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LEPROSY CONTROL: PERSPECTIVES & EPIDEMIOLOGICAL AND OPERATIONAL ASPECTS

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SUMMARY

Objectives: As a starting point, a vast variety of 200 technical papers and documents published during the ten years 1999-2008, from Brazilian and international organizations dedicated to the control of leprosy, was taken. A study was then undertaken to investigate its future evolutive possibilities by employing resources obtained from scenario analyses. *Design:* The methodological reconstruction in use was of a qualitative nature, based on a bibliographic review and content analysis techniques. The latter were employed in a documental, categorical, contingent, frequency-based format, in compliance with appropriate and pertinent conditions. *Results:* Nowadays, important elements on epidemiological and operational aspects have been regained, as well as respective perspectives. *Conclusions:* A projection is made towards the fact that the maintenance of the disease's present incidence levels constitute economic and sanitary challenges that confront issues ranging from the neoliberal model of global societal organization to specific competences of actions taken by health teams in the field.

KEYWORDS: Leprosy; Control; Epidemiology.

INTRODUCTION

Leprosy continues to be a great Public Health problem in Brazil, as it is recognized even by sectoral authorities, those responsible for the control of disease in our country¹. Efforts have been hampered by gaps in information relating to important specific aspects, exacerbated by the absence of appropriate instruments for evaluation and routine systematic analysis²⁰.

The exploration of possible health evolutions within the next few years has been drawn to attention in several important publishing materials, including the official periodical issued by the World Health Organization (WHO) who published a review¹³ on the health dimension of 31 previous studies on global scenarios. The review showed three possible prospective alternatives expected: i) infectious diseases; ii) medical technology, and iii) sustained health. Focusing on the first, it deals with the reemergence of former diseases or the appearance of new ones, and stems from social, political and economic factors which lead to human movements that facilitate new contact with microbes, which are associated to changes concerned with productive activities, such as deforestation, road construction and changes in irrigation systems. Microbial resistance, personal behavior and environmental pressures relate to the second period, which, if accompanied by social balance, will go through a time when: a) public policies shall actually protect the natural needs of future generations; b) global surveillance and monitoring shall lead to the eradication of disease; c) despite

the aging process of the world's population, health will be easily at hand and, "moreover, disparities among poor and rich countries shall eventually disappear".

Under this line of scenario analysis, leprosy control has been intensely analyzed by some experts¹⁴. In fact, an epidemiological model was adopted based on figures regarding new detected cases obtained from 1985, using national data published by the WHO's Weekly Epidemiological Records, working with 14 countries where such values were equal or greater than 2000 in 1998. The respective temporal series were shown to be rather unstable, thus reflecting - although with some delay - changes that were introduced to the policies of control. Three basic evolutive incidence standards were obtained: i) stable or rising, as for the cases of Brazil and India; ii) a sudden rise, as for Myanmar, Nepal, and Madagascar, and iii) a decline, as for the Philippines, China, and Vietnam; fluctuations in Guinea were too harsh. It was observed that, as several possible scenarios are simulated, the time corresponding to the reduction of 50% was seven to 14 years, according to differentiated interventions of the BCG vaccination, universal adoption of multidrug therapy (MDT) and socioeconomic changes; "the most important conclusion is the slow rhythm of disappearance in all the scenarios taken into account". Given that the elimination of such condition received WHO attention, which differs from concepts conferred among others, it is recognized¹⁵ that "sick people with no current urge for treatment, though possibly physically impaired, were removed from formal records" and, therefore, will continue to coexist with the disease.

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METHODOLOGY

As a starting point, a vast variety of 200 technical papers and documents published during the ten years 1999-2008, from Brazilian and international organizations dedicated to the control of leprosy, was taken. A study was then undertaken to investigate its future evolutive possibilities by employing resources obtained from scenario analyses. The methodological reconstruction in use was of a qualitative nature, based on a bibliographic review and content analysis techniques. The latter were employed in a documental, categorical, contingent, frequency-based format, in compliance with appropriate and pertinent conditions.

EPIDEMIOLOGICAL ASPECTS

The reasons for the inaccuracy of the information obtained from registered prevalence studies have become of common knowledge. In addition to the so-called epidemiological "iceberg" due to low coverage by health services, the first question posed refers to patients in relapse or drug-resistant bacillus carriers, who are both ordinarily discharged from hospital. Inconsistencies when defining cases and diagnoses formulated under different criteria make comparisons between successive years or different regions a difficult experience, "if not impossible". Point prevalence rates, i.e., a day defined in the year, as it is employed in leprosy, are also known to be affected by the duration of the condition, as they do not consider patients who undergo treatments lasting less than one year (currently the paucibacillary and probably the multibacillary in the future).

Indignation is concentrated in an official document issued by the WHO²², which quotes "non-existing patients" regarding a "diagnosis validation study" carried out in several regions of India: two "individuals with significant clinical experience" reviewed patients initially evaluated by health professionals in order to check the diagnostic accuracy and they discovered that approximately 30% of diseased persons in Delhi's clinic hospitals could not be confirmed at the addresses provided, which, in a few cases, were even fictitious. The author begins by questioning the qualification of "validation" ascribed to research, as this category does not solely imply consideration with an independent evaluator, but also with independent instruments, which, for leprosy, consist of skin smear, biopsy, and application of Polymerase Chain Reaction (PCR) in order to detect bacillary DNA.

The second criticism is directed towards the terminology created for "non-existing patients", as everyone working with leprosy knows that many "existing patients" use the mistaken address strategy to minimize the effects brought on by stigma and ostracism either for themselves or their families. The third factor that generated confusion was the recommendation according to which 1/3 of the diseased should be discharged from the record when, in compliance with the previously mentioned argument, these patients are the ones in greater need of record and follow-up.

The lack of acquiescence would be even greater if information circulated about a few current practices that are legitimated as MDT is adopted. For instance, the immediate discharge of the active record of patients presenting incomplete treatment who have been absent from a health care unit for over a year, as revealed during the consideration of the favorable impact of such a therapeutic scheme in the Regional Health

Department of Juiz de Fora, an inland city in Brazil, with nearly half a million inhabitants²³.

Control of patients' contacts continues to be an important question to be resolved: in Brazil, even in epidemiologically well surveilled regions, it is usually not higher than 1/3 of registered notifications²⁶.

In specific reference to the African reality, it has been found out³ that official figures can often provide an "overoptimistic" image of the situation. As quoted by the authors, a fair example is noticing that the number of records in many countries, at the end of the year, is smaller than the one of multibacillary cases detected during the period. Well, if leprosy takes on any importance, that is owing to the incapacities it presents: these "are supposed to attract a lot more attention than they presently receive".

As SOUTAR²⁴ puts it, "it is possible to suggest that past failures related to other control initiatives, such as, for example, the ones of malaria and tuberculosis, contain lessons that WHO might as well perceive as far as leprosy elimination is concerned".

OPERATIONAL ASPECTS

Perseverating through the specificities of leprosy, SAUNDERSON²¹ provides quite indispensable additional elements. Amongst the "manifold challenges" that are bound to appear, he envisages that the first to show up with recent concern is to maintain sufficiently trained health professionals as much as taking action against the disease in endemic countries.

Within the presented context, it is clear that the ongoing globalized neoliberal model features the shrinking of the State, deletion of the worker's social and occupational welfare conquests, support to the action of generalists to the detriment of those holding specific competences, the fragility of human bases in economic relations - including the third sector, devoted to service rendering - , finally, by a wide range of factors that lead us to easily understand that "many experienced clinicians, from immediate assistance level up to the scopes of supervision and backup will no longer be working with leprosy patients in the next five to ten years" (in Brazil, we can say that this situation has already been true for at least the same period of time). Therefore, the control of the entire individual health care network is put at stake - from diagnosis up to the handling of complications - either on a quantitative or qualitative basis, both being aspects of the highest relevance.

As a complement, following Saunderson's thinking, how should young professionals learn to examine, treat and guide leprosy carriers? Through digital technology resources provided by distance learning? Teleconferences invading the cyberspace?

Quite straightforwardly in that respect, in a text published by the WHO Bulletin¹⁰ where any conflict of interest is denied, the existence of negative effects in the "campaign" to eliminate the disease are recognized, which should be confronted in the immediate future, focusing on those that refer to the personnel education agenda, research and interaction among services. The key category in such analysis is the mistake committed in understanding the proposal in terms of, if ever being eliminated, the disease falling back into importance. In an apparently ingenious pragmatism, the following is put into question: "Who can

pursue a career regarding a disease that is considered to be extinct?"

The mentioned scale of difficulties refers to the conditions to integrate control in local health care units, a guideline adopted by most countries - due to process economic reasons. Also at this level, it is true that qualified professionals are scarce as well as the facilities required (they quote the case of a Hindu province where there is a health care center for 200 thousand people when these figures amount to 30 thousand in other regions). Surveillance needs to be the central strategy to be developed, mainly in areas where integration is found, even in different moments of deployment: either incidence must be meaningfully raised through an increase in detection or abandonment through the difficulties to go ahead. Within this context, an additional challenge appears: non-governmental organizations are particularly invited to redesign respective performances for the substitution of vertical actions.

As a consequence, they predict hindrances to occur in activities which are to be maintained, i.e. in the identification of cases, treatment application, incapacity prevention, and determination as well as the conduction of neural lesions. In the first aspect, they admit that diagnosis, although simple, calls for competence in the formulation of differentials as well as in the perception of neural involvement (they highlight the fact that anesthetic changes are not found in one out of three multibacillary patients).

As a complement, nosographic peculiarities become priorities as well, mainly the following:

- i) increasing demand for recognition in communities and services, of cases presenting a high bacillary load, which call for at least 24 months of MDT, as it is of common knowledge;
- ii) tendency for the adoption of operational schemes devoid of intake supervision, contrarily to what is adopted in relation to tuberculosis, a biologically similar mycobacteriosis that presents failed adherence in unmonitored regimens;
- iii) gradually increasing the urge to assess the relapse rate five years after the introduction of the drug;
- iv) the event of reactive phenomena in one out of three multibacillary patients, requiring primary health care units to supply immediate access to make corticoids available and a reference system for more complex centers, for which special conditions are required;
- v) prevention of incapacities, devised to last for the patient's whole life, which is critical to achieve control success as even nowadays most treatment events comprise ulcerations and other respective outcomes;
- vi) the fight against stigmatization and insertion in public social inclusion programs, in addition to a reduction in poverty and misery - conditions associated with the highest rates of disease.

As a powerful manifestation of reality, World Health Organization stood out as it published a document regarding the global strategy to reduce leprosy in the morbidity of countries and also the maintenance of control activities.²⁷ Clearly, its sense is, on one side, to confirm the previous Organization documents in relation to classic actions taken against the endemic disease; dialectically, when pursuing such a conservative principle, it innovates and in doing so implies recognizing that the condition follows its shameful course in the midst of populations. The central ideas are actually surprising:

- i) In three years (2001 to 2003), only by considering official data and disregarding the old epidemiological prevalence "iceberg"¹⁸, nearly

two million citizens were infected worldwide!

- ii) The campaign-prone approach must be banned! More clearly to "maintain control activities in the long run, the 'campaign-like' approach must be reinterpreted towards a long-term service maintenance process against leprosy, which is able to deliver high quality, integrated services".
- iii) "Specific competence in leprosy as well as its control must be maintained within both national and subnational levels".

Above all, voices questioning the resolute MDT validity concerned with disease control and mainly physical sequelae have been heard once again, in a new approach of well-known controversies that appeared at a time when such strategy was introduced as a routine, redeeming measure⁹. Some of them point to the absence of evidence on how it reduces leprosy incidence and to the difficulty in separating its own effects from the action caused by confounding factors². Specifically, they state that no consensus has been reached by experts concerning its early administration and prevention of incapacities.

In fact, this issue had already been closely examined and drawn into incisive conclusion²⁵. Even in the sense that WHO ascribes to "cure" as the "successful conclusion of a given evolution with MDT", if cure is attained in levels up to 67% for paucibacillary patients and 38% for the multibacillary and such situation cannot be due to drug resistance, then the medication at issue is not able to solve the endemic situation. Furthermore, it is said that the cure by MDT, therefore, in addition to being mistaken, leads to serious outcomes, such as drawing attention away from more severe situations associated with the disease. For the sake of clarity and depth: "leprosy shall remain a health issue until the quality of life of those affected by this condition is meaningfully enhanced".

Then, how to rebuild it? It is emphatically sustained⁶ that the future of collective issues posed by leprosy will only find a solution through the integration to general health care services. Indeed, reports thereto are not scarce in respective technical literature, either in Brazil⁷ or in other countries¹⁷ and even in terms of operational research, with a long description about how a non-governmental organization took action in India¹⁹.

PERSPECTIVES

It is this effervescence of a leper's singular situation, which is visible before perceptive eyes that the disease tends to follow through. Everlasting for so many individuals in the past, present and future, such situations cannot be forgotten or solely dealt with by means of bandaging. They make up elements from greater units to be considered in a non-segmented mood. They are inseparable parts of subjects who, on their turn, interact in society. They live together even when walls and fences are built in-between.

In other terms, a reference is made here to the need to get over previously mentioned gaps and stumbling blocks, the search for and discovery of other prophylactic measures and therapies, which are not only centered in medicative action against the bacillus in a mechanical and isolated way.

As a solution, there is the synthesis that combines research in fundamental science and investigative development devoted to practical

control aspects²⁸. This speech would refer to the evolution of microbial genomes, pathogen-host interactions, susceptible genetics, biological instruments against transmission blocks, drug resistance, detection of soluble cytokines, comparative genomics, molecular epidemiology at last directly, bacillary neurotropism and immunology as priorities requiring high dedication and financing.

Within this context, the rediscovery made by the contribution of the academic community played by systematic physical activity practice for primary, secondary and tertiary leprosy prevention was a conquest that is disclosed in few, remote parts of the world. As an element used previously to its full extent and successfully for decades inasmuch as it refers to non-transmissible diseases, it has only recently been reconsidered in relation to transmissible illnesses. By deconstructing misunderstandings derived from previous views⁸, leprosy has deserved special attention in such a respect that if it is not taken into account as a priority in poor countries, it is hardly supposed to be taken seriously in developed ones, where it is not the priority of health policies. An important way to be taken, in that sense, is the one pointed out in Brazil by MONTEIRO & GONÇALVES¹⁶ in their investigation in a hospital context. They found out that, although physical activity may be presented as a risk factor for the disease outbreak and development, it also means, on the other hand, a protective factor concerned with neuritis events. It is also undeniable that there still is a lot to be known in that respect as well.

It is worth quoting that it is a matter of providing people with practical intervention, which, under specific interaction features, outdoes isolated pedagogic, playful, competitive or biologic aspects. When incorporating new perspectives, personal as well as social aspects of inclusion in society should be dealt with. Specifically, the rehabilitation process would lose its strict meaning of “habilitating again” but it would start to favor personal autonomy by respecting the characteristics of what is experienced by each individual.¹¹

As recalled¹², the guidance “philosophy” towards inclusion goes through an enhanced autonomy of people in disadvantage, with interventional participation as well as collaborative participation. Objectively, social environments do not need to be mandatorily adapted because when these users are treated for their disadvantages, they become active from their personal diversities in needs and expectations. In other words, focus passes by and goes beyond strictly environmental adaptations.⁴

CONCLUSIONS

1. It was possible to specify a way to apply the qualitative methodology of scenario construction in order to give a sense of future to the evolution of leprosy control among us in distinguished epidemiological and operational aspects.

2. From different perspectives, including that of the World Health Organization, it is estimated that, unlike reiterating forecasts, leprosy is not supposed to be eliminated as a public health problem in the near future.

3. Within this unsuccessfulness, in opposition to previous manifestations made by sectoral leaders, Brazil is one of the most remarkable countries. Several authors mention, among respective causes, the low prioritization conferred upon the actions of disease control to follow through and put the health service network into practice.

4. It is recognized that the internationally adopted strategy of multidrug therapy presented positive outcomes as to its complete

application (i.e. the cure, according to the WHO) to over 10 million people. However, important shortcomings remain, mainly non-reduction of endemic disease and negative balance generated by campaign-like activity adopted by the strategy. In relation to that, it is recognized as being absolutely necessary to overcome some of its most serious consequences. Reduction and non-replacement of qualified professionals is one of these, as well as the progressive absence of public permanent health services in control of the disease.

5. The number of infected people is great in comparison to the reduction of specialized centers, which has been observed regarding treatment units for the disease and its derivatives. Clearly phrased, the greatest fear is that the population grows simultaneously with the decreased resources and interest for the purposes of handling and control.

6. A possible alternative that is interpreted as a solution might be political decisions towards making contemporary scientific and social development also suitable for specific issues of the disease.

RESUMO

Controle da hanseníase: perspectivas e aspectos epidemiológicos e operacionais

Objetivos: A partir de acervo de 200 textos acadêmicos e de documentos de organismos nacionais e internacionais voltados ao controle da hanseníase publicados no período de 1999 a 2008, procurou-se estudar respectivas possibilidades evolutivas futuras, empregando-se os subsídios do recurso de análise de cenários. *Métodos:* A reconstrução metodológica adotada foi de natureza qualitativa, fulcrada nas técnicas de revisão bibliográfica e análise de conteúdo. Esta última foi empregada na tipificação documental categorial frequencial contingencial, de acordo com devida fundamentação pertinente. *Resultados:* Recuperaram-se elementos atuais importantes de natureza epidemiológica e operacional, bem como de respectivas perspectivas. *Conclusões:* Projeta-se que a manutenção dos coeficientes de incidência da doença coloca reptos econômicos e sanitários a desafiar desde o modelo neoliberal de organização societária mundial até competências específicas das ações das equipes de saúde em campo.

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