
Comments on the article:

Sanmartino M, Forsyth CJ, Avaria A, Velarde-Rodríguez M, Gómez i Prat J, Albajar-Viñas P. The multidimensional comprehension of Chagas disease. Contributions, approaches, challenges and opportunities from and beyond the Information, Education and Communication field. Mem Inst Oswaldo Cruz. 2022; 117: e200460.

Reflections, suggestions for putting into practice the principles of information, education and communication - IEC on Chagas disease in a community context

Before presenting specific suggestions or proposals about the activation of a process of information, education and communication on Chagas disease (IEC Chagas), it is necessary to take note of a reality that is almost always present in the different contexts affected by the disease: Chagas disease is not necessarily a priority neither: (i) for the communities historically endemic which have lived with Chagas and have got used and adapted to live without having answers or solutions; (ii) nor for those who have recently discovered the problem and do not really know it. Both kinds of communities are called by “other” problems that limit their right to health and life dignity, often considered more urgent to resolve due to the impact they have in terms of morbidity and mortality. Even for internal migrants to large Latin American cities and for migrants to other countries or continents, health needs are almost always different than Chagas. Moreover, not responding to the needs perceived as more urgent risks transforming the IEC Chagas process into an external imposition, damaging its effectiveness. Therefore, it is essential that IEC Chagas is included in a multi-purpose intervention that provides an integral and continued (over time) approach to the priority health problems of a community. In fact, the impact of an IEC component oriented to a specific health problem depends on a multi-purpose community intervention that has as its final objective the right to health, thanks to a permanent integral action. Inevitably, therefore, an IEC Chagas must be integrated as part of an intervention aimed at improving the health of a community.

How to ensure, however, that an IEC tool or strategy activates a process of change in which the community is the main actor, an active player who proposes and participates in the decision-making process; who acts like an interlocutor and not a simple collaborator or executor of actions decided by others? The methodology, applicable to the different contexts and with the necessary adjustments, must include some key elements, not necessarily sequential or separated from each other chronologically, but always based on a permanent dialogue with all levels and actors.

The first step aims at confirming the existence of the problem (to see), qualifying and quantifying it (to analyse) and evaluating or assessing the weight of the need to intervene, leaving the communities, representatives and/or leaders, and associations the necessary time for discernment and decision.

The second step is to listen to the community, its representatives and leaders to identify the perception they have about the problem in its complexity and multidimensionality and transmit basic, essential information with adequate tools. Doing so, we ensure that everyone is aware of the most important aspects of Chagas disease, such as existing transmission, parasite cycles in nature and dwellings, health implications, possibilities of diagnosis and treatment, progress in guidelines for detection and healthcare, prevention and transmission control.

The third step is to define an action plan with communities, civil society and cultural organisations and identify the role of each actor or group of actors. This is the step in which the community has a key role in proposing concrete actions to address the problem that are in line with its culture, traditions and vision of the world.

In the strategy envisaging the leading role of communities, the IEC material, generally proposed by experts from public or private institutions, should be re-elaborated or adapted by the communities as an expression of empowerment, a seizing of knowledge.

The IEC tools developed outside the communities, and especially in the framework of a national public policy risk being considered “external” to the vision of the community and therefore may encounter obstacles to their understanding and implementation. There is no doubt that the key points of the message should be discussed and proposed at national level and will have their own value, especially in the training of health professionals. The IEC material or tools, must hence be reworked and translated into the feeling and language of the communities, so that it is interiorised by each reality and ethnic group with its own paradigm of the disease and its transmission. This is true for: urban suburbs; rural suburbs with historical knowledge about transmission and disease, known by the community; new transmission areas and therefore with an unknown problem for the community; migrants from endemic areas and therefore connoisseurs of Chagas; migrants from hypoendemic territories who have never heard of Chagas; indigenous communities (with big differences among different indigenous nationalities), African Americans...

The fourth step is to develop an intervention and epidemiological surveillance with the community resulting from shared decisions and responsibilities between communities and technicians.

The IEC process is completed by the implementation with periodic community evaluations of the intervention that allow to recognise successes, highlight limits and criticalities and make the necessary corrections. Documenting the intervention and its impact are an opportunity to strengthen the awareness of the self-determination capacity of a community, human group or migrants often forced to live on the margins of society, without a voice and vote in decisions concerning their life.

Paulo Freire sees education as a mean to free the person. “Seeing, judging, acting” are cornerstones of his vision and what he identifies as key elements of any health intervention aiming at restoring the deserved role to the communities and traditionally forgotten periphery. A liberating education should be in charge of improving health and life conditions and give communities a political voice.

At this point it is worth pointing out the existence tools to promote and facilitate dialogue that health personnel can use throughout the intervention. The objective is to allow communities to have a more complete vision of the problem at their community level, but also at the level of a sector, zone or district of health. Some relevant examples are:

- maps showing data that everyone, even those who cannot read, can understand; identify the communities most affected and apply the principle of equity when deciding which communities should be prioritised in an intervention;
- the mortality data of the community itself (rather than official statistics that often underestimates the numbers and/or are too general for a local analysis), which allow to introduce the concept of avoidability (or prevention) of events, identifying areas and elements that make mortality prevention easier;
- the discussion of life stories about severe health conditions or deaths, in communities in which it is possible to do so, because the discussion is accepted by the community and can be transformed into sensitisation or conscientisation events.

The communities in the Northern area of Esmeraldas, Ecuador, often say “Our deaths help us to walk”. This translates their reflection on unavailability, where death events are transformed into life events and normalised.

In some endemic areas of Chagas disease in Bolivia, the map showing the cardiovascular mortality (especially from heart failure and sudden death under the age of 60), has allowed communities to focus their attention on Chagas, and subsequently to call for public interventions of screening and control measures. The life stories of Latin American migrants infected with *Trypanosoma cruzi* on the waiting list for a heart transplant in Northern Italy motivated participation in the IEC meetings and subsequent screening.

Those who support the IEC process must know:

- the community, its culture, its problems, its social organisation (social and anthropological knowledge);
- their understanding or vision of the health-disease relationship (including traditional medicine);
- community leaders that have a key role to play and can and must be involved (interculturality and leadership knowledge);
- health personnel who already work in the communities (and have the community support) and can open doors or facilitate the walk of new paths together.

Consequently, in order to support the IEC process, it is essential that health personnel be trained in dialogue with patients and communities. Training health personnel who intervene, in dialogue, at the community level, should be compulsory (not optional), and the responsibility of the training should be in the first instance of both, the university and the health system. A team that communicates with the community should know how to give space to collective creativity and to individuals in the transmission of educational messages, in communicating the results of the intervention and in the remaining challenges to be faced.

Currently some social sectors attempt to “medicalise” society, making it exclusively dependent on medical knowledge and technologies. However, the languages, images, traditional songs and poems (art expressions) developed by communities contest the way current medicine frequently approaches the world. “Community life” can: take back nonsense medicalisation; prove to be competent to face most critical and neglected aspects of health; work in the communication and democratisation of knowledge, avoiding to be subjected to the impositions of external experts, announcing that communication has rediscovered its deep roots because returned to be part of communities to the point of being part (incorporated) in the language of its life and celebrations.

Writings, songs, drawings elaborated by the communities carry important messages to be faithful to their desire of developing an eco-response to the aspiration and needs of people, as individuals and society. Medicine, epidemiology and communication must be made accessible and understandable to everyone. Technical knowledge must learn the law (as simple as it is not heard) of the importance of being present in the communities and walking with communities. The practice of medicine (prevention, diagnosis, treatment, follow-up, transmission control...) can and must be one of the “normal” things that are implemented, concretised in every socialisation place (home, meeting places, sport courts, celebration locals...). In this way, the community, its health agents and representatives are not agents of another discipline or an external institution, but they are the living memory that all communities can be protagonists of their own health. That will be true if: the health empowerment is considered one of the tools to free themselves from fears; they acquire consciousness about the possibility to seek and choose solutions; they speak and discuss health as one of the elements to build their own future, as they do with homes, work... This is one of the greatest challenges and opportunities for the IEC in general, IEC Chagas, IEC on neglected tropical diseases, IEC on chronic noncommunicable diseases and more.

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