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The WHO–ILAR COPCORD Bhigwan (India) model: foundation for a future COPCORD design and data repository

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Abstract Launched by the International League of Associations for Rheumatology (ILAR) and the World Health Organization (WHO), the Community oriented program for control of rheumatic diseases (COPCORD) aims to fill the gaps in the knowledge on the global burden of rheumatic musculoskeletal disorders (RMS). During the population survey (Stage I), data on symptoms (pain and disability in focus), rather than diseases or syndromes, is collected. The survey may be followed by a planned stage to impart health education, identify risk factors, and devise preventive and control strategies. Several countries in the Asia Pacific and Pan-America have completed COPCORD survey. Africa has recently joined. Only COPCORD Bhigwan (India) has continued into the tenth year. COPCORD Bhigwan is a fast-track model that has provided significant data on rheumatic disorders. Using COPCORD Bhigwan model, the Bone and Joint Decade (BJD) India has launched several population surveys to measure the RMS burden. There is an urgent need for a COPCORD data repository. Several COPCORD have differed in their methods. Differences pertain to population sample size, techniques for data collection and recording, chronology of events and phases, and classification of symptoms/diseases/disorders. The COPCORD model in current global use needs to be revised. Based on the COPCORD Bhigwan model, a future design for COPCORD is proposed. COPCORD needs to have a uniform and

standardized core program with a flexibility to cater to regional needs. It must imbibe some of the recent advances in rheumatology while retaining its socioeconomic appeal. It must have a planned follow-up/longitudinal observational phase. Above all, it must serve and benefit community. WHO–ILAR COPCORD and the global BJD initiative must join hands to serve a common cause of controlling rheumatic musculoskeletal disorders. COPCORD is also a reflection of the ILAR mission statement “think global, act local.”

Keywords COPCORD · COPCORD Bhigwan · ILAR · Rheumatic disorders · Rheumatology · WHO

What should be the future design of the World Health Organization and International League of Associations for Rheumatology’s (WHO–ILAR) Community oriented program for control of rheumatic diseases (COPCORD)? How best can COPCORD fulfill its original objective to “fill the gaps in knowledge of rheumatic musculoskeletal disorders (RMS) disorders, particularly in developing countries?” How should COPCORD adapt to the requirements of the changing world and advances in our knowledge of RMS? COPCORD came into existence over two decades ago [1]. Unfortunately, rheumatology continues to be a lesser known and underutilized science in the developing countries and COPCORD is still unrecognized [2]. The global “Bone and Joint Decade 2001–2010” (BJD) initiative, supported by United Nations and WHO, is a new reality [3] and it ought to be taken more seriously.

My colleagues and I have enthusiastically carried on the COPCORD Bhigwan (India) maiden Indian project for over 10 years in a village in West India since its inception in 1996. The Bhigwan experience or what we prefer to call the “COPCORD Bhigwan model” has taught us several lessons, which should be considered while proposing a future COPCORD design.

<http://www.rheumatologyindia.org>

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Preamble

Recent reviews have highlighted the historical perspectives, objectives, outcome, and some future aspirations of the WHO–ILAR COPCORD [4, 5]. COPCORD was conceptualized to fill the large gaps in the knowledge on the global burden of RMS. However, to begin with, the priority was to target the rural communities in the developing countries. COPCORD was designed to be a low-cost, low-infrastructure program. The principal objective was to recognize the symptoms of RMS, with pain and disability in focus, rather than attempt to identify precise diseases or syndromes.

The COPCORD model envisaged collection of data on RMS (Stage I) in three successive phases—house to house survey to identify cases (Phase I), acquire data on pain and disability (Phase II), and finally to capture the clinical/rheumatological profile (Phase III). During the follow-up phase, preventive strategies based on community data would be planned, executed, and evaluated.

The BJD (<http://www.bonejointdecade.org>, [6]), through its network organizations all over the world, is intensely engaged in pragmatically identifying the global burden and impact of RMS. Can the WHO–ILAR COPCORD step in and provide the vexed answers and data to BJD?

Background [7]

A beginning for COPCORD was made in the Philippines. Surveys have been completed in Australia, Malaysia, Indonesia [8, 9], India, China, Pakistan, Thailand, Vietnam, Taiwan, Bangladesh, Kuwait, Canada, Brazil, Mexico, Chile, and Egypt. The Indonesian COPCORD was followed by a regional health education program and a national awareness program to control gout [5]. COPCORD Bhigwan (India) has been continued to date ([10], <http://www.rheumatologyindia.org>) as per a predetermined plan.

Important differences in methodology between various COPCORD only permit crude comparisons of prevalence data [7, 11]. Major differences pertain to population sample size, techniques for data collection and recording, time framework of various phases, and symptom/disease/disorder classification. Community data has been collected by different categories of personnel [2]. COPCORD did not provide the investigators with a common minimal disease definition criteria/classification system nor insist on a common, reasonably acceptable, and valid method to measure disability and quality of life. Several COPCORD publications do not even account for all the RMS cases identified in Stage I, phase 1.

Copcord Bhigwan (India) [11–15]

The Indian COPCORD was carried out as per a modified COPCORD design, community requirements, and scientific needs [12]. Certain modifications in the source model

were necessitated by the ground realities. COPCORD Bhigwan has added several dimensions to the source model pertaining to fast-track data acquisition, classification and diagnosis of RMS, socioeconomics, field research (including immunogenetics), community services health education, and coalition with other service providers and programs (in particular, BJD India). The Bhigwan community has been provided with free of cost therapy guidance and, in several instances, free medicines for the needy. Almost a thousand patients from over 170 neighboring villages and rural regions have visited Bhigwan to seek rheumatology opinion and care. The findings of the COPCORD Bhigwan have certainly enriched Indian rheumatology [15].

A recently carried out SWOT (strengths, weaknesses, opportunities, and threats) analysis [16] of selected factors (A. Chopra, unpublished data) is shown in Table 1. The analysis was performed by a group consisting of senior COPCORD Bhigwan team members and advisors using an independent empirical rating system. All members met to finally arrive at a consensus grade for each variable. It was concluded that there were several opportunities to upgrade the strengths further. Though the program had sustained itself for over 10 years, the group felt that better funds would perhaps improve the yield of the model, in terms of “data” and the existing community services.

Presurvey concerns [12]

The community demanded treatment and follow-up services, which were then included in the project. The rural practitioners were reassured that COPCORD would complement their practices.

Notably, a manikin was used to record pain. An Indian version of HAQ (<http://www.rheumatologyindia.org>) (modified Stanford Health Assessment Questionnaire), which was validated earlier, was used to assess disability.

Survey [12]

The initial population survey of 7,000 was completed in 5 weeks. Unlike the source model, all the phases of Stage I were carried out in parallel in a fast-track data

Table 1 SWOT analysis of COPCORD Bhigwan

Factor	S	W	O	T
Community support	4	2	5	2
Coalition (administration, doctors, politicians)	3	1	4	2
Funds	2	3	4	3
Core competence including leadership	4	2	4	2
Data	4	2	4	2
Bhigwan model	4	2	5	2

S Strengths, W weaknesses, O opportunities, T threats
Grade 1, minimal; Grade 2, below average; Grade 3, average; Grade 4, above average; Grade 5, maximal. See text for details

capture model using predetermined schedule and time table. Phase I and II questionnaires were filled by the health workers selected from the village. All RMS cases were finally evaluated by a single rheumatologist. Though not encouraged by the conventional model, basic laboratory services were set up, and further blood/sera stored in Center for Rheumatic Diseases (CRD), Pune at -70° . It was difficult, if not impossible, to define the rheumatic burdens of the community purely on clinical grounds as envisaged by the original COPCORD model. Also, cases needed an early follow-up to establish diagnosis. Despite several evaluations and workup, many cases defied precise diagnosis and were followed with a symptomatic (e.g., knee pain) or a broad based approach (e.g., unclassifiable/undifferentiated inflammatory arthritis) [12, 14].

and vague initial clinical profile often misled the diagnosis. An early follow-up was mandatory. In fact, a resurvey [10] was carried out 3 years later to validate the earlier observations and results. Few patients who had been evaluated earlier during the survey with predominantly soft tissue pains later manifested clinical rheumatoid arthritis (A. Chopra, unpublished data). The majority of the patients with inflammatory arthritis actually suffered from undifferentiated seronegative (for rheumatoid factor) inflammatory arthritis [11].

We were able to evaluate certain risk factors [13]—lifestyles, occupation, and immunogenetics [17]. A long-term longitudinal observational phase, as in the case of the Bhigwan study, is an excellent opportunity to provide education to the community and rural practitioners based on the regional findings. Figure 1 shows the general outline of a population model for the study of rheumatoid arthritis and other forms of inflammatory arthritis based on the COPCORD Bhigwan follow-up (A. Chopra, unpublished data).

Follow-up [10, 13]

Several confounders connected with poor medical records, surreptitious medications (? corticosteroids), self-denial,

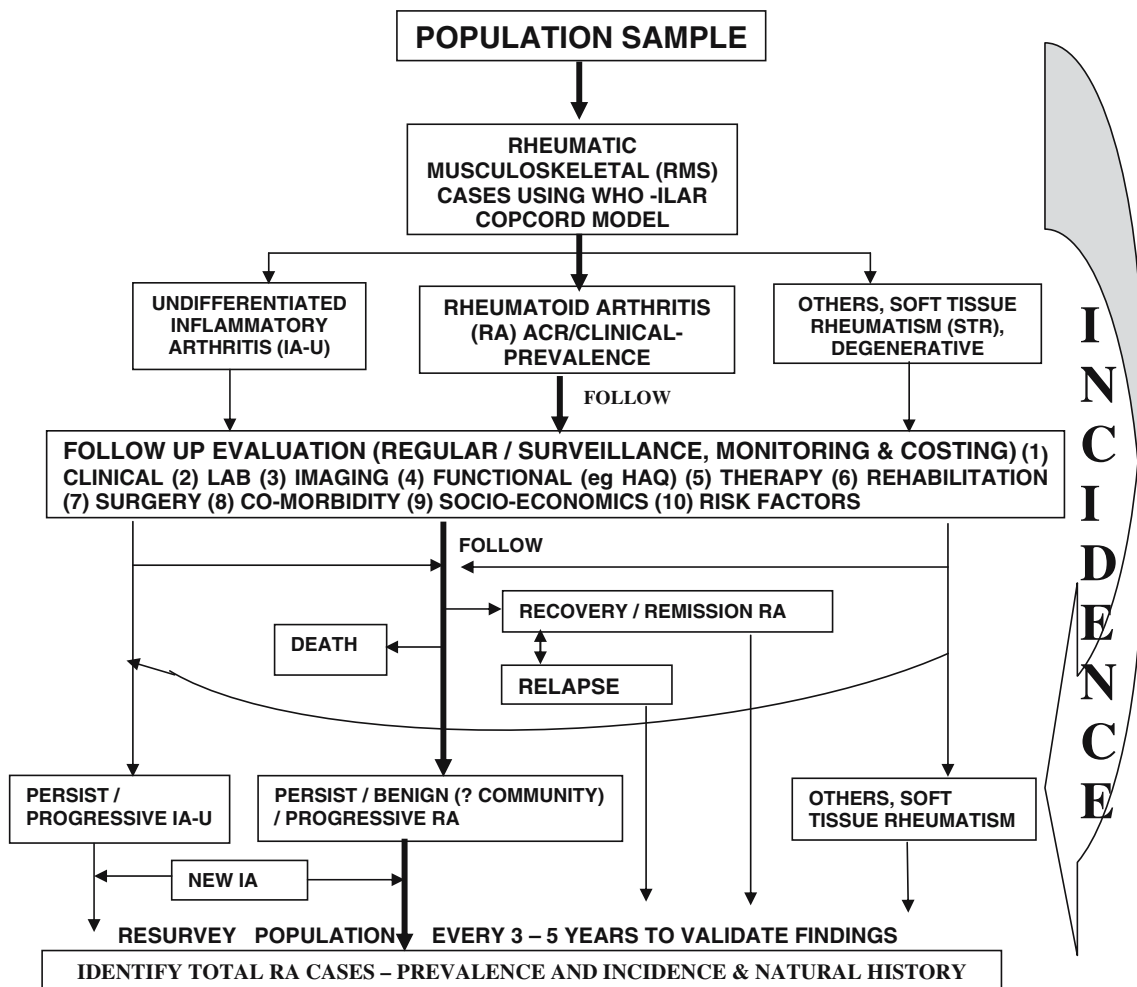


Fig. 1 A model for population study of rheumatoid arthritis based on the WHO-ILAR COPCORD (Community oriented program for control of rheumatic diseases) Bhigwan 1996–2004

Data

We always knew that RMS is the commonest problem in a community but COPCORD Bhigwan was needed to provide data and compelling evidence [11, 14]. Almost one-fifth of RMS patients have never visited a doctor but almost all patients recorded some degree of functional disability on the HAQ. Soft tissue rheumatism was the most common ailment. Knee and back pains, often without precise etiopathological and diagnostic definitions, have been the most frequent symptoms in several COPCORD surveys [7, 14, 18].

COPCORD Bhigwan has adopted and maintained a meticulous system of keeping records, both hard copy and electronic. Indigenous software programs have been created for data entry that is both user-friendly and statistically worthy.

Conclusions and recommendations

So, what have we learned?

The COPCORD area and the target population should be well-defined. Reconnaissance must be carried out to ensure proper strategy for data collection. Support from the local community leaders, practicing doctors, and administration must be sought. The COPCORD team should stay away from sociopolitical alliances and influences. A well-rehearsed protocol should be in place.

The COPCORD model in current global use needs to be revised so as to ensure a reasonable extent of uniformity and comparability between different studies. A standardized core program, especially with reference to Stage I, must be strictly adhered to. At the same time, it must allow appropriate modifications and additions dictated by regional needs. All data must be recorded and monitored. A uniform measure of pain and disability is required. Several COPCORD have highlighted the lacunae in the current classification criteria. The investigators should use a common list of diagnostic terminology, criteria, and classification system for reporting their observations and findings. The future model must incorporate modern practice of rheumatology.

Though optional at present, each COPCORD must have a planned follow-up program right at the inception stage. I must admit that before beginning COPCORD Bhigwan, we were skeptic about the “follow-up” for several reasons, including manpower and economics. However, the Bhigwan community pushed us along. The expenditure of COPCORD Bhigwan during the first 3 years, excluding specialist (rheumatology and orthopedic) expertise and time, was less than US\$2 per person in the village (A. Chopra, unpublished data, presented in the ILAR meeting 2002, Edmonton, Canada). Sometimes, there have been trade-offs between expenditure on data and community services. Somehow, we have been extraordinarily careful while handling COPCORD community matters.

Any future COPCORD must consider providing some kind of treatment services and health education. The

community must feel benefited. Only then will the community allow a robust COPCORD to move along. Above all, the COPCORD model must remain friendly both to the community and the field investigator.

The COPCORD Bhigwan model is more versatile than the source model and may be considered to restructure the future COPCORD. The WHO–ILAR COPCORD is ideally suited to measure the burden of RMS. Nothing could be more suitable than the ongoing BJD global program. BJD India has accepted the COPCORD Bhigwan model to sponsor an ongoing multiregional national urban population survey program for RMS ([15], <http://www.bjdindia.org>).

Finally, the COPCORD is not only an important function of the ILAR but an excellent reflection of its recently structured mission statement of “think global, act local [19].”

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