

## SCORE study: quality indicators for rheumatology nursing clinics

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**Abstract** Nursing clinics in rheumatology (NCR) are organizational care models that provide care centred within the scope of nurses abilities. To analyse patients differences in the knowledge of the disease, adherence to the treatment, quality indicators of the Rheumatology Departments included quality perceived by the patients with and without NCR. National multicenter observational prospective cohort study 1 year follow-up, comparing patients attending rheumatology services with and without NCR. NCR was defined by the presence of: (1) office itself; (2) at least one dedicated nurse; (3) its own appointment schedule, and (4) phone. Variables included were (baseline and 12 months)

Batalla, Haynes–Sackett, Morisky–Green and quality perceived tests. In addition, another specific questionnaire was drawn up to collect the healthcare, teaching and research activities of each Rheumatology Department. A total of 393 patients were included; 181 NCR and 212 not NCR, corresponding to 39 units, 21 with NCR and 18 without NCR (age  $53 \pm 11.8$  vs  $56 \pm 13.5$  years). Significant differences in favour of the NCR group were found in Haynes–Sackett ( $p=0.033$ ) and Morisky–Green ( $p=0.03$ ) tests in the basal visit. Significant differences were found in questions about “the courtesy and/or kindness received by the nurse”, being “good or very good” in greater proportion in the NCR group. The publications from the last 5 years were significantly higher in the NCR group in both, national ( $p=0.04$ ) and international ( $p=0.03$ ) journals. A higher research activity and quality perceived by the patients are observed in the Rheumatology Departments with NCR.

The SCORE working group has been processed in Appendix section.

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### Introduction

The growing importance of nursing clinics in rheumatology (NCR) is a topical issue. For some years, organisations and institutions working in the area of rheumatology have been focusing on strengthening its role and making recommendations on what its competences should be [1–5]. Most agree that an NCR should provide care (metrology, monitoring of medications, training of patients in self-administration of drugs, health promotion and education, care hotline, monographic visits, specific rheumatology and general nursing procedures and diagnostic techniques, among others) and management and coordination tasks and teaching

and research work. A recent survey conducted by the European League Against Rheumatism (EULAR), given to nurses, rheumatologists and patients in 23 countries revealed a high level of agreement for its recommendations on the role of nursing in the management of patients with chronic inflammatory arthritis; but nevertheless, it showed a low, inconsistent level of implementation [6]. While in northern European countries such as Holland and Scandinavia, they are widespread [7, 8], and implementation of NCR is still limited [9].

Previous studies have shown that the NCR is a cost-effective method for improving effectiveness and/or for reducing the direct and indirect costs (decrease in hospital visits and admissions, consumption of drugs or days lost due to temporary inability to work) [10–16]. Some of these studies also show that patients managed in NCR show greater satisfaction with the care received and have better knowledge of the disease [8, 10, 12, 14].

The SCORE study (*Seguimiento y Control en Reumatología-Enfermería-Monitoring and Control in Rheumatology-Nursing*) is a multicenter project that was created with the objective of estimating the efficiency of the NCR and comparing the quality of care with that of rheumatology departments without NCR. To reduce the variability in the results, the study was limited to patients with rheumatoid arthritis (RA) and ankylosing spondylitis (AS) patients with long standing disease that proceeded from 20 rheumatology departments of our country.

In a previous study, the data on clinical and quality of life findings, clinical status, function and costs (direct and indirect) was presented [17]. In this article, we showed that patients from the NCR group had better outcomes in disease inflammatory activity and functional indexes, in the patients' state of health measured by EQ-5D and in working productivity. With regard to the use of healthcare services, the costs resulting from consultations carried out at healthcare centres were significantly higher in the non-NCR group. No significant differences were observed between the two groups in terms of the total annual cost of the use of services.

In this paper, data relating to other quality indicators in the rheumatology departments, including quality perceived by the patient, are presented. These are different from data of the previous published study that were mainly related with the activity of the disease.

## Methodology

This is an observational study on two prospective cohorts, one for patients seen in rheumatology departments with NCR and the other for departments with non NCR. The selection of NCR and non-NCR departments was

conducted randomly between the rheumatology departments in our country who responded to a survey about the availability of NCR. The criteria for definition of the NCR were based on a previous study using the Delphi [9] methodology. According to which, NCR is regarded as the organizational device comprising at least: (1) own office for nursing consultation; (2) at least one nurse whose is assigned to working in the NCR; (3) schedule for appointments; and (4) phone.

A sample size of 200 patients/cohort that can estimate differences of 14% ( $\alpha=0.05$ ;  $1-\beta=0.8$ ) was planned assuming maximum indetermination (e.g. if the compliance of a given quality variable in NCR is 50% and 36% in non-NCR). Participation of 20 departments/groups with a contribution of ten patients/departments was planned. To reduce the variability of results, the work was limited to patients with rheumatoid arthritis (RA) and ankylosing spondylitis (AS).

Each service included, on consecutive days, the first patient who met the following inclusion criteria: >18 years, diagnosed with RA or AS; and treated with at least one disease-modifying antirheumatic drug (DMARD) or a biological agent.

Each patient was monitored for a year. Each researcher collected information during the baseline visit (V0), at 6 months and at 12 months (V6 and V12). A questionnaire was used for the three visits to record the following from the clinical history: demographic data, comorbidity, habits, and variables related to rheumatic disease (RD) and resource consumption (use of services and treatment). Patients in V0 and V12 completed questionnaires with sociodemographic and occupational variables, as well as specific tests to evaluate the clinical status, function and quality of life (the detailed description of these tests was performed in a previous study [17]). In addition to those tests, the patients in V0 and V12 filled out a questionnaire on their knowledge of the disease: *Batalla Test* and self-reported compliance: *Haynes–Sackett Test* and *Morisky–Green Test* (as an indicator of adherence to the treatment) [18–20] and a number of issues on perceived quality of care extracted and adapted from the best questionnaires used in our country. *Batalla*, *Haynes–Sackett* and *Morisky–Green* tests are self-fulfilling tests with categorical answers (yes or no). The first is a two question test that tries to define the knowledge of the disease: “The patient knows that their rheumatic disease is a lifelong illness” (yes or no) and “The patient knows that his disease can be controlled with diet and medication” (yes or no). The *Haynes–Sackett* test has only one categorical question: “Has difficulty taking the medication?” Finally, the *Morisky–Green* test has four questions to define the adherence to the treatment (Table 2).

In addition, to provide variables that would make it possible to understand the characteristics of the department,

another questionnaire was drawn up to collect information on key aspects of the rheumatology department (e.g. whether it had residents teaching yes/no, number of physicians, department resources, number of patients with RA or AS seen per year, etc.) and other quality indicators on structural and process, as determined by the project's scientific committee.

For improving the quality of patients selection and data collection, a pilot study was undertaken, training was given to the researchers at the beginning of the study, and 100% telephone monitoring of questionnaires with inconsistencies were performed.

The data collection forms used for RA patients, for patients with AS and for the rheumatology department, are available in Spanish upon request.

### Data analysis

Categorical variables are expressed as the percentage. Continuous variables with normal distribution were presented as mean and standard deviation (mean  $\pm$  SD) and without normal distribution, with median and percentiles 25 and 75 (median,  $P_{25}$ – $P_{75}$ ).

NCR and non-NCR departments were compared using the Chi-square test in categorical variables (or Fisher's exact test when a cell had an expected count  $<5$ ). For quantitative variables, the Student's *t* test was used under normal distribution or Mann-Whitney *U* test if normality is not assumed.

### Ethical considerations

An epidemiological, non-interventional study was conducted in which the patient is not exposed to additional tests, treatments or visits other than those established in the department's protocol. All patients signed the informed consent form. The sponsor and researchers guaranteed the confidentiality of the information and ensured compliance with the stipulations contained in our country laws on Personal Data Protection. We receive research ethics committee approval for this study.

### Results

In anticipation of possible losses 48 centres were recruited (27 NCR and 31 non-NCR), of which 39 (21 NCR and 18 non-NCR) participated, with a total of 393 patients (181 NCR and 212 non-NCR) in the V0. During the follow-up, there were 13 patient losses. In addition, a non-NCR centre changed group to incorporate an NCR during the study. There were 380 patients in V12 (198 NCR and 182 non-NCR). For the purposes of the descriptive analysis, this

centre in V0 is considered non-NCR and NCR in V12. The patient questionnaire was filled out by the 393 patients in V0 and 380 in V12.

The inclusion period was extended from July to December 2012, and the data collection period from July 2012 to January 2014.

The demographic variables for both cohorts are shown in Table 1. There was no significant difference except in the average age of the patients and C-reactive protein (CRP) levels that were significantly higher in non-NCR services.

The findings of the tests used to assess knowledge about the disease and adherence to treatment found significant differences between groups in favour of the NCR group for both the Haynes–Sackett test and some items of the Morisky–Green test. For the final score summarising adherence to treatment (Morisky–Green test), reduced adherence was noted in the non-NCR group (69.3% vs 79.01% in the NCR group;  $p=0.030$ ) at the baseline visit. For the 12-month follow-up visit, the difference between groups did not reach a significant difference (Table 2) for the final score, showing an improvement of the non-NCR group. This could be influenced by this study itself.

In respect of the perceived quality of care, both at the baseline visit and at 12 months, significant differences were found in some of the questions such as “the courtesy and/or kindness received by the nurse”, being “good or very good” in greater proportion in the NCR group. Furthermore, a higher proportion, also in the NCR group, believes that the frequency of visits in the rheumatology department is “good or very good” (Table 3).

All departments, except one non-NCR, belonged to the public health system. The baseline characteristics of participant rheumatology departments are similar both in terms of human resources and number of beds, and crude and adjusted indicators of care activity (Table 4). Questionnaires were administered to the patient regularly on perceived quality of care in a similar proportion (19.0% in non-NCR and 18.5% in NCR).

Research conducted by the rheumatology department found significantly higher activity in the NCR group compared to the non-NCR group in publications from the past 5 years in national journals [9 (range 4.5–18.5) vs 4.0 (range 2.0–8.0);  $p=0.04$ ] and international journals [16.5 (range 5.0–23.0) vs 4.0 (range 1.0–19.0)  $p=0.03$ ] (Table 4).

The departments with an NCR “always or almost always” carry out the following activities in statistically significant higher proportions than non-NCR departments: Global assessment of disease (GAD) with visual analogue scale (VAS); Pain VAS; assessment of the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI); assessment of the Health Assessment Questionnaire (HAQ); follow-up according to drug protocol; analytical control of treatments

**Table 1** Baseline characteristics of patients

Variable	Non-NCR (N: 212)		NCR (N: 181)		<i>p</i> (Chi-square)
	<i>N</i>	%	<i>N</i>	%	
Gender					
Male	82	38.7	54	29.8	0.061
Level of education attained					
No formal studies	14	6.8	11	6.15	0.763
Primary education	87	42.2	83	46.4	
Secondary education	64	31.1	56	31.3	
University graduate	41	19.9	29	16.2	
In active employment					
Yes	128	60.4	105	58	0.634
Retirement due to RD					
Yes	43	54.4	25	52.1	0.797
RD diagnosis					
RA	160	75.5	142	78.5	0.485
AS	52	24.5	39	21.5	
Rheumatoid factor					
Positive	114	55.3	105	62.9	0.14
Negative	79	38.3	48	28.7	
Not applicable	13	6.3	14	8.4	
ACPA					
Positive	106	55.5	94	60.3	0.15
Negative	56	29.3	32	20.5	
Not applicable	29	15.2	30	19.2	
	Mean (SD)	Median (P25–P75)	Mean (SD)	Median (P25–P75)	<i>p</i> ( <i>t</i> test)
Age (years)	56.3 (13.5)	57 (47–67)	53.2 (11.8)	54 (45–61)	0.017
Years of evolution*	9.5 (8.9)	6 (3–14)	10.6 (8.8)	7 (4–15)	0.083*
ESR (mm)*	16.3 (15.2)	11 (6–22)	17.5 (16.1)	12 (7–23)	0.428*
CRP (mg/L)*	6.4 (11.5)	3.1 (1.2–5.6)	5.0 (9.0)	1.6 (0.3–5.5)	0.001*

*NCR* nursing clinics in rheumatology, *RD* rheumatic disease, *RA* rheumatoid arthritis, *AS* ankylosing spondylitis, *SD* standard deviation, *P25–P75* percentile 25–percentile 75; Age has normal distribution an "*p*" value is calculated using the Student's *t* test; Items marked with \*do not show normal distribution, so the "*p*" values are calculated using the Mann–Whitney *U* non-parametric test

under protocol; participation in multidisciplinary meetings; collaborative assessment of Disease Activity Score for 28 joints (DAS28); Tender Joint Count (TJC) and Swollen Joint Count (SJC) in RA; assessment of Bath Ankylosing Spondylitis Functional Index (BASFI) in AS; cooperation in implementing the Bath Ankylosing Spondylitis Metrology Index (BASMI); specific nursing clinical record; questions to the patient about adherence (Table 4).

The departments with an NCR “always or almost always” carry out all activities related to healthcare education for patients in statistically significant higher proportions than departments non-NCR (Table 5). In respect of research conducted and training provided for nursing staff, departments with an NCR were more involved in studies (clinical trials and observational studies) and publications. In addition, the number of rheumatology courses is

significantly higher in the NCR group ( $2.7 \pm 1.3$  vs  $1.7 \pm 0.9$  in the non-NCR services;  $p = 0.022$ ).

## Discussion

Many treatment tasks are carried out in the NCR, and these can reasonably be assumed to lighten the treatment load of the rheumatologist, and some, as shown by the data in this study, are very specific to the NCR. These are activities that support the clinical evaluation of the evolution of the disease, as well as the monitoring of the treatments, without forgetting the functions of educating and informing the patient. For authors such as Hill [21], the specialist nurse in rheumatology is key and plays an indispensable role in the multidisciplinary team.

**Table 2** Knowledge of the disease, treatment, and thereof adherence to prescribed treatment

Test	Item	Baseline visit			12-month visit					
		Non-NCR (N: 212)		NCR (N: 181)		Non-NCR (N: 182)		NCR (N: 198)		
		N	%	N	%	N	%	N	%	
Bataalla test	The patient know that their RD is a lifelong illness	201	97.1	174	97.8	178	99.4	195	99.5	1.000*
	The patient knows that his disease can be controlled with diet and medication	190	94.5	168	96.6	171	97.2	183	94.3	0.422
Haynes-Sackett test	Has difficulty taking the medication	23	11.0	9	5.0	14	7.8	20	10.2	0.422
Morisky–Green test	Sometimes forgets to take the prescribed medication	36	17.2	25	13.9	28	15.4	33	16.8	0.718
	Takes medication at the specified times	200	96.2	174	96.2	176	97.2	188	95.4	0.353
	When the patient feels well, they stop taking the medication	16	7.7	10	5.5	21	11.8	11	5.6	0.031
	If the patient ever feels unwell, they stop taking their medication	13	6.25	3	1.7	4	2.2	12	6.1	0.075*
	Final score: adherence to treatment	147	69.3	143	79.0	137	75.3	145	73.2	0.649

Baseline visit and 12-month visit depending on group

The "p" values were calculated using the Chi-square test. Where an \* is marked, the values were calculated using Fisher's exact test

NCR nursing clinics in rheumatology, RD rheumatic disease

**Table 3** Perceived quality of care received during the baseline visit and during the 12-month visit

Item	Baseline visit			12-month visit					
	Non-NCR (N: 212)		NCR (N: 181)		Non-NCR (N: 182)		NCR (N: 198)		
	N	%	N	%	N	%	N	%	
The first time you attended the rheumatology department, access was easy/very easy	113	54.1	107	59.4	110	60.8	103	52.02	0.086
The time you had to wait in the waiting room before you were seen by the rheumatologist or nurse was short/very short	41	19.4	49	27.2	43	23.8	44	22.2	0.723
The waiting room was comfortable/ very comfortable	79	37.6	75	42.4	73	40.8	76	38.4	0.634
Courtesy and/or kindness shown to you by the rheumatologist was good/very good	198	93.8	171	95.0	171	94.5	188	95.4	0.671
Courtesy and/or kindness shown by the nurse was good/very good	168	86.2	169	94.9	158	89.8	192	97.0	0.005
The information provided by the healthcare professional was clear/very clear	191	91.0	166	92.7	158	87.3	181	91.4	0.192
Thinks the frequency of the visits in the rheumatology department is good/very good	167	79.5	157	87.7	131	72.4	161	81.3	0.039
Thinks the time allocated for the visits was sufficient/more than enough	164	78.5	153	85.0	141	78.3	157	79.3	0.82
Overall level of satisfaction in respect of care received at the rheumatology department was good/very good	197	93.4	174	96.7	171	94.5	192	97.0	0.228

NCR nursing clinics in rheumatology

The "p" values were calculated using the Chi-square test

**Table 4** Care which nursing staff provide always or almost always in the rheumatology department

Variable	Non-NCR (n = 18)		NCR (n = 21)		p
	N	%	N	%	
GAD with VAS	4	23.5	18	69.2	0.005*
Pain VAS	4	23.5	18	69.2	0.005*
RADAI assessment	0	0.0	4	14.8	0.279*
BASDAI assessment	4	23.5	17	63.0	0.015*
HAQ assessment	4	25.0	17	63.0	0.027*
Quality of life questionnaire	1	5.9	5	18.5	0.380*
Follow-up in accordance with drug protocol	7	41.2	24	88.9	0.002*
Analytical control of treatments under protocol	5	29.4	20	74.1	0.004
Collaboration in arthrocentesis/infiltrations	8	47.1	18	66.7	0.198
Channelling unplanned visits	10	58.82	21	80.77	0.117
Participation in multidisciplinary meetings	2	11.76	16	59.3	0.002*
Engaging with primary care nursing staff	2	11.8	3	11.1	1.000*
Mantoux and booster	4	23.5	14	51.9	0.114*
Collaboration in assessing DAS28 in RA	3	17.6	17	63.0	0.005*
TJC and SJC in RA	2	11.8	16	59.3	0.002*
BASFI assessment in AS	5	29.4	19	70.4	0.008
Collaboration in conducting the BASMI in AS	1	5.9	14	51.9	0.003*
Conducting FRAX index in osteoporosis	0	0.0	4	14.8	0.147*
Specific nursing clinical record	2	11.8	16	59.3	0.002*
Ask patient if they are following their treatment	5	33.3	23	85.2	0.001*
Hand out patient-satisfaction questionnaires	3	18.75	2	7.4	0.344*
Hand out patient-perceived quality of care questionnaire	3	18.75	1	3.7	0.137*

The “p” values were calculated using the Chi-square test. Where an \* is marked, the values were calculated using Fisher’s exact test

NCR nursing clinics in rheumatology, GAD global assessment of patient, VAS visual analogue scale, RADAI rapid assessment of disease activity, BASDAI bath ankylosing spondylitis disease activity index, HAQ health assessment questionnaire, DAS disease activity score, RA rheumatoid arthritis, TJC tender joint count, SJC swollen joint count, BASFI bath ankylosing spondylitis functional index, AS ankylosing spondylitis, BASMI bath ankylosing spondylitis metrology index, FRAX fracture risk assessment

**Table 5** Patient healthcare education and research work conducted by nursing staff in the rheumatology department

Variable	Non-NCR (n = 18)		NCR (n = 21)		p
	N	%	N	%	
Healthcare education (always/almost always)					
Information about the disease	3	18.75	24	88.9	<0.001
Information about medications	5	31.25	24	88.9	<0.001
Training in self-administration of medications	9	56.25	26	96.3	0.002
Measurements for joint ergonomics	4	25.0	19	70.4	0.005
Research and training					
Participation in clinical trials	11	52.4	24	88.9	0.008
Participation in observational studies	4	19.0	21	77.8	<0.001
Participation in publications	2	9.5	12	44.4	0.011
Courses in rheumatology	13	81.3	24	88.9	0.655
Management courses	1	7.1	1	3.7	1.000
Research methodology courses	4	26.7	8	29.6	1.000
Other courses	3	23.1	11	50.0	0.162

NCR nursing clinics in rheumatology

The “p” values were calculated using Fisher’s exact test

Most of the previous studies that assess the NCR focus exclusively on patients with RA [7, 8, 10–12, 15]. The effectiveness and/or efficiency of the NCR were noted in all of them. In the SCORE study, which also includes patients with AS, better clinical outcomes without a significant increase in costs were found [17]. Like other previous studies that measured patient satisfaction [8, 10, 12, 15], the SCORE study found higher rates of patient satisfaction who were attended to the departments with NCR, specifically for items that relate to the courtesy and kindness of the nurse and the frequency of visits to the rheumatology department. However, satisfaction for most of the items is also good in non-NCR departments.

Measuring the level of adherence is very difficult due to the large number of factors involved. The direct methods (determining metabolites or markers of drugs in the patient's body fluids) are expensive and beyond the reach of a study of this type. Indirect methods are simple and inexpensive yet not very objective and with low diagnostic yield. The recommendation would be to combine a high sensitivity test with another high specificity test [22]. This study measured adherence or therapeutic compliance by means of two indirect methods reported by the patient. On one hand, we used the Batalla test validated to assess knowledge about the disease and the treatment of other chronic conditions (hypertension and diabetes), which has a high sensitivity (85%), and on the other hand, the high specificity (94%) Morisky–Green and Haynes–Sackett tests were used [23]. The SCORE study did not detect differences in knowledge on the disease, and thereof treatment using the Batalla test, nor at the baseline visit nor at 12 months. Work conducted by Hill [10, 12] found that patients who were seen by specialist nurses in rheumatology were better informed and could better self-manage the disease. Nonetheless, the overall score for the Morisky–Green test shows better compliance at the baseline visit for the NCR group, although not at 12 months, where the compliance with the non-NCR improves, matching the NCR. It is possible that after answering the extensive questionnaire at the baseline visit, patients in the non-NCR group became more aware about aspects related to adherence to treatment.

Although the baseline characteristics of the rheumatology departments for both groups are similar in terms of human resources, beds and indicators of clinical activity, the volume of scientific activity in the department is significantly higher in the NCR group. The observed greater research activity of the departments with an NCR could be encouraged, in part, by the increased participation in clinical tests and in observational studies by the nursing staff in these departments. The logistical support of the nursing staff when gathering data and coordinating activities related to a project could be vital to the research.

According to the findings of the study, a large part of the patient assessment and monitoring of the treatments in departments with NCR is carried out very frequently during the nursing consultation. In the case of the RA, determining the DAS28 is a time-consuming process especially having to explore swollen joints, which also requires a significant level of training. Some years ago Van Hults [24] showed that when a nurse determines the DAS28, followed by a consultation with a rheumatologist if the DAS28 is >3.2 to adjust treatment, it is an effective method for keeping the patient with low RA activity. The SCORE study has shown that in almost two out of three departments with NCR the nurse is actively involved in assessing the DAS28 including the tender and swollen joint counts. This greater involvement in the nurse's care work can lead to a greater interest in the development of other activities such as research. Although no differences were seen between NCR and non-NCR in respect of the type of training courses received by the nursing department, there are differences within the number of courses of rheumatology, being much higher in the NCR, which implies better preparation for carrying out care activities which the nursing staff do in these departments.

The first EULAR recommendation on the role of the nurse in the management of chronic inflammatory arthritis is based on consensus of the patient to be educated about their disease [3]. One of the tasks related to nursing which the findings from the SCORE study more strongly associated with departments that have NCR are healthcare education, both in respect of information about the disease and joint ergonomics and on medication and self-administration. The remaining recommendations in the EULAR document are also reflected to a greater extent in the NCR departments that took part in the SCORE study.

### In conclusion, the existence of NCR

- Improves perceived quality of care.
- Develops more educational activities for the patient.
- Releases the rheumatologist from multiple care tasks.
- Is associated with increased research undertaken in the department.
- Facilitates the research activities of the nursing staff.
- Improve specific training in rheumatology nursing.

### Compliance with ethical standards

**Funding** This work was supported by an unrestricted grant from the Spanish Society of Rheumatology and Abbvie.

**Conflict of interest** Santiago Muñoz-Fernández, Ma. Dolores Aguilar, Raquel Almodóvar, Laurra Cano-García, Sandra Fortea, Cristina Patricia Alcañiz-Escandell, J. Ramón Rodríguez, Laura Cebrián and Pablo Lázaro declare that they have no conflict of interest.

**Ethical approval** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 19,634 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed consent** Informed consent was obtained from all individual participants included in the study.

## Appendix

### SCORE working group

Hospital	I Investigator
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