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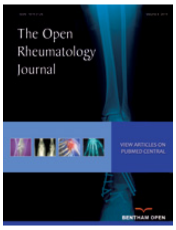

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RESEARCH ARTICLE

Association between Health Literacy, Patient Activation, and Functional Capacity in Individuals with Rheumatoid Arthritis

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Abstract:

Objectives:

To describe health literacy, patient activation, and functional capacity in individuals with rheumatoid arthritis and to evaluate the associations of health literacy and activation level with functional capacity.

Methods:

A cross-sectional study involving patients with rheumatoid arthritis was carried out at the rheumatology service of a teaching hospital. Health literacy was assessed by applying the short version of the Test of Functional Health Literacy in Adults. Patient Activation was measured by using the summarized version of the Patient Activation Measure. The Health Assessment Questionnaire was applied to evaluate functional capacity. Sociodemographic and clinical variables were also collected to carried out univariate and multivariate analyses by using logistic regression.

Results:

The sample was composed of 179 patients, of whom 90.5% (n = 162) were women. The participants' average age was 58.3 ± 11.4 years. The prevalence of patients with inadequate or marginal health literacy was high (67%). In contrast, 74% of the patients showed high activation levels. The average score on the Health Assessment Questionnaire was 1.08 ± 0.7. Adequate health literacy was negatively associated with higher Health Assessment Questionnaire scores (OR = 0.42; 95% CI 0.20 – 0.86; $p = 0.018$), and high activation levels were negatively associated with moderate to severe functional limitation (level 3/moderate activation level – OR = 0.24; 95% CI 0.10 – 0.56; $p = 0.001$; level 4/high activation level – OR = 0.22; 95% CI 0.08 – 0.50; $p = 0.000$).

Conclusion:

Health professionals must be aware of health literacy and activation levels of patients with rheumatoid arthritis, given that interventions to improve them represent an opportunity to increase functional capacity.

Keywords: Functional capacity, Health literacy, Patient activation, Patient reported outcome measures, Rheumatoid arthritis, Shared decision making.

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1. INTRODUCTION

Rheumatoid Arthritis (RA) is a chronic, inflammatory, and autoimmune disease that affects mainly joints [1]. When the disease is not properly controlled, joint damage may occur, leading to irreversible incapacity in patients and a reduction in their quality of life [1, 2]. Pharmacological treatment of RA is complex and usually demands frequent changes in posology and type of drug [3, 4]. Given the several therapeutic alternatives available and the need to reduce the disease's activity up to remission and to offer the best possible care to patients, the current guidelines for RA treatment recommend that decisions be shared between patients and professionals [3, 5, 6].

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Shared decision-making has been seen as an essential component in the treat-to-target strategy [3, 7], an approach based on strict monitoring of the disease's activity and the promotion of changes in treatment if therapeutic goals are not reached by the established time [3, 5, 8]. This strategy has contributed to more patients with RA reaching and maintaining remission over the years [9]. However, achieving sustained remission remains a challenge for most patients, and improving shared decision-making can be a way to improve these results [9].

Many factors can influence shared decision-making, such as communication and the therapeutic relationship established between patients and health professionals, lack of knowledge and training about shared decision-making, the nature of decisions, disease type, patients' health literacy levels, and patients' motivation to have control over their health [10 - 13]. The present study directly addresses two of these factors: health literacy and active participation in care for patients with RA. Health literacy is a concept that encompasses how patients understand health information that they receive and how they use it to make decisions in the health care context [14]. Patient activation refers to their level of knowledge, confidence, and ability to commit to health self-management [15]. Therefore, health literacy and patient activation are closely related concepts that can be improved by the healthcare team and have been shown to influence shared decision-making and, consequently, functional capacity [11, 16 - 18].

Barton *et al.* [16] showed that low health literacy level in patients with RA were associated with deficient communication for sharing decisions. Additionally, engagement in treatment choices is one of the domains and is frequently found in patients with high activation levels [17]. Voshaar *et al.* [11] reinforced the idea that success in the treatment of patients with RA strongly depends on patient self-management, which is related to patient activation. A study carried out in the United States showed a strong association between low health literacy in patients with RA and reduced functional capacity [18].

The functional capacity of patients with RA is assessed by analyzing three domains centered on individuals: limitations, pain, and global health status [19]. The Health Assessment Questionnaire (HAQ) is used to measure functional capacity. This was one of the first instruments designed to measure results reported by the patients themselves; that is, it focuses on the perspective of persons who receive care [19]. Applying the HAQ helps to evaluate the effectiveness of RA treatment, given that maintenance of patients' functional capacity indicates good results, and its improvement over time is one of the benefits of sustained remission [4, 9, 20]. Therefore, the potential of improving functional capacity through the promotion of shared decision-making and the modifiable factors that can influence it, such as patient activation and health literacy, should be explored [21 - 23].

In a context of promotion of shared decision-making between health professionals and patients with RA, the objectives of the present study were to describe the functional capacity, health literacy, and activation level of these patients and evaluate the associations of health literacy and activation level with functional capacity.

2. MATERIALS AND METHODS

This was a cross-sectional study carried out in the rheumatology outpatient facility at a high-complexity teaching hospital that provided care to 395 patients with an RA diagnosis. A sample with 179 patients was selected, taking into account a 95% confidence level and a 5.45% margin of error for prevalence between 1.0 and 50.0%.

The participants included in the sample met the following inclusion criteria: being 18 years old or older, meeting the criteria defined by the American College of Rheumatology /European League Against Rheumatism in 2010 or by the American College of Rheumatology in 1987 for RA classification [24, 25], having at least one year of formal education and being able to read (patients who could sign their name but could not read were excluded), not having neurological or psychiatric disorders that affect cognition, and having enough visual acuity to read. The last three criteria were defined primarily by considering the skills necessary to perform the health literacy test.

The patients were invited to participate in the present study while they waited for medical care in the outpatient facility. The instruments were applied by the first author, and graduate and undergraduate pharmacy students were trained before the study was initiated. This study was approved by the Ethics Committee of the Federal University of Minas Gerais (UFMG) (process number CAAE-25780314.4.0000.5149). All participants provided signed informed consent.

2.1. Data Collection and Variables

Health literacy was measured by applying the short version of the Test of Functional Health Literacy in Adults (STOFHLA). The Brazilian version was translated and adapted by Carthery-Goulart *et al.* [26]. This tool had 36 questions to assess patients' reading comprehension and four items to evaluate numeracy. A weight equal to 2 was attributed to each reading comprehension item, totaling 72 points for this part, and a weight equal to 7 was attributed to each numeracy item, totaling 28 points. Consequently, the total score on the instrument was 100 points. Health literacy levels are defined as follows: 0 to 53 points; inadequate health literacy level; 54 to 66 points; marginal health literacy level; and 67 to 100 points; adequate health literacy level [27].

The Patient Activation Measure (PAM-13B) instrument, validated to be used in Brazil [17], was applied to assess patient activation. This instrument had 13 items, with each having an ordinal answer scale with five options: "Disagree Strongly" (1 point); "Disagree" (2 points); "Agree" (3 points); "Agree Strongly" (4 points); and "Not applicable" (0 points). Consequently, the number of points obtained by applying the tool might vary from 13 to 52. The obtained score was converted into a scale ranging from 0 to 100 points to determine the activation score. The conversion table was used, and score cutoffs were obtained by acquiring the license to use PAM-13B [28]. The PAM was a result measurement reported by patients. The higher the score, the higher the patient activation level. Levels 1 and 2 were classified as low activation, level 3 was categorized as moderate activation, and level 4 indicated high activation [29].

Functional capacity, another result measurement reported by patients, was assessed by using the Health Assessment Questionnaire Disability Index (HAQ-DI). This instrument had 20 questions encompassing eight components: dressing, arising, eating, walking, hygiene, reach, grip, and other usual activities. Each of the 20 questions had the following answer scale: "without any difficulty" (0 points); "with some difficulty" (1 point); "with much difficulty" (2 points); and "unable to do" (3 points). The HAQ-DI result was the sum of the highest scores in each component divided by 8; that is, the average of the highest scores in each component [4]. If the average obtained by a patient was between 0 and 1, it indicated that patient had mild to moderate difficulty; an average from 1 to 2 indicated moderate to severe limitation; and an average between 2 and 3 showed that they had severe to very severe limitation [19].

Sociodemographic variables data, such as gender, age, skin color, monthly income, level of education, cohabitation, marital status, and occupation, were collected by using a questionnaire designed and tested by the authors of the present study. This questionnaire also included a collection of data about the patients' reading habits, the need for help to manage their health, and a search for information about RA. Information about the type and number of health problems and medications taken were gathered by consulting the patients' medical records available at the studied facility.

2.2. Data Analysis

Descriptive data analysis was carried out by determining the absolute and relative frequencies of the qualitative variables, in addition to means and standard deviations of the quantitative variables.

For univariate and multivariate analyses, the dependent variable was functional capacity with moderate to very severe limitation (HAQ-DI scores > 1). Independent variables were gender, age (in whole years – continuous variable), skin color (black *vs.* brown *vs.* white – classification defined by the Brazilian Institute of Geography and Statistics), monthly income (up to one minimum wage *vs.* two to three minimum wages *vs.* more than three minimum wages), years of formal education (in complete years - continuous variable), cohabitation (yes *vs.* no), the number of medications used to treat RA (continuous variable), the number of medications used to control RA symptoms (continuous variable), health literacy level (adequate literacy *vs.* marginal literacy *vs.* inadequate literacy), patient activation (low activation *vs.* moderate activation *vs.* high activation), and other comorbidities (reported in the medical forms – zero to two diseases *vs.* three or more diseases, with the categorization based on the median). The diagnosis of depression, fibromyalgia, or osteoarthritis (yes *vs.* no in the three cases), and comorbidities of patients with RA that might affect the HAQ-DI result directly were also considered independent variables [30].

Logistic regression was used to perform univariate analysis. All the independent variables were included in the multivariate model and were calculated by applying stepwise logistic regression, despite the p-values obtained in univariate analysis, since this stepwise method, by itself, has a parsimonious model as the final result. This approach was adopted to allow the evaluation of all independent variables' behaviors in regard to the independent variable simultaneously. The Hosmer-Lemeshow test was carried out to evaluate the adjustment quality of the multivariate model. Univariate and multivariate analyses were based on Odds Ratio (OR) results and their respective 95% Confidence Intervals (95% CI), estimated by logistic regression. A 5% level of statistical significance was the criterion adopted to identify the characteristics independently associated with the dependent variable. All the collected data were entered into Excel® software spreadsheets and subsequently transferred to and organized in a Stata® version 12 software databank (StataCorp College Station, United States). This software was used to run all the analyses in the present study.

3. RESULTS

The sociodemographic questionnaire was applied to 225 patients. However, 46 of them were subsequently excluded from participating in the study as 26 had vision problems that led to reading difficulties, 18 were illiterate, and two were excluded because of a dementia diagnosis. Consequently, the final sample was composed of 179 patients, of whom 90.5% (n = 162) were women. Table **1** shows the sociodemographic and clinical characteristics of the patients. The participants' average age was 58.3 ± 11.4 years. Most of them had brown skin (55.9%; n = 100). Only 25 patients said that they lived by themselves (14%). The family income of 97 (54.2%) patients was between two and three minimum wages (the minimum wage in Brazil was $ 261.07 in 2018 and $ 252.97 in 2019). The average years of formal education of the participants were 7.8 ± 3.3 years.

Regarding RA pharmacotherapy, 91.6% of the patients took synthetic disease-modifying antirheumatic drugs (DMARDs) (n = 164), 48.6% used methotrexate (n = 87), 15.1% resorted to a combination of synthetic DMARDs (n = 27), and 36.3% took biological DMARDs (n = 65). Ninety-eight participants (54.8%) used prednisone (n = 98). One hundred patients (55.9%) had three or more health problems in addition to RA.

The average score obtained on the HAQ-DI was 1.08 ± 0.7, ranging from 0 to 2.875. Application of the STOFHLA instrument indicated that 53% of the patients had inadequate health literacy, 14% had marginal health literacy, and 33% had adequate health literacy. The participants' average reading comprehension score was 32.6 points, with the total score on this part of the instrument being 72 points. The average obtained for numeracy was 20.1 points out of a possible total score of 28 points. Approximately 70% of the patients reported that they did not use websites, social media, or other sources to get information about RA. The average activation score calculated by using the PAM-13B was 65.72, with 10.1% of the patients showing a very low activation level (level 1), 15.6% having a low activation level (level 2), 39.1% showing a moderate activation level (level 3), and 35.2% having a high activation level (level 4).

Table 1. Sociodemographic and clinical characteristics of 179 patients with rheumatoid arthritis who received care in the rheumatology service at a teaching hospital.

Characteristics	N (%) or Average Value
Average age in years (range)	58.3 (26 – 88)
Gender	-
Female	162 (90.5)
Skin color	-
Black	35 (19.5)
Brown*	100 (55.9)
White	44 (24.6)
Average time of formal education in years (range)	7.8 (2 – 17)
Activity	-
Employee	46 (25.7)
Homemaker	33 (18.4)
Unemployed	14 (7.8)
On leave/retired/annuitant	86 (48.1)
Marital status	-
Single	37 (20.7)
Married/in a common-law marriage	90 (50.3)
Divorced	21 (11.7)
Widow(er)	31 (17.3)
Cohabitation	-
Yes	154 (86.0)
Family income	-
Up to 1 minimum wage	59 (33.0)
2 to 3 minimum wages	97 (54.2)
> 3 minimum wages	23 (12.8)
Other health problems	-
0 to 2	79 (44.1)
3 to 7	100 (55.9)
Use of synthetic DMARDs	164 (91,6)
Methotrexate	87 (48.6)
Use of biological DMARDs	65 (36.3)
Use of JAK inhibitors (tofacitinib)	8 (4.5)
Use of prednisone	98 (54.8)
HAQ	-
Mild to moderate limitation – score 0 to 1	92 (51.4)
Moderate to severe limitation – score 1 to 2	70 (39.1)
Severe to very severe limitation – score 2 to 3	17 (9.5)
Health literacy	-
Inadequate	95 (53.1)
Marginal	25 (14.0)
Adequate	59 (32.9)
Activation level	-
Very low	18 (10.1)
Low	28 (15.6)
Moderate	70 (39.1)
High	63 (35.2)

*Brown: a term used to designate miscegenation among different Brazilian races;
HAQ = Health Assessment Questionnaire; JAK = Janus Kinase; DMARD = Disease-modifying Antirheumatic Drugs.

According to univariate analysis, adequate health literacy, PAM level 3 and 4 (moderate and high activation level, respectively) were associated negatively and in a statistically significant way ($p < 0.05$) with the presence of moderate to very severe limitation as indicated by the HAQ-DI (Table **2**). Brown skin, being older, and a higher number of medications used to control pain were positively associated with a reduction in functional capacity ($p < 0.05$).

Table 2. Results of univariate and multivariate analyses of the characteristics associated with moderate to severe limitation according to the functional capacity evaluation (HAQ), n = 179.

Variables		Univariate Analysis		Multivariate Analysis	
		OR (95% CI)**	p value***	OR (95% CI)#	p value##
CATEGORICAL	**Male gender**	0.55 (0.19-1.55)	0.254	0.29 (0.9-0.98)	0.047
	Skin color	-	-	-	-
	Black	-	-	-	-
	Brown	2.33 (1.06-5.16)	0.036	2.55 (1.28-5.08)	0.008
	White	0.97 (0.39-2.43)	0.943	-	-
	Monthly income (in minimum wages)	-	-	-	-
	Up to 1	-	-	-	-
	2 to 3	0.67 (0.35-1.28)	0.223	-	-
	> 3	0.51 (0.19-1.35)	0.175	-	-
	Cohabitation	1.50 (0.63-3.55)	0.356	-	-
	Patient activation	-	-	-	-
	Low	-	-	-	-
	Moderate	0.26 (0.12-0.60)	0.001	0.24 (0.10-0.56)	0.001
	High	0.20 (0.09-0.47)	0.000	0.20 (0.08-0.50)	0.000
	Adequate literacy	0.45 (0.53-0.99)	0.016	0.42 (0.20-0.86)	0.018
	Diseases that may affect HAQ	-	-	-	-
	Depression	2.24 (0.94-5.34)	0.069	-	-
	Fibromyalgia	1.93 (0.54-6.82)	0.310	-	-
	Osteoarthritis	1.17 (0.51-2.64)	0.714	-	-
	Number of other health problems	-	-	-	-
	0 to 2	-	-	-	-
	3 or more	1.80 (0.99-3.26)	0.055	-	-
CONTINUOUS	**Age**	1.03 (1.01-1.06)	0.013	-	-
	Years of formal education	0.95 (0.87-1.04)	0.230	-	-
	Number of medications to treat RA	0.67 (0.42-1.05)	0.083	0.64 (0.38-1.07)	0.089
	Number of medications to control symptoms	1.57 (1.10-2.25)	0.014	1.56 (1.05-2.31)	0.014

**Odds ratio (95% confidence interval): estimated by logistic regression;

***p-value: estimated by logistic regression;

#Odds ratio (95% confidence interval): estimated by stepwise logistic regression;

##p-value: estimated by stepwise logistic regression; statistically significant when < 0.05.

Multivariate analysis showed that gender, skin color, health literacy, patient activation, number of medications to treat RA, and number of medications to control pain remained in the final model. It indicated that a high HAQ-DI score had a negative association with adequate health literacy (OR = 0.42; 95% CI 0.20 – 0.86; p = 0.018) and higher activation levels (level 3/moderate activation level – OR = 0.24; 95% CI 0.10 – 0.56; p = 0.001; level 4/high activation level – OR = 0.22; 95% CI 0.08 – 0.50; p = 0.000).

4. DISCUSSION

The main results of the present study are pioneering, given that, to the authors' knowledge, there are no publications addressing the correlation between patient activation (as measured by the PAM) and functional capacity in the literature. Additionally, this is the first study carried out in Brazil to confirm a negative association between adequate health literacy and worse HAQ-DI scores in patients with RA.

The prevalence of patients with inadequate or marginal health literacy was high (67%) in the examined population. Gong *et al.* [31] and Hirsh *et al.* [32] used the same instrument to evaluate this parameter in patients with RA in studies conducted in Canada and the United States, respectively and found lower prevalence rates: 14.5% and 28%. In contrast, a study carried out in the United States with immigrants, people who did not speak English, and racial minorities also indicated a high frequency (71%) of patients with RA and limited health literacy [33]. Considering the average score in the STOFHLA obtained in the present study, the participants' performance in reading comprehension (average of 32.6 points out of a maximum score of 72 points) was poorer than their performance in numeracy (average of 20.1 points out of a maximum score of 28 points), which may suggest that they had more difficulty in reading and understanding general instructions about health than interpreting numeric aspects related to medical prescriptions and laboratory exams.

In the present study, the patients' average score on the PAM-13B, equal to 65.72, was higher than the average activation in patients with RA measured in investigations carried out in other countries [34, 35]. Joplin *et al.* [34], in a study conducted in Australia, obtained an average score of

60.01. In a study carried out in the Netherlands by Zuidema *et al.* [35], the average activation score was 47.8. Most of the patients included in the sample of the present study were classified as having level 3 activation, which means that they were already developing self-management skills and felt that they were part of the care team [29]. Although 53% of the patients showed inadequate health literacy, 74% had higher activation levels. Therefore, it is possible to infer that, despite these patients' difficulties with understanding information and applying it in the health context, they considered themselves able to learn the skills needed to manage their health, which may facilitate interventions designed to encourage them to engage in their self-care. There is already a RA choice decision aid tool for patients with RA and low health literacy in the literature. It helps increase these patients' knowledge and engagement [33]. Consequently, given a population in which more than half of the people show inadequate health literacy, it becomes necessary to identify them and consider the best strategies available to guarantee that shared decision-making is also accessible to them [33].

After control of the variables that might affect functional capacity in patients with RA, male gender, adequate health literacy, and high activation levels showed a negative, statistically significant, and independent association with moderate or severe limitation. In contrast, brown skin color and a higher number of medications to control pain correlated significantly and independently with worse functional capacity. The findings of the present study corroborated the results described by Caplan *et al.* [18], which indicated a strong association between inadequate health literacy and reduction in functional capacity. Also, adequate health literacy has been considered to be a significant predictor of better scores on the HAQ [36]. In the study carried out by Caplan *et al.* [18], the male gender was associated with lower scores on the HAQ, that is, with a lower functional limitation level. The negative association found in the present study between high activation levels and moderate to severe limitation furthers understanding of the factors associated with the functional capacity of patients with RA, and consequently, with control of the disease. Other studies addressing the association between the PAM and HAQ instruments for this group of patients have not been found to date.

The literature has pointed out racial and ethnic disparities in the results for the functional capacity of patients with RA, but they have not shown a well-defined standard [37 - 39]. In a study conducted in the United States in different settings, the authors found that African-American and Hispanic people obtained worse scores on the HAQ when compared with non-Hispanics white people [39]. However, this result was statistically significant in only one of the settings. In another study, Bruce *et al.* [37] observed a statistically significant worsening in functional limitation in African-Americans and Hispanics in comparison with the results for non-Hispanics white people. Yazici *et al.* [38] found that Hispanics showed scores on the HAQ that were significantly lower in comparison with the results calculated for African-Americans and white people. The variations found in different studies and different settings disproves the existence of a genetic or biological basis for the observed racial and ethnic differences [39].

The number of medications used to treat RA did not remain in the adjusted model, which may indicate that variations in RA pharmacology do not correlate directly with functional capacity. Alternatively, as expected, increased use of medications to control pain, which may point to worsening disease control, was associated with worsening limitation.

The present study has some limitations. One is a consequence of the study setting. It took place in a teaching hospital that is a reference center for the treatment of patients with RA in the public health system and usually receives patients with a more severe condition and a less favorable disease prognosis. Another limitation was using medical records for the collection of data about the medications being used and health issues; as a secondary source kept at a specialized service, these records might present incomplete information. Also, specific variables associated with disease duration, disease activity, and disease severity were not collected in the present study. On the other hand, it is important to acknowledge that HAQ was evaluated, and it indirectly reflected these aspects of the disease as previously demonstrated by Verstappen *et al.* [40] and even in a Brazilian sample by Medeiros *et al.* [41]. Lastly, it must be taken into account that the cross-sectional design of the present study does not allow the determination of causality. However, the study showed that there is a significant association between health literacy, patient activation, and functional capacity that should be further explored in a longitudinal perspective. Thus, the study limitations are counteracted by its contribution to the understanding of the factors associated with functional capacity in patients with RA in a real-world setting.

Considering that gender and skin color are nonmodifiable factors, the findings of the present study reinforce the idea that health professionals should identify and be aware of health literacy and activation levels of patients with RA, given that interventions to increase these measures are an opportunity to improve functional capacity.

CONCLUSION

The present study contributes to the understanding of the factors associated with the functional capacity of patients with rheumatoid arthritis. Adequate health literacy and high activation levels of patients were negatively associated with the presence of moderate to severe limitation as measured by the Health Assessment Questionnaire, indicating a potential protective factor.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was approved by the Ethics Committee of the Federal University of Minas Gerais (UFMG) Brazil. (process number CAAE-25780314.4.0000.5149).

HUMAN AND ANIMAL RIGHTS

No Animals were used in this research. All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the

Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

All participants provided signed informed consent.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study will be made available upon request to the corresponding author (IVO).

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CONFLICT OF INTEREST

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