

CHALLENGES TO EPIDEMIOLOGIC STUDY OF RHEUMATIC DISORDERS IN THE DEVELOPING COUNTRIES

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Rheumatological problems are not new. But attempt to fight this public health menace logically through intensive knowledge generation is certainly a recent initiative. Appreciation goes largely the Community Oriented Program for Control of Rheumatic Disorders (COPCORD) initiative without which the developing countries may not have seen the host of reports on epidemiological studies that currently extend our acquaintance of the problem in a largely otherwise unseen population. Besides the research outcomes, through this initiative, investigators in this field of study have to a great extent been able to appreciate and partly overcome the difficulties which plagued such research works until recently. These works obviously had an ice-breaking effect on research impediments that almost constantly included fund constraints, inadequacy of appropriately trained research manpower, poverty and illiteracy prevalent in the target communities, low priority ascribed to the problem in policy, lethargic and often passive bureaucracy, deceptive political will, the trend of crisis oriented short-sighted health planning, lack of organized community surveillance and Management Information System (MIS) and lack of vision of the researchers amongst others. In observation of this new reality an attempt will be made here to explore in depth the multifaceted challenges that tend to upset epidemiological studies in the Asia-Pacific, expressly in the rural areas. Efforts will also be made to hint how these challenges can be addressed in the current perspective.

Exploring the Challenges

It is known to even the most adept researchers that, illiteracy, poverty, poor infrastructure, and cultural differences frequently pose difficulties in conducting appropriate field level surveys in most developing countries. Participants of rural surveys are often poor and illiterate. They require both reading and comprehension assistance for self-administered instruments. Many of them are marginalized with ill-remunerated and barely subsistence level impermanent employment that either disapprove their

participation or adversely affect productivity. Information gathering on petty matters may become difficult. Experience suggests that matters like the duration of symptoms may be difficult to make out as was in some parts of Africa. Quite ironically it may simply mean that 'when there is no clock, time does not exist'.¹ Vocabulary used by particular communities may sometimes pose critical barriers. In such cases significance of decisive issues like 'morning stiffness' can be misunderstood by both surveyed subjects and the surveyors in the rural areas.² Cultural barriers can often be embarrassing as, it was considered to be impolite to point to the lower back in parts of Java.²

Some system factors sometime complicate the problems. Transportation, particularly to inaccessible areas, can often be difficult but accessible areas may also become inaccessible with variation of seasons. For example, during rainy season, the COPCORD villages in Bangladesh remain such inundated that the investigators have to travel with boat and wading their way through the water hyacinths.³ Over-the-counter availability of steroids and NSAIDs have the possibility of distorting the presentation and lead to an underestimation of prevalence of inflammatory arthropathies.⁴ Regional conflicts and political disturbances may also have unfavorable effects on execution as well as continuance of projects. A delay of six years between phase I and II of stage I COPCORD rural study because of the Civil War in Philippines is one of such difficult experiences that may have excruciating effects on funds as well as manpower availability.^{5, 6}

Inconsiderate importance and priority given to the research on rheumatic disorders is another challenge. In most of these resource constrained countries, health research grants are rather popularly funneled to infectious diseases, coronary heart disease, diabetes mellitus and cancers. Because of paucity of data and weakness of advocacy, proposals on epidemiological works on rheumatic disorders (RD) do not get priority. The funds even when available are meager. The consequences of such

dealings can be many. In that case laboratory facilities for definite diagnosis of some RD, e.g., rheumatoid factor for rheumatoid arthritis, X-ray for knee osteoarthritis for example can not be used liberally even when and as often as necessary. One may even be compelled frequently to engage less educated manpower as interviewers.

A further major challenge is that the majority of the departments in medical schools do not have any research master plan. Funds are often given for nominal or sketchy research works with little eventual outcome. There is also a dearth of manpower trained in research methodology. Clinical disciplines are often segregated from departments of epidemiology so that epidemiologists often don't get exposure to rheumatologic epidemiology. Research even when done are patchy, subsequent researches do not follow a logical order and the outcome frequently do not find an eventual way for implementation. A major cause for such erratic trends may lie in the fact that many such researches are personally designed and owned and are neither owned nor consumed by the system.

If one scrutinizes the healthcare systems in many countries one may vividly notice their poor structure. As such hospital based prevalence surveys are impossible in the majority of the countries, as the hospitals do not have fixed catchment areas. For the same illness, the patients can move from one hospital to another based on their choice and more often out of dissatisfaction with one without there being any referral linkage. These hospitals often lack a proper record system and their disease classification systems also vary widely. In such situations, if someone takes the initiative of collecting data from hospital records, it is likely to be a formidable task in the first place, and secondly, it may be even more difficult to arrange them according to a singular classification. On the other hand, vast majority of the patient population never reaches a formal healthcare facility. Thus, even after overcoming all above said drawbacks, the prevalence figures are threatened to remain underestimates. It means otherwise that for estimation of true community prevalence, there are no plausible alternatives to community surveys that in turn greatly increases not only the costs but in deed the magnitude of the task.

It can be recalled here that the ultimate objective of COPCORD is the reduction of the community burden of RD. A great fallacy is to be included in the challenges before this part of the discussion is winded. In many communities, prevalence rates of

the RD are being estimated, sometimes repeatedly, at different times and different parts of the country. But seldom any effort is seen in using the generated evidences for its clinical or community management including prevention.

Being Face to Face with the Challenges

How these problems can be mitigated is not an easy question to be answered. Conceivably, they are required to be addressed at different of understanding, planning and execution. Some of the challenges relate to socio-politico-economic conditions which are beyond the scope of healthcare workers though they may consistently engage themselves in utilizing every advocacy opportunity. It appears appropriate that the policy makers and managers take the morbidity and productivity related costs of RD into account in addition to the aspects of human suffering and its overall growing burden to ascertain its priority as a healthcare agenda. On the other hand, there are challenges which undeniably fall within the purview of the managerial, leadership and scholarly roles of specialist physicians.

Improvement of transportation, alleviation of poverty and illiteracy and political stability do not come under the purview of the healthcare workers. But they can highlight the health consequences of these social adversities. To find a frontier position in the healthcare priority queue epidemiological researchers in the developing countries need to win the confidence of the healthcare policy makers as well as the consumers by being closer to the community to explore the actual healthcare needs of the societies and also provide actual support to fulfill the needs. Chopra has appropriately suggested that "future COPCORD must consider providing some kind of treatment services and health education. The community must feel benefitted. Only then will the community allow a robust COPCORD to move along".⁷

To find a plausible alternative for the community surveys, the hospitals need to be entrusted with defined catchment areas. All hospitals in a country should adopt and follow a singular disease coding system. Management Information System in hospitals should be developed. This will help networking among hospitals in a region and development of a more effective surveillance system.

The curriculum developers in these countries are expected to accord greater emphasis on epidemiology and research methodology in both under-graduate and post-graduate education. The rheumatologists should work hand-in-hand with epidemiologists for development of research collaboration, mutual

exchange of knowledge and ideas. Where such differentiated professionals are not available, an alternative may be more appropriate that the rheumatologists gain relevant competencies in epidemiological works. To make subsequent researches more relevant in communities in which disease prevalence rates have already been estimated, the investigators should proceed to estimation of the burden of common RD. The burden may include disability, work loss, loss of DALYs, and economic impact. Substantial volume of data on disease burden may convince policy makers to put due emphasis on RD in allocating research and healthcare funds. The researchers may also attempt to identify the risk factors for common RD and develop lifestyle and behavior change communication (BCC) modules for their management. They should also endeavor to develop outcome measurement instruments to assess the effectiveness of management strategies. It can not be overemphasized that the ultimate success of the rheumatological epidemiologists will lie in providing enough substance for designing BCC modules effective in reducing community burden of RD. There are reasons to believe that right efforts in this direction will help all to reach the right destination of containing this huge public health menace.

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