

## Community rheumatology in India

### *A COPCORD driven perspective*

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#### ABSTRACT

The current perspective is based on the author's experience with COPCORD (community oriented program for control of rheumatic diseases) in India and clinical practice in Center for Rheumatic Diseases (CRD), Pune. Almost half of the patients at the CRD consist of people from rural areas and small towns scattered all over Maharashtra. CRD also coordinates 13 COPCORD survey sites all over India. During the last three decades or so, COPCORD has accumulated an unprecedented quantum of community data on musculoskeletal pain and life styles and is thus an appropriate platform for describing the status and challenges of community rheumatology in India.

**Keywords:** *Community rheumatology, COPCORD.*

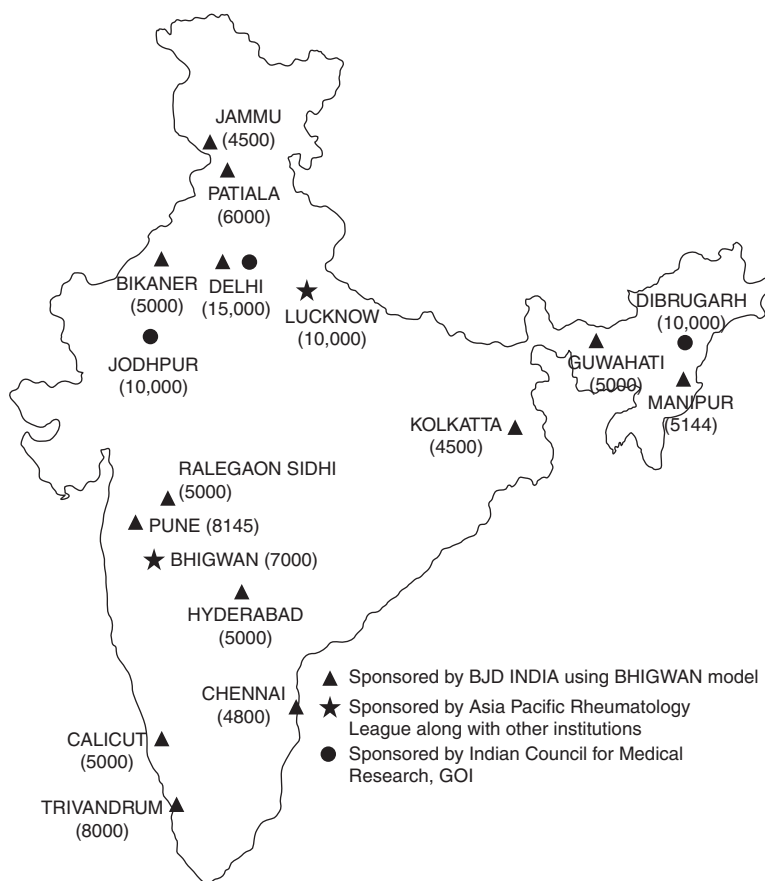
The current perspective is based on my experience with COPCORD<sup>1</sup> (community oriented program for control of rheumatic diseases) in India and clinical practice in Centre for Rheumatic Diseases<sup>2</sup> (CRD) which is a private rheumatology facility in a community setting. Almost half of the daily attendance (70–85) of patients at the CRD consists of people from rural areas and small towns scattered all over Maharashtra. CRD also coordinates thirteen COPCORD survey sites all over India (Fig. 1), in particular the ongoing COPCORD in the Pune urban and rural (Bhigwan) region (Fig. 2).

COPCORD was born due to a need to gather data on pain and MSK disorders with an emphasis on developing rural economies.<sup>3–5</sup> During the last three decades or so, COPCORD has accumulated an unprecedented quantum of community data on pain and life styles.<sup>6</sup> Therefore, COPCORD reflects rheumatology disorders and complaints common within the community.<sup>6</sup> The maiden Indian COPCORD survey was carried out in village Bhigwan in 1996 followed by a long-term community program which is presently in its 14<sup>th</sup> year.<sup>7,8</sup> COPCORD Bhigwan has evolved into a unique

community model<sup>9</sup> whereby meaningful clinical data is continuously gathered while providing free of cost quality clinical services which include diagnosis, therapy guidance and monitoring of response. With increasing popularity (and demonstration of usefulness), the cover has extended to a rural population of 50,000 from neighbouring villages. The emphasis is on clinical skills as investigation facilities and socioeconomics are highly constrained.

#### PREAMBLE

From the outset, it is prudent to state that rheumatology continues to be a poorly recognized specialty. Few, if any, fresh medical graduates consider rheumatology as a worthwhile subject to specialize. There are less than 100 dedicated whole time rheumatologists serving a billion plus people. I suspect a third of them practice rheumatology in a truly community setting far from the academia and savvy corporate hospitals. However, in view of awesome disease burden



**Figure 1** Population survey sites for arthritis and rheumatism using WHO-ILAR COCPORD (community oriented program for prevention and control of rheumatic diseases) Model 1996–2008.



**Figure 2** Doctors, paramedics and patients at the COCPORD site in village Bhigwan.

and scanty health care (and often nonexistent specialists) community health problems are bound to spill over into the latter and thus all rheumatologists do encounter community rheumatology. On the other hand, millions of sufferers of rheumatic musculoskeletal disorders (MSK) seek relief from care providers in the community and may never go beyond a family practitioner (or worse still a chemist in this country!). Irrespective of the health care scenario, it is “pain” which pulsates and sustains community rheumatology.

### COMMUNITY PAIN

Rheumatology is preordained to deal with aches and pains. And the large majority of these painful situations are MSK in origin. Often, they defy precise clinical or even an

anatomic physiological description. The community labels them as “rheumatic”. Irrespective of the cause, pain is the red flag. Unfortunately, the latter is often not realized because in suave rheumatology clinics and tertiary super specialist hospitals, “red flags” are reserved for inflammatory arthritis. MSK pain is the most frequent self reported ailment in the community and less than 10% of all such cases are inflammatory arthritis.<sup>8</sup> This was my first lesson in community rheumatology taught by Bhigwan COPCORD several years after my meritorious training in medicine and rheumatology and a booming practice. Our medical curriculum is highly skewed away from the community and our young doctors of today are poorly equipped to tackle community “aches and pains”.

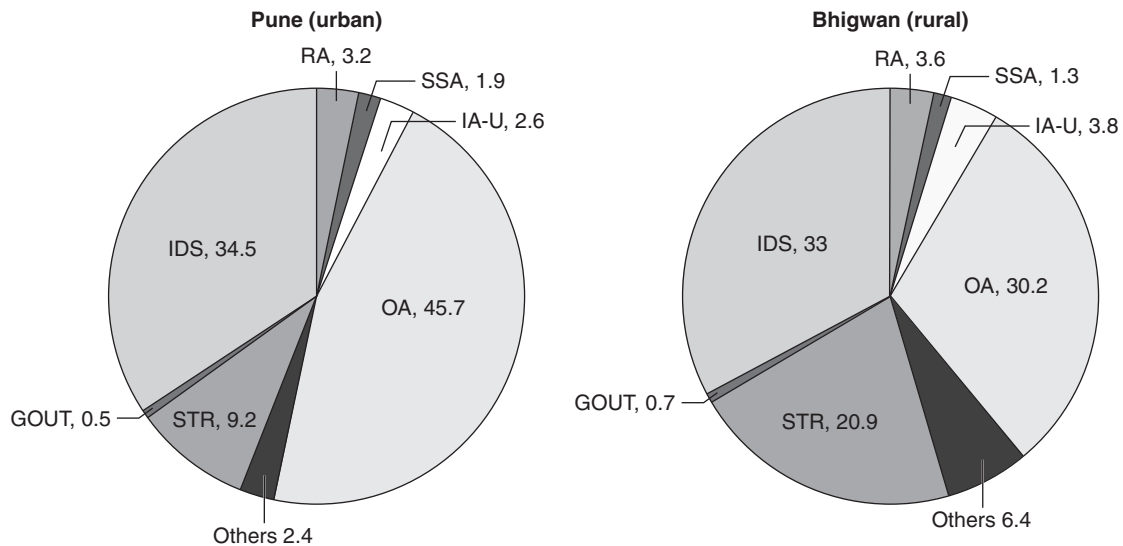
One of the earliest problems encountered with the Bhigwan survey data was the lack of a classification system that could correctly capture MSK pain and early arthritis. This is of immense importance in a community setting. What would you call a “painful elbow” or a “neck pain” without further evidence (clinical and/or historical) to describe the aetiopathogenesis or form the basis for any specific therapy? Sometimes, as in the Bhigwan rural community, circumstantial evidence may point towards an occupation (or the inadvertent accumulation of tissue trauma) as a likely cause but it would be unjustified to label the painful elbow as “arthritis” and painful neck as “spondylitis”. It may be prudent to add that in a community setting such as Bhigwan, investigation facilities are grossly limited. Clinical skills are indeed the only tools in providing diagnosis and care in a socioeconomically disadvantaged community setting. In contrast, patients in the community may be over investigated with a fervent hope to find some abnormality. Many patients with “neck pain” are likely to be over diagnosed with “spondylitis” based on subtle or nondescript findings on an ill intended MRI scan. Doctors rush in to pronounce a diagnosis of rheumatoid arthritis based purely on the presence of seropositive rheumatoid factor without any reference to the atypical clinical profile. Investigations performed and interpreted by unscrupulous naïve medical brains are an important cause of needless expenditure and undue physical and mental stresses in the community. In any clinical setting, clinical probability and strong suspicion must dictate the extent of investigations to arrive at a reasonably sound diagnosis before embarking on a therapeutic mission.

In Bhigwan, we decided to classify all non syndromic (as a general rule all those who could not be clinically labelled as “inflammatory” and/or “degenerative”) aches and pains into either a “symptom related disorder” (SRD) or “soft tissue rheumatism” (STR).<sup>10</sup> SRD related to “nothing else other than a symptom” and STR had some further description/evidence of the problem (be it generalized or

regional). Over time, we have learnt to establish likely relationships of the latter groups with occupation, trauma and posture, and subsequently could push several of the first time SRD under the encompassing umbrella of STR. Eight years later, in the Pune COPCORD, we recorded less of SRD (though still meaningful) and more of STR.<sup>11,12</sup>

There is a wide spectrum of rheumatic MSK disorders in any community (Fig. 3) and the type of experience one gains depends upon the style of practice. Even in a community, one could perhaps designate MSK disorders into red flags (the burning hot inflammatory disorders) and yellow flags (the docile STR and the degenerative disorders) and focus on the red ones (hoping that the yellow ones can be dealt by the general practitioners, orthopaedists, physiotherapists or practitioners of complementary and alternative medicine). Undoubtedly, in tertiary hospital settings, the inflammatory and complex rheumatic disorders dominate and rheumatologists spend more and more time on lesser frequent disorders. But at a community level, all that is MSK pain and not traumatic in origin must be evaluated and managed in the rheumatology domain. “Why” and “how” are important questions (see below), especially in view of the sheer disease burden, but should not dissuade the practice of wholesome rheumatology?

In contrast to the community setting, patients in a tertiary hospital setting are amenable to detailed investigations and often present with fully blown text book picture of the disease. Multidisciplinary approach and collective thinking are useful tools, especially in difficult clinical situations, but not readily available in a community setting. Whatever may be the case, patients universally warrant a diagnosis and doctors must (go all out to) provide the same. But this equation can be detrimental especially in an early case or an atypical clinical profile. Often, patients in the community suffer more from the diagnosis label than the actual disorder. Besides the psychological burden of a wrong diagnosis, the underlying disorder may continue to elude a correct diagnosis (and treatment) therefore leading to progression of the disease at an alarming extent. A classical situation would be a missed infection (rampant in the community) under a presumable cloak of inflammatory arthritis. An equally damaging trend in the community, also recorded in Bhigwan and several other COPCORD, is the over diagnosis of certain disorders, albeit important but based on practice bias. Some of the latter are rheumatic fever arthritis, hyperuricemia, gout, tuberculosis sacroiliitis, rheumatoid arthritis and osteoarthritis/spondylosis. The author has also witnessed the rampant (though often claimed to be empirical) use of several drugs (in particular steroids, oral penicillin and allopurinol) in patients with ill defined rheumatism.



**Figure 3** Distribution (percent) of rheumatic musculoskeletal disorders in Pune urban & Bhigwan rural community survey: a WHO ILAR COPCORD (community oriented program for control of rheumatic diseases) Pune region study. RA=rheumatoid arthritis; SSA=seronegative spondyloarthritis; IA-U=undifferentiated inflammatory arthritis; IDS=ill defined aches and pains; OA=osteoarthritis; STR=soft tissue rheumatism).

**Table 1** Frequency (percentage) of current pain at various sites (indicated on a human manikin) in patients from Pune urban survey and a comparison with Bhigwan rural survey: a WHO ILAR COPCORD (community oriented program for control of rheumatic diseases) Pune region<sup>12</sup>

	Pune urban			Bhigwan rural		
	Male (n=4010)	Female (n=4135)	Total (n=8145)	Male (n=2003)	Female (n=2089)	Total (n=4092)
Pain any site	10.0	18.1	14.1	13.2	22.5	17.9
Neck	1.5	3.9	2.8	3.4	9.5	6.5
Upper back	2.3	4.7	3.5	4.9	10.9	7.9
Low back	5.4	9.8	7.5	7.8	15.8	11.9
Back any site	7.0	13.2	10.2	8.7	17.3	13.1
Calf pain	2.7	5.7	4.2	4.3	8.5	6.5
Shoulder	2.0	4.0	3.0	4.9	9.8	7.4
Elbow	1.0	3.6	2.3	3.9	7.9	5.9
Hand/wrist	1.6	3.9	2.8	4.2	10.3	7.3
Knee	6.1	12.2	9.2	9.5	15.8	12.7
Ankle/feet	2.9	5.8	4.3	5.2	20.7	8.0

There are several more painful lesions for community practice. Soft tissue MSK pains were found to be the dominant rheumatic ailment by almost all COPCORD surveys<sup>11</sup> and not surprisingly the most frequent sites reported were those of knees and lower back; the prevalence was >5%

with higher values reported from the rural survey (Table 1).<sup>12</sup> In fact, almost all disorders and painful sites were more prevalent in the village Bhigwan as compared to the neighbouring urban site in Pune and that would mean that the rheumatologic burden is no less in a rural community.<sup>12</sup>

Several other important painful sites (e.g. forearm, upper arm, upper back, thigh, calf, heel, sole) were also described in COPCORD Pune (Fig. 3) which though frequently complained in practice are usually neglected by the doctors and find very little mention in the literature.<sup>12</sup>

There are no precise measures for the large number of MSK pains. COPCORD has used a validated Indian version of HAQ (Health Assessment Questionnaire)<sup>1,8,13</sup> to demonstrate the impact of MSK pain on daily living and functional ability. 11% of the patients in village Bhigwan who were finally classified into an ill-defined symptoms (IDS, see later) category recorded a high HAQ disability.<sup>12</sup> This is a strong rejoinder of the fact that irrespective of the medical perspective (medical fraternity), community suffers the consequences of chronic non specific MSK pain. HAQ has been a useful tool in COPCORD to assess arthritis and monitor treatment response. The paramedics were trained to complete HAQ, sometimes during house visits. On the other hand, HAQ actually looks much beyond pain. By evaluating “function” in a systematic manner, HAQ is assuring and restores confidence in a patient. I believe it improves compliance and convinces the patient on “how serious the doctor is” about pain and disability. “Visual analogue scale” and HAQ are well suited to capture pain and function in a community setting. Despite heavy patient loads, the rheumatologists need to be objective in their assessment and medical records.

There are several medical care providers in a community, and rheumatic disorders are extremely popular with the complementary and alternative medicine practitioners and other untrained and unqualified healers in the “quack” category. It is unfortunate that the modern medicine doctor is perceived as somebody who can only give pain killers and steroids to treat MSK disorders and modern medicines are full of side effects. A great and sincere effort is required to educate the community on this aspect. But there is a twist. Often the community is adept to look after its aches and pains without bothering the elite medical community or making a fuss. Almost 20% of the sufferers with MSK pain in the Bhigwan community did not visit (or more suitably disturb) a doctor. Better still, there is tremendous sense of acceptance and tolerance of pain (and so many other deprivations) amongst people who live from hand to mouth. But the doctor must acknowledge the “pain” and empathize with the sufferer even when there is little to offer for meaningful relief.

## COMMUNITY PERCEPTIONS

The precise aetiology and pathology of several forms of MSK pain, especially in the case of STR, is poorly understood.

In absence of any hard core evidence of causality, speculations generated by the community and the doctors flourish to calm down an anguished patient. I have already alluded to the association of occupational overuse with soft tissue and articular pains.<sup>8,12</sup> COPCORD Bhigwan also recorded a large extent of trauma that the community considered to be responsible for their current MSK pain.<sup>8</sup> Inadvertently, the Bhigwan data also demonstrated a higher frequency of oral tobacco use in respondents with MSK pain as compared to the healthy population. The role of tobacco in osteoporosis, autoimmune inflammatory arthritis and atherogenesis is well established Worldwide and the same may be true for the Indian community. Though meticulously recorded, fibromyalgia (as classified by ACR and a better known form of diffuse STR) in Pune COPCORD (prevalence <0.1%) was not enough to explain the extent of diffuse non-syndromic MSK pain in the community. I believe that generalized chronic soft tissue pains vacillate on a continuum causal equation anchored by occupational overuse and overburdened psyche.<sup>12</sup>

Several perceptions and attitudes were recorded by COPCORD which were then put together on a common platform to counsel and treat patients (and research). Every doctor working with the community should have some grounding in the community KAP (knowledge, attitude and practices). Rheumatologists must also play a proactive role in educating community on arthritis and rheumatism. Our patients struggle with pain and disability in a socioeconomically challenging and unfriendly environment. Doctors ought to have grass root knowledge about the “way” and “quality” of life in the community before they begin to preach on what is right and what is wrong. Let me illustrate this by two important issues that have been central to my work in the community-tobacco use and open field toilets.

The COPCORD surveys recorded a much higher use of oral tobacco in respondents with MSK pain, especially in village Bhigwan. Despite our loud condemnation of tobacco during several years of COPCORD Bhigwan, its use (tobacco) remains rampant. This is despite the fact of an enviable rapport with the community over several years. Nothing attracts the community more than tobacco (it is relatively cheap) to find solace, peace and freedom (though transient) from fatigue, pain (MSK) and boredom of the routine. Despite such an intense program and participation by almost all the local doctors, I have not seen or even heard of a single case of oral cancer in village Bhigwan till date. The villagers are aware of the proven link between oral tobacco and oral cancer but that does not deter its use. They believe that the use of tobacco is traditional and that it helps them in various ways. Several have also stated that following the morning application of oral tobacco, the bowel evacuation is smooth



and rapid. I believe that our rhetoric (condemning tobacco) will only work if we can provide the villagers with an equally soothing alternative.

The Bhigwan COPCORD data showed that the prevalence of RA in young women was higher than every other similar population report in a WHO publication on MSK burden at the start of the new millennium.<sup>14</sup> The experience from urban Pune was similar. Therefore, India is likely to have an extremely high burden of RA in young women. Knee and low back pain (often due to osteoarthritis) were the dominant pain sites.<sup>12</sup> The Bhigwan data also showed that over 80% of the villagers used open fields for defecation and urination. It would not be difficult to imagine the plight of a patient with chronic progressive knee pain/arthritis in the latter setting and what could be more worse if that patient happens to be a young woman with rheumatoid knee. There are several other factors which compound the agony. Patients on medication must consume enough water. Monsoon rains play havoc for at least 3 months and the fields are flooded. The mechanical consequences of the Indian habit of squatting and sitting cross legged on floor must be questioned seriously for its adverse impact on knee arthritis. Also, the socioeconomics of the rural community are heavily loaded against surgical interventions like joint replacement. I have made it a point to address the several disadvantages of open field defecation during almost every public arthritis session in the village. In fact, COPCORD Bhigwan paid for the construction of first proper toilet in the "gram panchayat" premises for women and followed it up with constructing a modern toilet unit in the village primary school. Today, 55–60% of the villagers have a modest toilet in their home. Several arthritis patients now use indigenously designed chair commodes in their homes.

## COMMUNITY RHEUMATOLOGY SETTING

On the net, a Google search with "clinical rheumatology" is likely to fetch over 1,700,000 responses. Community rheumatology is a serious subject in the developed World.<sup>15</sup> Rheumatologists practicing in the community consider themselves distinct from those in the hospital and academia settings. They follow an orderly pattern of relationship with the GP, community and the hospital and interactions and references are inbuilt into the work model. In contrast, there is no order in our community practice setting. The latter is driven by an overwhelming patient work load and stringent economics. The inflammatory and complex rheumatic disorders are bound to take precedence over the lesser attractive disorders of ill defined MSK pain, STR and osteoarthritis.

The overall break up of patient load in a community rheumatology clinic is likely to be quite similar to that demonstrated by COPCORD. The disdain for the nondescript ill defined MSK pain is a universal phenomenon. The orthopaedic-rheumatology dilemma on ownership of certain MSK disorders is a thorn in the flesh of both the specialties. The patient load is intense. But how do we handle such a load? We need more man power (assistant doctors and paramedics) if we are to work efficiently in a community specialty clinic. Currently, CRD outpatient is conducted by five doctors (includes three rheumatologists), three nurses, four receptionists and six paramedics and has a dedicated laboratory and referral database entry units.<sup>2</sup>

The GP is the first port of call and can be made an efficient provider of basic rheumatology care. Majority of MSK painful disorders (in particular STR and degenerative) can be well treated by a GP. Disorders like heel pain needs reassurance, local therapeutic measures and physiotherapy, proper foot wear, work advice and pain relief. However, inflammatory disorders like RA will require definite discretion for consulting a rheumatologist and beginning a DMARD based regimen. Even then, GP would be an essential player to ensure patient compliance, attend to emergency needs especially those of pain relief, monitor therapy, ensure communication with the specialist and schedule follow up visits (with the rheumatologist). This is precisely what we have done in COPCORD Bhigwan. COPCORD data was used to carry out multisession CME, annual medical updates and social gatherings for the rural GP. We included one and all, including so called unqualified healers, in these sessions. We realized that several so called quacks were popular with the community in regions without any access to trained and qualified medical care. Every health care provider was useful to the program as far as he/she enjoyed the community trust and faith. Safe and evidence based practices were encouraged. Despite earlier apprehension, several patients in the village community were started on combination DMARD after active participation of the local GP. During COPCORD, we discovered rampant indiscriminate use of steroids, often surreptitiously as herbal formulations, and have fought tooth and nail by increasing awareness and education of the community and medical fraternity to curb the menace.

## COMMUNITY RHEUMATOLOGISTS AND RHEUMATOLOGY ASSOCIATES

Community rheumatologists have a tough job. Several newer concepts have emerged in managing rheumatic pain and are

relevant to a community practice.<sup>17</sup> Chronic aches and pains are a nuisance not only to the patient but also to the doctor. The doctors may even deny that the problem exists. This seems to have been the case in a recent COPCORD survey where the investigators decided to label 9.6% of their respondents with MSK pain and disorders as “normal” (because of lack of any objective clinical evidence).<sup>16</sup> What the mind does not know the eye does not see.

Can community rheumatology in India be served by a handful of rheumatologists? So the billion people’s question is “how do rheumatologists intend to reduce the enormous burden of rheumatic diseases?” We need to work very closely with the GP, physicians, orthopaedic surgeons, community (arthritis support groups) and health care planners to create standard of care practices, both for treatment and prevention. Rheumatology as a community service ought to be peripatetic—we need to go to the community.<sup>15</sup> Every rheumatologist ought to spearhead and coordinate some such regional rheumatology work force. The ongoing “Bone and Joint Decade 2000–2010” (BJD) program is an excellent platform to integrate and get working elements and forces in the realm of MSK pain and disorders.<sup>1,11,14</sup>

Community physicians crave to attend update/CME/conferences/workshops conducted by academia, and there are plenty of such events around the year. But academia must also venture forth from their safe air-conditioned haven to brave and address the community lament (read aches and pains in case of rheumatologists). This could be in the form of “arthritis camps” in the underprivileged community areas or hold medical meetings in a community venue (district hospital or a rural hospital) and involve medical practitioners. Arthritis camps are a great way to popularize rheumatology and do clinical research.

## CONCLUSION

Rheumatology is a neglected subject in the medical and health care domain. MSK pain is the dominant suffering in any community. COPCORD India with its vast experience of collecting community data on MSK and pain in both urban and rural regions is an appropriate platform for describing the status and challenges of community rheumatology in India. The distinction between academic and clinical rheumatology practice in India is nebulous, primarily because of our socioeconomics and community KAP. Every medical practitioner should be trained in the basic principles of diagnosis and management of MSK pain and disorders.

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