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To Tell or Not to Tell: Shared Decision Making, CAM Use and Disclosure Among Underserved Patients with Rheumatic Diseases

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Abstract: The purpose of this analysis was to assess the impact of perceived shared decision-making (SDM) on complementary and alternative medicine (CAM) use and disclosure in a sample of urban, underserved minority patients ($n = 109$) with rheumatic diseases. Nearly three quarters of the patients (71.6%) reported CAM use. Of these, 59% disclosed CAM use to their provider. Logistic regression models were created. In model 1 SDM significantly predicted CAM use; however, the overall model fit was not significant. In model 2, gender, ethnicity, and SDM predicted CAM disclosure with 73.2% correctly classified. Females were more likely and Hispanics were less likely to disclose CAM use. Those with higher SDM scores were more likely to disclose CAM use. SDM played a role in whether patients used CAM and disclosed CAM use to their providers. Improving SDM strategies may be especially important among patients who are least likely to disclose CAM use.

Keywords: shared decision-making, rheumatic disease, arthritis, complementary and alternative medicine, patient-provider communication

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Introduction

“The foundation of good medical care is a comfortable and evolving relationship between the patient and the physician.”¹

Arthritis is the most common cause of disability in the United States, with 22% of the population reporting physician-diagnosed arthritis.² The chronic nature of arthritis/rheumatic disease can result in severe decrements in physical and psychosocial functioning, affecting patients’ overall quality of life (QOL). Approximately 21 million adults report activity limitations related to their arthritis, including activities of daily living, occupational capacity, social functioning, and cognitive ability.^{2,3}

In addition to chronic pain and generally lower QOL, arthritis and other rheumatic diseases are often accompanied by additional complex co-morbidities. Research suggests that rheumatic disease is a risk factor for cardiovascular disease.⁴⁻⁶ Rheumatic disease patients also suffer a higher risk for certain cancers, gastrointestinal (GI) disease, and infections, and certain common treatments for rheumatoid arthritis (RA) can increase risk for illness.⁶ Additionally, patients suffering from rheumatoid arthritis (RA) have higher depression rates than the general population, with the prevalence of depression ranging from 13%–47%.⁷⁻¹⁰ Depression can influence pain perception due to negative self-perceptions.¹¹

Particularly in patients with chronic and debilitating illnesses, a patient-provider partnership based on trust in full disclosure from both the patient and their provider is an essential element of good clinical practice that supports healthy behaviors. “Shared decision-making” often comes as a result of open communication and trust between patients and their providers.

Shared decision-making (SDM)

The quality and depth of shared decision-making between patients and providers have become increasingly important variables to consider when examining disparities in the provision of care and in patient outcomes. However, it remains unclear how to best optimize these patient-centered characteristics in the most vulnerable and underserved patients with chronic and debilitating illnesses such as rheumatic diseases. SDM has been described as a “deliberation” and is “interactional in nature”; both the patient and the provider are invested in the final decision regarding

the course of the patient’s treatment.¹² It has been suggested that physicians can dominate patient-provider interactions simply because they may be more “knowledgeable” than patients.¹³ However, *shared* decision-making (SDM) in healthcare is considered ethical¹⁴ and has been shown to lead to better health outcomes.^{15,16} Since there is no “cure” for arthritis, involving patient preferences and values in treatment decision-making is arguably necessary.¹⁷

CAM use among patients with rheumatic disease

Because of the immense burden associated with rheumatic disease, time and energy have increasingly been invested into identifying effective treatment options, including complementary and alternative medicine (CAM). Approximately 38% of US adults use CAM, defined as “a group of diverse medical and health care systems, practices, and products that are not generally considered part of conventional medicine” (also referred to as “Western” or “allopathic” medicine).¹⁸ One recent study showed that nearly 50% of arthritis patients in particular report CAM use alone or in conjunction with “conventional” medicine.¹⁹ While arthritis patients increasingly use CAM to manage pain and symptoms, disclosure rates vary.^{20,21} Evidence suggests that CAM use is associated with practicing positive health behaviors and may even contribute to health behavior change,^{22,23} potentially through patients’ awareness of improvements in physical and emotional health resulting from CAM therapies.²⁴ Another study identified improved awareness of the connection between behavior and health as a result of CAM therapy. Additionally, integrating CAM therapies and encouraging individuals to take responsibility for their health can motivate individuals to make positive behavior changes.²⁴

Given the physical and psychosocial burden known to accompany rheumatic disease it is arguably necessary for integrated, evidence-based and individualized treatment plans to be devised for optimal care. Shared decision-making has been advocated as an optimal core concept in contemporary medical encounters. SDM includes “considering patient preferences during medical encounters”.²⁵ Patients adopt a more active, demanding, and informed role than before.

Inadequate communication between patients and providers negatively affects the level of trust patients



have in their providers, highlighting the need for providers' strong interpersonal skills.²⁶ Patient disclosure of CAM use may be more forthcoming if there is trust and open communication between the patient and their care provider. A recent survey conducted by the National Center on Complementary and Alternative Medicine (NCCAM) and the AARP (formerly known as the American Association of Retired Persons) revealed the two main reasons that patients report not discussing CAM use with their providers, the first being that the provider never asks (42%) and the other being that they did not know they should raise the issue (30%).¹⁸ In an effort to address this, NCCAM sponsors "Time to Talk," an educational campaign to encourage patients 50 or older to openly discuss the use of CAM with their health care providers.¹⁸ Considering this and other campaigns addressing patient-provider relations, it is of interest that an individual's self-efficacy and their level of participation in health decision making are both "potentially modifiable" factors given the positive outcomes attributed to SDM.²⁷

Research has emphasized the benefit and importance of incorporating shared decision-making into treatment decisions, particularly for patients with rheumatic disease.^{28,29} The study by Sleath and colleagues examining decision making among rheumatic disease patients (n = 2,178) found that patients who rate their physicians as using participatory styles are more likely to disclose the use of CAM, suggesting that if providers involve arthritis patients in treatment decisions, patients might be more likely to disclose more fully what they are doing to self-treat their arthritis.³⁰ Our study extends the findings of the Sleath study by focusing on a purposive sample of underserved minorities with rheumatic diseases. In regards to patient-provider discussions of CAM use among diverse patient populations, the need to create optimal environments for shared communication become even more important. The purpose of this analysis was to assess the impact of perceived SDM on CAM use and disclosure in a sample of underserved minority patients with rheumatic disease.

Material and Methods

Recruitment, setting, and sample characteristics

This analysis included participants 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 Washington, DC residents. User profiles for the Unity Health Care Upper Cardozo Clinic as a whole indicate that 84% of the clinic users fall at or below the federal poverty line, and only 1% are privately insured (<http://www.unityhealthcare.org/HealthCenters/2009FactSheets/UpperCardozo2009.pdf> retrieved August 24, 2012)³¹. Patients included in our analysis were enrolled in the Health Beliefs and Health Behavior Practices among Minorities with Rheumatic Diseases Protocol (NCT00069342). The study was approved by the NIAMS Institutional Review Board. After patients provided written informed consent, face-to-face assessments were conducted in both English and Spanish depending on participant preference. Demographic characteristics of participants are presented in Table 1. The sample was predominately female (75.2%) female, and Hispanic (57.8%). Over one third of the sample identified as Black (36.7%). Additionally, an overwhelming majority of participants reported pain both in the past 12 months (97.2%) and the past 30 days (98.2%).

Measures

Face-to-face interviews were conducted with patients on-site at the Upper CHC using several validated measures. To measure acculturation for the Spanish speakers, the Short Acculturation Scale (SAS) was used. The SAS is a brief, validated measure of acculturation based on preferred language usage (English versus Spanish) in specified situations.^{3,32} The Wong-Baker Faces Pain Scale consists of six cartoon faces ranging from a smiling face (no pain) to a tearful face (worst pain).^{33,34} This scale was chosen because of potential language and literacy barriers and because the use of traditional pain scales has elicited mixed results with Hispanic populations.^{3,35} Another pain measure included questions asking patients to indicate whether they had pain in the past 12 months and the past 30 days. The Arthritis Self-Efficacy Scale³⁵ consists of eight items surrounding confidence to perform day-to-day activities, ranging in score from one (very uncertain) to ten (very certain). This scale has an internal reliability ranging from $\alpha = 0.88$ to $\alpha = 0.93$ based on studies in six geographic locations

**Table 1.** Patient characteristics (n = 109).

	n (%)
Gender	
Male	27 (24.8)
Female	82 (75.2)
Race	
White	46 (42.2)
Black	40 (36.7)
Other	20 (18.3)
Missing	3 (2.8)
Ethnicity	
Hispanic	63 (57.8)
Non-hispanic	46 (42.2)
Diagnosis	
Osteoarthritis	17 (15.6)
Rheumatoid arthritis	18 (16.5)
Arthritis	5 (4.6)
Other	39 (35.8)
Unknown	1 (0.9)
Missing	29 (26.6)
Pain/stiffness—past 12 months	
Yes	106 (97.2)
No	3 (2.8)
Pain/stiffness—past 30 days	
Yes	107 (98.2)
No	2 (1.8)
	Mean (±SD)
Age	51.27(±13.22)
Acculturation (4–20)*	5.84 (±3.90)
Pain, past 30 days (0–10)	7.44 (±2.33)
Pain now (Wong-Baker scale, 0–10)	5.26 (±2.88)
Self-efficacy score (0–8)	5.34 (±2.20)
Depression (CESD 0–60)	24.82 (±9.81)
Shared decision-making score (0–12)	7.64 (±2.60)
Help doctor with decisions on treatment (0–4)	2.72 (±0.97)
Doctor gives control over treatment (0–4)	2.53 (±1.24)
Doctor encourages to take responsibility on treatment (0–4)	2.39 (±1.35)

Note: *n = 45.

in the United States and Latin America with various Hispanic populations. The Center for Epidemiologic Studies Depression Scale (CES-D) is a 20-item scale representing any symptoms experienced during the past week including depressed mood, feelings of guilt/worthlessness, helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. The CES-D has been validated in a variety of settings, with test-retest reliability ranging from 0.32 to 0.67 and good internal consistency; split-half correlations range from 0.77 to 0.85. Co-efficient alpha and Spearman-Brown coefficients were 0.90 or higher.^{36,37} The Spanish version of the CES-D was

based on the version published by Gonzalez and colleagues.³⁵ A “Complementary and Alternative Medicine Use in Arthritis” (I-CAMP) questionnaire was used to evaluate the use of CAM, including eight specific categories.³ Similar to the approach of Sleath and colleagues (2005) the prevalence of SDM was examined using a 3-item participatory decision-making scale at the end of the I-CAMP.^{16,30} Patients were asked to rate physicians on a five-point scale across three questions: (1) If there were a choice between treatments, would this doctor ask you to help make the decision, (2) How often does this doctor make an effort to give you some control over your treatment, and (3) How often does this doctor ask you to take some of the responsibility for your treatment? For a more extensive description of the others measures utilized, refer to the paper published by Wallen and colleagues.³

Statistical analysis

The relationships between SDM and perceived self-efficacy, depression, and CAM use were examined using Pearson’s correlations. Two backward stepwise logistic regression analyses were conducted to predict CAM use (model 1) and CAM disclosure (model 2). Variables of interest for both models included gender, ethnicity, race, age, pain levels, and SDM. Self-efficacy (as measured by the Arthritis Self-Efficacy Scale) was an additional variable in Model 2. For the purposes of the logistic regression analysis race was identified as a categorical variable with three categories (White, Black and Other) with “White” identified as the reference category. Ethnicity was identified as a categorical variable with two categories (Hispanic, Non-Hispanic) with Hispanic identified as the reference category. All analyses were conducted using SPSS (Statistical Package for the Social Sciences) version 17.0.

Results

Nearly three quarters of the patients interviewed (71.6%) reported using at least one CAM modality (n = 78), with 25% of the total sample reporting the use of more than five modalities specifically for arthritis. Over half of the patients (52%) reported using modalities listed under the spiritual/mind-body category (Table 2). The three most frequently reported subcategories under the spiritual/mind-body

**Table 2.** Complementary and alternative medicine (CAM) use (n = 109).

CAM modality	n (%)
Spiritual/mind-body-prayer	52 (47.7)
Rubs/lotions	49 (45.0)
Movement activities	44 (40.4)
Herbs/supplements	26 (23.9)
Vitamins/minerals	24 (22.0)
Bracelets/magnets	22 (20.2)
Special diets	10 (9.2)
CAM providers	8 (7.3)

category included prayer about the disease (n = 37), drawing upon religious or spiritual beliefs (n = 29) and attending religious services regularly (n = 26). Of those patients reporting CAM use, 59% reported that they had discussed this use with their health care provider. Among the Spanish-speaking participants, less acculturated patients reported slightly higher CAM usage. Univariate analysis using Pearson's r correlations further revealed significant ($P < 0.01$) positive correlations between pain (both current and the last 30 days) and depression. Significant ($P < 0.05$) positive correlations were also found between the number of CAM modalities reported and both depression and SDM scores. Significant ($P < 0.01$) negative correlations existed between self-efficacy scores and pain scores as well as between self-efficacy and depression scores, indicating that as self-efficacy scores increased, depression and pain scores decreased.

In Model 1 (Table 3), patients' SDM scores were significantly predictive ($P < 0.05$) of CAM use (OR: 1.25, 95% CI: 1.04–4.52) however the overall model fit was not significant. In Model 2 (Table 4), gender,

Table 3. Model 1: generalized estimating equation results predicting whether patients use CAM.

Variable	Odds ratio (95% CI)	S.E.	β
Ethnicity			
Hispanic	0.59 (0.18, 1.98)	0.61	-0.52
Non-hispanic	-referent-	-	-
Race			
White	-referent-	-	-
Black	0.66 (0.18, 2.43)	0.67	-0.41
Other	0.38 (0.10, 1.44)	0.68	-0.98
Age	1.01 (0.98, 1.05)	0.02	0.01
Pain	1.17 (0.98, 1.39)	0.09	0.15
SDM score	1.26 (1.04, 1.52)	0.10	0.23

Table 4. Model 2: generalized estimating equation results predicting whether patients disclose CAM use to their providers.

Variable	Odds ratio (95% CI)	S.E.	β
Gender			
Male	-referent-	-	-
Female	10.20 (1.95, 53.40)	0.85	2.32
Ethnicity			
Hispanic	0.08 (0.02, 0.44)	0.86	-2.49
Non-hispanic	-referent-	-	-
Race			
White	-referent-	-	-
Black	1.03 (0.21, 4.94)	0.80	0.03
Other	1.68 (0.31, 9.24)	0.87	0.52
Age	1.01 (0.97, 1.06)	0.02	0.01
Pain	0.85 (0.68, 1.06)	0.11	-0.16
SDM Score	1.51 (1.13, 2.04)	0.15	0.42

ethnicity, and SDM scores were significant in predicting CAM disclosure ($P < 0.05$), with self-efficacy approaching significance ($P = 0.067$). Of those who disclosed their CAM use to their provider, 84.1% were correctly classified, whereas 55.6% of those who did not disclose their CAM use were correctly classified. The overall model was significant ($P = 0.001$) with 73.2% of the patients correctly classified. Females were 10 times more likely than males to tell their provider about CAM use (OR: 10.2, 95% CI: 1.95–53.40). Hispanics were less likely to disclose CAM use (OR: 0.83, 95% CI: 0.15–5.44). Those with higher SDM scores were more likely to disclose CAM use (OR: 1.51, 95% CI: 1.13–2.04).

Discussion

SDM played a significant role in whether the rheumatic disease patients in this underserved minority sample used CAM and whether they disclosed this use to their provider. These data are congruent with the findings of Sleath and colleagues,³⁰ suggesting that patients with rheumatic diseases are more likely to disclose CAM to their providers if their physicians exhibit a participatory style of decision-making and involve patients in the outcome of their own care. Interestingly, those patients who reported a higher level of SDM with their providers were more likely to report being CAM users. This may indicate that a collaborative decision-making style shared between patients and providers encourages patients to explore alternative options for treatment such as CAM,



and encompasses a general “share and tell all” partnership between patients and providers.

Rheumatic disease burden has the potential to be reduced through the integration of CAM modalities, but honest and open communication of these treatment modalities to and among providers is necessary for optimal integrated care. Communication is necessary regardless of whether these treatments are used specifically for relief of arthritic symptoms or whether they are used for general wellbeing, health promotion and disease prevention purposes. Shared decision making could provide the “missing link” that binds the integration of multiple modalities and ultimately improves patient outcomes.

Shared decision making utilized in a health care setting provides patients with a greater sense of control, greater perceived self-efficacy, and the sense that they possess the capacity to take actions that will directly contribute to the relief of debilitating symptoms directly attributable to the trajectory of their illness. Self-efficacy has been cited as crucial in health behavior change.³⁸ Successfully improving one’s own health, observing someone else improving their health, and being encouraged to perform a behavior can increase self-efficacy beliefs and potentially facilitate health behavior change.³⁹ Self-efficacy approached significance as a predictor of CAM disclosure among patients who reported using CAM in our sample. It is unclear whether self-efficacy would have been a significant predictor of CAM disclosure in a larger sample size, and this possibility should be considered in future research.

Evidence suggests that CAM use can vary by ethnicity or level of acculturation. Interestingly, Su and colleagues⁴⁰ found that as immigrants have been in the United States longer or as their English becomes more proficient, they are more likely to use CAM. These results indicate that as people are in the United States longer and become more acculturated, their use of CAM increases to that of a native-born Americans, while recent immigrants have lower rates of CAM use. Similar to these findings, one study found that Hispanics using English as their primary language had similar patterns of CAM use as non-Hispanic whites.⁴¹ The level of acculturation in our sample was low (mean 5.84; SD \pm 3.90) with little variability (see Table 1) thus making any conclusions regarding the relationship between acculturation and CAM

use or disclosure in this sample difficult to interpret. Our data further illustrate the importance that gender and ethnicity may play in CAM disclosure between patients and their providers, with men and Hispanic patients being less likely to disclose their CAM use. These data suggest that providers may need to be particularly cognizant of these differences in disclosure rates and provide additional focused assessment of CAM use in these patients.

This study is not without limitations. More females than males participated in this study, which relied on a convenience sample and therefore limited the generalizability of our results. All data were self-reported and were not independently verified in participants’ medical records. This was a cross-sectional analysis and did not address any longitudinal trends in CAM use and disclosure among our population of interest.

Future Directions

Future research should investigate how to include typically “excluded” populations (less literate, less acculturated, less educated, older, and more severely ill patients) in SDM, since SDM has been proven to lead to better health outcomes and these populations may benefit from it the most. It is also necessary to examine how to encourage patients to initiate discussions about their treatment since evidence suggests that physicians are more likely to engage in SDM behavior when these discussions occur.⁴² It is important to delineate further the specific relationship between SDM and the use of various CAM modalities in order to educate underserved groups of CAM-users who may be less likely to disclose CAM use to their providers.

For providers, it would be useful to explore how to dispel assumptions that they may have about patients from disadvantaged populations not wanting to play a role in their care.⁴³ For patients and providers alike, it is necessary to emphasize that quality of communication may be more important than duration of the visit,⁴⁴ and to adjust the belief among physicians that SDM necessarily results in longer office visits. The amount of time it takes to complete assessment tools that support SDM is a major barrier to incorporating SDM into primary care settings. More recent studies have focused on implementing health care information technology to decrease the amount of time needed to complete these assessments, and resultantly



increase the acceptability and feasibility of incorporating SDM into each healthcare encounter.⁴⁵

Author Contributions

Conceived and designed the experiments: GW. Analyzed the data: GW, AT. Wrote the first draft of the manuscript: GW. Contributed to the writing of the manuscript: GW, AT. Agree with manuscript results and conclusions: GW, AT. Jointly developed the structure and arguments for the paper: GW, AT. Made critical revisions and approved final version: GW, AT. All authors reviewed and approved of the final manuscript.

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Competing Interests

Author(s) disclose no potential conflicts of interest.

Disclosures and Ethics

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