

Delphi Study on Eliminating Leprosy in India

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As India struggles to reach its goal of leprosy elimination (eradication), it is essential that every possible help and advice is provided urgently through concerted research from all concerned. Delphi, a powerful management tool, was used to identify the challenges and implementation gaps in NLEP through 12 leprosy experts with their consent, who identified the major challenges such as high leprosy stigma; rural-urban migration of patients; lack of vaccines; weak political commitment and inadequate motivated medical staff. Main Implementation gaps included missed diagnosis, wrong diagnosis and wrong classification; inadequate or incomplete treatment, superficial training regarding self-care, neuritis and side effects of MDT; inadequate IEC, poor public contacts, and lack of quality control or supervision. It is concluded that without adequate and trained manpower; effective monitoring & supervision and active participation of the community, the elimination of leprosy in near future may remain only a distant dream.

Key Words : India, NLEP, Elimination, Eradication Leprosy, Delphi

Introduction

After eliminating Leprosy as a public health problem based on prevalence, the final frontier of NLEP will be the revised "elimination" formerly termed as eradication, to reduce the incidence of leprosy to zero (Gitte 2019). The WHO global leprosy strategy for 2016-2020 for acceleration towards a leprosy-free world provides a clear Operation Manual (WHO 2016). Several articles were published in national and international journals on implementing and measuring the impacts (Chaptini & Marshman 2015, Mensah-Awere et al 2015, Anand et al 2020, Panda et al

2020), but most studies have merely repeated what is already known as the barriers, and very few have addressed the solutions (WHO 2020). Despite massive and consistent inputs provided by India's National Leprosy Eradication Program (NLEP), it seems that reaching the targets of zero leprosy or even zero disability appears a distant unattainable dream (Scollard et al 2006, Kumar & Dogra 2009, Smith 2013).

Every public health programme faces challenges due to lack of technology, geographical constraints, cultural barriers, but there are also deficiencies or "gaps" in its implementation,

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which make success elusive (Rao 2012, Rao & Suneetha 2018). Thus, the WHO call for acceleration is difficult to carry out firstly, without a clear identification of major challenges and gaps, and secondly necessary corrective actions through a variety of training and service strategies (Kar 2007).

Challenges to any major public health venture arise from external forces such as sociocultural and technological limitations while the gaps are usually due to internal factors such as management inadequacies, lack of proper perceptions, strategies, weak monitoring and poor motivation (Kuipers et al 2013, Sundar Rao 2015). The efficient implementation of MDT has helped India to reach a major milestone of eliminating leprosy as a public health problem in December 2005 and now to reach the next critical milestone of eradication needs the wisdom, cooperation, active involvement, great will and dedication of all stakeholders, government, non-government, general public, leprosy affected persons and all well-wishers (Kumar & Karotia 2020). Sustaining the gains made so far in controlling leprosy is a big challenge and there is no time for complacency (Singal & Sonthalia 2013).

The Delphi Technique developed during the 1950's was originally aimed at predicting the impact of technology on warfare, but now it has gained popularity in several health areas (Dalkey & Helmer 1963). It is a systematic and interactive forecasting method to obtain the opinions of a panel of experts without necessarily bringing them together face to face. The experts answer a questionnaire in two or more rounds. Over the past 3 decades, this technique has undergone many adaptations and modifications, used for different target groups with diverse objectives, simplified, and re-defined (Niederberger & Spranger 2020). Despite such variations, a relatively constant feature has been the objective

of obtaining consensus among expert panellists anonymously in at least two rounds in an iterative fashion. The utility and power of Delphi technique was demonstrated in many health areas, e.g., in podoconiosis (Deribe et al 2015), preventable health problems in China (Wu et al 2018), communicable diseases surveillance (Sahal et al 2011), mental health (Hart et al 2009), palliative care (Junger et al 2012) just to name a few.

Given the background, cost-effectiveness and value of using the Delphi technique, research was undertaken during 2020, on challenges and gaps in implementation of India's National Leprosy Eradication Program (NLEP). The methodology and findings are presented in brief with a critical discussion on the way forward.

Material and Methods

Delhi, the National Capital Territory of India, was chosen as the setting for this research. Based on review of published articles by international and national experts on possible challenges facing India's NLEP activities, a draft list of questions was prepared and finalized after discussions with three experienced consultants. This list was then circulated among the panellists. From the list of eminent leprosy researchers in India, a short list of 16 persons with a wide range of leprosy experiences, was chosen and approached for informed consent. Finally, 12 experts constituted the Panel for this study.

The Delphi technique, a tool originally developed by RAND (Dalkey & Helmer 1963) was modified as used by other investigators for many epidemiological and health research studies (Wu et al 2018, Deribe et al 2015). It is a mixed-methods iterative approach using internet to reach a consensus among the panel of leprosy experts in India, using the comprehensive list of open-ended questions. The research used two rounds, where each round used feedback from the previous round from the

same group of experts anonymously, after suitable editing. The second round used the same panelists were given the edited list to rank the items based on a Likert scale, measuring their importance. There were no face-to-face discussions. Wherever needed, the experts were requested to elaborate, clarify and provide

suitable examples. All experts took active interest and responded in the assigned time frame.

Results

After a detailed analyses of the responses from the second round, the findings are summarized by specific challenges faced by the NLEP and the

Table 1 : Epidemiological/Clinical Challenges

S.No	Challenge	Detail
A	No effective Vaccine against Leprosy	Vaccines have proved to be crucial in many other life-threatening infectious chronic diseases and will be a boon to current anti-leprosy programmes. Despite much concentrated and expensive research, an Effective Vaccine against leprosy is yet to be formulated (Geluk 2013).
b	Humans may not be the sole reservoir	Several well-designed investigations have (Turankar et al 2016) demonstrated the presence of viable <i>M. leprae</i> in extra-human sources such as soil, water, environment of residences of multi-bacillary leprosy patients, some animals and plants, threatening existing theories of transmission and prevention.
c	<i>M. leprae</i> cannot be cultured in the laboratory	The longest and most painstaking research on culturing <i>M. leprae</i> has led to dismal failures, This impedes further pursuit of leprosy research on preventive measures (Charles & Joyce 2010).
d	Transmission of leprosy still not clear	Till better evidence of transmission links are available, age-old methods of early detection and prompt treatment with MDT are effective means of reducing transmission (Marfatia et al 2020).
e	Prognostic tests of Reactions	Detecting subclinical disease or infection has provided great strength to many diseases but this is still a major unsolved challenge in Leprosy. Even if there are prognostic tests for predicting reactions or other complications such as nerve involvement, this would be a great strength (Khanna & Shahunja 2019).
f	Drug resistance and MDR drugs	Rifampicin and clofazimine resistance are rearing their ugly heads. Unless they are nipped in the bud, it could result in major overhauling of anti-leprosy therapy as seen for Tuberculosis. The corollary is the absence of suitable drugs for MDR leprosy posing a major challenge needing urgent research.
g	No viable alternative to MDT	While MDT has been a massive boon from the dapsone era, one must be prepared to face future challenges of drug resistance or availability, and develop viable alternative to current MDT regime.

Table 2 : Social, Geographic, Cultural Challenges

S.No	Challenge	Detail
a	Hard to reach geographic areas	Many indigenous and tribal villages, are difficult to access due to hilly terrains, forested, isolated and lacking any roads. Such areas in fact might act as reservoirs of infection and must be given special attention (Katkar et al 2017, Wu et al 2021)
b	Floating populations	Urban cities tend to have domestics, vendors and migrant workers who form slums or live on Pavements, Homeless, and nomadic without proper addresses, poor hygiene and vulnerable to leprosy and other diseases, and being mostly uneducated, tend to avoid good health care. Being a focus of epidemics.
c	Leprosy stigma	Probably the most difficult challenge for NLEP would be the prevailing leprosy stigma, both perceived, and enacted. Unless this ancient scourge is removed, NLEP will be unsuccessful in eliminating leprosy (Sundar Rao 2015).
d	Archaic leprosy discriminatory laws	Deny equal rights and opportunities for affected persons to avail all the opportunities for leprosy care.
e	Public apathy	Involving the people is a One of the major obstacles to any national programme even through a variety of motivational activities and latest social media (Pandey & Rathod 2010, Samraj et al 2012).
f	Weak political will	No national programme can be successful and sustainable unless there is a strong political will.

Table 3 : Health System Related Challenges

S.No	Challenge	Detail
a	NLEP has no active interaction with other leprosy practitioners	India boasts of a variety of health practitioners of various systems of Medicine and Dermatology who work independently or attached to a medical College, treating significant numbers of leprosy patients. How to involve such practitioners in the national programme is a challenge.
b	No central registry of leprosy patients	Despite a massive framework for the NLEP, there is no Centralized registry of Leprosy patients, which could refine the actual burden, avoiding duplications or missing cases.
c	Complex data collection systems	Over the period of time, NLEP has chosen to improve the recording systems and ended up with more Complex Formats for collecting and analysis.
d	Poor referral system	For a large country with multiple treatment centres, hierarchically constituted in rural and urban areas, it has been difficult to keep track of upward referrals, and the benefits to the patients. For almost all major diseases in India, referral systems are poor.

Table 4 : Implementation Gaps: Leprosy Services

S. No	Gaps
a	Poorly trained & inadequate qualified health staff; Weak monitoring & supervision.
b	Discrepancies, Inaccuracies in diagnosis, classification, treatment and follow-up.
c	Delay and incompleteness in screening of contacts, Inadequate care of patients with complications, Poor referral system, linkages and coordination (Desikan 2012).
d	Lack of non-leprosy drugs for simple morbidity, No proper arrangements for testing, no diagnostic kits for BI and other tests (Porichha 2015).

Table 5 : Implementation Gaps: Community, Pals, And NGOs

S. No	Gaps
a	Poorly trained & inadequate qualified health staff; Weak monitoring & supervision.
a	No community participative activities (Prakoewa et al 2020).
b	Poor public-private partnerships.
c	Absence of any group activity, involvement.
d	No involvement of women, youth, school children.
e	Inadequate public advertisements, wall posters, street plays.
f	No involvement of persons affected by leprosy (PAL).

possible gaps in the implementation. The challenges were broadly divided into medical and social aspects, and require urgent and substantial research to provide feasible and effective solutions.

Seven major challenges pending further medical breakthroughs are summarized in the Table 1.

Apart from the clinical and medical challenges, the experts identified another group of challenges that include social, geographic, and cultural factors as depicted in Table 2.

A third group of challenges refers to health systems itself as displayed in Table 3.

Apart from the above challenges, there are many “gaps” in the leprosy services that can be immediately solved through efficient and urgent management policies and actions. A long list of such “gaps” are presented in Tables 4 and 5.

The experts then suggested a 10-point programme to close the gaps, these are listed in Table 6.

Discussion

The results of the Delphi exercise have narrowed down the implementation gaps and challenges facing India's NLEP in a succinct manner. The NLEP must take these suggestions to re-engineer and build upon earlier successes through a multi-pronged attack involving the great resources that exist outside NLEP (Desikan 2012, WHO 2016). It is time for all well-wishers and stakeholders to put in their best efforts to eradicate leprosy and show the world how it can be done (WHO 2019, WHO 2020, GPZL 2019, Rao et al 2020).

The declaration that India has achieved “elimination” of leprosy in December 2005 was hailed as a stupendous victory for a large democratic country such as India and encouraged many other

Table 6 : Panel's Recommendations on Solutions and Correctives

S. No	Solution	Detail
a	Recognize Two sides of the equation on Supply and Demand	On one side it is the need for greater zeal of leprosy workers with effective training, monitoring and supervision, adequate supply of MDT and other essential drugs to treat complications, timely logistical support and encouragement. The other side is the need to promote active involvement of the community, the families of patients and the patients themselves in every aspect of prevention and care of affected including removal of unjustified discrimination and stigma.
b	Promote voluntary self-reporting	Implement massive health education, hold special detection camps and surveillance activities at educational institutions, construction sites and other underserved areas.
c	Consider judicious Monetary incentives	This might help as done for several health programmes such as antenatal care.
d	High endemic areas	Focus on empowering them with all facilities; treatment, follow up, management of reactions and for carrying out RCS.
e	NHM can support	By providing timely, adequate resources for NLEP, posting dedicated programme managers at District level and strengthening implementation of IEC; removal of stigma.
f	Involve qualified Dermatologists	Long felt need and should be inducted into the final elimination stage by linkage of MO I/C of health facilities with skin HOD of hospitals for coordination.
g	Mobilize persons affected by leprosy (PAL)	After complete treatment for counselling contacts and members of the public eliciting their cooperation in early detection and early treatment much before disability occurs.
h	Encourage civil society organizations	They should play an active role in monitoring progress in abolishing discriminatory provisions in addition to documenting specific instances of discrimination against persons affected by leprosy. Case stories expressing the effect of discriminatory laws, legal aspects may be beneficial in this regard.
i	Post exposure prophylaxis (PEP)	Can be a useful in preventing the chain of transmission may be brought about by early detection of cases, for contacts and sensitizing all HCWs on clinical manifestations of leprosy (Tiwari et al 2017).
j	Strengthen drug resistance surveillance	More organized comprehensive mechanism in the country.

nations to seek such goals (Gitte 2019, Kar 2007). There were great expectations that the next milestone of zero incidence would be reached soon but this is not so easy, is seen by the facts

that more than 15 years after elimination, new cases continue to occur the same rate and with alarming disability rates as reported by many investigators (Scollard 2019). From ancient times,

Leprosy was treated more as a social or spiritual problem and less as a disease that is curable (Sundar Rao 2015). Disability was considered inevitable, and a person diagnosed with leprosy written off as dead. Hence the plethora of shameful laws and other civil practices of isolation, discrimination and torture were prevalent. Much progress was made over the past century to change this picture through discoveries of dapsone, rifampicin, steroids and other powerful anti-inflammatory drugs that have fully transformed leprosy into a manageable disease with practically no disfiguring disabilities (Smith 2013). After listing the challenges (Tables 1, 2, 3) and the implementation gaps (Tables 4, 5), the Delphi panel suggested many practical solutions (Table 6) to close the gaps which are probably responsible for continued endemicity and preventing eradication of leprosy in the near future (Steinmann et al 2020).

The Delphi has shown that even the most powerful medicines will be ineffective in the light of apathy, ignorance and gross negativity of the public who still maintain the former image of leprosy as punishment or evil-driven, and thus make every opportunity the government has provided to cure and prevent leprosy, ineffective. There should be more operational research and demonstration projects to remove much false information, fear and irrational behaviours. The experts also emphasize that without strong political will and support from the government, all efforts will be in vain or yield poor outcomes. Thus, leprosy must be attacked now as a social evil rather than a medical problem. The downside of declaring "elimination" in 2005 had an adverse effect in misinforming leaders that we have in fact eradicated the disease. Thus, educational efforts must also be directed towards our leaders and policy makers as emphasized by the experts. There is more than enough published literature

on the problems and the editors should now invite and encourage more papers on solutions and cleansing operations on stigma.

Conclusions

The research using a modified Delphi technique with a panel of 12 highly experienced leprosy specialists have elegantly summarised the challenges and implementation gaps in the present performances of NLEP in "eliminating leprosy through attaining zero incidence. Although the list of stumbling blocks looks formidable, the panel concluded that the NLEP goal of decreasing incidence to zero was not "Mission Impossible" but definitely attainable if immediate steps are taken and considerable political will is generated. Briefly the steps include leprosy manpower resources greatly strengthened with ground level training and motivation, purposeful monitoring and refining the record systems, involving qualified leprosy practitioners outside NLEP mainly qualified professional dermatologists, and initiate massive community based participatory activities involving youth, women, service organization and persons affected by leprosy. The experts uniformly agree that the major challenge lies in this area of public education, participative management, and aggressive campaign to promote the positive aspects of leprosy care. The experts agree that this is not an easy task but can be done if NLEP focusses more on training manpower accordingly. While we await vaccine, and practical safe post-exposure prophylaxis, it is wise to expend all efforts to clear the way through changing the tough intractable mind-sets of people (Scollard 2019). The Delphi efforts ended on a positive optimistic note, and proved to be a valuable input to NLEP and all well-wishers of eradicating leprosy from India. Thus, while immense challenges still remain and will continue, they cannot impede leprosy elimination/eradication.

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