

Congenital Zika Syndrome: Focus groups with mothers and health professionals

APRIL 2016

Introduction

➤ Objectives

To collect data and information to inform the development of new methodologies to support mothers and families with children diagnosed with Congenital Zika Syndrome (also known as microcephaly) and other neurological disorders

Methodology and sampling

Grupos	Number of groups	Number of participants	Profiles
Health professionals	1	9 professionals	Community health agents, phono audiologists, doctors, nurses
Mothers in the initial process	1	5 mothers, with their babies (between 5 and 13 months)	Mothers in the initial process starting to deal with microcephaly
Engaged mothers	1	6 mothers, with their babies (between 5 and 8 months)	Mothers who are well informed and participate in organizations or groups of mothers of children with the syndrome.

➤ Methodology and sampling: mirror room



Results

➤ Introduction: research findings

The mothers of children affected by the Congenital Zika Syndrome (known as microcephaly) and professionals responsible for treating the children share the same feeling of helplessness and lack of confidence in front of the disease:

- ✓ the feeling originates from an insufficient degree of knowledge about microcephaly associated to zika virus.

Perception of the mothers → it is a new condition about which they know very little:

- ✓ they know it is a kind of brain paralysis *“which enters the child’s brain”* and those children affected by microcephaly need much stimulation;
- ✓ those who are familiar with Down Syndrome compare the behavior and the symptoms of the children affected by microcephaly to that condition.

➤ Introduction: research findings

Health professionals → they too are overwhelmed by the disease:

- ✓ the knowledge about microcephaly which they obtained from other cases is not sufficient. Ever since microcephaly was associated to zika virus the deficiencies presented by children have become larger and more complex:

“Brain paralysis presents with visual and auditory alterations, hypersensitivity...the children undergo a process of seizures which the others did not have and cease to grow because of those episodes...I perceive that, in some babies, the virus is not settled, it grows into something worse.”

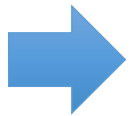
The experience the mothers and health professionals have in the case of zika virus syndrome are full of difficulties, uncertainties, emotional tension and extreme pain

- ✓ the outcomes presented here aim at understanding the background of the segments involved with the discovery, the supervision and the treatment of the disease;
- ✓ Each statement reveals its peculiarities, uncovering experiences different but complementary to the process itself.

About the mothers interviewed for the research

➤ About the mothers interviewed for the research

The two segments of mothers included in the study - engaged mothers, who are more involved in the disease process, and the mothers in the initial process, beginning to deal with microcephaly - both share many experiences, anxieties, difficulties and expectations.



Although the engaged mothers were more informed about the syndrome, no significant differences were seen between the mothers interviewed for the research:

- ✓ the experience they share -to have their children affected by microcephaly - re-signified, for those mothers, the sense of being a mother itself;
- ✓ the responsibility, their dedication and commitment for the rest of their lives, their renunciation is what defines what being mother means for all the women:

“It means no sleep, going to the pediatrician, the psychologist, 24 hours work...it means work for the rest of your life.”

“It means responsibility, to care for the child, because it needs us...It’s a commitment, to renounce, leave everything aside, to do whatever you like and dislike for them.”

Mothers: initial confrontation with the disease

➤ Initial confrontation with the disease

- ✓ The mothers only knew about their newborns having acquired microcephaly after their birth;
- ✓ some of them experienced anguish of not knowing with certainty what was going on with their children after they were born: they were informed imprecisely, with different initial reports, until they were told it was microcephaly;
- ✓ the way the diagnosis was communicated was also a shocking experience for most of the mothers: they complain about not having been properly prepared to receive such an announcement, which was, most of the times, presented in a hopeless and fatalistic tone by professionals in the health care system.

➤ Initial confrontation with the disease

“My baby stayed at the ICU for 60 days. When he was discharged, the doctor asked me: do you have a job? I said, yes I do. Then she went on saying: you will from now live only for him. Up to now I still don’t get how a professional which has spent so long with him didn’t tell me what was going on”.

“ I was informed at the hospital, as soon he was born, that he missed the back of the brain. They were rude to me. I was longing to know how long he would stay at the hospital and I was told: from now on she will no longer belong to you, since she is Government’s propriety, because she will be hospitalized”.

“The doctor told me: you better get used to it, you have a baby with special needs, you need to get used to it, that’s it. I was expecting she would explain it to me, but in a more gentle way...she lacked manners! We really don’t want to hear about our child being sick, crippled, it’s a lost generation. Nobody wants to hear that, you only want to hear that he will be supported, stimulated.”

“I discovered it in the worse possible way, during labor, by a doctor being very insensitive. She placed him on me and told me that my son was not normal.”

➤ Stigma and discrimination

- ✓ The Congenital Zika Syndrome is getting more press coverage. In turn, women have been subjected to public opinions and, often, attacked;
- ✓ Mothers were emotionally torn apart, being astonished by discovering having a baby affected by microcephaly. This was boosted by the prejudices the mothers hereafter, on a daily basis, faced from strangers and, in many cases, from their social network.

➤ Stigma and discrimination

“I was on the bus and a woman said to me: oh, oh, isn’t that one of those babies which don’t grow at all? I answered: no madam, those who do not grow at all are dwarf babies.”

“There was a man saying once there was a plague of locust and now babies with microcephaly are another plague... There is this soap opera “The 10 Commandments”, and they are relating those facts to microcephaly, they keep saying our children are one of those plagues coming.

“Society is very prejudiced, people make comments on the bus, even at the hospitals...a woman wanted to take a selfie to show her niece why she shouldn’t get a baby.”

Mothers: economic impact

➤ Economic impact

The birth of a baby with microcephaly invoked a financial impact in the lives of all the families → the household budget of those families has been undermined by expenses including remedies, milk and frequent visits to the care centers, often in distant places:

- ✓ the concern of getting money to continuously giving due care to the children with microcephaly is a constant burden in the life of those families. They are compelled to sell their few belongings to afford paying the treatment this disease demands;
- ✓ they report facing difficulties even adding credit to their cell phones, which in turn increases insecurity, since they cannot phone for help / guidance in a moment of crisis;
- ✓ most of them had to quit their jobs to accompany their baby to the health center.

➡ **meaning, there was an increase of costs and, at the same time, a decrease of family income**

➤ Economic impact

The only solution they have is to borrow money from their closest social network → however, most of the times, they do not count on financial support, not even from their own family, since they can either not afford or wish to contribute due to lack of responsibility in those cases:

- ✓ they experience a constant anxiety, trying to find solutions allowing them to get the minimum necessary for a continuous care attendance for their child with microcephaly.

Not even the family supports, not even my mother, whenever I ask her for support she keeps saying to me: it's your child! My mother doesn't even hold him. Neither do my sisters."

"Have you ever heard a sister-in-law saying: 'he was born sick because you was looking for it, you shouldn't have got pregnant'. That hurts me...support, I only get it from my husband."

Mothers: family and social support

➤ Family and social support

To adapt to this new reality imposed by microcephaly, mothers are expected to count on family support as well as from closer relatives and friend`s → however it was not always the case:

- ✓ the husband is recognized as the main support;
- ✓ most husbands help, some with less involvement, others offer a committed support;
- ✓ they take over with domestic tasks, like taking care of the couples' other children, and, whenever possible, accompany the mother visiting health centers.

Lack of commitment from the husbands → although, there are exceptions:

- ✓ however, some mothers heard rumors or statements about fathers who abandoned their home and accounts of husbands beating the mother on the assumption that the mothers were only taking care of their children while, the husbands, felt “forgotten”.

➤ Family and social support

Even if the mothers reported that they received their husband's support, it did not necessarily mean there were no conflicts in their pivotal family environment:

- ✓ the mothers do recognize that they feel exhausted, in no mood or no time to take care of the rest of their children, who, on their side, feel lack of attention, which in turn generates a feeling of guilt in the mothers;
- ✓ except some cases in which the husband does the cooking or stays at home, unemployed, their domestic routine has been compromised, particularly regarding time schedules and meal preparation;
- ✓ fathers who are more involved with their children miss their work and feel like they are putting their job at risk;
- ✓ in some cases, husbands disregard taking care of their child: even if they are eager to assist, they totally depend on the mother to know what to do.

➤ Family and social support

Regarding to the support they expected to receive from other family members and close friends, expectations were not always met → the relationship with their social network is also characterized by some difficulties:

- ✓ in many cases, their grandparents and aunts refuse to assist and help taking care of the children. If they assist, they do it in an evident hostile manner;
- ✓ relatives, friends and neighbors do not take the initiative to help by means of simple gestures like, for instance, offering a ride in their car, which could at least decrease the burden of the mother's day;
- ✓ friends who used to come to their home quit visiting them.

➤ Family and social support

Those mothers, who are overloaded, experience in their daily routine exhaustion and stress and the limited support from the family and the closer social network increases that → they withstand inhuman conditions to give due care to their children:

- ✓ being with their children, constantly caring for them, even overnight, means few hours of sleep;
- ✓ standing and moving around during most of the day causes exhaustion and leg and toes swelling;
- ✓ poorly feeding themselves, since they cannot afford sitting at the table to have a proper meal nor eating quietly whenever they are outside their home (it is common for them to hold the child in the arms in fear of what could happen to him);
- ✓ not even being free to go to the rest room (there are reports of urinary infection resulted from that situation).

➤ Family and social support

Personal care and activities they used to perform for self-esteem purposes and independence were also abandoned:

- ✓ many of them had to quit their job and miss having “their own” money to cover their minimum personal needs (to buy clothes sanitary pads or clothes).

It is important to highlight that the mothers interviewed report cases from other families facing even more difficulties.

- ✓ They mentioned stories about abandonment of children, fathers who leave their homes not being able to cope with the disease of the children or sending away the mother and the baby.

➤ Family and social support

“I know a mother who gave up, had her baby and left it in a shelter...about fathers, there are plenty of cases.”

“Some colleagues of mine told their husband had left home because the baby cried too much early in the morning and they had to work the next day.”

“I know about mothers who are alone, mothers who talk about husbands beating them because they only take care of the baby.”

“There was a girl whose husband sent her away with her baby as soon as she was eighteen.”

Mothers and health care system

➤ Health care system

Despite the negative experiences they went through when microcephaly was diagnosed, often in a cold and in an imprecise manner, the mothers recognize that the support and assistance given by professionals of the health care system was important for them to feel supported.

- ✓ they acknowledge that, in many cases, the assistance provided some visible outcomes in the treatment of their children → and those achievements are valued by the mothers.

“I feel like I am being supported here by these professionals. The pediatrician is always around to hear me.”

“My son is doing physiotherapy. He didn’t open his hand and now he does.”

However, they said their journey to achieve the necessary health care was dilacerating and uncertain, exposing the mothers to several difficulties.

➤ Health care system

MAJOR CHALLENGES FOR THE HEALTH CARE SYSTEM

- ✓ Insufficient availability of health care services: those mothers who are now dealing with microcephaly report difficulties in obtaining the health care for their children;
- ✓ In case of an emergency, children was not treated by ER → the child was referred to a hospital, delaying health care and increasing the anguish of their mother;
- ✓ Mothers informed that the children do not received preferred health care in the hospitals. Even in cases of emergency, they have to wait the whole day for a doctor.

➤ Health care system

MAJOR CHALLENGES FOR THE HEALTH CARE SYSTEM

- ✓ Unprepared professionals: they said that there are specialized doctors, but there are also some of them who lack knowledge about dealing with their baby's condition;
- ✓ Lack of products: they face shortage of vaccine and remedies, which should be distributed for free by the public health care system;
- ✓ Lack of attentive care for “traditional” baby health issues: health issues, which apparently do not relate directly to microcephaly, do not receive proper attention (catarrh, urinary infection, high fever, one doctor did not realize the baby girls had labial adhesion);
- ✓ Wrong therapeutic approach: in some cases, the babies were wrongly treated (giving them Dipirona as a fever treatment, a remedy to which the baby was allergic; treating a crying baby with Luftal, as for colic symptoms, and not considering it a seizure).

➤ Health care system

MAJOR CHALLENGES FOR THE HEALTH CARE SYSTEM

When they manage getting access to the different treatments their baby needs, those services are decentralized:

- ✓ mothers and their baby have to face a exhausting and expensive journey

“We live out of our home from Monday to Friday, we attend the therapist, the phono audiologist, the physio, visual and audio stimulation sessions.”

“My son spends 4 days a week in therapy in 3 different places.”

Many trips mean transportation costs:

- ✓ not all the mothers interviewed had a free bus pass;
- ✓ not showing up at the health centers they would loose their rights to treatment, they therefore live in anguish of not getting enough money for the transportation.

➤ Health care system

MAJOR CHALLENGES FOR THE HEALTH CARE SYSTEM

One of the core issues of the current health care system is the multidisciplinary health care approach for the children, a solution is expected by the mothers:

- ✓ health care services are, currently, only available in the capital city of each state;
- ✓ They emphasize the need for inland centers to offer better quality in health care → there are rumors of improperly trained professional staff only being available inland.

“We heard about some professionals not being good, pediatricians who are not even able to identify the problem the babies go through.”

➤ Health care system

MORE ACKNOWLEDGEMENT AND SUPPORT FROM HEALTH CARE SYSTEM

Mothers do not feel respected by the health care system → they said doctors are more interested in research and the children and mothers are not prioritized:

- ✓ they do not feel they are being heard by the health care professionals and they would like to receive a more qualified and sensitive health care;
- ✓ Often they do not have access to the results of the examination of their children;
- ✓ they feel, ultimately, excluded.

“They kept calling my daughter in for further examinations, for their research. I always keep saying, but nobody cares. They asked me: did you have zika? They carry out research and give us no attention at all.”

*Mothers: special care at
home*

➤ Supervision and home treatment

BASIC CARE

Even when counting on public health care professional advice, the mothers do not feel completely secure in terms of taking care of their children at home. They do not know how to proceed in order to care for the symptoms identified in their baby, especially:

- ✓ the irritability which leads the baby to cry frequently and for long periods (babies should not be upset since they have difficulties to stop the crying / they become red when they are tearful);
- ✓ choking, provoked by thick saliva, are difficult to administer and care for;
- ✓ seizure crisis.

➤ Supervision and home treatment

Engaged mothers feel more confident and seem to have assimilated the information they received more efficiently:

“They teach us how to do the things, if they like it the way we perform it, we continue doing it...

When he is very irritated, I swing him and play some music for him, like I sing a lullaby to him...

Bathing is also fine, you warm the water, put him in the bathtub then he stays calm...

To talk, music...I place him in the wheel chair and keep talking to him and he gets very calm...Pediatricians suggest to talk with the babies while they are in the womb.”

➤ Supervision and home treatment

The **mothers in the initial process**, who just started dealing with microcephaly, feel more anguish, and they admit to not knowing what the remedies for their babies are prescribed for:

- ✓ according to empirical observation of the baby's reactions the mothers learn by doing;
- ✓ the mothers do not necessarily follow the directions given by the doctors, and they can change the dose prescribed and introduce procedures which they believe help controlling the symptoms of the disease.

“To swing the baby when it has seizures helps...My baby indeed likes strong people, my husband is big and when my big friends come and stay at home with him, then he gets calm. My daughter gets calm with trees...when the leaves swing, she keeps staring at them.”

➤ Supervision and home treatment

STIMULATION EXERCISES

In this field, the differences between engaged mothers and mothers in their initial process dealing with microcephaly become more evident:

- ✓ **engaged mothers** show more confidence and are familiar with this task → they receive and assimilate the information on how to proceed stimulating the baby at home.

“We need to complete our tasks. We need to find half an hour to repeat the exercises at home... Sometimes the babies have the flu, they are agitated and can’t perform the therapies.”

“I do it at home, but when she gets too stimulated she has a crisis. If you pull for too long, she gets seizures. When she stays calm, I keep massaging her.”

“At home I do the stimulation exercises the doctor suggests me to do. I play with her, perform the visual part, the auditory one, up to 20 to 30 minutes. When she is not too rigid, I stimulate other parts too: rolling and seating, so she gets steadier.”

➤ Supervision and home treatment

STIMULATION EXERCISES

- ✓ **the mothers in their initial process**, who just started dealing with microcephaly feel more insecure. They show some familiarity with the practices of stimulation at home → although, they have many questions:
 - they describe that health care professionals try to guide them;
 - however, they admit to not always succeed at putting into practice what they learn.
- ✓ **the mothers in their initial process** search, then, to empirically find a way to “stimulate them”.

“I can’t succeed in putting into practice what I learn. He (the baby) feels irritated or doesn’t want to do the exercises. I try to find a way to stimulate him, he stays on my lap watching TV...I lay him on the carpet with some toys and our little pet...”

Mothers: knowledge and information

➤ Mothers: knowledge and information

Even if they live with the syndrome 24 hours a day, the mothers are aware of their lack of knowledge about microcephaly:

- ✓ they not only ignore what microcephaly is really about nor do they know their child's future perspective (for instance, how the child's condition is going to develop with time or with due care positively or not);
- ✓ the lack of information increases their anguish for their child's development and future perspective, and also, makes home supervision more difficult.

➤ Mothers: knowledge and information

WHERE THEY OBTAIN INFORMATION

The most reliable source of information for the mothers are health care centers → however they also search for other sources of information:

- ✓ Google search;
- ✓ they trust the guidance and advices given by the other mothers acquired during the conversations they have while they wait at the health care center).

➡ They miss an emergency health care service, like a 24/7 phone number where they can get guidance and instructions from

➤ Mothers: knowledge and information

WHERE THEY OBTAIN INFORMATION

Despite the effort health care professionals make, the mothers feel they are lacking support, mainly a space where they among peers can share experiences, listen and be listened to:

- ✓ support groups in WhatsApp originated out of this need;
- ✓ The group **UMA-União de Mães de Anjo** was specifically created as a tool, not only of support but also to advise each other and is quite well valued by the mothers:
 - the group performs assistance activities, raise donations and distribute relief items for the mothers (diapers, clothes, etc.);
 - it also provide beauty advice to boost self-esteem and recreate feminine aspects for the mothers;
 - they also perform activities to built up their capacity to take care of the baby, like a course in Shantala massage, supported by private companies.

➤ Mothers: knowledge and information

The sharing of experiences is a very important element of the group and is well valued by the mothers:

- ✓ It keeps them connected in a constant sharing of information about what to do, how to proceed and even which remedies to give to their children whenever there is a crisis / onset of the disease;
- ✓ For the mothers it represents a quick response when they experience a problem.

Certainly, the support group represents an important initiative, which contributes to minimizing the feeling of social isolation and helplessness → even if it stands as a parallel source of information which may involve some risks:

- ✓ it makes it possible for the members to share their experiences and give advise to other mothers giving the impression of “authority knowledge” which may not be the proper advice or applicable to other children who, despite sharing the same disease, present with their own peculiarities.

➤ Mothers: knowledge and information

MAJOR GAPS IN INFORMATION

- ✓ lack of knowledge about the disease: what is microcephaly truly about? Which damages / risks does it imply? What future will unfold to the child affected by the disease? Will the condition get better with time and with due care?
- ✓ imprecise and unclear information regarding the medical circumstances of the babies: they are not clearly informed about the diagnosis and they do not have access to get any explanation about the results of the examinations (***“I know almost nothing about what he has or lacks”***);
- ✓ they do not receive information about what to do in case of emergency (i.e., in case of a seizure);
- ✓ they do not receive any advice about proper food for the child, often leading to learning by doing methods and following beliefs systems.

➤ Mothers: knowledge and information

MAJOR GAPS IN INFORMATION

- ✓ they do not feel capable of fulfilling the basic care for their child in association to the symptoms of the disease → how do they proceed when the child has a seizure, is un-soothably crying and presents with bouts of irritation? How to proceed when it has difficulties swallowing the food or even the saliva? How to clean the baby's mouth? Which kind of bottle is the most recommended one?
- ✓ there is a lack of information about how to stimulate the baby, which in turn increases the necessity of going to the health care center;
- ✓ they do not know what changes are relevant to be observed and cannot inform the doctor, contributing to difficult supervision;
- ✓ women who become a mother for the first time need some guidance about health care, not restricted to microcephaly.

Mothers: identifying their needs

➤ Mothers: identifying their needs

It is evident that mothers face an overwhelming sense of responsibility and lots of work and many of them feel like they are performing at the limit of their capacity:

- ✓ for those who do not have Whatsapp, suggested actions, like meeting groups, are not perceived as a priority support nor is psychological supervision → they argue they would not even have the time to participate in those activities;
- ✓ besides, some of them already have received psychological support at the reception centers.

“I can’t do my home tasks anymore...”

No more patience, I arrive at home exhausted, sometimes without having had a meal.

I work, leave my daughter with my mother, but I will have to quit the job. Since she breastfeeds, I am trying to substitute the milk, but she doesn’t like it, she just wants to breastfed.

➤ Mothers: identifying their needs

CARE ATTENTION

The mothers expect a more organized support structure to be built up which should follow these steps:

- ✓ centralization of health care, to relieve the daily exhaustion for the mother and the baby;
- ✓ regular clinical health care for the mothers, so they can take care of their own health, located in the same centers where they bring their baby (as it is now, they can not themselves visit the doctor) → this expectation also reveals the fear of becoming sick and not being able to take care of the baby with microcephaly (***“If I fall sick, who is going to take care of my baby?”***);
- ✓ support to the mothers at the health care centers where their baby receives care, like making someone available to help them by looking after the baby so they can have lunch, rest, go to the restroom with no rush, etc.

They also desire a stronger support in regard of the information needed:

- ✓ advice and material (colored balls, rattles, toys, pads) to stimulate the baby at home;
- ✓ a more precise guidance about the diagnosis and treatment of their baby.

➤ Mothers: identifying their needs

According to their opinion, this information should be communicated by different means:

- ✓ **Talks** → the verbal transmission of information, mainly pertaining to a precise diagnosis and the baby's medical condition: this kind of communication can strengthen the trust thus generating an active involvement, which in turn makes the assimilation of knowledge easier;
- ✓ **Helpline** → to provide an immediate health care, via telephone, in emergency cases;
- ✓ **A guidebook** → to strengthen and complement, in writing and with drawings, the guidelines and advice they receive from health professionals, particularly in the following subjects:
 - basic care relating to the symptoms;
 - stimulation;
 - feeding and breastfeeding;
 - general guidance for mothers in their initial process.

➤ Mothers: identifying their needs

Another urgent need of the mothers relates to transportation → they already achieved the right to a free bus pass, but it presents with some difficulties:

- ✓ to get the pass means bureaucracy and it is time consuming, and the provisory document they receive is not always accepted by the bus driver or ticket collectors who refuse it;
- ✓ also, they describe the treatment they receive by the bus employees is lacking in respect as the bus employees attack them with prejudiced comments about their baby;
- ✓ they believe it is the Government's duty to provide due transportation for the mothers and children who live inland and have to travel to get treatment → Currently, the prefecture offered them few cars, but the service is not always efficient and they fear for delays which could compromise the baby's health care;
- ✓ they also demand free bus passes for their under aged children, who do not have microcephaly but who cannot be left alone at home.

➤ Mothers: identifying their needs

Also perceived as an aggression is the bureaucratic health care by state employed staff, from whom they depend to get the benefits like free access to remedies:

- ✓ many mothers feel humiliated, not for having their benefit denied, but for not being heard and for being treated with undue attention.

Another relevant concern expressed by the mothers refers to the future of their children:

- ✓ some of them dream of a favorable resolution of the disease and they hope the baby can enjoy its life as any other infant (***"I hope they date, run, fall, climb trees and go to college."***);
- ✓ however, other mothers show more skepticism, arguing that their child's future seem uncertain → they express concern in relation to education: with the deficiencies of the national education system, mothers wonder whether the Government will guarantee educational inclusion to the children with microcephaly.

Health professionals

➤ Impact on health professionals

Health professionals from different fields participating in the treatment of microcephaly were taken by surprise. The condition developed without even having time nor capability to care for the huge amount of cases arriving at the care centers they work at:

- ✓ they felt insecure on what to do, how to respond and how to proceed;
- ✓ they are very shocked when confronted with the gravity of certain cases and the suffering of the mothers and the baby;
- ✓ they understood they had to be involved with the patients' family → health care could not just be medical treatment: the mothers and fathers of children with microcephaly also needed psychological and social support.

Currently they feel uplifted, since they realize the care they offer is limited but none the less relevant

➤ Impact on health professionals

“I couldn’t take care of those children, I wasn’t able to cope with it. I kept getting out to cry, I couldn’t hold them. There was a day where we received 70 children, it was very tough. Now I am more confident, since I know I am here to assist and help them to a better condition.”

“There is by any means not enough information. We have the basics, and it is on that ground we perform some interventions, but we do need more training.”

*The health care
professionals: their
approach to the families*

➤ Health care professionals: their approach to the families

Reports from health professionals match with the statements from the mothers → as they too identify exhaustion, conflicts or even desperation, as the feelings present in many mothers and fathers.

- ✓ they feel overloaded by the difficulties in supervising the parents in their search for different health care and by the difficulties the parents face on a daily basis, which includes neighbors complaining when the baby cries;
- ✓ there are cases in which the family does not accept the diagnosis and refuse to take the child to health care;
- ✓ there are mothers consulting psychologists, as they have doubts and think of abandoning the baby or attempting suicide;
- ✓ they feel many fathers are abandoning the family, which leads the mothers to ask for support from health agents to engage fathers in support groups.

➤ Health care professionals: their approach to the families

“I have heard mothers saying ‘I don’t know how I didn’t become mad yesterday. Please don’t enquire, I am afraid of opening up and not being able to lock it up again. Nowadays I count on the psychologist in the room close to this. The psychologist comes and we see her’.”

“Many fathers do not want to participate anymore, they do not abandon, but they do not participate in caring for the baby. They say: ‘I lack the strength to take care of a child overnight and the next day having to wake up early to go to work and, on top of that, not having money to see a therapist’.”

➤ Health care professionals: their approach to the families

Besides their concern regarding the mothers and fathers of the infants, the professionals understand that the emotional state of the parents is a key factor which should be given much more attention → they realize it can interfere with the treatment and development of the child:

- ✓ when the mother enjoys moments of “peace of mind”, it seems to contribute to create a proper environment for the care they provide to the child.

“Whenever there is family support, the effect on the baby is better... When the mother is unhappy with an absent partner, we realize that the child doesn’t achieve the best results... A calm mother can pay better attention to everything.”

➤ Health care professionals: their approach to the families

Moreover, fatigue, overloading in tasks, stress and emotional draining can affect the infant's development:

- ✓ in those cases observed where the mother misses health care sessions, does not stimulate her baby at home or does it improperly or excessively the desired results are compromised.

“There are children with higher potential , they do interact, but, when they return, they cannot walk properly... A mother with many children and without support does not get involved and cannot stimulate at home.”

“There are cases in which the babies do not react because they missed some sessions or the mother is doing it wrongly or not doing at all.”

➤ Health care professionals: their approach to the families

Those statements confirm, according to health professionals, that it is necessary to make efforts to support mothers and get them involved in the process → to succeed, however, means assuming the following conditions:

- ✓ to provide mothers with psychological and social support, counting on trained professionals (psychologists and social workers) to hear, advise and support them in achieving their rights, like free bus pass;
- ✓ establish a mutual trusting relationship between the mothers and those professionals who care for their babies. That means learning to listen and learning to speak the language of the mothers;
- ✓ be confident of those informations conveyed about the health conditions and the development of the child.

➤ Health care professionals: their approach to the families

“We need to deal with the mothers’ fears. If we succeed at conveying the information in reliable manner, it helps...we need to create a connection so they feel more supported.”

“There was a mother who started crying whenever I talked about microcephaly. So, I changed slowly my discourse so I could approach her.”

“When a mother tells me she can’t afford getting the free bus pass, then I speak to her as a social worker. After, the mother tells me she succeeded at getting it...that’s the moment they start trusting us.”

“As I hear her speaking, I start realizing what her needs are. The diagnosis, for instant...the tomography was a mystery to the mother, but she can positively understand what calcification is about, I show her those spots, speak in her terms, so she can understand.”

*The health care
professionals: the health
care system*

➤ Health care professionals: the health care system

According to health care professionals, the health care for children with microcephaly is still in its initial stage and still lacks structure. The system is still far from offering the ideal care:

- ✓ there are children with the disease who are not being cared for;
- ✓ health care centers focus on Recife, the city capital, thus making the mothers travel many hours to have their baby treated;
- ✓ not all the children receive all the care they need;
- ✓ there is no control of the health care being given to each child: there are children who did not have any tomography, while others undergo a high number of them, which, indeed, can put their health at risk;
- ✓ doctors do not have access to the results of the examinations carried out → access is essential: without those informations, the team assisting the child (Occupational Therapy, Phono audiology and Physiotherapy) eventually perform their job without knowing whether the child sees or hears.

➤ Health care professionals: the health care system

The integration between professionals of different fields represents an issue considered a priority → there are projects, initiatives and concerns, but the problem has not been resolved properly yet:

- ✓ there are no available professionals to build a bridge between the different services every patient needs.

“There is a project where the child and the family are attended to at the same time: once per week the family gets a visit, every 15 days the nurse visits and once a month the doctor visits them so the family gets more the attention. That’s a strategy. That’s what we call shared care. The doctor tells and assesses their needs, calls the nutritionists...

“We are performing as partners (pediatrician and phonoaudiologist), we get to know things we didn’t know about before and it provides us with mobility. For example, Ana didn’t come to care, so I send her a message asking why she didn’t come. We go at their place to know the reason. Had we built a bridge it would have been easier since they could choose in which center they would like to bring their child.”

➤ Health care professionals: the health care system

SUSPECTED CASES OF MICROCEPHALY IN PREGNANT MOTHERS

Health professionals report that pregnant mothers suspected of carrying babies with microcephaly have been attended at the health care center following a standard procedure → these professionals seem to be more prepared to receive and offer the mothers the necessary care:

- ✓ their main concern is prevention → they advise the mothers in the waiting room to take care of the quality of the water and the garbage, they give them some leaflets, etc.;
- ✓ the health professionals know that there, currently, are no effective means to control the life conditions in which the mothers live nor to provide them with a basic support.

The health professionals are aware that prevention will continue to be a main concern as long as the governments lack to ensure basic sanitation for all the communities, a stronger support and information to the people.

➤ Health care professionals: the health care system

SUSPECTED CASES OF MICROCEPHALY IN PREGNANT MOTHERS

“We can’t even imagine the conditions in which they live, there are places where health agents can’t even reach...there are houses with no beds at all, where they sleep in cardboard boxes.”

“I keep asking them whether they received any insect repellent, how do they store the water... These women say that zika is not at their house, but in the surroundings, they blame the people around them.”

“They don’t even have money to buy bread, you can guess what buying insect repellent means! It is unacceptable to identify a pregnant woman and not give her insect repellent.

Health care centers deliver condoms, but the pills of 21 days cycle are missing.”

“We keep speaking, guiding them not to get pregnant, but the ultimate decision is theirs.”

*The health care
professionals: information
and communication issues*

➤ Health care professionals: information and communication

For the health care professionals it is a fact that mothers do not have access to or assimilate the information necessary to provide proper care for their child with microcephaly:

- ✓ they are aware that to establish an efficient communication with the mothers it is necessary to gain their trust → to make them feel welcome;
- ✓ besides, they agree that it is necessary to listen to them and make an effort in translating the information to them. They desire to speak in a language specifically designed for the mothers;
- ✓ meanwhile, they know that it is not what actually happens → the lack of communication is, in fact, an issue which pervades the relationship between health care professionals and the mothers.

➤ Health care professionals: information and communication

Issues of communication often begin at the moment of informing the mothers the diagnosis of microcephaly and continue during the entire health care provided → health care professionals point out that in those moments it is necessary not only to convey information, but also to offer love to the mothers shocked by the news.

“I heard of mothers being informed at the moment of delivering that the baby was not a normal child.”

“It is important to share information and to give much love and knowledge.”

“There are mothers who receive the news and start all at once to research, ask to be given advise on how to stimulate. They themselves say that it’s a lot of information, too many things to do alone. Let me make myself clear: that kind of information may not be adequate to her, we need to be cautious.”

“Once a mother told me that a neurologist said to her that her daughter would be like a vegetable. Then the baby, who was at the carpet, started making a sound and I told her: a vegetable wouldn’t want to learn how to talk. I do need to give her support and by her listening to what I am telling her she will acquire a more positive thinking.”

➤ Health care professionals: information and communication

Health professionals point out the relevance of succeeding in establishing good communication with the mothers → information transmitted in a language mothers may easily understand is a major challenge:

- ✓ the identification with the discourse is a key factor to build confidence and get the mothers' attention → the emotional bond hold the key to understanding and memorizing the information;
- ✓ communication represents, without doubt, a necessary tool for the mothers to assimilate the information → it is fundamental for the mothers to understand the medical condition of their child and the medical guidance they receive.

Clarity in conveying and understanding the information is the only way to avoid mistakes which can, eventually, make the treatment of the affected child difficult → examples:

- ✓ up to what point is the crying described by the mothers not, in fact, seizures?
- ✓ the mothers thought that calcification is not severe, which in fact it is, since it is not noticeable → thus, they overestimate their children's health condition.

➤ Health care professionals: information and communication

Health care professionals also mentioned the WhatsApp support groups, which originated as an alternative for the mothers to share experiences and search information:

- ✓ they point out, as already mentioned, that this tool involves the risk of generalizing and give recommendations that do not apply to all cases;
- ✓ scarcely judicious information may lead to mothers adopting improper procedures for their child's treatment.

“They believe that what's useful for one child is useful for the rest, they share remedies and all that through the Whatsapp groups...I warn them to be careful with the information in the group, I ask her what she was told to do and I guide her from thereon.”

The health care professionals: main needs

➤ Health care professionals: main needs

Health care professionals acknowledge there is a need to structure and train health care professional teams, so they can safely care for microcephaly → main needs identified:

- ✓ On-site and practical training about microcephaly → not just theory, but also practical training by having contact with the baby;
- ✓ Doctors → upgrading / training in their fields, specializing in babies (for instance, neuropsychiatrics) and conditions like dysphagia, which currently is considered to be a main concern;
- ✓ Health agents → they have only received improper and superficial training: they would like to receive more knowledge not only basic information about microcephaly, but also practical training on how to communicate with the mothers, especially, how to convey the bad news and deal with its outcomes;
- ✓ Phono and TO → training on stimulation as a whole, starting from an integrated perspective of baby based therapies (***“I learn with TO and they learn with me, we practice in a very integrated approach”***).

➤ Health care professionals: main needs

Besides the training, health agents, who did not receive any protocol on how to deal with microcephaly, emphasize the need of having accessible tools to utilize during health care procedures:

- ✓ to have a vaccine card, a notepad to follow the child's development (i.e.: from 0 to 2 months it already raises its little neck);
- ✓ to include, in this notepad, basic and relevant information, with pictures, about microcephaly (something like explaining how a good postured child looks like).

➤ Health care professionals: main needs

Health care professionals, from different fields, point out other necessities:

- ✓ to reorganize the health care system so it can be more efficient and less exhausting for the mothers and their children;
- ✓ to invest in preventive primary health care, thus avoiding overloading health agents, who each one attend more than two hundred families: ***“Health agents are the most important actors in the health care system, as they are visiting the child’s home to see whether the child is sleeping on an unbalanced matrass .”***
- ✓ to redesign the inside of health care centers to stimulate and ease the team work health care agents carry out in their work (i.e.: currently doctors consult at one floor and TO is based at another one).

*The health care professionals:
participants suggested actions*

➤ Health care professionals: participants suggested actions

Some initiatives, already undertaken in health care centers, were considered as relevant and promising by the health care professionals → they believe it would be important to replicate and improve them:

- ✓ Workshops for doctors about physiotherapy, TO and phono audiology, carried out at Oswaldo Cruz;
- ✓ Interdisciplinary Symposium on Microcephaly, promoted by FAV → just lasting a few hours: it contributed to share information although it would have been more productive to discuss the subjects further and deeper. This is the reason they suggest longer periods for this kind of events and with less subjects to allow for a deeper and more complete understanding of each subject;
- ✓ To health care with the support of a Whatsapp group, which is online 12 hours a day: ***“Every day a health agent visits their home to make stimulation exercises. Two more people visit them and supervise the exercises they were given. They don’t know how to bring forth any orientation on the supervision.”***

➤ Expected improvements

Besides, the professionals resumed some already mentioned issues they would like to see fixed:

- ✓ to promote a more efficient multidisciplinary and integrated health care → to integrate the professionals responsible for collaboration of the different wards which offer health care to children with microcephaly;
- ✓ to geographically expand the health care system to other regions;
- ✓ to develop alternatives to increase the incomes of the families with additional children → to identify something the families could produce and trade so they could earn money instead of limiting the support to WhatsApp groups which get donations for diapers and milk;
- ✓ to routinely establish supervision groups to support health care professionals to overcome their anguish and stress which come along with their work, and to exchange knowledge and experiences.

➤ Expected improvements

Finally, health care professionals highlighted the need for a deeper involvement of the Government with microcephaly issues, specifically the Ministry of Health, claiming more effective actions like, for instance:

- ✓ get deeply involved with the reality of microcephaly: ***“Nobody at the Ministry knows what we are doing.”***
- ✓ to ease / facilitate and improve the procedures depending on state bureaucracy (social security benefits, reassessment of criteria, since income alone should not be determinant: families who have to take care of a child with microcephaly cannot afford living with an income established by the benefits).

They also mentioned their concern about the educational inclusion of children with microcephaly, an issue considered very severe

Conclusions and recommendations

➤ **Conclusions and recommendations**

The interviews of the mothers and health care professionals show how dilacerating the experience provoked by zika virus has been for both segments:

- ✓ from an emotional and financial perspective this situation appeared in the life of the mothers without them having been prepared for it;
- ✓ taken by surprise by this harsh reality, the mothers now experience feelings of abandonment and powerless, but they keep waiting, with some hope still, for support and real assistance.

The stories from the mothers and the health care professionals highlight three priorities, equally important, which represent a first step to overcome the difficult task of supporting and improving the life conditions of children with microcephaly and their families:

- ✓ health care for the basic needs of the families;
- ✓ emotional acceptance;
- ✓ the need for information.

➤ Conclusions and recommendations

BASIC NEEDS

- ✓ A child born with microcephaly causes an enormous financial impact and a profound subversion of the life conditions for the family, which in most cases in the research were already present, thus characterizing a highly alarming situation;
- ✓ Basic needs of the mothers, even related to normal hygiene, have not been attended to because of the lack of resources and support even inside their social and family network;
- ✓ Besides having to face the extreme difficulty of providing health care for their child with microcephaly, mothers and fathers must overcome countless privations in their daily routine.

➤ Conclusions and recommendations

BASIC NEEDS FOR CARE

There are many problems which demand urgent solutions from which is worth highlighting:

- ✓ often the conditions at the house / home are completely inappropriate for a child with microcephaly (according to the statement of health care professionals who keep direct contact with the families);
- ✓ no fulfillment of the mothers' basic needs, since they do not usually count on third parties in supporting their daily routine (difficulties in feeding themselves, take care of their health, walk on streets with no side walks, etc.);
- ✓ lack of money for transportation to health care centers, for buying remedies, milk or other essential products (even to add credit to their cell phone, which they may need in emergency cases);
- ✓ the exhausting days to get an appointment at the health care center for treatment of the child, which usually is attended to in different facilities.

➤ Conclusions and recommendations

BASIC NEEDS

Brief remarks about the needs identified highlight their relevance → we may ask, for instance:

- ✓ which result can we possibly expect from a child who, with an enormous sacrifice gets health care attendance 3 or 4 times a week, but sleeps at an improvised cardboard mattress?
- ✓ what would happen if the mother of a child with microcephaly had health problems, which is a real concern, given the circumstances they must face in their daily routine?

➤ Conclusions and recommendations

EMOTIONAL ACCEPTANCE

The need for the mothers to be listened to and accepted when they describe their experience with microcephaly is a constant → emotional acceptance is directly associated to the issue of communication (1):

- ✓ whenever we are exposed to overwhelming experiences we miss our capacity we, as human beings, have to share our experiences;
- ✓ the loss of this capacity makes it difficult or even impossible to communicate between the two parts: the one who experiences and the one who listens to (in this case, the mothers and health care professionals).

(1) see BENJAMIN, Walter. O narrador: considerações sobre a obra de Nikolai Leskov. Magia e técnica, arte e política: ensaios sobre literatura e história da cultura. São Paulo: Brasiliense, 1994, pp. 197-221

➤ Conclusions and recommendations

This process, which can be recognized in the mothers' statements, affected the health care professionals as well:

- ✓ they admitted their difficulty in listening to and communicating in a proper manner with the mothers and to share with them, in a proper language, favoring empathy, informations about medical conditions and possible treatments for the children with microcephaly.

The need to improve communication with the mothers goes beyond psychological and social care:

- ✓ it should precede any health care we want to provide to the mothers and children with microcephaly, since a trustful relationship between the mothers and health care professionals, as well as a committed involvement of the mothers depend, to a great extent, of their capacity for communicating.

➤ Conclusions and recommendations

Some health care professionals experience, as already mentioned, how communication may lack and how to re-establish it. It is worth recalling them:

“Once a mother told me that a neurologist said to her that her daughter would be like a vegetable. Then the baby, who was at the carpet, started making a sound and I told her: a vegetable wouldn’t want to learn how to talk. I do need to give her support, by her listening to what I am telling her she will acquire a more positive thinking.”

“As I heard her speaking, I started realizing what her needs are. The diagnosis, for instant...that tomography was a mystery to the mother, but she can positively understand what a calcification is about, show her the spots and in their terms, so they can understand.”

“There was a mother who whenever I talked about microcephaly started crying. So, I started changing my way of speaking so I could reach her... “It is important to share information, and give much love and knowledge.”

➤ Conclusions and recommendations

Health care professionals acknowledge how important it is to establish a relationship with the mothers in a language which invites trust and sharing of experiences → communication may interfere directly with the development of children with microcephaly:

- ✓ the mothers assimilate easier the information given to them;
- ✓ they feel more secure in carrying on with the child care at home;
- ✓ they obtain a better balance, and keep calm.

It is important to remember that the mothers themselves, when asked about the need for information, demanded for **talks** with health care professionals, mainly about issues regarding the diagnostic and the medical condition of their child. In the same way, health care professionals expressed their need to count on the support of **supervision** groups to share their anguish and experiences.

➤ Conclusions and recommendations

THE NEED FOR INFORMATION

The mothers' massive shortage of information about microcephaly and related medical conditions interferes with the health care of the children as well as their emotional state:

- ✓ information they need is abundant and complex;
- ✓ thus, it is necessary to make an effort to provide them with synthesized, useful, well organized and illustrated information;
- ✓ an appropriate format could be a guidebook.

➤ Conclusions and recommendations

The research identified some areas perceived as fundamental by the mothers:

- ✓ to describe, in the language of the mothers, what microcephaly is about and its implications;
- ✓ to explain properly the medical condition of the child affected by the disease;
- ✓ to guide appropriately regarding basic care which the mothers should provide the child, particular two subjects:
 - what can they do in moments of crisis / the appearance of the symptoms (such as crying, seizure, choking)
 - how to properly stimulate the child;
- ✓ to consider information about the most appropriate food for children with microcephaly;
- ✓ to provide guidance about general care for the baby, since many of them are mother for the first time.

➤ Conclusions and recommendations

The systematization of knowledge is also one of the needs health agents pointed out:

- ✓ they feel the absence of tools to carry out their job, like a simple notepad with basic information and pictures about microcephaly (i.e. portraying what is a good positioned child) and where they can take notes to supervise the development of the child:
 - to indicate children age (from 0 to 2 months, for instance) and developmental (i.e.: it raises its little neck).

Finally, another request from the mothers is a “Helpline”, free attendance, for those who need to be supported with information in cases of emergency.

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