Bare Foot Applications of HAQ, and Identification of Some Risk Factors in WHO-ILAR COPCORD Bhigwan (India) Stages II and III: an Ongoing Longitudinal Population Based Study 1996-2004

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In 1981, World Health Organization (WHO) and International League of associations for Rheumatology (ILAR) launched COPCORD (community oriented program for control of rheumatic diseases). It's objective was to acquire data on the prevalence of rheumatic and musculoskeletal symptoms/diseases (RMSD) and measure diseases burden with special reference to disability. COPCORD was to focus particularly on the rural communities in the developing countries. The COPCORD epidemiological model envisages 3 stages. In Stage I, which is essentially a population survey, the data is conventionally collected in 3 successive phases- population demography and identification of patients with RMSD (Phase 1), detail record of patient's narration of history and symptomatology, and functional disability (Phase 2), and a detail rheumatological evaluation (phase 3). In Stage II 'risk factors' are identified while in Stage III steps are taken to control risk factor and improve health care, primarily through health education. In fact, it is in Stages II and III that the community benefits most from the COPCORD.

Numerous Asian-Pacific countries have completed COPCORD Stage I surveys. The Indonesian COPCORD has successfully applied some of the features of Stages II and III with reference to their 'gout program' and health education. Under the aegis of APLAR, the first Indian COPCORD survey was conducted in village Bhigwan (Dist Pune) in 1996 followed by a well-planned ongoing community driven COPCORD program till 2004. The Bhigwan COPCORD is designed to implement Stages II and III but in addition for the first time in the World has a sharp focus on providing free of cost rheumatological services to the community. The Bhigwan COPCORD population today consists of about 7,000 adults but increasing popularity and public awareness of the rheumatological problems, especially through the recently launched Bone and Joint Decade program in the region, has extended the community cover for free rheumatological counseling and therapy consulting services to over 30,000 adult villagers; the poor and the needy in the COPCORD Bhigwan zone are provided with free medicines and assist devices..

Few population based long-term longitudinal studies and none in the COPCORD World over to the best of our knowledge, have ever used HAQ. One of the primary aims of COPCORD Bhigwan is to critically evaluate the role of HAQ in measuring and monitoring the functional disability of rheumatic diseases, inflammatory arthritis (RA, undiffererentiated forms, SSA, etc) in particular, in this rural population. Since 1994, we have been using a validated modified Stanford Health Assessment Questionnaire/HAQ adapted to the Indian environment (J Rheumatology 2000; 27:1365-72) for controlled drug trials and clinical practice (Sample Enclosed), and the same has been used as a quality of life instrument, both on a generic and specific basis, in the COPCORD Bhigwan

Method

Trained health workers (CHW) from Bhigwan used modified ILAR COPCORD core questionnaires (APLAR J Rheumatology 1997; 1:145-54) to interview 6034 villagers in the initial 1996 census survey (Stage 1). 774 cases (Phase 1) reported RMS (Rheumatic musculoskeletal pains) and completed HAQ (Indian version, see above). All patients have been followed up till date. New cases have been identified. A COPCORD pattern resurvey was carried out in 1999. The COPCORD medical team, including rheumatologists, continues to visit the village every 3-4 weeks till date.

1) HAQ: Prior to the team's visit, the CHW completes HAQ when visiting patients in their houses/work place to monitor progress or report new cases. A trained CHW takes 3-5 minutes to complete the HAQ. HAQ is also completed for every patient reporting for follow up evaluation to the

rheumatologist (AC). Generally, a HAQ is filled up every 6-8 weeks for every patient with inflammatory arthritis or earlier in case of a flare up/ relapse.

The total HAQ score (maximum 24) was averaged for the 8 activities into a HAQ disability index (HAQDI, range 0-3); each activity being scored on the basis of difficulty (nil=0, little=1, much=2, unable=3). The individual activity score was upgraded by 1 (maximum possible score = 3) if the individual required an assist device or help from another person. In the Bhigwan HAQ the disability index (HAQDI, 0-3) was arbitrarily classified cases into mild (0-1.0), moderate (1.1-1.5) and severe (1.51-3). Because numerous respondents with relatively low HAQDI reported significant difficulty (>1) in some activities, we weighted (W) HAQ based on the maximum difficulty grade (2-3)in any single activity; the HAQDI (W) in such cases would be at least 'moderate' or 'severe'.

2) Risk Factors: Based on the community concepts and hypothesis generated from interactions with the local doctors, we have attempted to explore the role of certain putative risk factors in this community. Controls have consisted of healthy adult villagers from Bhigwan region. Stage I, Phase II, questionnaire was used during the initial and subsequent resurvey (1999) to document the role of trauma. 'Hypermobility' and fibromyalgia vis a vis work related soft tissue rheumatism has been evaluated during the resurvey in all the patients identified. Dietary surveys were carried out using standardized proformas, developed by the School of Health Sciences, University of Pune. We have also looked at the HLA DR locus in this population and this work is being presented by a colleague in this COPCORD workshop session.

HEALTH ASSESSMENT QUESTIONNAIRE (MODIFIED – CRD PUNE VERSION)

NAME:_____ AGE:____ SEX:____ DATE:_____

_____We are interested in learning how your illness affects your ability to function in daily life. Please feel free to add any comments on the back of this page. Please check the response which best describes your usual abilities OVER THE PAST WEEK.

ARE YOU ABLE TO:	**Without Any Difficulty (0)**	**With Some Difficulty (1)**	**With Much Difficulty (2)**	**Unable (3)**	
I: **DRESSING**					_____
1) Dress yourself, plus doing buttons ?	_____	_____	_____	_____	
2) Wash your hair ?	_____	_____	_____	_____	
3) Comb your hair ?	_____	_____	_____	_____	
II: **ARISING**					_____
4) Stand up straight from a chair ?	_____	_____	_____	_____	
5) Get in & out of bed ?	_____	_____	_____	_____	
6) Sit cross-legged on floor & get up ?	_____	_____	_____	_____	
III: **EATING**					_____
7) Cut vegetables?	_____	_____	_____	_____	
8) Lift a full cup /glass to your mouth ?	_____	_____	_____	_____	
9) Break chappati with one hand ?	_____	_____	_____	_____	
IV: **WALKING**					_____
10) Walk outdoors on flat ground ?	_____	_____	_____	_____	
11) Climb up five steps ?	_____	_____	_____	_____	
V: **HYGIENE**					_____
12) Take a bath ?	_____	_____	_____	_____	
13) Wash & dry your body ?	_____	_____	_____	_____	
14) Get on & off the toilet ?	_____	_____	_____	_____	

□ Indian □ Western □ Field;
□ Can sit easily □ Sit with support
□ Stand □ Stand with support

ARE YOU ABLE TO:	Without Any Difficulty (0)	With Some Difficulty (1)	With Much Difficulty (2)	Unable (3)	Score
VI: **REACHING**					_____
15) Reach & get down a 2 kg. object (such as bag of sugar) from just above your head ?	_____	_____	_____	_____	
16) Bend down to pick up clothing from the floor ?	_____	_____	_____	_____	
VII: **GRIP**					_____
17) Open a bottle previously opened ?	_____	_____	_____	_____	
18) Turn taps on and off ?	_____	_____	_____	_____	
19) Open door latches ?	_____	_____	_____	_____	
VIII: **ACTIVITIES**					_____
20) Work in office / house ?	_____	_____	_____	_____	
21) Run errands and shop ?	_____	_____	_____	_____	
22) Get in & out of a bus ?	_____	_____	_____	_____	
23) Get in & out of a car / Autorickshaw ?	_____	_____	_____	_____	
				TOTAL SCORE	_____

Please check any **AIDS** or **DEVICES** that you usually use for any of these activities :
☐ Cane ☐ Walker ☐ Crutches ☐ Wheelchair ☐ Special Built Up Chair ☐ Raised Toilet Seat

Categories for which you need **HELP FROM ANOTHER PERSON** :
☐ Dressing & Grooming ☐ Eating ☐ Arising ☐ Walking ☐ Hygiene ☐ Reach ☐ Grip ☐ Errands

Results and Discussion

1) HAQ: 900 completed HAQ forms have been analyzed for this report.

During the initial survey, the main HAQ activities (Table 1) with significant difficulty amongst patients in the age group 25-54 yrs were walking, hygiene, arising, occupation, and reaching; an inability to walk, work and hygiene-care was expressed by 11%, 4% and 4% patients respectively. As per the HAQDI scores, 79%, 15% and 6% of the initial survey patients were classified into mild, moderate and severe grades respectively; the same on 'W' reclassification changed to 43%, 39% and 18% respectively (Table 2) About 10% patients had ceased to work because of RMS. 21% patients scored a significant HAQDI, which when weighted for individual HAQ activities increased to 57%.

Table 1.

DIFFICULTY ACTIVITY	MUCH			UNABLE		
	M	F	TOTAL	M	F	TOTAL
DRESSING	3.0	1.4	2	0	0.3	0.2
ARISING	22.5	15.9	18	2.2	3.2	2.9
EATING	3.0	3.6	3.4	0	0.7	0.5
GRIP	0.75	2.1	1.7	0.75	0	0.2
HYGIENE	30	22.4	24.9	3.75	4.7	4.4
REACHING	14.2	13.7	13.9	1.9	2.5	2.2
WALKING	29.3	28.6	28.8	9.7	11.5	11
OCCUPATION	17.2	9.0	11.7	2.2	6.5	4.4

Table 2.

HAQDI (W)	MILD	MODERATE	SEVERE
ALL	43	39	18
RA	22	41	37
OA	33	44	23
STR	51	35	14

2) Therapeutic responses: Besides recording clinical evaluation and certain lab indices of activity and response, HAQ has been completed for all patients. The CHW also visits the house of defaulters and those who withdraw from COPCORD follow up program to keep a track of their disease state and fill HAQ. Fig 1 shows graphically the therapeutic responses measured as total HAQ score in patients with RA on various DMARD regimen. Patients with moderate-severe disease have been on combination DMARD with methotrexate. However, it is the oral chloroquin that has been rather liberally used in this rural setting with satisfactory response.

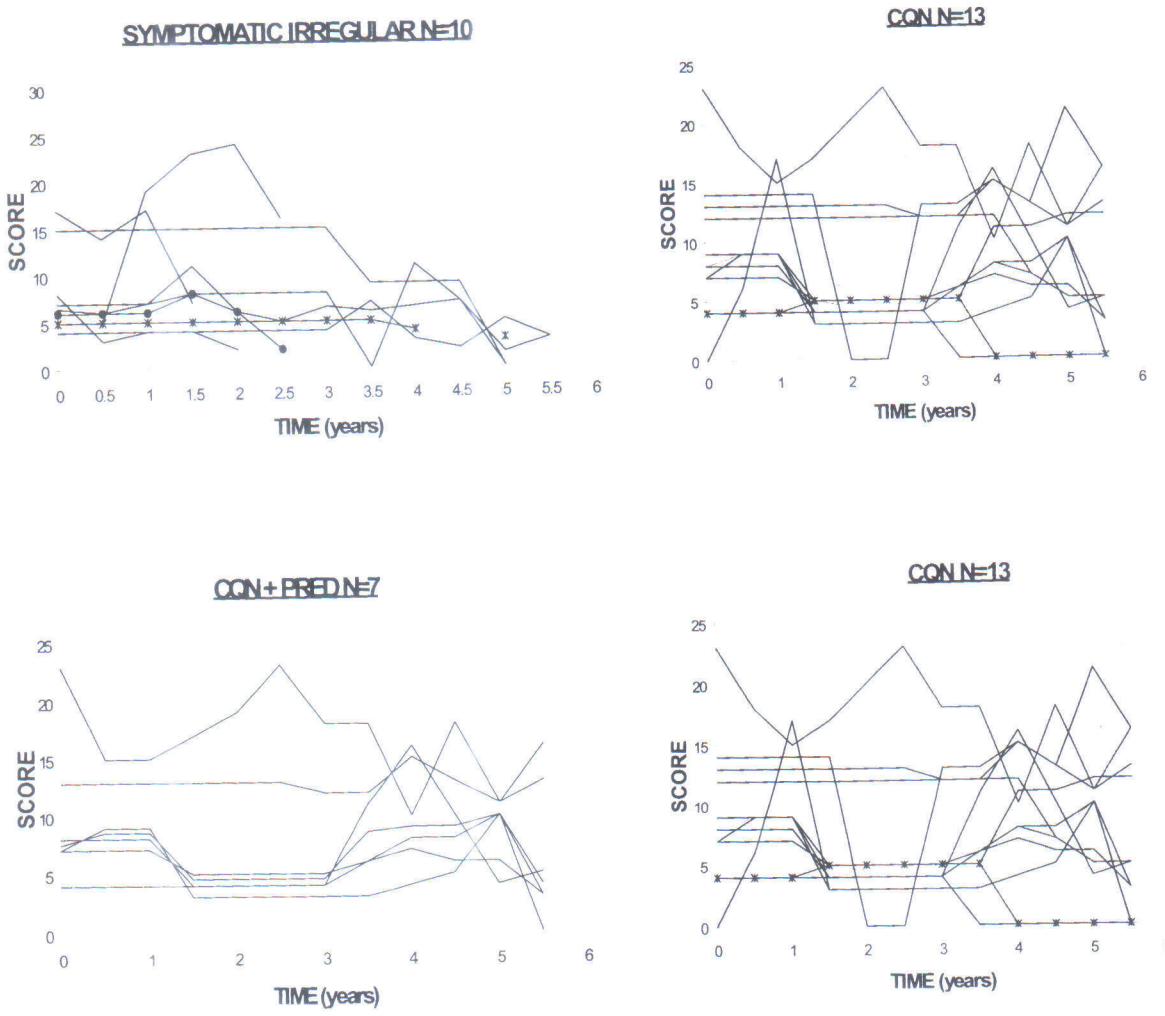

Fig 1. Therapeutic responses as measured by total HAQ score to different DMARD regimens in patients with RA from COPCORD Bhigwan (India) [X-Axis: Time(years); Y-Axis: HAQ Score; N=Number of patients; CQN: Chloroquine; Pred: Prednisolone; MTX: Methotrexate]

Other benefits: The follow up HAQ provided a robust estimate of the disease status and therapy response. Moreover the patients feel enthusiastic about filling HAQ and consider it an important part of the evaluation of their chronic problem. They felt that the doctor is providing more attention, concern and care because the impact of their rheumatic pains is being considered in detail. The patients especially felt satisfied because in HAQ we are also addressing their concerns regarding their traditional life style of squatting and sitting cross legged on the floor. They also felt that this will provide better treatment and it also contributed towards the success of the ongoing COPCORD program.

Risk factors:

1. Community concepts and beliefs: Aging, weather, mental stress and heredity were considered to be the cause of RMS by 20%, 11%, 6% and 1.5 % patients respectively. 2.7%, 15.5% and 28.2% patients reported association of their RMS with summer, monsoon and winter respectively; 41.3% patients did not find any association with weather

2. Trauma: 169 (23%) patients recorded a past history of trauma which they believed could have contributed to their current ailment; motorized vehicle accidents and falls were reported by 29 patients (17.2%) and 119 patients (70.4%) respectively. While 77% of the accident patients were males, the falls were sustained almost equally by both the sexes. In 82% of trauma patients, it was a non-fracture soft tissue injury.

3. Hypermobility is not very uncommon in oriental communities and is likely to affect the expression of arthritis. Also, arthritis itself can cause a certain amount of hypermobility in affected joints. It also adds to the work related abuse of posture and certain repetitive particular motions. Data on some of these aspects will be presented.

4. Work related soft tissue rheumatism and fibromyalgia like illness has been often encountered in Bhigwan COPCORD.Almost 55% of the survey patients had some form of soft tissue aches and pains, and the majority did not fulfill the classical ACR criteria of fibromylagia. Only 21% of the patients with generalized chronic soft tissue rheumatism satisfied the ACR criteria for fibromyalgia. The prevalence of Knee pains and backache in the survey was 12-13% and almost 60% of these cases are in the age group 25-45 years. We believe that work conditions and lack of posture and joint care in the community contributes to these soft tissue aches and pains.

5. A large section of community believes that certain dietary items contribute to rheumatic pains. We have carried out a large survey in patients with chronic rheumatic pains and found that less than 10% recall a distinct association with diet. We have also analyzed the consumption of Omega 3/6 in the rural diets and the data will be presented.

6. Tobacco Use: The frequency of tobacco/mishri (a popular custom in the region whereby a form of burnt tobacco is rubbed on gums and teeth, often several times in a day) use in both males (55.1%) and females (47.1%) amongst the RMS subjects was significantly higher ($p<0.001$) than the controls (male 42.7%, female 33.3%). Besides the alleged use to cleanse teeth and stimulate bowels, the Bhigwan people have repeatedly told us that tobacco enhances their work performance by reducing fatigue and relieves body aches and pains at the end of a hard day. It may be speculated that tobacco has helped this rural community to bear the RMS pain. But it can also be argued that this sense of pain relief has made these villagers negligent towards posture and joint care during work involving repetitive or demanding postures, which then probably has contributed toward chronicity and disability. But this paradigm of tobacco use and RMS would need further scientific evaluation in socio-anthropological studies.

Health education: Community Health workers and paramedics have been trained to conduct small didactic sessions with the patients both in the village COPCORD center and during house visits. Small group sessions on various health issues related to arthritis were held during the resurvey (1999) community education program based on a WHO sponsored comprehensive health education publication. This publication in the local language is illustrated with cartoons based on the community beliefs and perceptions and will be distributed free of cost in the Bhigwan region, and its impact will be recorded. Mission arthritis India (MAI), a patient support group has also sends its volunteers to distribute health material and talk to patients and community during the visit of COPCORD medical team to the village. A special health education drive was initiated during the 'Bone and Joint Decade Activity Week' in October 2001 where more than 800 people including patients from the region attended the free of cost arthritis

camps held under the aegis of COPCORD Bhigwan.

Conclusion

A well-designed HAQ, that captures the functional status and disability of the patients, provides immense clinical and therapeutic information. It also reposes faith and certain enthusiasm in patients towards doctors and their population RMS studies. A suitable validated version of HAQ should be included in every long term COPCORD.

The community concepts and beliefs should provide the platform both for health education and generating hypothesis for risk factor analysis. Lack of posture and joint care appears to cause many forms of chronic rheumatic aches and pains.

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