Lepr Rev (2016) **87,** 146–150

EDITORIAL

An important perspective on the recent history of leprosy - and its implications for the current Global Strategy

PAUL E.M. FINE*
**London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK*

Accepted for publication 4 May 2016

The Sasakawa Memorial Health Foundation (SMHF) has just published a fascinating book: “A Life Fighting Leprosy: a collection of the speeches and writings of Dr Yo Yuasa”, which will be of interest to many readers of *Leprosy Review*, and beyond.[1] Few, if any, individuals have played so many important roles in the field of leprosy over the past several decades as has Dr Yuasa: from clinical medical officer in leprosy hospitals in Hong Kong and Nepal, to Secretary and then President of the International Leprosy Association, to Medical and then Executive Director of the Sasakawa Foundation, which has been one of the largest and most influential supporters of leprosy work around the world over the past 40 years.

The book consists of 22 speeches and essays by Dr Yuasa, delivered or written over 30 years, 1982 – 2012. Few of them have been published before, and all are elegantly written. They cover the important period from the initiation of MDT as recommended by the WHO Study Group in 1981, to the elimination declaration by the World Health Assembly (WHA) in 1991, to the struggles to maintain the ILA and the International Leprosy Journal in the early 2000s, and include reflections on the successive strategies developed and promoted through ILEP, the ILA and WHO through 2012. They reveal their author to be both a pragmatist and a philosopher.

The book contains many references to major figures in the leprosy world of recent decades, providing glimpses of personal interactions and events behind the scenes at important points in the history of leprosy policy. There are fascinating historical anecdotes – such as how what became known as the first International Leprosy Congress in Berlin was organised in 1897 because of concerns over 34 leprosy cases among Russian immigrants to Prussia. And we learn of a bargain between Riochi Sasakawa, founder of the SMHF, and Halfdan Mahler, Director General of WHO, in 1974/5, when WHO accepted $500,000 for leprosy work only on the condition that an equivalent amount from the SMHF went to rescue a funding shortfall of the Smallpox Eradication Programme.

Correspondence to: Paul Fine, London School of Hygiene & Tropical Medicine, Keppel Street, London WC1E 7HT, UK (e-mail: Paul.Fine@lshtm.ac.uk)

0305-7518/16/064053+05 $1.00

For many readers, the most interesting portions of the book will be those which describe the background to and evolution of the global leprosy elimination initiative and its sequelae, with which Dr Yuasa was intimately involved for the latter 20 years of his career. This is touched upon in several of the essays and speeches, and documents changes in the author's own views concerning the nuances of the declaration's wording and associated policy implications. Given the continued interest in this topic in the leprosy community, and the proliferation of elimination targets for many diseases in recent years, these reflections are an important contribution to public health in general, reaching well beyond the leprosy field itself.

Dr Yuasa describes how the word 'elimination' was adopted from a policy promoted by the US CDC for the 'elimination of tuberculosis in the United States', in which elimination was defined as reducing the 'case rate of tuberculosis to less than one per million population by the year 2010.' The adoption took place in the course of discussions between Yuasa and Dr J W Lee (subsequent Director General of WHO) and Dr R Jacobson (of Carville) in the Western Pacific Regional Office (WPRO) in Manilla in 1989. In considering options for leprosy control in the region, Yuasa, Lee and Jacobson decided to call the policy 'Elimination of leprosy as a major public health problem by the year 2000'. There is an interesting comment (p 263) that Dr Lee was 'reprimanded' for this decision by Dr Noordeen, in Geneva, for not consulting beforehand with the WHO leprosy Unit!

We also learn how Noordeen then adopted the elimination target idea from WPRO, and proposed it to the World Health Assembly in 1991, but with an important change – the removal of the word 'major' - so that the target was phrased as 'elimination of leprosy as a public health problem by the year 2000', defined in a footnote thus: "Elimination of leprosy as a public health problem is defined as the reduction of prevalence to a level below one case per 10 000 population." Yuasa comments with perfect irony that this was done in Geneva with no consultation with WPRO (p 263)! This little anecdote provides a unique insight into the genesis of the WHA declaration, and may lead us to reflect on the nature and extent of consultation appropriate for declarations put to international bodies, which can in turn be so influential in directing national and global policies and actions.

Equally if not more important than the issue of process is the precise wording change between the WPRO and WHA declarations – from "elimination as a major public health problem" to "elimination as a public health problem". Yuasa is sensitive to this semantic issue, and refers to it explicitly in an essay published in 2011 (p 222). This may have been particularly problematic because of the leprosy context, insofar as it appeared to place the WHO at odds with the responsibility of leprosy workers on the ground. Leprosy is an infectious disease, reflecting past transmission of an infectious agent from some source, and the possibility of further transmission to others in the community. These are public health concerns, by definition. Beyond that, leprosy is unusual in terms of the stigma and fear it raises in most societies, which often brings a variety of complex issues for communities with leprosy cases. Dealing with these issues is part of the responsibility of leprosy workers at every level, worldwide, and one can easily argue that every single leprosy case raises public health issues, and is thus of public health importance. In this vein one may agree with the 1989 WPRO resolution's wording, and with Dr Yuasa, that a small number of leprosy cases may not constitute a *major* public health problem, given that there may well be other problems of greater magnitude, be they HIV or polio or measles vaccine coverage . . . but to imply that they raise no problem at all is less appropriate.

It is interesting that Dr Yuasa discussed the wording of the WHO resolution on so many occasions, reflecting, and in response to, the widespread concern with this issue throughout the leprosy community. Though he described the 1991 elimination declaration as a "brilliant marketing manoeuvre" which encouraged the mobilisation of resources and energy for leprosy during the 1990s (p 170), several chapters document his growing concern that the elimination word became less appropriate after the initial phase of the programme – in particular that it logically implies the need for eradication (reduction to zero), a target which he came to appreciate was as not feasible in practice. He explicitly comments on the importance of the animal reservoir in some areas of the world, which makes eradication effectively impossible (p 141). As a result of his reflections on the semantics of elimination, and his own deep concerns over the important social implications of leprosy, even as a symbol of human intolerance, Dr Yuasa came to favour a goal for leprosy control described at the time of the 1998 Beijing Congress as 'a world without leprosy' and later as 'a world without leprosy-related problems, both medical and social.' (p 242). It is interesting that a version of the shorter, former, phrase (which was ultimately rejected by Yuasa as implying eradication and thus effectively impossible – p 264), is included as subtitle for WHO's recently released "Global Leprosy Strategy 2016 – 2020: Accelerating towards a leprosy-free world".[2] The tension between aspiration versus marketing versus politics versus feasibility of public health ambitions and slogans is palpable throughout this book.

All this makes for fascinating reading, and is important history, documenting the experiences, opinions and reflections of one of the most influential figures in the leprosy world of recent times. We are grateful to Dr Yuasa for his many contributions, and to the Sasakawa Foundation - not only for their generous support of so much leprosy work – but for their decision to publish this revealing memoir.

II

The Yuasa memoir provides a thought-provoking background against which to contemplate the current Global Strategy.[2] The WHO document refers to the successive quinquennial plans and notes that "They have been moving from targets on 'elimination' in terms of prevalence of the disease to targets that emphasise a decrease in the number of new cases with Grade 2 Disability (G2D) to promote early detection and reduction in transmission." (p 2) Specifically it outlines a *vision* of a "leprosy free world" (apologies to Dr Yuasa!), a *goal* "to further reduce the global and local leprosy burden" and three main *targets*: "Zero G2D among paediatric leprosy patients"; "Reduction of new leprosy cases with G2D to less than one case per million population": and "Zero countries with legislation allowing discrimination on the basis of leprosy".

An ambitious series of activities is proposed, including the collection of 23 performance indicators, ranging from new case detection statistics, to the proportion of contacts screened, to the availability of data to assess the level of stigma, to the number and proportion of drug resistance cases. There is emphasis on six *guiding principles*: strengthening government commitment, sustaining expertise, providing quality services focusing on women and children, enhancing participation of persons affected by leprosy in leprosy services, protection of human rights, and encouraging research. There are three *pillars*: to strengthen government ownership, to stop leprosy and its complications, and to stop discrimination and promote inclusion. Finally there are *Implementation plans*, set out in four categories, relating to: regional and country implementation, monitoring of targets and indicators globally and at country level, advocacy, and changes to WHO technical advisory bodies. It is a very large agenda, and while all involved in leprosy may agree with most of the proposals, some will wonder if the programme can succeed on so many fronts. Some prioritization will be necessary. One may ask, for example, to what extent targets need to be achievable, as well as – or as opposed to – being aspirational. This is a major issue in public health (indeed in all aspects of development) today as targets proliferate, with goals to "eradicate" this, "eliminate" that, "interrupt" this, "stop" this, "end" that . . . .

We have just completed the last quinquennial plan (2011 – 2015), which proposed a target of "reducing the rate of new cases with Grade-2 Disability per 100,000 population by at least 35% by the end of 2015 compared to the baseline at the end of 2010".[3] Unfortunately, not only was this target not met, but the detection rate of G2D hardly changed at all.[2,4] Should one ask why the target was missed? Should one ask how the target came to be set in the first place? If it was an error, or a miscalculation, should such mistakes be avoided in the future? Does it matter? What are targets for?

In considering targets, it is interesting to reflect that Dr Yuasa became concerned that some of the targets which had been proposed were not achievable, once the armadillo reservoir of *M. leprae* had been recognised. This fact is not mentioned at all in the Global Strategy, despite its elegant confirmation through genetic sequencing of bacilli from human and armadillo sources in recent years,[5] and the recognition that this reservoir is now increasing in geographic extent in at least one country, the USA, along with associated human cases.[6] The reservoir species is found throughout most of Latin America – but there is as yet no solid evidence of its role in human leprosy south of the Rio Grande River. This is now an important research question.

The latest numerical targets (Zero G2D among paediatric leprosy patients, and Reduction of new leprosy cases with G2D to less than one case per million population) might in theory be achievable, even if *M. leprae* infection is to persist, if it could be ensured that incidence of infection in humans is low and cases are recognised early, and managed properly. Assurance of these conditions in practice will not be easy, however, given the difficulty of diagnosing early leprosy and the state of many leprosy control services, which have been wound down as a result of WHO's declaration that leprosy was no longer a public health problem and the misinterpretation by some that leprosy had in effect been eradicated.[4,7,8] We may recall Dr Yuasa's concern over words and their implications.

Several authors have argued for the introduction of more systematic contact tracing and chemoprophylaxis, which would probably reduce new infections and incidence, and this is referred to in the new Strategy document, with the proviso that practicability in the field still needs to be shown.[2,4] If this can be organised and funded, so much the better, as it might accelerate leprosy's decline to some degree. However, the relative contributions of improved living standards, widespread BCG vaccination of infants (not mentioned in the Strategy) and case detection and treatment, let alone chemoprophylaxis of contacts, to declines in leprosy incidence, are likely to differ between populations, and have nowhere been rigorously defined.

It has been noted that new case detection numbers at the global level have remained relatively constant in recent years.[4] In fact, they have varied considerably within and between countries, but the global total has declined every year but one (it increased from 226,626 to 232,857 between 2011 and 2012).[9] One might argue, however, that the problem is not that the numbers of new cases appear to be declining slowly in recent years, as a slow decline is at least a decline, and a rapid decline is unlikely for a condition with a long incubation period, let alone no test for infection and generally poor control services. The larger problem is that many of the published numbers are of questionable validity.[10]

Surveillance is an essential aspect of public health, and this poses a major problem in the leprosy field. It is therefore commendable that the new strategy does mention a commitment for "strengthening surveillance and health information systems for programme monitoring" and states that "A pool of monitors shall be trained." This is crucial, as the programme ultimately turns to the numbers reported in order to monitor progress. However, nineteen (40% of) African nations are recorded as 'NR' (no report) in the most recent summary.[9] Europe does not report at all. Some Latin American countries report zero new or prevalent cases after reporting more than a hundred a very few years ago. And the India data (specifically the 66% decline in numbers of cases detected, from 474,286 to 161,457 between 2000 and 2005) have repeatedly been questioned . . . , all leading to the claim that millions of cases may have failed to be reported in recent years.[11] At the end of the day, the numbers are what matters, and if they are not robust, and not credible, the entire programme suffers. Programmes with serious surveillance typically include a condition that the comparison of numbers to targets must be based upon high quality surveillance - and they set out hard criteria for such quality (the polio programme is the most prominent example of this today).[12,13] We encourage that this aspect of the leprosy strategy, to improve and monitor surveillance in all endemic countries, receives high priority and critical attention, in the years to come.

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