
Knowledge, Practices and Self-Care Management Behaviors for Rheumatoid Arthritis Patients

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ABSTRACT

Background: Rheumatoid arthritis (RA) has a significant impact on all facets of health-related quality of life, including social, emotional, physical, and spiritual. Elevated levels of self-care management behaviors, practices, and information about rheumatoid arthritis may improve the physical function, health, and quality of life for rheumatoid arthritis patients. **Aim of the study:** This study aimed to assess knowledge, practices, and self-care management behaviors for rheumatoid arthritis patients. **Subjects and method:** In this study, a descriptive research design was adopted. The rheumatology outpatient clinics at El Shifaa Medical Complex and Al Salam Hospital, which are connected to the Egypt Health Care Authority in the Port Said Governorate, Egypt, served as the study's locations. In this study, 73 rheumatoid arthritis patients who visited the aforementioned locations were included in a purposive sample. **Tools:** Three instruments were used to gather the data: a self-reported checklist of patients' practices, a structured interview questionnaire covering information about rheumatoid arthritis and its self-care management, and a self-care management behaviors scale. **Results:** According to the study, all rheumatoid arthritis patients had unsatisfactory knowledge regarding their disease and its self-care management, practices, and behaviors. Furthermore, a statistically significant positive association was observed between the aggregate knowledge, aggregate practices, and aggregate self-care management behaviors of patients with rheumatoid arthritis. **Conclusion:** Inadequate knowledge, practices, and self-care management behaviors were present in rheumatoid arthritis patients. **Recommendations:** In order to improve and sustain rheumatoid arthritis patients' understanding, practices, and self-care management behaviors, the study suggested offering ongoing health education programs.

Keywords: Knowledge, patients, practices, rheumatoid arthritis, self-care management behaviors.

INTRODUCTION

Rheumatoid arthritis is a long-term, autoimmune-related systemic inflammatory arthritis that mostly affects the synovial joints. It can lead to increased mortality and widespread severe morbidity. According to Karada (2018), it is the second most prevalent kind of arthritis. Although the exact origin of RA is unknown, it is believed to be complex and to involve both environmental and genetic factors (Gabriel & Crowson, 2018).

Symmetrical peripheral polyarthritis, which results from an autoimmune inflammatory response impacting the synovium, is a complication of rheumatoid arthritis. Joint abnormalities are the outcome of the disorder, namely affecting the proximal interphalangeal (PIP), metatarsophalangeal (MTP), and metacarpophalangeal (MCP) joints. Peripheral joint inflammation, the first sign of RA, causes inflammatory pain that usually worsens in the morning and becomes better throughout the course of the day. Joint deterioration and abnormalities, such as ulnar deviation of the MCP joints and subluxation of the fingers and wrist, might result from the disease's progression. Moreover, RA is linked to a higher risk of cardiovascular disease, which increases the burden of the condition and may increase the rates of morbidity and death for individuals who are impacted (Dedmon, 2020).

Patients with RA may require sufficient information in order to follow complicated instructions, make decisions about their course of therapy, and take care of themselves. As a result, ignorance affects the prognosis, follow-up, patient's health, and the frequency of complications. RA patients need education to change their behavior, adhere to medication, and eventually prevent disability. Evaluating the degree of knowledge of RA patients is crucial because it makes it easier to choose training program themes by weighing the needs of the patient and the teacher. The education will only be used as a routine program by healthcare practitioners and will not be effective if the needs of RA patients are not considered while building the curriculum (Ibrahim et al., 2023).

RA is an ongoing medical condition. Patients with RA, however, are ignorant of their own practices on appropriate self-care for their illness. Determining the practice areas that need patient education based on patients' needs is essential to promoting health among these patients (Laitinen et al., 2022). Furthermore, patient participation in

appropriate self-care management behaviors is essential to the effective management of RA. High levels of self-care management behaviors (such as energy conservation and tiredness management techniques, pain management, medicine, exercise, diet, and joint protection) may enhance RA patients' quality of life (QOL), physical function, and overall health. In order to meet the demands of RA patients while developing health care plans, it is imperative to evaluate the self-care management behaviors of these patients.

Significance of the study

With an estimated prevalence of 0.3% in rural Egypt and 0.3–1% globally, rheumatoid arthritis is a chronic, devastating illness. According to the World Health Organization [WHO], (2019) and Usenbo et al. (2015), RA typically strikes adults between the ages of 20 and 40, when they are most productive. Patients with RA gradually lose their ability to function physically, which limits their everyday activities and lowers their level of functional independence. Moreover, higher degrees of handicap might be harmful to their social and psychological health. Significant direct and indirect costs associated with RA for individuals and their families include missed work and medical expenses. High levels of RA-related knowledge, practices, and self-care management behaviors may improve the physical function, health status, and quality of life of RA patients. Thus, the purpose of this study is to evaluate RA patients' knowledge, practices, and self-care management behaviors.

AIM OF THE THE STUDY

This study aimed to assess knowledge, practices, and self-care management behaviors for RA patients. This goal was accomplished by using the following:

- Assess the level of knowledge for RA patients.
- Evaluate RA patients' practices.
- Evaluate RA patients' self-care and management behaviors.

SUBJECTS AND METHOD

1. Technical design

The technical design comprises the study design, subjects, setting, and data gathering instruments.

Study design

A descriptive study design was adopted.

Study Setting

The rheumatology outpatient clinics at El Shifaa Medical Complex and Al-Salam Hospital, which are connected to the Egypt Health Care Authority in the Port Said Governorate, Egypt, served as the study's locations.

Study Subjects

A purposive sample of RA patients who visited the outpatient rheumatology clinics in the aforementioned hospitals and agreed to take part in the current study under the following conditions:

1. Having reached the age of eighteen.
2. Having RA for more than six months.
3. Not participating in any RA training program.

Sample size

The Epi-Info 7 program used the following parameters to compute the sample size:

1. Population size = 300 (the total number of patients admitted over a three-month period to the rheumatology outpatient clinics at the pre-selected hospitals in Port Said). In 2023, information about the overall count of these patients was gathered from patients' affairs.
2. 50% is the expected frequency.
3. 10% is the acceptable mistake.
4. 95% is the confidence coefficient.

73 patients made up the sample size, according to the program. The total sample size consisted of 81 patients because the 10% projected withdrawal rate was met.

Tools of data collection

In this study, three tools were employed:

Tool I: A Structured Interview Questionnaire

The researcher translated this English-language tool, created by Rodère et al. (2022), into Arabic in order to evaluate patients' medical histories, sociodemographic information, and level of understanding on RA and self-care management. After examining pertinent literature, certain changes were made (Bobos et al., 2018; Datta, & Phil, 2008).

The following three parts were present

Part 1: Patient sociodemographic information

Data on age, gender, marital status, education, occupation, place of residence, and family income were addressed in this section.

Part 2: Medical History

It contained information about the length of time someone has been diagnosed with RA, the treatment for RA, medication adherence, other chronic illnesses, RA in the family history, and smoking.

Part 3: Patients' knowledge questions

In order to gauge patients' understanding of RA and its self-care management, the following 42 questions were used in this part:

- Information about RA, including its definition, risk factors, signs, and symptoms, complications, course and prognosis, diagnosis, and treatment. The information is presented in 21 questions.
- A set of 21 questions regarding self-care management of RA that cover topics such as joint protection, nutrition, rest, physical activity, drug safety, follow-up, and pain and fatigue management.

Scoring System

There were two possible answers for each question in this section: "correct" and "incorrect." The literature indicated in advance what the right response was. For every right response, a score of "1" was awarded; for every wrong (misconception) or absent (do not know) response, a score of "0" was awarded. Per the Bloom's cut-off point (Feleke et al., 2021):

- A score of $\geq 60\%$ on the overall knowledge was deemed satisfactory.
- A knowledge score of less than 60% was deemed inadequate.

Tool II: Self-reported checklist of patients' practices

Zaky (2016) created it, and the researcher changed it depending on relevant literature (Grekhov et al., 2020; Perry et al., 2019). This section, which included 15 items, assessed the RA patients' practices. These included five hand exercises, five-foot exercises, three heat therapy items, one cold therapy item, and one Benson relaxation technique item.

Scoring System

In addition to being questioned whether or not they carried out these activities, patients were also asked to show how they did so. There were two options for each question in this section: "done" and "not done." When something was not completed or completed incorrectly, a score of "0" was assigned; otherwise, a score of "1" was given. As per the Bloom's cut-off point (Feleke et al., 2021):

- A practice was considered satisfactory if its overall score was 60% or more.
- A practice score below 60% was considered insufficient.

Tool III: Self-care management behaviors scale

The researcher translated this English-language tool, created by Nadrian et al. (2019) named "a Self-care Behaviors Scale (SCBS) among patients with RA", into Arabic then retranslated to English language to ensure the right or accurate translation. This tool was designed in order to evaluate how RA patients manage their own care. And consisted of 25 items were broken down into eight subscales: six items were related to

physical activity or exercises; three items were about medications and follow-up; three items were about joint protection; three items were about nutrition; three items were about managing daily activities; three items were about pain management; two items were about stress management; and two items were about tobacco/opium use.

Scoring System

"The frequency of performing various self-care management activities for their arthritis on a regular basis" was the question that the patients were asked to answer. A five-point Likert-type scale served as the basis for the response format: 0 = not at all, 1 = seldom, 2 = occasionally, 3 = often, and 4 = constantly. The scale's theoretical range is zero to 100. According to the Bloom's cut-off point (Feleke et al., 2021):

- A behavior was considered satisfactory if its overall score was $\geq 60\%$.
- A behavior score of under 60% was considered insufficient.

2. Operational design

Content validity, reliability, field work, and a pilot study are part of this project's operational design.

Content validity

The study tools were reviewed by nine experts: six experts from Faculty of Nursing in the field of Medical-Surgical Nursing, two rheumatologists, and one physiotherapist to test the validity of the study tools. Afterwards, the needed modifications were applied to these tools.

Reliability

The reliability of the study tools was assessed using Cronbach's Alpha test. Cronbach's Alpha for the structured interview questionnaire covering information about RA and its self-care management, the self-reported checklist of patients' practices, and the self-care management behaviors scale were 0.931, 0.717, and 0.863 respectively.

Pilot Research

To assess the applicability, objectivity, and feasibility of the tools as well as to estimate the time required to fill out each tool, pilot research involving nine patients, or 10% of the study sample, was conducted. The patients were then removed from the sample. Before starting the study's fieldwork, it was carried out for two weeks in the aforementioned settings. Following receipt of the pilot study data, the appropriate adjustments were made (in area of prescription drugs), and the final form was created.

Field Work

The collection of data took place from the start of February 2023 to the end of June 2023. The researcher was present at the study settings three days a week, from 9 a.m. to 3 p.m. In the rheumatology outpatient clinics at the hospitals mentioned earlier, the researcher conducted individual interviews with each patient. The researcher introduced herself and clarified the study's purpose. Afterward, verbal consent was obtained from patients who met the study's inclusion criteria and agreed to participate. The researcher then assessed knowledge, practices, and self-care management behaviors for RA patients using study tools to determine their needs. The researcher required about 20 minutes to fill in these tools with each patient.

3. Administrative design

The directors of the study settings were contacted and notified in an official letter from the dean of the Faculty of Nursing, Port-Said University, requesting their cooperation and permission to conduct the study at outpatient rheumatology clinics.

Ethical Consideration

Based on committee norms, the Faculty of Nursing, Port Said University, and adherence to the Declaration of Helsinki, the study was approved by the Research Ethics Committee (REC) of the faculty with code number NUR 7/4/2024 (36). Furthermore, after the purpose of the study was explained, permission to undertake it was granted by the directors of the designated institutions. Additionally, after outlining the study to each patient, verbal consent was sought for them to participate.

4. Statistical Analysis

IBM SPSS software package version 20.0 was used to feed data into the computer and analyze them (Armonk, NY: IBM Corp.). Numbers and percentages were used to describe the qualitative data. The distribution's normality was confirmed using the Kolmogorov-Smirnov test. The terms range (minimum and maximum), mean, and standard deviation were used to characterize quantitative data. Two quantitative variables that were normally distributed were correlated using the Pearson coefficient. At the 5% level, the results' significance was assessed.

RESULTS

Table (1): Socio-demographic data of RA patients (n = 73)

Socio-demographic data	No.	%
Age		
20 - <30	3	4.1
30 - <40	2	2.7
40 - <50	17	23.3
50 - <60	25	34.2
≥ 60	26	35.6
Min. – Max.	20.0 – 65.0	
Mean ± SD.	53.19 ± 9.79	
Gender		
Male	10	13.7
Female	63	86.3
Marital status		
Single	6	8.2
Married	58	79.5
Widowed	8	11.0
Divorced	1	1.4
Education		
Illiterate	9	12.3
Read & write	11	15.1
Basic education	5	6.8
Secondary education	26	35.6
Higher education	21	28.8
Postgraduate studies	1	1.4
Occupation		
Officer	16	21.9
Laborer	5	6.8
Retired	14	19.2
Housewife	38	52.1
Residence		
Urban	73	100.0
Family income		
Not enough	73	100.0

SD: Standard deviation

Table 1 indicates that 35.6% of RA patients were 60 years of age or above. In addition, 86.3% of the patients were female, 79.5% of these patients were married, and 35.6% had completed secondary education. In addition, 52.1% of the patients were housewives, all of whom lived in cities and had insufficient family income.

Table (2): Medical history of RA patients (n = 73)

Medical history	No.	%
Disease duration		
From 6 months to less than one year	4	5.5
From one year to less than 3 years	3	4.1
From 3 years to less than 5 years	10	13.7
5 years or more	56	76.7
Rheumatoid treatment		
Prescribed medications	70	95.9
Prescribed medications & physiotherapy	3	4.1
Prescribed medications		
Cortisone	39	53.4
Hydroxychloroquine	45	61.6
Sulfasalazine	3	4.1
Methotrexate	37	50.7
Leflunomide	27	37.0
Imuran	5	6.8
Biological therapy	23	31.5
Adherence to prescribed medications		
No	3	4.1
Yes	70	95.9
Suffering from other chronic diseases	46	63.0
If Yes: n = 46		
Hypertension	28	60.9
Diabetes mellitus	20	43.5
Osteoarthritis	3	6.5
Osteoporosis	7	15.2
Others	24	52.2
Family history of RA		
No	67	91.8
Yes	6	8.2
Smoking		
No	70	95.9
Yes	3	4.1

Table 2 shows that 76.7% of patients with RA had the condition for at least five years. 95.9% of patients with RA reported taking their prescribed drugs, 61.6% of them used hydroxychloroquine, and 95.9% of them complied with their prescriptions as directed. Additionally, hypertension affected 60.9% of these patients. Besides, 91.8% and 95.9%, respectively, of patients did not have a family history of RA and did not smoke.

Table (3): Total knowledge of RA patients (n = 73)

Knowledge Level	Unsatisfactory (< 60%)		Satisfactory (≥ 60%)	
	No.	%	No.	%
Information about RA	69	94.5	4	5.5
Information about self-care management of RA	73	100.0	0	0.0
Overall Knowledge	73	100.0	0	0.0

It is evident from Table 3 that the overall amount of information that all RA patients possessed regarding RA and how to manage their own care was inadequate.

Table (4): Total practices of RA patients (n = 73)

Practices overall	No.	%
Unsatisfactory (< 60%)	73	100.0
Satisfactory (≥ 60%)	0	0.0

Table 4 illustrates that the overall level of practices for all RA patients was unsatisfactory.

Table (5): Total self-care management behaviors of RA patients (n = 73)

Self-care management behaviors overall	No.	%
Unsatisfactory (< 60%)	73	100.0
Satisfactory (≥ 60%)	0	0.0

All RA patients had unsatisfactory self-care management behaviors regarding their disease, as Table 5 demonstrates.

Table (6): Correlation between knowledge, practices, and self-care management behaviors of RA patients (n = 73)

	r	P
Knowledge vs. Practices	0.235*	0.045*
Knowledge vs. Self-care management behaviors	0.454*	<0.001*
Practices vs. self-care management behaviors	0.501*	<0.001*

r: Pearson coefficient

*: Statistically significant at $p \leq 0.05$

The total knowledge and total practice scores of RA patients exhibited a statistically significant positive connection, as indicated by Table 6. The overall knowledge scores and the total self-care management behaviors scores of RA patients also showed a statistically significant positive connection. Additionally, RA patients' overall practice scores and their total self-care management behavior ratings showed a very statistically significant favorable link.

DISCUSSION

According to the current study, over one-third of RA patients were 60 years of age or older and the majority of them were female. Furthermore, the majority of patients were married, over one-third had a secondary education, and over half of them were housewives. The study also discovered that all RA patients reside in cities and have low family incomes.

The study found that over three-quarters of the individuals had RA for five years or more based on their medical histories. When it came to their RA treatment, most of the patients said they took their prescription drugs—more than three-fifths of them used hydroxychloroquine—and they mostly took them as directed. Furthermore, hypertension affected over three-fifths of these patients. Furthermore, the vast majority of patients did not have any family history of RA. Remarkably, the great majority of the patients abstained from smoking.

The current study also clarified that all RA patients had an unsatisfactory level of total knowledge about RA and its self-care management. The decline in total knowledge about RA and its self-care management might be due to a lack of sources of information, including awareness through direct contact between patients and health care professionals such as doctors and nurses, multimedia supports, and patients' associations. This result is in line with Rezik et al. (2022) who found that the knowledge of RA patients was low. Similarly, this goes with Kamruzzaman et al. (2020) who revealed the knowledge level of RA patients about their disease was poor.

Furthermore, this result is consistent with El Saman et al. (2020), who demonstrated that the upper Egyptian population has inadequate awareness and knowledge of rheumatic disorders like RA, necessitating the implementation of extensive mass education and learning initiatives. Additionally, this is in keeping with Mohammed et al., (2023) findings, which indicated that prior to putting self-care guidelines into practice, over half of women with RA had inadequate understanding.

Furthermore, this finding is consistent with that of Hussein et al. (2022), who reported that inadequate knowledge of RA was had by over 75% of women with the illness. This is also consistent with the findings of Bara et al., (2023), who found that individuals with RA lacked enough understanding, particularly about corticosteroid medication. This result, however, conflicts with the findings of Honsali et al., (2023), who reported that RA patients' knowledge levels were generally excellent.

Furthermore, this study shows that the overall practices of all RA patients were subpar. Patients may not have received enough instruction in self-care management techniques or abilities, which could be the cause of the decline in overall practices. This result is consistent with that of Mohammed et al., (2023), who showed that prior to putting self-care guidelines into practice, over three-quarters of women with RA had inadequate self-care practices. This is also in line with the findings of Hussein et al., (2022), who found that prior to the implementation of nursing guidelines for RA self-care, the majority of women with RA had low self-care practices for their disease. Furthermore, this finding aligns with the findings of Laitinen et al., (2022), who noted that RA patients exhibited certain impairments in their ability to manage their own care, particularly with regard to foot self-care.

According to the study, the overall level of self-care management behaviors was poor for all RA patients. Patients with RA may not know enough about RA and its self-care practices, which are important for adopting and sustaining positive self-care management behaviors. This could explain the unsatisfactory level of total self-care management behaviors. This result is consistent with El Saman et al., (2020), who showed that there is a need for extensive mass education and learning programs due to the upper Egyptian population's inadequate and defective attitudes and behaviors surrounding rheumatic diseases like RA. This, however, runs counter to the findings of Honsali et al., (2023), who found that RA patients' behavior was generally satisfactory.

Overall knowledge and overall practice ratings of RA patients exhibited a statistically significant beneficial link, according to the current study. According to the study, this might be the case because RA patients who have more information are better able to comprehend and acquire self-care management techniques. This result is consistent with that of Mohammed et al., (2023), who found a strong positive association between women with RA's knowledge and self-care practices. This also aligns with the findings of Hussein et al., (2022), who noted that women with RA are less likely to adopt effective self-care techniques for their condition if they are unaware of the nature of their illness.

Additionally, this study showed that the overall knowledge scores and the total self-care management behavior ratings of RA patients showed a statistically significant positive link. This finding implies that self-care management behaviors of RA patients may be significantly predicted by their knowledge of these patients. Stated differently, more awareness about RA aids in the adoption and maintenance of disease-specific self-care behaviors by patients.

This result is consistent with Chen and Wang's (2007) findings, which showed a strong positive association between patients' self-care behaviors and their level of knowledge of RA. This is also in line with the findings of Sierakowska et al. (2005), who showed that patients' pro-health behaviors, such as their self-care management behaviors, are influenced by their level of knowledge on RA and its self-care.

Lastly, the current study found that the overall practice scores and the total self-care management behavior scores of RA patients showed a highly statistically significant

positive link. According to the study, this might be the case because patients' behaviors clearly change when they adopt self-care management techniques for RA. Put another way, learning the self-care management techniques of RA has a variety of behavioral consequences, such as accelerating performance, forming a habit, and lowering the cognitive load needed to complete the activity.

Limitations of the study

The majority of the patients in this study were female, which could have affected the representativeness of the sample and the generalizability of the results. This is one of the study's weaknesses.

CONCLUSION

The current study's findings indicate that all RA patients' overall understanding of RA and its self-care management, practices, and behaviors was inadequate. Furthermore, a statistically significant positive association was observed between the aggregate knowledge, aggregate practices, and aggregate self-care management behaviors scores of patients with RA.

RECOMMENDATIONS

The present study's conclusions lead to the following recommendations being put forth:

- Providing RA patients with ongoing health education programs to improve and sustain their understanding of the condition, practices, and behaviors associated with self-care management.
- Encouraging family members to participate in patient education so they may better understand the patient's condition and actively assist them during it.
- Promoting ongoing evaluations of RA patients' knowledge, practices, and self-care management behaviors in order to identify their requirements and develop educational programs that are specifically designed to meet those needs.
- More research to evaluate the variables affecting RA patients' knowledge, practices, and self-care management behaviors.

Declaration of conflicting interests

There are no competing interests.

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معلومات وممارسات وسلوكيات الرعاية الذاتية لمرضى التهاب المفاصل الروماتويدي

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الخلاصة

يُعد التهاب المفاصل الروماتويدي مرضاً مزمناً من أمراض المناعة الذاتية الذي يؤثر تأثيراً كبيراً على جودة الحياة البدنية والعاطفية والاجتماعية والروحية. قد تؤدي المستويات العالية من المعلومات والممارسات وسلوكيات الرعاية الذاتية الخاصة بمرض التهاب المفاصل الروماتويدي إلى تحسين الوظيفة البدنية والحالة الصحية وجودة الحياة لهؤلاء المرضى. لذلك صممت هذه الدراسة الوصفية لتقييم معلومات وممارسات وسلوكيات الرعاية الذاتية لمرضى التهاب المفاصل الروماتويدي في العيادات الخارجية بمستشفى السلام ومجمع الشفاء الطبي التابعين لهيئة الرعاية المصرية في محافظة بورسعيد. وقد أجريت هذه الدراسة على 73 مريضاً. وقد تم جمع البيانات باستخدام ثلاث أدوات: استبيان المقابلة الشخصية التي تحتوي على أسئلة المعلومات الخاصة بالتهاب المفاصل الروماتويدي بالإضافة إلى قائمة التقرير الذاتي لممارسات المرضى ومقياس سلوكيات الرعاية الذاتية. أظهرت نتائج الدراسة عن أن جميع مرضى التهاب المفاصل الروماتويدي لديهم مستوى غير مرض من المعلومات والممارسات وسلوكيات الرعاية الذاتية الخاصة بمرضهم، كما أوصت الدراسة بتوفير برامج التثقيف الصحي المستمر لمرضى التهاب المفاصل الروماتويدي لتعزيز والحفاظ على معلوماتهم وممارساتهم وسلوكيات الرعاية الذاتية لديهم فيما يخص مرضهم.

الكلمات المرشدة: التهاب المفاصل الروماتويدي، المرضى، معلومات، ممارسات، سلوكيات الرعاية

الذاتية