SERIES NO. 5

LEAP

LEPROSY
ELIMINATION
ACTION
PROGRAMME

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TASK TODAY

Disease control : principles

Sustaining leprosy control : perceptions

Improving quality care : prescriptions

ALERT-INDIA'S
30th FOUNDATION DAY
SPECIAL ISSUE

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" Quality is never an accident . . . . "

The ALERT-INDIA is releasing their latest publication "Task Today, Series No. 5", on 23rd October 2008, to coincide with opening of the National Workshop on "Sustaining leprosy control and improving quality of services" at Mumbai.

One of ALERT-INDIA's mission is to improve scientific knowledge and bring concepts of quality and sustainability as guiding principles to national leprosy control efforts. This publication and others in the Series have highlighted these principles. I have extensively drawn inspiration from these writings while formulating WHO's *Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities: 2006-2010*.

The concept of ***quality*** in public health-care in general and leprosy-care in particular, is not expected by both, the provider and the receiver. We take for granted that low-cost or free-of-cost care as equivalent to low-quality care? Any high-cost care cannot be simply considered as "high-quality" care or for that matter high quantity of investigations and prescriptions cannot be equated to high quality.

The concept of quality in health-care is basically an expression of sincerity, honesty, empathy, capability and dedication of the provider, which translates into a sense of well-being, satisfaction and gratitude in the unfortunate receiver and his / her family and community. In my opinion, for a successful disease control programme, **quality** must form an over-arching bridge on all its components.

In the words of William Foster: *"Quality is never an accident; it is always the result of high intention, sincere effort, intelligent* direction and skilful execution; it represents the wise choice of many alternatives".

I recommend you to read this publication and spend some "quality" time on reflecting on its messages for health-care in public services. It may help you to make a difference in your own area of work, to improve the quality of life of those whom you have selected to serve.

Finally let me wish readers in the beautiful words known as The Serenity Prayer: *'may God grant you the - humility to accept things you cannot change; courage to change things you can; and wisdom to know the difference".*

17th October, 2008
New Delhi

Dr. V. Pannikar
Team Leader, Global Leprosy Programme
World Health Organization

'Task Today'

The 'Task Today' is an effort to share information and gather informed support of one and all to sustain leprosy control efforts and to provide quality care to the leprosy affected in our country.

'Task Today' Series-5 comes out at a time when there exists an overall critical review of policies of the recent past and an all around. positive initiative and exploration in favour of policy change and search for appropriate actions.

T*his series contains three parts that provide a wide range of articles that are relevant for the steps one may choose to take for leprosy control.*

The first part is a collection of articles on the principles of disease control and its application. It is precisely the lack of application of these principles of disease control prevailed over the post elimination policy thrust. The ground reality was put out of sight and the feedback from the programme managers were given due cognisance and consideration. Today, the consequences of this policy are glaring at us and need urgent policy measures. The main players are fortunately in the grasp of this reality and concerned about the next steps.

The second part deals with the perceptions and views expressed by those concerned about sustaining leprosy control over the last 5 years. These perceptions mark the end of the euphoria prevailed over achieving elimination target. These perceptions can guide and shape the immediate and long term policy frame work.

The third part deals with the core area of providing quality care to the leprosy affected in the integrated public health setting. The articles selected provide several insights into the possibilities by way of guidelines and concrete suggestions. Quality care is the right of every leprosy affected person.

The principles of disease control, the perceptions on sustaining leprosy control and prescriptions to improve quality care are brought out to solicit support of the public health and leprosy specialists for a concerted common action to combat leprosy in our country.

Sion, Mumbai
23rd October, 2008

A. Antony Samy
Chief Executive

1

The principles of disease elimination and eradication

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Introduction

Elimination and eradication of human disease have been the subject of numerous conferences, symposia, workshops, planning sessions, and public health initiatives for more than a century. Although the malaria, yellow fever, and yaws eradication programmes of earlier years were unsuccessful, they contributed greatly to a better understanding of the biological, social, political and economic complexities of achieving the ultimate goal in disease control. Smallpox has now been eradicated and programmes are currently under way to eradicate poliomyelitis and guinea-worm disease.
In 1993, the International Task Force for Disease Eradication evaluated over 80 potential infectious disease candidates and concluded that six were eradicable[1]. In 1997, the World Health Assembly passed a resolution calling for the "elimination of lymphatic filariasis as a public health problem". Also in early 1997, WHO listed leprosy, onchocerciasis, and Chagas disease as being candidates for elimination "as public health problems within ten years".

With this background, the Dahlem Workshop on the Eradication of Infectious Diseases was held in March 1997[2]. The Workshop was unique in that it focused on the science of eradication, with the understanding that the present Atlanta Conference would address specific candidate diseases for elimination or eradication in the context of global health strategies.

The workshop addressed four questions 1) How is eradication to be defined and what are the biological criteria? 2) What are the criteria for estimating the cost and benefits of disease eradication? 3) What are the societal and political criteria for eradication? and 4) When and how should eradication programmes be implemented?

Source : *Excerpts from Bulletin of the World Health Organization, 1998, 76, (Suppl 2), 22-25*

Definitions

Eradication has been defined in various ways – as extinction of the disease pathogen[3], as elimination of the occurrence of a given disease, even in the absence of all preventive measures[4], as control of an infection to the point at which transmission ceased within a specified area[5], and as reduction of the worldwide incidence of a disease to zero as a result of deliberate efforts, obviating the necessity for further control measures[1]

Differences in these efforts made a distinction between the disease caused by the infection and the infection itself, the level of reduction achieved for either of these, the requirement for continuation of control efforts, and, finally, the geographical area covered by the intervention efforts and their outcomes. Although definitions outlined below were developed for infectious diseases, those for control and elimination apply to non-infectious diseases as well.

- **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 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.*

Principal indicators of eradicability

In theory, if the right tools were available, all infectious diseases would be eradicable. In reality, there are distinct biological features of the organisms and technical factors of dealing with them that make their potential eradicability more or less likely.

Today's categorization of a disease as not eradicable can change completely tomorrow, either because research efforts are successful in developing new and effective intervention tools or because those presumed obstructions to eradicability that seemed important in

theory prove capable of being overcome in practice. Three indicators were considered to be of primary importance: an effective intervention is available to interrupt transmission of the agent; practical diagnostic tools with sufficient sensitivity and specificity are available to detect levels of infection that can lead to transmission: and humans are essential for the life-cycle of the agent, which has no other vertebrate reservoir and does not amplify in the environment.

The effectiveness of an intervention tool has both biological and operational dimensions. Elimination validates the effectiveness of an intervention tool, but it does not necessarily make the agent a candidate for eradication. Highly developed levels of sanitation and health systems development may make elimination possible in one geographical area but not in another.

Diagnostic tools also have both biological and operational dimensions. The tools must be sufficiently sensitive and specific to detect infection that can lead to transmission, and also sufficiently simple to be applied globally with a wide range of capabilities and resources. Eradication is a much more feasible target of deliberate intervention when human form an essential component of the agent's life-cycle. An independent reservoir is not an absolute barrier to eradication if it can be targeted with effective intervention tools.

Economic considerations

Meeting the biological criteria is only one step in the decision to embark upon an elimination or eradication programme. Health resources are limited and resources cross sectors. Therefore, decisions have to be made as to whether the use of resources for an elimination of eradication programme is preferable to their use in non-health projects, in alternative health intervention, in continued control of the condition or even in the eradication of other eradicable conditions. All of these decisions necessitate an evaluation of the cost and benefit of eradication and the alternative use of resources. There is no easy answer.

Formal economic analytical techniques are not ideally suited to eradication programmes. It is not clear for example, how to handle future benefits and cost particularly long-term effects. Equally unclear is whether and how to discount future effects. Of the available techniques, the Workshop concluded that cost-effectiveness analysis appeared to be most useful when the outcome is expressed in health terms. This techniques allows evaluation of disease eradication in comparisons with other health sector projects.

The costs and benefits of global eradication programmes can be grouped into two categories – direct effects and consequent effects. The direct effects

of eradication are that no morbidity or mortality due to that disease will ever again occur. Control programmes can cease. The consequent effects are those that impact positively and negatively on the entire health care system. Because of the close interrelationships between eradication programmes and other health programmes, the Workshop concluded that eradication goals and activities should be expressed in the context of overall health services. Explicit efforts should be taken to maximize the effectiveness of both eradication and comprehensive health programmes.

Social and political criteria

A set of social and political criteria was identified by Workshop participants. These and other related factors are summarized as follows:

- The success of a disease eradication initiative like any public health programme, is largely dependent on the level of societal and political commitment to it from the beginning to the end. Considering the potentially enormous cost of failure, any proposal for eradication should be given intense scrutiny.
- The disease under consideration for eradication must be of recognized public health importance with broad international appeal, and be perceived as a worthy goal by all levels of society. There must be specific reasons for eradication. The demands for sustained support, high quality performance, and perseverance in an eradication programme increase the risks of failure, with a consequent significant loss of credibility, resources, and health workers self-confidence.
- A technically feasible intervention and eradication strategy must be identified, field-tested in a defined geographical area, and found effective. The accumulation of success in individual countries or within a region generates the momentum needed for international support.
- Consensus on the priority and justification for the disease must be developed by technical experts, the decision-makers, and the scientific community.
- Political commitment must be gained at the highest levels, following informed discussion at regional and local levels. A clear commitment of resources from international sources is essential from the start. A resolution by the World Health Assembly is a vital booster to the success of any eradication programme.
- An advocacy plan must be prepared and ready for full implementation at global, regional, and national levels. Eradication requires an effective alliance with all potential collaborators

and partners. Finally – a recurring theme – the eradication programme must address the issues of equity and be supportive of broader goals that have a positive impact on the health infrastructure to provide a legacy in addition to eradication of the disease.

- Disease eradication programmes are conceptually simple, focusing on one clear and unequivocal outcome. At the same time, however, their implementation is extraordinary difficult because of the unique global and time-driven operational challenges. The limitations, potential risks, and points of caution for eradication programmes include higher short-term costs, increased risk of failure and the consequences of failure, an inescapable sense of urgency and diversion of attention and resources from equally or more important health problems that are not eradicable, or even others that may be eradicate.
- Care must be taken that eradication efforts do not detract or undermine the development of the general health infrastructure . Other limitations are the high vulnerability of eradication programmes to interruption by war and other civil disturbances: the potential that programmes will not address national priorities in all countries, and that some countries will not follow the eradication strategy; the perception of programmes as "donor driven", placement of excessive, counterproductive pressures and demands upon health workers and others; and the requirement of special attention for countries with inadequate resources and or weak health infrastructure (including hit-and-run strategies).
- The favourable attributes and potential benefits of eradication programmes are a well-defined scope with a clear objective and endpoint and the duration is limited. Successful eradication programmes produce sustainable improvement in health and provide a high benefit-cost ratio. Eradication programmes are attractive to potential funding sources because they establish high standards of performance for surveillance, logistics, and administrative support; develop well-trained and highly motivated health staff; assist in the development of health services infrastructure including, for example, mobilization of endemic communities; and provide equity in coverage for all affected areas, including urban, rural, and even remote rural areas. They also offer opportunities for other health benefits (e.g. for dracunculiasis eradication : health education and improved water supply), improved coordination among partners and countries, and dialogue across frontiers during war.

- Decisions on initiating a global disease eradication campaign should also take into consideration the ideal sequencing of potentially concurrent campaigns. Eradication programmes consume major human and financial resources. Careful consideration must be given to whether two or more eradication programmes are to be conducted simultaneously or sequentially, or if the target disease is confined to a limited geographical area.
- Disease elimination and eradication programmes can be distinguished from ongoing health control programmes by the urgency of elimination and eradication programmes and the requirement for targeted surveillance, rapid response capability, high standards of performance, and a dedicated focal point at the national level.
- Eradication and ongoing programmes constitute potentially complementary approaches to public health. There are areas of potential overlap, conflict and synergy that must be recognized and addressed. In many cases the problem is not that eradication activities function too well but that primary health care activities do not function well enough. Efforts are needed to identify and characterize those factors responsible for improved functioning of eradication campaigns, and then apply them to primary health.

Conclusion

In summary, elimination and eradication programmes are laudable goals, but they carry with them an awesome responsibility. There is no room for failure. Careful and deliberate evaluation is a prerequisite before embarking on any programme Elimination and eradication are the ultimate goals of public health. The only question is whether these goals are to be achieved in the present or some future generation. ■

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2

Disease elimination / eradication and sustainable health development

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Conclusions

There are intrinsic and unavoidable tensions between the concepts of eradication and sustainable health development. These tensions arise because of polarization between vertical and integrated approaches – specific rather than comprehensive goals, "top-down" rather than "bottom-up" directions, and a time-limited rather than long-term agenda. It is essential acknowledge and overcome these tensions so that eradication programmes can contribute to health development. In addition, the following belief and acts of faith accompany eradication programmes: first, there is a legacy of wider benefits than simply the achievement of eradication or complete absence of cases; second, the cost-benefit of eradication is greater compared with the achievement of high levels of control; and third, commitment must be made on the grounds of beliefs or alternatively, further eradication endeavours must be postponed until the prerequisites can be confirmed.

Besides gaining insight into the technical feasibility of eradication, rules are being developed that create a discipline that was not previously acknowledged. These rules encompass resource mobilization, strategic planning, human resources and training and social mobilization. Detailed, meticulous planning is essential to take full advantage of the opportunities created by eradication programmes. Thereby avoiding the potential for unwanted negative effects. However, the experience with eradication programmes to date has shown some of the limitations of the planning process.

Ideally, the potential benefits of eradication to health development should be identified at the outset. Similar to the eradication targets, measurable targets should be set for achieving these benefits. The eradication programme should be held

Source : *Excerpts from Report of the Workshop, Bulletin of the World Health Organization, 1998, Vol. 76 (Suppl. 2) 72 - 79*

accountable for the attainment of these wider objectives. Resources for eradication activities should be additional to those available for basic health care services and should in no way be detrimental to existing services or those that are planned, except in situations where the consequences have been carefully considered.

Health policy/ health systems

- Eradication programmes should not be held responsible for curing the ills of existing health systems.
- Eradication programmes should have two objectives: 1) reduction of the target disease to zero incidence, which can be maintained even when all intervention ceases; and 2) further development and strengthening of health systems, especially with regard to monitoring and surveillance, supervision, and programme management.
- Eradication initiatives should be implemented with the support of a broad coalition of partners; great efforts should be made to build consensus.
- Managers of eradication initiatives should respect the importance of other, ongoing public health programmes.
- To the extent possible, peripheral-level decision-makers should be allowed to reach centrally established targets in a flexible and locally appropriate way.
- Successful eradication programmes are powerful examples of effective management, building management capacities to be carried to other health programmes.
- Efforts should be made to design eradication programme activities that further the development of leadership and managerial and technical skills among health personnel.
- Eradication initiatives should actively participate in the development and implementation of effective surveillance systems which can be readily adapted to meet the needs of other national priority programmes after eradication is achieved.

Human resources, training and social mobilization

It is essential for eradication programmes to include the following features.

- Training in management, quality assurance, leadership and epidemiology should be generally available and offered in integrated courses.
- Training for eradication programmes should explicitly cover skills that can be widely used; acquired knowledge and competencies have to apply to other health programmes as well.

- Social mobilization has to be for improved health, and not only for a specific programme, involving non-health personnel, because of long-term benefits in terms of sustainability, community support and epidemiological surveillance.
- It is essential for eradication programmes to avoid the following pitfalls.
- Capacity building without appropriate attention to health information systems and evaluation.
- Building parallel or temporary structures whereby human resources are fostered and jettisoned.
- Concentrating on the central level and over-looking the need to remember human resources at district and community levels.

Financing and resource mobilization

The benefits eradication brings to health programme financing include those outlined below

- Additional resource mobilization at global , national and local levels for bother further eradication and basic service costs.
- Innovative financing mechanisms (e.g. sponsorship).
- The capacities to identify progress and sustain donor interest in health financing.
- Actual and potential dangers of eradication for the health system and health development include those mentioned below.
- Opportunities "foregone", especially for countries in which the eradication effort has a low impact in terms of health outcomes.
- Failure to accurately estimate the needs of the eradication efforts, leading to subsequent "forced" resource diversions once the effort is underway.

Planning

Early planning is needed to identify accurately costs (both long-term for strengthening the health system and additional costs for the eradication efforts) and benefits. Planning should include the following.

- Evaluation of current budgets and capacities (national and intenational).
- Financial and human resource needs.
- Cost-effectiveness and affordability of the proposed eradication effort.
- Specific cost criteria for evaluation of performance of the eradication effort (e.g. the cost of a child protected for various country situations).
- A careful, transparent process for decision –making on new eradication efforts, based *inter alia* on factors

such as assessment of the global capacities for resource mobilization and financing; assessment of opportunity costs at national and global levels, opportunities for public health synergy of different eradication efforts; and the need to balance the requirements of centrally driven goals with the potentially very different peripheral level priorities – especially important when decentralization leads to district level autonomy in resource prioritization.

Development of sustainable health services

- Planners must assess the capacity of the current system to meet the requirements of the eradication intervention and identify opportunities for capacity building.
- Planning and design must maximize the partnerships of all potential stakeholders.
- Eradication must ensure the quality of delivery regarding safety, coverage, effectiveness, and efficiency
- Any eradication programme must include "surveillance for action" – both for eradication and for development of the surveillance infrastructure including all public and private sector stakeholders.
- Countries must carefully weigh consequences of their eventual decision to adhere to an eradication initiative, and consider the value of strengthening their health systems as a contribution to the success of the eradication programme. Similarly, eradication initiatives can contribute to strengthening health services and these benefits should be identified whenever possible.

Eradication should remain exceptional and be carefully designed to maximize the chances of success and positive effects for sustainable health development. ■

Leprosy and poverty

A link between leprosy and poverty has long been suspected, but is difficult to demonstrate at national, community, or even individual levels. There are no clear correlations between national GDP levels and leprosy new case detection rates. Population growth and inequality may cause over-crowding so facilitating aerosol transmission of *M. leprae*. It is particularly interesting that the level of inequality rather than absolute poverty should be correlated with leprosy case rates. Wilkinson has argued that inequalities produce unmet social needs and so impair health. Leprosy should perhaps be seen as an affliction of an unhealthy society. This is an interesting new twist for a disease that has long been associated with blame being put on the individual who is then stigmatized.

Source: *Excerpts - Diana NJ Lockwood, London School of Hygiene and Tropical Medicine, Keppel St, London, WC1E 7HT, UK, Lepr Rev (2007) 78, 317–320*

3

Control of diseases : Post-elimination / eradication strategies for sustaining disease control activities

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Principles in disease eradication

From time immemorial, man has suffered from various kinds of diseases, mostly due to a variety of infections and infestations. Edward Jenner's discovery of vaccine for protection against smallpox ushered in a new era of some diseases being protected by vaccination. Thomas Jefferson, professed the possibility of disease eradication (1780). The global eradication of small pox declared at the World Health Assembly in 1980 is the first successful disease eradication programme in the world. In practice, after attempts to eliminate rabies in UK, yaws at the international level and efforts at global malaria eradication since 1957. In response to international interest to eradicate diseases, WHO and many agencies established at CDC USA, an International Task Force for Disease Eradication, which submitted a report in 1990/1991. The Task Force studied and evaluated 94 diseases and reported that most of them are not eradicable. Dracunculosis and poliomyelitis are considered possible candidates with mumps, rubella, taeniasis and lymphatic filariasis as potential candidates. Some aspects can be eliminated (not all) in a few diseases which include IDD, Hepatitis B, tetanus neonatorum, onchoceriasis, trachoma, yaws and rabies. It is noted that evaluation results may change with time, epidemiology transition, developments such as new drugs, vaccines and disease control technologies (e.g. leprosy became eliminable with the use of Multi-Drug Therapy).

The technical feasibility of disease eradication, according to the Task Force depends on:

- availability of effective intervention technology
- diagnostic tools with sufficient sensitivity / specificity
- absence of non-human reservoirs etc.

Source : *Regional Health Forum, Health and Security, Volume 11, Number 1, 2007, P 1-9*

- demonstrated interruption of transmission for a prolonged period in a large geographical area.

Between the extremes of disease "control" and "elimination" and "eradication", there can be several intermediate levels of impact on diseases[6]. Dowdle (1995) quoted by Heyman (2006) defines "control of diseases" as a reduction in incidence, prevalence, morbidity and mortality of an infectious disease to a locally acceptable level. With "elimination" in between, "eradication" is defined as a permanent reduction to zero of the worldwide incidence of infection.

Strategy for sustaining leprosy control services

The main activities during the post elimination era are:

Integrated services

- An integrated strategy, together with simplification of operational procedures is the best option for sustaining leprosy control services.
- A prerequisite for integration is an adequately functioning basic health infrastructure. Myanmar has a well developed basic health infrastructure.
- A specialized leprosy service must be maintained at the central and intermediate levels, down to the selective district level.

Patient management

- Case-finding, based on self-reporting and examination of contacts of new patients and surveillance of other risk groups.
- Basic health workers are trained to recognize the suspicious signs of leprosy and, in general, diagnose and treat leprosy, with fixed duration chemotherapy (MDT) and refer difficult cases.
- Passive, post-treatment surveillance for those who have disabilities to prevent a worsening of disabilities.

Programme management and training

- Leprosy will continue to be a part of the curriculum of medical and public health, para-medical and nursing institutes and also included in the refresher courses and retraining for basic health staff.
- Appropriate, high-level scientific training to central and intermediate level leprosy staff is essential.
- A simple information management system integrated in the general health information system.
- Physical, social and economic rehabilitation of leprosy patients and People Affected with Leprosy (PALs) are to be included in the general community-based rehabilitation services (CBR), coupled with effective pubic education. ■

4

A renewed effort to combat entrenched communicable diseases of the poor

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A human rights approach, driven by the principle of non-discrimination, requires the State, and all other actors in a position to assist, to establish a health system that gives a high priority to the control and elimination of neglected diseases. Any health system that neglects poverty-related diseases is inconsistent with the international right to health.

A right-to-health approach to neglected diseases and populations requires accessible, transparent and effective human rights mechanisms of monitoring and accountability.

The donor community also has a human rights responsibility to ensure the optimal coordination between the numerous global initiatives that bear upon health in the country.

Key features of a right-to-health approach to neglected diseases :

Community participation

Participation is an integral feature of the right to health, and as much importance should be given to the processes by which health-related objectives are achieved as to the objectives themselves. Innovative arrangements are needed to facilitate the participation – in all four stages – of those who are usually excluded from policy-making. Preference revelation enables people to identify their preferences, i.e. what objectives they wish to achieve. Policy choice refers to the stage at which policies are formulated and decisions taken regarding the allocation of resources among alternative uses. People living in poverty are usually left out of this crucial stage of the process. The implementation stage: opportunities must be created to

Source : *Excerpts from Strategic and technical meeting on intensified control of neglected tropical diseases, Report of an international workshop, Berlin, 18–20 April 2005, Chapter 3: Neglected diseases and the right to health, WHO/CDS/NTD/2006.1*

enable those living in poverty, and other disadvantaged groups, to participate in the implementation of the chosen policies. Monitoring and accountability is the final stage of participation, and people who are affected by policies should be able to participate in this.

Stigma and discrimination

In many societies, neglected diseases such as leprosy, lymphatic filariasis and leishmaniasis are sources of fear, stereotypes and prejudices. Discriminatory attitudes, beliefs and actions can contribute to the spread of neglected diseases and worsen their impact on those affected. Fear of stigmatization can lead people living with neglected diseases to avoid diagnosis, delay seeking treatment and hide the diseases. Stigma is thus an impediment to effective prevention and treatment of neglected diseases, and to care and support for those affected.

The socioeconomic consequences of stigma and discrimination associated with neglected diseases may have a particularly severe impact on people living in poverty, who are often subject to overt and implicit discriminatory attitudes by public authorities and private actors alike. Wide-ranging measures are required to combat all forms of discrimination and stigma associated with neglected diseases, including through the implementation of health-related laws and policies, grounded in human rights, which confront discrimination in public and private sectors.

An integrated health system that is responsive to local priorities

The right to health requires the development of an effective, inclusive health system of good quality for all. In other words, the right gives rise to an obligation to establish a system of health protection, including health care, and the underlying determinants of health, such as adequate sanitation, which provides equality of opportunity for all people to enjoy the highest attainable standard of health.

Thus, the State has a responsibility to maximize the use of all resources at its disposal. For example, if a State already has a mass drug administration (MDA) in relation to one disease and, at minimal extra cost, another drug for another disease could be safely administered with it, the State has a responsibility to organize such co-administration. If it does not, the State is not using all the resources available for its implementation of the right to health – and this is inconsistent with its right-to-health obligations.

From the point of view of the right to health, a key objective must be an integrated health system that is responsive to local priorities. As far as possible, an intervention for one disease should be designed in such a way that it can also be used as a vehicle for one or more interventions in relation to one or more other diseases. All interventions should form part of – be integrated into – the regular health system. In no circumstances may any intervention undermine or jeopardize progress towards the long-term goal of an effective, inclusive health system of good quality for all.

Monitoring and accountability

Human rights empower individuals and communities by granting them entitlements and placing legal obligations on others. Critically, rights and obligations demand accountability: unless supported by a system of accountability they can become no more than window dressing. Accordingly, a human rights – or right-to-health –approach emphasizes obligations and requires that all duty-holders be held to account for their conduct.

A right-to-health accountability mechanism establishes which health policies and institutions are working and which are not, and why, with the objective of improving the realization of the right to health for all. Such an accountability device has to be effective, transparent and accessible. In relation to a human right as complex as the right to health, a range of accountability mechanisms is required and the form and mix of devices will vary from one State to another. The right to health requires effective monitoring and accountability in relation to specific right-to-health standards, with a view to enhancing enjoyment of the right to health for all, including those living in poverty and other disadvantaged individuals and communities.

Conclusions and recommendations

A right-to-health approach to neglected diseases and populations requires accessible, transparent and effective human rights mechanisms of monitoring and accountability. This requires the establishment of a right-to-health unit that is responsible for monitoring those policies, programmes and projects relating to neglected diseases. Significantly, the unit should monitor and hold to account national and international actors in the public and private sectors. The guiding question should be: have all duty-bearers done all they reasonably can to promote and protect the right to health of those suffering from, or vulnerable to, neglected diseases? ■

5
Develop advocacy for public health : viewpoint

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First and foremost step in the process of advocacy is identification of problem and there is no denying the fact that health professionals are expert in recognizing the health problem. They are also best at reviewing literature to collect evidence for solving the health problem. However, they often fail to communicate the solution to the public and to the politicians.

To be an effective public health professional, sharing of knowledge with public at large is as important as gaining of knowledge. Therefore, health professionals need to advocate for the evidences. World Health Organization defines advocacy for health as "a combination of individual and social actions designed to gain political commitment, policy support, social acceptance, and systems for a particular health goal or program". [1]

It emphasizes responsibility of health professionals as advocates of health at all levels in society. It is though paradoxical that health professionals still relate themselves to treatment of the disease rather than to prevention of the disease, whereas their role as defined in primary health care relates more to disease prevention.

It may be argued that advocacy requires technical know how, evidence based information, identification of stakeholders and opponents. It is believed that rather than devoting their time on advocacy, doctors have bigger things to do; most important of all is 'saving lives'. Only this can not be the end of the role of a health professional. Political, economic, socio-cultural, behavioral, environmental and biological factors affect public health. Advocacy aims at making these conditions favorable for health. Therefore, the challenge before all health professionals is to enter into the arena of health advocacy.

Health professionals often remain aloof from advocacy considering that policies and decisions on public health issues are the responsibility of politicians and bureaucrats. Should health professionals not approach political leaders to advocate

Source : *Excerpts from Indian Journal of Community Medicine, Vol. 33, Issue 2, April 2008*

that health posts should be closer to the community? Of course yes, health professionals have to consider community not as a passive receiver of services but as a stakeholder. And they are not only service providers but are also health advocates. Advocacy and lobbying can not be left to the market forces.

Along with the need of advocacy one needs to understand and recognize that the sustainability and effectiveness of any program can be enhanced by the commitment of policymakers. Seeking such commitment is an important step in planning and launching any health strategy. There are examples from Israel and Canada where nutrition and tobacco control movements have been successful due to effective advocacy and behavior change communication[2].

It cannot be denied that the health professionals collect and share knowledge within their own profession but find it difficult to hold advocacy meetings with the community or with the politicians. They are good at holding formal meetings using technical terms, while advocacy demands informal meetings with stakeholders using simple non technical terms. To make national health programs responsive to the health needs of the community, health professionals require opening dialogue with the political leaders, the policy makers, and the community. Holding advocacy meetings with stakeholders is an important step to create policy environment. Instead of limiting the discussions within the elite professions, civil servants and the government, it is important to involve civil society starting with the informal meetings with the Non-Governmental Organisations to take into account the policy options. Then, the debate can move on to formal meetings with other stakeholders like politicians and bureaucrats.

This is the right time that health professionals take the role of a health advocate to build public opinion. They should also approach media for advocacy using mass media and new technologies, direct political lobbying, social mobilization and alliance building etc. Chapman characterizes past public health advocacy efforts unplanned. He emphasized that a strategic plan should be adopted after systematic analysis of the public positions of opposing forces[3]. The issues of equity and public good must be debated using media. Health professionals should clarify the doubts associated with the policy and should lobby for generating positive environment. NGOs represent community and can create support for the policies that can be responsive to the needs of people. Health professionals must share the responsibility of advocating public health cause. ■

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6

'Elimination' of leprosy and the need to sustain leprosy services : Expectations, predictions and reality

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Epidemiologists have been very sceptical regarding the statement that leprosy will die out naturally after a prevalence rate below 1 per 10,000 has been reached. And the scepticism only became stronger when a few years ago a new slogan was launched by WHO: "The Final Push" strategy with the message that 2.5 million remaining cases have to be detected and cured, suggesting that there will be no transmission anymore after the target of 1 per 10,000 has been reached[1].

The Technical Forum has done an extensive literature search for evidence supporting this statement, but that was not found and therefore, the conclusion is that there is no evidence that once a predefined level of prevalence rate is reached, leprosy will necessarily die out.

So, it is obvious that the prevalence of cases registered for treatment is not an appropriate indicator for progress towards real elimination. Are there better indicators? We are often so impressed by the prevalence curve, that we do not realize what actually happens with the case detection figures. But what does "elimination" look like, if we look at case detection only? How can one logically explain that since the indicated point in time, leprosy has been eliminated and is going to die out naturally?

There is a great risk that irrational interpretation of the elimination goal results in situations in which countries claims that the leprosy control service has successfully eliminated the disease, and as a consequence, could be discontinued. The danger is that we will end up with continuing transmission and hundreds of thousands of new cases every year, but without leprosy services that can deal with them.

Two mistakes have been made. In the first place, the wrong indicator (the prevalence of patients registered for MDT) has been

Source : *Excerpts from International Journal of Leprosy, 2003, Volume 71, Number 3*

selected to reflect the progress towards elimination of leprosy (i.e., reduced transmission and incidence). The second mistake is a classical error that is often made in public health: instead of using the indicator as a limited tool to reflect the progress towards the goal of reduced transmission, the indicator itself has become the goal, and the actual goal has practically gotten out of sight.

Regarding the use of indicators, the Technical Forum concluded that prevalence alone is of limited value as an indicator of leprosy control. The new-case detection-rate may be a better indicator, in conjunction with other indicators. The treatment completion rate is an important indicator of the effectiveness of patient management (BP). "BP" means that this is considered as the best practice.

The new-case detection-rate is the most logical proxy-indicator of incidence. However, it also poses some problems of interpretation. (i) It is directly influenced by the frequency and quality of detection. (ii) A number of newly detected cases may have developed leprosy several years earlier. But at the same time, (iii) some people who develop symptoms will be detected only after a number of years, and thus will not be included in the current year's case detection rate.

In spite of these limitations, trends of case detection reflect trends of incidence, on condition that there has been no important change of detection activities. For routine use in integrated programs the most appropriate indicators are: (i) number (rate) of new cases, both paucibacillary (PB) and MB; (ii) proportion of newly detected patients with disability grade II, which reflects the degree of delay before detection, and if it is stable the trends of case detection reflect trends of incidence; and (iii) treatment completion rate. These indicators are also useful for self-evaluation by the health workers. They can be easily translated into their major responsibilities: find patients before they have developed disability and cure them.

Another relevant indicator is the proportion of children among new cases. A large proportion is a sign of recent transmission of the infection. Thus, it is an important epidemiological indicator, even though the proportion can also be influenced by operational factors, such as school surveys. In 2000, the global data showed a child proportion of 17%. The issue of indicators for routine programs brings us from the chapter on epidemiology and control to the chapter on the organization of services. We have seen that the number of new cases detected globally has changed very little over the years.

Moreover, some countries that had not reached the elimination target by the end of 2000, may have difficulties reaching it by the year 2005. To reach the elimination target the number of registered cases has to reach a level of about 100,000. In many states in India it will not be feasible to achieve the elimination target, unless we reduce case detection activities, or further reduce the duration of MDT.

The Technical Forum concluded that significant numbers of new patients will continue to present for many years. Thus, it is essential to ensure that leprosy control activities have to be sustained, even in countries or areas that have officially reached the elimination target (BP).

For many years to come, every year hundreds of thousands of new cases will occur. They must be detected at an early stage and given regular and complete treatment with MDT. Some of the new patients will have disability at diagnosis, and many are at risk to develop disability after diagnosis. Moreover, about 3 million "cured" cases are disabled and in need of care. Leprosy services will need to be sustained far into this century[2].

Disease control can be defined as reduction of the incidence and prevalence of the disease, and of the morbidity and mortality resulting from the disease to a locally acceptable level as a result of deliberate efforts. Continued intervention is required to maintain the reduction[3]. The strategy to achieve control of leprosy has four major elements: (i) early case detection, (ii) adequate chemotherapy (MDT), (iii) prevention of leprosy related impairments, and (iv) rehabilitation.

Implementation of this strategy ideally requires accessible, cost-effective, and sustainable health services that cover the population fully, and are accepted by the community and the patients. This strategy implies that leprosy control activities should be implemented by the general health services. Several integrated programs have shown that leprosy control can be effectively implemented by general health workers[4].

There is a broad consensus on the need to integrate leprosy services into the general health system. WHO, the International Federation of Anti-Leprosy Associations (ILEP), and ILA see this as the most realistic strategy to sustain cost-effective leprosy services. Integration is also a central element of the health sector reforms.

Integration means that day-to-day patient management will become the responsibility of general health staff. Integration does not mean that specialized elements need to disappear from the health service. On the contrary, specialized

components must be available within the general health service at the central and intermediate levels for planning, evaluation, training, technical supervision, referral services, and research.

Depending upon local conditions, each country or region must decide at which level of the health system such specialized support should be available. Where case-detection rates are low, a focused approach is appropriate, whereby services are provided mainly in selected general health facilities in the areas in which leprosy still occurs.

The skills of general health workers will be limited mainly to suspecting leprosy and referral of suspects to specialized staff at the intermediate levels to confirm the diagnosis and begin treatment. Continuation of treatment could be delegated to the peripheral health facility serving the community in which the patient resides. The resources devoted to leprosy must be in balance with those required for other, often much more serious, public health problems (BP).

In summary:

- Government must make a commitment to sustained leprosy control activities.
- General health service infrastructure must function adequately.
- The integration process must be carefully planned, appropriate to the local situation.
- Maintain a well-functioning central leprosy unit, usually housed in the Ministry of Health.
- An uninterrupted supply of anti-leprosy drugs must be guaranteed.
- Follow appropriate (simplified) field procedures, including recording and reporting.
- National strategies should clearly define the role of the private sector.
- Non-governmental organizations supporting leprosy control continue to be important partners with governments in integrated leprosy control programs.
- It is important that the various agencies involved in leprosy control collaborate and coordinate their activities, in order to increase their effectiveness.
- In integrating leprosy control into general health services, equity and quality of care for leprosy patients should be assured.

This implies that the services for leprosy patients should provide the same level of quality as do the services for other health problems (not less, but not more either).

- Training of all categories of staff involved in leprosy control should be

task-oriented. Leprosy should be included in the curricula of medical faculties and paramedical schools (BP).

- Information, Education and Confirmation (IEC) activities result in increased knowledge, change of behavior, and reduction of stigma (EB). They should preferably be combined with IEC for other health problem (BP).
- Leprosy elimination campaigns (LEC) can play an important role in the process of integration. Case-finding in LEC must be based on self-reporting to the general health staff (BP).

Although there is consensus on the need for integration and the consequent need for simplification of the leprosy control activities and procedures, there is a serious disagreement on the interpretation of the word "simplification." Simplified guidelines should still respect well defined, minimal acceptable levels of quality and effectiveness, and that a number of recent WHO guidelines concerning diagnosis, treatment, and prevention of disability are unacceptably oversimplified. These issues are discussed in the other three chapters of the Technical Forum report: the diagnosis and classification of leprosy, chemotherapy, and prevention of disabilities and rehabilitation.

The conclusion is that the WHO elimination goal has created a broad and strong commitment to the fight against leprosy. However, the number of new cases detected globally has changed very little. This is mainly explained by the disappointing additional impact of MDT on transmission. The strong decrease in registered prevalence is not based on a decreasing incidence, and can be explained by the shortening of treatment duration and cleaning of the registers. Since leprosy will continue to be a problem beyond 2005, leprosy services have to be sustained. ■

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Detailed information and extensive literature references are available in the full report.

7

Strategic surveillance - key to attainment of leprosy control and elimination goals at the local level

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Currently the prevalence of leprosy in six countries is still above the level of 1 per 10 000 population, defined in 1991 by the World Health Assembly as the target prevalence level for attainment of leprosy elimination[1].

Together, India, Brazil, Madagascar, Mozambique, United Republic of Tanzania, and Nepal represent approximately 90% of the global leprosy burden, and new cases continue to be detected with about 620 672 registered in 2003[2].

Of these, approximately 20% are at risk of developing nerve function impairment and subsequent disability, the most serious consequence of leprosy both to the patient, their family and community[3].

In February 2003, the WHO Technical Advisory Group on Elimination of Leprosy met to evaluate the intensified strategy for global leprosy elimination. Panel members noted that while many leprosy-endemic countries have achieved elimination at the national level, India and Brazil are unlikely to attain a prevalence rate below 1 per 10 000 population within the next 2 years. The panel observed that most countries successful in achieving national elimination goals have developed strategies for reaching elimination goals at regional and local levels[4].

As countries focus ongoing and renewed efforts for leprosy elimination and control at regional and local levels, those with pockets of high endemnicity face particular challenges. Techniques for case detection that are rapid, practical, accurate, and cost effective are needed to effectively monitor progress of control and elimination strategies. Lot quality assurance sampling (LQAS) is a quality control technique developed in industry in the 1920s for products manufactured on a factory assembly line, whereby a small number of units from a particular lot are randomly selected for examination[5].

Source : *International Journal of Epidemiology, 2004; Vol.33; No.2: 349-350*

If the number of defective units in the small sample exceeds a certain predetermined number, the entire lot is rejected. In public health, LQAS has been used to assess immunization coverage, neonatal tetanus mortality, response to antimalarial treatment, and use of oral rehydration therapy[6].

To employ LQAS for assessment of public health programmes, a critical value d is calculated based on an estimate of disease prevalence and represents the maximum allowable number of cases with the disease of interest per sample population group. If the number of cases in the sample population exceeds the critical value, the prevalence rate of disease in the larger population from which the sample was derived is considered to exceed the upper limits of the original prevalence estimate, indicating that further intervention is needed.

The objective of Gupte *et al*. is to validate the applicability of LQAS in monitoring the progress of leprosy elimination in Tamil Nadu, a highly endemic state in India[7].

In this and previous papers, the authors utilize cluster sampling (CS) techniques to determine whether the prevalence of leprosy exceeds a maximum allowable number[8,9]. CS is frequently employed in surveys; primary considerations to employ CS over simple random sampling (SRS) include the prohibitive cost of SRS and difficulty or impossibility of constructing a sampling frame for the population. Also, the population may be so widely distributed geographically that sampling naturally occurring units such as villages and households may prove to be the most economical method for estimating disease prevalence. CS is simpler to perform than SRS because there are fewer sampling units (clusters) to identify and they are more easily selected and characterized. Comparing variances derived from CS and SRS, investigators are able to compute a design effect which is used to inflate sample size calculations to accommodate the clustered sampling design. We believe this technique is appropriate to monitor the progress of leprosy elimination programmes, but that it is important to consider the impact of decreased precision (increased variance) that accompanies CS. In the present study, Gupte *et al*., calculated within and between-cluster variances and determined that the design effect for their sample was a combined 1.06. Consequently, the authors did not experience a penalty for implementing a cluster sample and did not need to increase their sample sizes.

To further monitor progress in leprosy elimination and control, consideration should be given to incorporating surveillance methods that are capable of predicting the future needs of the particular population at risk. Clinical prediction rules have been previously described that could be used for early identification of patients at greatest risk for subsequent development of nerve function impairment (NFI)[3]. Based on

simple tests of sensory function, patients would be assigned as having a low, intermediate, or high risk of future development of NFI. Application of these prediction rules could serve as a guide to determine the appropriate length of time to conduct surveillance after initial patient registration. With this information, programme managers can more effectively allocate precious resources for elimination and control programmes in high endemnicity areas.

The importance of assessment for NFI in leprosy patients is corroborated by Richardus *et al* [10]. The authors provide data from a prospective cohort study of 2664 new leprosy patients followed up to 5 years for the development of NFI. The occurrence of NFI in leprosy patients has previously been demonstrated in numerous studies; however, this study is notable for the length of the follow-up period, 3 years beyond completion of multidrug therapy (MDT). The authors conclude that multibacillary patients with longstanding NFI at first registration have a high likelihood of developing new NFI within, but not beyond 2 years. This demonstrates the importance of conducting surveillance among high-risk patients for at least 2 years. In this cohort of patients, the majority of NFI cases involved sensory or motor impairment without skin signs of reversal reaction or erythema nodosum leprosum (ENL), also known as silent neuropathy, highlighting the importance of creating early awareness among patients and their families to take steps to prevent further disability.[11]

In summary, it has been said that: leprosy is one of the few infectious diseases that meet the demanding criteria for elimination, namely, practical and simple diagnostic tools, the availability of an effective intervention to reduce its transmission and a single significant reservoir of infection - humans[12].

To maintain the momentum and progress being made towards leprosy elimination, as the prevalence of leprosy decreases, countries will need to employ more sensitive strategies to detect and manage cases. Gupte and Richardson, while addressing different aspects of leprosy management, have both provided effective strategies for surveillance to evaluate progress in leprosy elimination in regions where endemnicity remains high. ■

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The stigmatization of leprosy in India and its impact on future approaches to Elimination and Control

On January 30, 2005 India celebrated the elimination of leprosy as a public health problem after achieving the nationwide prevalence of 1 case / 10,000 population, though not without criticism regarding the accuracy and choice of target parameter. This is a remarkable achievement given that in 1981, two years before NLEP, there were nearly 4,000,000 cases with a prevalence of .50 cases/10,000 population.

However, in a population of more than a billion people, up to 100,000 people with leprosy remain, representing approximately half of the world's disease burden. Some regions, mostly rural, still have up to five times the national average of cases; these areas have become the next targets in leprosy control.

The future of leprosy control and elimination offers several challenges with both structural and cultural dimensions. Efforts to decrease health inequity due to poverty, especially in rural areas with limited access to health care, may help with leprosy control. However, if cultural beliefs are not addressed, increased availability may not translate into an appropriate increase in utilization.

Cultural aspects of leprosy affecting its control include traditional medicine and stigma. Only limited efforts have been made to include the numerous nonallopathic (traditional) practitioners in India in leprosy control and elimination efforts, but their inclusion is important to its success.

Source: *Excerpts - Jacob JT and Franco-Paredes C (2008) The Stigmatization of Leprosy in India and Its Impact on Future Approaches to Elimination and Control. PLoS Negl Trop Dis 2 (1): e113.*

8

Partnership for sustainable leprosy control beyond 2005

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Partnership

Partnerships have always played an important role in leprosy control. The World Health Organization (WHO) and national and international non-governmental organizations (NGOs) provide a significant supportive function in partnership with national governments. Among the NGOs involved, the members of the Federation of Anti-Leprosy Associations (ILEP), The Nippon Foundation, Novartis and the World Bank have played a prominent role. Partnership can be defined as: 'Inter-organizational relationships involving activities (beyond that which contracts or authority alone would demand) aimed at achieving shared goals based upon close working relationships'. There are more definitions of partnership but they usually include these common themes: commitment to shared objectives; mutuality, equality and open dialogue; sense of trust and respect between the partners; and reciprocal obligations and accountability.

Partnership does not mean that partners should agree on all aspects, but implies that there is a willingness on both sides to 'give and take' so as to reach consensus.

ILEP as a federation is a good example of a partnership between organizations that share common objectives. For many years, WHO and ILEP shared an outstanding partnership that had been exemplary to other disease control initiatives. Although a difference in opinion on technical issues led to partnership problems at the international level in 2001, WHO and ILEP members continued their fruitful collaboration in most countries at the national level. However, since last year, the constructive collaboration between WHO and ILEP has been fully re-established at the international level. This is a very positive development.

Challenges for the 'post-2005' period

Despite a dramatic reduction in the number of leprosy patients registered for

Source : *Editorial, Leprosy Review (2005) 76, 194–197*

treatment, resulting in the achievement of the 'elimination' target (a prevalence of leprosy cases registered for treatment below 1 per 10,000 population) in 113 countries, the number of newly detected cases has not shown a comparable decline, for various reasons, in many of the endemic countries. In fact the decline in case detection as seen at the global level during the last 2 years can be attributed mainly to the reduction in case detection in India alone. It is inevitable that a significant number of new patients will continue to present for many years, and there is now a clear consensus among leprosy workers that it is essential to sustain leprosy control activities to further reduce the disease burden. This is also necessary in countries that have reached a prevalence rate of below one per 10 000 population.

There is, however, a considerable risk that political commitment will diminish in counties where the elimination target has already been achieved. Politicians, including ministers of health and other decision makers, often interpret 'elimination' as 'eradication'.

It is important that decision-makers are convinced that 'elimination', though an important milestone in the long march towards the goal of a 'world without leprosy', does not in itself constitute an end to the leprosy problem. Governments and all agencies, supporting leprosy control work should therefore continue to allocate the resources necessary for sustaining leprosy control activities. Leprosy control activities incorporate all activities aiming at the reduction of morbidity and suffering resulting from the disease including diagnosis, treatment wit MDT, patient and family counselling, community education, prevention of disabilities, rehabilitation, referral for complications, etc.

Without political will and support, public health programmes cannot be successful. However, this does not mean that public health related managerial decisions should be made on the basis of political criteria alone. In selecting public health priorities we must find the right balance between technical and political priorities in order to attain a successful process.

The 'elimination' target has been very effective in obtaining political commitment and, consequently, in intensifying anti-leprosy activities. However, the number (prevalence) of patients on the treatment register is not the most appropriate indicator to reflect the progress towards true elimination of leprosy (i.e. reduced transmission and incidence). The ILA Technical Forum, the ILEP Technical Commission and the WHO Technical Advisory Group (TAG) all have, in the absence of efficient tools to measure transmission and incidence, identified new-case detection (numbers

and rates) as the preferred proxy indicator for monitoring progress in leprosy control. This indicator should preferably be used in conjunction with the proportion of newly detected patients with disability grade 2 for optimal monitoring. The treatment completion rate is an important indicator of the effectiveness of patient management. These indicators are also useful for self-evaluation by health workers as they reflect their major responsibilities: to find patients before they have developed disabilities and to cure them.

Today, we have an excellent opportunity to build on the achievements of the elimination campaign, such as growing awareness for leprosy, strong political commitment, increased involvement of the general health services and the recognition of the importance of partnership among the major stakeholders.

Towards sustainable leprosy control

Even though the leprosy burden has been reduced, new cases of leprosy will continue to appear in significant numbers for the foreseeable future in most of the current endemic countries. Given such a scenario, although much has been achieved, it is important to secure Partnership for sustainable leprosy control beyond 2005 the provision of accessible leprosy services in communities in which new cases of leprosy will continue to be detected, and to further reduce the disease burden. Disease control is defined as reduction of the incidence and prevalence of the disease, and of the morbidity and mortality resulting from the disease to a locally acceptable level as a result of deliberate efforts.

Continued intervention is required to maintain the reduction. Effective leprosy control ideally requires an integrated approach, which provides wider equity and accessibility, improved cost-effectiveness and long term sustainability. This implies that leprosy control activities should be implemented by the general health services, including integrated referral facilities. WHO, ILEP and ILA all see integration as the most realistic strategy to sustain leprosy control activities. Integration is also a central element of the health sector reforms. Integration not only improves accessibility to treatment, but also reduces the stigma and discrimination faced by persons affected by leprosy. The integration process will need careful planning and probably different approaches within each country, depending on the local leprosy burden and the health infrastructure. If donors wish to ensure the establishment of sustainable leprosy services, they must work with and strengthen the national general health services system.

Improved access to quality leprosy diagnosis and case management will remain the cornerstone of the leprosy

control strategy beyond 2005. The recently published WHO Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities (2006–2010) recognizes the need to sustain leprosy control services for many years to come. A change is required from the campaign-oriented approach to the long-term approach of sustaining integrated quality leprosy control activities, which in addition to case detection and treatment with MDT, also include prevention of disability (PoD) and rehabilitation.

Role of partners

The role of the partners in the short to medium term will focus on strengthening the national capacity to provide quality leprosy services, to provide technical advice, funding for core activities, free MDT drug supply and logistics and global advocacy. It is important that the partners involved in leprosy control continue to collaborate and coordinate their activities to increase their effectiveness. The government, particularly the ministry of health (MoH), is the owner of the programme, and should coordinate national and international donor support to the country. Effective donor coordination is an important requirement for a consistent and uniform implementation of the programme activities throughout the country. All partners should know how their resources are utilized, and should therefore be involved in the planning and evaluation process. It is necessary that the MoH and its partners, including WHO and ILEP Members, reach consensus on the implementation of the Strategy, plans of action and budgets. This will be greatly helped by organizing joint programme reviews by the MoH and all partners.

It is important that WHO continues to provide technical leadership at the international level and participates in the partnerships at the international as well as the country levels. The partners must agree on the major strategic issues for the fight against leprosy after the year 2005 and on the specific role of each partner in the Global Strategy. ILEP is a prominent international partner for WHO, along with the governments of the leprosy endemic countries, TNF and Novartis. The fact that WHO has developed the Global Strategy 2006–2010 in close consultation with the member states, regions and local and international partners, including ILEP, makes the restored effective international partnership evident. The united endorsement of this Strategy will strongly contribute to sustaining the achievements made to date and to further reducing the disease burden.

Conclusion

Our challenge is to ensure that all persons affected by leprosy, wherever they live, have an equal opportunity to be diagnosed and treated by competent health workers,

without unnecessary delays and at an affordable cost. We need to ensure that the achievements made so far in controlling leprosy are sustained, that the burden of the disease is further reduced, and that affected communities continue to receive quality leprosy services as long as they are needed. At the same time efforts to increase community awareness are required so that we can put an end to the prejudice and discrimination still faced by affected persons and their families in many societies. Effective collaboration between the MoHs of endemic countries, WHO, ILEP, TNF and Novartis will strongly contribute to ensuring that this happens. ■

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Public involvement in health care

What public involvement means?

Public involvement and other allied terms are used to mean a variety of activities or objectives. The involvement of members of the public in strategic decisions about health services and policy at local or national level-for instance, about the configuration of services or setting priorities. Public involvement is different from patient involvement, which refers to the involvement of individual patients, together with health professionals, in making decisions about their own health care.

Why is public involvement desirable?

Advocates of increased public involvement argue that public services are paid for by the people and therefore should be shaped more extensively by them, preferably by a fully representative sample. One assumption made is that greater public involvement will lead to more democratic decision making and, in turn, better accountability, but neither is necessarily the case. A second assumption is that more public involvement is an intrinsic good. This belief is based on values or ideology and thus cannot be tested, but it is often allied to beliefs that can be tested empirically. A second argument for increasing public involvement is that it will make services more responsive to the individuals and communities who use them and that more responsive services will lead to improved health. Underpinning these assumptions is the belief that professional definitions of benefit in health care can be at best only partial; only the users or local communities themselves know what they need, and it is ultimately their assessment of benefit that matters.

Source: *Excerpts from Dominique Florin and Jennifer Dixon, Health Policy, King's Fund, London W1G 0AN, BMJ 2004; 328 : 159 – 61*

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Leprosy strategy is about control, not eradication

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At the end of 2000, WHO declared that leprosy had been eliminated as a global public-health problem. Elimination is defined as a prevalence, per 10 000 population, of less than one patient diagnosed with leprosy and registered for treatment. The global prevalence fell from 5·35 million (12 per 10000) in 1985 to 597035 (one per 10000) at the end of 2000.

Elimination was achieved by implementation of short-course multidrug therapy (dapsone, rifampicin, and clofazimine for 6 or 12 months depending on the type of leprosy), simplified diagnosis without examination of slit-skin smears for acid-fast bacilli, and accessible treatment with drugs in blister packs that are free at the point of delivery. The shortened course of treatment, reduced from more than 5 years with dapsone alone, reduced the prevalence without changing the number of new cases detected annually[1]. The 17th International Leprosy Congress (in Hyderabad, India) ended on Feb 4, 2008, with calls to now move from an elimination strategy for leprosy to one of eradication. Is that call the logical progression from elimination and does the evidence support such a change in strategy?

The elimination strategy was focused on a time-bound target and had many non-sustainable elements, including vertical programmes, dedicated staff, ring-fenced funding, special campaigns and action projects, and a high level of political commitment. The current WHO global strategy for leprosy (for 2006–10) aims to sustain activities to control leprosy and to further reduce the disease's burden by provision of good-quality care integrated within general health services[2].

Sustainability is vital to maintain the achievements of elimination. The most recent data[3] on trends in case-detection in leprosy show that four countries have still to reach the elimination goal: Brazil, the Democratic Republic of Congo, Mozambique, and Nepal. Case-detection is being sustained in the Americas and the

Source : *The Lancet 2008; 371:969 - 970*

eastern Mediterranean and western Pacific regions, but not in Africa (although some countries have still to report) and southeast Asia, where case-detection in India fell by more than 60% from 367143 cases in 2003 to 139252 in 2006. These recent decreases in reported case-detection are unlikely to have resulted from reduced transmission of the disease, and indicate that case-detection is not being sustained[4].

Leprosy does not meet the scientific criteria for eradicability in terms of its epidemiological vulnerability, because there is no tool to diagnose infection and non-human reservoirs exist. Indeed the sources of infection, patterns of exposure, mode of transmission, and the early host-response remain to be elucidated.

The International Task Force for Disease Eradication considers leprosy as not now eradicable, the chief obstacles being the need for improved diagnostic tests, social stigma, and the potential reservoir in armadillos[5]. However, there is some political will and popular support as evidenced by the statement by Klaus Leisinger[6] of the Novartis Foundation at the Congress' inaugural session and reinforced by the outgoing president of the International Leprosy Association, Shaikh Noordeen, at the closing session. The elimination programme has not had a major effect on transmission[7]. Although scenario models suggest that reducing the delay in detection would have an effect, no current approaches can achieve this aim[8]. BCG has a protective effect against leprosy, and the worldwide coverage with BCG will have a positive effect in prevention of the disease[9]. There is growing evidence on the effectiveness of chemoprophylaxis in contacts, and this approach might get included in future strategies, particularly in areas with low endemicity[10,11]. The lack of new effective interventions to prevent transmission and tools to detect infection are major limitations to an eradication strategy. However, work is in progress to develop a leprosy-specific T-cell assay with unique antigens selected from the genome as a new way to detect infection[12].

Eradication of leprosy may be a politically desirable aspiration but the scientific case for such a strategy cannot be justified at the moment. Major advances in research are needed to develop an eradication strategy. The current reality is that sustaining leprosy control through case-detection and treatment of leprosy and its consequences, within integrated health programmes, must be the priority. ■

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Indicators - Designing for Results : Quantitative and Qualitative

Indicators consist of information that signals change. An indicator is a quantitative or qualitative factor or variable that provides a simple and reliable means to reflect the changes connected to an intervention. Indicators enable us to perceive differences, improvements or developments relating to a desired change (objective or result) in a particular context. Indicators are inevitable approximations. They are not the same as the desired change, but only an indicator of that change. They are imperfect and vary in validity and reliability.

Where the desired change is concrete, tangible, and measurable, indicators are not needed. Where the intended change is more abstract, indicators help approximate the change. Indicators are used in establishing baselines, monitoring, and evaluation. Information is gathered in the baseline to set the target for the indicator. Indicators can then be used for determining progress toward results in monitoring as well as in monitoring the context of the conflict.

At best, this indicator tells us that a change we are interested in is happening. Indicators cannot explain why or how that changes occurs. Success in selecting and developing good indicators is directly related to the depth of the situation analysis, the understanding of the context, and expertise in designing effective interventions. Indicators need to contain certain basic information and also be able to pass tests of reliability, feasibility and utility in decision making.

Quantitative indicators are measures of quantities or amounts. Qualitative indicators are people's judgments or perceptions about a subject. Most qualitative indicators contain a number or numeric components so you need to look beyond numbers to what is actually being measured. Check to see if the change in question relates to some sort of opinion, belief, or way of thinking. If not, it is most likely a quantitative indicator. If it describes the implementation of an activity or a one-off event, it is almost certainly a quantitative indicator.

Source: *Excerpts from Michael Quinn Patton, Utilization-Focused Evaluation, SAGE Publications, Chapter 4 : Indicators - Designing for Results, p 43 – 60, 1996.*

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Leprosy eradication – a discussion of meaning, feasibility and implications

WHO Technical Advisory Group on Leprosy Control

Several arguments indicate that leprosy eradication is not feasible: including the evidence for at least one animal reservoir of *M leprae* (the armadillo), the absence of any test for infection, the very long incubation period and our current ignorance of basic aspects of the natural history of leprosy (e.g. the role of sub-clinical "carriers" in transmission). The single argument in favour of "eradication" was that such a declaration might be justified as a purely aspirational goal and in order to attract resources for leprosy work. It was noted that there has been no economic analysis of the risks and benefits involved.

The presentation concluded that leprosy eradication is not possible technically and that an unrealistic eradication declaration would devalue the definition of eradication as a term and lead to embarrassment. Eradication as a target with a time-bound goal would be inconsistent with integration and the current global strategy.

It was noted that the 1993 International Task Force for Disease Eradication and the 1998 WHO supplement on eradication both considered leprosy not to be eradicable. Considering all the provided evidence the TAG members resolved not to consider leprosy to be an eradicable disease at this point in time.

Conclusions and recommendations

(1) The TAG noted that while leprosy appears to have declined in many populations, the disease remains endemic in the large majority of countries. It is recognized that the interpretation of routine data is difficult because of the important influence of operational factors which differ greatly between countries. Further efforts are needed to improve the quality of routine case detection data at the national level, based on standardized methods, to ensure consistency and comparability within and between countries and to show trends over time. Reporting should focus on new case detection and should include breakdowns by age, sex, type of disease and disability grade, as well as treatment completion rates.

Source : *Excerpts from Report of the Ninth Meeting of the WHO Technical Advisory Group on Leprosy Control, Cairo, Egypt, 6–7 March 2008, WHO, SEA - GLP - 2008.3*

(2) After an in-depth review of available information, the TAG does not consider leprosy to be an eradicable disease. The evidence of an animal reservoir in armadillos, gaps in current understanding of epidemiology, transmission, immunology and the lack of effective tools to reduce incidence, mean that it would not be appropriate or credible to embark on an eradication strategy at this point in time.

(3) The workshops for health service managers and the accompanying training guides, developed for the implementation of the Global Strategy and its Operational Guidelines, are endorsed by the TAG, and their use in strengthening and sustaining capacity in national programmes is strongly recommended.

(4) National Programme Managers should be aware of the clinical problem of HIV/leprosy co-infection. These patients are at risk of severe reactions and may present with Immune Reconstitution Syndrome after starting Highly Active Antiretroviral Therapy (HAART). The TAG noted that research in this area may improve our understanding of the immune response in leprosy.

(5) Longitudinal monitoring of drug resistance in leprosy is critically important to ensure the continued effectiveness of the leprosy control strategy based on MDT. In this regard, annual reporting of the number of relapses and their verification will be an important activity as part of the national surveillance for drug-resistant leprosy.

(6) Future research in leprosy chemotherapy should focus on simplified regimens. Appropriate treatment regimens need to be developed for patients with Rifampicin resistant leprosy and those who cannot tolerate Rifampicin.

(7) Further action is needed to improve patients' access to currently available interventions for early detection and management of leprosy neuritis and reactions. The TAG also noted that research is needed for the development of improved tools for leprosy prevention, diagnosis and chemotherapy.

(8) The TAG reiterated the principle that self-care is an important component of disability prevention and rehabilitation initiatives. The TAG recommends that persons affected by leprosy be routinely provided information on self-care such as that recommended in the WHO booklet "*I can do it myself*".

(9) The TAG recognizes that stigma associated with the disease has had a negative impact on all aspects of the Global Strategy for Leprosy Control. Social action is required at all levels to reduce stigma. Further research is required in developing indicators for measuring the degree and impact of stigma and discrimination. The indicators may be useful for the evaluation of interventions to reduce stigma. ■

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Revitalize primary health care for confronting current public health challenges

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Thirty years ago, in 1978, the World Health Organization (WHO) espoused the Primary Health Care strategy to achieve the goal of 'Health for all'. Since then, considerable progress has been made in population health around the world, particularly in developing countries. However, required investments have not been made and the full potential of primary health care has not been realized. In the last three decades, unprecedented technological and political changes that swept the world have ushered in an era of 'globalization'. The influence of the 'market' is growing and the long-cherished public health values of social solidarity are under serious threat. Macroeconomic policies are squeezing public spending on social services in several countries. The weakening of industrial regulations is not only threatening the health of the working population but is also leading to environmental crises in many communities. Trade liberalization and the extended reach of mass media advertising are encouraging the consumption of unhealthy products on a large scale. Rapidly expanding global travel is providing newer opportunities to microbes to affect communities far away from their habitat. Traditional governance structures are increasingly losing relevance and the comprehensive primary healthcare strategy stands abandoned.

Keeping society healthy is the prime task of Community Physicians. That is why rather than only managing patients in cozy clinics, they are always busy in planning, organizing or evaluating Health Promotion or Disease Control Programs. And the principal task of those who are engaged in academic community medicine is to produce a health workforce, which is not only capable of protecting, but also has competency in promoting people's health. Community physicians have always been interested in knowing why some communities or various groups within the

Source : *Editorial, Indian Journal of Community Medicine, Vol. 33, No.1, January 2008, P 1-2*

same community are healthier than others. The prime focus of this investigation has been to find out the causes of ill health. The physical and/or social conditions in which people live and work, described as the determinants of health, have been established as the underlying causes of health inequalities around the world. However, rather than arguing for fundamental change in the social policies for promoting health, community medicine has largely adopted a technocentric approach to disease prevention and control during the last century. This approach has been successful to some extent in prolonging life but the goal of 'health for all' by the turn of the century remained largely unfulfilled.

In these extraordinary times, revitalization of primary healthcare approach for promoting health, protecting the environment, controlling disease and making healthcare accessible to all has become a big challenges. To confront emerging challenges, primary healthcare concepts and approaches need to be re-emphasized. The Health Field Concept [1], Alma Ata Declaration [2], the Ecological Perspective [3] and Health Promotion Strategy [4] have enriched our discipline, Shelter, food, water, income a stable ecosystem, social justice and equity are the basic requirements of human existence. Community physicians have to advocate consistently for social action to fulfil these prerequisites and mediate between different interests of society so as to enable people to achieve their full health potential. In this respect, the United Nations' Millennium Development Goals provide a comprehensive framework for action [5].

The effects of 'market' – oriented development policies on peoples' health need to be investigated in local contexts so as to provide evidence for advocating a reversal of those public policies that do not promote health. Academic programs of Community Medicine should build advocacy skills among health professionals for promoting evidence-based public policies and for mobilizing public opinion in favour of these policies. Building partnerships with civil society organizations and social movements [6] is vital at this stage.

Technological advance in communication, which has led to the shrinkage of space and time, should be harnessed for advocacy, social mobilization and for building alliances at community, national and international levels. Educational opportunities must be enhanced for the creation of not only a technically competent but also socially responsive health workforce. Sufficient number of positions ought to be created for them in the public health system so that all 'development' policies are reviewed for their impact on population health and the State can perform its 'stewardship' role

more effectively in order to achieve the goal of right to health and healthcare for all in the foreseeable future.

The Health Survey and Development Committee, popularly known as the Bhore Committee (after its chairperson Joseph Bhore), had recommended a plan for creation of national health service [7]. Recently, the National Commission on Macroeconomics and Health has also provided a blueprint for the provision of comprehensive primary and secondary healthcare to the Indian population [8]. However, the challenge is to allocate sufficient resources. India consumes about 4.6% of its gross domestic product (GDP) for healthcare but most of the expenditure is privately done by the citizens themselves as the government spends only 0.9% of the GDP on health [9]. Compared to even several developing countries, this is very low and has been declining, but a reversal has occurred recently. The Government of India has planned to raise health-spending to 2-3% to finance the National Rural Health Mission [10], which is a step in the right direction. But innovation and prudence is required to expand primary healthcare delivery options so that universal coverage is achieved quickly not only in rural areas but also in urban slum populations. An independent monitoring and evaluation system is also required to measure the coverage and impact of the health and development programs. ■

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12
Where are the patients in the quality of health care?

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While the achievements of the Organisation for Economic Co-Operation and Development (OECD) Health Care Quality Indicators (HCQI) Project[1] are laudable and enable international comparisons of health care systems in terms of a particular type of quality, it is important to remember that quality is not value neutral. As Donabedian pointed out, 1981, explicit measures of quality carry with them the values of those who have defined the measures, and such measures are amenable to being used as instruments of control[2].

Who defines quality and who measures it are pivotal questions for those who engage in its pursuit. However, it would seem there is little consensus about the meaning or measurement of quality from the stakeholders involved in health. Of greater concern is that, despite the apparent plethora of attempts to gauge patient satisfaction with their health care experiences, there is a worrying downgrading of patients' perspective views of what they feel comprises quality health care.

In most instances quality health care is assumed to occur with quality medical care[3,4,] including in Donabedian's seminal Structure / Process / Outcomes model[5], yet even physicians have a difficult time agreeing on the nature of quality[3]. In general, to the physician, quality health care leads to 'cure'[5,] measured, somewhat naturally, by patient health outcomes. Many of the available indicators used in the OECD HCQI Project can be classified as patient health outcomes.

It is not only physicians who judge quality by patient health outcomes. To the nurse quality health care is the process that enables recovery[6]. Thus for nurses the process of health care is the site of quality, yet this is largely assessed by patient health outcomes.

Source : *International Journal for Quality in Health Care; April 2007, Volume 19, Number 3: pp. 125-126*

Process—what is done—can be more sensitive than outcomes—what happens[7–9], yet patient health outcomes are so intrinsically appealing as measures of quality that often, even when purporting to assess process, outcomes are used as indicators[7, 8]. Furthermore, whether indicators of outcomes or process are used, it is easier to use firm, quantifiable indicators that adds another problem if the nature of quality is not such that it can be easily quantified. The very nature of a project such as the HCQI Project means that, in order to achieve international viability, the indicators used must be of a concrete nature, whether these be indicators of outcomes or indicators of process.

From the above discussion of the centrality of patient health outcomes as indicators of quality, it would seem that the patient is central to concepts of quality health care. The only concern is whether patient health outcomes are central to patient definitions of quality health care and, if not, how much weight is given to that which patients consider defines quality health care from their perspective?

Patient satisfaction questionnaires are plentiful, yet patient satisfaction with health care does not seem to be associated with the effect of care received as high patient satisfaction with the care received can be found even if the desired patient health outcome has not been obtained[10].

The question then becomes what is the nature of the association between patient satisfaction with care, quality of care and patient health outcomes? There is a risk of patient-centred care being downgraded to care that leads to satisfied patients and to patients being sidelined in terms of their views of what constitutes quality health care. If patients are not placing the same weight on patient health outcomes as the rest of the health care community, it may lead to the argument that the same weight does not need to be applied to their definitions of quality, only whether or not they are satisfied?

Patient health outcomes measurement of 'quality' means that its measurement is largely independent of patient' perceptions of satisfactory health care[10]. Do patients equate satisfactory health care with quality health care and just use different (unknown) outcome measures or are we not measuring patients' views of quality?

If we are to be confident of delivering health care of the highest quality, we must be confident that we are listening to patients at every step of the quality journey, allowing patients to define the outcomes they desire for their interactions with the health care system and, thus, allowing patients to define quality health care.

What we continually move toward using as indicators of quality tend to relate to

the human biology aspects of Lalonde's multi-dimensional model of health[1] rather than any factor in lifestyle or the environment. It is possible that the latter two aspects of health determinants are of more relevance to patients and that outcomes in these areas, although difficult to validly and reliably measure, are of more relevance to what patients see as quality health care.

It is possible that, despite the plethora of satisfaction, needs assessment and quality of care forms collected, the patient is becoming an evermore silent partner in the health care system as their views of quality have largely been sidelined by the number of attempts to determine patient satisfaction with health care. Perhaps the voice of patients is being swamped by patient health outcome driven quality.

It is known that patient health outcomes are not the core of quality from a patient perspective. Perhaps these illusive measures of quality from the patients' perspective are to be found in either the environment or lifestyle aspects of Lalonde's model[1]. These outcomes, whatever they may be, will be difficult to define and hard to measure but they are essential to discover if patients are to be truly involved, on their own terms, in defining quality health care. ■

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Classifying leprosy patients - searching for the perfect solution?

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In medicine, the classification of a disease is used to identify the different aspects of disease presentation and this affects prognosis, treatment and scientific understanding. This is the only way in which the scientific community can share knowledge and improve patient care. Why do patients with leprosy need classifying according to disease type? Classification helps in understanding disease; clinical features can be better interpreted by linking them to the underlying pathology and immunology.

Classification allows the risk of complications to be predicted; patients with borderline leprosy are at a much higher risk of developing reactions than patients with tuberculoid disease. The risk of ENL is also related to disease type with Lepromatous Leprosy patients having a odds ratio of 3·2 for developing ENL when compared with patients with Borderline Leprosy (BL).[1] Many studies have shown that borderline patients having the highest prevalence of Type 1 reactions.[2] The risk of disability is also related to clinical form of leprosy, also being higher in the borderline types.[3] The risks of these complications have practical consequences. Patients can be warned about them and so can take part in managing their own disease, clinicians will be alerted to the possibility and will recognise them more quickly and precious resources and manpower can be focused on the groups at greatest risk. Treatment schedules are determined by classification. Patients with high bacterial loads need and receive longer treatments with multi-drug therapy. Knowledge of the classification pattern within a leprosy-endemic district is important for health services, in terms of provision of anti-leprosy drugs and corticosteroids.

Classification is also important for programme and evaluation and for epidemiological purposes in monitoring the pattern of disease, trends over time, and international variations. This provides information that may indicate reduction

Source : *Editorial, Leprosy Review (2007) 78, 317 – 320*

in transmission or that there is under-diagnosis when only LL cases are being detected. The need for an internationally accepted classification system for leprosy was recognized long ago. The first system proposed at an international meeting was in Manila in 1931. This was followed by systems proposed in Cairo in 1938, Rio de Janeiro in 1946, Havana in 1948 and Madrid in 1953, followed by an Indian classification in 1955.[4] These evolving classifications were based on clinical features with some support from histological and prognostic features and lepromin testing. They separated out the tuberculoid and lepromatous poles and recognised borderline, dimorphous or intermediate categories in between.

In 1966 Ridley and Jopling published a paper[5] that used clinical, histological and immunological criteria to classify leprosy patients across the spectrum, and suggested five member groups: Tuberculoid (TT), Borderline Tuberculoid (BT), Borderline (BB), Borderline Lepromatous (BL) and Lepromatous (LL). This classification recognised the complex pathogenesis of the disease and, for the first time, made sense of the numerous clinical syndromes that leprosy presents, the validity of this classification was later confirmed by Meyers in a clinical–histological study.[6] The timing of this classification was important because it coincided with the initial laboratory work on the immune response to M. leprae, both in man and in the mouse. Key studies in patients confirmed that the immune response determines the clinical and histological manifestations of leprosy in all its different forms. The classification has also been modified; an Indeterminate category was added and Ridley later outlined how patients might enter the disease process and move on the spectrum.[7]

In 1982, WHO recommended an additional classification, of paucibacillary (PB) and multibacillary (MB) types of leprosy, for operational purposes.[8] It was introduced to simplify disease recognition and to ensure that patients were appropriately treated with multidrug therapy. As an operational classification it has been a great success, it has made classification simpler, determined by the number of skin lesions. This meant that expertise in defining the morphology of skin lesions ceased to be a prerequisite for field workers classifying leprosy patients, although health workers do have to recognise the wide range of presentations when suspecting leprosy. Treating leprosy patients has also been made simpler by the WHO classification with just two types of treatment that are now provided in blister packs. Simplification, however, has come with some implications. Since 1982 the WHO classification has changed. Initially it incorporated slit skin smears, and patients with a BI of 2+ were classed as MB. In 1988 a positive skin smear result at any site was sufficient for classification as

MB.[9] Later the need for slit skin smears was dropped altogether, so the current classification of MB includes anyone with 6 or more skin lesions.[10]

Individual countries have also made local modifications; in Brazil, for example, in reference centres where slit skin smears are performed, all patients with positive slit skin smears are classified as MB patients and, in field conditions whenever there is doubt about the classification, patients are treated as MB. In addition, in some regions patients are classified by counting both skin lesions and enlarged nerves. Another impact has been on research. The repeated changes in the WHO classification means that it is almost impossible to compare the results of work that was done 20 years ago with work done more recently. Also, the different diagnostic criteria used complicate the comparison of data among countries and even within a country itself. There is also the risk of misclassification. This has been highlighted in a study done in Brazil, Nigeria and Nepal[11] where very different rates of PB / MB classification were found in these countries and also misclassification when using either slit skin smears or PGL antibody detection to assess bacterial status. Furthermore assessing skin lesions is not always easy and depends on the amount of skin examined, and the quality of the light. Furthermore the number of skin lesions may change over time. For example a study from the Philippines comparing WHO classification with the Ridley-Jopling classification found that in patients whose leprosy was classified as paucibacillary, 38%–51% of them had multibacillary leprosy according to Ridley-Jopling criteria and were thus at risk of under-treatment.[12] Both groups are heterogonous. The PB category comprises patients with indeterminate, TT, BT, BB and even early BL leprosy types. The MB category is equally heterogonous and comprises BT, BB, BL and LL patients. In a recent study in Northern India where new MB patients were recruited histological examination found that 60% of these new MB patients were smear negative BT patients.[13] These patients were thus at risk of being over-treated. However it should also be noted that both clinicians and pathologists show intra and inter observer variability in assignment of patients to the Ridley-Jopling groups. The two classifications, Ridley Jopling and WHO, should be seen as being complementary rather than exclusive. It is best to focus on the situations where each classification performs best. In the field the WHO classification is appropriate, especially in highly endemic, low resource settings. It is easy to use and teach, general health care workers can be confident in their diagnosis and it is easy to allocate patients to the appropriate treatment regimen.

Referral centres should probably use both classifications. The WHO classification remains useful for allocating patients to

treatment groups. In the context of research, however, it is better to use the Ridley-Jopling classification, which promotes a better understanding of the disease pathology, prognosis and the risk factors for complications. In research a classification is needed that provides reflects the spectrum of the immune response and provides standardisation and comparability over time and place. It is more complex and requires access to at least slit skin smears and should be supported by histopathology where ever possible. It would now be timely to establish agreed clinical and histological case definitions for classification together with protocols for patient classification.

It is strongly recommended that the Ridley-Jopling classification is used for any study looking at immune processes in leprosy and for genetic studies identifying genes for susceptibility to either the disease or its complications.18 It has also been agreed at the Editorial Board that research papers submitted to Leprosy Review should use the Ridley-Jopling classification unless there is a good reason not to such as in field based operational studies. ■

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14

Rapid assessment of referral care systems - a guide for program managers

Kim Cervantes, René Salgado, Misun Choi and Henry D. Kalter

Background

For successful referral, there must be first and foremost geographical access to referral care facilities. Provided referral services are accessible, referral staff must be trained to provide quality care, services must be affordable, and essential drugs, supplies, and equipment must be available. The most complex aspect of referral care is often the caretaker's acceptance of and compliance with a referral recommendation. This is often determined by a variety of factors, including the perceived need of a referral (disease severity), caretaker / community experience with and impressions of the referral facility (quality), and cost (time and resources).

In most countries there are two major types of health facilities - primary care facilities and hospitals. Health care systems are often designed to encourage caretakers to seek care first at the primary level and then be referred, if necessary, to a higher level of care. If this reflects actual care seeking behavior, then health care costs for the caretaker will be minimized[1].

In many countries, however, caretakers often bypass primary care facilities and seek care directly at referral care hospitals for illnesses that could be easily treated at the primary care facility[2]. This can overburden the referral facility, and is often costlier for the caretaker and the health care system. There are varying reasons why patients seek care directly from hospitals. Bapna found that in India, 55.7% of caretakers sought care directly at the referral facility because they perceived that the referral facility provided better quality services. There have been several scientific studies conducted to look at the operations of referral systems, some looking at barriers[3] and others simply describing referral patterns[4]. Although many similar factors influencing referral have been documented, they vary by country and region. For example, in contrast to patients seeking care at referral

Source : *Excerpts from Basic Support for Institutionalizing Child Survival Project (BASICS II), United States Agency for International Development, Virginia, USA, November 2003. www.basics.org*

facilities in India and Zambia, Tulloch found that most mothers in Indonesia refused to accept referral to the hospital because they perceived it as a place where children go to die[5].

Caretakers may be faced with a number of barriers before they comply with referral advice. Such barriers can be financial, geographic, and cultural. The relative importance of these barriers is presently unknown to public health planners in most countries implementing IMCI; consequently, interventions to improve caretaker compliance with referral are difficult to develop. Health workers may also have difficulty in complying with guidelines for referral - especially in rural areas where caretakers may be faced with many communication and transportation barriers.

Factors predicting health care utilization also vary, although similar barriers are often found- particularly the cost and lack of transportation, the cost and perceived quality of medical services, unrecognized disease severity, and seasonality[6]. The timeliness of referral is key to preventing mortality and morbidity.

Conceptual Models for Studying Referral

There are two conceptual models that can be used to clarify the referral process. One of these is the Pathway to Survival[7], developed by the Centers for Disease Control and Prevention (CDC) and the BASICS Project. The Pathway to Survival offers a framework for tracking the status of an ill person through actions taken inside and outside of the home, and by informal and formal health care providers. The pathway begins with the caretaker's recognition that the person is ill and requires care. The caretaker assesses the level of severity, examines her options, and makes a decision whether to give care in the home or to seek outside care. By definition, severely ill person who are given home care (instead of seeking outside care) are receiving inappropriate care. If the caretaker decides to seek care outside the home, she can use either formal or informal health services. Frequently, caretakers will use more than one provider at the same time or at different times as the illness progresses. The quality of care by the different providers is an important determinant of outcome, and includes whether the provider appropriately refers the person to a higher level of care. A person who exhibits signs of severe illness but is not referred is receiving poor quality care. At first-level and referral facilities, compliance with referral guidelines by both the provider and caretaker becomes very important, as does the quality of care at the referral facility. The Pathway to Survival offers a clear and precise way for looking at pathways and impediments to survival in most situations. For the purpose of this assessment, actions related to referral can be examined. The second model explains how the referral process actually takes place in a given country.

In most countries there are tiered systems of health care, often having three levels.

At the primary or first level, one can usually find health stations or posts and health centers. These two types of facilities are usually the main avenues for dealing with the health problems of the population. Often, the smallest facilities (e.g., health stations or posts) are staffed by one or two health assistants, who have at their disposal a minimal number of materials and drugs. These health workers manage a variety of illnesses and are also responsible for the health care needs of adults, maternal and reproductive health, etc. Health stations and posts refer severe or difficult cases to a higher level of care, usually to a health center or mini-hospital located nearby. Often, however, guidelines stipulate that a health station or a health post can refer directly to a district or national hospital when it is deemed that the severity of the illness or the potential for caretaker non-compliance warrants it. All health centers may not be configured equally. Some health centers in peri-urban areas and in the main cities may not have inpatient services, while facilities farther away from population centers may have a small number of inpatient beds. Health centers are generally staffed with a larger number of personnel, have a wider range of services, and may even have facilities to perform basic laboratory tests (e.g., malaria, hemoglobin, etc.). A number of severe cases may be resolved at this level, but often, referral may be necessary to the district, regional or national referral hospitals. Although health centers may constitute a referral site, they are usually considered a primary-level facility.

At the secondary level, there are usually district hospitals. These hospitals offer basic specialized services - pediatrics, gynecology and obstetrics, internal medicine, and surgery. They are generally equipped with more sophisticated equipment and can perform surgery and other complex procedures and tests. They receive cases sent from health stations and health centers and may refer cases to regional and national referral hospitals.

Finally, at the tertiary level, there may be regional hospitals or a national referral hospital, often located in the capital city. Most hospitals have both outpatient and inpatient services. They see all referrals made from within the city where the hospital is located, but also receive referrals from regional and district hospitals, or even from primary care facilities. Referral hospitals may also receive high numbers of self-referred patients who bypass the primary and secondary levels of care altogether. A discrete pathway for referral actions can be constructed for most health systems through consultation with MOH officials. Theoretically, health stations or health posts refer cases to health centers. From health centers, health workers are advised to refer cases to district hospitals. These hospitals are usually identified as secondary care facilities. The last steps of the referral pathway may include regional and possibly national referral

hospitals. Although a relatively simple referral pathway can often be constructed, for the purposes of the referral assessment, all possibilities for capturing referred cases should be explored.

In some situations, health stations and health posts may choose to refer directly to the district, regional, or national referral hospitals. Similarly, health workers in health centers may skip the district hospital and refer directly to the national referral hospitals. These skips may be justified by a variety of factors, including:

1. Knowing that certain conditions can only be treated at a specialized level of care;
2. Knowing that there is a closer / more easily accessible facility (that is not their assigned referral site); and
3. Making alternative recommendations in cases where caretakers may not go to the recommended referral facility (e.g., previous bad experience, lack of drugs, etc.).

For example, if a health worker is aware that the provider working at the referral site is at an in-service training course, or if drugs are generally not available, he or she may send a case to a higher level of care than that which is usually recommended. These kinds of situations need to be contemplated when studying referral.

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The full document of Rapid Assessment of Referral Care Systems: A Guide for Program Managers can be downloaded from the publications section of the BASICS II Website, www.basics.org. All instruments are available in Microsoft Word format for use in field research.

15

Potential role of dermatologists and dermatological services in developing and sustaining the leprosy control referral system in resource constrained settings

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Introduction

Many countries are now faced with the challenges of sustaining leprosy control services under the circumstances of diminished disease burden and in the face of ongoing health sector reforms[1,2]. The World Health Organization (WHO) and members of the International Federation of Anti-Leprosy Associations (ILEP) have responded by developing a global strategy for further reducing the burden of leprosy and sustaining the activities[2]. More recently, a set of operational guidelines has been produced, which should be used as a template for developing national guidelines[3].

Country programmes remain challenged with decisions of who should implement the proposed strategies. Hitherto, many countries had specialized leprosy programmes right from the lowest implementation levels, through supervision at district and regional levels to national levels. It was also commonplace to have medical doctors specialized as leprologists.

These and other aspects of leprosy control programmes will no longer be cost effective in the future. New strategies have to be developed for ensuring quality care for the leprosy cases that will continue to be detected. The backbone of the strategies is thought to be integration of leprosy control activities into the general health services[4–6].

Dermatological services, although considered as one option for managing integrated leprosy services, have been deemed inappropriate for taking over the responsibility for the control of leprosy because they concentrate mainly on curative treatment[5]. That not withstanding, dermatologists will continue to play a pivotal role in sustaining leprosy control services.

Source : *Leprosy Review (2007), 78, 34-37*

Relative distribution of dermatologists and the leprosy burden

The relatively few dermatologists in developing countries are mainly concentrated in cities and universities[5]. Dermatologists in the public sector are usually so occupied with administrative issues that they are left with lesser time to practice their profession. The services of the ones in the private sector are usually not affordable. In the particular case of Africa, there are not even enough dermatology books to consult[8]. Like dermatologists, leprosy cases are unevenly distributed, although the concentration of the latter follows a different pattern. Early leprosy would most appropriately be diagnosed in a general health care setting that pays due attention to skin conditions. In Uganda (where practically all dermatologists are located in large towns), about 3% only of new leprosy cases are detected in urban settings; an even lower proportion are actually residents of urban or peri-urban areas[9]. Extremely few of them are either diagnosed by a dermatologist or ever get to see one throughout the course of their treatment.

Leprosy control services

Leprosy control services usually refer to those dedicated to suspicion, diagnosis, medical management and rehabilitation of people affected by leprosy. They may take the form of fully or partially integrated services at different levels of the health system: national, regional, district or in implementing health units. Front line implementation of multidrug therapy (MDT) services is often the responsibility of general health workers supported by a supervisory system made up of general purpose or specialized supervisors.

Basic dermatological services at primary health care (PHC) level

These could be defined as the services comprising the diagnosis and management of common skin problems and channeling the more complicated ones into an appropriate referral system. Leprosy can be accommodated into the system either as one of the common skin conditions (if it is present in the area) or one covered by the referral service (if it is rare). It is usually not doctors and definitely not specialists who implement these and other PHC functions. They are commonly provided by multipurpose health workers with appropriate skills. The efficiency of such health workers is dependent on a number of factors like the level of training and the availability of effective support supervision.

Dermatology may not be reflected as an entity in national health plans because of its crosscutting nature but can be implied as part of practically all aspects of any basic health care package. In contrast, leprosy is a stand-alone item in national health plans but at the same time remains listed among the 'neglected tropical diseases'[10]. One of the essential criteria

for inclusion in the latter group is having low profile and status in public health priorities. Since health policies of many resource constrained countries require that strategies for control of communicable diseases be integrated into PHC services, it is quite logical to make leprosy control part and parcel of dermatological services which (however scanty they may be), are already integrated into the PHC services.

Role of dermatologists

In the above context, the few dermatologists, given their relatively high profile in the health service hierarchy, would have the following opportunities to promote sustainable leprosy control services:

- Having access to decision making processes regarding the content of curricula of Medical Schools and other pre-service training institutions.
- Being involved in the implementation of various training programmes.
- Having easy access to the normal cross-referral (horizontal) system involving other specialties like General and Orthopedic Surgery and Ophthalmology.
- Making better use of the vertical referral system already under development in the country; this could involve, for example, the engagement of Dermatology Clinical Officers (paramedical specialists) to support the basic services at Regional level.

The training of Dermatology Clinical Officers offers significant amounts of time to leprosy[11]. Through taking advantage of those and other opportunities, the dermatologists would carry the responsibility to ensure that leprosy cases identified along the way receive good quality care. In addition they would be made more alert to their duty to continue the search for solutions to the many unanswered problems posed by dermatology in general and leprosy in particular[12].

Role of National Leprosy Programme managers

Even in countries where dermatologists are not yet in any formal relationship with the National Leprosy Control Programme, they have the potential to form an essential component of the referral system for leprosy. In addition to formalizing that relationship, the National Managers have the responsibility to get their other already existing partners to support the development of dermatological services especially by training some more dermatologists and Dermatology Clinical Officers or their equivalent. In this way, both the national managers and their partners would be responding appropriately to the main objectives of the Global Leprosy Control Strategy.2 It may be quite reasonable to take the approach of encouraging present day specialists in Medicine and even leprosy alone to study dermatology[11].

National Programmes should ensure that the few dermatologists (whether in the public or private sector) remain well versed with trends in the leprosy control field not only for purposes of perfecting their own practices but also for developing and leading the dermatological services' referral system with leprosy as an integral part. ■

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Does nerve examination improve diagnose efficacy of the WHO classification of leprosy?

Nerve examination is a tool that has been employed for decades in the examination of leprosy patients. It can be easily taught and mastered with continued use.

Thus it seems to be an effective alternative to the slit skin smear in order to classify leprosy patients for the purpose of treatment.

This can even be used in remote centres and in resource poor settings, as it does not require any laboratory equipments and trained technicians.

Source: *Excerpts from Chandana R, Patnaik A, John O, Rao PSS, Indian J Dermatol Leprol, 2008, 74, 327 – 330.*

'Benchmarking'

Benchmarking is a process for finding, adapting, and applying best practices. The concept of learning from others' experience is perhaps as old as human society; however, the first widely publicized use of the term “benchmarking” was in 1970s.

In general, the two key concepts in benchmarking are the idea of systems or processes and the concept of “benchmarks.”

Benchmarking typically focuses on innovations in managing a given work system or process, while the “benchmark” is the measure by which that system or process is judged to be successful or effective. Because benchmarking is a quality improvement approach focused on processes, the process of interest must be defined. This is partly why many benchmarking efforts are connected to strategic planning processes.

However, benchmarking can be used as a stand-alone tool for developing a new service or improving an old one. One of the important ideas to keep in mind is that benchmarking does not mean replicating someone else's process exactly, but rather seeking out aspects of a successful process that could improve your own work.

Ed Kelley, Joanne Ashton, Thada Bornstein
Applying ‘Benchmarking’ in Health, Quality Assurance Project,
Center for Human Services, Bethesda, MD 20814-4811 USA

ICT in health care

"The sheer size of healthcare sector in the country will necessitate extensive use of information and communication technology (ICT) infrastructure, services and databases for policy planning and implementation.

Such a framework would require services based on inter-operable and sharable technology, connecting various institutions and service providers.

The vision is to establish ICT as a major facilitator of heath care and knowledge management in the country, which will enable various stakeholders to have easy and affordable access to information, whenever and wherever they need it.

The medical knowledge and health care information generated as an outcome of this endeavor will significantly improve the health status of the people of India."

Management of Health Sector in India
- Recommendations for the National Knowledge Commission (NKC),
Report of the working group on Health information network, 2007