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Itinerários terapêuticos, cuidados e atendimento na construção  
de ideias sobre maternidade e infância no contexto da Zika

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## dossier

Zika virus: an epidemic in/and its social world

## Therapeutic paths, care and assistance in the construction of ideas about maternity and childhood in the context of the Zika virus

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Based on an ethnographic field research, we followed the therapeutic paths of caregivers of children with the Zika congenital syndrome in order to understand the way different contexts (discovery, household, health units, social work, associations) contribute to creating notions about maternity and childhood. The concept of “vital conjunctures” in generational rites of passage singularizes experiences that lead to stabilization and/or inverted paths in the passage between stages. The practical and symbolic construction of maternity and childhood oscillates among a multiplicity of meanings marked by the obligatoriness of women to strive in the task of caring and experiencing suffering and care sacralization, in a daily reality that ties their lives to searches for causal explanations and diverse therapeutic answers without marked generational changes. Those who take these therapeutic paths build a multifaceted image of themselves in a direct or indirect relationship to maternity, childhood and their social and biological affiliation.

*Keywords:* Therapeutic paths. Care. Maternal-child images. Zika. Vital conjuncture.

The Congenital Zika Syndrome (SCZ) engenders a social mechanism which raises “care for others” to a motto of life. Caring for others is an action strewn with notions of sacrifice and of an ambiguous self-esteem. It is a choice among few options which affects the life of people who face



the misfortune of having to decide how to deal with the very exacting demands of children who were born with microcephaly and its associated symptoms. Since SCZ is a new pathology, caretakers and infants have embarked on unknown trajectories concerning childhood growth potential and in search of a better quality of life<sup>(g)</sup>. Examples of limitations imposed upon persons with disabilities and rare diseases point to an uncertain future full of barriers that, generally, appear to be insurmountable. Along the route, one of the symbolic resources which looms as most effective is to hold firmly onto the positive nature of maternal dedication and the regard of infancy and childhood and all their associated relationalities.

This article argues that the practical and symbolic construction of maternity and infancy oscillates among a multiplicity of meanings which mark the obligation of men and women to dedicate themselves as participative caretakers, in a daily reality which ties their lives to an incessant search for diverse causal explanations and therapeutic responses. Invariably, those that follow the therapeutic itineraries suggested by this search are creating multifaceted images of themselves in direct and indirect relation to maternity, to childhood and to biological and social filiation.

This article accompanies the therapeutic itineraries of dozens of caretakers in many different social and life spaces, such as: 1) pregnancy and the institutions which inform families about the presence of the SCZ in the child, 2) the neighborhood and its relational networks, 3) the services of therapeutic institutions, 4) social work and welfare services, and 5) associations that protagonize efforts to improve health services as well as life conditions for the caretakers and the children. Instead of presenting details about social relations and the organization of the specific places that were visited during the ethnographic experience of the research project on "Doing ethnography of Care."<sup>(h)</sup>, we emphasize how different contexts encountered during therapeutic itineraries favor contrasting constructions of notions of maternity and childhood done in accordance with value-ideas (Dumont) emphasized in each context<sup>1</sup>.

Necessarily the symbolic and emotional construction concerning life experience of the practice of care points to varying ways of living the human condition related to the SCZ, emphasizing both vulnerabilities and resiliencies for caretakers and for care receivers as they pass through processes of understanding maternity and childhood. Sometimes fully medicalized

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<sup>(g)</sup> The term "quality of life" evokes diverse semantics, expectations and references depending on the perspectives of those who think of it as a "positive end" in itself. We understand that the notions the term brings up vary in accordance with the context of reference included in discourse about such ends.

<sup>(h)</sup> SCOTT, R, P et al. "Etnografando Cuidados e Pensando Políticas de Saúde e Gestão de Serviços para Mulheres e Seus Filhos com Distúrbios Neurológicos Relacionados com Zika em Pernambuco, Brasil" (Doing ethnography on Care and ThinkingHealth Policy and Adminiistration of Public service for women and their children with Zika-related neurological disorders in Pernambuco" (MCTIC/FNDCT -CNPq / MEC-CAPES/ MS-Decit No 14/20. Process 440411/2016-5, Approved nº 2.001.642. Health Research Ethics Committee Comité of the Fedral University of Pernambuco. Version for Institutional Links-Newton Fund APQ-0553-7.03/16- Action Ethnography on Care, Disability and Health Policy and Administration of Public Service for Women and Caretakers of Zika vírus affected Children in Pernambuco, Brazil.

meanings will be used, and other times efforts will be made to keep distant from the medicalization of the meaning of life, bringing forth questions about the implications of taking on symbolic and material responsibilities of care in which the “vital conjuncture”<sup>2</sup> of SCZ has placed their daily lives.

### **Therapeutic itineraries, maternity and childhood**

Much of the literature on maternity and childhood directly or indirectly derives from the recognition of Elizabeth Badinter<sup>3</sup> that there is an historical marker which intensely highlights private life in the modern world by neatly separating feminine work as associated to the less-valued reproductive spheres and masculine work to the better paid and, symbolically, comparatively more-valued productive sphere. The following centuries saw the multiplication of social and cultural instances in which maternity and practices of care contributed to the forming of a super-valued composite myth which was “proven” by way of its association to acts of love, tenderness, dedication and sacrifice. Scientists searched avidly into biological and genetic links which were seen as proof reinforcing the division between reproductive and productive spheres by means of a medicalized discourse<sup>4</sup>. At the same time a rich theoretical and practical tradition in maternal-child health established itself as one of the most hegemonic medical discourses<sup>5</sup>. There is no need to review this literature which is widely available, especially in the form of critical disciplinary perspectives that deal with questions that go well beyond medicine itself<sup>6, 7</sup>. What is most important is to call attention to the repeated questioning of this myth among feminist theorists whose aim is to revert the hierarchical and highly unequal valuing of the sexual division of labor which associates women with the family and with care<sup>8,9,10</sup>. In this way feminist theorists include women in the interpretative and legal framework of modern individualism and equal rights for men and women, understanding that dedication to the private or the public sphere should be a question of choice and not an imposition of the sexual division of labor.

It is by way of these tense lines of interpretation<sup>11</sup>, that the experience of maternity and childhood is marked while following therapeutic itineraries that may, or may not, contribute to successfully face a quality of life that has been dilapidated by SCZ. “Therapeutic Itineraries” is a complex and holist concept<sup>12,13,14</sup> which sheds light on searches, not restricted only to the medical field, by people who suffer from pathologies whose solutions seem either out of reach, or simply nonexistent. It helps focus on the signs the body produces and the multiple meanings and interpretations of such signs that are proportioned by different alternatives sought along the itinerary, providing frameworks for what might be judged relevant for understanding the life experience through which they are having to pass. The oft-heard therapy of “learning to live with the problem” suggests that the maximum that any path followed can bring in search for help, support or solutions is a partial or paliative act. That leaves things continually open to follow other paths. In the field of medical science a response to this multi-site search by those who suffer, is to

value integral health, or simply, integrality, recognizing a diversity of possible contributions. Quality of life, even when desired, is the opposite of the dissatisfaction provoked by the fact of having to live with a chronic disease, a degenerative disease, mental illness, persistent hypertension, sickle-cell anemia, disabilities, or other rare diseases and syndromes and hard-to-solve afflictions<sup>15</sup>.

Following a varied holist or integral therapeutic itinerary is not necessarily the result of an alternative philosophy of life, being better characterized as simply a search for a solution to some specific affliction. Such an itinerary has an extraordinary power to offer contrasting symbolologies for the experience of different specific conditions, such as those of maternity/motherhood and childhood, focussed in this article.

Our idea of construction of notions about maternity and childhood along diverse therapeutic itineraries followed as a way of dealing with the consequences of SCZ requires an explanation about the understanding of how to approach disabilities. However complex and unknown the implications of SCZ for infant and child development may be, it is unquestionable that those implications are experienced as “deficiencies” in contexts which do not favor inclusion. The limiting implications of the biomedical privileged usage of the concept of deficiency as an abnormality derived from a biological disadvantage shadow a more englobing understanding, known as the social model of disability, which conceives having a disability as “a bodily form of being in the world”<sup>16</sup>. A symbolic and social reading of the practice of living with SCZ helps to formulate questions about created skills, as well as about exclusion, prejudice and demands of human rights. When Diniz<sup>16,17</sup> deals with this theme she pays special attention to human subjects not usually conceived of as disabled (especially the elderly and caretakers) to enable her to develop an argument about a social world that brings together the relational repercussions of experiencing lesions, of promoting rights of women and of the elderly and of children. In short, being in the world cannot be restricted to being under the care of professional health workers; therefore, forming notions of maternity and childhood results from a myriad of possible focuses and wider understandings of social processes which make up the world of babies and children with SCZ and their caretakers, be they women or men. With so many ways of discussing perceptions of maternity and childhood it is necessary to choose a guiding idea for our observations. A life course described in generational terms, ever since the seminal work of Van Gennep, identifies a model of stages and phases of rites of passage for all societies in which people pass from one state and/or generation to another, from (pre)birth to post-life. The passage from one stage to another confers values to certain characteristics which mark changes upon the entrance to a new stage. We have questioned the linearity of such passages in previous work<sup>18,19</sup>, preferring to follow what Johnson-Hanks<sup>2</sup> calls “vital conjunctures” which permit the understanding of singular and special situations which may lead to stabilization in one stage or to inverted passages which do not obey expected sequencing. This is the exact phenomenon lived by a mother, hopeful that the birth of child will incarnate the expectation of being involved in a sequence of stages that contribute, passage by passage, to assert her qualities as a mother who knows how to bring up a child until she reaches the point of being an

elderly mother who must be cared for by her child. An infant with SCZ-caused microcephaly presents a new “vital conjuncture” condition for the mother. The unexpected demands force a reelaboration of contents which convey different meanings to what might be expected as proper practice now that she is a mother of a newborn child with very special needs. Even if it annuls the expectation of linear passages, it demands all that a mother can give! As one mother said “It’s as if you just received a newborn baby and you have to care for a newborn baby all the rest of your life...”

This is when the practice of “caring” takes on far greater attributions than was imagined that it would have, and this caring is much more closely related to the idea of suffering. The first part of a common saying in Portuguese “Being a mother is suffering in Paradise” gains greater importance, and the second part “suffers” an uneasy question. Will it be an unending infancy? Will the child always be a baby? Thinking about who she is as a mother, and who her child with a potentially prolonged infancy is, establishes many possibilities of interpretations forged through therapeutic itineraries they will live together, from context to context.

It is a maternity with an amplified feeling of suffering, since it is impossible to dissociate the experience of disability from the emotion of suffering. According to Duarte<sup>1</sup>, the theme of the value of suffering is a foundational condition of societies, and it permits access to “legitimate levels of social conditions”. It is exactly this condition of permitting “access to legitimate levels of social conditions” which introduces a key idea about how to overcome the diminished expectation of rewards coming from the experience of accompanying her child along his/her life course, sacralizing acts of caring. However limited and limiting it may be, such a sacralization can furnish a “legitimate” reward for her, but the construction of such a notion faces a series of setbacks during the process of caretaking. It is inevitable that, by way of the practice of caretaking, so firmly debated in feminist literature and in biomedical tradition, such an access to legitimate levels of social condition will occur in association with the adoption of practices of care related to mothering.

## Methodological Routes

Since November of 2016, one year after the discovery of the peak of the epidemic in Recife in 2015, the two basic research concerns have been 1) to accompany the caretakers and their infants in their search for treatment and 2) to understand the organization of State services concerning SCZ from the standpoint of demands for treatment and care. Since we are emphasizing ethnographic research our researchers (13, as well as 6 more from 3 partner institutions), work closely with the two principal associations that bring together caretakers and children with SCZ. We use multifaceted data sources. Our registers include field diaries concerning daily observations from accompanying caretakers and infants and their relational networks formed in diverse spaces (home, health and therapy units, festivities, courses, associations, etc.) as well as doing deeper

interviews with people in their networks and in State services. We assiduously attend seminars, workshops and events which present and discuss results of local and national research. All this is complemented by documental internet research and daily following of constant outcoming news about SCZ.

We use all these sources and have decided to protect personal and institutional identities in an effort to reinforce our intention to widen the comprehension of the phenomenon and to stimulate a fruitful exchange of ideas between providers and users of services, as well as researchers in the scientific community, without provoking specific constraints or accusations which might have negative repercussions. This decision does not annul critical attitudes and questioning stances which can contribute to mutual understanding and to more effective actions for all agents involved.

### **Caretakers, networks and itineraries**

As is common knowledge in genealogical research, each relational network differs for each person chosen as the point of reference. It is also necessary to emphasize that in each social context for which information is sought there are different priorities for interaction and for meanings, creating many perspectives and possibilities of interpretation which vary in organization according to the involvement with the contexts. There is no intention to establish hierarchies of importance, of chronology, of efficiency or, of any other specific criteria seen while following therapeutic itineraries of the infants and their caretakers. What is sought is a greater comprehension of each context and how it contributes to the construction of complex notions of maternity and childhood.

**a) from pregnancy to maternity:** Conversations about the discovery that the baby has SCZ originally were restricted to the confirmation of microcephaly, and, soon after, to many other neurological complications<sup>20</sup>. Among the mothers an allusion to the idea that a marvellous trip to some new and distant destination was planned, but the travel ticket was emitted for some other local and undervalued destination, repeatedly connotes a deception for not having fulfilled the expectations of a pleasant maternity. As one mother said: "...so it was a forced adaptation, and the worst part of you being a special mother, victim of a new virus, is that you see this virus develop in the worst way, which is in your child and in his or her colleagues." The response of the medical field was to rapidly make the time of birth go beyond a simple confirmation of microcephaly, becoming part of a declaration of a *State of Emergency*. The obligatory notification by the health system requires procedures which open doors to a medicalization of lives in

function of the diagnosis of limiting lesions and other unknown effects that are expected to be negative. This confirmation is represented by scientific researchers as an iceberg whose submerged composition covers many of the other nefast aspects of the SCZ condition. This iceberg is shown both in scientific forums and in meetings with mothers and other caretakers.

Medical Technologies (especially ultrasonography) are rarely available to most mothers whose experience of pregnancy includes prenatal appointments in family health units that usually do not allow an advanced understanding about the baby's condition, as was clearly shown by Faya-Robles<sup>21</sup> and Scott<sup>22</sup> about access to, and experience in, maternity wards in the city of Recife. When awareness of the microcephalic condition became well known, this medical technology only became slightly more available. Some mothers who were able to confirm the microcephalic condition preferred an interruption of their pregnancy and used the medical exams as a basis for the request, but they had their requests denied on the base of existing legislation. Such requests, kept almost as secret as the many offers informally made by people in their relational networks to help find a way to interrupt, seem, in the end, to represent a minor proportion of experiences of pregnancy. The majority of mothers felt they had no other option except to have the child<sup>(i)</sup>.

A child, born in these conditions, is not an undesired entity. What happens is exactly the opposite. There is a sharpening of the conviction of the need to intensify emotional links and create a positive image of the child who will depend and demand much more than other children. It is a construction which shows the previously mentioned strong relation between pain, suffering and gratification.

**b) at home:** Even when physicians and other health professionals in contact with the mothers do not question them about their contraceptive and general preventive practices, news reports and campaigns reinforce an idea of blaming the population for not controlling the vector which transmits the disease. Pregnant women are constantly advised to avoid exposition to the mosquito, doubling attention at home. The health surveillance sector and State-organized task forces scour local environments from house to house in poor neighborhoods where most of the mothers reside. It is easy to understand that the preferential environments of mosquitoes in poor neighborhoods indicates a policy of urbanization that excludes the poor and penalizes them with unhealthy

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<sup>(i)</sup>In renowned, prize-winning, studies of the history of Zika the research team of Celina Turchi<sup>20</sup>, has, as a principal finding, the discovery of a masked relation between microcephalic Zika and interruptions of pregnancies in French Micronesia whose health system is open to such options for pregnant women.



environments, yet such an understanding is frequently shadowed by discourse that blames them for having unhealthy behavior and practices. In this way, the veiled accusation of individual blame is never fully dispelled. Many mothers say that they spent extense periods of time isolating themselves at home well beyond the time prescribed by the tradition of postpartum confinement, alleging the difficulties of adapting to their new condition. Some stay isolated despite the active outreach programs organized by health instituions in order to include them in research samples of those affected by SCZ, providing more favorable treatment and use of more resources furnished by the generalized concern of health sectors in the country, and especially in states with high prevalence of the disease.

At home conversations are more about how the experience of living with and bringing up the expected child will be. How will house visitors be treated and what kind of support might be expected from those who spend more time than just a "visit", as happens principally with grandmothers, but also with other relatives and even close friends that take on tasks in the house. Some husbands or partners may also participate in domestic tasks, but less is expected of them since the are less likely to do very much. They prefer to dedicate themselves to reinforcing contacts in more public spaces where they can be seen as providers as well as contact with the world beyond home. The fact that the expected or newborn child has already been diagnosed as having SCZ intensifies expectations of support in caretaking from all those who are most closely related. Independent of Zika, there is an ever-increasing number of households headed by women with no co-resident partners in poor neighborhoods, and in the case of Zika, the reasons frequently cited by mothers for their abandonment by men is that men have no intention of increasing their dedication to domestic service. They also believe that the child's demands may have negative consequences for their relationship with the mother, since is is likely the women will be more mothers to their children than wives to their partners.

Men who "help" are praised, highlighting their capacity to dedicate themselves to the new demands. This does not occur to the same degree with [grand]mothers, sisters, women friends and even other mothers in similar situations since help and solidarity is no exception, being expected from other women. Even in the middle of this set of supporting activities, mothers of SCZ/Zika children do not escape from a sensation of isolation. Other women are notably more reluctant to participate in holding these babies, because they don't sleep well, are irritable, don't sustain themselves alone, have problems in swallowing food, suffer frequent convulsions, and, in general, present a very vulnerable condition. They are susceptible to other illnesses and are constantly being taken to doctor's

appointments, hospitals, clinics, and therapy institutions. All that is sufficient to dispel many potential co-caretakers at the same time that it contributes to a high appreciation of those who in fact do collaborate.

The neighborhood is not always a solidary place, and the child's very humanity or the mother's salubrity are often put into question. This disturbs many in the community and can lead to a poor quality of coexistence with neighbors, often on the basis of dichotomies which separate good and evil and are sharpened by accusatory religions whose practitioners do not seem to know how to live with disabilities. Such comments incite doubts and insecurity in mothers and their networks, who delve into self-questioning about their own origins and about the transmission of undesired traits, provoking conflicts with these neighbors or even family members. As one mother said: "when my brother found out that my baby daughter had microcephaly, he told me that it was a punishment because I worked too much and should dedicate myself more to taking care of my children", suggesting that motherhood is an invitation to an experience that should be lived more as a burden than a pleasure.

For many reasons the lack of resources becomes more intense for these families, especially when mothers leave their jobs and have growing needs for medicines, expensive special food, therapeutic instruments (to favor deglutation, ambulation, posture, vision, etc.), all of which extrapolate the limits of what can be obtained through donations or through obligatory furnishing by fragmented and insufficient health, philanthropic and social welfare systems. The astuteness and inventivity of mothers and their networks lead to the discovery of improvised ways of getting access to instruments that function as if they were those instruments recommended by physicians and therapists whose experience stems from their insertion in an overpriced market of health goods and services, totally out of reach of their incomes. Even with these efforts to find solutions that are inexpensive, impoverishment is intensified. This is especially true in cases in which the entire family moves to a new residence to diminish costs by living nearer to where they may be treated, or to get access to programs offered by other municipalities such as distribution of milk, transportation or other social programs such as housing by "My Home, My Life" ("*Minha Casa Minha Vida*").

**c) therapeutic institutions:** The dimensions of SCZ, a new disease discovered in Northeast Brazil, caused various commotions, well beyond the question of how to treat the babies and their mothers. It caused an identity commotion concerning the reputation of the country about its capacity to deal with the epidemic, taking into account that recent memories highlight that some African countries had their

legitimacy and competence questioned because of their difficulties in dealing with the Ebola epidemic. Something similar would be inadmissible in Brazil! Another commotion is the international dread of the prospective rapid and extense dissemination of a disease transmitted by a mosquito that inhabits many corners of the world. In function of this concern international agencies and regional political blocks roll up their sleeves and open their bank accounts to invest, prioritising prevention and cure of the disease, and only secondarily, leading with the treatment of those affected by the epidemic. All these questions come together in dealing with the scientific commotion which intensifies its competitive environment, building prestige out of collaborating to raise information that can clarify anything about SCZ. The result of all this is a fourth commotion: how should treatment or care services of the SUS – National Single Health Service System and its allies - proceed in order to treat those affected by the disease? The fragmentation of health and social services, documented by many researchers<sup>23,24,25</sup> presents partial results marked by contradictions and questions such as: would increasing the number of centers of rehabilitation solve the problem?; would centralizing care ease the access for those who need it?; should investments be done more in short- or long-term responses?; should existing protocols be reformed to provide early stimulation and care for the disabled so that they may include the newly affected population?; should SCZ demands be associated to the women´s movement demands that so keenly understand women and health?; should these new demands for treatment be included in demands of people with rare diseases?; would it be proper to ease access to medicines, diminishing costs for the families?; should access to special exceptional spaces be open to include SCZ families in benefits, social services and transport?; should proposals of philanthropic, charitable and even private institutions to furnish therapeutic treatment be stimulated?; is it feasible to articulate a parliamentary front to pressure for results and actions?; should investment be made in technologies and in scientific research on prevention and cure?; should there be an intensification of the hygienization of environments where the mosquito reproduces?; should new spaces for discussion with national and international networks of researchers be used to promote action and research?; etc. This generalized mobilization, still operating and still multidirectional, is strongly marked by some health professionals, researchers and volunteers. There is an enormous will to do the right thing, principally guaranteeing that babies may be “able to live” but there are very few proposals that prioritize listening to mothers and their networks.

So many different efforts open many channels to potential treatment and therapy for the babies, accompanied by their caretakers. Even when the therapeutic institutions demonstrate extraordinary qualities and practices that are very well received by the mothers, these mothers perceive that they contain many of the same limitations found in SUS and private institutions, with notable aggravating factors because of their child's condition. Scheduled appointments cancelled without notice; broken equipment and lack of material; long waits; laboratory diagnostics not made available to the patient and family; very little individualized care; proposed discharge from treatment even when the infant shows no signs of improvement; few specialists in necessary areas of knowledge; insufficient funding subsidies because of limitations imposed on appropriate treatment expenses; enormous distances to be covered to get to different locales of treatment that do not communicate with one another.

In short, despite all the mobilization and the very positive production of actions and intentions, the systemic flaws in the system still discourage many of the caretakers who, knowing that they are the focus of exceptional attention, yet very aware of the gravity of their child's difficulties, cannot avoid a sensation that the State is unable to tune its activities in a manner that respects the demands they have as mothers and caretakers.

What most repeatedly erodes relations between mothers and the State are acts which suggest that the sector in which the child is in treatment has abandoned hope in his/her improvement, whether it be because of neglectful organization, or because of flagrantly false discharges which are systematically understood as dismissals due to productive inviability. It is as if they were one of many patients of emergency wards in which few physicians and health professionals openly take on the responsibility of choosing to treat those that "have a better chance." It transform a message communicating that "we are doing all we can to help you and your child" to one that communicates "we are desisting and you will have to bear the weight of caring for your child from here on". Another reason for concern that adds more motives of distrust is the information that circulates among mothers, especially over internet and in their associations, about cases in which SCZ children have died. During 2017 mothers became more concerned because they perceived an increasing mortality, leading them to believe that these cases are being under-registered by the State.

**d) social services and welfare:** As mentioned above priorities were established and exceptions were created in the continuing benefit payments system (BPC) and in transportation voucher cards, contributing expressively to shorter waiting

periods to obtain these benefits which normally takes a long time. Barriers exist in these services of social aid whose primary objectives are not directly related to health treatment. The principal barriers are those that condition eligibility to a state of poverty and of need which basically turns the beneficiaries into beggars for the State. Proof of poverty is required to keep the BPC payments coming when the system demands verification of eligibility. A residential address in a wealthy neighborhood arouses suspicions that mothers may be trying to fool the State when filing for the benefit. Even when residence is in poor neighborhoods, other criteria may be seen as impeditive to receiving the benefit, such as having electric appliances or ceramic floors. In any case, having a BPC benefit does not assuage the anguish of caretakers. Legislation is seen to determine the prohibition of legalized labor with a "working card" for those who desire welfare security, as the following mother points out: "I desire a long life for my son, but if in the next 15 or 20 years he happens to die, I will no longer be able to get retired. Who is going to want to employ a 45 or 50 year-old woman? What will this mother have to live on? Have you ever thought about that?"

If she takes a free bus on their transportation voucher received because of their child's needs, she must be careful to not be caught taking more than a certain number of trips without taking her child along. If she is caught above that number she will lose her "right." Costs of financing liberated for companies offering therapeutic services, when announced, present calculations that once again afford a picture of perception by others of improductivity and of diminishing profits or returns to those who offer services. The State, at the same time that it promotes services moved by the commotion of the *state of emergency*, also contributes to subestimate the value of caretakers, of their networks, and of the children in need of treatment.

**e) mothers' associations.** The interminable pilgrimage in search of solutions that may offer a better quality of life to their SCZ child marks the experience of maternity as a sacrifice for the good of another person, elevating biological and/or social maternity to an exacerbated level, to a new condition. Difficulties encountered and reencountered create a space that favors mediation which, above all, values maternity, and, secondarily seeks to transform this recognition into self-esteem. Among different forms of mediation, those that have more devoted adepts among caretakers are associations that are explicitly for mothers. Even more so, it is those that explicitly declare that they are directly interested in SCZ, in disabilities and deficiency, and in rare diseases. They are directed by mothers whose own experience includes following therapeutic itineraries in search

of solutions for their own children, having dealt: with the discovery of the pathology during pregnancy or in maternity wards; with the reorganization of their social networks in their places of residence; with the practice of therapeutic institutions; and with their relation to demands for social services. They see two fundamental sides to this condition. First, the disrespectful concealment of their many acts which, directly or indirectly, challenges the valuing of their very efforts as mothers who are caring for their children, dedicating themselves to identify faults, questioning negative opinions, facing disorganization and prejudice along the way. Second, they perceive that there are conditions favoring collective action that can confer value to themselves and their efforts, as well as to obtain better treatment and benefits. The two strongest associations in the city and in the state have an interconnected history and deal with experience, objectives and practice, which converge and diverge as they pursue their aims.

Their names include explicit reference to maternity and also explicit reference to the dependents that they take care of, euphemistically highlighting both the difficulties of involving themselves with the customary list of health services and other governmental services, and, at the same time, with the emotional charge that is felt by the mothers themselves. Whatever may be the disability of the child, it is exactly what motivates these women to occupy a higher level of value earned by sacrifice. The conviviality which makes up part of the functioning and planning of activities furnishes a sociability that solidifies the bond between those that deal with similar situations, but who also are dedicated to taking care of themselves! All this occurs through the multiplication of spaces for treatment, the creative and adapted offering in their institutions of services precariously offered by therapeutic institutions, the articulation of support that generates both donations that alleviate material scarcity and voluntary services that are fundamental for daily caring of their children, the offering of activities which generate alternative sources of income by way of activities that are sensitive to the mothers' conditions, as well as offering training in diverse skills, in leisure and entertaining activities and in aesthetic services that may "care for caretakers." Involvement in these associations channels attention to a combination of continuity of dedication to a sacrificial maternity, and widening of the scope of possible response to material and emotional problems that are faced daily.

The emergence of SCZ is a multifaceted mobilizing condition. It favors more attention to rare diseases that have a history of exclusion. It favors donations of very significative dimensions. It creates an environment of growth and expansion, even if only for a short time. Above all, it creates an associational space which permits interaction with others, including politicians, NGOs associated with several

different causes and actions (including their own, since the associations themselves are NGOs!), with networks of researchers and volunteers, with therapeutic institutions, with civil servants who embrace the cause and act in health and social services, and, most importantly, with other mothers in a similar situation that are trying to be something more than simply a mother of a special needs child in order to gain self-esteem and be valued by others.

## Conclusions

Following therapeutic itineraries of caretakers of children with SCZ in this work neither had the intention of knowing their capacity to respond to a demand to solve health problems nor of evaluating health services. The intention was to understand how these routes contribute to a complex formation of ideas about maternity and childhood for women who follow them. These caretakers live a maternity that involves sacrifice and is of supreme value for them and for others, earned through dedication to their children in a radical change of their routines. They create a frustrating expectation that their child may not be able to overcome the harm inflicted on him/her by a little known pathology which promotes dependence at the same time that they participate in environments that enhance the sacralization of the attention demanded by their children for all that these children represent. These women are thrown into a highly publicized international whirlwind of commotions. This runs the spectrum from solidary acts by closely related people on their daily-life networks, all the way to international articulations involving governmental and non-governmental organizations active in finding solutions for SCZ-caused problems. In this way, the intensity and visibility of the vital conjuncture that they must face constructs a notion of maternity always associated with extreme dependence on a disabled child, rather than an experience leading to transitions out of childhood. In the most collective sense, their experience goes beyond that of other mothers with children with better-known disabilities, however rare they may be, that are out of the spotlights.

The external sacralization of attention to children occurs in function of what they represent as carriers of secrets to be discovered by Medical Science in its efforts to eradicate diseases and affirm the value of science and of prevention, as well as the image of the nation as able to face pathologies. Nevertheless it is not this sacralization that is important for the mothers, firmly concerned with living a positive maternity and knowing they are excellent caretakers. However many actions may be especially directed to the mothers, caretakers and children, and however sincere the sensitivity of many health professionals and other people, including all levels of civil servants, the symbolic violence suffered by them is severe. Several examples were given of violence in their neighborhoods stemming from the "difference" of their child; the fragmentation of health services, of intersectoral social services and welfare services which repeatedly assert the poverty,



incapacity of caretakers and subject them to enormous efforts; tests of patience and extenuating routines of mobility while hearing non-comforting, if not outrightly accusatory, words on their way to getting to therapeutic institutions!

The sociability they find in associations, which have become more visible with the onset of SCZ, identifies these as places where a maternal dedication opens up doors to overcome barriers and limitations in order to reach a "new level of social condition", more strongly related to medical and social services, bringing them to act together with social movements and fronts which defend their interests, as well as getting involved in activities which generate income and resources, and participating in festive and enjoyable activities which allow them to think of themselves as valued beyond being caretakers. These are small victories in a flow of enormous and repeated difficulties!

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All of the authors participates in research, discussion of results and approval of final version.

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