Leprosaria – a continuing social challenge

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The Leprosy Mission International

Accepted for publication 12 August 2007

Opening

In the early days of leprosy care, with very little in the way of chemical treatment, the recognised way of treating leprosy was to remove people from their homes and put them into leprosaria. The 1897 Leprosy Congress recommended that leprosy could be prevented by isolation. They took as their model for leprosy control the model Hansen had set up in Norway consisting of compulsory registration, control and isolation. All over the world there were large leprosy colonies, some were institutions such as Carville, others were islands such as Robben Island and Spinalonga. In India and other endemic areas the approach to leprosy was the same. People affected by leprosy were put into colonies or institutions and leprosy control was run as a vertical programme.

Leprosy was not unusual in this; other diseases were similarly treated. There were TB sanatoria, mental asylums, schools for asthmatics, institutions for the disabled. The idealised approach was to provide high quality specialised care and to protect the community from harmful or potentially infectious diseases. However, the reality was that it removed from society ‘deviants’ who, because of disease or disability or behaviour out of the accepted norms, did not fit and were seen to be shameful or a burden or a threat. Leprosy seems to be all those things. Hence in the west the treatment was more akin to being sectioned in a mental asylum, with people being virtually smuggled in barges into Carville or arrested.¹

Although some of the best leprosy research took place in the institutions, it was inevitable that this social isolation would enhance stigma and produce institutionalisation. At no point did there seem to be any consultation with the people affected by leprosy. This social isolation was deemed for their own good even if it involved separating mothers from children or wage earners from their families.

The WHO expert committee report in 1953 noted the difference between ‘open and closed’ leprosy and started to introduce the notion that not everybody should be isolated. They also noted that ‘institutional isolation alone has not given the results expected of it and has failed as a control measure even when applied vigorously and on an adequate scale’.² It wasn’t until 1960 that the second report talked openly of the psychology of being disabled and having leprosy. The authors were now convinced that institutionalisation was not the way forward, particularly for the disabled.³ No doubt that emergence of Dapsone and the
possibility of control through survey, early case finding and treatment influenced the change of approach. However, the change in social and political climate also played a part.

Closure

The 1960s was the time when there was recognition in Europe that asylums, particularly mental asylums, were actually detrimental to the well being of people. The publication of the book ‘Sans Everything: A Case to Answer’ by Barbara Robb highlighted this and led to significant change in the care of people with mental health problems, with the emphasis being put on community care rather than institutionalisation.

When I first became involved in leprosy control in 1976, the closure of leprosaria was starting to take place. In Papua New Guinea, where I worked, they were nearly all closed and replaced by community care by the early 1980s. Those of us involved in the closures saw a mixture of reactions from the people affected by leprosy. There was not a stampede for the gates but rather a cautious and fearful attitude with many patients building homes, if not directly on the leprosarium property, as close as they could get. The ‘Institutional Neurosis’ described by Russell Barton in his book of that name was certainly evident. He described symptoms of apathy, lack of initiative, loss of interest and submissiveness in those who had spent a long time in institutions. These symptoms were caused, Barton said, by such factors as loss of contact with the outside world, enforced idleness, brutality and bossiness of staff, loss of friends and personal possessions, poor ward atmosphere and loss of prospects outside the institution. In the case of leprosy, you could add stigma and fear into this mix.

Still there

So are there still leprosaria in the 21st Century? It seems so. In many places the old leprosaria have made the transition into centres of excellence for the care of people affected by leprosy. Some have specialised in rehabilitation, others dermatology and others leprosy research. Many are trying to make the transition to community hospitals with an increasing emphasis on general care as well as leprosy. Long-term admissions and life-long patient care is a thing of the past. However my experience is that somewhere on their campuses you will see a row of cottages or an area of wards for those who are old, infirm and disabled. Just as the problem of anaesthesia does not go away nor it seems does stigma.

Leprosy laws are slowly being repealed. In 1996, Japan was perhaps the last country to finally repeal its laws incarcerating people affected by leprosy in institutions. Other attitudes and discriminatory practices are taking longer to change. The socially excluded – the ones who could not, dare not or would not return to their homes and communities – remain. They feel a need for a safe place where they can be accepted as normal and not rejected.

Age Care

The article ‘Current situation of leprosy colonies/leprosaria and their future in P.R. China’ in this issue describes the situation in China and the government’s desire to do something about the standard of care of the elderly people who remain in leprosaria. In the McKean
Rehabilitation Institute in Thailand, some former residents are returning simply because living with families is proving to be too hard and attitudes are still negative. Their memories of life in the institution and of an accepting community are good so they return in their old age and infirmity. This has led the team there to have a vision for an Age Care Centre to provide social and medical care for those who cannot remain with their families. They are responding to changing social trends in Thailand: a population that lives longer and a society where care by the extended family is becoming less of a normal pattern. These changes are often economic as countries like Thailand take up the western model of urban life, but they can also be related to the HIV epidemic.

The leprosy world would do well to look at the hospice movement as a model and accept that there will need to be refuges in the future. The psychiatric world came to this conclusion in terms of their community care programmes some years ago. These centres will be mainly for the elderly disabled and so do not need to be staffed by leprosy specialists. There will be a need, however, for therapists and nurses who understand the problems of anaesthesia and wound care. What will be needed are people with skills in gerontology and psycho-social care and an acknowledgement that these care centres should be run as a cooperative partnership with health workers and with people affected by leprosy.

**Colonies and Villages**

The Leprosy Mailing List discussion group had an extensive discussion last year on the issue of leprosaria-colonies and what to do with them. It seems that they are still very present, and in the case of colonies, often using rather creative approaches to social economic development such as gun-and-drugs-running. It should come as no surprise to us that those who society rejects in turn reject society’s values.

Perhaps the institutional neurosis has been replaced by anger. Not an unusual phenomenon in leprosy. I think that our approach to leprosaria in the past has been to make decisions as to what is best and appropriate from a public health viewpoint, with little attention to the social or psychological aspects.

**Shifting the Power**

It is my opinion that this was the reason that closure of leprosaria in the ‘60s and ‘70s was only partially successful. The trouble was that apart from some health education, little was done to help people affected by leprosy make the psychological adjustment to living in the community. Nor was any approach made to the communities who needed to receive them. This may yet be the dilemma that faces China and the solutions that are proffered by Jianping Shen, Musang Liu and Min Zhou in the article in this issue. They are aware of the need to avoid the compulsory isolation of the past. I wonder what approaches have been made to receiving communities, or how they will consult with the people in the leprosaria regarding the move. There will need to be much dialogue and counselling to help the ex-patients cope with the changes, disruption and emotional insecurity that will result.

Today we need to consider human rights and recognise that people affected by leprosy want to have a voice and be treated with dignity and respect. MORHAN in Brazil have taken this approach with their first national seminar on former Hansen’s disease colonies in 2005.
Volunteers, health professionals, social workers and people from the colonies met and worked together to diagnose the problems with the colonies and to develop a plan for restructuring them. There were 126 recommendations that included improving the health care facilities, improving safety, preserving and valuing the memories and history of the colonies, improving buildings and infrastructure, changing the management to include human rights and empowerment, improving the environment, dealing with legal matters and ownership of the land, looking at jobs and training and changing the governance of the colonies. Colonies also agreed to communicate and interact with one another more. Time will tell as to how successful this has been.

My experience with the leprosy villages in Nigeria is that listening and facilitating discussions on what would make their life better had a profound effect. When we returned to the villages in 2001, the majority of the changes that were identified had taken place with only limited external input. Clinics had been built, wells dug and requests to NGOs made for help with staffing and pumps. This empowering developmental approach may be the next phase for leprosaria and colonies.

The challenge for the future will be for health workers, social workers and people affected by leprosy to work together in a constructive way to ensure that dignity and quality of life are the main objectives in the political, social and health reform of leprosaria and colonies.

References

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