

RHEUMATOID ARTHRITIS, SELF-CARE, AND PHARMACOLOGICAL TREATMENT: A SCOPING REVIEW

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Highlights:

(1) Four groups were identified: individual, disease-related, treatment-related and third-party. (2) The presence or fear of side effects was the most frequently reported factor. (3) Individualized assessment allows for the identification of specific factors for each person. (4) The use of Dorothea Orem's Theory may enhance interventions.

PRE-PROOF

(as accepted)

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ABSTRACT

Objective: To summarize the evidence on pharmacological treatment and its relationship with self-care in individuals with rheumatoid arthritis. **Method:** This scoping review was conducted in the first half of 2023. Articles published since 1985 were included, covering indexed journals, gray literature, and reference lists, with no language restrictions. Study selection was performed using Rayyan software, and data were extracted using a standardized questionnaire in Excel. The protocol was registered on the Open Science Framework (doi.org/10.17605/OSF.IO/H3SZK). **Results:** A total of 31 studies published between 1999 and 2022 were retrieved, mostly cross-sectional and published in English. The most frequently reported factors related to pharmacological treatment and changes in self-care included medication side effects, number of medications, indefinite treatment duration, self-medication, knowledge of treatment, positive treatment effects, as well as fear and negative beliefs. **Conclusion:** The relationship between self-care and pharmacological treatment in individuals with rheumatoid arthritis involves multiple variables. An individualized approach may facilitate the understanding of specific factors for each person and support the management of improved self-care.

Keywords: Rheumatoid Arthritis; Self-Care; Pharmacological Treatment; Rheumatic Diseases; Nursing.

INTRODUCTION

Rheumatoid arthritis (RA) is a disease that may have a genetic, epigenetic, infectious, or hormonal etiology, causing inflammatory changes in the synovial tissue of the joints, cartilage, bone, and extra-articular sites¹. The clinical manifestations of RA include symmetrical joint pain, morning stiffness, swelling, warmth, erythema, joint involvement, hand and foot deformities, as well as extra-articular symptoms².

The global age-standardized prevalence of RA in 2019 was estimated at 12.21 per 100,000 people³. In Brazil, the average prevalence in 2019 was 7.57 per 100,000 people. Prevalence increases with age, particularly among individuals over 60 years old, those who identify as white, and residents of urban areas⁴.

Pharmacological treatment involves the use of disease-modifying antirheumatic drugs (DMARDs), biological DMARDs (bDMARDs), and targeted synthetic DMARDs

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(tsDMARDs). Nonsteroidal anti-inflammatory drugs (NSAIDs), opioid and non-opioid analgesics, immunosuppressants, and systemic corticosteroids may also be used for symptomatic treatment⁵.

Self-care is defined by Dorothea Orem as the care performed by an individual for themselves. The individual who engages in self-care is referred to as the self-care agent and possesses essential capabilities to carry out self-care actions. The Self-Care Deficit Nursing Theory is the core of Orem's general theory, composed of three interrelated theories: self-care, self-care deficit, and nursing systems⁶.

Nurses should apply practical knowledge to determine how an individual can engage in self-care within their life context and support networks. The theory includes four main operations in practice: diagnostic, prescriptive, treatment or regulatory, and case management. It has been used as a framework for interventions in chronic conditions, primarily focused on improving quality of life, with even greater potential in advanced nursing practice⁷. Due to its disabling symptoms, RA leads to decreased quality of life, functional impairment, and loss of productivity—factors that directly affect self-care and may increase healthcare system costs⁸.

Among individuals' perspectives on their self-management support needs is the impact of pharmacological treatment⁹. Medication side effects and the complexity of the therapeutic regimen may hinder the adoption of self-care behaviors, while treatment and schedule flexibility may serve as facilitators¹⁰.

The objective of this study was to summarize the evidence on pharmacological treatment and its relationship with self-care in individuals with RA.

METHOD

This is a scoping review. This type of review aims to map the main concepts that support a research area and, as it examines a broader field, it can identify gaps in the knowledge base, clarify key concepts, and report the types of available evidence¹¹. The guiding question of the review was formulated using the PVO strategy (Population – individuals with RA, Variable – pharmacological treatment, and Outcome – self-care): “What is the evidence on the relationship between pharmacological treatment and self-care in individuals with RA?”

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The research was conducted in the first half of 2023. Full articles, theses, and dissertations were included. The reference lists of the selected publications were reviewed to identify all relevant studies on the topic of interest. There were no language restrictions. Studies published from 1985 onward (the year of the final publication of Orem's Self-Care Deficit Theory) were included. Unfinished articles, duplicates (considered only once), and publications such as letters to the editor, editorials, and expert opinions were excluded.

To formulate the search strategy, an initial search was conducted in two databases (PubMed and CINAHL) to verify the existence of relevant articles and to identify the most frequently used keywords. The following keywords were then selected for this study: RA and drug therapy and self care. Uncontrolled descriptors were not added, as they did not improve the sensitivity of the search. Tests to exclude these descriptors were performed in both aforementioned databases. The search engines and databases used, as well as the search strategies, are described in Table 1.

Table 1 – Search strategies in search engines and databases. Brazil, 2024.

Search Engines / Databases	Search Strategy
Embase	#1 'rheumatoid arthritis'/exp AND 'drug therapy'/exp AND 'self care'/exp AND [article]/lim
Scopus	#1 (ALL("rheumatoid arthritis") AND ALL("drug therapy") AND ALL("self care")) AND (LIMIT-TO(DOCTYPE, "ar"))
PubMed	#1 (("Arthritis, Rheumatoid"[Mesh]) AND "Drug Therapy"[Mesh]) AND "Self Care"[Mesh]
Web of Science	#1 ((ALL=(arthritis, rheumatoid)) AND ALL=(drug therapy)) AND ALL=(self care)
CINAHL	#1 arthritis, rheumatoid AND (drug therapy OR pharmacotherapy OR medications OR drugs) AND (self care OR self-care OR self-management OR self management)
BVS	#1 (Arthritis, Rheumatoid) AND (Drug Therapy) AND (Self Care) #2 (Artrite Reumatoide) AND (Tratamento Farmacológico) AND (Autocuidado)
Opengrey	#1 "rheumatoid arthritis" AND "self care" #2 "rheumatoid arthritis" AND "drug therapy" #3 "Reumatoide artritis" AND "drugs therapie" #4 "Reumatoide artritis" AND "zelfzorg"
CAPES Theses and Dissertations Portal	#1 "Artrite Reumatoide" AND "Tratamento Farmacológico" #2 "Artrite Reumatoide" AND Autocuidado #3 "Rheumatoid Arthritis" AND "Drug Therapy" #4 "Rheumatoid Arthritis" AND "Self Care"
RCAAP	#1 "Artrite Reumatoide" AND "Tratamento Farmacológico" #2 "Artrite Reumatoide" AND "Autocuidado" #3 "Rheumatoid Arthritis" AND "Drug Therapy" #4 "Rheumatoid Arthritis" AND "Self Care"
ETD Portal	#1 "Rheumatoid Arthritis" AND "Drug Therapy" AND "Self Care" #2 "Rumatoide artritis" AND "Dwelinterapie" AND "Selfsorg"

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Trove	#1 "Rheumatoid Arthritis" AND "Drug Therapy" #2 "Rheumatoid Arthritis" AND "Self Care"
DART	#1 "Rheumatoid Arthritis" AND "Drug Therapy" #2 "Rheumatoid Arthritis" AND "Self Care"
Theses Canada	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
EThOS	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
DIVA	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
OASISbr	#1 Artrite Reumatoide AND Tratamento Farmacológico #2 Artrite Reumatoide AND Autocuidado #3 Rheumatoid Arthritis AND Drug Therapy #4 Rheumatoid Arthritis AND Self Care
DOKS	#1 Reumatoide artritis
Theseus	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
Melinda	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
Thèses	#1 Polyarthrite rhumatoïde AND Drug Therapy #2 Polyarthrite rhumatoïde AND Self-Care
Deutsche Nationalbibliothek	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
HKU Theses Online	#1 Rheumatoid Arthritis
Global ETD	#1 "Rheumatoid Arthritis" AND "Drug Therapy" #2 "Rheumatoid Arthritis" AND "Self Care"
BASE	#1 "Rheumatoid Arthritis" AND "Drug Therapy" #2 "Rheumatoid Arthritis" AND "Self Care"
TesiOnline	#1 Artrite Reumatoide AND terapia farmacologica AND automedicazione
JAIRÓ	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care
CiNii Dissertations	#1 Rheumatoid Arthritis AND Drug Therapy #2 Rheumatoid Arthritis AND Self Care

*Searches were performed using only one descriptor, as the addition of others yielded no results.

Source: Prepared by the authors.

The search strategies were reviewed by a researcher with experience in review studies. Study selection was carried out by two reviewers using the Rayyan software; in cases of disagreement, a third reviewer was involved. Data extraction was performed using Excel, collecting the following variables: title, authors, year of publication, study location, objectives, study design, evidence on the relationship between pharmacological complexity and self-care, and study limitations. The level of evidence was structured according to the Joanna Briggs Institute¹².

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Review protocol registered in the Open Science Framework (OSF), DOI: <https://doi.org/10.17605/OSF.IO/H3SZK>. The review report was prepared in accordance with the PRISMA Extension for Scoping Reviews (PRISMA-ScR)¹³ and the Flow Diagram¹⁴.

RESULTS

A total of 33 studies were retrieved, with 23 (69.7%) obtained from data sources and gray literature, and 10 (30.3%) identified through reference list analysis. The flow of study retrieval and selection is described in Figure 1.

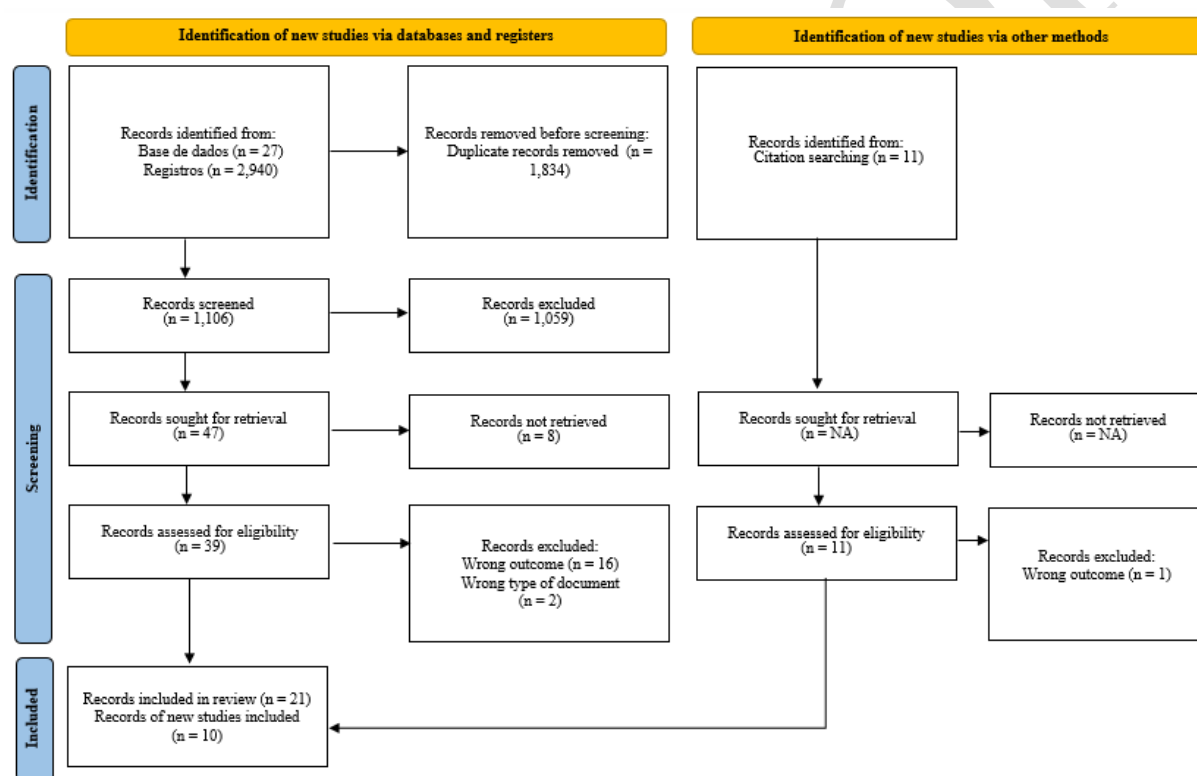


Figure 1 – Flow Diagram of the database and reference list searches. Brazil, 2024. Source: Prepared by the authors using the Flow Diagram¹⁴.

The search results from each search engine and database were as follows: Scopus (215); CINAHL (136); PubMed (58); Embase (62); Web of Science (115); BVS (273); Opengray (1); CAPES Theses and Dissertations Portal (7); RCAAP (64); ETD (13); Trove (197); E-teses (17); Theses Canada (52); EThOS (10); DIVA (175); OASISbr (255); DOKS (24); Theseus (277); Melinda (110); Thèses (0); Deutsche Nationalbibliothek (87); HKU

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Theses Online (11); Global ETD (26); BASE (263); TesiOnline (447); JAIRO (40); CiNii Dissertations (5).

The analysis of the studies enabled the identification of factors associated with self-care and pharmacological treatment in individuals with RA. These factors were grouped into four categories for better understanding, as shown in Figure 2: individual factors, disease-related factors, treatment-related factors, and third-party actions/interventions (by partners or healthcare professionals).

Favorable factors associated with self-care and pharmacological treatment			
Individual factors <ul style="list-style-type: none"> • Knowledge about RA • Participation in decision-making process • Experiencing positive/desired effects of the medication • Perception of real risk • Positive beliefs about treatment • Routine maintenance • Use of support tools and coping strategies • Treatment tolerance • Persistence with treatment • Expectation of discontinuing the medication 	Disease-related factors <ul style="list-style-type: none"> • Good general health status • Absence of comorbidities • Reduction or suppression of pain • Higher disease activity • Symptom relief 	Pharmacological treatment factors <ul style="list-style-type: none"> • Self-manageable/self-administered regimen • Lower use of medications • Handling and disposal of medications • Use of over-the-counter drugs or those used prior to prescription • Treatment effectiveness • No or few side effects • Self-medication • Self-adjustment of the dose 	Actions/Interventions by third parties <ul style="list-style-type: none"> • Educational intervention based on active methodologies • Medical and social support • Recommendations from other health professionals • Opinions of other people with RA • Pharmacist involvement
Unfavorable factors associated with self-care and pharmacological treatment			
Individual factors <ul style="list-style-type: none"> • Little knowledge about RA • Avoidance in the decision-making process • Experiencing negative effects of the medication • Perception of unreal risk • Negative beliefs and fear about the treatment • Disruption of routine • Absence of support tools and coping strategies • Treatment intolerance • Discontinuation of treatment 	Disease-related factors <ul style="list-style-type: none"> • Poor general health status • Presence of comorbidities • Significant pain • Lower disease activity • Symptom flare-up 	Pharmacological treatment factors <ul style="list-style-type: none"> • Polypharmacy • Treatment failure • Presence of side effects 	Actions/Interventions by third parties <ul style="list-style-type: none"> • Lack of educational intervention • Little or no medical and social support • Absence of participation by other health professionals

Figure 2 – Favorable and unfavorable factors associated with self-care and pharmacological treatment. Brazil, 2024.

Source: Prepared by the authors.

The most frequently reported factors in the studies were: medication side effects, number of medications, indefinite treatment duration, self-medication, knowledge of treatment, positive effects, fear, and negative beliefs. A detailed description of the factors related to self-care and pharmacological treatment found in each study is provided in the supplementary material. Table 1 presents the frequency of each factor by group across the studies.

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Table 1 – Presence of factors by group identified in the studies (n=33). Brazil, 2024.

Factors	n	%
Medication side effects	10	30,3
Knowledge and beliefs about treatment	10	30,3
Self-medication and self-adjustment of dosage	8	24,2
Number of medications	7	21,2
Therapy persistence and complexity	7	21,2
Symptom relief and expected effects	6	18,1
Coping strategies	6	18,1
Treatment decision-making process	4	12,1
Indefinite treatment duration	3	9,0
General health status and disease activity	3	9,0
Inadequate therapeutic behavior	2	6,0
Opinions of others with RA and specialists	2	6,0
Treatment costs	1	3,0

Source: Prepared by the authors.

Regarding the countries in which the studies were conducted, the Netherlands, Iran, Lithuania, Japan, and Singapore each had one study; the United States, Spain, and Belgium each had two studies; Mexico and France each had three studies; Canada had four studies; and the United Kingdom and Sweden each had five studies. The two review studies addressed multiple countries. English was the predominant language in 30 studies, with one study in Lithuanian, one in Japanese, and one in Portuguese.

In the analysis of methodological design, cross-sectional studies predominated, with 26 studies (78.79%), while randomized clinical trials and longitudinal studies accounted for two studies each (6.06%), and prospective cohort, integrative review, and scoping review designs were each represented by one study (3.03%). A qualitative approach was used in 16 studies (48.5%), and a quantitative approach in 15 studies (45.45%). The review studies included both observational and experimental designs (6.05%).

There was significant variability in the study populations. In quantitative studies, sample sizes ranged from 68 to 1,530 (median = 202), and in qualitative studies from 7 to 83

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(median = 23). According to the JBI levels of evidence, level 4.b predominated, with 16 studies (48.48%), followed by level 3.e with 13 studies (39.4%), and levels 1.c and 3.b with two studies each (6.06%).

DISCUSSION

The studies described the presence of side effects, noting that fear of potential adverse effects tends to increase over time and may be related to the number of medications used^{16,17,20,26,27,35,37,40,47}. Fear^{17,27,40,43} or the actual occurrence of side effects³⁷ can lead individuals to adjust dosages on their own or withhold information about their medication use from healthcare professionals. A lack of information about the effects of prescribed medications is closely linked to the fear of side effects³⁷. An international review conducted by Chinese researchers on mild, severe, and discontinuation-related side effects of methotrexate indicated that 20–30% of individuals discontinue methotrexate within the first year due to its adverse effects, which can persist for up to five years⁴⁸.

Side effects may be perceived as worse than the symptoms of RA and are often seen as frustrating and stressful³⁵. Although individuals may believe in the necessity of the medication, there is apprehension, particularly regarding long-term use. Often, understanding the necessity of the medication helps counterbalance these fears, but this varies by individual³⁶.

Individuals taking multiple medications may express a desire to reduce or eliminate some due to concerns about side effects, adverse reactions, and toxicity²⁶. Medications used prior to diagnosis are perceived more positively, yet there is concern about quantity, and reducing the number and/or dosage of medications is often seen as a sign of improved health²⁷. A study conducted in Japan found that the use of glucocorticoids, high disease activity, history of hospitalization, comorbidities, and public assistance were associated with polypharmacy, while disease duration was not⁴⁹.

Using medications for an indefinite period may require individuals to engage in continuous internal negotiations regarding their own identity, as well as external negotiations with healthcare providers¹⁸. Disruptions in routine or a high number of medications were reported as barriers to adherence, especially over extended periods³². The prolonged duration

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of pharmacological therapy can be a contributing factor to non-adherence, as it relates to patient-specific challenges⁵⁰.

Managing medication supplies, self-reducing or temporarily stopping medications, and persistence with therapy may support adherence and, consequently, self-care^{22,44}. However, self-administration of injectable medications can have the opposite effect—reducing adherence and self-care—compared to administration by a healthcare professional²⁹. High hospitalization rates, anxiety, and other obstacles have also been associated with treatment preferences⁵⁰.

Higher disease activity is associated with a lower likelihood of individuals modifying their dose or treatment duration²⁴. RA flare-ups (symptom exacerbation episodes) may prompt individuals to increase or decrease their dosage^{25,31}. This condition was also described in another study, which noted the use of analgesics and, to a lesser extent, corticosteroids among the medications self-administered during flares⁵¹.

Having knowledge about RA^{17,19} and the long treatment journey enables individuals to ask relevant questions and to take ownership of their disease and treatment³⁸. To meet the need for disease-related knowledge, individuals with RA often seek information from others living with RA⁴⁷ and from multiple healthcare professionals⁴⁶. Knowledge, especially when combined with the initiation of biological therapy, can enhance levels of self-care, and the integration of knowledge from both healthcare professionals and patients can improve outcomes^{30,52}.

Negative beliefs about treatment^{19,32,34,35,39} and inadequate therapeutic behavior⁴¹ can lead to the discontinuation of therapy and the pursuit of alternative treatments. Such beliefs may improve after one year of treatment, as initial unfamiliarity with the therapy's effectiveness may be related to the inconsistent use of essential medications. The emotional and psychological impact perceived by the patient is also influenced by negative beliefs⁵³.

Experiencing positive effects^{19,23,40,44}—especially related to pain, stiffness, fatigue, improved capacity, and activity—contributes to continued treatment, facilitates a return to daily living activities, and enhances self-care. Individuals with RA who do not notice changes in their symptoms after starting medication may be more likely to stop using it for long periods and have less awareness of disease activity and its consequences⁵⁴.

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Multidisciplinary interventions may have beneficial effects^{15,45}. Interventions using the disease-modifying antirheumatic drugs (PBL) method can promote lifestyle changes and patient empowerment²⁸. This method is commonly used in student education but has proven effective in educating patients with chronic conditions⁵⁵ and can be implemented in people with RA through 90-minute sessions over the course of one year, following a plan that addresses: self-awareness and self-confidence, interpersonal relationships, stress and relaxation, physical activity and rest, medications and herbal remedies, tobacco and alcohol, and food and beverages²⁸. Self-management interventions are carried out by various professionals and measured using different outcome indicators, often resulting in moderate or low levels of effectiveness. The variables that influence self-management are diverse and may vary between countries and contexts⁵⁶.

The presence of medical and social support can enhance treatment continuity. The opinions of other individuals with RA help meet emotional support needs, and the involvement of another health professional—especially a pharmacist—can influence treatment choices and adherence⁴⁷. Individuals with RA tend to seek information from three primary sources: rheumatologists, pharmacists or other healthcare professionals, and the internet⁵⁷. It has been observed that the greater the disease activity, the less likely individuals are to want to make decisions about their treatment²¹. However, the literature shows the opposite: people with RA prefer to be actively involved in treatment decisions⁵².

An analysis using Orem's theories helps identify specific outcomes among the study participants included in this review. According to the Self-Care Theory, the most affected requirements are those related to health deviation self-care, which arise when nursing care is required due to illness⁵⁸.

Based on this identification, the Self-Care Deficit Theory outlines the following modes of action: acting or doing for others; guiding others; supporting others; providing an environment that promotes development; and teaching others. The Nursing Systems Theory defines the extent to which nursing needs to compensate for deficits in self-care⁵⁹. In this review, most studies align with the partially compensatory or supportive-educative systems. Promoting self-care through the use of this theory may improve autonomy and empower individuals to manage RA-related complications.

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This study has some limitations, such as the difficulty in finding articles that specifically address the relationship between self-care and pharmacological treatment. Nevertheless, the evidence identified provides meaningful contributions and takes into account the diversity of factors that influence self-care in individuals with RA. Further studies on this topic are recommended to better elucidate the subject.

CONCLUSION

The main evidence regarding the relationship between pharmacological treatment and self-care in individuals with RA points to a stronger association with fear of side effects, the number of medications, and the indefinite duration of treatment. Other, less frequently reported variables may also be associated and, depending on the individual, may have a significant impact on the relationship between pharmacological treatment and self-care. Individualized assessment combined with the application of Orem's theory may enhance the treatment of individuals with RA.

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