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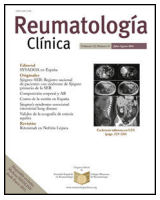

Original Article

Patients' and rheumatologists' perceptions about shared decision-making implementation: A Latin-American survey

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ABSTRACT

Background: Shared decision-making (SDM) has been linked to improved patient- and physician-reported outcomes. To achieve these benefits, both parties need to agree on implementing SDM. The objective of the study was to compare the perception of SDM process implementation in daily practice between patients with rheumatic diseases (RMDs) and rheumatologists.
Methods: This cross-sectional study was conducted in April 2024 in Latin America (LATAM). Adult patients diagnosed with RMDs and rheumatologists were invited to participate in a web-based survey based on the Spanish patient version of the 9-item SDM questionnaire (SDM-Q-9) and the physician version (SDM-Q-Doc). Both versions were validated tools for evaluating patients' and physicians' perceived levels of SDM. Descriptive statistics and comparative tests (e.g., chi-square or Mann–Whitney *U* test) were used to analyze the data. Statistical significance was set at $p < 0.05$, and analyses were conducted using STATA 17 software.
Results: We received surveys from 369 patients, primarily systemic lupus erythematosus (51.8%) and rheumatoid arthritis (19.5%), across 17 countries. The largest number of responses was from Mexico (42%) and Colombia (11.9%). The survey was completed by 144 rheumatologists from 10 countries, primarily from Colombia (52.8%) and Chile (23.6%). Physicians most frequently strongly agree/agree that they engaged in the different steps of the SDM process, compared to patients, and this difference was less evident for the step "sharing with the patient the different options for treating the condition." Also, a higher percentage of rheumatologists (96.5%) reported engaging in SDM during clinical practice compared to patients (62.3%), $p = 0.001$.
Conclusions: In LATAM, rheumatologists more frequently referred to implementing the SDM process during clinical care than patients with RMDs. Further research is needed to improve patient-centered care.

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Percepciones de pacientes y reumatólogos sobre la implementación de la toma de decisiones compartida: una encuesta latinoamericana

Palabras clave:
Toma de decisiones compartida
Bioética
Autonomía personal
Medidas de resultado informadas por el paciente
Enfermedades reumáticas
Estudio transversal

R E S U M E N

Antecedentes: La toma de decisiones compartida (TDC) se ha relacionado con mejores resultados informados por pacientes y médicos. Para lograr estos beneficios, ambas partes deben estar de acuerdo en la implementación de la TDC. El objetivo del estudio fue comparar la percepción del proceso de TDC en la práctica diaria entre pacientes con enfermedades reumáticas (ER) y reumatólogos.
Métodos: Estudio transversal realizado en abril de 2024 en América Latina (LATAM). Se invitó a pacientes adultos diagnosticados con ER y a reumatólogos a participar en una encuesta web basada en la versión para pacientes en español del cuestionario SDM de 9 ítems (SDM-Q-9) y la versión para médicos (SDM-Q-Doc). Ambas versiones son herramientas validadas para evaluar los niveles de TDC. Se utilizaron estadísticas descriptivas y pruebas apropiadas. El estudio fue aprobado por el Comité Ético de Investigación.
Resultados: Recibimos encuestas de 369 pacientes, principalmente con lupus eritematoso sistémico (51,8%) y artritis reumatoide (19,5%), de 17 países. El mayor número de respuestas procedía de México (42%) y Colombia (11,9%). La encuesta fue completada por 144 reumatólogos de 10 países, principalmente de Colombia (52,8%) y Chile (23,6%). Los médicos estuvieron más frecuentemente de acuerdo en que participaron en los diferentes pasos del proceso de TDC, en comparación con los pacientes, y esta diferencia fue menos evidente para el paso «compartir con el paciente las diferentes opciones para tratar la enfermedad». Además, un mayor porcentaje de reumatólogos (96,5%) declaró haber participado en el proceso de TDC en comparación con los pacientes (62,3%), p = 0,001.
Conclusiones: En LATAM, los reumatólogos refirieron con mayor frecuencia implementar el proceso de TDC durante la atención clínica que los pacientes con ER.

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Introduction

Rheumatic diseases (RMDs) are a group of chronic disorders that primarily affect the musculoskeletal system but can also involve systemic manifestations, many of which may have an autoimmune origin.

Treatment options include traditional and modern agents and non-pharmacologic interventions.[1] However, while advancements in treatment interventions are significant, they should not overshadow the recognition that patient-centered care is the best approach for patients with RMDs.[2,3] Multiple models and frameworks have been developed for describing patient-centered care.[4] In 2014, Sholl et al. described a model with four main principles that constituted essential prerequisite activities to implement patient-centered care in daily clinical practice. The authors highlighted patient involvement in shared decision-making (SDM) as an essential activity.[5,6] SDM is the process in which patients and clinicians collaborate to develop a treatment plan that incorporates evidence-based information, clinician expertise, and patient preferences, values, and goals.[7]

SDM in rheumatology has been extensively studied primarily in the USA, Asia, and Europe, where research has demonstrated that SDM improves patient satisfaction, treatment adherence, and overall outcomes in conditions such as rheumatoid arthritis (RA).[7] However, there is a notable research gap focusing on Latin America (LATAM), a region characterized by diverse healthcare systems, disparities in the rheumatology workforce distribution – particularly in rural areas – and significant variation in healthcare coverage across countries, ranging from 22% in Paraguay to 100% in Argentina, Brazil, and Cuba.[8] These contextual factors may influence the implementation and perception of SDM differently than in other regions. Limited data from LATAM suggest potential challenges, including cultural factors and the organization of healthcare teams and systems, which could impact effective SDM engagement between patients and rheumatologists. Addressing this gap is crucial to tailoring SDM approaches that are culturally and systemically appropriate for LATAM populations, thereby ensuring equitable and patient-centered rheumatologic care.

With these points in mind, the study aimed to initially address the topic and investigate the perceptions of the SDM process implementation in daily practice among patients with RMDs and rheumatologists from LATAM.

Methods

Study design and population

This cross-sectional study was conducted in April 2024 across Spanish-speaking countries in Latin America (LATAM). Adult patients (≥18 years old) diagnosed with RMDs and under the care of a rheumatologist were invited to participate. Patients were recruited through collaborations with the Liga Panamericana de Asociaciones de Reumatología (PANLAR) and various national patient associations within LATAM. The project leader communicated the study objectives to these organizations, which, upon approval, disseminated the survey to their patient databases. Additionally, rheumatologists attending the 2024 PANLAR meeting were encouraged to share the questionnaire with their patients. Parallelly, practicing rheumatologists in LATAM were invited to participate via similar organizational channels and social media platforms. The survey was distributed once to both patients and physicians, employing a convenience sampling approach.

Survey administration

A web-based survey was developed using Microsoft Forms and initially piloted with 20 rheumatologists and their patients from three countries to assess face validity from the patients' perspective. Following pilot testing, the survey was disseminated via QR codes and shared on social media platforms including WhatsApp, Facebook, Instagram, and X (formerly Twitter). The survey instrument was based on the validated Spanish version of the 9-

Table 1
Distribution of patients and rheumatologist surveys by country.

	Patient surveys $N = 369$	Rheumatologist surveys $N = 144$
Mexico	155 (42)	2 (1.4)
Colombia	44 (11.9)	76 (52.8)
Ecuador	39 (10.6)	3 (2.1)
Venezuela	34 (9.2)	7 (4.9)
Argentina	32 (8.7)	11 (7.6)
Peru	18 (4.9)	5 (3.5)
Guatemala	17 (4.6)	4 (2.8)
Uruguay	9 (2.4)	1 (0.7)
Chile	6 (1.6)	34 (23.6)
Paraguay	4 (1.1)	0
Nicaragua	3 (0.8)	0
Panama	2 (0.5)	0
Dominican Republic	2 (0.5)	1 (0.7)
Cuba	1 (0.3)	0
El Salvador	1 (0.3)	0
Bolivia	1 (0.3)	0
Honduras	1 (0.3)	0

Data are presented as the number (%) of patients or physicians.

item Shared Decision-Making Questionnaire (SDM-Q-9), designed to evaluate patients' perceived levels of shared decision-making (SDM). Each item corresponds to a distinct step in the SDM process and is rated on a 6-point Likert scale ranging from 0 ("completely disagree") to 5 ("completely agree") (see Supplementary Material). Higher scores indicate a stronger perception of SDM. The survey also included a final dichotomous item assessing participants' overall perception of SDM during clinical care (Yes/No).

For physicians, the corresponding SDM-Q-Doc version of the questionnaire was used and distributed similarly.[9] The patient survey incorporated an additional question regarding their most recent consultation's treatment plan, offering four options: no treatment changes, initiation of new treatment, treatment switch, or treatment cessation; patients selected the option that applied to them. Physicians reported their years of clinical experience.

Statistical analysis

Descriptive statistics characterized both patient and rheumatologist variables, using frequencies and percentages for categorical data, and means or medians with standard deviations (SD) or interquartile ranges (Q25–Q75) for continuous variables, depending on data distribution, which was assessed using the Shapiro–Wilk test. The chi-square test compared categorical variables between groups, and the Mann–Whitney *U* test compared continuous variables between two groups. Statistical analyses were conducted using STATA 17 software, considering a two-sided *p*-value <0.05 as statistically significant.

Ethics

The study received approval from the Research Ethics Committee of Hospital San Vicente Fundación in Medellín, Colombia, which waived the requirement for written or verbal informed consent.

Results

Patients' and rheumatologists' characteristics

A total of 369 patients from 17 LATAM countries completed the survey, with the highest responses coming from Mexico (155 surveys, 42%) and Colombia (44 surveys, 11.9%) (see Table 1 for detailed country distribution). The majority of patients were diagnosed with systemic lupus erythematosus (SLE) (191 patients, 51.8%) and RA (72 patients, 19.5%). Other conditions represented included fibromyalgia (20 patients, 5.4%), axial spondyloarthritis (formerly ankylosing spondylitis) (14 patients, 3.8%), systemic vasculitis (21 patients, 5.7%), idiopathic inflammatory myopathy (12 patients, 3.3%), along with primary Sjögren syndrome, osteoarthritis, and undifferentiated connective tissue disease (each with eight patients, 2.2%). Less common diagnoses included systemic sclerosis (six patients, 1.6%), psoriatic arthritis, primary anti-phospholipid syndrome, and osteoporosis (three patients each, 0.8%). Regarding treatment modifications at their most recent rheumatology consultation, 260 patients (70.5%) reported no changes, 55 (14.9%) started a new treatment, 43 (11.7%) switched treatments, and 11 (3%) discontinued treatment.

The physician survey was completed by 144 rheumatologists from 10 LATAM countries, predominantly from Colombia (76 surveys, 52.8%) and Chile (34 surveys, 23.6%) (refer to Table 1 for country-wise distribution). Among these respondents, 69 rheumatologists (47.9%) reported 0–10 years of clinical practice, 35 (24.3%) had 11–20 years, and 40 (27.8%) had over 20 years of experience.

Comparison of patients' and physicians' perceptions of the SDM process

Fig. 1 highlights that rheumatologists more frequently agreed that they actively engaged in the various steps of the SDM process compared to patients. This discrepancy was less pronounced for the specific step of "sharing with the patient the different options for treating the condition," where alignment was greater. Physicians particularly agreed more strongly on their role in providing patients with information about different treatment options. Notably, a significantly higher proportion of rheumatologists (139; 96.5%) reported engaging in SDM during routine clinical care compared to patients (311; 62.3%), with this difference reaching statistical significance ($p = 0.001$). These findings align with results from the pilot phase of the questionnaire.

Relationship between SDM, physician experience, and treatment plans

Analysis showed no significant variation in perceived SDM implementation among rheumatologists by years of clinical experience: those with less than 10 years (67; 97.1%), 11–20 years (33; 94.3%), and over 20 years (39; 97.5%) reported similar SDM levels ($p = 0.706$). Regarding patient treatment plans, of the 260 patients reporting no treatment changes, 161 (61.9%) perceived that SDM occurred. Among 109 patients who experienced treatment changes, 74 (67.9%) perceived SDM involvement, with the difference between groups not reaching statistical significance ($p = 0.277$).

Discussion

After its initial description in 1972,[10] the SDM process has evolved and become a cornerstone of the quality of medical care. It is now recognized as the first principle in creating a treatment plan, and its application is mandatory in most national and international disease-specific treatment guidelines.[7] SDM has demonstrated benefits in patient and physician outcomes. However, for these benefits to be realized, both members of the patient–physician partnership must perceive that SDM is being implemented as part of routine clinical care.

This study involved rheumatologists and patients with different RMDs from 17 countries in LATAM. It contributes to our current knowledge by addressing the lack of research studies conducted in the region,[11,12] and the scarcity of studies that included patients with RMDs other than RA.[11] We observed a significant

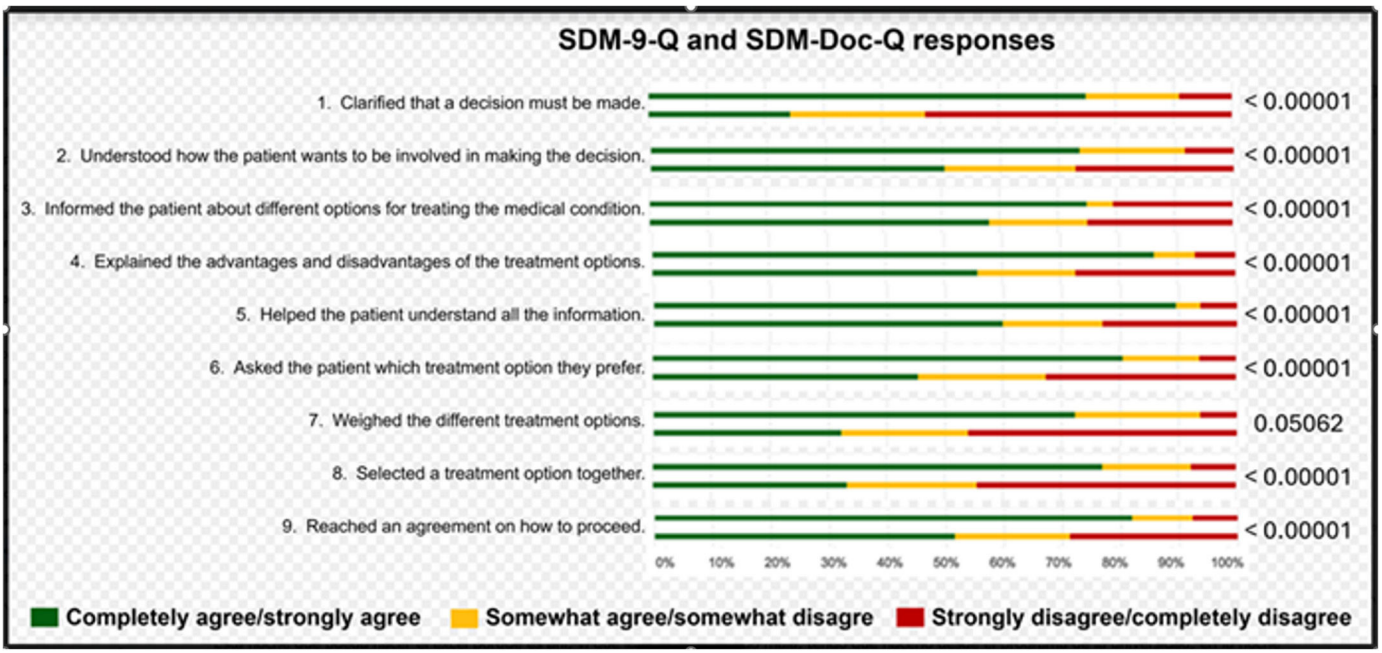

Fig. 1. Comparison of physicians' and patients' perceptions of the SDM process. The figure shows the SDM-Doc-Q scale responses at the top (physicians) and the SDM-9-Q responses at the bottom (patients) for each step of the SDM process.

difference in how rheumatologists and patients with RMDs perceive the implementation of SDM, with rheumatologists perceiving better engagement than the patients. This difference was less evident in the "sharing with the patient the different options for treating the condition" statement. Surprisingly, almost 97% of the physicians reported SDM implementation, and based on their responses, it may reveal that physicians misconceive the whole process. Results of a cross-sectional, exploratory, online survey completed by 147 healthcare professionals from the Netherlands (87% were rheumatologists) confirmed that healthcare professionals lacked a complete conceptual understanding of SDM.[13] The findings of a qualitative systematic review highlight consistent results in tertiary care[14]; the review emphasizes that many clinicians lack formal training in SDM and communication, leading to uncertainty about whether they are applying SDM correctly.[14] Our results might also reveal a physician paternalistic approach to the SDM process, confirmed among rheumatologists (and patients with RMDs) in Mexico.[15] Meanwhile, the significant gap in the SDM implementation observed among the patients (compared to the physicians), despite similarly perceiving the step of "sharing the treatment options," might reflect the complexity of the process from the patient's point of view, which depends on many factors at the levels of the patient, the physician, the healthcare team, and the healthcare system organization.[16,17]

Several limitations need to be taken into account. First, the sample size and geographic distribution across LATAM were uneven, with a predominance of patients from Mexico (42%) and Colombia (12%), and rheumatologists mainly from Colombia (53%) and Chile (24%). This disproportion may limit the generalizability of the findings to the entire region, which is characterized by significant heterogeneity in healthcare coverage, access, and cultural factors influencing SDM.[8] Such imbalance can skew the results and hinder understanding of country-specific differences in SDM implementation. Future studies should aim to recruit larger and more representative samples evenly distributed across Latin-American countries or apply appropriate statistical adjustments to mitigate this bias.

Second, the potential impact of social desirability bias must be considered, especially among rheumatologists, who may have over-reported their involvement in SDM processes to align with perceived expected behaviors. This bias likely contributes to the notably higher proportion of physicians (approximately 97%) reporting SDM implementation compared to 62% of patients who perceived it. The discrepancy may also reflect physicians' incomplete understanding of the SDM concept.[13] To address this bias, future research should incorporate strategies such as ensuring anonymity, using indirect questioning, and integrating qualitative assessments to obtain more accurate representations of SDM practices.

Moreover, patients and physicians did not evaluate the same medical encounters, which might have influenced the differences in their perceptions. Patients' diagnoses were self-reported and not verified through medical charts, which is another limitation to consider.

Conclusion

In conclusion, while this study reveals significant discrepancies in the perceived implementation of SDM between rheumatologists and patients with RMDs in LATAM, these findings should be interpreted carefully given the methodological limitations. Addressing these issues in future research will be critical to capture the complexities of the SDM process better and ultimately improve patient-centered care in the diverse healthcare settings of Latin America.

Practice implications

The results emphasize the need to educate patients and physicians about the SDM process so that the gap highlighted in the current study results can be acknowledged and reduced.

CRediT authorship contribution statement

ALVG: methodology and supervision of the study, acquisition, analysis and interpretation of data, writing and review of the draft; MRE: acquisition, analysis and interpretation of data; AAC:

acquisition, analysis and interpretation of data; GSOG: acquisition, analysis and interpretation of data; LLW: acquisition, analysis and interpretation of data; GAQ: acquisition, analysis and interpretation of data; VPR: conceptualization, visualization, design, methodology and supervision of the study, acquisition, analysis and interpretation of data, writing and review of the draft. All authors read and approved the final manuscript.

Ethics approval and consent to participate

The study was approved by the Research Ethics Committee of Hospital San Vicente Fundación in Medellín (Colombia). The Committee waived the written or verbal informed consent requirement. It was assumed that explicit consent was given upon completion of the survey.

Consent for publication

Not applicable.

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Declaration of competing interests

The authors declare that they have no competing interests.

Data availability

All data generated and analyzed during the development of this research are available upon request to the corresponding author.

Appendix A. Supplementary data

Supplementary data associated with this article can be found in the online version available at https://doi.org/10.1016/j.reuma.2025.501974.

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