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Meanings of Neglected Diseases in the Global Health agenda: the place of populations and territories

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Abstract *The global health agenda has made significant strides in neglected diseases. In a dynamic movement, throughout the past two decades, it has assumed different priorities, strategies and meanings. Nevertheless, important challenges persist in terms of geopolitical, economic, epistemological and social development. The designation and location of neglected diseases in certain territorial spaces and populations is historically related to some dynamics such as those of a colonial and capitalistic nature. They reveal continuities in the rationality of policies and actions, pervading asymmetries between peoples, institutions and nations. Although it has positively included the debate on neglected diseases, it can be argued the global agenda of public health has yet to assume and evoke the dimension of neglected bodies and populations with more theoretical and methodological vigor, by intensifying the dialogue between biomedical and political-economic fields. It means reinforcing the critical understanding of the historical vulnerabilities of individuals in the production of knowledge, as well as giving prominence and taking into account their ways of leading their lives in conjunmction with local public health priorities and practices.*

Key words *Neglected diseases, Global health, Coloniality, Vulnerability*

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Introduction

The shaping of global agendas reveals abilities to attract resources and powers, as it mirrors guidelines and trends in the ways of knowledge production. These agendas include the elaboration of territory- and population-oriented policies. A significant ensemble of authors has devoted time to discuss global policies, their dynamics, contours and priorities, especially with regard to questioning knowledge production and interventions projects, as well as repercussions on the life and health of vulnerable populations. These relationships have been put into analysis in dialogue with the contexts of different national realities[1-5].

Tensions in the production of knowledge and their repercussions in the field of health, records of global policies and health practices are addressed in this article. Healthcare operating ways in the concrete lives of individuals and populations are investigated from the concept of neglected diseases, which are agreed upon in global health agendas, such as those that historically affect vulnerable populations and attract scarce resources from countries and businesses[6].

Notwithstanding scientific advance, neglected diseases persist due to several shortcomings: lack of awareness – insufficient knowledge; market failure – high cost of existing drugs and vaccines; and public health failure – poor planning, negatively affecting access to low-cost or free drugs[6].

The production of knowledge (research, development, innovation, clinical protocols, among others) is not immune to several interests, cannot be mainstreamed to any context or even assumed as of epistemic neutrality[7]. Especially in the Latin American context, debates in the field of public health undertake analyses based on a critical reading of the relationship between knowledge production, policies and health practices anchored in a project that transforms social conditions. This concept stems from the understanding that the set of health ideas, institutions and practices are a fundamentally community-based, multi-actor and interdisciplinary field including society at large and diversity[8-11].

In line with the critical understanding of the health knowledge generation, as opposed to a univocal and hegemonic conception of modern Western science, Lock and Nguyen[7] question the excessive autonomy of biomedical devices, per se, by referring to other realms, such as economic and social ones, (...) *including culturally informed values and constraints, specific local and global objectives, economic disparities and inconsistent or non-existent regulations.*

Is addressing global policies, their objectives and epistemic bases recognizing the existence of something called 'global'? What would be global processes that generate legitimacy for certain transnational agendas? In a setting with a strong presence of diseases that are well known to mankind, affecting populations of countries with a considerable poverty index, especially from the African and South American continents, some underpinning dynamics and concepts, their agents, the political alignments and strategies of action, as well as possible dialogues between different knowledge – global and situated are being proposed for discussion. As proposed by Haraway[12], valid knowledge must be a situated knowledge, understood as an embodied and localizable process, and therefore responsible to the extent of its accountability. This concept is important for social studies of science not only analytically, but also in terms of the production of socially relevant, emancipatory, yet often subalternized knowledge.

Meanings of the global agenda under debate

Recognizing the existence of a global agenda implies confronting the discussion about the phenomenon of globalization. Santos[13] points out the intensification of different transnational relationships that operate new phenomena, such as internationalization of production systems and redefinition of national states' borders for capital market operations, a milestone on which various designations, such as 'global process' and 'globalization' have rested. The author states this is a complex phenomenon with multiple interrelated realms: economic, social, political, cultural, religious and juridical.

With a very close meaning, the approach proposed by Milton Santos[14] abdicates to address the global and local realms as duality, reinforcing the idea of relational complexity, as dynamics in a constantly performing movement. The author proposes the overcoming of 'globalist' or 'localist' approaches, since "the world is everywhere", implying a more dialogic understanding of global/local, universal/particular and general/specific. It

Ciência & Saúde Coletiva, 23(7):2291-2302, 2018

highlights the globalization movement as a hegemonic effort, which advocates in favor of understanding the phenomena as global that produces certain agenda's framing.

When referring to globalization as a phenomenon of different dimensions, Santos[13] points out that it is not something consensual, since it entails tensions of varied natures and interests, both hegemonic and subaltern/counter hegemonic. However, it recognizes the power of hegemonic forces in the construction of consensuses and that establish the faces of globalization, conferring on it its dominant characteristics, as well as legitimizing them as the most appropriate.

Based on the matrix of accumulated transnational capital, globalization assumes several faces, and one of its most perverse nuances is found in social and health inequalities. Health and development are historically overlapping, provided they are conceived as politically, economically and socially produced[15]. Around 90% of the burden of disease worldwide is concentrated in poor countries, which have no more than 10% of global health resources – the '10/90' gap[16]. About one fifth of the world's population does not have access to health systems and services, including essential medicines. The global coverage of basic sanitation services is 64%, covering around one third of the world population, or about 2.5 billion human beings lacking the most basic services in the 21st Century[17].

Otherwise, the Organization for Economic Cooperation and Development (OECD) countries, which consists of 18% of the world's population, accounts for 86% of the world's health expenditure, with a yearly per capita spending of about US$ 2,900. While per capita spending remains insufficient and does not explain internal inequalities of countries such as Brazil, over the last decade, South American countries have made efforts to increase health investments (Figure 1).

African countries have the lowest percentage of health spending, with a large proportion of the actions financed by external donors, which direct guidelines and priorities, shaping national agendas (Figure 2)[18].

The contemporary globalization movement is significant in the area of health arranged around the Global Health concept. Established as a field of multiple meanings – conceptual, political, strategic and epistemological, it is appropriated differently by different agents. Authors such as Koplan et al.[19] question the polysemic idea of 'global health' and undertake efforts in the conceptual stabilization of the field. They argue that the lack of definitions blurs important differences of conceptions, with consequences on strategies and priorities conjured by different agents. The stabilization effort is linked to the need to agree on global health's common goals: approaches, priorities and ways of using resources. The intent of such a conceptual agreement would ultimately be to promote alignment in the international health agenda.

Global health can be understood as an area of studies, research, policies and practices that aims at equity in health for all and around the world. It involves disciplinary bodies not only from the health sciences by promoting interdisciplinary collaboration[19]. In this embedded concept, the idea of sharing and solidarity between countries does not necessarily take into account the interests and specific plots of the globalized capital's asymmetry. Although authors acknowledge that the 'developed world' does not have a monopoly on 'good ideas' and that better ways of handling diseases and environments must be sought in different cultures, issues specific to political economy remain subsumed in their considerations.

The asymmetric distribution of resources and powers, with the predominance of some forms of knowledge, confers innumerable privileges of a political, economic, social and epistemological nature to a given notion of the 'global'. Globalization types respond to transnational imperatives, where "local conditions are disintegrated, disorganized and eventually restructured as subaltern inclusion"[13].

Biehl[20] questions the so-called global health by asserting that an understanding of its contours should take into account the interests of 'donors', which predominate in the operations of international organizations, not necessarily aligned with the interests of 'recipients'. They tend to reinforce asymmetries in the existing power relationships. Magic-bullet-type initiatives are widely criticized by a number of actors in the field. The counterpoint to this model would be the production of strategies geared to the subjects in their territories, and not only etiological agents in isolation, since they act on the assumption of bodies devoid of subjectivities, in the words of the author: "It is time to assign to the people we study and describe the kinds of complexities we recognize

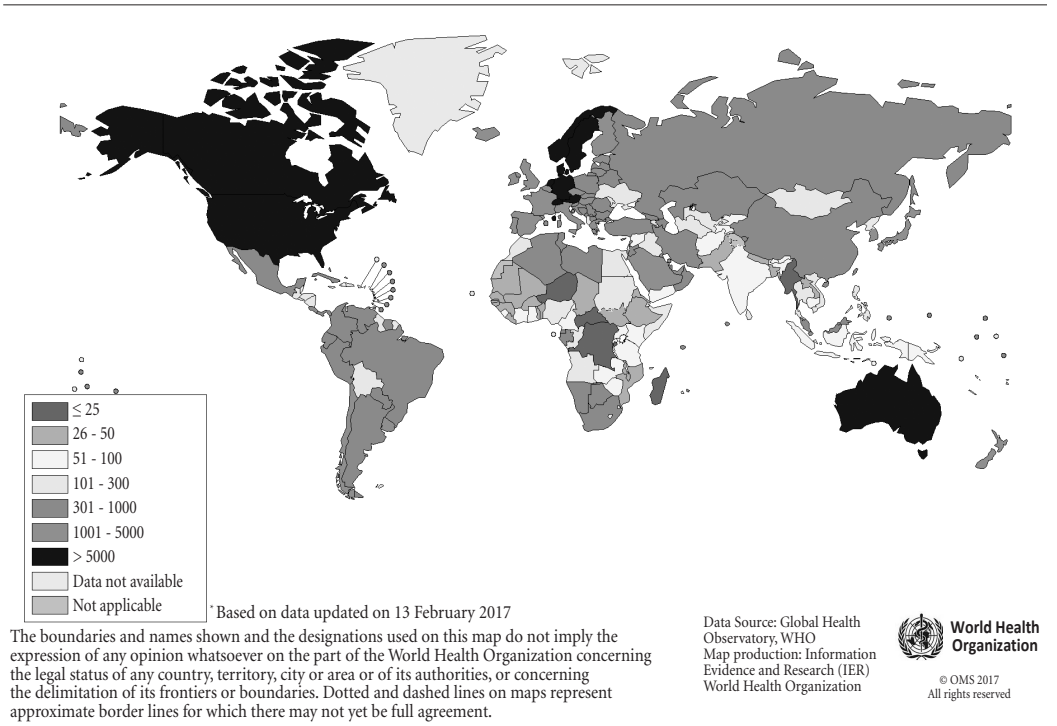

Figure 1. Health spending per capita, by country (US$), 2014.

Source: World Health Organization (WHO) - Global Health Observatory. Map Gallery[18].

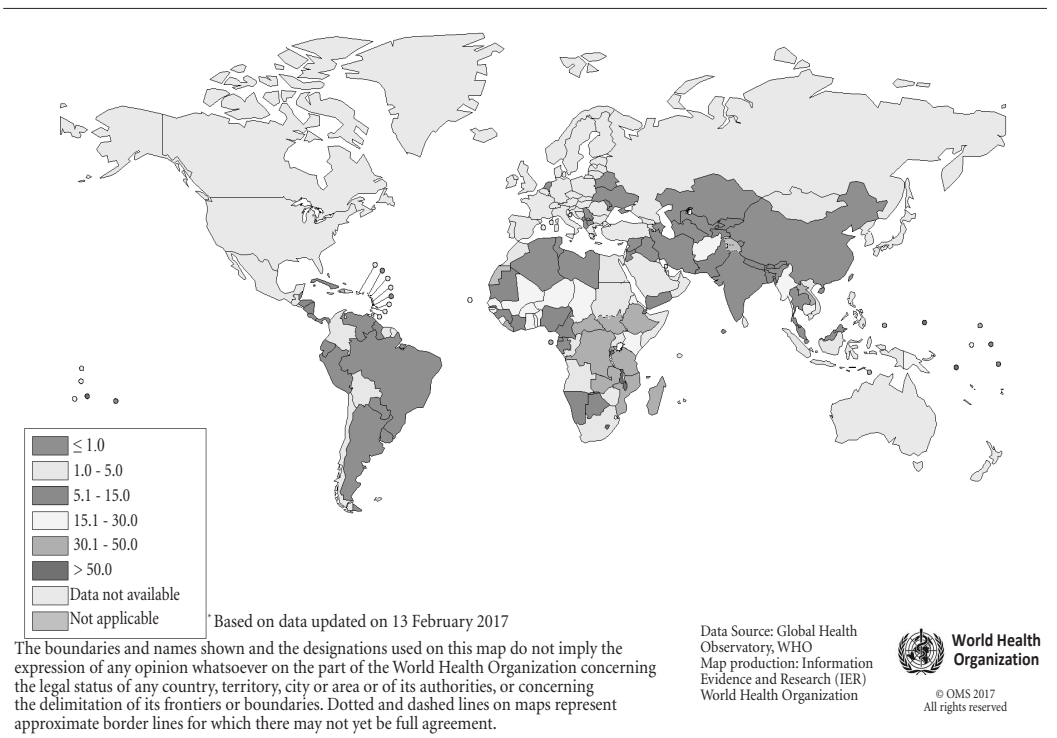

Figure 2. Resource from external sources in relation to total health spending, by country (%), 2014.

Source: WHO, Global Health Observatory. Map Gallery[18].

Ciência & Saúde Coletiva, 23(7):2291-2302, 2018

in ourselves, and bring these complexities into the global health landscape[20]." The concept of 'antiretroviral globalism' proposed by Nguyen[5] also questions this understanding as, upon the emergence of AIDS, the action´s bet was focused on access, not necessarily universal, to a restricted list of drugs.

In works developed with infectious diseases in Haiti, Farmer[2] proposes the idea of 'structural constraints and personal agency', advocating for the power of initiatives that integrate, in an integrated way, health care actions with strategies of longitudinal follow-up of the patient's life. A bet both on coping with structural constraints and the leading role anchored in the agency of subjects in their ways of leading their lives[21].

In recent years, global health has been called to consubstantiate health policies and practices. Lock and Nguyen[7] identify a certain continuity of elements between international health and global health, based on the role of donors and the preponderance of the contributions of biomedicine, which already conformed the so-called tropical and colonial medicine. Colonial spaces served as 'trials' of biomedical practices, and their success grounded the principle of 'biological commensurability'. Thus, these practices were able to return to the metropolis, to the European continent and then stabilized as social practices, embodying something called 'global' in medical terms. However, the concept of 'biological commensurability' located in human bodies implied the search for new rationalities that could uphold the validity of the principle of difference – typical of colonial medicine. Thus, difference is then located in the culture's registry[1,7]. Considerations of this nature propose to reinstate analyses on the establishment and *modus operandi* of global health in other bases, since they are anchored in the situated conditions of the various subjects and territories, under the concept of local biologies[4,7].

Emerging, reemerging and neglected diseases – Global Health taxonomies and agendas

The global health agenda is multidimensional, polysemic and traversed by debates such as disease priorities, control, research, development, and health actions. There is a wide-ranging understanding of the concept of emerging, reemerging and neglected diseases, arising from some debates such as the theory of epidemiological transition and its limitations, especially due to its insufficient explanatory power when AIDS emerges. The epidemiological transition theory presupposes a linear and evolutionary movement of change in the morbimortality of populations – from the overcoming of infectious/transmissible diseases to the chronic-degenerative/non-transmissible diseases. It is based on the assumption of improved living conditions and demographic transition – increased life expectancy and declining birth rates in countries with better human development indices[22].

The epidemiological picture of Latin American countries is challenging the epidemiological transition paradigm. The proposed models do not apply to the different realities, given the coexistence of presumably different patterns in the ways of illness. Brazil and Mexico are exemplary: infectious-parasitic diseases and chronic-degenerative diseases share space with equivalent degrees of importance from the epidemiological viewpoint. There is also a resurgence and/or recrudescence of diseases such as Dengue and Cholera, and more recently, Yellow Fever, Zika virus and Chikungunya[23].

Much in the same way, the emergence of AIDS and recrudescence of tuberculosis have changed the bases of this explanatory model, paving the way for the establishment of a new assumption: that of emerging and reemerging diseases. The emergence of new diseases and recrudescence of old ones, in a complex coexistence due to territorial, economic and social issues imposed new challenges[22].

The case of tuberculosis is paradigmatic. In the late 1990s, the World Health Organization (WHO) announced that tuberculosis was responsible for the deaths of millions of people and was considered a reemerging disease. The return of tuberculosis to high levels is addressed by Farmer[24] as a 'revenge', since the understanding of disease 'return' blurs the permanence of its high incidence in several parts of the world. This 'surprise' on the part of international agencies lies in silencing the tuberculosis situation as a social, economic and health issue on the world's poor populations – with high incidence rates and deaths. Both have been preventable from a biomedical viewpoint since the 1950s and have been relatively well resolved in the richer countries[24].

In the face of this new situation, current challenges are diverse, such as the definition of priority. This is not unequivocal. Priority criteria are

debatable, depending on the social and economic positions held by agents[15].

In 2006, Brazil defined neglected diseases as those that not only prevail in conditions of poverty, but also contribute to the maintenance of inequality, since they are a strong obstacle to development. Guidelines have been formulated to include research, development, and increased access to medication, among others[6,16]. The national agenda is in line with the international agenda. The World Health Report for 2004[25] defines health research as a priority, recognizing it as a health promoter. Understood as insufficient for a wide range of diseases, aspects of research are discussed: belief in the triad health, science and technology as a requirement for economic and social development; recognition of the "10/90 gap"; relevance of the private sector; discrete presence of the least developed countries; international patent protection legislation that hinders less favored populations' access to diagnostics, vaccines and drugs; and the need for health research systems to generate public interventions.

The term "neglected diseases" was originally proposed in the 1970s under the auspices of the Rockefeller Foundation, titling a program called "The Great Neglected Diseases"[6]. The term is further systematized in the document "Fatal Imbalance" by organization Médecins Sans Frontières, which proposes an international agenda around the development and availability of medicines and brings the following taxonomy of diseases: Global – those occurring around the world; Neglected – most prevalent in developing countries; and Most Neglected – unique to developing countries. Then, a working group called the Drugs for Neglected Diseases Working Group (DND) is set, fostering the involvement of countries in systematic and sustainable actions[26].

The WHO Report on Macroeconomics and Health[27] proposes another systematization of diseases in three categories: Type I diseases – affect large populations in both rich and poor countries. For these diseases, the market solves the entire productive spectrum (research, production of medicines and vaccines and their distribution); Type II diseases – while found in rich countries, they are more prevalent in poor countries and resources for research are less abundant; Type III diseases – almost exclusively found in poor countries. Research resources are low and medicines, although known in some cases, are not fully accessible. According to WHO, neglected diseases are in this group and are conceived as such because they establish a group strongly associated with poverty. Many have already disappeared from much of the world with improved living conditions[17].

While having a strong influence on health conditions, neglected diseases have historically received insufficient attention from international and country agendas. They exerted little attraction on industry because they were more circumscribed to low-paying populations. They proliferate in poor environmental and housing conditions. Many are lethal or have disabling consequences, which entails compromising family and social dynamics; they burden health systems in already economically disadvantaged countries and affect the productive capacity of their population, setting a vicious cycle with high repercussion on human development. Because they are more circumscribed diseases to already deprived populations, they exacerbate social exclusion, reinforce historically plotted stigmas and narrow future generations' perspectives[6].

The inflow of Neglected Diseases into the global agenda reflects WHO's leading role. In 2007, we witness concerted actions among multiple global players. The Global Plan to Combat Neglected Tropical Diseases 2008-2015[28] is an effort to shape the global agenda, which includes setting priorities, guidelines, strategies and targets for reversal to a range of diseases. The overall plan is expected to control, eliminate and eradicate diseases by defining interventions such as expanding access to therapeutic and prophylactic drugs. It defines a list of seventeen neglected diseases targeted by transnational actions, namely: Chagas Disease, Dengue, Buruli Ulcer, Cysticercosis, Dracunculiasis, Echinococcosis, Fasciolíasis, Human African Trypanosomiasis, Leishmaniasis, Leprosy, Lymphatic Filariasis, Onchocerciasis, Rabies, Schistosomiasis, Helminthiasis, Trachoma and Yaws. Chikungunya was recently included[28].

The main planned actions involve: preventive chemotherapy and transmission control; vector control; provision of drinking water and sanitation; zoonosis control; and case management intensification[17].

In the Reports *Working to Overcome the Global Impact of Neglected Tropical Diseases*[29,30]; *Sustaining the Rive to overcome the global impact of neglected tropical diseases*[31]; *Investing to Overcome*

the Global Impact of Neglected Tropical Diseases[32]; and *Integrating Neglected Tropical Diseases in Global Health and Development*[33] the WHO shows a set of global policy outcomes over the past few years, highlighting achievements and persisting challenges. Issues such as the linkage of diseases to the issue of poverty – the vicious cycle of diseases that victimize the poorest, and the geographic delimitation with a focus on the tropics – are reiterated.

When a taxonomy of diseases is being compared to a given cartography and includes and associates other delimitations in records social and economic 'culture', it conveys the establishment of a political *modus operandi*, ratifying assumptions at a global rhetoric level. These slippages can set political and epistemological narratives that sideline the relationships between institutions and countries. In a historical anchorage, colonial records are questioned in the delimitation of spaces and populations. In contemporary times, the old project of colonization assumes a renewed guise in the terms of coloniality, since it preserves and carries the colonial classificatory elements of the world, updating them in the historical dynamics[34-36].

When a significant set of international actors agrees on and designates a group of diseases as "neglected tropical"[26,28], it ratifies not only the question of neglect, but also the territorial demarcation for the performance of a science directed to the tropics. The use of the term 'tropical', in turn, does not only refer to a geographical and boundary delimitation, coinciding with another limit: that of colonial spaces – living territories with people, culture, expertise, politics, knowledge and phenomena of health.

In geopolitical terms, the map of 'neglected tropical diseases' reinforces some delimitations, such as: North/South; Tropical Areas; and geolocation of poverty and inequality, in a collage with the cartography of the colonial world, as can be seen in the example of leprosy (Figure 3).

The 2015 Report[32] emphasizes the linkage of poverty to neglected diseases and brings important inflections by questioning the guideline of specific and focused actions, as well as the shift in the discourse on poverty eradication versus sharing of prosperity, with a focus on sustainable development. This approach expanded lenses on neglected diseases, pointing to development challenges beyond health issues. Global policy successes analyses highlight elements such as adherence by agents and countries; improved living conditions; and 'generous' donations from global partners[33].

However, important contradictions remain on the global agenda. Guidelines for the control of neglected tropical diseases are still largely based on access to treatment, chemoprophylaxis and the use of pesticides for vector control. It is recognized that there are proposals to expand the capacity of national health systems, especially African ones, and most guidelines are geared to partnerships between governments, international organizations and the pharmaceutical industry[30-33].

Macro-structural actions – while present in all documents, reduction of poverty, sanitation and education, as well as intersectoral actions suffer from more programmatic guidelines. Actions such as these would impose large-scale macroeconomic policies that would imply revised global geopolitics that are absolutely unchallenged, among other reasons, because it is not part of liberal capitalism's agenda. The global investment in improved living and health conditions of these people and the construction of foundations to foster the productive autonomy of health systems and the industrial health complex of these countries, in their various realms, have a rather tenuous and differentiated presence in the agendas, when compared to the other policies discussed here.

The 2000s witness a certain inflection in the way which the international community conceives the relevance of certain diseases, based on the poor life and health conditions of the populations in many parts of the world. An important milestone is its inclusion in agendas such as the Millennium Development Goals (MDGs) and the Sustainable Development Goals (SDGs). This latest realignment of the global agenda - the '2030 Agenda for Sustainable Development', considered Neglected Diseases, proposed as follows: "By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases"[32].

Global Health Initiatives (GHIs) have involved country cooperation programs, especially those with low human development (HDI) and developed countries. The investments and results of cooperation projects have had important

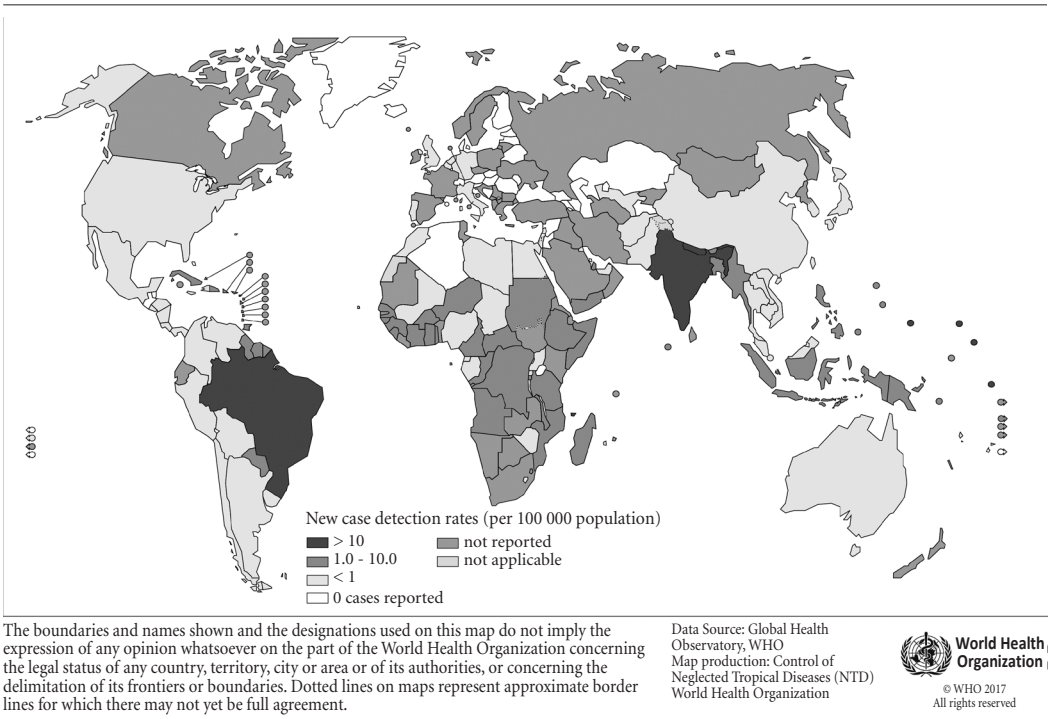

Figure 3. Global distribution of leprosy according to the detection rate of new cases, 2016.

Source: WHO, 2017. Global Health Observatory. Map Gallery[18].

implications for the formulation of strategies, especially those related to the pharmaceutical industry[37]. Despite national efforts to tackle relevant endemic infectious diseases, an important gap is yet to be overcome – lag in research and innovations in this field, due to factors such as low attractiveness of the pharmaceutical industry given the inadequate payment capacity and weak national research and innovation systems. The lack of own resources by governments of many countries for the required investments is extremely relevant[38].

The affected countries are mostly of low economic development and a vicious circle is, thus, in place. Investment in research, development and innovation and new vector control methods are required in addition to coping with inequalities and development. In the case of neglected diseases, while funding is available for research, knowledge produced has not necessarily been sufficient for some advances – production of new drugs, diagnostic methods and vaccines. Morel[6] highlights important initiatives aimed at the production and access to medicines, among which are: *Drugs for Neglected Diseases Initiative* (*DNDi*), *Global Alliance for TB Drug Development (TB Alliance)* and *UNITAID – Laboratory for Innovative Financing for Development*.

Although recognizing the importance of initiatives and the positive inflection in the 'global' setting, it is noticed that, because actions are focused on production and access to drugs, solutions based mainly on the biotechnological matrix are predominant. However, it is noteworthy that, in Brazil, due to the consolidation of the SUS, advances are not only restricted to access to drugs, but also encompass research and development, which have become a priority agenda[39].

A considerable part of the cases reported in studies[37] emphasize that cooperation initiatives

Ciência & Saúde Coletiva, 23(7):2291-2302, 2018

have received specific funding for certain diseases, with actions previously planned by donors and with low systemic intensity. Global Health Initiatives (GHI) interventions have expanded access to health care and medication actions for some diseases, but given weak national health systems and their low organizational response, services are compromised in systemic terms. Actions focused on some diseases, which are the target of non-systematic external financing have disorganized the already weak health systems insofar as phenomena such as attracting and concentrating professionals exclusively to some regions and actions occur, without the necessary integration with other health policies[5,37].

Studies on the impacts of international strategies include, residually, analyses related to the specificities of the affected populations in their ways of living. In studies on the effectiveness of GHIs, the participation of the affected population in the decision-making process is somewhat "shy". However, the intentionality of interventions' design contains guidelines for the inclusion of this population, besides governments and non-governmental organizations. The realm of citizen participation in policy-making is insufficient and of low expressiveness. The decentralization guideline provided for in the guidelines is more restricted to regional and local government management actors, not necessarily the affected population. Studies do not address the issue of participatory forums, which put in debate the guidelines proposed by agencies, with a leading role and based on the knowledge of local agents[37].

Final considerations

Undeniable advances have been made in recent decades in tackling neglected diseases worldwide. Data on increasing access to prevention and treatment of all these diseases, based on epidemiological priorities, have been consistently monitored, evaluated and made available. However, global policy initiatives evidence a yet insufficient synergy between the science forums (research, development and innovation) and health care and promotion actions around these diseases. Synergistic actions imply in multiple languages and participation, and, consequently, in changing practices that are simultaneously social, political and economic.

Concrete spaces, where "ways to walk a life"[21] are manifested and the ways in which subjects need, feel, interpret, translate and conceive health and illness has not necessarily been the setting for health services.

The emergence of a specialty in the field of medical knowledge, aimed not only at infectious diseases, but at a "specific" type of these diseases, called "tropical"[40] is added to other references that are beyond medical evidence, but which, however, inform their practices. In his study of the US military occupation in the Philippines, Anderson[41] discusses the realization of a medical science that is a priori aimed at proving the differences between "ethnicities" and their "bodies". This author seeks to understand the construction of hypotheses and conceptions of illness in the tropics, starting with the very elements of the environment, such as climate. With the emergence of microbiology, the focus shifts to the bodies of the colonized, hosts of microorganisms, while themselves components of a 'space' to be domesticated. The differentiation of bodies and the pattern of illness among white settlers and 'natives' emphasized ethnical differences, consubstantiating discriminatory policies. Taming the disease and the environment means guarding and domesticating 'native' bodies, controlling the territory and ways of living[41]. The designation 'tropical disease' carries elements of coloniality, since it indicates colonial practice continuity lines.

While the control and surveillance realm of the public health paradigm is kept in central countries, the valid concept of control in the sphere of traditional (colonial) tropical medicine and its unfolding are of a diverse nature. A given management of people and ambiences forged non-dialogically takes center stage as a *modus operandi* and is incompatible with the principle of autonomy of individuals, communities or even nation. This geopolitical asymmetry takes us back to the basis of abyssal thinking, in which the concept of surveillance is part of the autonomous/regulatory paradigm for the metropolis (global North), while for the outskirts of the world-system[42] – the endemic tropical zones (global South), what may be in question is the binomial appropriation / violence – of cultures, knowledge and autonomy of subjects[43]. Therefore, paying attention to discursive collages between terms such as 'neglect' and 'tropical diseases' provides a means to think critically about global initiatives

and their translations into national policies and their repercussions on human lives.

The notion of neglect has to be assumed, not only in terms of disease, but also in terms of people and their bodies. They are neglected diseases because they are neglected people. Recognizing the true realm of neglect must presuppose critically questioning rationalities that inform ways of operating policies that, despite undeniable advances in terms of public health, maintain rules and contours in the subordination and dependency milestones.

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