system for patients with chronic conditions has the potential to lead to positive outcomes.⁴ Existing research emphasizes the benefits of social support for patients with arthritis,^{9–11} but there is limited evidence delineating the quantity and quality of social support that is most prominent in diverse Hispanic populations.

Operationalization of social support. How an individual perceives social support encompasses the “cognitive appraisal of being reliably connected to others,”^{12, p. 416} but does not necessarily quantify the number of sources or the amount of contact with each source. Sources of social support may include family, friends, and in certain cases health professionals (eg physicians, nurses, or nutritionists). Types of social support are often categorized into emotional support, tangible/instrumental support, and informational support. All three types of support (from various sources) are associated with improved health outcomes.^{13–18}

Social support among Hispanics. Among Hispanic populations, social support has been cited as a protective factor for patients with varying conditions.¹⁹ The role of family as a fundamental source of social support is rooted in cultural beliefs and practices, particularly emotional support from family.²⁰ Most Hispanics adhere to *familismo* (a sense of loyalty to family and placing the family’s needs over their own²¹), *simpatia* (tendency to promote harmony in interpersonal relationships), and *respeto* (respect), which conform to a socio-centric dictum. This relates to a collective perspective wherein there is a tendency to understand oneself through others while emphasizing family, social, and emotional bonds.²² It is also important to note that acculturation may also play a role when considering health outcomes of Hispanics. Among Hispanics, increasing levels of acculturation are associated with decreases in healthy behaviors²³ and poorer health outcomes. Protective health factors may deteriorate as immigrants spend more time in the US, which has been referred to as “negative acculturation.”²⁴

Understanding the number of supporters and quality of social support present may improve chronic disease management among those with rheumatic diseases. The goal of this mixed method analysis is to elucidate the amount, type, and source of social support among a sub-sample of Hispanics seeking treatment for various rheumatic diseases and assess correlations between social support and demographic/outcome variables of interest.

Methods

Sample and setting. This analysis is part of a larger study entitled “Health Beliefs and Health Behaviors among Minorities with Rheumatic Diseases” (NCT00069342), which was designed to explore psychosocial and cultural factors related to rheumatic diseases in minorities. Participants were recruited

from the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Community Health Center (CHC) in the Upper Cardozo Clinic run by Unity Health Care, Inc., a health management company providing health care to underserved residents of Washington, DC. The study was approved by the NIAMS Institutional Review Board. After patients provided written informed consent, face-to-face interviews were conducted. Of the 109 individuals who participated in this study, 46 self-identified as Hispanic and thus were included in this analysis. One of the overarching research questions of the study focused on relationships between physical and psychosocial correlates and outcomes in minority patients with rheumatic diseases. In our previously published study, complementary and alternative medicine (CAM) was higher among Spanish-speaking patients. A detailed description of the recruitment methods, sample, and measures can be found in Wallen and Brooks,²⁵ Wallen et al.,²⁶ and Wallen et al.²⁷

Measures. Interviews were conducted on-site at the CHC in both English and Spanish. Basic information collected included gender, race, ethnicity, height, and weight. To measure acculturation for the Spanish speakers, the Short Acculturation Scale (SAS) was used to assess preferred language usage (English vs. Spanish) in various life situations.^{27–29} To assess patients’ functional status, we used the Health Assessment Questionnaire Disability Index (HAQ-DI). The HAQ, which assesses eight areas of patient function, was developed by Fries and colleagues in 1980 and has been validated in Hispanic populations.^{30,31} Although the HAQ-DI was used to measure functional ability, when analyzing the final data, it was observed that one of the questions under the *Eating* category—Open a new milk carton?—was inadvertently deleted from the questionnaire during the translation process. Consequently, for each participant, the score for the category (eating) was computed based on the other responses in that category. Pain assessments included the Wong–Baker Faces Pain Scale, which asks patients to rate their current pain level from 0 to 10,^{32,33} an additional 0–10 scale assessing pain intensity in the last 30 days, and dichotomous (yes/no) measures of whether the patient had experienced pain in the last 30 days and/or in the last 12 months.

Social support was measured using the individual’s perception of support as it related to their illness (“Who or what provides your strongest source of support to cope with your illness and related symptoms?”). Options included no support, partner/spouse, family member, friend, health professional, religious affiliation, and an “other” write-in option. The quantity of social support was operationalized as number of sources each individual identified as providing him or her with social support related to rheumatic disease. This score did not reflect the quality or the amount of support that each identified supporter provided.²⁹

Quantitative analysis. We sought to identify the prevalence of various sources of social support, the number of sources



of social support that participants reported, and whether either of these correlated with selected demographic variables. After univariate analyses were conducted with all demographic variables (see Table 1), bivariate Pearson's correlations were explored between age, acculturation, body mass index (BMI), and pain levels. Finally, we examined whether the number of perceived sources of social support was associated with acculturation, BMI, functionality, or the Wong–Baker pain variable through Pearson's correlations. Non-parametric tests were utilized to test association between number of perceived sources of social support and gender (Mann-Whitney *U* test) or race (Kruskal–Wallis test).

Qualitative analysis. A second open-ended question sought to ascertain the nature of the support being received: “Describe how this person (or these people) is (are) supporting you.” We chose to analyze the data in a “joint matrix” type of format, which examines a quantitative categorical variable (type of social support) alongside qualitative themes.³⁴ Through analyzing qualitative responses of participants, we examined how individuals felt they were supported through various sources and what implications these thematic responses may have had in their chronic disease management. Qualitative responses were coded into “type of social support,” and categories were thematically grouped into emotional, instrumental/tangible, informational, spiritual, and other. Emotional support includes “intimacy and attachment,” which contributes to feelings of belonging. In our analysis, emotional support was defined as moral support or encouragement specific to rheumatic disease. Instrumental/tangible support refers to “direct aid or services” (eg, money, transportation, taking care of chores, etc). In this analysis, instrumental/tangible support referred to presence/aid of an institution, medication, or physical assistance. Informational support involves providing information or giving advice.¹⁸ Informational support in the current analysis included obtaining knowledge specifically related to their disease. Although not a well-referenced type of social support, “spiritual” emerged as a category in the sample and encompassed references to religion, spirituality, church, God, and/or prayer. Some responses were coded as more than one type of social support.

Results

As depicted in Table 1, the sub-sample was mostly female (84.8%) and the majority reported at least one source of social support in their lives (87%). A total of 52% of the sample originated from Central America. The largest group originated from El Salvador (39.1%). The two most commonly cited types of social support were emotional and instrumental/tangible, and the two most common sources of support were family (52.2%) or spouse (32.6%). An overwhelming majority of the sample reported experiencing pain, both during the last 12 months and the last 30 days. The sample was generally unacculturated (mean = 5.84, SD ± 3.90 out of a potential range of 4–20), with the average length of time

Table 1. Patient demographics.

	N (%)
Gender	
Female	39 (84.8)
Male	7 (15.2)
Race	
White	27 (58.7)
Black	3 (6.5)
Other	12 (26.1)
Missing	4 (8.7)
Interview language	
Spanish	41 (89.1)
English	5 (10.9)
Country of origin	
El Salvador	18 (39.1)
Colombia	4 (8.7)
Guatemala	4 (8.7)
Bolivia	4 (8.7)
Other	15 (32.6)
Presence of social support	
Yes	40 (87.0)
No	5 (10.9)
Type of social support*	
Emotional	25 (54.3)
Tangible/instrumental	20 (43.5)
Informational	4 (8.7)
Spiritual	1 (2.2)
Other	1 (2.2)
Source of social support	
Family	24 (52.2)
Partner/spouse	15 (32.6)
Health professional	7 (15.2)
Friend	4 (8.7)
Religious affiliation/God	2 (4.3)
Other	3 (6.5)
Self-reported diagnosis	
Rheumatoid arthritis	9 (19.6)
Arthritis	6 (13.0)
Osteoarthritis	4 (8.7)
Multiple diagnoses**	2 (4.3)
Other	6 (13.0)
Missing/don't know	19 (41.3)
Pain/stiffness past 12 months	
Yes	45 (97.8)
No	1 (2.2)
Pain/stiffness past 30 days	
Yes	46 (100.0)
No	0 (0.0)
	MEAN (±SD.)
Age (Range: 25–89)***	49.7 (13.4)
Acculturation (Range: 4–20)+	5.8 (3.9)
Length of time in U.S. (in years) (Range: 0.25–49)	13.2 (11.8)
BMI (Range: 20.3–52.9)	30.7 (7.9)
Wong-Baker Faces Pain Scale (Range: 0–10)	5.52 (3.1)
Pain intensity (last 30 days) (Range: 4–10)	7.41 (1.9)
HAQ-DI Score (Adjusting for devices) (Range: 0–2.63)	0.9 (0.7)

Notes: *Some responses were coded as more than one type of social support. **Multiple diagnoses were “rheumatoid arthritis, systemic lupus and erythematosus” and “arthroporosis and arthosis.” ***All ranges reflect *actual* ranges. +Only 45 of the 46 participants filled out the acculturation scale, so n = 45 for that variable.

in the US being 13.2 years, and all except one participant completed the interview in Spanish. The average HAQ-DI score of 0.9 in the sample reflects mild to moderate difficulty in everyday activities.



The number of sources of social support that patients reported was not significantly correlated with gender, race, age, baseline pain levels, or acculturation. However, BMI was significantly correlated with the perceived number of sources of support. As BMI increased, the number of sources of support also increased ($r = 0.44, P < 0.05$). Only seven individuals cited a health professional as a source of social support. Among the accounts of patients reporting health professionals as social support, emotional and instrumental/tangible examples of support were cited.

Table 2 highlights the selected qualitative responses to “type of social support provided.” There were multiple ways through which patients felt supported, and many experienced social support in more than one way. For example, one patient responded “en todo: comprensiva” (“in all, comprehensive”). Emotional support was centered on patients having people who were supportive, listened to them, built confidence, or simply communicated (eg, telephone calls). Supporters conveyed a sense of understanding the feelings of patients and provided encouragement. Instrumental/tangible support included managing medications, massaging for the purpose of alleviating pain, transportation to medical appointments, and financial support. Translation between English and Spanish was also mentioned as tangible support, which is specific to immigrant populations. One person viewed his healthcare provider as a source of support (“my doctor gives me medicine”). Most patients considered informational support to be associated with healthcare—including a patient’s doctor and a friend who was a nurse. Informational support included referrals and recommendations for self-care and disease management strategies. Only one Hispanic individual cited spiritual support, “en Dios and amigas” (“in God and friends”), which was mentioned slightly more frequently in the non-Hispanic sample.

Discussion

In this mixed methods analysis, we sought to examine the presence of social support and explore themes and mechanisms of support that may be particularly relevant in this Hispanic sample. Emotional support was more prevalent than instrumental/tangible support. Participants identified numerous ways that they felt supported through families, friends, and healthcare providers. These findings begin to shed light on the potential importance of social support for rheumatic disease self-care regimens in this particular population. In 2009, Deng and colleagues³⁵ wrote a paper commissioned by the Institute of Medicine’s summit on integrative medicine and the health of the public. One of their recommendations for integrative health research was promotion of self-care and resilience. Patients cited various ways that social support could enhance their potential for self-care of their rheumatic disease(s), and these are important for healthcare providers and researchers to both assess and understand. Specifically, patients’ own operationalization of social support may be important to understand when providers or researchers assess levels of support through varied measures.

Table 2. Examples of types of social support given.

<i>(Age, Diagnosis, Gender)</i> —when provided by patient	
EMOTIONAL	
[Translated from Spanish]	“In everything: comprehensive.” -51, osteoporosis, female
[Translated from Spanish]	“They (female) are very communicative.” -39, arthritis, female
[Translated from Spanish]	“They support me in what I speak about. They listen to me and help me.” -28, diagnosis not provided, male
[Translated from Spanish]	-30, Systemic Lupus Erythematosus, female
[Translated from Spanish]	“She talks with me, the confidence that she gives me. My niece also helps me with her confidence and talks.” -47, Systemic Lupus Erythematosus, female
	“When I’m in pain they listen to me, tell me to rest. Do things for me to help me.” -54, rheumatoid arthritis, female
[Translated from Spanish]	“He treats me well.....He understands how I feel.” -59, rheumatoid arthritis, female
[Translated from Spanish]	“Conversing, my spouse encourages me...” -54, arthritis, female
[Translated from Spanish]	“Talking with me...” -49, carpal tunnel syndrome*, female
INSTRUMENTAL / TANGIBLE	
[Translated from Spanish]	“She comes with me to the doctor, if I am feeling bad she gets something for me.” -51, diagnosis not provided, female
[Translated from Spanish]	“In everything: comprehensive.” -57, osteoporosis, female
[Translated from Spanish]	“She finds me the pills, rubs my hands.” -39, rheumatoid arthritis, female
	“My doctor gives me medicine.” -30, Systemic Lupus Erythematosus, female
[Translated from Spanish]	“When I need help with the language. She takes me to my medical appointments. She helps me.” -48, diagnosis not provided, female
	“Husband—with pain he checks on meds/wrists supports family—family calls, keeps track. When I was pregnant my husband would massage my hands.” -28, carpal tunnel syndrome*, female
	“Helps financially.” -34, fibromyalgia, female
[Translated from Spanish]	“My husband cooks, he doesn’t let me wash the dishes, he massages my hands.” -56, rheumatoid arthritis, female

(Continued)



Table 2. (Continued).

INFORMATIONAL
[Translated from Spanish] "In everything: comprehensive." -57, osteoporosis, female
[Translated from Spanish] "When I need help with the language. She takes me to my medical appointments. She helps me." -48, diagnosis not provided, female
"Friend was a nurse in her country, has similar symptoms and recommends exercises. Does exercises with me." -56, osteoarthritis, female
"Son takes me to MD visit, provides me with good information. Doctor gives me referral to other specialists." -57, osteoarthritis, male

Important to note is the fact that once we limited the sample to only Hispanics, some previously significant relationships between variables were no longer significant. For instance, BMI significantly correlated with HAQ-DI in the larger sample ($P < 0.01$), in that individuals with higher BMIs reported greater disability. The individuals with higher pain levels also reported greater disability levels ($P < 0.01$) and those with more perceived sources of social support reported higher functional performance as measured by the HAQ-DI.³⁶

Interestingly, the number of sources of social support (which could also be considered the "variety" of sources) was not correlated with most of other variables in this sample, which may suggest that the type of support may be more important than the number of sources reported for improving health outcomes. Additionally, as BMI increased, the perceived number of sources of social support also increased. Given the lack of variability in functional status and the intensity of pain in this sample, it is unclear why patients with high BMI identify more sources of social support, and further investigation into larger samples with more variability is warranted. Future research should also examine the relationship between varying levels of acculturation and social support, and consider the potential needs of persons with varying types of rheumatic diseases and their accompanying functional limitations.

The majority of participants were female (84.8%) and the study was conducted in a single location, which limit the generalizability of the results. Furthermore, this sample was largely unacculturated, which limited our ability to interpret the relationship between acculturation and social support, functionality, and health outcomes.

Conclusions

Social support is a dynamic aspect of individuals' lives and should be considered when evaluating the burden of chronic disease in diverse Hispanic/Latino samples with rheumatic diseases. Language barriers, scheduling issues, and cultural

sensitivity may be important factors in attempting to optimize continuity of care, and social support may influence each of these factors. Presence of instrumental social support could be the only reason an individual is able to adhere to specific plans for care including attending medical appointments and maintaining needed supplies of prescription medications (ie, a friend or family member providing a ride). Something as simple as patients having a friend or family member translate at a doctor visit could influence quality of care. Because the majority of individuals in this sample reported receiving social support from a partner/spouse and/or family member, these individuals may play a key role in integrated chronic care management. Incorporating aspects of social support into targeted interventions and interdisciplinary plans for care may prove to be an important component of culturally sensitive health promotion and chronic disease management in growing immigrant samples such as the one described here.

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Author Contributions

GRW and ATB conceived and designed the experiments. ATB, KRM, and GRW analyzed the data. ATB wrote the first draft of the manuscript. ATB, REA, KRM and GRW contributed to the writing of the manuscript, agreed with manuscript results and conclusions, jointly developed the structure and arguments for the paper, made critical revisions and reviewed and approved the final manuscript.

DISCLOSURES AND ETHICS

As a requirement of publication the authors have provided signed confirmation of their compliance with ethical and legal obligations including but not limited to compliance with ICMJE authorship and competing interests guidelines, that the article is neither under consideration for publication nor published elsewhere, of their compliance with legal and ethical guidelines concerning human and animal research participants (if applicable), and that permission has been obtained for reproduction of any copyrighted material. This article was subject to blind, independent, expert peer review. The reviewers reported no competing interests.

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