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ETHICAL AND LEGAL RECOGNITION OF FAMILY CARE: THE CASE OF ZIKA VIRUS CONGENITAL SYNDROME IN BRAZIL

*O reconhecimento ético e jurídico do cuidado familiar:
o contexto da síndrome congênita do vírus Zika no Brasil*

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Received: 08/30/2018. Revised: 04/08/2019. Approved: 04/11/2019.

ABSTRACT

This article deals with the ethical and legal recognition of the care relationships developed within the framework of affective family relationships. Starting from the description of the concrete demand for care that is presented to the families by the Zika virus congenital syndrome context in Brazil, in the years of 2015 and 2016, to analyze the theoretical contributions to the discussion of the protection of family care relationships in the Moral and Law fields, respectively, by the ethics of care, as initially formulated by Carol Gilligan, and by the legal approach of the care relationships, as formulated by Jonathan Herring and José Roque Junges.

Keywords

Right to Health; Ethics of Care; Family Relationships; Congenital Zika Syndrome; Vulnerability.

RESUMO

O presente artigo trata do reconhecimento ético e jurídico das relações de cuidado desenvolvidas no âmbito afetivo familiar. Parte-se da descrição da situação concreta de demandas por cuidados que se apresentam às famílias no contexto da epidemia da síndrome congênita do vírus Zika, incidente no Brasil em 2015 e 2016, para se analisarem as contribuições teóricas à discussão sobre a proteção das relações familiares de cuidado no campo da moral e do direito, respectivamente, pela ética do cuidado na abordagem proposta inicialmente por Carol Gilligan e pela abordagem jurídica das relações de cuidado, conforme formulações de Jonathan Herring e José Roque Junges.

Palavras-Chave

Direito à Saúde; Ética do Cuidado; Relações Familiares; Síndrome Congênita do Vírus Zika; Vulnerabilidade.

Introduction

The first laboratory confirmations of the presence of Zika virus in the Brazilian population occurred in May 2015, followed by the discovery, between August and October 2015, of its relationship with the alteration of the microcephaly pattern in the states of Bahia and Pernambuco. In November 2015, the Public Health Emergency of National Importance (ESPIN)¹ was declared, followed on February 1, 2016, by the Declaration of Public Health Emergency of International Concern (ESPPII) recommended by the Meeting of the Emergency Committee convened by the General Board of International Health Regulations (RSI-2005)².

Between epidemiological weeks (SEs) 45/2015 and 20/2018 (11/8/2015 to 5/28/2018), 16,028 suspected cases of changes in fetal growth and development possibly related to infection of pregnant women by the Zika virus and other infectious etiologies were reported. Of these cases, 2,053 (12.8%) were excluded and 2,629 (16.4%) remained under investigation at SE 20/2018. Of the completed cases, 7,286 (45.5%) were ruled out, 3,194 (19.9%) were confirmed, 506 (3.2%) were classified as likely to be associated to congenital infection during pregnancy and 360 (2.2%), as inconclusive. Among confirmed cases of newborns (NBs) and children, except deaths, 1,714 (62.2%) were receiving childcare, 1,004 (36.4%) in early stimulation and 1,788 (64.9%) in specialized care service³.

The lasting consequences of the congenital syndrome associated with the Zika virus, however, imply multiple, complex and continuous care that impacts the lives of the affected children and their families.

It is worth mentioning that the word “family” is adopted here in its broad sense, as proposed by the World Health Organization (WHO) in 1994, International Year of the Family: “The concept of family cannot be limited to blood ties, marriage, sexual partnership or adoption. Any group, whose connections are based on trust, mutual support and a common destiny, must be regarded as a family”⁴. In the same sense: “[...] Beyond the biological, the family group is built by those who, under the

¹MINISTÉRIO DA SAÚDE – MS. *Portaria n. 1.813, de 11 de novembro de 2015*. Declara Emergência em Saúde Pública de importância Nacional (ESPIN) por alteração do padrão de ocorrência de microcefalias no Brasil. Available at: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2015/prt1813_11_11_2015.html. Accessed on: 10 Jun. 2018.

²WORLD HEALTH ORGANIZATION – WHO. *WHO statement on the first meeting of the International Health Regulations (2005) (IHR 2005) Emergency Committee on Zika virus and observed increase in neurological disorders and neonatal malformations*. 1 Feb. 2016. Available at: <http://www.who.int/mediacentre/news/statements/2016/1st-emergency-committee-zika>.

³MONITORAMENTO integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 20 de 2018. *Boletim Epidemiológico*, Secretaria de Vigilância em Saúde, v. 49, n. 29, jun. 2018. Available at: <http://portal.arquivos2.saude.gov.br/images/pdf/2018/junho/29/Monitoramento-integrado-de-alteracoes-no-crescimento-e-desenvolvimento-relacionadas-a-infeccao-pelo-virus-Zika.pdf>. Accessed on: 25 Aug. 2018.

⁴OMS, 1994, apud ALARCÃO, Madalena. *(Des)equilíbrios familiares: uma visão sistêmica*. 3. ed. Coimbra: Quarteto Editora, 2000. p. 202.

same roof, or together and homeless, feel united by bonds of love, intimacy and the protection of the weakest”⁵.

Particularly impacted is the life of mothers, invested in the role, almost always lonely, of care. The family nucleus emerges, in this context, with a dual role: of caregiver and receiver of care, challenging an adequate ethical and legal treatment.

In this sense, this article brings some theoretical contributions related to the extent and limits of the promotion and protection of care in the family environment, taking into account the fact that the caregiver demands care and that the legal recognition of this care imposes obligations on all society and the State, in the face of their duties in guaranteeing the health and well-being of the citizen.

In the ethical field, theoretical questions were analyzed based on Carol Gilligan’s pioneering formulation⁶ on the ethics of care and feminist criticism that follows it, with authors such as Annette Baier⁷, Rosemarie Tong⁸ and Joan Tronto⁹.

In the legal field, the analysis was mainly based on the formulations of José Roque Junges¹⁰ and Jonathan Herring¹¹ on the appropriate legal treatment of care, considering the general vulnerability, inherent to human being and increased vulnerability, incident in situations involving the reduction of capacity and agency of the individual. In this approach, the personal and relational character of the care needed to overcome these vulnerabilities is emphasized.

Thus, the article seeks to offer a brief critical approach to the possibilities, limits and challenges in the ethical and legal recognition of care in the family environment and, for this purpose, is organized in three parts. The first presents a brief synthesis of the demands, anguishes and hopes of the mothers who face the incidence of congenital Zika virus syndrome, as well as the responses given by the government to these demands. In the second part, the reflections on the ethics of care are presented in the feminist perspective, aiming to subsidize, in this perspective, the legal approach family care relationships. The third part deals with the legal recognition of care within the family and obligations arising from it, attributable to society and the State, followed by final considerations.

⁵COLLADO, Adelina Gimeno. *A família: o desafio da diversidade*. Lisboa: Instituto Piaget, 2001. p. 73.

⁶GILLIGAN, Carol. *In a different voice: psychological theory and women’s development*. Cambridge, MA: Harvard University Press, 1982.

⁷BAIER, Annette C. The need for more than Justice. *Canadian Journal of Philosophy*, Supplementary, Canada, v. 13, p. 41-55, 1987.

⁸TONG, Rosemarie. The ethics of care a feminist virtue ethics of care for healthcare practitioners. *J Med Philos.*, UK, v. 23, n. 2, p. 131-152, Apr.1998. <https://doi.org/10.1076/jmep.23.2.131.8921>.

⁹TRONTO, Joan. *Caring democracy: markets, equality and justice*. New York: New York University Press, 2013.

¹⁰JUNGES, José Roque. *Bioética e os paradigmas da justiça e do cuidado*. In: JUNGES, José Roque. *Bioética: hermenêutica e casuística*. São Paulo: Edições Loyola, 2006. p. 73-102.

¹¹HERRING, Jonathan. *Caring and the law*. Oxford: Hart Publishing, 2013.

I. The factual situation and the response of the public power

This study had its initial motivation in the testimonies of mothers whose children were affected by the congenital Zika virus syndrome between 2015 and 2016, collected in public hearings promoted by the Federal Attorney for Citizens' Rights (PFDC) in January and February 2017, in Recife/PE¹² and Rio de Janeiro/RJ¹³, composing an account of the concrete problems, desires and expectations of these mothers.

The narratives, in general, involved requests for timely access to examination and consultation in different medical specialties (neurology, ophthalmology, pediatrics, among others); medicines, foods and special food supplements; rehabilitation; clinical information; and administrative information on available health and social assistance services. The complaints also emphasized the difficulty in access to multiple care, since the services, when they exist, were dispersed among different health units and were not adequately distributed territorially; added to this difficulty was the lack of adequate means of transportation and other equipment for collective use, such as kindergartens and schools, as well as the discrimination faced in access to all these services.

The testimonies also revealed the uncertainties and anguishes generated by the impact of congenital syndrome on the lives of mothers, who, in general, started to answer practically alone for the care required by the child. Almost all of them reported the fact that the birth of the child with the syndrome resulted in the postponement or cancellation of personal life projects, the renunciation of paid work and the study, training or professional specialization.

Today I am twenty-six years old, I am not graduated in higher education, but I lived the opportunity to dream about it, when I finished my technician in aesthetics and I said, well, now I will grow up, I will do higher education, I will be a successful beautician and I will be able to give a better life to my family, because I already had Beatriz and, when I finished, I found out that I was pregnant with William Gabriel. And during that time, when I was beginning my career, William was born and it was the discovery of microcephaly, after a month of birth, through the Zika virus, and then I stopped, cried, reflected and asked the question: why, God? That's not it? And at that moment, my dream, it was over. It ended up like this, parked it. Because, as many have said, we

¹² AUDIÊNCIA Pública "Políticas Públicas e Epidemia do Vírus Zika: Informação, Controle e Assistência aos Cidadãos". Recife-PE, 10 fev. 2017. *Ministério Público Federal - MPF*. Procuradoria Federal dos Direitos do Cidadão. Available at: <http://pfdc.pgr.mpf.mp.br/informacao-e-comunicacao/eventos/saude/audiencia-zika-pe/>. Accessed on: 25 Jun. 2017.

¹³ POLÍTICAS de prevenção e atenção às vítimas do vírus Zika são debatidas no RJ. *Ministério Público Federal - MPF*. Procuradoria Federal dos Direitos do Cidadão, 03 abr. 2017. Available at: <http://pfdc.pgr.mpf.mp.br/informativos/edicoes-2017/abril/030417/>. Accessed on: 25 Aug. 2018.

have to put our dream aside. Today I could be taking a higher education course, which I still have a dream to do Pedagogy, and I had to wait for that dream. Then I had to stop working. I had to leave the study on hold, in order to take care of William. (Susana, mother of William Gabriel, Recife/PE)¹⁴.

Many also reported the abandonment by the partner and father of the child.

The response offered by the Brazilian State to the health emergency, in legislative terms, was expressed in the edition of Law no. 13.301/2016¹⁵. Some of these measures, however, showed a rhetorical character, without effective repercussion to the situation that was installed with the epidemic, and others were even inadequate.

The widely announced assistance benefit to affected families did not represent an innovation in the legal system, as one would expect to face a new and exceptional situation. In fact, it only referred to an existing benefit - the Continuous Cash Benefit (BPC)¹⁶, as such, subject to family income *per capita* below one quarter of the current minimum wage. In practice, the benefit did not contemplate the concrete and specific reality of the financial impact of the syndrome in most families. Many of them, not fulfilling the requirement for perception of the assistance benefit, could also not bear the increase in family expenses related to child care associated with the reduction of family income, since most mothers, to assume the role of caregiver, had to leave the formal labor market.

A legal device inserted in Law no. 13,301/2016 - item IV of Article 1, paragraph 3 - provided for the vector control of the disease by urban dispersion of adulticides by aircraft, contrary to the state of the art of control and the experience accumulated in Brazil in more than three decades of vector control in fight against dengue, which makes serious restrictions to the chemical control of the adult vector, even with mosquito control truck, which offer greater control of dispersion¹⁷. The device was challenged by Direct Action of Unconstitutionality no. 5.592¹⁸.

¹⁴AUDIÊNCIA Pública “Políticas Públicas e Epidemia do Vírus Zika: Informação, Controle e Assistência aos Cidadãos”. Recife-PE, 10 fev. 2017, *cit*.

¹⁵BRASIL. *Lei n. 13.301, de 27 de junho de 2016*. Dispõe sobre a adoção de medidas de vigilância em saúde quando verificada situação de iminente perigo à saúde pública pela presença do mosquito transmissor do vírus da dengue, do vírus chikungunya e do vírus da zika. Available at: http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2016/lei/L13301.htm. Accessed on: 25 Aug. 2018.

¹⁶Artigo 20 da Lei Orgânica da Assistência Social. BRASIL. *Lei n. 8.742, de 07 de dezembro de 1993*. Dispõe sobre a organização da Assistência Social e dá outras providências. Available at: http://www.planalto.gov.br/ccivil_03/LEIS/L8742.htm. Accessed on: 25 Aug. 2018.n. 8.742, de 7 de dezembro de 1993

¹⁷FUNDAÇÃO OSWALDO CRUZ - FIOCRUZ. *Considerações técnicas sobre a aplicação aérea de inseticidas em área urbana*. Nota Técnica n. 4/2016/IOC-FIOCRUZ/DIRETORIA. Available at: http://www.fiocruz.br/ioc/media/NT04_2016_IOC_inseticida_aviao_dv_rlo_ppublicacao.pdf. Accessed on: 30 Aug. 2018.

¹⁸SUPREMO TRIBUNAL FEDERAL – STF. *Ação Direta de Inconstitucionalidade n. 5.592*. Petição inicial. Available at: <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5054307>. Accessed on: 25 Aug. 2007.

In addition, Law no. 13,301/2016 was the subject of Direct Action of Unconstitutionality Action no. 5,581¹⁹, proposed by the National Association of Public Defenders (Anadep) and the Doctors Union of Pará (Sindmepa) aiming at the declaration of unconstitutionality (i) the fixing of a fixed maximum period (three years) for the enjoyment of the continuous cash benefit; (ii) the imposition of misery proof for this purpose; (iii) the requirement of medical expertise by the National Social Security Institute (INSS) in locations where there was no agency of this autarchy; and (iv) the prohibition of cumulating maternity pay with the BPC. In the same action, the compliant interpretation was requested in order to extend the continuous cash benefit to cases where the infection did not occur through the vector - the mosquito *Aedes aegypti* -, but rather by the sexual transmission of the virus, and to acknowledge the non-compliance of fundamental precept in the face of the insufficiency of public policies designed to achieve the fundamental right to health. It was also requested to declare the constitutionality of termination of pregnancy when there was a diagnosis of Zika virus infection, aiming at protecting the mental health and reproductive autonomy of the woman - emphasizing that the WHO, among the measures to deal with the problem, recommended equitable access to safe services of termination pregnancy (where legal) and post-abortion care²⁰.

The questions brought to the Federal Supreme Court (STF), as a whole, show that state measures were far from contemplated, with the agility that the health emergency presupposed the concrete needs of women, children and families affected. The state approach, as seen, was focused mainly on fighting the mosquito, abstracting the general context of the epidemic and its environmental, behavioral and social variables.

There was, above all, an unjustifiable state omission to provide guidance campaigns regarding the risk of sexual transmission of the virus and regarding the personal protection actions to be taken that were related to the autonomy of women in determining their health and exercising their sexual and reproductive rights.

According to Galli,

Unfortunately, Brazil, one of the countries most affected by the Zika virus epidemic, has not yet adequately addressed legal restrictions and the various barriers that affect the exercise of sexual and reproductive rights, particularly for the most vulnerable due to their socio-economic condition, race, age and place of residence, to modern and safe methods of fertility regulation²¹.

¹⁹SUPREMO TRIBUNAL FEDERAL – STF. *Ação Direta de Inconstitucionalidade n. 5.581*. Petição inicial. Available at: <http://portal.stf.jus.br/processos/detalhe.asp?incidente=5037704>. Accessed on: 25 Aug. 2007.

²⁰ZIKA Strategic Response Plan. Revised for July 2016 – December 2017. World Health Organization – WHO, June 2016. Disponível em: <http://apps.who.int/iris/bitstream/handle/10665/246091/WHO-ZIKV-SRF-16.3-eng.pdf;jsessionid=A52ED2FD38042B7880780B2A33F62FC1?sequence=1>. Available at: 25 Aug. 2018.

²¹GALLI, Beatriz. *Zika e os direitos reprodutivos*. In: ENCONTRO INTERINSTITUCIONAL: SÍNDROME NEUROLÓGICA DO VÍRUS ZIKA – POLÍTICAS E AÇÕES DE PREVENÇÃO, CONTROLE E ASSISTÊNCIA. Brasília-DF, 06 dez. 2016. Available at: <http://pfdc.pgr.mpf.mp.br/informacao-e-comunicacao/eventos/saude/encontro-interinstitucional-zika-virus/apresentacoes/biagalli>. Accessed on: 25 Aug. 2018.

Given the inefficiency of state action, largely due to the confrontation model adopted, it is necessary to emphasize, in an opposite position, the welcoming role played by civil associations. In Recife, two of them had a remarkable performance: the Alliance of Rare Mothers and Families (AMAR), which already existed and which welcomed the new demand for care generated in the epidemic, and the Mothers of Angels Union (UMA), formed in the context of the epidemic and with the primary objective of facing it. The mothers' report highlights the role played by these civil associations in mutual support and encouragement, in identifying and understanding among women who share dramas identical or similar to those imposed by the syndrome, and in forwarding claims and solutions. These reports highlight the relevance of care support networks to overcome the serious effects of the epidemic on the health and well-being of the population.

We met at Oswaldo Cruz and decided to formalize and create the UMA, which today aggregates almost four hundred mothers across the state [...] Often the district is at one hundred, one hundred and fifty kilometers and the rural area at least two hundred. But we, as a mother, with all this commitment of therapy for our children, we try to go after this mother. Because, sometimes what she needs is just information, it is a hug, a piece of advice; it is to say that she has a right to that and that she should seek it. (Germana, Mother of William, President of the UMA)²²

It consists in a mechanism of social action that, because its characteristics, does not compete with state action nor can it be replaced by it, although it certainly should be valued and supported by the State, because the economic and social consequences of these actions, from different perspectives, are not irrelevant to political society. It is on this basis that we seek to evaluate, in this article, the need and appropriate forms of moral and legal recognition of care in affective and family relationships.

II. The ethics of care

In the 1980s, Carol Gilligan²³ proposed the theoretical and philosophical basis of an ethics of care. Its formulation contrasted the model of moral development of the child devised by Lawrence Kohlberg²⁴, who, by applying to groups of boys and girls tests based on the pattern of separation and autonomy of moral subjects and on judgments supported by principles and rules, undervalued the moral development

²²AUDIÊNCIA Pública “Políticas Públicas e Epidemia do Vírus Zika: Informação, Controle e Assistência aos Cidadãos”. Recife-PE, 10 fev. 2017, *cit.*

²³GILLIGAN, Carol. *op. cit.*

²⁴KOHLBERG, Lawrence. *Essays on moral development: v. I: The philosophy of moral development; v. II: The psychology of moral development*. New York: Harper & Row, 1981.

of girls, whose moral behavior, as evidenced later by Gilligan, obeyed a different pattern, founded on the interaction and relationship between moral agents and organized in the form of virtues.

Thus, an alternative model for moral development was evidenced, which was called *ethics of care* and was opposed to the model called *justice approach*²⁵. The latter, being partial, cannot be assumed separately as a prototype of human moral behavior. Once the distinctions between the two models are fixed, Gilligan defends their complementarity and integration into an ethical theory that overcomes incompleteness and reciprocal insufficiencies.

My goal is to broaden the understanding of human development, using the group left out in the construction of the theory to draw attention to what is missing. Viewed from this perspective, the discrepant data on women's experience provides a basis on which to generate new theory, with the potential to produce a more comprehensive view of the lives of both sexes²⁶.

The points of distinction between the two models were summarized by Rosemeire Tong²⁷ as follows: the ethics of care is presented as a contextualized and engaged perspective, opposed to the abstract and impartial perspective of the justice approach; the first marks the particular and the second, the universal; the first one focuses the interlacing and the human connection, the second, the human individuality and separability; the first privileges the communal relations, while the second focuses on individual rights; the first relates more to the private sphere, the second, to the public sphere; the first repeats the importance of affectivity and emotions, the second highlights the importance of reason and the logical argumentation; the first seeks to form a good character, from previous provisions, while the second seeks to reach the right action from correct judgments; the first seeks an ethics of virtues or attitudes; the second, an ethics of principles or norms; the first is associated with the feminine universe; the second is associated with the masculine universe.

Nell Noddings²⁸, in the first edition of "Caring", published in 1984, pointed out care as a *feminine ethic* conceptually drawn from the perspective of motherhood and possessing a double genesis: the natural affective response of human being and the memory of childhood care, shaping one's own individual identity. The author builds a critique of the male morality of principles and rules and proposes its replacement by a morality based on care. Care, in this conception, is always built contextually, starting from reciprocity. Therefore, it is restricted - and this is a frequent

²⁵ GILLIGAN, Carol. *op. cit.*, p. 30, 73.

²⁶ GILLIGAN, Carol. *op. cit.*, p. 3-4.

²⁷ TONG, Rosemarie. *op. cit.*

²⁸ NODDINGS, Nell. *Caring: a feminine approach to ethics and moral education*. Second edition updated. Los Angeles: University of California Press, 2013.

criticism of Noddings' theory - to close moral subjects, amenable to a reciprocal relationship, excluding the possibility of a universal care ethic²⁹.

Annette Baier³⁰ deals with some controversial aspects of the ethics of care from a feminist perspective. It questions, for example, the origin of the significant difference in the way women and men think about moral issues; if justice and care really represent the male and female perspectives and, in representing, what is the biological or social nature of this determination. Baier approaches the ethics of care of Hume's moral theory to demonstrate that both move away from obedience to universal principles and underscore the importance of cultivating virtues such as kindness, pleasantness, compassion, sympathy and moderation, placing trust as the fundamental concept of morality. The author states that, although important, the liberal and principiological conception of justice in Kantian molds is not adequate nor even gives account of the minimal social morality. It therefore advocates the harmonization of the ideals of care and justice as equally necessary and equally density aspects in the formulation of moral theories.

The feminist criticism of the ethics of care thus presents itself on a broad spectrum, ranging from those that, in a certain way, naturalize the ethics of care as a feminine ethic (as in Nell Noddings) to those that impute to the ethics of care the "slave morality" in the sense given by Nietzsche, intended merely to reaffirm the oppression of women in a rigidly defined pattern of sexual distribution of labor³¹. The authors cited, in general, diagnose the fact that care, when historically attributed to women, becomes socially devalued by patriarchy, determining the predominance of justice approach over ethics of care.

More contemporary feminist discussions, as pointed out by Ilze Zirbel³², seek to situate the ethics of care as part of a universal morality. The forms of reasoning and development of virtues commonly associated with the ethics of care, such as empathy, compassion and capacity for perception and response, are accessible and can develop regardless of gender. The very fact that the distribution of care activities between genders occurs according to an asymmetric, unequal and unfair pattern suggests that the concepts of ethics of care and justice approach should be discussed together in some way.

Joan Tronto³³ brings the discussion of the ethics of care to the field of political philosophy, problematizing the privatization of care and the tendency for

²⁹*Ibid.*, p. 90.

³⁰BAIER, Annette C. *op. cit.*, p. 41-55.

³¹PUKA, Bill. The liberation of caring: a different voice for Gilligan's "different voice". *Hypatia*, v. 5, n. 1, p. 58-82, 1990.

³²ZIRBEL, Ilze. *Uma teoria político-feminista do cuidado*. Tese (Doutorado) - Universidade Federal de Santa Catarina, Centro de Filosofia e Ciências Humanas, Programa de Pós-Graduação em Filosofia, Florianópolis, 2016.

³³TRONTO, Joan. *Moral boundaries: a political argument for an ethic of care*. New York: Routledge, 1993.

“work of care” to be performed in a way that benefits elites. The burden of care falls disproportionately according to the hierarchies of gender, race and social class³⁴. The author writes the expression *privileged irresponsibility* to describe the phenomenon that allows the most favored of society to buy care services, seeking to avoid responsibility for care and subtract their practice. The author does not rule out the use of the market³⁵, but warns that this recourse cannot lead to confusion between the consumption and the care relationship, which have different functions, nor to confuse consumer satisfaction with the proper care provision³⁶.

Joan Tronto formulates four phases of care, to which it associates four ethical qualities: (i) “**take care of**” attention matters (*attentiveness*), the recognition of the need for care and the consequent attitude of attention to it; (ii) “**care about**” involves taking responsibility (*responsibility*) for the work that needs to be done; (iii) “**offer care**” is the work itself and presupposes a technical and moral capacity, competence (*competence*) to do so; (iv) finally, “**receive care**” is the response to offering care and requires receptivity (*responsiveness*) from the recipient.

They are, as can be seen, qualities that emphasize reciprocity and the personal and relational character of care, bringing into its orbit the vulnerability of the moral agent itself who invests in the responsibility of care, which requires mutual understanding and mutual response between caregivers, caregiver and third parties who may intervene in this relationship.

It is worth noting that the relational character of care, even before the formulations of ethics of care presented here, had already been addressed by Milton Mayeroff: “Caring is the antithesis of simply using the other person to satisfy your own needs”. The author defines care as

a process, a way of relating to the other that involves development and, in the same way as friendship, can only arise in time through mutual trust and the deepening and qualitative transformation of the relationship³⁷.

José Roques Junges³⁸ warns that vulnerability and interdependence are the anthropological assumptions of the paradigm of care. Its denial prevents the development of the care attitude. The strong and independent does not need, or

³⁴ For a description of how paid and unpaid care reflects and generates female subordination, as well as the transnational character of the care commercialization, between developed and underdeveloped countries, check: HOCHSCHILD, Arlie R. *The commercialization of intimate life: notes from home and work*. Berkeley: University of California Press, 2003.

³⁵ TRONTO, Joan. *op. cit.*

³⁶ On the subject, check “*The logic of care: health and the problem of patient choice*” by Annemarie Mol (New York: Routledge, 2008) a work in which the author analyzes the distinctions between the logic of choice, which informs the market, and the logic of care, which informs the care relationship.

³⁷ MAYEROFF, Milton. *On caring*. New York: Harper & Row, 1971. p. 1.

³⁸ JUNGES, José Roque. *op. cit.*

does not recognize that he needs, the care and, therefore, is also unable to care. His “care” would be, rather, a declaration of power to turns inferior the care receiver. The ontological vulnerability of the being is the basis and the limit of care, since not only the person who receives care, but also the one who cares is vulnerable and limited in the care action. This determines the need for a care network, linking everyone involved in providing and receiving care.

The reality of this interdependence is better understood if one considers the pluridimensional character of human vulnerability: somatic, psychic, social and spiritual. The person providing physical care may find himself in a situation of psychic, social or spiritual vulnerability. Pain, suffering and reduced capacities, inherent to situations of illness, demand or imply interiorization, understanding, alternation of roles and search for meanings, which involves all the dimensions mentioned. Thus, interdependence reveals its ecological dimension, that is, the understanding of reality in terms of its connections, making the paradigm of care transcend the human species to encompass the environment and the other species that share it.

Junges points out that the exclusive valorization of the strong and autonomous human being, as a work of Modernity, inspired achievements and allowed the accumulation of wealth and, in a certain dimension, the possibility of well-being. In contrast, it left a trail of destruction and exclusion. The revaluation of the paradigm of care can offer an adequate horizon for vulnerability and interdependence are assumed in a positive sense in order to enrich the understanding of the human being as such.

In summary, the ethics of care that has been discussed by feminist thought since the early 1980s, by critically exposing the arbitrary attribution of the care activity to the female sex, restores the central focus of ethical commitment from the perspective of vulnerability, interdependence and reciprocal human responsibilities.

In this perspective, the care approach, by connecting equitably, relationally and ecologically those who provide and those who receive care, offers not only better opportunities to overcome the unavoidable vulnerability that emerges from situations of illness and disability, as well as better opportunities for all those involved in the care of apprehension and understanding of the care network in which they live, or may come to live, in facing the always dynamic and challenging circumstances of life in society.

III. The legal recognition of care in the family environment

José Roques Junges³⁹ recalls that the perspective of care can also be developed in its legal framework - especially if we consider the law transposing the formalistic, liberal and procedural paradigms, described by Francesco D'Agostino⁴⁰ and

³⁹JUNGES, José Roque. *op. cit.*

⁴⁰D'AGOSTINO, Francesco *apud* JUNGES, José Roque. *op. cit.*

that emphasize formal autonomy, to achieve the relational paradigm of law, which emphasizes the reality of the subject in relation and the symmetry and reciprocity of the rights associated with it.

In the liberal tradition, legal systems are, as a rule, founded on the formal assumption of competent individuals, isolated and independent, holders of autonomy and self-determination rights compatible with the justice approach previously exposed. The concrete reality, however, reveals individuals largely ignorant, vulnerable and interdependent. Their reality and strength are not only found in autonomy, but also in the possibilities of interrelationship and cooperation.

In the liberal paradigm, a frequent distortion of care is the glamour, the invention of an idealized and artificial image, worthy of sacrifice, which does not correspond to its concrete reality. Rather, this is an instrumental perspective of patriarchy, which attributes characteristics of an overrogatory act and, in theory, associated with docility and charity as “female virtues”. This rhetorical appreciation does not preclude care and women as subjects of the relationship, both being deprived of the just, proportional and necessary recognition.

The care activity involves physical and psychological burdens, doubts, anxieties, frustrations and sacrifices of personal projects and can lead to abusive relationships that, therefore, require adequate social and legal support. The voluntary nature of sacrifices does not authorize the conclusion that they must be naturalized to exclude their legal protection or to rule out the recognition of rights. It is important, in this sense, that the legal recognition of care is based on an adequate strategy of institutionalization and legal support. One possibility, in this direction, would be the construction of a “right to care”, with suggested contours, among others, by Noelia Igareda González, Nuria Belloso Martín and Laura C. Pautassi.

Noelia Igareda González⁴¹, within the framework of the Rule of Law, proposes the “right to care” (*derecho al atendimento*), as an autonomous social right, equivalent to the right to health and education, corresponding to a duty of the State to ensure minimum welfare to society, providing care to individuals who are not, at some point in their lives, able to guarantee their own survival, such as children, the elderly and people who, for different reasons, face a reduction in their capabilities.

Nuria Belloso Martín⁴², with a similar direction, part of the description of the “crisis of care” (*crisis de los cuidados*), which is produced when have women

⁴¹ IGAREDA GONZÁLEZ, Noelia. El derecho al cuidado en el Estado social de Derecho. *Anuario de Filosofía del Derecho*, v. 28, p. 185-206, 2012. Available at: https://www.boe.es/publicaciones/anuarios_derecho/anuario.php?id=F_2012_ANUARIO_DE_FILOSOF%C3%83%82%20DEL_DERECHO. Accessed on: 30 Mar. 2019.

⁴² BELLOSO MARTÍN, Nuria. La proyección del cuidado y de la afectividad en el principio de solidaridad (familiar): una propuesta del cuidado como derecho social. In: PEREIRA, Tania da Silva; COLTRO, Antônio Carlos Mathias; OLIVEIRA, Guilherme de (Orgs.). *Cuidado y afectividad*. São Paulo: Editora Atlas / Grupo GEN, 2016. p. 406-443.

access to the public sphere and to paid work, but maintain their role as caregivers in domestic setting, resulting in the “double female presence” (*doble presencia femenina*). The author goes through the considerations of the principle of solidarity in its repercussion in the family to propose care as a social right that reflects on a true public system of education, health and care for the elderly to reconcile family and work life, with pensions and day kindergartens of sufficient quality so that care does not have to be supplied or complemented by private or family initiatives. The author understands that the challenge is not to relegate care to the private sphere, integrating it to the public sphere, the only way of not promoting gender inequality and making possible a broader conception of social justice.

Laura C. Pautassi⁴³ defends the recognition of the “right to be cared for and to self-care” as a personal universal right that, although not expressed in these terms, is implicit in the framework of international human rights systems. These rights range from qualitative and quantitatively adequate food to the right to the development of comprehensive social security systems, including the right to health, education, housing and decent work. It is, in fact, a plexus of rights embedded in the idea of a right to care, within the framework of guarantees of equality and non-discrimination, to be progressively implemented by States and controlled by international human rights systems.

The formal recognition of a “right to care”, in the contours outlined above, is guided by the conception of law as a system of guarantees and fundamental rights as rights of protection for the weakest, as formulated by Luigi Ferrajoli: “*The fundamental rights are always asserted as laws of weakest as an alternative to laws of the more strong that governed and would govern in its absence*”⁴⁴.

However, this article understands that relevant or more relevant than the recognition of the formal right to care is to recognize, within a relational logic, care as a relationship that justifies broad legal protection by the State, thus affecting the different branches of national and international law. In contrast, it is important that state support for family care does not mean its reduction to the field of health, or the mere investiture of the family nucleus in health care, replacing peculiar functions and responsibilities inherent to public and private health care systems.

The theme of the interweaving of care in the family environment with health services seems to find a balanced equation in the approach that Emerson Elias Merhy⁴⁵ makes of the nucleus caregiver from the perspective of health services.

⁴³PAUTASSI, Laura C. *El cuidado como cuestión social desde un enfoque de derechos*. Santiago de Chile: CEPAL, oct. 2007. (Serie mujer y desarrollo; 87). Available at: https://repositorio.cepal.org/bitstream/handle/11362/5809/1/S0700816_es.pdf. Accessed on: 30 Mar. 2019.

⁴⁴FERRAJOLI, Luigi. *Derechos y garantías: la ley del más débil*. 10. ed. Madrid: Editorial Trotta, 2010. p. 54.

⁴⁵MERHY, Emerson Elias. A perda da dimensão cuidadora na produção da saúde: discussão do modelo assistencial e da intervenção no seu modo de trabalhar a assistência. In: CAMPOS, Cezar Rodrigues (Org.). *Sistema Único de Saúde em Belo Horizonte: reescrevendo o público*. São Paulo: Xamã, 1998. p. 103-120.

Such an approach proposes an intercessory relationship with the subjective world of the person cared for, in order to represent health needs and build a welcoming relationship that includes the person cared for as a subject of knowledge and practices, which allows to create links and responsibilities among those involved in the health acts and to enable the professional nucleus from the world of the recipient of care, and not the other way around, in a relationship that is oriented towards the construction of autonomies and the agency of moral subjects individually and collectively involved in the defense of life and health.

To discuss the recognition and legal protection of care from a relational perspective, a fundamental contribution is made by Jonathan Herring⁴⁶. The author sees in the ethics of care, discussed in the second part of this article, a challenge to rethink not only the extent, but especially how the role and nature of legal rights and responsibilities are commonly understood by law. His analysis is based on the recognition of the general human vulnerability inherent to the human condition and the increased vulnerability that occurs at some point in the course of any individual's life. Such vulnerabilities affect not only the individual who needs care, but also those who relate to it, making intersubjective dependence an inevitable facet of human life. Consequently, mutual care is an essential and unavoidable aspect of the functioning of life in society. From this reality, Herring draws the consequence that the care activity must be recognized and valued within the legal systems.

The State is not neutral towards family organization. Historically, it seeks to regulate it according to its interests, with a wide range of provisions referred to it. The question that currently arises, however, is about the quality and adequacy of this interference. The constructive and just action of the State on the family environment goes through the support that can give to the relationship and the care activity that is established and developed in it.

The legal perspective in which care relationships have usually been addressed remains, in very restricted limits, focused on the theme of its costs and on the exclusive focus of paid and institutional care activity, neglecting the theme of voluntary care, free of charge, non-professional and non-institutional that develop in the context of family and affective relationships. This position of the State is reflected in the law, in its different branches, including those in which, in theory, the care relationship should have a prominent place, such as Family Law and Medical Law.

Family law traditionally sees the family as a result of sexual and genetic relationships, not as a result of affectionate and caring relationships. Usually, this branch of law approaches the doctor-patient relationship in a unidirectional and biomedical manner, abstracting care relationships that exceed it. As a rule, the ethics

⁴⁶HERRING, Jonathan. *Caring and the law*, *cit.*

of Medical Law individualizes the patient and his health, which does not correspond to the relational reality of care and the health-disease process.

The legal recognition of the care relationship therefore challenges new and efficient political-legal approaches. It is not possible, in the extension of this article, to deal exhaustively with the protection and support of care relationships to be fostered by legal provisions - including because it is an open range of possibilities for the legislator and the public policy maker. However, the following may be cited as an example: financial support; provision of public services; legal assistance; protection and encouragement of the employment of caregivers, including part-time; affirmative inclusion and anti-discrimination policies in kindergarten, schools and other public facilities; among other measures. As important as the measures themselves is the cultural change they bring about in the understanding of care relationships as relations of public interest, allowing and giving rise to the assumption of caring as the responsibility of the whole society.

There is, in contrast, the need to establish the contours of family and personal care, in the pragmatic objective of making it a concept that is operable in legal terms. It is necessary to define what care is, as well as what care challenges legal protection and imposes obligations on the State. What branches of law are affected and how can they contribute to the legal discipline of care relationships?

An important criticism of the legal approach to care is made from the perspective of the rights of person with disabilities and addresses to the passive position to which the recipient of care can be relegated in some of its conceptions. This criticism largely stems from the consideration of care as a relational activity, addressed in more detail by Herring⁴⁷. The author relates, for this purpose, four markers to be considered in the care activity: (i) filling a need; (ii) respect; (iii) responsibility; and (iv) relationality; the following summarized:

(i) **filling a need:** every care activity presupposes the existence of a need that requires a concrete, effective, corporal action. The author distinguishes between care about and care for. Care about is a mental attitude. Care for is a current action that aims at concrete results. This marker is therefore related to the moral concept of virtue as thinking and feeling supported by action and habit.

(ii) **respect in the exercise of care:** repels the view that denies the *status* of the subject to the person who receives care, treating it as a mere receptacle of attention. The attitude of care, on the contrary, must recognize in the person cared for his nature as a dignified and autonomous subject, with interests to be defended, able of express will in the extension of his possibilities. As a consequence, the caring

⁴⁷ HERRING, Jonathan. *Caring and the law*, cit. Também: HERRING, Jonathan. The disability critique of care. *Elder Law Review*, v. 20, n. 8, p. 1-15, 2014. Available at: <http://classic.austlii.edu.au/au/journals/ElderLawRw/2014/2.html>.

attitude must be attentive not only to the needs, but also to the interests and, fundamentally, to the will of the person cared for.

(iii) **responsibility**: care involves the acceptance of a person's personal responsibility by another person. The ability to provide care is limited, as a person can only personally and responsibly care for a finite number of people. In contrast, personal care does not mean relieving others of their responsibilities. The distribution of the burden of care is a way to avoid abusive relationships. The ideal is the establishment of care networks, in which primary caregivers are supported by secondary caregivers and so on, with responsibilities redistributed across the community.

(iv) **relationality**: the relational character of care involves the need for reciprocal and free acceptance between the caregiver and the person receiving care. The relational view of care emphasizes the interdependence inherent to human beings, giving rise to mutualism.

The affective and voluntary nature of care may suggest alternative forms of legal approach, but it hardly justifies the mere disregard of legal protection in a just and supportive society. The care relationships developed in the family nucleus are of interest to the State not only because they comprise an unavoidable dimension of human existence, but also because such care directly impacts on the costs and responsibilities incumbent on it as a guarantor of the right to health and well-being of citizens.

It is interesting to mention some existing relationships between the care approach and the capacities approach of Amartya Sen⁴⁸ and Martha Nussbaum⁴⁹. This approach deals with the development of the human being based on the consideration of their **functioning**, understood as beings and doings typical, and their **capabilities**, understood as the substantive freedom to choose, among beings and doings, those that will be effectively undertaken in the achievement of individual life projects.

Nussbaum emphasizes the importance of addressing capacities in understanding gender inequality. To place at the focus of the discussion, from its inception, access to the capacities for being and doing individual makes it possible to identify and face the inequalities to which women are subjected in access to resources and opportunities, from the most intimate and family spheres to the public sphere. In contrast, it is very evident the role that care, in the perspective treated in this article, has for the effective development of basic functions and individual substantive

⁴⁸ SEN, Amartya. O desenvolvimento como expansão de capacidades. *Lua Nova*, São Paulo, n. 28-29, p. 313-334, 1993. Available at: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-64451993000100016. Accessed on: 06 Jun. 2018. <http://dx.doi.org/10.1590/S0102-64451993000100016>.

⁴⁹ NUSSBAUM, Martha C. *Creating capabilities: the human development approach*. Harvard: Belknap Press, 2011.

capacities. Nussbaum⁵⁰ states that the ways of dealing with human need and dependency, compatible with the self-respect of recipients and, at the same time, which do not exploit caregivers, are a central issue for gender justice and women's effective access to functions and the free exercise of capacities.

It is noteworthy that two important points of connection between the capacities and care approaches are: the central role that both confer on the agency in the execution of life projects; and the legal protection that they advocate to the sphere of individual and family relationships as relations that unquestionably reverberates in the public sphere. Thus, models that reject State intervention to what they call the public sphere, neglect the protection and legal support for care within families.

In summary: the perspective of care developed in the legal sphere demands the transposition of the formalistic, liberal and procedural paradigms of law to achieve its relational paradigm. The care thus seen, due to the vulnerability and the intersubjective dependence inherent to every human being, departs from the usual perception of care as an overrogatory action or "female virtue", restricted to the private sphere, to acquire contours of central value of society to have repercussions in the public sphere and require legal protection. The four markers of care activity listed by Herring - (i) need; (ii) respect; (iii) responsibility; (iv) relationality - allow the conformation of the care relationship as a reciprocal responsibility relationship, between caregivers and recipient of care, to be encouraged, protected and guaranteed by legal provisions in all branches of law.

Final Considerations

Almost four years after the identification of the first cases of congenital Zika virus syndrome in Brazil, the facts seem to confirm the statement by Débora Diniz⁵¹ in 2016, when the international health emergency ended, that women were forgotten as the main victims of the epidemic. Although in this period there was the persistence of scientific and academic interest, with a significant volume of publications, mostly in the epidemiological field⁵²; the impacts of the epidemic on the lives of families and women has lost its place in the news and political pronouncements.

The Continuous Cash Benefit (BPC), announced as a measure to face the epidemic, although it deserved some efforts to streamline the specific demand by the INSS, did not receive any initiative to circumvent the insufficient coverage reported

⁵⁰NUSSBAUM, Martha C. Capabilities as fundamental entitlements: Sen and social justice. *Feminist Economics*. UK, v. 9, n. 2-3, p. 33-59, 2003. <https://doi.org/10.1080/1354570022000077926>.

⁵¹DINIZ Debora. *Zika: do sertão nordestino à ameaça global*. Rio de Janeiro: Civilização Brasileira, 2016.

⁵²ALBUQUERQUE, Maria de Fatima Pessoa Militão de et al. Epidemia de microcefalia e vírus Zika: a construção do conhecimento em epidemiologia. *Cad. Saúde Pública*, Rio de Janeiro, v. 34, n. 10, 14p., 2018. Available at: <http://www.scielo.br/pdf/csp/v34n10/1678-4464-csp-34-10-e00069018.pdf>. Accessed on: 30 Mar. 2019. <http://dx.doi.org/10.1590/0102-311x00069018>.

in this article. On the contrary, in March 2019, when this article was written, it was considered to reduce the amount of the benefit, in the midst of the ongoing pension reform project⁵³. In addition, the BPC may also be affected by the abandonment of the policy of actual earnings of minimum wage, with annual readjustments limited to the inflationary replacement⁵⁴.

Between 2015 and 2018, state actions in the health field were punctual, focused mainly on the diagnosis and clinical care for children⁵⁵, cannot identify initiatives aimed at the broader social support of affected families and women or the protection of the care relationship, in the sense advocated in this article.

The incidence of congenital Zika virus syndrome in the most socially unprotected population in Brazil dramatically highlights the role of the family nucleus as a care locus to face long-term effects, as well as the need for external support to the family. The benefits of this protection can be evidenced in the practice of the civil associations that supported the affected families. The context and practice of these associations should give rise to a broad reassessment of the ethical and legal perspectives of the relational paradigm of care and its possibilities, its limits and its challenges, as described in the article.

The personal and voluntary action of care is an essential and inevitable aspect of human existence, crucial for survival, emotional well-being and the identity of individuals and groups. In the ethical field, the ethics of care brings the moral significance of the relational nature of the human being, refractory, therefore, to an exclusively individualistic conception of interest and well-being. The ethics of care recognizes and emphasizes the individual and reciprocal responsibility existing in care relationships, and its overflow to a life in society through care networks.

The ethical relevance of the care thus outlined is reflected in the requirement for its legal protection. State regulation in the different branches of law is called to recognize and protect reciprocal care relationships, aware of the repercussions they represent for the public interest and for the stability of the political community. The recognition and legal protection of care relationships is a task that, due to the peculiarities exposed in this article, represents a current challenge to society and to the State.

⁵³ BARBOSA, Bernardo. Modelo atual do BPC é insustentável e precisa mudar, diz Mourão. *UOL*, 26 mar. 2019. Available at: <https://economia.uol.com.br/noticias/redacao/2019/03/26/mourao-bpc-reforma-da-previdencia.htm>. Accessed on: 31 Mar. 2019.

⁵⁴ TEMÓTEO, Antonio. Governo deve propor reajuste do mínimo só pela inflação, sem ganho real. *UOL Economia*, 29 mar. 2019. Available at: <https://economia.uol.com.br/noticias/redacao/2019/03/29/salario-minimo-reajuste-orcamento.htm>. Accessed on: 31 Mar. 2019.

⁵⁵ MONITORAMENTO integrado de alterações no crescimento e desenvolvimento relacionadas à infecção pelo vírus Zika e outras etiologias infecciosas, até a Semana Epidemiológica 52 de 2018. *Boletim Epidemiológico*, Secretaria de Vigilância em Saúde, v. 50, n. 8, mar. 2019. Available at: <https://portalarquivos2.saude.gov.br/images/pdf/2019/marco/22/2019-001.pdf>.

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