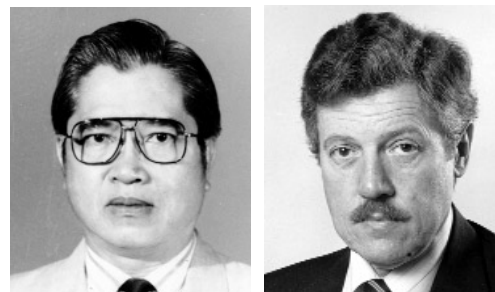


WHO-ILAR COPCORD Perspectives Past, Present, and Future



When strategies for control of diseases are addressed, population data are required upon which subsequent decisions and control programs are based. Epidemiology/clinical epidemiology and health economy will become important tools in contributing expertise to the research of burdens and outcomes of disease after intervention. This includes cost-effectiveness (health economy) of therapy of chronic diseases, which is particularly relevant to developing countries with limited resources.

It was feasible to carry out epidemiological surveys that provided valid prevalence rates of musculoskeletal disorders and disability in developing countries while saving manpower, time, and survey costs. The previous absence of information on musculoskeletal disorders in developing countries was then largely solved by epidemiological surveys completed in South America^{1,2} and Asia³⁻¹⁴. Several pilot studies of these epidemiological surveys are completed in Mexico, Chile, Brazil, The Philippines, Indonesia, Malaysia, Australia, China, Thailand, India, Pakistan, Vietnam, Bangladesh, and Kuwait. These countries are inhabited by almost half the world populations. A pilot epidemiological survey in Africa, COPCORD Egypt, has been launched.

These epidemiological surveys showed that demographic disparities yielded significant differences in prevalence rates of some rheumatic diseases. Gout was found to be a major cause of suffering, disability, and early mortality in Malayo-Polynesians¹⁵. With increasing affluence, longer average lifespan, and Western-type lifestyle, the prevalence rate of gout in Malayo-Polynesians will reach parity with the Polynesians⁷. Gout is one of the most prevalent rheumatic diseases in Polynesians, Malayo-Polynesians, and Malayo-Mongoloids, with a deleterious longterm outcome when hyperuricemia is not controlled. According to O'Duffy, *et al*, therapeutic prophylaxis of gout has resulted in near elimination of chronic tophaceous gout with a reduced incidence of urate nephropathies in developed countries¹⁶.

Based on the epidemiological data acquired, it was apparent that primary health care of patients with rheumatic disease was nonexistent or inadequate, and this was complicated by self-medication in developing countries⁷. Self-medication was defined when drugs were purchased and taken without medical supervision and often with incorrect dosages and frequency of administration over an insufficient period of time⁷. Self-medication was induced by lax enforcement of drug prescription laws and easy access to prednisone and nonsteroidal antiinflammatory drugs (NSAID) without prescription fees (these being relatively inexpensive drugs), and the combination of prednisone and NSAID that is relatively if not dramatically effective in early acute arthritis.

Further problems are lack of health insurance, and lack of well trained rheumatologists exacerbated by lack of or inadequate undergraduate rheumatology teaching of primary health care professionals. The lack of or inadequate undergraduate rheumatology teaching leading to inadequate primary health care emphasized the importance and immediate relevance of the Undergraduate Medical Education in Rheumatology project, the ILAR-UMER 2000 project, to developing countries¹⁷.

The longterm outcome of self-medication (symptomatic treatment without medical supervision) of chronic gout without control of hyperuricemia was obviously detrimental to the patient's quality of life because of high morbidity, disability, and early mortality due to untreated complications and associated conditions¹⁵. These complications and associated conditions were tophi, history of urolithiasis, hypertension, renal insufficiency, cardiac and cerebrovascular disease, and renal failure when chronic gout and hyperuricemia were not controlled for the long term^{15,18,19}.

As gout is generally easy to control it is justified to seek control of the disease in more than 200 million Indonesians. Due to the high prevalence rate of gout and hyperuricemia in Malayo-Polynesians⁶, control of the disease by a pilot

See The effect of control and self-medication of chronic gout in a developing country, page 2437

COPCORD Stage II Education Program was completed. Education was considered the least expensive instrument to minimize the national impact of self-medication of gout without control of hyperuricemia. Education of the community was proved to increase knowledge²⁰ of patients compared with controls.

Chronic gout was apparently adequately controlled by an education program and treatment over a 10 year period¹⁵. Outcome of patients with chronic gout over a period of 10 years is significantly better compared with uncontrolled hyperuricemia by self-medication in the dropouts from this observational study. Correcting hyperuricemia can eliminate the worst complications of chronic gout.

National awareness of the high prevalence of gout and definite prevention of morbidity by control of serum uric acid concentrations was brought home through cooperation with the Education Foundation of the Indonesian Medical Association (IMA). Monographs on diagnosis and therapy of gout and hyperuricemia were published and distributed free of charge to 15,000 of the 35,000 physicians in the country. When the Chairman of the Education Foundation of the IMA was appointed Minister of Health, the plight of patients with chronic gout was brought to the attention of the highest primary health care policy maker. Consequently, all primary health care community health centers in the country were supplied with almost free allopurinol tablets (100 mg). The longterm benefits on a national scale of this drug policy could be beyond expectation, as shown by a 10 year observational study¹⁵.

After completion of epidemiological surveys in 16 developing countries of Asia and South America, education of primary health care professionals leading to improved primary health care on the control of gout and hyperuricemia in Indonesia¹⁵, and identification of environmental and genetic risk factors for gout²¹, it is appropriate now to look back at the past, to the present, and ahead to the future.

The initiation of Stage I was an exercise in trial and error in the early 1980s by local clinical rheumatologists in developing countries, guided by 2 prominent epidemiologists, Eric Alander and in particular H.A. Valkenburg. The latter created the original COPCORD concept of Stage I in 1980, which was expanded to the 3 stages in 1983 by V. Grabauskas²². Not until a WHO-ILAR COPCORD Standard Core Questionnaire was designed by Sjef van der Linden in 1993 were subsequent international epidemiological surveys standardized.

The limited accomplishment of epidemiological surveys over a period of 20 years was due to lack of funding and the limited number of rheumatologist volunteers to start a population survey. With only US \$5000 annual funding (provided by the Asia Pacific League of Associations for Rheumatology as seed money, the rest of the research budget to be raised locally) it is no wonder that expansion of COPCORD Stage I takes place in only one developing

country each year. Notwithstanding the shoestring budget, the pioneers of WHO-ILAR COPCORD may see this project slowly expanding in breadth and in depth.

The results of education of rheumatic disease patients and primary health care professionals was measurable in chronic gout, where effective urate-lowering drugs are available and measurement of serum uric acid concentration is simple. Further, food habits and recently acquired Western-type lifestyle can be influenced by continuous patient education. Future prospects for control of gout and hyperuricemia in the developing world look promising.

However, the future of Stage III research on environmental risk factors of the common rheumatic diseases will prove a tremendous challenge. Lack of expertise and baseline data on the influence of environmental risk factors for the common rheumatic diseases such as chronic low back pain, osteoarthritis, osteoporosis, and rheumatoid arthritis, currently may seem insurmountable, except for gout and hyperuricemia.

Contemplation of future COPCORD research into low back pain⁹, osteoporosis, osteoarthritis, and rheumatoid arthritis⁸ may be limited to patient education and continuing medical education on these incurable chronic diseases. Financial constraints are and will remain an obstacle to the development of COPCORD.

Never have so few personnel, without epidemiological experience and almost no financial resources, provided valid and invaluable epidemiological data on rheumatic disease to so many developing countries as during the last 2 decades. The value of urate-lowering therapy as a worthwhile population measure has been established in a developing country with a high prevalence rate of gout.

ACKNOWLEDGMENT

The following pioneers and current contributors to the development of WHO-ILAR COPCORD are gratefully acknowledged: I. Glasunov, V. Grabauskas, M. Mitrofanov*, and Nicolai Khaltav from the WHO Division of Non-communicable Diseases; E. Allander* (EULAR), H. Boffi-Bogero (PANLAR), R.D. Wigley (APLAR), R.G. Robinson, K.D. Muirden, Jan Dequeker (Past President), Tahsin Hadidi (current ILAR President), K.D. Muirden and John Darmawan (Past Presidents of APLAR); J.J. Rasker (Past Secretary General of ILAR); and Marc Hochberg, Chairman, ILAR Standing Committee on Epidemiology. *Deceased.

JOHN DARMAWAN, MD,

WHO-ILAR COPCORD Coordinator 2001–2005,
Head, WHO Collaborating Center, Community-based Epidemiology,
Prevention, and Treatment of Rheumatic Disease,
Seroja Rheumatic Center,
Semarang, Indonesia;

KENNETH D. MUIRDEN, MD,

WHO-ILAR COPCORD Coordinator 1985–2001,
Former Head, Rheumatology Unit, The Royal Melbourne Hospital,
University of Melbourne,
Melbourne, Australia.

*Address reprint requests to Dr. Darmawan,
E-mail: jd131035@hotmail.com*

REFERENCES

1. Bennett K, Cardiel MH, Ferraz MB, Riedemann P, Goldsmith CH, Tugwell P. Community screening for rheumatic disorder: Cross cultural adaptation and screening characteristics of the COPCORD Core Questionnaire in Brazil, Chile, and Mexico. *J Rheumatol* 1997;24:160-8.
2. Reyes Llerena GA, Guibert Toledano M, Hernandez Martinez AA, Gonzalez Otero ZA, Alcocer Varela J, Cardiel MH. Prevalence of musculoskeletal complaints and disability in Cuba. A community-based study using the COPCORD core questionnaire. *Clin Exp Rheumatol* 2000;18:739-42.
3. Manahan L, Caragay R, Muirden KD, Allander E, Valkenburg HA, Wigley RD. Rheumatic pain in a Philippine village. *Rheumatol Int* 1985;5:149-53.
4. Wigley RD, Manahan L, Muirden KD, et al. Rheumatic disease in a Philippine village. II: a WHO-ILAR-APLAR COPCORD study, phases II and III. *Rheumatol Int* 1991;11:157-62.
5. Dans LF, Tankeh-Torres S, Amante CM, Penserga EG. The prevalence of rheumatic diseases in a Filipino urban population: a WHO-ILAR COPCORD Study. *J Rheumatol* 1997;24:1814-9.
6. Darmawan J, Valkenburg HA, Muirden KD, Wigley RD. The epidemiology of gout and hyperuricemia in a total population of Java. *J Rheumatol* 1992;19:1595-9.
7. Darmawan J, Valkenburg HA, Muirden KD, Wigley RD. Epidemiology of rheumatic diseases in rural and urban populations in Indonesia: a World Health Organisation-International League Against Rheumatism COPCORD study, stage I, phase 2. *Ann Rheum Dis* 1992;51:525-8.
8. Darmawan J, Valkenburg HA, Muirden KD, Wigley RD. The epidemiology of rheumatoid arthritis in Indonesia. *Br J Rheumatol* 1993;32:537-40.
9. Darmawan J, Muirden KD, Valkenburg HA, Wigley RD. The prevalence of soft tissue rheumatism in Indonesia — A WHO-ILAR COPCORD study. *Rheumatol Int* 1995;15:121-4.
10. Chaiamnuay P, Darmawan J, Muirden KD, Assawatanabodee P. Epidemiology of rheumatic disease in rural Thailand: a WHO-ILAR COPCORD study. *J Rheumatol* 1998;25:1382-7.
11. Chen S, Du H, Wang Y, Xu L. The epidemiology study of hyperuricemia and gout in a community population of Huangpu District in Shanghai. *Chin Med J Engl* 1998;111:228-30.
12. Farooqi A, Gibson T. Prevalence of major rheumatic diseases in the adult population of north Pakistan. *Br J Rheumatol* 1998;37:491-5.
13. Chopra A, Saluja M, Patil J, Tandale HS. Pain and disability, perceptions and beliefs of a rural Indian population: A WHO-ILAR COPCORD study. *J Rheumatol* 2002;29:614-21.
14. Al-Awadhi A, Olusi S, Al-Zaid N, et al. Validation of the Arabic version of the WHO-ILAR COPCORD core questionnaire for community screening of the rheumatic diseases in Kuwaitis. *J Rheumatol* 2002;29:1754-9.
15. Darmawan J, Rasker JJ, Nuralim H. The effect of control and self-medication of chronic gout in a developing country. Outcome after 10 years. *J Rheumatol* 2003;30:2437-43.
16. O'Duffy JD, Hunder GG, Kelly PJ. Decreasing prevalence of tophaceous gout. *Mayo Clin Proc* 1975;50:227-8.
17. Dequeker J, Rasker H. High prevalence and impact of rheumatic diseases is not reflected in the medical curriculum: The ILAR Undergraduate Medical Education in Rheumatology (UMER) 2000 project. Together everybody achieves more. *J Rheumatol* 1998;25:1037-40.
18. Tomita M, Mizuno S, Yamanaka H, et al. Does hyperuricemia affect mortality? A prospective cohort study of Japanese male workers. *J Epidemiol* 2000;10:403-9.
19. Wong KY, MacWalter RS, Fraser HW, Crombie I, Ogston SA, Struthers AD. Urate predicts subsequent cardiac death in stroke survivors. *Eur Heart J* 2002;23:788-93.
20. Darmawan J, Valkenburg HA, Muirden KD, Wigley RD. Arthritis community education by leather puppet (wayang kulit) shadow play in rural Indonesia (Java). *Rheumatol Int* 1992;12:97-101.
21. Padang C. A study of risk factors in patients with severe tophaceous gout in the northern part of Sulawesi and the development of educational strategies to reduce pain, disability and complication from the disease [DMed thesis]. Melbourne: University of Melbourne; 1997:73-6.
22. Grabauskas V. A World Health Organization perspective. *J Rheumatol* 1983;10:5-6.