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Supporting ‘the individual’ with leprosy: the need for a ‘post-elimination strategy’

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Leprosy elimination

The international policy of leprosy elimination has been used successfully to target leprosy as an international health problem. Leprosy elimination by the year 2000 was first proposed in 1986 at the 44th World Health Assembly, and in 1991 it was modified by the addendum ‘as a public health problem’ defined as less than one case per 10,000 population.¹ In 2001, WHO declared that leprosy had been eliminated ‘at a global level’ but rescheduled ‘elimination’ for 2005. Debates continue around the policy and its achievements, and there continues to be uncertainty about the future of leprosy control strategies and the role of leprosy workers and researchers after 2005.

Elimination is not eradication, and leprosy cases will continue to be present after the disease has been declared ‘eliminated’ in 2005. In 2002, Lockwood reported the successes of the elimination strategy but indicated that case numbers continue to rise in the major countries where leprosy is endemic and that opportunities for implementing evidence based policies to treat and control leprosy were being missed.¹ These concerns emphasize the understanding by people working in leprosy control first, that the disease will continue to occur after elimination; second, that its epidemiology is uncertain and third, that strategies need to be created to continue to control leprosy and treat and care for the individual leprosy patient after the disease has been eliminated. It is essential that leprosy continues to be recognized as an important disease by the international community, and that the disease does not ‘go underground’. The leprosy elimination strategy will have failed if leprosy disability is not prevented after it has been declared eliminated in 2005.

Philosophical perspectives on disease elimination and control

Tensions exist within philosophical perspectives and this is evident in public health and disease control.² At the beginning of the twenty-first century, the philosophical underpinnings of international public health practice and health policy creation continue to be dominated by the perspective of ‘utilitarianism’. ‘The greatest happiness of the greatest number’ is the basis of all utilitarian theories of ethics that were developed by Bentham, Sidgwick and Mill in the eighteenth century.³ One of the problems, however, with this approach is that, because it focuses on the majority, it can dismiss the importance of the individual. For example, in talking of the success of leprosy elimination, which has benefited the majority, we fail to recognize that there will continue to be both old and new people with leprosy, and this needs to continue to be addressed for the benefit of the public’s health. There are philosophical dangers in the current utilitarian approach to public health and as the philosopher Williams⁴ states ‘utilitarianism ignores the separateness of persons, and is prepared illegitimately *to sacrifice the interests of any given person* with the aim, not just of protecting, but even of increasing the aggregate welfare’.⁵ We need to make sure that this does not happen in leprosy control. Utilitarianism as a perspective needs to be balanced with other philosophical approaches, for example, the teaching of Immanuel Kant the great German philosopher, who indicated the importance of autonomy and treating others as ends in themselves and never merely as means to some (externally defined) end;⁶ in this case, ensuring that the success of leprosy elimination is not achieved through a lack of awareness and attention to those people who continue to suffer from leprosy. In order to ensure that the leprosy patient is not ‘sacrificed’ after elimination has been declared it is important that a powerful post-elimination strategy is discussed and created before 2005.

From ‘leprosy elimination’ to ‘post-leprosy elimination’

With a change in perspective from ‘leprosy elimination’ to ‘post-leprosy elimination’ comes a change in words, expressions and concepts; from a disease of high international priority to a disease of low priority; from a disease that is controlled through vertical programmes to a disease that is integrated into general health services; from a disease that is present, understood and discussed in a community to a disease that may no longer be present in a community; and from a disease that is perceived to affect large groups of people (populations) to a disease that affects a few (individuals). This change in perspective provides an opportunity to create a new strategy, focus and perspective that continues to help and support people with leprosy but at the same time ensures that *the individual is not sacrificed for the benefit of the population*; to ensure that each person with leprosy continues to be given the best opportunity to be a ‘whole’, ‘healthy’ member of their community. One way to achieve this is to use this shift in the focus of leprosy control within the post-elimination strategy as an opportunity to create a concept and focus for leprosy within the broad context of health.⁷ In many ways leprosy control efforts are already ahead of other infectious disease control activities in that control programmes already emphasize the broader concepts of health through a focus on the prevention of disability and, through socio-economic rehabilitation efforts to incorporate patients back into their communities.^{8–10} Leprosy control, through its work on stigma, has always emphasized the importance of ensuring that the person with leprosy remains an active member of their community.

What needs to be done?

1. We need to continue to be aware of leprosy as an international health problem and to ensure that appropriate evidence based policy decisions continue to be made at the international and national levels. There needs to be continued discussions at all levels and the collection of information, through action and operations research to understand what is happening within leprosy control programmes and among leprosy patients.¹¹ For example, what problems are being encountered as leprosy is integrated into the general health services and who is addressing these problems?
2. 'New' surveillance systems need to be created at international, national and local levels to ensure that the appropriate information on leprosy patients is collected and managed after elimination. Surveillance never goes away; it is an essential part of public health practice. If leprosy cases increase then this needs to be noted and checked. This can only happen if there is a surveillance system. As Henderson writes with reference to eradication, 'Surveillance has proved to be the most critical element, by far, for all eradication programs, with programs succeeding wherever it has been effectively employed, and failing consistently wherever it has not. Surveillance is defined in terms of disease reporting for action. Specifically, it is the routine, systematic collection of morbidity and mortality data; its compilation, interpretation and dissemination; and finally the implementation of necessary action based on these data'.^{12,13} It is important to be aware that we need to continue to look for leprosy cases for, as Fine and Warndorff¹⁴ state, '... an efficient way to make a disease disappear is to stop looking for it.'
3. Partnerships need to be created to support leprosy patients; for example links between communities, NGOs and other health organizations. Partnership in the health sector has been described by WHO as a process of bringing together 'a set of actors' for the common goal of improving the health of the population based on mutually agreed roles and principles.¹⁵ The theme of partnerships has been an important concept within the international community during the past decade,¹⁶ and is increasingly a part of infectious disease control strategies. For example, in India, there is an active process for linking the public and private health sectors in TB control¹⁷ and at the London School of Hygiene and Tropical Medicine we have been actively developing our research links with NGOs that work in leprosy and TB control.¹¹
4. Research into leprosy needs to be continued and supported. For example, in the six countries that account for 88% of new leprosy cases the numbers and incidence of new cases are rising; why?¹ There is also a continued need for research around disability and rehabilitation into society^{18,19} and research around the process of integration of leprosy into primary health care.²⁰
5. Systems and infrastructure need to be developed to support leprosy patients after 2005. For example, what plans are being made for the long term care of patients with nerve damage?¹ What systems are being developed to assist leprosy patients to reintegrate into their community and what plans are there to integrate experienced leprosy workers into the health system? Innovations are required to help patients, like that described by Benbow and Tamiru⁸ in Ethiopia with the use of leprosy self help groups and new systems are needed to help leprosy workers retrain in other areas of leprosy work or to develop their skills in other disease control strategies like TB or HIV. In addition to developing new infrastructures, systems used successfully in the elimination strategy, like survey techniques for example, need to be adapted and used to enhance the public's awareness of

leprosy in areas that continue to see new cases. Innovations, like that described in the article in this journal (Norman *et al.*, p. 34, this issue) where schoolchildren are used as active members in a leprosy survey are both provocative and interesting. Is this a useful way of increasing awareness of the problems of leprosy? Is it appropriate to use children in this way? It is apparent that potentially controversial systems may need to be generated to deal with post elimination leprosy.

6. Finally, Ministries of Health need to be made aware of the continued importance of leprosy through the creation of strong relationships. They need to understand that elimination does not mean that the disease has disappeared. Just as the WHO DOTS strategy for tuberculosis control has 'government commitment' as one of its five core principles, so those working in leprosy control need to actively interact with governments to ensure that the disease continues to be addressed in endemic countries 'post-elimination'.²¹

There are lessons to be drawn from the international TB control strategy that followed Alma Ata in 1978.²² A process of integration of TB into primary health care was instituted, but attention was not paid to detail or to the development of systems to follow the process. It could be argued that the international community 'stopped looking for it' and was thus unprepared for the dramatic resurgence of TB that occurred in the middle of the 1980s. Let us make sure that this story is not repeated in the 'post elimination' era of leprosy by preparing adequately and appropriately for life after 2005. One way to ensure that this does not happen is to work with the intention that the individual leprosy patient is not sacrificed for the benefit of the population.

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