

Report on Women Caregivers

The J.M de los Ríos Children's Hospital Case



This report seeks to make visible the serious situation of institutional violence by the Venezuelan State against women in Venezuela, specifically against women who perform care work in Venezuela's most important Children's Hospital (National Reference Center) Hospital José Manuel de Los Ríos (hereinafter Hospital J.M. de los Ríos).

First, we point out the context, characterized by the Complex Humanitarian Emergency and the COVID-19 post-pandemic, which leaves the population in a situation of generalized impoverishment and affects women in particular. Then, we address the specific situation of the Women Caregivers of the J. M. de los Ríos Hospital, pointing out the conditions that aggravate inequality and we present the story of four of them. Finally, we present the recommendations and the public policies that should be adopted to resolve the situation of the Women Caregivers. The information presented in this report was gathered through several years of fieldwork at the J. M. de los Ríos Hospital, as well as interviews with women caregivers and hospital health personnel.

The NGO Preparar Familia presents this report¹:

Prepara Familia is a civil society organization founded in 2008 that accompanies and defends the rights of children and adolescents hospitalized in public hospitals, and defends the rights of women who perform care work. We have three lines of action: 1) The defense of the human rights of hospitalized children and adolescents, in national and international instances; 2) The development of programs of care, assistance, and monitoring for hospitalized children and adolescents and those who attend consultations in hospitals and 3) The development of programs of care, accompaniment, and defense of the human rights of women caregivers in public hospitals.

¹ <https://preparafamilia.org/>

I. Context

1. Since 2015, Venezuela has been experiencing a complex and multidimensional humanitarian emergency, which is reflected, among other things, by the widespread impoverishment of its population. According to the Living Conditions Survey (ENCOVI), conducted before the COVID-19 pandemic, 96% of households in Venezuela live in poverty and 79% in extreme poverty. This situation has a differentiated impact on women and has been worsening exponentially.²
2. In health care, the consequences are expressed in the irregular supply of medicines and supplies, migration of medical personnel, lack of reagents, non-functioning equipment, failures in basic services, and deteriorated hospital infrastructure, among other things that put the most vulnerable at risk. Attending a hospital to be treated for any health complication is a risk, since there are no guarantees for obtaining adequate care. Admission to a hospital in Venezuela means a high risk of contracting a different disease or being exposed to health factors that compromise physical integrity.
3. This situation is reflected in the J.M. de los Ríos Hospital, a type IV hospital center of national reference, which treats children and adolescents from all over the country, since the hospital services present complications and failures that compromise the quality of care for children and adolescents.³
4. Every day, more and more children, with different types of pathologies, must be hospitalized. To be admitted, they must be accompanied full-time by one of their parents or representatives; in this case, the representative is always a woman.
5. Approximately 95% of the representatives who stay with the children are women who care for their children full-time. The need to understand this situation leads us to the Economy of Care. It is important to emphasize that there is a marked inequality and division of roles in the care of children and in this case hospitalized dependents, which means that women do most of the work, without receiving any payment. Since their contribution is so significant, it is important to account for, make visible, and value this dedication.⁴
6. This dedication is not a free and autonomous decision; it is biased by the unequal division of labor that assigns specific roles to both men and women and is the root of a series of inequalities within the family. The difference in the time commitment and in the distribution of care and unpaid work generates a vicious circle: co-responsibility and equality are not encouraged.

² <https://www.proyectoencovi.com/informe-interactivo-2019>

³ <https://cecodap.org/el-deterioro-del-hospital-jm-de-los-rios-cobra-con-muerte-de-ninos/>

⁴ <https://elestimulo.com/dia-de-la-madre/2022-05-07/las-madres-del-jm-de-los-rios-tambien-merecen-contar-su-historia/>

7. When women are admitted to the hospital with their children, they are exclusively dedicated to their care, they cannot enter the labor market and the work they perform lacks visibility due to its characteristics of unpaid work. Part of this invisibility is based on the fact that these services do not involve monetary remuneration or an accounting of the time invested, which makes it difficult to quantify and estimate their contribution to social welfare.

II. Women Caregivers “The J.M de los Ríos Children’s Hospital Case”.

8. Most of the women who take care of the children hospitalized in the J.M. de Los Ríos Hospital (mothers, aunts, grandmothers, sisters) are from the interior of the country and travel to Caracas due to the precarious situation of the public health system and in order to seek specialized care for the pathologies suffered by the children, at the most important national referral center. These women, who are "hospitalized" with the children do not have sufficient economic resources and, in addition, are forced to leave their jobs, studies, and family environment.⁵ Below, we detail the precarious conditions experienced by women who perform care work at the Hospital:
 - a) They do not have resources to cover their minimum personal needs, including food, personal hygiene supplies, and menstrual hygiene supplies.
 - b) They lack adequate and appropriate furniture to spend the night in decent conditions in the children's rooms. Currently, the chairs or sofa beds available for sleeping are broken, in poor condition, or have a bad odor, with the result that many female caregivers sleep on towels and sheets that serve as makeshift beds.
 - c) They lack sanitary services in good condition and a constant supply of water, which compromises their personal hygiene and puts them at risk of contracting diseases on the hospital grounds. When there is no water, the bathrooms are closed and this decision has a differentiated impact because it prevents women from meeting the minimum requirements of personal and menstrual hygiene.
 - d) In the J.M. de los Ríos Hospital, although two electric plants were installed, they do not cover the hospitalization tower or the isolation tower and when there are failures in the electric power supply, the rooms of the children and adolescents are left in darkness and the women are at greater risk.
 - e) They do not receive food; they are hospitalized with their children and relatives and are under the guardianship of the State. Most of them, due to a lack of economic resources, cannot buy food, additionally, they live in extreme emotional conditions that put at risk their personal health and their ability to care for the children or adolescents in their care.
 - f) They must go out to get donations from foundations, use social networks, sell what little they have, migrate to another country (leaving another woman in the family in charge of the child) etc. to try to acquire and/or pay for medicines, medical supplies

⁵ <https://efectococuyo.com/especial/madres-coraie-de-venezuela/>

and tests that must be performed in private establishments due to the lack of availability of equipment and reagents in the Hospital's laboratory.

- g) The Women Caregivers denounced and protested because they were not receiving food and since August 2017 the Ministry of Health began to supply them with food. However, on April 05, 2018, said supply was suspended without any explanation. We consider that this suspension is due to the criminalization of the protests that the women constantly carried out at the doors of the hospital.⁶ This is very serious because in the face of the economic crisis we are living in, women do not have the resources to be able to buy food for themselves. The organization Prepara Familia presented a communiqué denouncing the suspension of food for women who work as caregivers at the Hospital J.M. de los Ríos, which was signed by 92 human rights organizations and 25 individuals.⁷
- h) In addition to all the caregiving work they do, they also protest, hold rallies, write letters to management, collect signatures, and some have become activists.⁸
- i) The number of women caregivers at the J.M. de los Ríos Hospital is 95%. The needs, as well as the discrimination and violence to which these women are subjected, are invisibilized, while their rights to the full development of their capacities, to health, education, decent work, leisure and self-care are being postponed, if not violated.
- j) They must be at the children's bedside, day and night, if they go out to carry out some errands or procedures they must request permission, some are criminalized, others are afraid and do not denounce because they fear that the children and adolescents will suffer the consequences.
- k) On August 17, 2021, women, mothers of children and adolescents protested on the sidewalk at the entrance of the health center, denouncing the hospital's deficiencies and poor medical care. During the protest, a State-owned Yutong bus burst into the middle of the protest and mounted the sidewalk to intimidate protesters. The bus remained in the middle of the protest to dissolve it and divert it from its main purpose.⁹
- l) Mothers of children who died at the J.M. de los Ríos Hospital showed up on August 17, 2021, at the protest rally to denounce the hospital and medical care conditions that had an impact on the deaths of their children, as well as the demand to reactivate the Organ Procurement System, suspended since 2017. When they arrived at the entrance of the Hospital, the security personnel who were guarding the entrance

⁶ <https://cronica.uno/madres-del-j-m-de-los-rios-protestan-suspension-de-ayudas-de-minsalud/>

⁷ <https://cepaz.org/noticias/exigimos-respuesta-urgente-la-suspension-la-alimentacion-las-mujeres-cuidadoras-los-ninos-ninas-adolescentes-del-hospital-j-m-los-rios/>

⁸ <https://eldiario.com/2021/08/17/protesta-madres-jm-de-los-rios/>

⁹ <https://contrapodernews.com/madres-del-jm-de-los-rios-protestaron-por-insumos-y-mejor-atencion/>

notified them that they were forbidden to enter the health center without any justification.¹⁰

- m) In the Hospital's rules and regulations in No. 16 it is stated: "*For the nocturnal accompaniment of the patient, only one female person is allowed, who must request the respective pass from the Hospital management*", only in very exceptional cases, the accompaniment of the father is allowed, further accentuating the issue of inequality.
- n) When their children die in the hospital, women and families do not receive any kind of support from the hospital management or the State. They are left on their own with the help of very few civil society organizations to accompany them in the mourning, wake, burial, cremation, obtaining resources to pay for funeral services, and making arrangements for the transfer of the bodies to the interior of the country.¹¹
9. Starting in June 2018, the organization Prepara Familia made a partnership with La Vida de Nos (a website that collects stories of people in the midst of the crisis) and four testimonies of women were published under the title "Mothers of the J.M."¹² in which SG, AR, EA and JB tell us about their experience in the Hospital. Below are some paragraphs from the interviews, describing the women's experiences:
10. **SG:** "S is a mother in Caracas, 710 kilometers from her home, far from her family. Linked to the routine of a hamlet of yellow dirt roads -of no more than 160 families- close to a Piaroa community in Amazonas, she has had to get used to the rebuffs of the capital, where access to health care is an exercise of resistance, there are days when I do not deny it, I feel alone. She says she is tired of crying, my daughter has been wanting to eat soup for days and I only have pancakes to give her. She can hardly ever stick to the diet. We survive day by day because everything is so expensive. I can't buy anything."
11. **ÁR:** "She has handled her daughter's situation with the fortitude of someone who does not stop to wonder about what she has had to live through. -We left the maternity ward for the J.M. de los Ríos Children's Hospital and since then she has been under control. A with a strength born of the inevitable: we have to go on, to do what the moment demands. There is no drama, no crying, no set phrases: this is what has happened to me and this is how we face it. If everything continues to go well, Angela plans to spend another season working in Ecuador to raise some money to buy medicine for her daughter, but that plan will depend on a future neurological evaluation of the girl. She knows that peace of mind is just a moment, a few months, hopefully, a few years".

¹⁰ <https://talcualdigital.com/a-madres-de-ninos-fallecidos-en-el-jm-de-los-rios-se-les-prohibe-el-ingreso-al-centro-de-salud/>

¹¹ <https://efectococuyo.com/salud/jm-de-los-rios-dolor-nefrologia-tres-tiempos/>

¹² <http://www.lavidadenos.com/las-madres-del-j-m/>

12. **EA:** "Is perhaps one of the mothers who has been coming to the J.M. de los Ríos Hospital on a daily basis for the longest time. Her youngest child has been beating death since he was 45 days old, and continues to do so at the age of 11, of which the last 5 years he has had to undergo dialysis twice a week. Every Tuesday and Thursday, E wakes up religiously at 3:40 in the morning. The alarm gets her out of bed to act with the stiffness of a soldier. She prepares breakfast, puts away the lunch she cooked the night before, and gets ready the fuchsia-colored bag that takes her to her daily war. She bathes, dresses, and finally wakes up the child to leave for Caracas. An hour and a half drive awaits them. That's why she leaves her house at 4:30, when the sun is far from rising. With the bundle on her back, she carries the 20 kilos and 500 grams of E to climb the 72 stairs that take her to the main road of the Vista al Mar neighborhood, in Catia la Mar. At the top, panting from the strain on her thin body, she waits patiently for a jeep to pass. If they are lucky, it will arrive in half an hour; otherwise, she will have to walk, with the child in his arms, a long way to the terminal, from where their journey of more than 42 kilometers to Caracas begins. Sometimes I think, if I had a job, I could provide all the comforts for my two children".
13. **JB:** "JB had to face the death of her only son, SB, and her story tells how she overcame this loss by participating, accompanying, and defending the rights of hospitalized children, as well as requesting justice for the case of her son, who died from an infectious outbreak in the Hemodialysis Unit and the irregular supply of antibiotics. She has lost count of the funerals of children she has attended... The reality is that Judith spent the last 12 years in the corridors of a hospital and in the anteroom of pediatricians. Her muscles have had to acquire tone in waiting for dialysis services and in the pugilism with the doctors who every so often announced the imminent death of her son."
14. "JB is a lawyer. You wouldn't say that either. You wouldn't know why, but you'd bet she's a professional in something else. Psychologist, that could be. Nurse intensivist, such is the lightness of her tread, trained in a thousand sleepless nights and light sleep. From March 2017 the nephrology children started to get complicated, there were no antibiotics. After much inquiry, the patients' mothers were told that the osmosis plant had not been cleaned for months. They sent letters to the authorities. To all of them. They filed complaints. They protested. They blocked streets... and when they returned to the hospital waiting room, they heard their children screaming in pain. There were no supplies. There was no water in the hospital (they had to bring it on trucks). SB could no longer walk. They all lost a lot of weight. They had contracted the Klebsiella bacteria. At the beginning of May, 12-year-old RJ died. They were receiving expired antibiotics and irregular supplies.
15. "JB continued going to the hospital. Now she goes there as a member of Prepara Familia, an NGO created in 2008 to contribute to the prevention of violence against women, as well as to support mothers and children at the J.M. de los Ríos Hospital. For her, going back there every day means reliving painful episodes, but she never stops because she is determined to prevent all that tragedy from becoming invisible. In 12 years we only parted ways that night."
16. These four stories show us what women caregivers go through, and in JB's last case, the ability to overcome adversity, when she goes from victim to activist.

III. Recommendations to guarantee the rights of Women Caregivers:

17. The situation of women caregivers requires that the State immediately adopt a series of measures to guarantee the rights of women caregivers, not only in the J. M. de los Ríos Hospital, but in all health centers in the country. To this end, the social situation of women caregivers as unpaid workers in the health system must first be recognized, and then appropriate legislation and regulations must be established to allow the exercise of this valuable and irreplaceable social work. Thus, we recommend to the State:
 - a) Mainstreaming the gender variable in all health care programs.
 - b) Investment in programs to support domestic and community health care.
 - c) Programs for the temporary replacement of unpaid primary caregivers by other volunteers, so that they can have time for themselves and for the necessary self-care.
 - d) Incentives for male responsibility in the health care of sons/daughters. Leave for care of the sick and other dependents for both women and men.
 - e) The State should remunerate the work done by women who perform these care tasks in hospitals and those who perform them at home and care for chronically ill children and adults with a monthly contribution, thus recognizing the work they do.
 - f) Incentives and contributions to support the provision of care in the home and at home, social salary, family salary, and economic support to those who care for dependents.
 - g) The State must organize and constitute an Integral National System of Care that incorporates the care of people with chronic diseases, especially those who care for children and adolescents.