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Health Surveillance and Disease
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Report
of the
Technical Consultation
on
Information, Education y Communication (IEC)
on
Congenital Chagas Disease

(CLAP/PAHO/WHO, Montevideo, Uruguay, 17–18 May 2007)

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CHAGAS DISEASE

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Report of the Technical Consultation on Information, Education and Communication (IEC) on Congenital Chagas Disease

(CLAP, Montevideo, 17–18 May 2007)

I. Introduction

In epidemiological importance, congenital Chagas disease constitutes the third mode of *Trypanosoma cruzi* transmission to humans. The success of prevention and control efforts against the other two modes of transmission, i.e. vector-borne and transfusional, has brought about an increase in its visibility and perception, as well as its interest to public health: it is the only mode that is still active without any type of intervention in many endemic countries, as well as one of the modes of transmission present in the non-endemic countries.

Earlier technical activities such as the International Colloquium *Congenital Infection with T. cruzi: From Mechanism of Transmission to Strategies for Diagnosis and control* (Cochabamba, Bolivia, 6–8 November 2002) and *PAHO Technical Consultation on Congenital Chagas Disease: Its Epidemiology and Management* (PAHO/DPC/CD/301.04) (Montevideo, Uruguay, 24–25 June 2004) have described the problem in the Americas and in non-endemic countries both inside and outside the continent, thus contributing to the methodological and implementation aspects of diagnosis and treatment, as well as to health service organization when dealing with this problem.

It is estimated that in that the Americas, nearly two million women of child-bearing age are currently infected by *T. cruzi*, of which between 4% and 8% could transmit the infection to their fetus through the placenta, which consequently would lead to some 15,000 children being born each year with congenital Chagas disease. The majority of them would be asymptomatic or paucisymptomatic, which poses a challenge to the efficacy, efficiency, and timeliness of health services.

One of the greatest concerns is to succeed in assuring health coverage to the population of seropositive pregnant women, who are usually carriers of chronic trypanosomic infections.

To make this possible, the following would be necessary:

- Health professionals would have to identify the problem, its diagnosis, management, and treatment in both endemic and non-endemic countries.
- Among the general population, health professionals need to be knowledgeable of the problem and able to provide proper care for this public health problem.
- The population at risk must be knowledgeable of the problem as well and able to provide care when dealing with this public health problem.
- Among pregnant women who are seropositive for *T. cruzi* and who currently inhabit an endemic area or have in the past, as well as daughters of mothers with a background of risk or who have been at risk of having been exposed through blood transfusion, knowledge of the problem is essential to providing proper care both for them and for their children.
- In light of this reality, decision-makers must have a basic knowledge of the problem so that they can institute appropriate policies for the proper care of congenital Chagas infection.

This consultation lays the foundations for the information, education, and communication on which to raise consciousness among individuals, families, communities, society at large, professionals, and policy-makers, so as to act in a timely and sustainable way to diagnose and treat newborns infected by *T. cruzi*.

II. Recommendations

- 1) The Advisory Group reiterates the importance of congenital Chagas disease to public health in the Region of the Americas, in both rural and urban areas, on the continent and off, and in endemic and non-endemic areas. It recommends stimulating its adequate and timely diagnosis, as well as its management and treatment, in sustainable and continuous ways in the countries involved, based on the following:
 - The important incidence of congenital *Trypanosoma cruzi* infection (estimated at more than 15,000 cases annually in the Americas).
 - The increase in its frequency due to asymptomatic cases.
 - The need to integrate these actions with activities aimed at other infectious congenital pathologies.
 - The proven efficacy and efficiency of proactive action, with an optimal cost-benefit ratio.
 - The effectiveness of treatment during the first year of life, which is close to 100%.
 - The ethical mandates for patient care.

Curing a boy means avoiding immediate morbidity and mortality from this disease during his childhood, youth and/or adult age. Curing a girl decreases the odds of new cases of congenital Chagas disease and, for society as a whole, increases the number of potential blood and organ donors.

- 2) In areas where transmission is still active, the Advisory Group calls for the continuity and increase of vector-control measures carried out by the countries, for the purpose of diminishing the incidence and prevalence of infection among women.
- 3) Strengthen information, education, and communication (IEC) as essential and indispensable tools for putting the subject of congenital Chagas and its adequate management on national health agendas, for getting knowledge and information to the general and at-risk populations, and for training human resources.
- 4) Consider the congenital transmission of Chagas disease in light of the critical review of the “Goal of Elimination of Chagas disease” (WHA51.14), established by WHO in the 51st World Health Assembly in 1998.
- 5) Express the urgency of overcoming problems related to access to the drugs that the countries need for the etiological treatment of Chagas disease, with support from PAHO/WHO.
- 6) Reiterate the urgent need to have pediatric formulations of the drugs available and to develop new ones for the etiological treatment of *T. cruzi* infection.

- 7) Emphasize the need to incorporate Chagas infection into the group of vertically transmitted infections, in order to develop integrated strategies for prevention and control, while implementing the IEC component. Efforts to combine congenital Chagas disease with other programs (syphilis, HIV/AIDS, etc.) can contribute to obtaining the required level of efficacy and efficiency.
- 8) Point out how important it is that care for congenital Chagas disease be incorporated into primary care in regular health facilities, without lessening the levels of required complexity, and be integrated into care programs for all vertically transmitted diseases, with support from CLAP's Perinatal Information System (*Sistema de Información Perinatal / SIP*).
- 9) The management of congenital Chagas disease poses multiple ethical considerations that should be taken into account in such a way that any approach taken should pay sufficient heed to questions of equity, access, and sustainability and should seek to guarantee quality and humanity in its actions.
- 10) For its IEC strategy, the Advisory Group recommends establishing a group goal for its messages and output on congenital Chagas:
 - women and their family environment
 - health workers
 - educators
 - decision-makers
 - the general public
- 11) With reference to women and their family environment and with regard to IEC, a group goal should take the following into consideration:
 - women at risk of Chagas infection in rural and urban areas
 - infected and uninfected pregnant women
 - infected mothers and children
 - family members of infected persons

The fundamental IEC content aimed at this group will be as follows:

- Any child with congenital Chagas disease should be timely diagnosed, adequately treated, and cured.
- Any woman infected by *T. cruzi* can transmit the infection during pregnancy to her fetus, although not all do so.
- Transmission can occur in more than one pregnancy.
- Diagnosis is relatively simple in both the mother and the child.
- The lower the child's age, the more effective the therapeutic response at onset of treatment will be; in the first few months of life, there are very few adverse effects.
- Any infected woman and her child should receive care from the health system (diagnosis, treatment, and clinical follow-up) and should be duly informed of her and her child's situation, in order to improve their quality of life.
- Maternal Chagas infection does not call for any interruption of lactation.

- Diagnosing and treating a child in endemic areas requires that adequate action be taken against the vector in the child's household and locality, in order to avoid reinfection.
- The health system should provide the opportunity for diagnosis and care to all children of an infected mother.

12) With reference to health workers and IEC, the following should be considered as target groups:

- educators
- physicians (general practitioners and specialists)
- professional laboratory technicians and diagnostic laboratory assistants
- obstetricians and midwives (both professional and community)
- social workers
- nurses
- institutional and community health-care workers

The basic IEC package will be directed at these subgroups:

- It will be part of the university curriculum (both undergraduate and graduate), part of continuous education programs for professionals, and integrated into institutional and community technical courses to train health workers.
- Basic knowledge of the infection/disease, its natural history, diagnosis, and care will be compulsory.
- Bear in mind the need to guarantee adherence to treatment and to manage any adverse effects to the medication.
- Emphasize the obligation of the health system to provide diagnostic and medical care to all children of an infected mother and to her as well.
- All the above will be part of a strategy to strengthen the motivation, involvement, and obligation of health workers with regard to their basic skills, attitudes, and practices related to care for people with Chagas infection in general and congenital Chagas disease in particular.
- The package will contain, at the very least, the basic concepts already cited above and aimed at the women and their family environment; and these should be adapted to every particular group as needed.

13) With reference to IEC for educators, the following should be considered as target groups:

- primary-school teachers and staff
- middle- and secondary-school teachers and staff
- faculty and staff in higher education

The basic IEC package for these subgroups should contain basic information on Chagas disease, with special focus on the following:

- In the cases of elementary and secondary education, attempts should be made to convert the material and messages into elements of the curriculum with emphasis on risk factors, prevention, and control. In the case of secondary education, the package should include congenital Chagas disease and should be integrated into the reproductive health curriculum.
- For the tertiary level, see aforementioned Recommendation 12.

14) IEC efforts should address decision-makers from the following target groups:

- the health sector
- other sectors
- the national level
- the local level (provincial, state, departmental, regional, municipal, etc.)

The fundamental IEC package aimed at these subgroups should focus on the following:

- It should follow two basic strategic lines:
 - community “empowerment” on the subject and
 - advocacy at the level of decision-making.
- They will be encouraged to put the issue on the political agenda for policies in the health sector and in others to bring about activities at the national and/or local level.
- They will make clear reference to the socioeconomic impact that action or inaction regarding congenital Chagas disease implies.

15) One of the basic needs for this strategy for congenital Chagas disease is the incorporation of IEC both organically and officially into the countries’ national health systems, not only in design but in implementation.

16) The design and operationalization of the IEC strategy on congenital Chagas disease should take into account the necessary peculiarities for urban or rural, as well as endemic and non-endemic areas.

17) In accordance with the area in which the IEC strategy for congenital Chagas disease will be applied, suitable methodologies and instruments will be selected to meet the necessary technical specifications (type and size of population, message objective, group goal characteristics, cultural and ethnic diversity, etc.).

18) In relation to the nature of the IEC component, the Advisory Group pointed out the importance of forging partnerships to enable a diversification of techniques, tools, and dissemination strategies for releasing the desired IEC packages.

19) Bear in mind the importance of resource allocation in the health system and how it affects the implementation and operationalization of IEC activities for congenital Chagas disease, as well as the search for the greatest possible efficiency concerning an optimal cost-benefit ratio, which has already been proven with this type of intervention.

20) The evaluation of all IEC activities undertaken in congenital Chagas disease—be it for methodology, program evaluation, or obtaining a well-oriented idea of the overall impact—is essential for the success of what is being proposed here.

Montevideo, 18 May 2007

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Annex 2: Agenda

Day 1: 17 May 2007

9:00 - 9:15	Opening. Objectives
9:15 - 9:30	Chagas Disease in the Americas. Dr. R. Salvatella (PAHO/HDM/CD/CHA)
9:30 - 10:00	Congenital Chagas Disease. Dr. Y. Carlier (ULB)
10:00 - 10:15	Congenital Chagas Disease and Its Body of Knowledge among Other Vertically Transmitted Diseases. Dr. J.L. Díaz Roselló (PAHO/CLAP)
10:15 - 10:30	Coffee Break
10:30 - 10:45	IEC in the Strategy to Control Congenital Infection by <i>T.cruzi</i> . Dr. F. Torrico
10:45 - 11:00	Health Promotion and Social Communication on Congenital Chagas. Mag. M. Gonzalez y Lic. G. Delgado (PAHO-Uruguay)
11:00 - 11:30	Ethics and Congenital Chagas. Dra. D. Sánchez (PAHO-Uruguay)
11:30 - 12:00	The Problem of Etiological Treatment: Its Accessibility. Dr. P. Albajar (MSF) and Dr. C. Zackiewicz (DNDI).
12:00 - 12:30	IEC on Congenital Chagas: Experiences with Application. - Dr. W. Apt. - Lic. M. L. Fuentes
12:30 - 13:30	Lunch
13:30 - 17:00	Discussion Topics on IEC: - General population (Dr. E. Moretti) - Health professionals (Dr. H. Freilij) Coffee-break - Women at risk (Dr. B. Basso) - Political decision-makers (Dr. F. Torrico)

Day 2, 18 May 2007

9:00 - 10:15	Discussion
10:15 - 10:30	Coffee Break
10:30 - 12:00	Continuation: Discussion
12:00 - 13:30	Conclusions and Recommendations
14:00	Lunch and Closing Ceremony

Annex 3: Recommended Bibliography

Carlier Y, Torrico F. Congenital Infection with *T. cruzi*: From Mechanisms of Transmission to Strategies for Diagnosis and Control: Conclusions of Round Tables and Synopsis of an International Colloquium. *Rev. Soc. Brasileira de Medicina Tropical*, 2003; 36 (6): 767-771.

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