

Emergency and permanence of the Zika virus epidemic: an agenda connecting research and policy

Emergência e permanência da epidemia do vírus Zika: uma agenda que conecta pesquisa e política

Emergencia y permanencia de la epidemia del virus del Zika: una agenda que conecta la investigación y la política

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Recently, the Zika virus epidemic has caused a setting of health emergency in Brazil. This event has mobilized several stakeholders to look at this reality – where women, men and children born with the marks of these diagnoses are differently affected – as one with vectors, illnesses and obscure diagnosis situations. Recalling this recent memory means summoning the political realms to demand the commitment to the health of the population in contexts of health emergencies and their repercussions in the daily life.

The Zika virus epidemic is characterized as a total social fact ¹, precisely because it synthesizes several determinations about epidemic processes by combining factors of economic and social inequality and revealing processes of vulnerability. This situation triggers a chronology of events that establish and dismiss the emergency: in November 2015, the Brazilian Ministry of Health issued a National Public Health Emergency ²; in February 2016, the World Health Organization (WHO) classified the Zika virus epidemic as a public health emergency of international concern ³; in March 2016, the *Protocol for Surveillance and Response to the Occurrence of Microcephaly Related to Zika Virus Infection* ⁴ was published; in November 2016, the WHO no longer considered the Zika virus as an international emergency ⁵; and, in May 2017, the Brazilian Ministry of Health declared the end of the emergency ⁶.

These sequential events, responsible for inaugurating and ceasing emergencies, do not suspend the living experience: babies will grow up and need, in addition to rehabilitation services, nurseries and schools able to receive them; and parents and relatives will need to work and most likely will be burdened by their exhausting routines. The emotional vulnerability to which professionals and users of health system are submitted are equivalent within a chain of iniquities and search for knowledge. Moreover, this chronology delimits a process that risks sexual and reproductive rights in the name of securitization of epidemics ⁷, reinforcing fears and stigmatization.

If, on the one hand, international agencies and the Brazilian government position themselves and qualify emergencies, on the other, by anticipating them very closely, the scientific field – both clinicians and researchers – mobilizes itself for answers ^{8,9,10}.

Given this context, the National Network of Specialists of Zika and Related Diseases (RENEZIKA), among others, and studies on the biological and social aspects had the initiative of coming forward in a cooperation between national and international researchers to investigate and propose articulations for action.

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Almost three years after the first diagnoses, the data collection from the Social and Economic Impacts of Zika virus infection in Brazil, carried out in Rio de Janeiro and Recife (Pernambuco State), covering the subjects and rural regions of both these capitals, is concluded. This research was coordinated by the Oswaldo Cruz Foundation (Fiocruz), the Aggeu Magalhães Institute (IAM), the National Institute of Women, Children and Adolescents Health Fernandes Figueira Fernandes Figueira (IFF), the Federal University of Pernambuco (UFPE) and the London School of Hygiene & Tropical Medicine. In Rio de Janeiro, the research was based on two prospective cohort studies. In Recife, subjects were from case-control studies on microcephaly, being the cohort based on health services (primary and specialized care) and children with congenital Zika syndrome.

The qualitative data collection included 145 interviews in the metropolitan areas of Recife and Rio de Janeiro from April to November 2017, with participants distributed into five groups: health professionals from primary and specialized care, mothers of children with congenital Zika syndrome, other relatives involved in children's care (parents, grandparents and uncles/aunts), men and women at childbearing age, and pregnant women. Each of the groups was marked by peculiarities in the approaches, respecting regional differences.

The research also included a quantitative analysis through interviews with the primary caregiver of the child. Five questionnaires were applied to 215 participants in Recife and 271 in Rio de Janeiro. The measure of social support, understood as the resources available to people in situations of need was obtained through the *Medical Outcomes Study* (MOS) scale¹¹. The short form of the *Depression, Anxiety and Stress Scale* (DASS-21)¹² was used to evaluate depression, anxiety and stress symptoms. A third tool – *The Pediatric Quality of Life Inventory* (PedsQL) Family Impact Module¹³ – was included to measure the impact of chronic conditions on the quality of life of households. Questions about postpartum contraception, emotions regarding pregnancy and possible changes in the affective relationship after the child's arrival were applied to respondents¹⁴. To estimate the economic impact, the social cost to households and the costs of the Brazilian Unified National Health System (SUS) were used to calculate the cost of care.

To building a research design considering these differences meant working toward diversity. To perform an exploratory and strategic research, we exposed themes central to our interlocutors, such as sexual and reproductive health, prevention information, family arrangements and care. Assuming a research involved in social transformation, we built a critical knowledge that allowed us the formulation of policies. Our preliminary reflections are shown below.

After analyzing studies on disabilities and listening our interlocutors, we noticed that children with small heads are exposed to discrimination. However, other children, with nonvisible marks, and who can only be diagnosed by experts and clinicians' examination, are at risk of not being included from healthcare processes, such as follow-up, care and welfare programs. We must take into consideration how much children with visible disabilities can obscure the ones with nonvisible disablement and accentuate the importance of the former, who also depend on technologies. In addition, we must highlight and reflect on the rationale of care lines, which is the responsible for the poor relationships between primary and specialized care¹⁵.

Vaccines, repellents and mosquitoes become stakeholders¹⁶ and agents of a State that fosters no trust and safety¹⁷. As for the sexual transmission of the Zika virus, we highlight the discourse which is permeated with a logical model that relates the Zika's transmission to the HIV's one.

The Internet is a locus where people search for information and establish new networks, streamlining communication and information. New and old models coexist in the sexual division of labor that naturalizes the conception that the innate women's place is at care. Paternal abandonment, though not confirmed, is announced in the statements.

The Zika virus epidemic causes suffering in the mental health field, affecting in different manners and degrees the subjects involved, such as health professionals, mothers and families, who deserve well-thought-out answers to this effect. The suffering of a family can meet the demands for rearrangement of care, work and conjugality. Thus, the promotion of reception and support in the scope of primary care with specialized training is urgent. Regarding the health professionals, the lack of knowledge about the consequences of Zika virus on pregnancy and its repercussions on children's

lives become a source of suffering, to which promotion of institutional training devices that invest in exchanges, continuing education and production of articulation between research, teaching and services are required.

Finally, we must think more about the permanence of transforming and articulating life and politics, and less on the emergencies going in and out of agendas. The Zika virus epidemic can raise awareness of the other children with disabilities who also need care services but are currently neglected. These problems are not caused exclusively by the Zika virus epidemic, instead they refer to persistent inequities in health care and social, gender, class, racial and disability inequalities.

Contributors

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