

Leprosy (Hansen's Disease): the WHO, Courage, and the Myth of 'Elimination'

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Abstract

Despite a significant decrease in the prevalence of Leprosy since the introduction of Multi-Drug Therapy (MDT) in the 1980s, it remains a scourge. Unfortunately the World Health Organisation (WHO) has declared the disease 'eliminated', which is a significant misnomer. Leprosy is still a significant disease in certain countries, and new cases continue to emerge. Evidence also suggests that globally there has been a significant underestimation of the problem. The designation of the disease as 'eliminated' by the WHO has caused considerable difficulties in continuing to prioritise the disease in terms of funding, focus and training. Courage is required in Public Health circles to challenge the 'eliminated' designation and respond appropriately to the issue. Vested interests will undoubtedly oppose a more realistic designation of the disease, such as 'controlled'. It is an unfortunate reality that Public Health training seldom focuses on the issue of courage. Although ethics is often a standard element in medical and Public Health training, contemporary schooling in this topic often fails to address the topic of courage. Interestingly, courage features in more historical ethical schooling, as well as in the ethos of most of the world's major religions.

Keywords: Leprosy; Hansen's Disease; Courage; WHO; World Health Organization; Elimination

The decline in the global prevalence of Leprosy (Hansen's Disease), is largely attributable to the introduction of Multi-Drug Therapy (MDT) in the early 1980s following trials on the island of Malta [1]. MDT combines two or three drugs (Rifampicin, Clofazimine &

Dapsone), depending on the type of leprosy diagnosed [2], and was an important development given the standard treatment Dapsone became less effective given growing resistance [3,4]. However, despite the success of MDT, which is over 98% effective [5], Leprosy remains a highly stigmatized

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infectious disease that can, if untreated, eventually lead to disability, deformity, blindness, and psychiatric morbidity [6].

The global prevalence of Leprosy has declined significantly from 5.2 million in 1980 [7]. However, it is an unfortunate reality that many people in the West are completely unaware that Leprosy remains a significant issue with over 200,000 people being diagnosed annually [8,9]. It is alarming that there has recently been an increase in the global incidence of Leprosy [10].

Leprosy is notable in two ways. Firstly, because of its extended development time. It routinely takes 5 years to develop, although cases exist where it has taken up to twenty years to develop have been recorded [11,12]. The second unusual aspect to Leprosy is that although it is an infectious disease, compared to some other diseases, it is only mildly contagious [13]. Case index transmission of leprosy is thought to be based largely on nasal secretions, and it has often been assumed that only extended exposure within the context of a home or family is required. However, there is mounting evidence to suggest that effective case-finding should routinely include neighbours as well [13].

MDT is so effective in treating Leprosy that it may in part have been a victim of its own success. It was so effective that in 1991 the World Health Assembly set a goal of eliminating leprosy globally by the year 2000 [14]. Such a target is worthy, of course, but the WHO subsequently strayed outside of accepted definitions to define the 'elimination' of Leprosy as an incidence of less than one case per 10,000 population [15]. This arbitrary definition, unilaterally adopted by the WHO facilitated the organization to declare Leprosy 'eliminated' at a global level in 2000 [4,16].

This reclassification of the elimination of Leprosy is more than mere semantics and presents a number of real issues and impediments to combating the disease [4,17]. For example, the arbitrary nature of the threshold figure chosen (<1 per 10,000) lacks a scientific or evidence informed basis [16]. The metric chosen has been

termed an 'arbitrary bureaucratic goal' [17]. Another notable weakness in the WHO's approach to Leprosy was the time frame associated with its initial target for elimination i.e. within a decade. Although no doubt spurred on by the success of MDT, as noted above, as leprosy can take an extended time to develop the definition of the 'elimination' of leprosy within such a short timescale is not realistic (1991-2000) [11,12].

The term elimination in epidemiological parlance is usually reserved for an end to a disease within a specific geographical area, such as a country or region [18,19]. The term elimination is never normally used to define the reduction in incidence to a level other than 0 in an area. Such definitions are widely accepted in epidemiological and public health circles and can be seen in Box 1. A far more appropriate term for the reduction of leprosy to a level of less than 1 per 10,000 would be for it to be considered 'controlled'.

It is easy to assume that debates over the appropriateness, or not, of terminology and definitions is somewhat irrelevant. However, such a conclusion would be rash given the impact of such statements on a host of agents including practitioners, not-for-profit agencies, and governments. Lockwood has noted the adverse repercussions of the mistaken use of the term 'elimination' to describe the control of leprosy:

The rhetoric on elimination has discouraged dermatologists from engaging with leprosy programmes, even though they may be diagnosing cases in the private sector, because they believe leprosy is eliminated. Academic work on leprosy has declined; it rarely figures in medical school curriculums even in endemic countries, and research has declined. Young researchers perceive that the disease is eliminated. [4]

The debate over semantics and terminology concerning the supposed 'elimination' of leprosy may ultimately be irrelevant given the suspect status of much of the information that we have from many leprosy endemic countries on prevalence and incidence of the disease. Widespread concerns over under-reporting have emerged in recent years. In a cross-sectional study of almost 35,000 school children aged under 15 in the Ama-

zon region of Brazil that involved active case-finding Pedrosa et al. noted a prevalence rate of 11.58 per 10,000. Notably, this rate was 17 times higher than the official rate [20].

Even more alarming is emerging evidence that suggests that the actual incidence of Leprosy is significantly higher than official figures suggest. Research from Brazil indicates a longstanding under-reporting issue there [20,21]. Similar work has noted significant Under-detection of leprosy cases in Bangladesh [22-24], India [25-30], Papua New Guinea [31], Indonesia, Nigeria, and Nepal [21].

It has been suggested that India effected a transition from mandatory to voluntary reporting of leprosy cases as well as terminating active case seeking in order to meet the WHO's misguided target for elimination:

The difference between the reported and observed estimates suggests that up to half of India's leprosy cases are not being reported. India has been reporting about 130,000 new cases a year, which keeps it safely in the eliminated leprosy category. There is therefore no incentive to find new cases. [4]

It will come as no surprise therefore given the magnitude of the undercount to learn that 'The resulting difference between the expected and observed numbers of new cases of leprosy between 2000 and 2012 is approximately over 2.6 million. This number will increase to over 4 million by 2020' [32]. In 2016 Smith et al. have called for elimination to mean zero transmission [33]. Only when the significant issue of stigma is successfully challenged [34,35] and active case finding involving a particular focus on women and girls [29,21,36], which involves an expanded follow-up of family, friends and neighbours, will it be possible to accurately gauge the prevalence of leprosy [37]. A focus on these 'missing millions' [32] is particularly pertinent given concerns over growing antimicrobial resistance globally [38].

It must be acknowledged that in 2010 the Eighth WHO Expert Committee on Leprosy recommended a revision in the international indicator to monitor leprosy [39]. The revised

metric proposed was a Case Detection Rate (CDR) of Grade 2 Disability (G2D) cases per 1 million inhabitants [40-42]. A target CDR-G2D of 1 per million has been proposed [8,41,42]. However, it has been this revised metric has been critiqued for being equally problematic:

However, the CDR-G2D is less precise than the CDR due to small numbers in the numerator and this difference will make it difficult to use for monitoring small areas, i.e., small countries and local control programmes. Moreover, the CDR-G2D is influenced by early and late diagnoses and by the total incidence of leprosy, as measured by the total CDR.[8]

A major issue in combatting leprosy lies in the WHO designation of the disease as 'Eliminated'. This terminology has severely hampered moves to eradicate the disease in recent years. It is important to note that this is more than simply a matter of semantics. The terminology unilaterally adopted by the WHO was misleading and ill-chosen. Understandably, the designation of leprosy as having been eliminated has resulting in a reduction in funding and focus. As such the topic has been removed from medical curriculum training and few health professionals seek to specialise in this area [4].

The UN Sustainable Development Goals (SDG) have been summarised in the phrase "Leaving no one behind" [43]. SDG 3 target 3.3 aims "By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases". Leprosy is defined as one of the neglected tropical diseases included in this goal. However, for this target to become a reality an urgent volte-face is required in relation to the term 'Elimination' in the context of Leprosy. It is imperative that the Director-General of the World Health Organization urgently demonstrates clear leadership on this issue. It must however be anticipated that such a development will not be welcomed in many quarters. A change from the current designation of having leprosy 'eliminated' under current WHO terminology to 'controlled' may have adverse impacts on international tourism, trade and prestige. Leading

such a change will require courage in the face of criticism and inertia.

It is an unfortunate reality that the issue of courage in Public Health is seldom addressed [44]. Equally it is routinely ignored in most major branches of ethics that have emerged from the Enlightenment onwards. However, in classical elements of both Western and Eastern ethical traditions courage held a more central role. In Nicomachean Ethics, Aristotle discusses the importance of courage as one of the four cardinal virtues. In line with his measured approach to finding the moderate ideal, Aristotle recognized courage as the virtue at the mean between rashness and cowardice [45]. Similarly, under Buddhism Confucius identified courage as one of the three cardinal virtues of a person of virtue ('Junzi') [46]. Taoism similarly advocates the importance of compassion and vulnerability as pre-requisites of being brave [47]. While, in the Hindu faith the epic poem Ramayana details the courage and bravery of the monkey general Hanuman in attacking the demon king Ravana and his

army [48]. The importance of courage in speaking out is also discussed in both Judaism [49] and Islam:

Abu Sa'eed Al-Khudri reported: The Prophet, peace and blessings be upon him, said, "Let not fear of the people prevent one of you from saying the truth if he knows it." [50]

The need for the 'social courage of health workers' has long been noted in public health [51], an issue echoed by Keck who advocated for the need for courageous leadership in public health [52]. It is worthwhile noting that adopting such a potentially confrontational path may not come easily to public health as a discipline given analysis has noted its retreat from a campaigning and reforming activist orientation into public health science and epidemiology [53].

Combatting leprosy globally will require radical steps over a prolonged period. The first step in this process is a revision of the 'elimination' terminology utilised by the WHO. Such an about turn will require courage at the highest level. However, such a bold step will help direct the attention of governments, funders, health service

Control: The reduction of disease incidence, prevalence, morbidity or mortality to a locally acceptable level as a result of deliberate efforts; continued intervention measures are required to maintain the reduction. Example: diarrhoeal diseases.

Elimination of disease: Reduction to zero of the incidence of a specified disease in a defined geographical area as a result of deliberate efforts; continued intervention measures are required. Example: neonatal tetanus.

Elimination of infections: Reduction to zero of the incidence of infection caused by a specific agent in a defined geographical area as a result of deliberate efforts; continued measures to prevent re-establishment of transmission are required. Example: measles, poliomyelitis.

Eradication: Permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts; intervention measures are no longer needed. Example: smallpox.

Extinction: The specific infectious agent no longer exists in nature or in the laboratory. Example: none.

Fig. 1: Dowdle's Principles of Disease Control, Elimination, Eradication & Extinction

personnel, and the public towards the ongoing bane of leprosy. The second step required is a clear and accurate understanding of the incidence and prevalence of the disease globally. An important element in this process is a well-funded, comprehensive, in-depth, and sustained program to combat the stigma associated with leprosy. Another element of this stage should be a UN Convention, similar to the Framework Convention on Tobacco Control (FCTC), in which signatory partners agree to make the reporting of cases of leprosy a legal and mandatory requirement. The third stage will be the adoption of active case finding methodologies which will involve investigations of family and kinship networks, neighbours, friends, and in situations of re-location the inhabitants of previous abodes. Any time frames suggested in plans for combatting the disease must be cognisant of the sometimes extended period between exposure and the development of leprosy.

Resumo

Malgraŭ signifa malkresko en la prevalenco de lepro ekde la enkonduko de Multoble Kuracila Terapio ("Multi-Drug Therapy", MDT) en la 1980-aj jaroj, ĝi restas timiga. Bedaŭrinde la Monda Organizaĵo pri Sano (MOS) deklaris la malsanon "forigita", kio estas grava misnomo. La lepro estas ankoraŭ grava malsano en iuj landoj, kaj novaj kazoj daŭre aperadas. Evidenteco ankaŭ sugestas, ke tutmonde estis grava subtakso de la problemo. La klasifiko de la malsano kiel "forigita" fare de la MOS kaŭzis konsiderindajn malfacilaĵojn por daŭre prioritigi la malsanon rilate al financado, fokuso kaj trejnado. Kuraĝo estas necesa en publikaj sanaj rondoj por defii la "forigitan" nomadon kaj respondi taŭge al la afero. Vestitaj interesoj sendube kontraŭos pli realisman klasifikon de la malsano, ekzemple kiel "kontrolita". Estas malfeliĉa realaĵo, ke trejnado de Publika Sano malofte fokusigas la aferon de kuraĝo. Kvankam etiko ofte estas norma elemento en medicina kaj publika sano-trejnado, nuntempa instruado en ĉi tiu temo ofte malsukce-

sas trakti la temon de kuraĝo. Interese, kuraĝo ludas rolon en pli historia etika instruado, kaj ankaŭ en la etiko de la plejmulto de la ĉefaj religioj de la mondo.

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