

RESEARCH ARTICLE (ORIGINAL) 8

Functional autonomy as a determinant of quality of life in people with rheumatoid arthritis

A autonomia funcional como determinante da qualidade de vida em pessoas com artrite reumatóide

La autonomía funcional como determinante de la calidad de vida en personas con artritis reumatoide

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Abstract

Background: Rheumatoid arthritis (RA) is a chronic, progressive, and potentially disabling autoimmune disease. Self-care activities relieve symptoms and complications of diseases and reduce recovery time and hospital admission rates.

Objective: To assess the association between functional autonomy and quality of life (QOL) in people with RA.

Methodology: Descriptive, analytical-correlational, and cross-sectional study, developed in the northern region of Portugal, with a sample of 139 people with RA (79.86% women). The data collection instrument included a sociodemographic characterization, the Health Assessment Questionnaire (assessment of functional autonomy), and the EQ-5D Questionnaire (assessment of QOL).

Results: The mean value of disability was 1.029 (moderate disability), with 48.9% of the sample showing mild disability, 43.2% moderate disability, and 7.9% severe disability. 90.6% of participants had a reasonable QOL, and 9.4% had a poor QOL. People with greater disability and consequently less functional autonomy have lower QOL.

Conclusion: Functional autonomy impacts QOL, influencing it positively. Nursing interventions need to be adjusted to the needs of patients with RA to promote their autonomy.

Keywords: arthritis, rheumatoid; functional autonomy; quality of life

Resumo

Enquadramento: A artrite reumatóide (AR) é uma doença autoimune, crónica, progressiva e potencialmente incapacitante. As atividades de autocuidado aliviam os sintomas e complicações das doenças, reduzem o tempo de recuperação e a taxa de hospitalização.

Objetivos: Avaliar a relação da autonomia funcional com a qualidade de vida (QDV) em pessoas com AR.

Metodologia: Estudo descritivo, analítico-correlacional e transversal, desenvolvido na região norte de Portugal, com amostra de 139 pessoas com AR (79,86% mulheres). Instrumento de colheita de dados, onde consta: caracterização sociodemográfica; escala *Health Assessment Questionnaire* (avaliação da autonomia funcional) e Questionário EQ-5D (avaliação da QDV).

Resultados: O valor médio de incapacidade foi de 1,029 (incapacidade moderada), apresentando 48,9% da amostra incapacidade leve, 43,2% moderada e 7,9% elevada. Pontuaram com razoável QDV 90,6% dos participantes e 9,4% com fraca. As pessoas com maior incapacidade, logo menor autonomia funcional, apresentam menor QDV.

Conclusão: A autonomia funcional impacta a QDV, influenciando-a positivamente. As intervenções de enfermagem carecem de ser ajustadas às necessidades da pessoa com AR na promoção da autonomia.

Palavras-chave: artrite reumatóide; autonomia funcional; qualidade de vida

Resumen

Marco contextual: La artritis reumatoide (AR) es una enfermedad autoinmune, crónica, progresiva y potencialmente incapacitante. Las actividades de autocuidado alivian los síntomas y las complicaciones de la enfermedad, reducen el tiempo de recuperación y la tasa de hospitalización.

Objetivo: Evaluar la relación de la autonomía funcional con la calidad de vida (CDV) en personas con AR.

Metodología: Estudio descriptivo, analítico-correlacional y transversal, desarrollado en la región norte de Portugal, con una muestra de 139 personas con AR (79,86% mujeres). Se usó un instrumento de recogida de datos, donde consta: caracterización sociodemográfica; escala *Health Assessment Questionnaire* (evaluación de la autonomía funcional) y Cuestionarios EQ-5D (evaluación de la CDV).

Resultados: El valor medio de incapacidad fue de 1,029 (incapacidad moderada), el 48,9% de la muestra presentó incapacidad leve, el 43,2% moderada y el 7,9% elevada. El 90,6% de los participantes puntuaron la CVD como razonable y el 9,4% como mala. Las personas con mayor incapacidad, por lo tanto, menor autonomía funcional, presentan menor CDV.

Conclusión: La autonomía funcional impacta la CDV e influye en ella de forma positiva. Las intervenciones de enfermería deben ajustarse a las necesidades de la persona con AR para promover su autonomía.

Palabras clave: artritis reumatoide; autonomía funcional; calidad de vida



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Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory multisystem autoimmune disease that causes physical symptoms such as pain, joint stiffness, joint swelling, and deformities, as well as psychological symptoms including fatigue and depression (Shin, 2020). These symptoms lead to significant limitations that turn simple daily activities into challenges (Shao et al., 2020) and have a disruptive effect on family and societal experiences, self-concept, and moods (Ribeiro et al., 2020). Self-care activities alleviate the symptoms and complications of diseases and reduce recovery time and hospital admission and readmission rates (Santos et al., 2017).

Monitoring and managing quality of life (QOL) in people with RA is a challenge to reducing the impact of the disease itself.

This study contributes to the characterization of its target population and the development of e-Nursing interventions foreseen in a broader study where this one is included.

This study assesses the association between functional autonomy and QOL in people with RA assisted in the rheumatology consultation of a hospital unit in northern Portugal.

Background

RA is a chronic, progressive, autoimmune disease that is potentially disabling (Sousa et al., 2017). The causes are still unknown but, as an autoimmune condition, it occurs when the body suffers from dysregulation of the immune system and reacts against its structures (Figueiredo & Martins, 2016). In RA, the primary target is the synovial tissue. According to the Portuguese Society of Rheumatology (*Sociedade Portuguesa de Reumatologia*, SPR), at an early stage, this disease causes inflammation of the peripheral joints, especially in the joints of the hands and feet. As disease progresses, more joints can be affected, including shoulders, elbows, hips, and knees, leading to joint and periarticular tissue destruction (Rocha, 2019), which can cause deformities. These deformities cause asymmetry and have a significant impact on patients' functional autonomy, independence, and quality of life (Figueiredo & Martins, 2016).

RA affects 0.5% of the adult population worldwide, with a prevalence of 0.7% in Portugal (Sousa et al., 2017). It is two to four times more prevalent in women than in men, with its peak occurring after menopause. Despite this, it should be noted that it can occur at any age, including in adolescence (Figueiredo & Martins, 2016). Its clinical presentation is very heterogeneous and systemic, including joint inflammation and symptoms such as pain, fatigue, morning stiffness, loss of muscle strength, loss of joint range of motion, changes in sleep quality, or depression (Sousa et al., 2017). These symptoms have a significant impact on these patients' quality of life, requiring the development and adoption of self-care-promoting behaviors to improve quality of life (Ribeiro et al., 2020).

Functional autonomy comprises three aspects: autonomy of action, autonomy of will, and autonomy of thoughts. This study will assess the first meaning - autonomy of action - related to physical independence or ability to perform day-to-day tasks (Bravo et al., 2018), here perceived as self-care.

Dorothea Orem has conceptually defined self-care as an action performed by individuals themselves or others to maintain life, health, and well-being (Orem, 2001). The limitations experienced by people with RA reflect psychological and social effects, including interruptions in work capacity, social roles, and dependence, that compromise family functioning, activities of daily living (ADLs), self-concept, and mood, leading to psychological suffering (Ribeiro et al., 2020).

Therefore, self-care and self-management should be part of these patients' daily lives, involving intentional activities to prevent diseases and slow their progression (Ribeiro et al., 2020). SPR (2019) recommends exercises such as low-impact aerobic exercise, flexibility exercises, and mobilization of hands, feet, upper limbs, and lower limbs to improve joint range of motion and relieve pain. On the other hand, patients should avoid being exposed to extreme temperatures, wear clothes appropriate to room temperature, and use temperature control equipment. They should maintain a healthy body weight because being overweight increases pressure on the joints, aggravates complaints, and limits physical activity.

Due to the significant impact of RA on patients' lives, it is important to understand, assess, monitor, and intervene actively using several instruments to establish the diagnosis and determine disease activity, affected needs, and therapeutic effectiveness. Thus, appropriate and recommended interventions can be designed to improve QOL, which is a complex concept focused on several determinants such as physical and psychological health, level of independence, social interactions, personal beliefs, and environment, and may be defined as an individual's perception of their nature, position in life, goals, and concerns (Martinec et al., 2019).

Research question

What is the association between functional autonomy and QOL in people with RA assisted in the rheumatology consultation of a hospital unit in northern Portugal?

Methodology

A descriptive, analytical-correlational study was conducted using a cross-sectional approach. The nonprobability convenience sample consisted of 139 people with RA assisted in the rheumatology consultation of a hospital unit in northern Portugal between February and March 2020. This study is part of a broader research study entitled "Development and Feasibility of an e-Nursing Intervention with People with Rheumatoid Arthritis: Continuity of Care", whose methodological design fol-

lows the Medical Research Council (MRC) guidelines for complex interventions (Craig et al., 2008; Bleijenberg et al., 2018). It is part of the first step of the methodological framework: modeling intervention components and defining outcomes.

Sociodemographic variables, functional autonomy, and quality of life were assessed through the application of an *ad hoc* sociodemographic questionnaire and scales: Health Assessment Questionnaire (Santos et al., 1996): It assesses functional autonomy as autonomy of action, self-care activities. It consists of 20 questions in eight categories of activities (dressing, arising, eating, walking, hygiene, reach, grip, and usual activities). The disability index (DI) is obtained based on the patient's answer to each of the questions on a 0-3 scale, where 0 - *without any difficulty*; 1 - *with some difficulty*; 2 - *with much difficulty*; 3 - *unable to do*. The total score is obtained by calculating the mean of the eight categories. Thus, a score of 0-1 indicates *mild disability*, 1-2 *moderate disability*, and 2-3 *severe disability*. The lower the score, the greater the functional autonomy of the person with RA.

EQ-5D Questionnaire, Portuguese version (*Avaliação de Ganhos em Saúde*), 1997, 2013, EQ-5D-v2 (EuroQoL Group, 1987, validated by the Center for Health Studies and Research of the University of Coimbra). This questionnaire assesses QOL by combining two key components of any health-related quality of life measure used in cost-utility analyses: (a) a profile describing the health status in terms of domains or dimensions; (b) a numerical value associated with the health status described (Ferreira et al., 2014). The descriptive system defines health in five dimensions: Mobility, Self-Care, Usual activities, Pain/discomfort, and Anxiety/Depression. Each dimension has three levels: *no problems* (level 1), *some problems* (level 2), and *extreme problems* (level 3) experienced or felt by the individual. Thus, this system allows describing a total of $3^5 = 243$ different health states. Respondents are also asked to rate their overall health status on a visual analog scale from 0 (the worst imaginable health) to 100 (the best imaginable health), often called EQ-VAS thermometer. The Ethics Committees of the School of Health of Viseu and the hospital unit where the study was conducted gave a favorable opinion (reference no. 03/20/05/2019), and the hospital unit's Board of Directors authorized data collection. The rights of self-determination, intimacy,

anonymity, and confidentiality were ensured, and all participants signed an informed consent form.

The information in the data collection tools (questionnaire and scales) was encoded for further statistical treatment using IBM SPSS Statistics, version 24.0.

Data were analyzed using descriptive statistics to determine absolute and relative frequencies, measures of location (mean), and measures of variability (coefficient of variation and standard deviation). The Chi-Square Test of Independence and Fisher's Test were used for categorical variables.

The association between quality of life and functional autonomy was explored using analysis of variance (ANOVA). Statistical significance was set at $p < 0.05$.

Results

The sample consisted of 139 people with RA. The majority of them were women (79.86%; $n = 111$), aged 26 to 85 years, with a mean age of 63.05 years ($SD = 12.241$) and a moderate dispersion around the mean ($CV = 19.4\%$). The majority of the sampled participants were married (69.1%; $n = 96$), lived in a rural environment (79.1%; $n = 110$), practiced a religion (88.5%; $n = 123$), and attended school up to 4th grade (61.9%; $n = 86$). The results showed that 58.3% ($n = 81$) of them were retired or unemployed, classified as *not professionally active* (7.2% men and 51.1% women), and 41.7% ($n = 58$) remained professionally active.

The study of functional autonomy using the Health Assessment Questionnaire revealed that people with RA were unable to "Reach and get down a 5-pound object from just above your head" (12.9%; $n = 18$), followed by "Open jars which have been previously opened" (5.8%; $n = 8$), "Open a new milk carton" (5.8%; $n = 8$), and "Run errands and shop" (4.3%; $n = 6$). Patients with RA reported having much difficulty "Climb up 5 steps" (23.0%; $n = 32$). It should also be noted that 44.6% ($n = 62$) had some difficulty in "Dress yourself, including tying shoelaces and doing buttons". On the other hand, participants reported "Lift a full cup or glass to your mouth" and "Turn faucets on and off" without any difficulty, with percentage values of 63.3% ($n = 88$) and 60.4% ($n = 84$), respectively (Table 1).

Table 1*Characterization of the level of difficulty related to functional autonomy*

Variables	Without any difficulty		With some difficulty		With much difficulty		Unable to do	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Dressing								
Dress yourself, including tying shoelaces and doing buttons	59	42.4	62	44.6	18	12.9	0	0.0
Shampoo your hair	67	48.2	53	38.1	18	12.9	1	0.7
Arising								
Stand up from a straight chair	62	44.6	56	40.3	20	14.4	1	0.7
Get in and out of bed	61	43.9	60	43.2	17	12.2	1	0.7
Eating								
Cut your meat	50	36	58	41.7	27	19.4	4	2.9
Open a new milk carton	57	41	46	33.1	28	20.1	8	5.8
Lift a full cup or glass to your mouth	88	63.3	42	30.2	9	6.5	0	0.0
Walking								
Walk outdoors on flat ground	71	51.1	50	36	16	11.5	2	1.4
Climb up five steps	53	38.1	52	37.4	32	23	2	1.4
Hygiene								
Wash and dry your body	67	48.2	56	40.3	15	10.8	1	0.7
Take a tub bath	66	47.5	57	41	14	10.1	2	1.4
Get on and off the toilet	67	48.2	54	38.8	16	11.5	2	1.4
Reach								
Reach and get down a 5-pound object from just above your head	42	30.2	48	34.5	31	22.3	18	12.9
Bend down to pick up clothing from the floor	55	39.6	53	38.1	26	18.7	5	3.6
Grip								
Open car doors	75	54	50	36	9	6.5	4	2.9
Open jars which have been previously opened	57	41	56	40.3	18	12.9	8	5.8
Turn faucets on and off	84	60.4	42	30.2	12	8.6	1	0.7
Usual activities								
Run errands and shop	64	46	46	33.1	22	15.8	6	4.3
Get in and out of a car	63	45.3	54	38.8	19	13.7	2	1.4
Do the chores such as vacuuming or yardwork	53	38.1	56	40.3	26	18.7	4	2.9

The activities in which participants required more help were “Housework and shop” (35.3%; *n* = 9), followed by the activities “Gripping and opening things” (27.3%; *n* = 38) and “Reaching” (24.5%; *n* = 34). The most widely used aids were “devices used for dressing” (12.9%; *n* = 18), “long-handled appliances for personal hygiene” (9.4%; *n* = 13), “bath handles” (8.6%; *n* = 12), and “canes or crutches” to walk and “adaptations in their homes or utensils” (7.9%; *n* = 11).

As already mentioned, the EQ-5D instrument was used to assess quality of life. The health status of people with RA was explored in two ways. In the first phase, participants were asked to rate their health status on the

day of data collection using a scale (EQ-VAS) where 0 corresponded to the worst imaginable health and 100 to the best imaginable health. A mean value of 60.25 ± 24.86 mm was obtained. In the second phase, the five dimensions of the scale were assessed. The dimension of Participants had more problems in the Pain/discomfort dimension (51.8% had *some problems* and 12.9% had *extreme problems*), thus contributing to the decrease in the quality of life of the person with RA. The majority of participants reported having *no problems* (level 1) in the other dimensions. Few patients with RA reported *extreme problems*. Therefore, the vast majority had no or some problems (Table 2).

Table 2

Characterization of the quality of life of people with rheumatoid arthritis

Dimensions	No problems		Some problems		Extreme problems	
	<i>N</i>	%	<i>n</i>	%	<i>n</i>	%
Mobility	76	54.7	59	42.4	4	2.9
Self-care	83	59.7	51	36.7	5	3.6
Usual activities	73	52.5	59	42.4	7	5
Pain/discomfort	49	35.3	72	51.8	18	12.9
Anxiety/depression	95	68.3	36	25.9	8	5.8

The majority of the sample had a reasonable quality of life (90.6%; *n* = 126), and 9.4% (*n* = 13) of patients with RA reported *poor* quality of life. Moreover, 72.7% (*n* = 101) of women, compared to 18.0% (*n* = 25) of men, had a *reasonable* quality of life. None of the respondents obtained an index compatible with *perfect health*. A mean value of 1.029 was obtained for functional auton-

omy, corresponding to a *moderate* disability, with 48.9% having a *mild* disability, hence increased functional autonomy, 43.2% *moderate* disability, and 7.9% *severe* disability. The results also showed that the quality of life of people with RA increases as functional disability decreases, with strong statistically significant evidence ($F = 38,116$; $p = 0.00$; Table 3).

Table 3

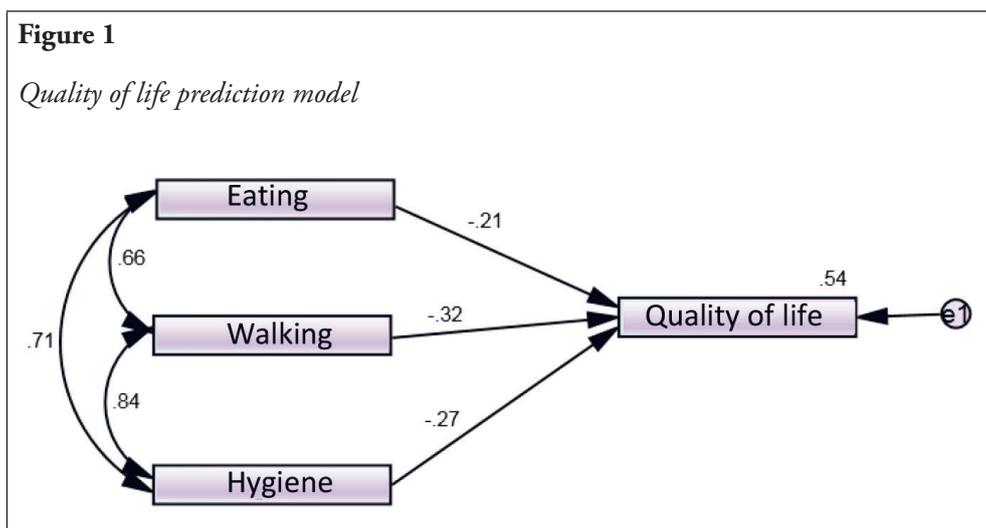
Association between quality of life and functional (dis)ability

QOL	Functional (Dis) Ability	Mild Disability (<i>n</i> = 68)	Moderate Disability (<i>n</i> = 60)	Severe Disability (<i>n</i> = 11)	ANOVA F	<i>p</i>
		OM	OM	OM		
		93.91	49.81	32.32	38.116	0.00

Note. QOL = quality of life; F = Fisher's test; $p < 0.05$ = statistically significant difference; $p \geq 0.05$ = statistically non-significant difference.

Of the eight assessed dimensions (Dressing, Rising, Eating, Walking, Hygiene, Reach, Grip, and Usual Activities), only

Hygiene, Walking, and Eating predicted the quality of life of people with RA, explaining 54% of variance (Figure 1).



Discussion

RA has significant physical, psychological, and social implications associated with a decline in functional autonomy and quality of life (Branco et al., 2016). This study assessed the functional autonomy and quality of life of people with RA and the association between them, showing that the symptomatology of this disease is associated not only with physical deterioration but also with impaired emotional and psychological health and, consequently, impaired quality of life. The sample consisted mostly of women with a mean age of 65.46 years, which is consistent with other studies (Branco et al., 2016, Cunha et al., 2016, Santos et al., 2019).

The nosological implications of RA, such as pain, reduce functional autonomy, which inevitably influences quality of life and average life expectancy (Branco et al., 2016). Functional autonomy is moderately preserved in this sample given that 48.9% of participants had a mild disability and 43.2% had a moderate disability, which are results similar to those reported in other studies (Santos et al., 2019).

This study found that some patients with RA were unable to perform activities such as reaching and grabbing objects, shopping, and doing errands. It also found that some patients had major difficulties in performing ADLs that are crucial in the daily lives of human beings, namely eating, walking, dressing and undressing, standing up, and personal hygiene. Their inability to perform ADLs as a result, among others, from the painful disease process is reflected in their capacity to perform self-care.

On the other hand, using instruments in everyday life helps these patients perform ADLs, promotes their independence, and mobility, and delays disease progression. People with RA tend to experience greater difficulties in physical activity, although it helps control the symptoms of their disease (Santana, 2014). They also tend to be less physically active than the healthy population, with a sedentary lifestyle, together with the disease process, being associated with reduced muscle mass and increased visceral fat, which can increase systemic inflammation and cause several inflammatory problems (Santana, 2014).

People with RA - the target of the study - who have more functional autonomy also have a better quality of life, with significant evidence ($F = 38,116$; $p = 0.00$). Concerning quality of life, 90.6% of participants rated their quality of life as reasonable, only 9.4% as poor, and none of them had an index compatible with *perfect health*. These results corroborate the premise that functional disability in self-care activities negatively influences the health status/quality of life of people with RA (Katchamart, 2019).

Although most of the studies consulted point to a positive association between functional autonomy and quality of life, participants reported low levels of quality of life (Seca et al., 2019).

The high percentage of participants with a reasonable quality of life in this sample may be because they were, on average, over 65 years of age and may have accepted their condition and acquired strategies throughout their lives to cope with their limitations.

Therefore, understanding the predictive factors of quality of life is crucial for health services and professionals to manage disease activity. It should be noted that health promotion plays a key role in increasing patients' ability to cope with their disease process. Among others, the level of literacy is particularly important because, when high, it is associated with lower scores in the Health Assessment Questionnaire, that is, greater functional autonomy (Branco et al., 2016).

Educating patients/caregivers, relieving disease-related symptoms, reducing disability and disease progression, and promoting physical and mental health are key pillars of a contemporary, holistic scientific nursing practice. It can be concluded that the singular mission of nursing contributes to the effective and efficient management of RA treatment, facilitating and promoting self-care activities that are crucial to the patient's well-being (Ribeiro et al., 2020).

Although this study extends existing knowledge on the impact of RA on the quality of life of patients with RA, it has some limitations: it was limited to a specific region in Portugal and the data collection period, due to the pandemic, limited sample size (139).

We believe that increasing the number of participants in the future can optimize the results.

The positive aspects include the 80% rate of participation and the concomitant diagnosis of care needs during the research process, which led to patient referral, the anticipation of consultations, and, consequently, health gains.

Conclusion

Functional autonomy proved to be a predictor of quality of life, being positively associated with it, specifically in the dimensions Eating, Walking, and Hygiene.

Health-related quality of life is presented as a complex and broad concept centered on physical and psychological health, level of independence, social interactions, personal beliefs, and the environment. Therefore, despite the potential negative impact of loss of functional autonomy on the quality of life of patients with RA, there is an urgent need to develop treatment strategies that significantly improve their daily lives, ensuring a more effective control of the disease.

Nursing interventions adjusted to the needs of patients with RA should also be developed to promote their functional autonomy and quality of life. The nosological entities under analysis should also be considered when planning educational/training interventions for patients, families/caregivers, and health professionals.

Lines for further research include auditing clinical practices, assessing the continuity of care, and involving the academy and the therapeutic community in monitoring patients' needs and satisfaction.

Author contributions

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