

Reflecting on the judicialization of health in chronic non-progressive encephalopathy

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Abstract

The Brazilian Federal Constitution of 1988 established health as a right of all and a duty of the State, which is responsible for implementing economic and social policies aimed at reducing health problems in the population. This article presents a theoretical reflection, based on the literature on the subject, and aims to discuss the challenges and perspectives of the judicialization of access to health for patients with chronic non-progressive encephalopathy undergoing treatment in the Unified Health System. The judicialization of public health due to weaknesses in the administration and distribution of the services offered by the system grew exponentially in Brazil. The judicialization of health care for people with disabilities, especially those diagnosed with chronic non-progressive encephalopathy, is little addressed in the scientific environment, but understanding the difficulties faced by this population helps in the formulation of public policies.

Keywords: Health's judicialization. Brain diseases. Cerebral palsy. Right to health. Unified Health System. Occupational therapy.

Resumo

Reflexão sobre judicialização da saúde na encefalopatia crônica não progressiva

A Constituição Federal brasileira de 1988 instituiu a saúde como direito de todos e dever do Estado, a quem cabe implementar políticas econômicas e sociais que visem à redução de agravos na saúde da população. Este artigo apresenta uma reflexão teórica, com apoio na literatura sobre a temática, e tem o objetivo de discutir desafios e perspectivas da judicialização do acesso à saúde realizada por pacientes com encefalopatia crônica não progressiva em tratamento no Sistema Único de Saúde. No Brasil houve aumento exponencial da judicialização na saúde pública devido a fragilidades na administração e na distribuição dos serviços oferecidos pelo sistema. A judicialização da saúde por parte de pessoas com deficiência, em especial com diagnóstico de encefalopatia crônica não progressiva, é pouco abordada no ambiente científico, entretanto compreender as dificuldades enfrentadas por essa população auxilia na formulação de políticas públicas.

Palavras-chave: Judicialização da saúde. Encefalopatias. Paralisia cerebral. Direito à saúde. Sistema Único de Saúde. Terapia ocupacional.

Resumen

Reflexión sobre la judicialización de la salud en la encefalopatía crónica no progresiva

La Constitución Federal brasileña de 1988 estableció la salud como un derecho de todos y un deber del Estado, que es el responsable de implementar las políticas económicas y sociales para reducir los problemas de salud en la población. A partir de la literatura sobre el tema, este artículo reflexiona teóricamente sobre los desafíos y perspectivas de la judicialización del acceso a la salud realizada por pacientes con encefalopatía crónica no progresiva bajo tratamiento en el Sistema Único de Salud. Brasil tuvo un incremento de la judicialización en la salud pública debido a las carencias en la administración y distribución de los servicios ofrecidos por el sistema. Aunque la judicialización de la salud por parte de las personas con discapacidad, principalmente con un diagnóstico de encefalopatía crónica no progresiva, es poco tratada en la literatura, comprender las dificultades que enfrenta esta población puede ayudar en la formulación de políticas públicas.

Palabras-clave: Judicialización de la salud. Encefalopatías. Parálisis cerebral. Derecho a la salud. Sistema Único de Salud. Terapia ocupacional.

The authors declare no conflict of interest.

Prior to the creation and implementation of the Unified Health System (SUS), health care was not considered a universal right for Brazilians, and state action in this area was limited to fighting endemic diseases or offering care exclusively to workers with a formal employment relationship¹. This period was marked by the unequal division of society into a structure in which the rich could pay for their own health care while workers with formal employment used healthcare services offered by the social security system. Those without formal employment relied on charity or selective public health programs when in need of health care².

In 1988, the 8th Brazilian Federal Constitution (FC) was promulgated, setting new parameters to be followed by the state in the sphere of public health. The guarantee of health is now understood by the interrelationship between social determinants such as food, education, housing, social security, security, employment and leisure, among others. To this end, the FC set forth in Article 196 the government's duty to design public policies to ensure the provision and maintenance of access to free health care for all who need it, without discrimination:

Health is the right of all and a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and other hazards and at universal and equal access to actions and services for its promotion, protection and recovery³.

In order that this right could be enjoyed by citizens, the Unified Health System was created by the 1988 Federal Constitution. Since then, the entire Brazilian population has had access to healthcare services through this system, which is considered one of the largest and best in the world and provides services ranging from outpatient care to complex procedures, such as surgeries⁴.

The SUS offers services and actions administered at the three levels of government—municipal, state and federal—and is also complemented by private services. Article 198 of the FC states that the SUS is a set of integrated public services that should be organized in a hierarchical and regionalized manner through three pillars: decentralization, with a single management at

each level of government; comprehensive care; and community participation³.

The SUS was fully implemented following the promulgation of Law 8080/1990, known as the Organic Health Law, which aims to define the conditions for the promotion, protection and recovery of health, as well as the organization and operation of the services⁵. Thus, the system is guided by doctrinal principles that express its ideology—universality, comprehensiveness and equity—and follows organizational principles that determine its mode of operation: hierarchy, regionalization, popular participation and decentralization.

The doctrinal principle of universality determines that all Brazilian citizens, without any kind of discrimination, have the right to access healthcare actions and services. Comprehensiveness has a multiple nature, as it considers the individual as a whole, ensuring that all their needs are met and the provision of healthcare services occurs in a continuous and coordinated fashion in order to further actions for promotion, prevention, treatment and rehabilitation³.

The principle of equity aims to reduce social differences in the country. To this end, it recognizes the needs of individuals and minority social groups and offers healthcare services that can mitigate social injustices. Besides the universal right to health, the 1988 FC introduces many innovations, such as the Brazilian democratic state, new political, administrative and institutional frameworks, and social rights³.

Divided into three spheres—fundamental, social and economic—social rights have undergone an expansion, especially with regards to health care as a safeguarded right for every citizen, with the state charged with supporting everyone without any kind of discrimination. In this context, the SUS is considered a victory in the history of democracy, as it guarantees social rights to the population. However, there is still much to be done in its implementation, as there are weaknesses in the system that harm the population^{6,7}.

In this context, it is noteworthy that historically, the SUS has faced challenges imposed by the public funding required to guarantee the right to health. The 1988 FC provides that SUS funding should come from the social security budget, the federal

government, the states, the Federal District, the municipalities and other sources. However, it was only in 2000, with Constitutional Amendment (CA) 29, that the obligation of the three levels of government to fund the SUS was agreed on and stable funding sources were determined, in an attempt to avoid crises⁸.

Therefore, states are now obliged to allocate a minimum of 12% of their tax revenue; municipalities, 15%; and the federal government, the amount allocated in the previous year adjusted for the nominal variation of the gross domestic product (GDP)². Thus, CA 29/2000 marks the beginning of earmarked funds for health, contributing to the increase in resources allocated to public healthcare actions and services, which in 2000 equaled 2.9% of the GDP, rising to 4.1% in 2017².

In 2015, CA 86 mandated the execution of individual parliamentary amendments and established that the minimum federal resources for health would now be calculated based on the federal government's net current revenue (NCR), starting with 13.2% in 2016 to reach 15% in 2020⁹.

These changes were a consequence of the earmarking of municipal and state revenues, as previously all resources came solely from the federal government. However, the SUS has never had the level of funding compatible with universal systems so as to guarantee the principles established in the 1988 FC².

Thus, health spending in Brazil equals 8% of the GDP, half of which consists of private expenditures. However, international evidence indicates that public spending committed to the universalization of health systems must be equal to or above 70% of the sector's total expenditure, i.e., Brazil is more than 20 percentage points below the expected level².

In this sense, there is a growing number of legal actions against the state in the current Brazilian health scenario. This phenomenon is called judicialization of the right to health and is characterized by the need to resort to the Judiciary to guarantee access to health services¹⁰.

The *World Report on Disability*, published by the World Health Organization¹¹, estimates that more than 1 billion people have some form of disability, around 15% of the world's population,

based on 2010 data. The report points out that the number of people with a disability tends to grow as the population ages, considering the increase in chronic health conditions associated with disabilities, such as diabetes, cardiovascular diseases and mental illnesses.

Article 1 of the Convention on the Rights of Persons with Disabilities, held in 2006 by the United Nations, defines disability as follows:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others¹².

This definition shows that people with disabilities face disabling obstacles in various spheres: ineffective public policies; exclusionary attitudinal barriers from an individual, structural and social perspective; and environmental barriers that hinder social participation. "Disability" is a concept in constant evolution, resulting from the interaction between people with disabilities and the barriers that prevent their full social participation on equal terms with others¹³.

Chronic non-progressive encephalopathy (CNPE) is the most common disability in childhood, with a prevalence of 2.1 cases per thousand live births. It occurs due to injuries to the still immature brain, causing neurological changes that affect child development in both sensory-motor and cognitive aspects. The clinical picture includes a heterogeneous group of clinical conditions that demonstrate central motor dysfunction, with changes in muscle tone, posture and movement¹⁴.

Although there is a great number of people with some kind of disability, there are not enough statistical studies focused on them, which leads to a dearth of public policies designed and implemented for this population. Also, as Brazil is strongly marked by social inequality, it is important to rethink the access of people with disabilities to the health system¹⁵, since the inclusion process for these people happens gradually—and it must be acknowledged they have been neglected for many years. Therefore, the development of public policies is necessary to guarantee constitutional rights.

Law 13,146/2015, the Brazilian Law for the Inclusion of Persons with Disabilities (Statute of Persons with Disabilities), is a milestone in safeguarding social rights, as it ensures and promotes equality and the exercise of fundamental rights and freedoms by people with disabilities. This law aims at social inclusion and citizenship, contributing to access to health as a fundamental right and providing accessibility to all places and services¹³.

It is also important to highlight that in 2002, the National Health Policy for Persons with Disabilities was published by the Brazilian Ministry of Health, establishing the following general purposes:

To protect the health of persons with disabilities; to rehabilitate persons with disabilities in their functional capacity and human performance, contributing to their inclusion in all spheres of social life; and to prevent conditions that lead to the emergence of disabilities¹⁶.

However, even though there is a political movement to ensure access to health care, people with disabilities still face disadvantages in having full access to the SUS, which often leads them to take legal action to obtain the care they need¹⁷. In this context, the goal of this study was to theoretically discuss the challenges and perspectives of the judicialization of health access by patients diagnosed with CNPE undergoing treatment in the SUS.

Method

This is a reflective article that proposes a discussion about the challenges and perspectives of the judicialization of health access by patients diagnosed with CNPE undergoing treatment in the SUS. To this end, documentary research was carried out in secondary databases, with an analytical, descriptive and retrospective approach, in which the full content of legal proceedings related to the treatment and care of patients with CNPE by the SUS was analyzed.

The reflective methodology is grounded in the close relationship between knowledge and how it is produced. Thus, linguistic, social, political and theoretical elements that contribute

to the development of knowledge suggest that researchers should have a critical view of what is established as certain. In addition, they should make sure that the results of the work undertaken are able to enhance knowledge and provide opportunities for reflection, as opposed to pursuing absolute truths in a given scientific field¹⁸.

The reflective methodology has two main characteristics: interpretation and reflexivity. The first trait agrees that any reference to knowledge arises from an interpretation of reality; in other words, it rejects the simplistic concept that observations, interviews or other information are merely representations of reality¹⁸. According to this methodology, research and its results are socially promoted processes through the negotiation of their meanings. The second trait involves different actors, such as researchers, the community, society, cultural and intellectual traditions, as well as the multiple narratives that pervade the research process¹⁸.

Persons with disability: chronic non-progressive encephalopathy

For a long time, people with disabilities were defined by Western thought as beings to be feared and despised, labeled as abnormal and seen as invalids or monsters. It was even common for circuses to display such individuals as attractions. There was also the view that they were degenerate beings who were the target of divine wrath or the result of some miracle, and their fate was often early death, especially in congenital cases¹⁹.

In a context of oppression of so-called abnormal bodies, the neologism “disablism” was created, which reflects the understanding that bodily impediments justify oppression and discrimination. However, although disability studies began late in the fields of social sciences and humanities, the discussion of the social model of this condition led to a redefinition of what disability is and what it means to be a person with a disability, concepts previously seen as defining something outside the norm²⁰.

Given the above, what can be considered normal? What should be classified within normality or so-called abnormality? Normality is understood as a way of biomedically dictating the standard

functioning of the species and a moral condition for productivity and regulation of social norms. Therefore, understanding disability goes beyond a biomedical concept, as it is related to the oppression of bodies with functional differences²⁰.

In the social context, negative attitudes and violations of the rights of this population are apparent, such as negligence and psychological, physical, property, sexual and institutional violence. Since this is the result of a social and ideological construction throughout history, disability must be viewed from a political perspective, so that public policies aimed at this social segment can be designed^{20,21}.

Among the ways disability may manifest—in the motor, auditory, visual or intellectual system, among others—is CNPE, better known as cerebral palsy, which is the most common cause of disability in early childhood. It is characterized by a heterogeneous group of non-progressive clinical syndromes that includes changes in movement, muscle tone and posture. It occurs in the process of brain development, i.e., in an immature brain^{22,23}.

This condition also causes sensory, communicative, perceptual and behavioral dysfunctions and seizures, leading to difficulties in performing functional and daily life activities²³. Therefore, a person with CNPE requires specialized services (physical therapy, speech therapy, occupational therapy, neurology), differentiated therapies (hippotherapy, hydrotherapy, TheraSuit) and supplies/medicines (diapers, wheelchairs, adapted beds, anticonvulsants, among others).

Judicialization of the right to health

The 1988 FC, in Articles 196 to 200 (Title VIII, Chapter I, Section II), provides that health is a social and fundamental right and sets forth elements that define principles, funding sources, structure and the responsibilities of the different levels of government under the adopted health model. Article 196, in particular, reinforces the universal nature of the health system and the state's commitment to guaranteeing it through social and economic policies³.

Moreover, Article 227 of the FC states that it is the duty of the family, society and the state to guarantee children, adolescents and young people,

with absolute priority, the right to life, health and nutrition, among other social rights. In addition, the Statute of the Child and Adolescent (Law 8,069/1990), in Article 4, stresses that the legislator has given urgency to the guarantee of priority, which translates into: 1) primacy of receiving protection; 2) service precedence; 3) preference in the formulation and execution of public social policies; and, lastly, 4) privileged allocation of public resources in areas related to the protection of children and youth²⁴.

Given the above, health is understood as a subjective right and of immediate applicability, allowing for legal action when the state fails to comply with what is legally provided. Therefore, the possibility of judicial protection has led to the phenomenon of the judicialization of health, which aims to ensure access to healthcare services through the Judiciary²⁵.

The increasing intervention of the Judiciary in the SUS is striking at different levels of health care offered by the system. As pointed out by Paula, Silva and Bittar²⁶, according to the Ministry of Health, the SUS is one of the largest public health systems in the world and its actions and services include outpatient care, organ transplants, drug control and implementation of health promotion policies, among other services. Therefore, the action of the Judiciary in the SUS is extensive and not limited to a single aspect, but rather encompasses all services offered and even administrative acts, such as, for example, bidding processes for the purchase of goods and services²⁶.

Judicial intervention is carried out by all bodies of the Judiciary, as provided in Article 92 of the FC. In other words, it involves from trial courts to the Federal Supreme Court, the highest body of the Judiciary, whose responsibility, set forth in Article 102 of the FC, is to give the final word regarding the interpretation and application of constitutional provisions. Therefore, the Judiciary's interference in the SUS occurs when the right to health is at risk. Judicial intervention in the SUS is justified by failures, mismanagement, omission and neglect of the state in guaranteeing minimum health conditions to the population²⁶.

There are two lines of technical-scientific debate on the judicialization of health and its consequences. The first considers that this

phenomenon does not guarantee the effectiveness of the collective right to health, and should therefore be avoided; the second claims it is a tool that favors the expansion of citizenship and the strengthening of democracy²⁷.

The arguments that legal action does not improve access to health are based on the view that intervention in the SUS would increase the lack of equity in access to health services. It would confer an advantage to social groups with greater power to demand services, meeting the needs of individuals or privileged groups to the detriment of other social groups and individuals. Another argument is that the judicialization of health strongly impacts the public administration, the public budget and issues of equality of rights^{28,29}.

On the other hand, there is an understanding that the two lines of debate do not necessarily oppose one another, since judicialization is a means to expand the social rights of the population and contribute to strengthening democracy. However, it is necessary to observe how this phenomenon is occurring and its future repercussions, considering that it could generate marked inequality in access to health goods and services for the less privileged population²⁷.

In the legal framework prior to the 1988 FC, the operating guidelines for public health care were merely technical-scientific and administrative. Following the integration of health as a universal right and duty of the state, the legal sector started being called upon to guarantee access to health services. Thus, ensuring that patients receive comprehensive SUS care became an argument to turn many unmet needs in the public system into lawsuits³⁰.

In addition, according to Fleury³⁰, the federal government has been contributing less and less to the SUS, which goes against Article 26 of the 1969 American Convention on Human Rights, which provides that governments should act to promote economic, social and cultural rights. However, what is observed is that the representation of the federal government is increasingly reductionist.

Therefore, when the right to health became universal, there were no longer any prerequisites for it to be enjoyed, other than the state providing the necessary means. However, it is a fact that the SUS survives under adverse financial conditions, which jeopardizes the equal distribution of quality services. Certainly, it is the discrepancy between

legislation and reality that causes the so-called judicialization of politics³⁰.

The judicialization of politics represents the strengthening of democracy and social inclusion, as it is a means of guaranteeing rights. However, this phenomenon can be considered the result of the negligence of the Legislative and Executive Powers. The former is inefficient in defining the legal framework and the latter is ineffective in agreeing on norms or standards to prevent the deterioration of state institutions, which therefore are not held accountable for patients' difficulties to receive health care. Fleury³⁰ uses the expression "counter-right to health" to refer to this circumstance.

Thus, the judicialization of health may be the greatest ally of the SUS, and the branches of government should act to correct social inequities and promote respect and recognition of differences, aiming at progressive funding and resource redistribution. Therefore, it is clear that the judicialization of health should not be opposed, but rather prevented from becoming yet another cause of social inequity, a criterion that supports the right and public administration³⁰.

It is worth noting that CA 95/2016³¹ harmed access to social rights, including the right to health, by freezing primary public spending for twenty years, resulting in an unprecedented measure in Western capitalist countries and a real blow against the SUS. The approval of this amendment stagnated social spending and in its early years increased social inequalities in Brazil^{31,32}. However, in 2023, CA 95/2016 was revoked, reinstating the federal constitutional floor for the SUS at 15% of the minimum current revenue, previously established by CA 86/2015⁹.

Final considerations

The SUS is an achievement of the entire Brazilian society, establishing a commitment to guarantee everyone access to health goods and services, free of charge and with no discrimination of any kind. Therefore, it is a state policy aimed at increasing social rights and guaranteeing the enjoyment of citizenship. However, the exponential increase in the judicialization of health in Brazil exposes the fragility of the administration and distribution of services offered by the SUS.

It was also observed that the judicialization of health for people with disabilities, especially those diagnosed with CNPE, is hardly addressed in the scientific milieu. In this context, a broad understanding of persons with disabilities and their difficulties in accessing SUS services may help in designing new public policies for this population.

This study shows the social and political relevance of the subject, as it addresses the defense of the right to access health, the formulation and implementation of public policies and the understanding of the complexities implicit in the judicialization process. Thus, it contributes to the reflection on judicialization carried out by people with CNPE to ensure their right to health.

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Received: 1.9.2024

Revised: 5.2.2024

Approved: 6.3.2024