

Social, epidemiological, and control determinants of Chagas disease in American Southern Cone - Working group

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Discussion was opened with the aim to contribute with the ALCUEH net work in preparation of a basis for training, divulgation, and definition of national policies concerning neglected diseases, in the context of Southern Cone Initiative for Chagas Disease (INCOSUR).

The first presentation (João Carlos Pinto Dias) summarized the most important historical and political antecedents of the initiative, as well as its most recent advances and principal challenges in the new millennium.

JR Coura - Starts the discussion asking the participants to focus their interventions in the three main purposes of the meeting, such as: (a) the neglected and or emergent aspects of the disease, requiring additional information to improve the pertinent political action; (b) the main projects for control qualifying and technological transfer; and (c) the regional details for each particular project. As an specific question, ask the participants their opinion about what to do with the other triatominae species in the Region, following the elimination of *Triatoma infestans*.

A Rojas de Arias - Giving her thanks for the invitation and nomination, she remembers that INCOSUR – besides its general and epidemiological purposes, has additionally the task for being an example and a model for similar initiatives in the whole region.

AC Silveira - Remembers that the secondary and native species cannot be eliminated, so obliging us to live together with them, looking for a situation of low density and no colonization. The strategy will be a continuous and strict surveillance, in all endemic areas, focused in the determination of the main risk factors for the vectoral Chagas disease transmission, such as the infestation degree, the colonization capacity, and the anthropophilic characteristic of each species. Finally, points out that, in Brazil, the most important species in the areas where *T. infestans* has been eliminated are *T. brasiliensis*, *T. pseudomaculata*, *T. sordida*, and *Panstrongylus megistus*.

R Zeledon - Agreeing with JC Pinto Dias exposition, reinforces its political aspects and launches two general

and one technical questions: (a) since the vector elimination represents a political question and considering that in general political actions are discontinuous and not stable, is it really the elimination an attainable goal? (b) What can be made to reinforce the political decision of national governments, so avoiding the loosing of the primary objectives? (c) Is it possible that residual Triatominae populations recover the initial scenery of housing infestation?

AC Silveira (answering Dr Zeledon) - It is very difficult the recovery of controlled Triatominae populations, specially in the case of *T. infestans* and after the conclusion of chemical attack phase. This recovery is generally too slow and the regular surveillance actions generally avoid indoors reinfestation. In Southern Cone most of *T. infestans* residual foci are peridomestic and the few and scarce sylvatic foci of this species seem to represent no significant danger for housing colonization. To sustain an effective surveillance it is required a good and fast feed back capacity in a local and decentralized health system, monitored and supported by national and regional health unities. A very frequent and preoccupant gap in such an approach consists in the insufficient and few trained local teams, with the lack of regional supervision.

AR Prata - Three main questions arise from this subject: (a) the need to insist in the elimination of other species strictly domiciliated, as the case of *P. megistus* in great part of Bahia, Brazil; (b) to maintain the regular epidemiological surveillance against the peridomestic species, looking for their withdrawal of indoors space as great as possible; (c) the need to keep in mind that the present success of control programs will certainly to be followed by several difficulties to maintain the priority for the control action.

Prof. Prata still considered that the priorities in Chagas disease tend to go down. Nevertheless, epidemiological surveillance will be required for a long time, being necessary to maintain it, as it has been done for the cases of the plague and yellow fever. He remembers that in the past several rationalities were invoked to impede the starting of regular programs, including in Brazil. For instance, interminable academic discussions were carried on, concerning the options between housing improvement and chemical fight for vector control. By another angle, chiefly in situations of decentralization, other priorities and problems of the local communities use to result in governmental deviations from the Chagas disease program objectives. It is the case, for instance, of several epidemics of dengue fever in Brazil, requiring human resources and even insecticides which fre-

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quently are deviated from the Chagas program. Finally, in his opinion, the recovery of big domestic populations of *T. infestans* after the attack phase will be very slow and difficult, not resisting to regular surveillance. This was been proved in several situations, mainly because the social circumstances are changing in all the Continent, specially in terms of the reduction of huts and rural poor dwellings.

R Briceño-León - Introduces his intervention pointing out the social and anthropologic dimensions of the disease and considering that the main questions from the control side are based in two points: (a) the sustainability of the control programs and, (b) the social exclusion of the population under risk, that means, a neglected population. To improve adequately this discussion, it is important to make the correct differences between neglected disease and neglected population, as it was stated in the first conference. Also considers that INCOSUR experience is paying attention not only to the technical and operative elements of the chemical fight against the vector, but also is dealing with other broader and complementary aspects involved in control consolidation and sustainability. And emphasizes that INCOSUR is demonstrating that is politically possible to attend a neglected disease, even in poor countries and regions. In a first moment, Chagas disease has been a problem attended by the national governmental control programs. Nevertheless, in a further step it will be necessary to focus the actions in the possible secondary species and in the social determinants of poverty and bad life conditions of the neglected populations, specially at the dwelling and educational sides. But also political actions are required, in order to provide structural transformations in the whole society.

R Storino - Chagas disease may be considered a model for complex socio-scientific thinking. The Social Sciences (including correspondent studies and actions) must be involved to understand and to resolve it. In particular, it is indispensable to involve the education, as a manner to maintain the priorities for attention and control, as well as to sustain the necessary surveillance. For instance, insecticides use to be inefficient in the peridomestic ambient, always remaining residual insects able to recover domestic infestation. So, we must understand that all those actions pertinent to Chagas disease control must not to be isolated, but carried on in an integrated, continuous, and connected form. Besides the insecticides of the control program, other actions must be implemented such as the serologic examination of the risk population, the medical examination of the sero positive pregnant women and blood donors, the specific treatment and follow up of young infected people, the medical attention for chronic individuals looking for the reduction of morbidity, etc. Also it will be necessary to awake the social awareness in the whole community concerning the disease and its control, specially at the rural level, involving directly rural teachers, local leaderships, students and householders. In the case of the peridomestic foci, we must understand that only the insecticide spraying is not sufficient to eliminate all the bugs,

but complementary actions such as physical changes in the walls and roofs, the replacement of old chicken house walls by galvanized wire fence, etc. could be implemented. The participation of the dwellers in such changes should be strongly stimulated, throughout educative activities, showing that not only the health aspects but also the economic ones are involved. In any case, to reach a high impact, all the biologic and social actions must be carried out in a conjugated and simultaneous pattern. With such a purpose, it is fundamental that the technical staff looks like to work attached to the whole community and its leaders, involving also the pertinent communitarian institutions and the mass communication equipments. It must be understood that, in spite of the central political and administrative instances, the decentralization process is inevitable, mainly for those more isolated rural communities. Thus, the implementation of any action plan must take into account five main directresses such as: (1) integrity; (2) complexity; (3) simultaneity; (4) availability; and (5) continuity. To make all of this possible, a real diagnostic is required, based on reliably statistics and not in minor or particular political interests. Another fundamental requirement concerns directly with the role of the community, but not as a passive actor who must obey vertical determinations based on hegemonic scientific or political power. A democratic relationship must be established, where the cultural characteristics of a community and its natural knowledge require to be respected and joined into the work planning. The community must be served, not merely used, thus being established the main difference between support and manipulation. The hegemonic, individualist, pragmatic, and biologicist medical model has historically denied the paradigm of being Chagas a disease centered in poverty, with its characteristics of stigmatization and social discrimination. Besides the biological problem of this disease it must be found a deep social dimension, with social needs not attended and several frustrated hopes. To deep the analysis of this social dimension of the health/disease process is fundamental, taking into account the historical, the political, the economic, and the cultural aspects of this process, because either the health or the disease are constructed by the social relationships, at the same time they are a product of them. As well as the psico-neuro-endocrin-immunology is demonstrating that the social strongly influences the biological, in each individual, in Chagas disease the clinical follow-up is strongly influenced by the whole social dimension. It must be definitely stated that the Chagas disease problem must be resolved by all, conversely it will never be resolved. Following the philosophical stream of the complex thinking of Edgard Marin, we must understand that Chagas disease is a transdisciplinary problem, requiring for its solution an integral approach.

JC Pinto Dias - Certainly the Initiative will have problems of sustainability at medium term. Because of decentralization it is imperative to assure an "expertise" at central and regional levels, able to maintain the roles of articulation, evaluation, and supervision of the whole

system. This is an additional reason to maintain alive the initiative, stimulating all the staff and the necessary integration. Other key point concerns with the epidemiological information, that must be correct, rapid, and universal, able to generate the adequate action from the health system. Unfortunately, and chiefly because of decentralization and weak central teams, this matter has been a critical point in a great part of INCOSUR, leaving under risk the future of the system. About the financial sustainability of the initiative and national programs, we must be realists in our demand and planning, since the costs in surveillance situations use to be fewer than in massive attack phase. Concerning decentralization, it must be considered as a dynamic and still incomplete process, probably irreversible in terms of the global political context. It seems that the most important will be to insert and to maintain the subject of Chagas disease and its control in the official agenda of the national, regional, and local governments of the whole endemic area. In parallel it is mandatory to insert the theme of this disease in both the basic and college *curricula*. Finally, to reinforce the political and participative processes, it is necessary to deal not only with the low self estimation of the depressed and chagasic population, but also as with the high self reliance emerged from the interruption of transmission and from the improved and vector free dwellings.

AC Silveira - Emphasizes that the recovery of *T. infestans* colonies in sprayed areas is a very slow process, that means a favorable aspect of the vector control. Remembers that the current control strategy is also highly favorable concerning secondary species, since a low density of domiciliated insects can be reached and maintained by regular surveillance. For these species, the residual foci are generally located in peridomestic ecotopes, a fact that drives the research to the physical management of the peridomicile. Also remembers that each vector species has its own behavioral characteristics, that must be focused by the programs according each particular situation. In the case of sylvatic species, the control actions must to delimit the operational area.

R Salvatella - INCOSUR and the respective region have the challenge of the continuity and sustainability of the actions concerning the prevention, the control, the surveillance and the medical attention of Chagas disease, that means: (a) to reach the adequate balance of the necessary information about the epidemiological advances of the program as much as the affaire to reach its political priority; (b) to understand that the priority of the program tends to decrease, but that is possible to maintain its sustainability by means of its insertion in correlated and integral health activities, as well in other social sectors such as agriculture, education, environment, etc.; (c) to maintain and to optimize the current surveillance actions, that must be effective against reinfestation and be able to detect new epidemiological situations such as new endemic areas, insecticide resistance, etc.; (d) to develop in the Initiative the component of medical attention; (e) to focus the major priority of INCOSUR in the biogeographical region of Chaco, where remain the

worst problems of *T. infestans* persistence and Chagas disease transmission.

Finally reiterates that seems to be very difficult the recovery of the past scenery of high infestation levels in the Region. Nevertheless, a supplementary program involving medical attention for already infected people must be implemented. The programmatic actions must prioritize those socially most depressed areas, but other specific points such as sylvatic triatomines also must be taken into account.

W Oliveira - The clinicians have been preoccupied with the infected people, generally by means of the current biotechnologist medical model. The chagasic patient must to be attended in an integral manner, considering his multiple social, psychological, and biological dimensions, thus involving other correlated professionals. It is mandatory to see the patient, not only the disease. By another angle, it is impossible to decentralize the program activities (including medical attention) if community participations does not exist. For this reason considers very important the existence of some entities like the association of chagasic patients (one of them working in Pernambuco, Brazil, since 18 years ago, with excellent level of participation and adhesion). From the epidemiological standpoint, the chronic forms are those that usually cause the higher social impact in terms of morbidity, mortality, loosing of productivity, and medical costs, specially the chronic cardiopathy. At the present, no doubts exist that a precocious and adequate intervention use to reach important medical benefits, especially in terms of heart failure prevention. Nevertheless, the chagasic patient is usually a poor person, having multiple limitations to receive an effective and continuous medical attention. For instance, it is necessary to provide a free "basic basket" of essential drugs for these patients, who usually have not conditions to by them, as well as bus tickets and lunches to make possible their regular program of medical assistance. A tragic situation could be the patient carrying a complex cardiac defibrillator (costing almost US\$ 60,000) that has not resources to pay the bus for going to the medical revision, or having not money to buy a simple diuretic... So, the control of Chagas disease overpasses a mere financial figure, but involves an exhaustive and fascinating battle, with the participation of the whole society and – above all – with a permanent political decision.

F Torrico - There was important advances in the history of INCOSUR, in spite of the frequent political changes in all the Region. Nevertheless, it is necessary to analyze the present frame of the disease at regional level. Particularly in Bolivia the impact of the actions has been very high: great interventions were carried out in the whole country, but is still necessary to implement the sustainable process of the program. The BID credit (that made possible such interventions) will finish in May 2006 and many troubles in its renewal can be foreseen. Three fundamental aspects must to assure the formulation of a policy for surveillance and control, as well to ensure the program sustainability: (1) the political determinants. The continuity of the control actions depends

on political decisions concerning all the levels of the program. Political decision must take into account the global aspects of the program (migration, intersectoriality), the integration (of strategies and resources), and the decentralization process. The worst situation for this disease is (1) the political forgetfulness, because this attitude means to forget the people; (2) the social determinants involve the social participation, the information process, education, the patient needs. With an effective community participation, the continuity of the actions will be accomplished; (3) between the both points above will stay the health staff and the researchers, looking for new strategies to face the challenges of the disease surveillance and control.

Angela Junqueira - Emphasizes the challenge of continuity, calling attention to the losing of technical experts, chiefly of professionals able to organize and to carry on the control programs at peripheral levels. Ask how this problem could be resolved.

HM Aguillar - No doubts about the advances and epidemiological impact of INCOSUR. The critical points correspond to program sustainability and the residual foci of different vector species. Remembers that the Sanitary Reform is changing the classical control structures, with different kind of impact, at long term. It is necessary to take care with euphoric reactions in face of the advances, since the over optimism use to be self-defeating when many challenges still exist. For instance, there are many situations of stagnation and even reversion of regional programs, or also non favorable results of some interventions and strategies. It is important to remember the reversion of expectative and results of the classical malaria programs in some areas, in the past, when monochromatic strategy was implemented all over the Continent. A good advice is always to search the modesty and the realism in the Public Health affaire.

JC Pinto Dias - It is recommended to insist in new complements to INCOSUR: (a) Chagas disease is not finished, at all; (b) there was incontestable advances and too much work along the way; (c) we must identify and involve in the Initiative the new protagonists of the Sanitary Reform, reinforcing the basis of INCOSUR with rational and intelligent proceedings. In the future some problems of program sustainability must be expected, such as the maintenance of vector activities in situations of very low densities and the absence of new cases, or even the prosecution the financing of blood donors screening when practically infected blood donors no more appear. Also the applied research must not to be stopped, since there are many new challenges and epidemiological situations to be faced in all the Region. Unfortunately, the priority for such kind of investigation is progressively decreasing nowadays, with problems in financing and publication. Considering this point, it is opportune to present the advances and principal needs of the Initiative to governmental authorities and research agencies, as a manner to maintain alive the importance of the work. In particular, a social conscience concerning the advances, the risks and the difficulties of

INCOSUR must be created in the whole population, with the objectives of community participation and community political pressure in the countries. Because of this it is absolutely necessary to improve the investment in Education, as well as in massive information, in order to get people opinion and to create political facts. In particular, it is necessary to identify and to work upon the main epidemiological, operational, political and institutional problems, and vulnerabilities of the Initiative.

JR Coura - Remembers that not only in Brazil but also in Chile, Paraguay, and Uruguay the major part of the advances were obtained before decentralization. In Brazil, decentralization was ill-timed and bad conducted, and probably today to reach the good results and program advances would be impossible. The owners of the situation and the conductors of the process are now the mayors and local political leaders, that means an enormous variability of interests, besides too much improvisation and immediatism. Believes that Argentina hardly will reach the national goals concerning elimination, because the program structure has been lost.

G Schmunis - We walked from euphoria to masochism, a natural situation in such a kind of discussions. Remembers that 15 years ago there were good partners in the countries and also the scientific community was ready and mature to launch the initiative. Remembers that social pressure in capital to generate political decisions, with an essential role for the Press. Chile has particularly been a very good example of this point, in the evolution of its national program.

A Rojas de Arias - Finally, to reinforce some of the points touched in the discussion, states that in spite of some advances concerning the health in American Indian People, most of the studies emphasize that many problems persist in several groups, making urgent the improvement of efforts to face them. Very few is known about Chagas disease and its epidemiological situation in several Indian populations. In recent studies several difficulties were pointed to implement and to maintain the epidemiological surveillance in some populations, some of them related to their idiom, others to the long distance between the tribes, others to the physical characteristics of the houses and peridomiciles. On the other hand, successful experiences could be disseminated in order to stimulate the information at local level. Web folders and popular hornbooks dealing with the most common situations and questions about the disease and its control would be very useful. Also useful is the dissemination of the information generated in research and reference centers to the staff involved in surveillance and control. The sophistication of the laboratories must be transferred to the action field: this process is accomplished by means of the formulation of applied investigation based on concrete needs, since their planning and conception. States that in her point of view there are two basic proposals concerning the qualification and the technological transference to the control and surveillance of Chagas disease programs. The first concerns with the health personal qualifying in terms of general planning

and geographical information, looking for a broader vision of the problem and the control activities in endemic zones, so making possible to concentrate the action in particular and limited spaces of transmission not detected by the regular program. The second emphasizes the particular characteristics and problems of each country or region. For instance, in Paraguay it has been essential the preservation of the structure of SENEPA (Paraguayan National Service of Malaria) to support the Chagas disease program, by means of technical arguments and strong political decision.

General conclusions and recommendations (by Antoineta Rojas de Arias and João Carlos Pinto Dias)

1. INCOSUR has accomplished satisfactorily its objectives, reaching significant reduction in the indexes of infestation and transmission, as well as the almost all coverage of blood banks screening in the Region. It is recognized that the Initiative has been very important for the maintenance of the priorities and the advances of the surveillance in those countries with their programs already structured, as well as to start the definite program in Bolivia and Paraguay.

2. It is recognized that the performance and the structure of INCOSUR have been implemented, according the initial purposes, and passing by adjustments and route corrections along the way. It has been a successful model, including by its dynamics and adaptation capacity.

3. Concerning the continuity and technical improvement of the Initiative, special role has been accomplished by some routine activities, standing out the intergovernmental meetings, the international supervisions, the organization of the memories of the work, and the workshops for discussion and elaboration of specific themes (indicators, surveillance, medical attention, etc.).

4. In all the activities and moments PAHO had an active and effective participation, acting as a catalytic and stimulator element. More over of its administrative role, PAHO effectively contributed with financial resources to support workshops publications and supervisions, also organizing the activities and yielding its technicians and epidemiologists to specific tasks of the initiative.

5. Nevertheless, it is recognized that there are still many things to be done, in terms of the consolidation of the attack actions and actions in priority zones, as well

as to maintain sustainable a permanent and effective surveillance program.

6. For this reason, the improvement of processes and strategies must be pursued for a long time, that means also the continuity of both basic and applied research.

7. By another angle, it is natural and expectable that the general interest and the priority of Chagas disease tend to decline, according as the epidemiological objectives are attained and the visibility of the disease decreases ("Acapulco Syndrome").

8. Thus, an articulated and continuous effort must to be made by the country partners and PAHO, to ensure a minimum political will, able to sustain the fight against Chagas disease in all its aspects. Besides the regular meetings and supervision, the "big media" must be involved, so helping community participation and reinforcing political pressure. Nevertheless, in such activities, inconsequent euphoria must be avoided, through-out a clear, coherent, and realistic information.

9. As some additional problems, future difficulties of program functioning and even of Initiative survival can be expected. The decreasing of program coverage and the retirement of technicians are being observed in most of the countries. The program of Bolivia will have hard difficulties since May 2006, when the BID lending will expire, so being necessary new appraisal and negotiations to consolidate the whole program. By another angle, it is visible the reduction of funds for applied Chagas disease research, including by the side of traditional agencies like TDR. It is important that the Initiative leaderships take into account all of these problems, discussing them and looking for their solution.

10. As a last point, it is reiterated to all the countries the urgent task to revise carefully their programs, problems, and necessities, having in mind to ensure sustainable and realistic activities. Specially, facing the progress of decentralization, the countries need urgently to adapt and to adjust their programs into the new system, to reach the necessary effectiveness and continuity. Concerning this point, the theme of Chagas disease must be inserted in the regional and municipal sanitary agendas. Very particularly, epidemiological surveillance and medical attention must be considered as sub programs extremely convenient for the peripheral practice.

