Letters to the Editor

Need for determining the incidence and prevalence of JIA in developing countries: the Indian predicament

Sir, Director-General Halfdan Mahler in his address to the 1976 World Health Assembly stated that ‘Perhaps the fundamental difficulty in regard to rheumatic diseases is that the problem is insufficiently appreciated and understood. Critical to this lack of appreciation is an information deficit’ [1]. Among musculoskeletal diseases, the least information available seems to be regarding those afflicting the paediatric population.

Juvenile idiopathic arthritis (JIA) is the most common chronic musculoskeletal disease of childhood. However, there seems to be little consensus on its prevalence in developed Western countries with studies predicting prevalence ranging from 1/1000 to 4/1000 children [2, 3]. The outlook is bleaker in developing countries where there is nearly a total absence of community-based data. Based on hospital-based incidence of diagnosis of JIA as well as RA at a tertiary centre and the community prevalence of RA in India, the prevalence of JIA was assumed to be around 1.25 per 1000 children [4, 5].

Filling the deficit in knowledge by measuring the burden of JIA would ensure that these disorders receive higher priority in health strategies by helping consolidate political will as well as increase focus of medical research on treatment of the problem. An excellent example is the 1994 WHO Study Group on Osteoporosis. Their findings regarding the frequency of osteoporotic fractures led to the setting up of The International Osteoporosis Education Project, which aims to improve the diagnosis and care of osteoporotic patients throughout the world [1].

It is imperative that we increase focus on the management and research of JIA. Dr G. Harlem Brundtland, Director-General of the World Health Organization, in her opening address to the WHO Scientific Group on the Burden of Musculoskeletal Conditions meeting in Geneva in 2000, mentioned that although the diseases that kill attract much of the public’s attention, musculoskeletal or rheumatic diseases are the major cause of morbidity throughout the world, having a substantial influence on health and quality of life, as well as inflicting an enormous burden of cost on health systems [1].

Costs involved in the care of a patient with JIA include the cost of treatment, out of pocket expenses and loss of income for parents in the short term. These costs were estimated in a recent article from Germany by Minden et al. [6] to vary between 2904 euros (persistent oligoarthritis) to 7876 euros (polyarthritis and systemic arthritis) per annum. In comparison, the direct cost of patients with RA is estimated to be around 5167 euros per year [7].

In addition, however, by affecting people in the prime of their lives JIA leads to substantially greater loss of productive years due to disability compared with adult rheumatological illnesses. To provide perspective, the indirect cost, due to loss of productivity, in RA patients is 3–10 times the direct costs. The all-inclusive cost of disease in RA is 14 906 euros per year [8]. The study by Minden et al. [9] also demonstrated that, contrary to popular perception, JIA tends to persist well into adulthood with ~41% of patients in their study showing persistent tender and swollen joints at a median 16.5 years after diagnosis. This leads to cumulative damage with time causing geometric increment in costs due to loss of productivity. Thus, a patient with JIA would have a much higher economic burden on the community than an adult patient with RA. Families who have children diagnosed with JIA suffer from not only a loss of income but also a significant impairment of quality of life, caregiver burden as well as higher rates of psycho-emotional disorders [10].

This is quite frightening given the epidemiological changes that are expected in various developing countries in the near future, particularly India. From 1995 to 2020 (and subsequently), India will be the country which will add the most to the world’s population. By 2050 India’s population will exceed that of China’s [11].

Between 1997 and 2001, India’s working age population has grown to become a larger proportion of the total population and this trend will continue till 2020 [12]. However, in the later decades (i.e. subsequent to 2050), this big chunk of the working population will age and will not be replaced by a similar size of population given the successful efforts at family planning. At that point in time (i.e. beyond 2050), the population that constituted the working population between 2020 and 2050 will be dependent on the population who would have been born between 2020 and 2050. Thus we need to make sure that the population born between 2020 and 2050 are not impeded in their ability to contribute to the economy and thus prevent India and China from collapsing under the economic burden of caring for their own aged population.

Prevention of malnutrition and infectious diseases is important. However, lifestyle diseases and chronic diseases are already becoming more prevalent among Indian and Chinese youth in response to better health parameters, an immunization programme and improving lifestyle. We can expect this trend to continue and therefore assume that chronic diseases specifically musculoskeletal diseases such as JIA would be an important cause of morbidity in the future population of children in these countries.

Hence, by not taking active measures to prevent morbidity due to JIA in children now and in the near future, China and India in the coming decades will face an unenviable task. There will not only be a disproportionately higher percentage of aged population to be supported,
but also a working population burdened by musculoskeletal morbidity on which this task will depend. Given that around half of the world’s population will reside in these two countries, by corollary, the rest of the world will be forced to share this burden as well.

References


Rheumatology 2010;49:1599–1600
doi:10.1093/rheumatology/keq020
Advance Access publication 13 April 2010

The demographics, educational attainment and current practices of rheumatology nurses and allied health professionals in the UK

Sir, In 2001, a report [1] was published defining extended roles undertaken by rheumatology nurses and health professionals (HPs). However, little is known about this present rheumatology workforce. British Health Professionals in Rheumatology, the Royal College of Nursing Rheumatology Nursing Forum and the Nurse Consultant Group in Rheumatology undertook a survey to ascertain the demographics, educational attainment and current practices undertaken by their members. There were 378 respondents comprising nurses, physiotherapists, occupational therapists, podiatrists, a radiographer, a psychologist and a pharmacist. The results show that the workforce is predominantly female (356/378: 94%) and relatively old with 37% (139) of the respondents aged ≥50 years; 113/272 nurses in the cohort (42%) fell into this category. Many respondents had worked in rheumatology for many years and it appears that once in post, many stay. This age and experience profile demonstrates the necessity of succession planning and ensuring that younger and less experienced colleagues assimilate knowledge and learn new skills. Knowledge transfer between and across professions can be highly efficient and cost-effective and 327 (90%) of the 364 nurses and HPs who answered this question are actively involved in education and training. Members of each of the professions teach other professional cohorts, including medical students, general practitioners and junior hospital doctors.

The Next Stage Review [2] states that ‘Staff in all roles and settings need opportunities to continuously update the skills and techniques that are relevant to delivering high quality care through, for example, work-based learning, distance and e-learning, and further education’. The respondents to this survey have enhanced their knowledge academically, with 25% (93) of them having obtained a Master’s degree or a PhD (n = 8). Many had undertaken