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Long-term trends in rheumatology care

Achievements and deficits in 25 years of the German national rheumatology database

The German national database (NDB) was established in 1993 as an instrument for monitoring the health care of inflammatory rheumatic diseases. A pilot project took place in 1992 at several outpatient clinics and rheumatological practices in Berlin. With the support of the German Federal Ministry of Health, the documentation could be expanded to a nationwide collection in 22 rheumatism centers. Data from 25,000 patients with inflammatory rheumatic diseases from 1998 were already analyzed in the first publications [1–3]. From 1997 to 2006, the NDB was funded by the Federal Ministry of Research and Technology within the framework of the Competence Network Rheumatism. With the expiration of federal funding, it was possible to achieve follow-up funding from 2007, which is jointly supported by the Association of Regional Cooperative Rheumatology Centers and various member companies in the Association of Corporate Members of the German Society for Rheumatology [4]. The NDB has been continued in this form for 13 years now. Community funding guarantees the German Rheumatism Research Centre (*Deutsches Rheuma-Forschungszentrum*, DRFZ) full academic freedom in the implementation of the project and the analysis and publication of the results. In the 25 years to date, more than 260,000 patients with inflammatory rheumatic diseases have been documented. Numerous national and

international publications have emerged from the data. Key findings include trend analyses of care and burden of diseases [5–8], employment and cost analyses [9–13].

All inflammatory rheumatic disease patterns are recorded in the NDB. These include rheumatoid arthritis (RA), ankylosing spondylitis (AS), psoriatic arthritis (PsA), systemic lupus erythematosus (SLE) and other collagenoses and vasculitides. There are also a handful of patients documented with rare diseases, even within rheumatology, e.g. cryoglobulinemia, brucellosis, thrombangiitis obliterans or Felty syndrome. However, since not every rheumatological disease can be recorded with specifically developed scores, the documentation focuses on the most common disease, RA [4].

The NDB is a long-term observational study which, in addition to clinical studies and registry data, is justified in mapping daily routine care within internal rheumatology. In this review, which was produced in the year of the 25th anniversary of the NDB, current results from the analyses compiled annually for the participating institutions are reported and the essential studies of the past decades summarized.

Patients

In the NDB, patients are documented in the participating institutions once a year—if possible consecutively. All inflammatory rheumatic diseases can be recorded on suspicion or confirmed diagnosis. About half of all diagnoses are RA,

while 10% of patients have AS, 10% PsA and about 6% SLE. The remaining cases are distributed among other arthritides, collagenoses and vasculitides. Patients can, but do not have to, be documented in the course of their treatment. For the interpretation of the data it is important that cross-sectional data from the individual years is presented, i.e. for each year all patients documented in that year are reported. The annual number of cases is declining (~13,000), this is mainly due to the number of participating institutions, which fell significantly in 2005 with the switch from the paper version to a computer-assisted input and, since then, has decreased to 15–17 institutions. The quality of the documented data has increased with the conversion to electronic documentation. The NDB is integrated into various documentation systems. Their use is not available in all facilities and makes it difficult to attract new participating centers. ■ **Table 1** shows the number of documented cases for RA, AS, PsA and SLE from 1996 to 2016.

Epidemiological trends

On the basis of the NDB, dynamics in the epidemiology of rheumatological diseases can be determined. In RA, and especially in AS and PsA, an increase in the age of onset of the disease over time can be observed (■ **Fig. 1**). In the case of RA, this applies in particular to seronegative patients (Δ 6 years). The age of onset does not show any change in patients with SLE. The reason for these observations is not known as yet. The proportion

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Table 1 Number of documented patients in the German national database for the period 1996–2016

	Rheumatoid arthritis			Ankylosing spondylitis			Psoriatic arthritis			Lupus erythematosus		
	N	Females (in %)	Mean age	N	Females (%)	Mean age	N	Females (%)	Mean age	N	Females (%)	Mean age
1996	15,105	77	58	2279	30	45	2378	55	49	1599	90	43
1997	16,196	76	58	2157	30	45	2535	56	50	1576	90	44
1998	18,105	76	58	2317	31	45	2919	54	50	1682	88	44
1999	17,377	77	59	2240	34	46	2958	55	51	1889	89	44
2000	16,550	76	59	2257	33	46	2717	56	51	1685	88	44
2001	12,970	77	59	1863	33	48	2275	56	52	1509	89	45
2002	12,637	77	59	2103	35	48	2441	57	52	1498	89	45
2003	12,299	77	60	1922	37	48	2326	57	53	1384	89	45
2004	10,143	78	60	1569	37	49	2014	54	53	1127	89	46
2005	3620	75	59	540	43	47	582	51	52	538	88	45
2006	4790	76	60	702	39	47	812	50	53	597	88	46
2007	7181	76	61	1327	38	47	1466	55	54	925	89	46
2008	6999	75	61	1272	35	48	1423	52	54	966	88	46
2009	7337	75	61	1387	34	48	1500	54	54	1007	89	45
2010	8362	74	61	1448	35	49	1720	54	55	1075	89	46
2011	8594	75	61	1502	36	48	1813	52	55	1057	89	46
2012	7967	75	62	1359	35	49	1712	54	56	1056	89	47
2013	8101	76	62	1339	35	50	1736	54	56	1001	88	47
2014	8304	75	62	1334	36	50	1709	53	57	1007	89	48
2015	8721	75	63	1402	37	50	1925	53	57	1044	88	48
2016	6364	74	63	1037	38	51	1421	52	58	846	88	48

The number of cases (N), the proportion of female patients and the mean age in years are given

Table 2 Hospitalization and work participation: a comparison of 1996 and 2016

	RA		AS		PsA		SLE	
	1996	2016	1996	2016	1996	2016	1996	2016
Number of patients	15,105	6364	2279	1037	2378	1421	1599	846
Inpatient hospital stay in the previous year	27%	10%	11%	9%	14%	7%	26%	7%
Hospital days, median	28	14	22	13	22	12	24	8
Number of patients <65 years	10,501	3366	2178	876	2160	1009	1475	730
Employed females	37%	60%	58%	68%	46%	63%	43%	55%
Employed males	47%	69%	66%	72%	71%	79%	55%	64%
Patients with sick leave in the previous year due to the rheumatic disease	48%	25%	49%	30%	40%	25%	41%	18%
Days absent due to illness in all patients with sick leave, median	28	15	28	20	21	15	21	15
Days absent due to illness in all working patients, mean value	30	9	26	10	22	7	24	9

The data on incapacity for work are from 1997 (first recorded)

RA rheumatoid arthritis, AS ankylosing spondylitis, PsA psoriatic arthritis, SLE systemic lupus erythematosus

of women is constant in RA (74–75%), PsA (52–55%) and SLE (88–90%), while it has risen from 30% to 38% in AS. The proportion of rheumatoid factor-positive patients has not changed substantially (61–70% in the years 2009–2016); the proportion of smokers has also remained similar since 2005 (52% in 2005, 54% in 2016). The proportion of patients with a higher level of education has increased significantly (16% with over 13 years of education in 1993, 31% in 2016). This corresponds to an overall higher level of educational attainment among the population. The mean age in all diseases has increased over time (Table 1). This is mainly due to the fact that less newly referred but more patients with long disease duration are recorded.

Developments in rheumatological care

The proportion of patients that visit a rheumatologist within 12 months of the onset of symptoms has increased in

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Long-term trends in rheumatology care. Achievements and deficits in 25 years of the German national rheumatology database

Abstract

Background. Since 1993, data on the care and quality of life of patients with inflammatory rheumatic diseases have been collected in the German National Database (NDB) of the regional collaborative rheumatology centers.

Objective. In this review long-term trends on treatment, disease activity and gainful employment of the most common inflammatory rheumatic diseases are presented and the most important analyses from 25 years of the NDB are summarized.

Methods. Between 15 and 17 rheumatological institutions take part in the NDB and once a year collect data from a total of more than 10,000 patients. The rheumatologists document the disease status and care, the

patients report on their state of health and the effects of the disease.

Results. The biologics era at the beginning of the twenty-first century has led to changes in the therapeutic spectrum of most inflammatory rheumatic diseases, especially in rheumatoid arthritis and ankylosing spondylitis. Some basic therapies formerly used are hardly used anymore and glucocorticoids are used less frequently. Methotrexate has remained the standard therapy for rheumatoid arthritis over the years. Nowadays, nearly 30% of patients with rheumatoid arthritis receive treatment with biologics. Disease activity, functional and

social restrictions have decreased across all diseases.

Conclusion. The improved health status of many patients with rheumatic diseases confirms the high level of care provided by the rheumatism centers involved in the NDB. The increasing specification of measuring instruments and the standardization of documentation systems are major challenges that the NDB will have to face in the coming years if it is to remain in the digital age.

Keywords

Inflammatory rheumatic diseases · Treatment · Disease burden · Level of care · Quality of life

Langzeittrends in der rheumatologischen Versorgung. Erfolge und Defizite im Spiegel von 25 Jahren rheumatologischer Kerndokumentation

Zusammenfassung

Hintergrund. Seit 1993 werden in der Kerndokumentation der Regionalen Kooperativen Rheumazentren Daten zur Versorgung und Lebensqualität von Patienten mit entzündlich rheumatischen Erkrankungen erhoben.

Fragestellung. In dieser Übersichtsarbeit werden Langzeittrends zu Therapien, Krankheitsaktivität und Erwerbstätigkeit der häufigsten entzündlich rheumatischen Erkrankungen vorgestellt und die wichtigsten Analysen aus 25 Jahren Kerndokumentation zusammengefasst.

Methoden. Zwischen 15 und 17 rheumatologische Einrichtungen nehmen an der Kerndokumentation teil und erfassen 1-mal jährlich Daten von insgesamt mehr als 10.000 Patienten. Die Rheumatologen dokumentieren den Krankheitsstatus und

die Versorgung, die Patienten berichten über ihren Gesundheitszustand und die Auswirkungen der Erkrankung.

Ergebnisse. Der Beginn der Biologikaära Anfang des 21. Jahrhunderts hat das Therapiespektrum insbesondere der rheumatoiden Arthritis und ankylosierenden Spondylitis verändert. Einige früher häufig verwendete Basistherapeutika werden heute kaum noch eingesetzt, Glukokortikoide werden seltener gebraucht. Bei der rheumatoiden Arthritis hat sich Methotrexat über die Jahre hinweg als Standardtherapie etabliert, knapp 30% der Patienten mit rheumatoider Arthritis erhalten heute eine Biologikatherapie. Krankheitsaktivität, funktionelle und soziale Einschränkungen sind krankheitsübergreifend zurückgegangen.

Schlussfolgerungen. Der verbesserte Gesundheitsstatus vieler Rheumaerkrankter bestätigt das hohe Versorgungsniveau innerhalb der an der Kerndokumentation beteiligten Rheumazentren. Die zunehmende Spezifizierung der Messinstrumente und die Vereinheitlichung der Dokumentationssysteme sind wesentliche Herausforderungen, der sich die Kerndokumentation in den nächsten Jahren stellen muss, um im digitalen Zeitalter bestehen zu bleiben.

Schlüsselwörter

Entzündlich rheumatische Erkrankungen · Therapie · Krankheitslast · Versorgungsniveau · Lebensqualität

all diseases. However, it is still low for AS at 45% in 2016 (RA: 73%, SLE: 71%, PsA: 66%). The mean disease duration at the first contact with a rheumatologist has decreased (median 1994/2016: 1.0/0.5 years [RA], 5.0/2.1 years [AS], 2.0/0.6 years [PsA]). But here, too, AS has the highest proportion of patients that have been ill for several years before seeing a rheumatologist.

Treatment changes

The most significant changes in drug therapy have occurred with the introduction of biological disease-modifying antirheumatic drugs (bDMARDs). In 2001, the first patients were enrolled with bDMARDs, and by 2016 the proportion had increased to 28% (RA), 33% (PsA) and 50% (AS) (■ Fig. 2). In RA and PsA, more than half of bDMARD therapies are combined with a conventional syn-

thetic (cs) DMARD (60%), most commonly with methotrexate (MTX). In AS, bDMARDs are predominantly administered as monotherapy (84%). Etanercept and adalimumab are the most commonly used substances, followed by rituximab and tocilizumab (RA) or golimumab (AS, PsA). MTX is the most commonly used csDMARD as a mono- and combination therapy. MTX and sulfasalazine are used less frequently in AS. The use of glucocorticoids decreased slightly in 2016,

Fig. 1 ◀ Increase in the age of disease onset, comparison 1990s and 2000s. Patients with a symptom duration of <5 years (RA, SLE, PsA) or <10 years (AS) were considered. Reference lines show the median. The difference in the median age of onset for the two periods 1994–1996 and 2014–2016 was 3 years (RA), 5.5 years (AS), 6 years (PsA) and 0 years (SLE). RA rheumatoid arthritis, AS ankylosing spondylitis, PsA psoriatic arthritis, SLE systemic lupus erythematosus

with 45% (RA), 10% (AS), 18% (PsA) and 62% (SLE) receiving glucocorticoids. At the same time, the proportion of patients treated at doses above 7.5 mg prednisolone equivalent per day decreased from 28% (1996) to 12% (2016) for RA, from 26 to 14% for PsA and from 38 to 13% for SLE. Nonsteroidal anti-inflammatory drugs (NSAIDs) are also on the decline, with 25% (RA) to 45% (AS) receiving NSAIDs in 2016. The use of analgesics has increased (18% AS, 20% RA in 2016).

» Osteoporosis prevention and treatment take higher priority today

In collagenoses and vasculitides, the development of biologics has not yet led to pronounced changes in the therapy spectrum. In 2016 less than 10% of all patients with collagenoses or vasculitides were treated with biologics. Antimalarials were used in 67% of all SLE patients in 2016. Mycophenolate mofetil (13%) has

been established as an alternative to azathioprine.

Today, osteoporosis prophylaxis and therapy have gained more importance across all diseases and are used in 47% (RA), 27% (AS), 31% (PsA) and 55% (SLE). Physiotherapy has been used slightly more frequently as non-drug therapy since 2008, while occupational therapy, rheumatic functional training and patient education have all been recorded in less than 5% of patients. Joint replacement due to RA is continuously declining (5% in 1996, 2% in 2016).

Decrease in disease activity and severity

The proportion of RA patients that are classified by rheumatologists as having a high degree of severity has fallen from 23% (1994) to 13% (2016). The mean disease activity score 28 (DAS28) decreased from 4.6 (1997) to 3.1 (2016). The proportion of patients in remission (DAS28 < 2.6) increased during this pe-

riod from 13 to 39%, especially in patients with long disease duration. The proportion of patients classified by rheumatologists as having low disease activity (0–3 on a numeric rating scale (NRS) of 0–10) increased from 49 (1996) to 84% (2016).

The proportion of AS patients with inactive/moderate disease (ankylosing spondylitis disease activity score (ASDAS) < 2.1) increased from 39% (2011) to 47% (2016). The average Bath ankylosing spondylitis disease activity index (BASDAI) fell from 4.2 (2005) to 3.5 (2016). Further disease-specific activity or functional markers are not collected in the NDB or are only collected in a small number of cases. The systemic lupus erythematosus disease activity index (SLEDAI) has been included in the documentation of SLE patients since 2005, but is only documented for 1–12% of cases ($N=6$ –101 patients). The disease activity index for psoriatic arthritis (DAPSA) was calculated retrospectively for PsA. This requires 66/68 joint counts, which were only recorded in the specific PsA module from 2007 for about

Fig. 2 ◀ Changes in drug therapy in the period 1996–2016. Until 1999 only non-selective NSAIDs were recorded, from 2000 also coxibs. Data for 2005 and 2006 are not shown. RA rheumatoid arthritis, AS ankylosing spondylitis, PsA psoriatic arthritis, SLE systemic lupus erythematosus

a quarter of all PsA patients. As this group differs from the overall collective in terms of age structure and therapy, the authors cannot make any statement on changes in the proportions of remission in SLE and PsA.

Patient-reported parameters

Functional status has significantly improved. The mean Hannover functional ability questionnaire (FFbH; function of 0–100%) in RA patients increased from 67 (1994) to 74 (2016). The mean FFbH is 80 in patients with a disease duration of <10 years. The proportion of patients with impaired functional status (FFbH < 70) decreased from 53 to 36%. The mean Bath ankylosing spondylitis functional index (BASFI) in patients with AS decreased from 4.2 (2005) to 3.6 (2016).

The proportion of patients reporting severe pain (7–10 on a NRS of 0–10) decreased from 33% (1993) to 16% (2016) for RA, from 32 to 19% for AS, from 26 to 16% for PsA and from 17 to 12% for SLE.

Decline in hospital stays and increase in gainful employment

Inpatient stays are declining and occurred in ≤10% of all patients in 2016. The average duration of stays has fallen substantially across all diseases (Table 2).

The proportion of employment at working age (<65 years) has risen steadily (Table 2). This applies to all four disease groups, men and women, as well as younger and older patients. Incapacity to work due to rheumatic diseases is also declining strongly, accompanied by a decrease in sick leave in days (Table 2; Fig. 3). Between 1996 and 2016, for example, the average number of absentee days for all gainfully employed RA patients fell from 30 to 9, despite higher labor force participation. In the other reported rheumatic diseases, absenteeism due to illness has also fallen to around one third.

Discussion

The idea of establishing a long-term monitoring system for internal rheumatological care with the NDB more than 25 years ago has led to a very successful and nationally and internationally known project. Due to the high willing-

ness of the participating rheumatologists and patients to document information on the disease status over many years, a unique database could be established. With a high continuity of the measuring instruments, it reflects long-term trends over time with regard to therapeutic care, disease activity and disease burden of those affected.

Changes in age at disease onset, in health behavior and also in educational status are variables of epidemiological relevance when historical and current data are compared. Analyses of differences in disease activity in early and late RA patients [14], in the prevalence of comorbidities in women and men [15] and also the gender-specific influence of overweight on disease activity parameters of RA [16] are examples of the association of sociodemographic factors that need to be taken into account in all analyses. The association of gender, education and region of residence was also evaluated in relation to the employment of patients with rheumatic diseases [11].

The decrease in disease activity across all diseases indicates a fundamental improvement in the situation of patients with inflammatory rheumatic diseases. Indirect factors such as the increase in gainful employment [9, 10] and the de-

Fig. 3 ◀ Decline in incapacity to work among employed patients: a comparison of 1997 and 2016. The box plots show the median (line in the box), the 25–75th percentile (boundaries of the box) and the 10–90th percentile (boundaries of the thin lines above and below the box). RA rheumatoid arthritis, AS ankylosing spondylitis, PsA psoriatic arthritis, SLE systemic lupus erythematosus

cline in sick leave and hospitalization confirm a lower burden of illness today. A reduction in lost working days to less than one third is a dramatic change that not only reflects a higher quality of life for those affected, but also significant economic savings. These developments are evident for patients with RA [5], AS [6], PsA and SLE [7, 17].

» Today, the disease burden in patients with inflammatory rheumatic diseases is significantly lower

In the 1990s patient-reported outcomes that significantly restrict the quality of life of patients, such as pain, fatigue, sleep disorders and psychological stress were reported as early on as the 1990s. An

analysis of the ACR/EULAR remission criteria developed in 2011 showed that pain and fatigue were often the main reasons why the new remission criteria were not met, despite fulfilling DAS28 remission [18]. In addition to the recording of disease activity and damage, patient-reported outcomes are now an established and indispensable measure for evaluating the burden of disease and are increasingly being recorded on a disease-specific basis. At this point, the NDB as a disease-overlapping project has increasing limitations, even if the PsA module and sporadically documented disease-specific questionnaires were used in an attempt to address the peculiarities of individual rheumatic diseases.

The NDB shows significant changes in care services. Nevertheless, some forms of therapy are used surprisingly consistently. The first publication already re-

ported that in 1998 56% of patients received MTX as basic therapy [2]. Today, this share is almost identical at 60% [19]. However, MTX is more commonly used today in combination with biologics and biosimilars. Other DMARD therapies have been replaced by more effective substances. In 1998, almost one tenth of rheumatologically treated patients received parenteral gold [2]; today, gold is only used sporadically. The most relevant change is the proportion of patients that are currently treated with bDMARDs, which reaches almost one third in RA [19] and even half of all AS patients [6].

Alongside the successful changes in therapy, the NDB also reveals deficits in the care service. For many years inadequate implementation of the guidelines in everyday life has been observed [20], which in some patients is reflected in a delayed change of therapy, a high supply of glucocorticoids [21] and an inadequate supply of physical and complementary therapies [22] as well as rehabilitation [23].

A constant topic is the supply of glucocorticoids [24, 25]. A high prescription rate of glucocorticoids has been observed over the years, with dosages above 7.5 mg prednisolone equivalent decreasing and only a few patients being treated with high-dose glucocorticoids today [19]. However, almost 50% of long-term RA and polymyalgia rheumatica (PMR) patients remain on glucocorticoid therapy [19, 21]. Today's recommendations to use glucocorticoids only as briefly as necessary have not yet established themselves among patients that have been ill for many years.

» The NDB reveals not only successful changes in treatment but also deficits in the care service

In comparison to data from clinical studies, the NDB illustrates what happens in everyday rheumatological care. The NDB is also an indispensable supplement in comparison to the biologic registry RAB-BIT, since the NDB also includes patients that have sufficiently controlled disease

activity without any or with their first csDMARD therapy. In the estimation of the frequency of prognostically unfavorable factors, the data of the NDB proved to be very helpful, since there is no selection of a prognostically unfavorable patient cohort as in RABBIT [26].

High practice variation in drug treatment was reported as early on as in the first years of the NDB [3]. Despite the development of numerous guidelines, this has not homogenized over the years. Differences among the participating institutions in the supply of bDMARDs and glucocorticoids and also in outcomes that cannot be explained solely by different patient collectives continue to be observed. Why there are still such great differences at this point remains a topic for discussion.

Limitations and strengths of the NDB

Due to the focus on RA, there are barely any specific instruments for other rheumatic diseases, or they are filled out in an insufficient number of cases, e.g. European Consensus Lupus Activity Measurement (ECLAM) or SLEDAI for SLE. With today's abundance of disease-specific measuring instruments, cross-disease documentation can no longer provide specificity. On the other hand, non-specific but uniform instruments such as the recording of pain, fatigue and function allow a comparison across diseases, which enables the disease burden of other rheumatic diseases to be classified in comparison to RA [8].

Data collection is carried out via and in addition to routine documentation, and the patients receive additional questionnaires. The recording is handled differently in the facilities depending on availability (rheumatologist, study nurse, assistant, tablet/paper, etc.). A complete registration of all outpatients seen in the facility is aimed at, but not required. In contrast to rheumatological registries (e.g. RABBIT) and clinical studies, there is only limited demand for missing values. Therefore, the completeness of the data in the institutions varies according to the resources available. For some values the documentation is almost complete

(e.g. for the FFbH), other parameters are insufficiently filled in and cannot be included in evaluations (e.g. radiological status).

A comprehensive picture of the disease status of patients with rheumatic diseases is only possible through supplementary interpretation of the results from various data sources. The analysis of health insurance data by linking data from patient questionnaires in the PROCLAIR project is a helpful supplement to the NDB, especially in the area of health care services [27]. Comparison with data from PROCLAIR enables a classification at population level. There are many comparable results, especially with regard to patient-reported outcomes of pain and functional status, which confirm the quality of both sources [27]. On the other hand, there are large deviations, e.g. in the degree of DMARD care, which is much higher for rheumatologists in the NDB than in the claims data [28] or in the prevalence of co-morbidity diagnoses [29], which are significantly more frequent in the claims data than in the NDB. Since it is not possible to rule out insufficient reporting in the NDB as well as over-reporting in insurance data, the authors estimate the information provided by rheumatologists on concomitant diseases in the NDB to be somewhat too low and the claims diagnoses in the insurance data to be somewhat too high.

Conclusion

The 25 years of the NDB have provided a comprehensive picture of changes in the care of patients with inflammatory rheumatic diseases. The data are a valuable complement to clinical studies and analyses from observational studies, since they are collected under daily practice conditions. Whether the NDB is still future-proof under the increasing number of specific disease registers also depends on whether the collection of patient data can be standardized in the future and whether it will succeed in a modern digital format.

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Compliance with ethical guidelines

Conflict of interest K. Albrecht, J. Callhoff and A. Zink declare that they have no competing interests.

All the investigations on humans described were carried out with the consent of the competent ethics committee, in accordance with national law and in accordance with the Helsinki Declaration of 1975 (as amended). A declaration of consent is available from all patients involved.

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