SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

Pediatric cardiology health brigades: from medical triage to social triage

Brigadas de salud en cardiología pediátrica: del triaje médico al triaje social

María Fernanda Olarte-Sierra[1], Roberto Suárez[2], María Alejandra Rubio[3]

[1]PhD in Social Sciences. Co-researcher, Program for Innovation in Rare Human Congenital Heart Diseases for Colombia (PINOCCHIO), Fundación Cardioinfantil, Instituto de Cardiología. Researcher, Group of Medical Anthropology, Department of Anthropology, Faculty of Social Sciences, Universidad de los Andes, Bogotá, Colombia.

[2]PhD in Education Sciences. Associate Professor, Principal Researcher, Group of Medical Anthropology, Department of Anthropology, Faculty of Social Sciences, Universidad de los Andes, Bogotá, Colombia.

[3]Anthropologist. Research Assistant, Program for Innovation in Rare Human Congenital Heart Diseases for Colombia (PINOCCHIO), Fundación Cardioinfantil, Instituto de Cardiología, Bogotá, Colombia.

ABSTRACT This article explores the sociocultural aspects of a program of pediatric cardiology health brigades that provides care to children from low-income populations in peripheral regions of Colombia. We analyzed the brigades as a humanitarian strategy to close the gaps of inequity in access to health care, and as a particular context of the medical encounter, the experience of heart disease and the definition of care trajectories. Based on ethnographic observation of brigades and interviews with families receiving care and with health personnel, carried out in 2016 in five different cities, we looked at the dynamics that shape the medical encounter and questioned the mechanisms (medical and social) through which it is evaluated and decided which families can access care in Bogota. We conclude that the brigades, as initiatives that continue to be anchored in humanitarism instead of contributing to the transformation of the conditions that generate health inequities, reproduce and exacerbate such inequities by selecting which lives receive priority to be saved.

KEY WORDS Health Services Accessibility; Delivery of Health Care; Social Work; Vulnerable Populations; Colombia.

RESUMEN Este artículo explora aspectos socioculturales de un programa de brigadas de cardiología pediátrica para la atención de menores de poblaciones de escasos recursos que habitan en regiones periféricas de Colombia. Problematizamos las brigadas como estrategia humanitaria para cerrar las brechas de inequidad en el acceso a la atención en salud, y como contexto particular para el encuentro médico, la experiencia de la cardiopatía y la definición de las trayectorias de cuidado. A partir de la observación etnográfica de brigadas y de entrevistas a familias asistentes y personal de salud, realizadas durante el año 2016 en cinco ciudades diferentes, indagamos en las dinámicas que configuran el encuentro médico y cuestionamos los mecanismos (médicos y sociales) mediante los cuales se evalúa y decide qué familias pueden acceder a atención médica especializada en Bogotá. Se concluye que las brigadas, al ser iniciativas que continúan anclándose en el humanitarismo, en lugar de contribuir a la transformación de las condiciones que generan inequidades en salud acaban reproduciéndolas y exacerbándolas en la medida que seleccionan las vidas con prioridad para ser salvadas.

PALABRAS CLAVES Accesibilidad a los Servicios de Salud; Prestación de Atención de Salud; Servicio Social; Poblaciones Vulnerables; Colombia.

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

INTRODUCTION

Access to health care is a core process in modern world societies. This process involves clinical, social and cultural aspects that determine how health and illness are signified, as well as subsequent trajectories of care. Illnesses such as congenital heart diseases, because they are diagnosed during childhood and due to the role and the imaginaries associated with this life stage in the contemporary world, become a medical experience that redefines the life trajectories of children and their families.[1,2] This fact is accentuated in populations that face difficulties in accessing real health care on account of their socioeconomic conditions.

The consideration of the role of certain factors different from the merely biological in the health-disease process has given rise to a model known as social determinants of health. According to this model, the state of health of individuals is determined by the intertwining of conditions at different orders of magnitude occurring throughout their lives. Developed by the World Health Organization,[3] the conceptual framework of the social determinants of health establishes that the social context produces a stratification that assigns individuals different ranks depending on social class, gender, race, ethnicity, occupation or educational level. These ranks create differential material and well-being conditions – in regards to housing, access to public and social services, food safety, and working conditions – which in turn set off processes of health inequity. The health brigades, proposed on the basis of a humanitarian rationality, attempt to be a socio-clinical functional event that recognizes and, in a practical manner, meets the health needs in those populations identified as vulnerable due to their conditions of poverty and marginality. Although these brigades seek to confront the social determinants of health by bridging the gaps of inequity in the access to health care among these populations, their efforts may entail practices that exacerbate the social determinants of health, as they are based on the recognition and reinforcement of socioeconomic criteria for the allocation of aid. Therefore, as health brigades assess the levels of poverty and social vulnerability in order to decide who will access medical attention, the mechanism of exclusion ends up being replicated for those who face extreme levels of vulnerability, for example people with associated disabilities or in precarious living conditions. This is precisely the tension that we address in this article, where we studied a brigade program that has aimed to effectively meet the health needs in low-income populations by means of the diagnosis of congenital heart diseases in children and the transfer to the capital city of the patients who need and deserve treatment.

In this sense, this study takes an interest in understanding the health brigades as the social context in which congenital heart diseases and the consequent therapeutic trajectories are built as a particular experience for the families living in certain social conditions. We assert that, in certain cases, the notions of vulnerability, risk, uncertainty, abnormality, and disease are resignified; while in other cases, these notions are reinforced and reasserted. Therefore, taking into account that the diagnosis of a congenital heart disease has an impact on the life trajectory of the children and their families at a medical, economic, emotional and family level, we have focused on the moment the diagnosis is given. This is because at this moment, the manner in which families face the diagnosis is shaped, as is the care practices they will adopt.[2] Thus, we understood the medical encounter within the framework of the health brigade as an observation unit and we explored – in that context – the relationship between health, disease and socioeconomic conditions to track the process of cultural signification of the disease as well as the circumstances of access to medical attention, diagnosis, and care. We discovered that the brigades, despite being a strategy to reduce the inequalities regarding access to health care, consist of dynamics that exacerbate the characteristic power relationships of the medical encounter such as the discordant

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

communication between health professionals and the families, and explicitly manifest the social determinants of health. Thus, we problematized the brigades in three ways: as a humanitarian strategy to close the gaps of inequity in access to specialized pediatric cardiology services, as a particular context for the medical encounter and the care of vulnerable populations, and as a mechanism of reproduction of the social determinants of health considered to be a practice of "social triage."

The health brigades in context

Congenital heart diseases represent a significant social, cultural, and economic burden for countries as they have undeniable effects on individuals, families and health systems; nevertheless, the highest burden of congenital heart diseases occur in low- and middle-income countries.[4,5] In Colombia, congenital heart diseases are one of the leading causes of perinatal and child death[6] and are the third leading cause of congenital anomalies after Down syndrome and the conditions associated with cleft palate.[7] Although the prognosis of the different heart diseases in children is variable, early diagnosis and treatment increase the expectations and probabilities of effective results. Therefore, strategies have been sought to assure the appropriate medical attention for the children from all socioeconomic strata.

Nevertheless, according to different international indicators,[8] Colombia shows high levels of economic and well-being inequity with a limited access to health care. This situation has provided a fertile ground for humanitarian aid in the form of health brigades for poor populations. In this sense, the health brigades have become clinical and sociocultural spaces that, apart from their medical nature, are also spaces where the benefited social groups and the medical staff create a way of narrating and facing health and illness. Therefore, in this study, we understand the health brigade as an administrative, social, cultural and political unit for the provision of health care that is composed of different moments and actions characterized by the visible and continuous effort of empathetic, compassionate and humanitarian interactions to relieve the burden of disease in the life histories of families and individuals. Nevertheless, over time, the particular dynamics of the brigades cause tensions and dissonances at the moment of the encounter between physicians and families, and breakdowns in the life and care trajectories of the children and their families.

Although conditions of social inequality determine access to health care in relation to the fact that different social groups do not have equal access to health care when facing the same needs,[9] these inequities are not limited to unnecessary, unfair, and avoidable differences regarding real access, but also include the conditions in which people are born, grow, live, work and grow old. For this reason, despite the fact that they are presented as a strategy to combat inequities in access, the brigades do not contribute in and of themselves to the transformation of the conditions of inequality that influence the determinants of health in the broad sense of the term. Such determinants include the context, the living conditions in which health develops and the structural mechanisms that determine the social position of individuals and groups, which lead to disparities in the health outcomes in the populations.[3]

Nevertheless, in Colombia, the brigades organized by the private sector as a strategy for the treatment of congenital heart diseases have grown in importance given that the national social security system does not provide real access to specialized health services in the regions where health centers have historically been scarce or absent, and the geopolitical conditions have been characterized by violence and poverty.[10] The brigades we refer to in this article have been in operation for more than 20 years in different intermediate cities of Colombia and have become a clinical and symbolic reference for the populations as they are perceived to be an actual response to health needs that provides certainties about the state of health of the

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

children who attend the service. These particular brigades appeared in the 1970s, when the Colombian physicians Camilo and Reinaldo Cabrera Polanía, after their return from the US and having studied internal medicine, cardiovascular surgery, and cardiology in adults, developed the idea of creating a medical institution for the care of resource-poor children with cardiovascular conditions. Working in several hospitals, and with the aid of physicians from different regions of Colombia, they identified a large number of children with heart diseases and without access to specialized health services, for whom access to medical attention was only possible by means of humanitarian activities supported by international funds and local donations. For this purpose, in July 1973, they established the Child Cardiology Foundation [*Fundación Cardioinfantil*] in Bogotá and managed to motivate the social commitment and the philanthropic spirit of the regional elites to put into practice their ideas of humanitarian aid with the aim of improving the access to health care of the so-called vulnerable populations as well as consolidating the education and training of local physicians in specialties related to cardiovascular surgery. In 1980, the current office of the foundation was built in the north of Bogotá. It was equipped with material and technological infrastructure suitable to go from sporadic medical interventions for children living in the marginal regions of Colombia to structured medical interventions in terms of teams of experts, appropriate technology, and diagnostic and treatment services at all levels according to the type of medical condition. By the early 1990s,four thousand cardiovascular surgeries had been performed.[11] This consolidation of the capacities of the foundation helped not only to expand the institution to Child Cardiology Foundation – Institute of Cardiology (FCI-IC) [*Fundación Cardioinfantil – Instituto de Cardiología*] but also to create health brigades of the foundation in regions far from the capital city. Over time, the activity of the brigades has become regular, reaching the current average of 10 per year in intermediate cities, that is to say urban centers with no more than 1,300,000 inhabitants (Figure 1). These cities are designated by the social and political-administrative partnerships established between the founders, the cardiologists and the populations living in the regions that can enable real access to the services provided by the foundation. Currently, the activity of the health brigades is limited to the institutional program of social responsibility called "*Regale una Vida*" [Give a Life].

This said, the emergence of these brigades and other similar brigades was not random but, on the contrary, they responded to a generalized feeling of solidarity in the form of humanitarian aid. As in many Latin American countries, in Colombia, the history of humanitarianism has been characterized by religious concepts associated with the idea of providing help to the poor, along with policy approaches to reduce social inequity.[12] From the 1930s to the 1960s and 1970s, America witnessed the rise of several public policies and social and political movements and non-governmental organizations (NGOs) with the aim of helping the poor, such as Liberation Theologyin Brazil, the Popular Economic Organizations in Chile, or the actions of foundations like Healing the Children, Save the Children, Oxfam, The Global Fund to Fight AIDS, Tuberculosis and Malaria, Project Hope, International Red Cross, Médecins sans Frontières, Caritas, among many others.[13,14] Although in recent decades several Latin American countries have been reforming their social security systems in order to extend the population coverage for health care, there are still a large number of people without real access to health care who are seeking solutions to their health problems outside the general social security system. These people perceive humanitarian aid as a true resource to respond to their health problems.[15,16] This is the case of the health brigades under analysis in this article. These brigades are, for the population benefiting from them, a socio-clinical functional event that practically recognizes and meets the health needs of people that, otherwise, would have neither medical attention, nor the required care. Nevertheless, and according to Didier Fassin,[17] the

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

Figure 1. The Brigades carried out by the program Give a Life in Colombia in 2015.

Source: Own elaboration.

moral imperative to protect life has helped to develop practices that, instead of tending to a true social justice, reproduce the social inequality and the regional disparities. This author defines "humanitarian reason" as the logic by which morally legitimate but politically questionable practices are carried out. In the contemporary world, these practices act as a palliative for structural violence. In this sense, for anthropology, to problematize the humanitarian interventions in the field of health is a particularly relevant task given that health, expressed in terms of practices, programs and policies, beyond simply being a physical and mental state of individuals, shows the political, ethical and economic interests of a society.[18] From an anthropological perspective, the health-disease process is sociocultural in two dimensions. On the one hand, how health and illness are understood, appropriated and experienced is determined by sociocultural values; on the other hand, the socioeconomic and cultural factors function as determinants of health and care. Thus, although the brigades for the diagnosis and treatment of heart disease in children living in marginal regions perform morally legitimate and medically effective actions,they involve practices that may be problematized as they are marked by sociocultural dynamics, principles of morality and justice, practices of judgment which have an effect on the life trajectories of the children and their families.

METHODOLOGICAL CONSIDERATIONS

During 2016, within a six-month period, we conducted an ethnographic approach in five of the ten health brigades carried out by the FCI-IC, visiting different cities (Pasto, Valledupar, Montería, Cartagena and Cúcuta). The demographic target of the FCI-IC brigades are the people who are members of the subsidized health regime. In Colombia, the health system is organized by the General Social Security System in Health, which requires compulsory affiliation and consists of two schemes to cover the entire population: contributory regime and subsidized regime. The employees and self-employed workers with contributory capacity are affiliated to the contributory regime and the poor population selected on the basis of proof of income is affiliated to the subsidized regime. The subsidized regime is based on a cross-subsidy of the contributory regime and resources from the national general budget.[19] The population that attends the brigades has these main sociodemographic characteristics: low-income households and households headed by women that share the same housing unit with several other nuclear families.

In each brigade that we attended, we carried out direct social observation and thorough descriptions[20] of the medical practices, the family practices, the social interactions between different actors, the administrative

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

procedures, and the bureaucratic trajectories. Thirty-two semi-structured interviews were conducted with parents and caregivers, and two semi-structured interviews were conducted with minors (persons under 18 years old in accordance with Colombian law). The uncommon congenital heart diseases taken into account for the population "triage" were: Ebstein's anomaly, pulmonary valve stenosis, interruption of the aortic arch associated with DiGeorge syndrome, heterotaxies and Williams syndrome. At the same time, a work based on documentary sources was developed in the general archive of the FCI-IC. Fieldwork data were classified and systematized to create categories that were used for the construction of narrative matrices. The research study followed the ethical guidelines of all the participating institutions and there was no conflict of interest by the researchers. In addition, the informed consent was obtained from the adults interviewed and the informed assent was obtained from the children interviewed as well as the authorization of their parents, who were present during the interviews in all cases. Both the data and the documents related to the research were systematized to strictly preserve them and maintain their confidentiality, that is to say only the members of the research team had access to those data and documents.

RESULTS

The spatio-temporality of the brigade

The medical encounter has been widely studied from the point of view of medical anthropology and it has been persistently noted that it is both a clinical and cultural space where social interactions converge on multicultural contexts marked by power relationships[21] in which aspects such as the doctor-patient relationship, ethics, trust, the lexicon used, and non-verbal language turn the diagnosis into an "endurable truth" or a tragedy to face. It has also been stated that the reporting of the diagnosis is usually characterized by a lack of information considered relevant by the patients as well as a lack of time for health personnel to answer queries and, in certain cases, a lack of empathy,[22] all of which has an effect on defining the best possible approaches for handling the diagnosis and the care trajectories.[23] Nevertheless, the health brigade, regarded as an administrative, social, cultural, and political unit for the provision of health care, represents a particular context for the medical encounter, as it especially comprises a range of successive instances connected by the waiting times and the dynamics of the humanitarian reason.

The pediatric cardiology health brigade offers the opportunity to carry out several activities in one day: the pediatric consultation, the diagnostic tests to identify or rule out any heart disease, the consultation with a pediatric cardiologist to determine the treatment and the prognosis, and the possibility of a medical transfer to the facilities of the FCI-IC in Bogotá to perform the required medical procedures. Thus, the families attending the brigade accept the dynamics imposed during the medical appointment (Figure 2), while experiencing feelings of concern, self-sacrifice, and hope at each instance, feelings which will shape how the heart disease, as an illness and as a condition of life, is constructed within the framework of the brigade.

Upon arrival, people line up to go through the administrative procedures usually before the main door of the building or the fences that delimit the place chosen for the brigade. There, caregivers, accompanying persons, and children wait for the beginning of the admission process. Nevertheless, in many cases, their route has already begun with the trip from their places of origin, which sometimes may have taken more than eight hours traveling by road or waterway transport.

After this first stage, people are placed in another venue to attend the inauguration of the brigade, in which the local authorities, the allies, and the FCI-IC hold an opening ceremony. There, the brigade team is deployed: local volunteers of different ages and with different functions, health personnel of the hospital, engineers and other professionals

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

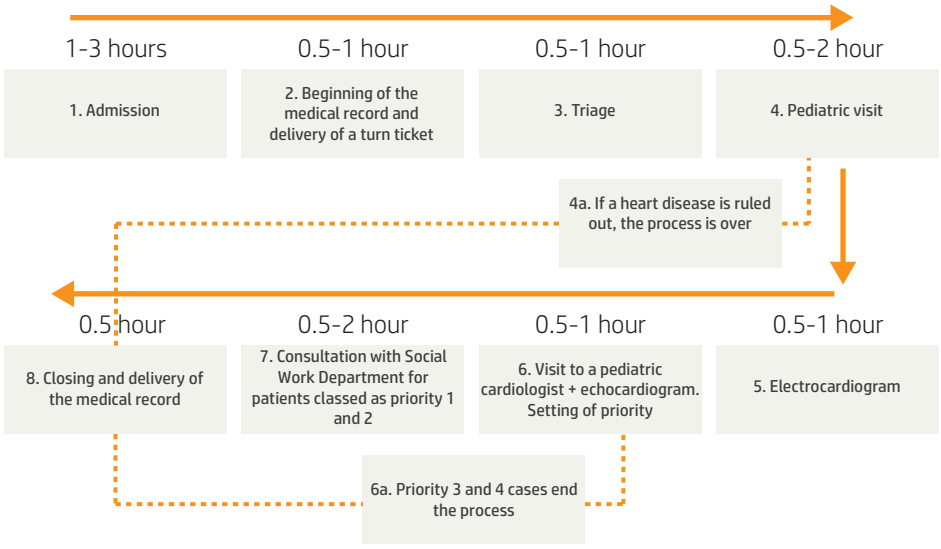

Figure 2. Family trajectory during the brigade and waiting time averages per instance.

Source: Own elaboration.

from the capital city to support the medical activities throughout the day, local journalists, and in certain cases, even public figures or regional authorities.

This opening ceremony is performed in an extremely formal way in which the discourse shows the narrative consciousness of health care through the triad of solidarity, philanthropy and professional expertise for vulnerable populations. This ceremony, in addition to serving as a passage between the administrative and the medical sphere, helps to consolidate the ideology underlying the aid, the humanitarian mission and the social partnership between institutions and populations. Once the event is over, people go first to the holding areas to wait for the "triage", in which nursing staff take vital signs and measurements of height and weight, before being called by a pediatrician.

Although the waiting times are a key element throughout the brigade, they cannot be isolated from the places where they occur. The waiting rooms are, then, adequate spaces according to the instructions provided by the brigade, which require paying attention to the calls from the medical personnel. Nevertheless, these rooms are not only defined by having chairs and being close to the doctor's office, but they are also spaces determined by other factors, such as the perceived waiting time, the weather, the background noise, the color of the walls, the recreational activities, the access to restrooms, and whether people may be sitting, socializing with the person sitting next to them, or if the administrative and medical interactions were positive, thus reducing the anxiety caused by the appointment, among other aspects.

Generally, the space for the medical appointment is a facility that includes technological, administrative, and medical teams. However, when patients, accompanying persons, and members of the brigade arrive, the space acquires another meaning in which the expected architectural objectivity, defined by the medical nature, is signified by the dynamics, attitudes, and practices of the brigade members as well as of those who attend them. In this way, although the medical space

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

is divided into multiple spaces assigned according to the administrative dynamics of the work day, it is also inhabited and signified by emotions, experiences, representations, social interactions, and practices that build up the meaning of the illness and the brigade.

After the visit to the pediatrician, the waiting time may be resumed if it is decided to perform tests such as an electrocardiogram and/or echocardiogram, and whether the patient has to receive pediatric cardiology care and social services, as detailed below. In contrast to the medical consultation, which may last between five and ten minutes, the waiting time throughout the whole day may last between five and twelve hours. Therefore, the children and the accompanying persons assume the role of patients who are resigned to endure throughout the day.[24] In this way, the waiting time plays a significant role in the medical encounter and the experience of the brigade, given that it determines the willingness to listen, understand and accept the (bureaucratic and medical) route to follow.

The medical encounter: the biological triage

The heart diseases, the administrative procedures, and the waiting times become worthwhile when the encounter with the pediatrician is about to take place, given that the diagnosis depends on it. From there on, the doctor-family relationship is initiated to eliminate any suspicions, to review the life history of the patient or to validate a previous therapeutic process. Therefore, the first question of the doctor to the accompanying person (generally the mother) is: "*Mom, why are you here today?*" This questioning is a narrative form established by the doctor to trigger the dialogue and to introduce the successive questions directed to determine whether there is a heart disease or not. The clinical interview carried out by the doctor seeks symptoms and their evolution, along with a general auscultation to know the physical and emotional state of the children in their daily lives. In this encounter, symptoms that may indicate an illness are described using colloquial expressions, and it is the moment when the cultural translation by the medical personnel is initiated or reinforced, in order to establish an assertive and expert communication in relation to the illness, the diagnosis, the treatment and the health care.

This encounter refers to children and accompanying persons attending the brigade for the first time. For those families who have already been treated in previous brigades and who have a better knowledge of the heart diseases diagnosed, the participation in the brigade is radically different. In these cases, the heart disease, which is already a part of their lives, is narrated with a specialized lexicon that attempts to communicate the previous and current state of health. For them, the disease is not an imagined or suspected condition, but it is a reality they have to face daily. The following is a verbatim transcription in which a mother, having incorporated a specialized language, is able to interact with the doctor in a different way. Thus, the fear arising from the suspicion of an illness is replaced with the uncertainty of the recovery process and wellbeing.

> *I would like to clarify some doubts because the doctor had told me that the gradient was 57, and that if it reached 60, she would have to have a cardiac cath done, but I read that if it was 50, she would also need to have surgery done. The hardest thing is that in Valledupar there's no doctor with the experience required, that can be reassuring. Today, I can look the doctor in the eye and feel good. It's just that every time the doctor uses a phonendoscope and auscultates her, I'm scared.* (Mother 1, Valledupar, 2016)

The stories of people with a previous medical history with brigades show how their knowledge about heart diseases and their capacity to describe them in a qualified way enable these people to create mechanisms that bridge the gaps in the communication with the medical personnel and reduce the uncertainty about

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

the life trajectory of the child. In other words, this lexical integration empowers the caregiver to act regarding the overall life of the child, at the same time that it is a way of creating a relationship with the heart disease that, combined with their own belief systems, builds the meaning of health and illness in that context.

The diagnosis: healthy heart or social work

Apart from being an event in the medical trajectory of people, diagnosis may be understood as a sociocultural category and as a narrative that mediates the relation between medicine, illness and communication between caregivers and other people. Moreover, it may be understood as a practice of objectivity that is necessary in medicine to name and give meaning to explicit or invisible symptoms of a person. From this perspective, it implies a semantic problem which, when named and communicated, can then build a semantic network between those who determine it and those who receive it. In the case of the brigades, it is evident that the diagnosis is a standardized procedure that follows a guideline for its determination. For that reason, both the narratives and the technological staging represent the expertise and the truth to stifle the perception of risk and fatality surrounding the heart diseases for the families. The diagnostic tests required by the pediatrician, such as the electrocardiogram, echocardiogram, or both, legitimize and testify to the veracity of the diagnostic process. The case of the echocardiogram makes evident how technology, as a visualization tool, not only fulfills its function of objective support, but also validates in sociocultural terms the process of waiting for the care of a specialist who has traveled all the way from the capital city. This test is performed by a pediatric cardiologist, however, there is minimal interaction with the doctor as they are focused on the observation of the equipment screen and on writing the diagnostic impression in the medical record. For the accompanying persons, this moment is remembered by one of three statements: "healthy heart," "please come back in a year," or "please move on to social work." The limited number of words exchanged is characteristic of the doctor-family communication, due to the waiting list and the urgency to which doctors are subject during the brigade.

Nevertheless, the report of the diagnosis is immersed in a context that determines how it is presented. For that reason, there is a wide range of ways to communicate it, which respond to each doctor's subjectivity. For some of them, one way of showing empathy is by drawing the heart to explain the disease, using diminutives or adopting a body position by which the caregiver feels protected in psycho-affective terms. For others, it is about a communicative action that is assumed to be neutral and that must be performed without any type of cultural mediation to be considered effective — short and direct. For example: "*The gradient has been maintained at a stable level, come back to checkup in a year. Any questions?* [after a few seconds] *Well, you may leave now*" (Pediatric cardiologist, Brigade 2).

Each of the communication stages of diagnosis places the caregiver in different areas of understanding and triggers different approaches to patient care, determining the possibilities to face and to follow the treatment.[23] For instance, when perceptions of abnormality and risk are significant to the families, and the medical encounter does not dissuade their impression of the gravity of the heart disease, the impact of the diagnosis keeps being replicated in the narratives of the families. Thus, the fear and uncertainty consolidate an idea of care that exceeds the medical aspect and strictly regulates all of the areas of the children's lives: the physical activity, their social interactions and the search for an aseptic environment in the places they regularly visit.

Furthermore, the lexicon used in the moment of announcing the diagnosis affects how heart disease is understood and the way it redefines the life trajectories of both the child and the family. Thus, as they are rare

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

congenital heart diseases whose names denote abnormality (for instance, anomaly, syndrome), the negative perception of the heart disease is aggravated.

> *The first time a doctor told me that my girl had a heart condition, I asked if it was serious and she told me it wasn't, she told me "don't be scared" and I asked her if it would go away, because my husband's niece also had a murmur and it closed up on its own. But now I heard something about Williams* [syndrome]*... what was it that they said?* (Brigade 5, Mother 5).

The abovementioned woman started crying when she left the doctor's office while asking why she was told her daughter suffered from a syndrome. Then, she wondered if that was the reason why her daughter was so "restless and naughty" and so physically different from her siblings. Moreover, when the heart disease is asymptomatic and there is no perception of the need to adopt specific care practices, children may face discontinuous treatments, lack of perseverance with medical consultations or with medication, and may not modify their habits and lifestyle (for example, nutrition and physical activity).

DISCUSSION

The brigade as "social triage"

Although the encounter with the pediatrician is an unavoidable filter to determine if the child suffers from a heart disease, the moment in which the possibility of access to health care and treatment in Bogotá is determined is at the social work office, which functions as "social triage". There, the attention is on the caregivers of the child, who are interviewed in order to first determine the socioeconomic conditions of the family, and then to evaluate the possibilities different families have to access the promise of health care. Therefore, the transfer of the children for treatment is prioritized according to therapeutic needs, medical prognosis, and resources available in the Foundation. Other factors taken into account are each family's condition to travel to Bogotá and to be in charge of the care practices the treatment of the child may require. The questions made in this instance, which we call "social triage", inquire about family income, housing conditions, access to basic services such as water and sanitation, house routines and care roles. Some examples of questions include: "who lives in the house where the child lives?"; "what do they do for a living?"; "is the house in an urban or rural area?"; "does the family rent or own the home?"; "what is the household income?"; "what are the household expenses?"; "while you're working, who takes care of the children?"; "when you travel, who will take care of the other children?" Therefore, the medical encounter, apart from being an instance where the illness is constructed, and where both the language used to name and give meaning to the illness and the care trajectories of people are defined, it is also an instance within the humanitarian logic that decides who will get access to medical attention among those considered vulnerable.

In this sense, the moment of "social triage" turns out to be the connection point between the humanitarian reason and the access to real medical attention, reached through sociocultural dynamics which involve the principles of morality and justice and the practices of judgment. In the instance of social triage, there is an assessment of the sociocultural resources of the families and it is determined who can receive medical attention according to those needs. For instance, it considers whether there are crucial situations of family dysfunction, if there are any guarantees that those family members who will stay at home will be fine while the mother and child are absent, or if there are any issues related to the legal custody of the child. All these issues have to be solved before traveling to Bogotá. In one case, a child who was under the care of her maternal grandmother due to the mother's cognitive impairment, and who was in need of urgent surgery, had to be legally adopted by the grandmother in

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

order to travel with her to Bogotá. Furthermore, given the rhetoric of humanitarianism regarding helping the most vulnerable, medical attention priority is given to children who will be able to access opportunities with which they may contribute in a productive way to their communities. For that reason, the cases which are not elected are those of children with complex diseases and associated syndromes, or those of families where the mother cannot afford the minimum amount required to pay any additional expenses during their stay at the foundation.

Finally, in the context of the humanitarian brigade, the medical encounter not only takes a particular form shaped by the multiplicity of instances intertwined by the extensive wait and the possible discordances, but also the construction of meaning of medical attention, diagnosis, heart disease and care is shaped by mechanisms inherent to humanitarianism. In this sense, the doctor-family interaction is mediated by space, time, emotions, technology, language and barriers, but mostly by mechanisms of subjection, assessment, and identification of the vulnerable population. Then, throughout the brigade, families, accompanying persons and children are assisted and, at the same time, their social competencies are evaluated in order to decide if they will receive aid. Thus, through patience, consultations, and triages, a mechanism of subordination operates. This mechanism transforms the brigade into something more than just a medical experience, and the act of waiting, into something more than a temporality. It is, at the same time, an experience of hope, resignation, submission and obedience.[24] Therefore, the implacability of the rhythms and languages of the brigade inevitably affect the construction of the heart disease, and may not dissipate the feelings of anxiety, fear, and uncertainty that usually mediate the ideas of what the families consider pathological and normal. On the contrary, the people who attend the brigade perceive the tiredness, the barriers, and the questions as the cost for the benefit of the medical attention they will receive from a specialist they would not otherwise be able to access. Ultimately, for those who are part of the brigades as well as for those who receive care, the experience becomes a type of explicit verification of the social determinants of health.

FINAL CONSIDERATIONS

As it was suggested by several authors who discuss the role of humanitarianism in the modern idea of progress and equity, the ethical aspects of the desire to do good, at any cost, from the private sector are questionable.[25] The positive aspects of a health brigade are clearly visible – it is, most of the times, the only possibility that many people have to access good quality medical attention. However, as evidenced above, the medical encounter in the context of a brigade exacerbates the difficulties and problems surrounding the communication of the diagnosis, and exposes the social determinants of health, not only regarding inequities in access, but also in relation to the allocation of medical attention according to a humanitarian rationality.

Generally, a medical diagnosis is not information that can be easily assimilated[21,22] and especially when it is heart disease in a child. But the medical encounter in a brigade is affected, additionally, by multiple waiting moments, administrative procedures, political discourses about humanitarianism, spaces occupied by technologies and different sources of information that are not necessarily desired by the patients and their families, and which make the process of signification of the heart disease more complex. On the one hand, the medical personnel seek to assure medical attention for all the children present, and in that attempt to do so, the diagnosis is experienced by the families as an expert verdict that may be understood as a life or death sentence. On the other hand, the accompanying persons, tired of all the waiting times, immersed in the anxiety of a diagnosis and placed in a spatial and social position of subordination, do not always ask

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

questions. The reason being that they do not want to be bothersome, they want to accelerate the process of diagnosis, they want to return to their homes or workplaces, or simply because they did not understand what the specialist stated. It should be noted that, for the families, the signification of the heart disease is marked by the perception of risk, abnormality and vulnerability, so it is necessary to continue attempting to culturally mediate the social interactions in the context of the brigade, as the complexities of this medical encounter affect the care of children in their daily lives.

Other elements may be highlighted in order to understand the role of health brigades in Colombia, where people live in noticeably inequitable conditions. Although state policies establish the necessity of universal access to health care for all, stemming from a health system based on insurance, this turns out to exclude those most harmed amongst the vulnerable. In this sense, the brigade can define a therapeutic scenario that articulates medicine with humanitarianism in order to minimize political, cultural, communicative or economic barriers. Therefore, although the gestures, narratives, expert languages and the brigade staging reproduce the power relationships of the conventional medical system within the medical humanitarian aspect, the population faces the brigade as a healing pilgrimage in which the administrative procedures, travels, waiting times, hunger, fatigue, diagnosis and therapeutic care are experienced as an authorized response to the uncertainty about the children's state of health.

Humanitarianism, to an extent, reproduces and shows the social structures of inequity, and makes evident that the events of health and illness cannot, in any way, be assumed as merely biological, but that the social context is as relevant and decisive. This is the case of, for instance, the center-periphery order, given that the possibility of treatment is offered from the capital city, or the hierarchical social structure which places the population that receives aid in a position of subordination and waiting, which do not bridge even the communication gaps that determine the care narratives. Moreover, the space identified as "social triage" – as it is the instance of assessment – and decision to determine, according to the socioeconomic criteria, which families can access health care in Bogotá– reinforces the structural violence with which health disparities are formed. The brigades, being initiatives that continue to be anchored in humanitarianism instead of contributing to the transformation of the conditions that generate health inequities, reproduce and exacerbate such inequities by selecting which lives are prioritized to be saved.

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

ACKNOWLEDGMENTS

This article is part of the results of the Project "The heart of the family: Sociocultural dimensions of the diagnosis and treatment of heart disease in children for less favored families in Colombia" from the Program for Innovation in Rare Human Congenital Heart Diseases for Colombia (PINOCCHIO), funded by the National Fund for the Financing of Science, Technology and Innovation, Francisco José de Caldas-Colciencias (Contract 662-2015). This research study was conducted from March 2016 to March 2018. We thank the different groups involved in the development of the brigades of the Child Cardiology Foundation – Institute of Cardiology. We also thank the allies of the social program "Give a Life" and the participating families for their generosity and willingness to work with us. We also thank Miguel Ronderos, Marlene Rodríguez, Adriana Díaz del Castillo, Daniela Palacio, Juan Camilo Arboleda and Angélica Vélez for their contributions to the preliminary versions of this manuscript.

REFERENCES

1. James A, Prout A. Constructing and reconstructing childhood: contemporary issues in the sociological study of childhood. London: Taylor and Francis; 2015.

2. Tak YR, McCubbin M. Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. Journal of Advanced Nursing. 2002;39(2):190-198.

3. World Health Organization. A conceptual framework for action on the social determinants of health [Internet]. Geneva: WHO; 2010 [cited 19 Feb 2018]. Available from: https://tinyurl.com/hphekdb.

4. Hoffman JIE. The global burden of congenital heart disease. Cardiovascular Journal of Africa. 2013;24(4):141-145.

5. Van Der Linde D, Konings EE, Slager MA, Witsenburg M, Helbing WA, Takkenberg JJ, Roos-Hesselink JW. Birth prevalence of congenital heartdisease worldwide. Journal of the American College of Cardiology. 2011;58(21):2241-2247.

6. Sandoval N. Cardiopatías congénitas en Colombia y en el mundo. Revista Colombiana de Cardiología. 2015;22(1):1-2.

7. García A, Caicedo M, Moreno K, Sandoval N, Ronderos M, Dennis R. Diferencias regionales en cardiopatías congénitas. Revista Colombiana de Cardiología. 2017;24(2):161-168.

8. Joumard I, Londoño JL. Income inequality and poverty in colombia - part 1: the role of the labour market [Internet]. OECD Economics Department Working Papers No. 1036. OECD Publishing; 2013 [cited 19 Feb 2018]. Available from: https://tinyurl.com/ydamrx3w.

9. Oliver A, Mossialos E. Equity of access to health care: outlining the foundations for action. Journal of Epidemiology and Community Health. 2004;58(8):655-658.

10. Hernández M. El Derecho a la salud en Colombia: obstáculos estructurales para su realización. Revista de Salud Pública. 2000;2(2):121-144.

11. Fundación Cardio-Infantil, Instituto de Cardiología. Informe anual 30 años [Internet]. Bogotá: Fundación Cardio-Infantil, Instituto de Cardiología; 2003 [cited 19 Feb 2018]. Available from: https://tinyurl.com/y982vtfd.

12. Cueto M. La "cultura de la sobrevivencia" y la salud pública internacional en América Latina: la Guerra Fría y la erradicación de enfermedades a mediados del siglo XX. História, Ciências, Saúde-Manguinhos. 2015;22(1):255-273.

13. Clarke G. Non-governmental organizations (NGOs) and politics in the developing world. Political Studies. 1998;46(1):36-52.

14. Bremmer RH. Giving: charity and philanthropy in history. New Brunswick: Transaction Publishers; 2000.

15. Green A, Matthias A. Non-governmental organizations and health in developing countries. Londres: Palgrave Macmillan; 1997.

16. Piotrowicz M, Cianciara D. The role of non-governmental organizations in the social and the health system. Przeglad Epidemiologiczny. 2013;67(1):69-74.

17. Fassin D. El irresistible ascenso del derecho a la vida. Razón humanitaria y justicia social. Revista de Antropología Social. 2010;19:191-204.

18. Fassin D. Entre las políticas de lo viviente y las políticas de la vida: hacia una antropología de la salud. Revista Colombiana de Antropología. 2004;40:283-318.

19. Guerrero R, Gallego AI, Becerril-Montekio V, Vásquez J. Sistema de salud de Colombia. Salud Pública de México. 2011;53(2):S144-S155.

20. Geertz C. The interpretation of cultures. Nueva York: Basic Books; 1973.

SALUD COLECTIVA. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789

21. Johnson J. On receiving the diagnosis of multiple sclerosis: managing the transition. Multiple Sclerosis Journal. 2003;9(1):82-88.

22. Rivera-Navarro J, Cubo E, Almazán J. The diagnosis of Tourette's Syndrome: communication and impact. Clinical Child Psychology and Psychiatry. 2009;14(1):13-23.

23. Schouten B, Meeuwesen L. Cultural differences in medical communication: a review of the literature. Patient Education and Counseling. 2006;64(1-3):21-34.

24. Auyero J. Patients of the state: An ethnographic account of poor people's waiting. Latin American Research Review. 2011;46(1):5-29.

25. Murdock D. That Stubborn "doing good?" question: ethical/epistemological concerns in the study of NGOs. Ethnos. 2003;68(4):507-532.

CITATION
Olarte-Sierra MF, Suárez R, Rubio MA. Pediatric cardiology health brigades: from medical triage to social triage. Salud Colectiva. 2018;14(3):531-544. doi: 10.18294/sc.2018.1789.

Received: 27 Feb 2018 | Modified: 17 Apr 2018 | Approved: 13 Aug 2018

https://doi.org/10.18294/sc.2018.1789

The translation of this article is part of an inter-departmental and inter-institutional collaboration including the Undergraduate Program in Sworn Translation Studies (English < > Spanish) and the Institute of Collective Health at the Universidad Nacional de Lanús and the Health Disparities Research Laboratory at the University of Denver. This article was translated by Joaquina Enriquez and Juan Manuel Fidalgo under the guidance of María Pibernus, reviewed by Kailey Painter under the guidance of Julia Roncoroni, and prepared for publication by Paula Peralta under the guidance of Vanessa Di Cecco. The final version was approved by the article author(s).