

Leprosy in Pakistan: Lepra Elective Study

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Summary As part of the curriculum, medical students at the United Medical and Dental Schools of Guy's and St Thomas's Hospitals (UMDS), London, are encouraged to spend an elective period of 8 weeks in their final year anywhere in the world, studying any field of medicine they are interested in. Having lived in Tanzania for 10 years, I have had contact with people suffering from leprosy and my interest in leprosy continued after I moved to Europe to continue my education. I therefore decided to use my elective to gain hands-on experience with the disease so that I could understand and appreciate the impact of leprosy in developing countries such as Pakistan.

Leprosy situation in Pakistan (1996)

Very little has been published about leprosy in Pakistan and the available information is outdated and scanty—a MEDLINE search combining *leprosy* and *Pakistan* as textwords, for example, identified only one brief Japanese article since 1992.¹ 1995 was the latest complete year for which leprosy data were available for Pakistan. The population of Pakistan then was estimated at 118 million, distributed over an area of almost 800,000 square kilometres, with 13 million people living in Karachi, the capital city. The country is divided into four provinces (Punjab, Sindh, North West Frontier Province and Balochistan) and two disputed areas (Azad Kashmir and Northern Areas).

The leprosy control measures in Pakistan are part of the Provincial Health Services, which are administratively integrated and professionally vertical. Each Provincial Health Department works closely with a non-governmental organization (NGO), of which the Marie Adelaide Leprosy Centre (MALC) is the largest. Leprosy prevalence in all provinces declined to less than one active patient per 10,000 in 1993, the threshold below which leprosy ceases to be a public health problem according to the WHO definition.² However, the leprosy pattern in Pakistan is very focal, ranging from 35/1000 in Sukkur District in Sindh to less than 0.01/1000 in Punjab. The leprosy belt, which is now well controlled, originally stretched from Azad Kashmir over the Northern Countries to the North West Frontier Province to Northern

This study was undertaken during an 8-week period as a Lepra Elective Student.

Pakistan and along the seashore to the border of Iran. Hyderabad/Sindh, and especially Karachi, have contributed, and still are contributing, a large portion of the caseload.

There are 11 leprosy hospitals (four of which also admit TB and eye patients) in Pakistan with 377 beds, and there were 2885 admissions in 1995. The country has 104 leprosy field units, of which 91 are run by the government and nine by NGOs. The leprosy programme staffs 803 workers, including 21 medical officers, 412 paramedical and technical staff, and 362 administrative staff.

At the end of 1995, there were 42,800 patients registered in the National Leprosy Register, of whom 2953 were receiving chemotherapy, and 18,119 were under post-treatment surveillance. In all, 1405 untreated cases were detected in 1995 and 2208 were discharged from chemotherapy. At the time, Pakistan had a multidrug therapy (MDT) coverage of 88% (2611 cases) with a treatment completion rate of 97.5% of 1633 multibacillary (MB) and 99% of 359 paucibacillary (PB) cases, with only 17 relapses detected during the year.

The reduction of new leprosy patients to less than 1/100,000 per year had been achieved in four out of seven projects by the end of 1995. However, average disability rate was still 24% in newly detected cases because the annual case detection rate (1.62 patients per 100,000 population) was less than the disease incidence. Unfortunately, like many other countries,³ the annual incidence rate in Pakistan does not follow the prevalence rate and is only expected to decline after 10–20 years.

By the end of 1995, incidence rate for Pakistan was 1.08 per 100,000 population, and this included (per 100,000) 0.18 in Punjab, 0.65 in Sindh, 1.08 in the Northern areas, 1.09 in North West Frontier Province, 0.51 in Balochistan and 11.98 in Greater Karachi. However, because of the dramatic decrease in the prevalence of the disease in most areas of Pakistan since 1993, the leprosy programme has now undertaken additional tasks. For example, since 1995, leprosy programmes in Azad Kashmir and the Northern Areas also play a major part in tuberculosis control by re-training leprosy staff in tuberculosis management. Similarly, a Prevention of Blindness scheme (in the form of Community Eye Health Care and training of field workers as ophthalmic technicians) has now been implemented in Balochistan and the North West Frontier Province, Punjab and Sindh. In 1995, a total of 90,021 patients were seen by leprosy staff for eye problems, of whom 1154 were operated on for cataracts (79%) or other eye conditions (21%).

Many leprosy control programmes are now also involved in other areas of medicine, education and rehabilitation. For example, homes are now provided to the handicapped in Rawalpindi, Karachi and Faisalabad. Leprosy staff are actively involved in teaching school children as well as children and relatives of leprosy patients, particularly in Karachi and Balochistan. Furthermore, rehabilitation is provided not only for leprosy patients, but also for drug addicts in Sindh. Community-based rehabilitation programmes for children have been implemented in Karachi and income-generating projects for women, such as embroidery and leather patchwork, have begun in many areas of Northern Pakistan. Unfortunately, a large proportion of patients discharged from treatment still need rehabilitation. For example, a survey conducted in rural Sindh in 1995 covering 86% of the entire caseload revealed that 51% of all patients still needed further physical as well as psychological rehabilitation, perhaps for the rest of their lives.

The long-term targets of the leprosy programme in Pakistan include (a) to reduce leprosy prevalence to less than 0.1 per 1000 patients, when the disease is considered to be effectively controlled; (b) to reduce the incidence rates (i.e. the number of new cases found per year to less than 0.01/1000); (c) to discontinue monotherapy and implement MDT in all new leprosy

patients; (d) to enhance health education so that more than 90% of patients voluntarily report their symptoms before disabilities arise; and (e) educate at least 90% of disabled patients to care for themselves so that their deformities do not worsen. While the first three of these targets are likely to be achieved in the near future, targets for prevention of disability and voluntary self-reporting of the disease are not likely to be achieved before the millennium.

In summary, therefore, due to the long and unpredictable incubation period of the disease (3–40 years), there are an estimated 15–30,000 infected asymptomatic persons in Pakistan who will be detected and treated in the next 2 decades. Around 20,000 are still under surveillance to detect and treat any reactions and/or relapses and a similar number require physical rehabilitation.

Leprosy is now better controlled in Pakistan than previously. Preliminary data for 1996 indicate that the disease prevalence in Greater Karachi, the only area in Pakistan with a rate higher than that recommended by the WHO, has now fallen below 1/10,000. This has allowed the leprosy programme to work in other areas, such as prevention and rehabilitation, as well as contributing to the management of affiliated conditions such as tuberculosis.

Leprosy electives in Pakistan (Jan–Mar 1997)

MALC is situated in the centre of the Karachi and is run by Dr Ruth Pfau, honorary advisor on leprosy to the Ministry of Health, Social Welfare, and Population Planning, Government of Pakistan and Azad Kashmir. It caters for most of the leprosy patients in Karachi and its outskirts and is always full of patients. Leprosy sufferers who require treatment are treated free of charge at the MALC. A large proportion of the funding for the Pakistan leprosy control programme comes from Germany, Dr Pfau's home country, but donations are received from charity organizations around the world, including LEPRO and St Francis Leprosy Guild in the United Kingdom. Until a few years ago, much of the country had remained inaccessible, mainly due to political instability—the recent increase in provision of basic health care facilities to these regions has improved the leprosy situation in Pakistan.

MALC is also the national leprosy control centre for funding, data collection and training leprosy staff at all levels. Regular liaison, usually through meetings held at MALC, with officials from other leprosy centres around the country, provides MALC with an overview of the leprosy situation in Pakistan, identifies weaknesses and makes recommendations to overcome them. In smaller towns, there is a trained local worker who can diagnose, treat and report the disease, and has easy access to professional help. The advantage of this system is that the worker is known and trusted by the people, understands their customs and culture and speaks their native language. Around the outskirts of large cities, the main leprosy centre in the area has teams of workers who travel to these regions once or twice a week actively to seek new leprosy cases, correctly diagnose the type and severity of leprosy in new patients, treat the patients, as well as follow-up and rehabilitate known patients who are already being treated.

Working at MALC was an amazing experience, and more dramatic than I had expected. The first thing that struck me as I entered the hospital was the sheer number of people waiting to be treated. Having attended the clinics there, I later realized that some people had been waiting outside the hospital for days before they were seen by a doctor, sometimes having travelled for days from villages as far as away as Afghanistan. There is also an in-patient

facility for ill patients with complications such as severe type I and II lepra reactions or concurrent illnesses such as infections and severe trauma to anaesthetized limbs as a consequence of leprosy. It should be noted that patients seen at MALC do not have to pay for any of the services or treatments.

I was surprised to find few affected people in the city itself. By talking to patients at MALC, I found out that most of the leprosy patients had been banished from the city. The stigma of leprosy was so severe that many voluntarily left their homes and family when they were diagnosed with leprosy. Most of these patients ended up in Mangopir, a small town on the outskirts of Karachi, where they were treated and attached to a rehabilitation programme. This rehabilitation programme, according to the National Council on Rehabilitation, is aimed at restoring the patient to the fullest physical, mental, social and vocational and economical usefulness of which they are capable. Unfortunately, because of the stigma associated with the disease, even after complete rehabilitation, most of the patients remain in Mangopir where they are accepted as part of a community and can help newly arrived patients with their problems. Furthermore, many of these rehabilitated patients are also actively involved in projects for obtaining funds for the country's leprosy eradication programme, such as handmade carpets, jewelry, paintings, and artifacts, and provide for up to 10% of the programme's total income.

In conclusion, initial data for 1996 have revealed that the prevalence of leprosy has now declined below 1 in 10,000 in all areas of Pakistan, including Greater Karachi, where local political unrest had, until recently, isolated and prevented access to patients by health care professionals. With the disease now in control, more attention can now be paid to education, prevention and rehabilitation and linking with other programmes such as tuberculosis.⁴ It is only through sheer dedication and team work over 3 decades that such a feat has been achieved, and the programme certainly deserves a lot of credit for reaching the WHO-recommended target despite so much adversity.

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