White Paper

Stroke:

The Silent, Hidden Crisis Afflicting Our Society

Stroke: The Silent, Hidden Crisis Afflicting Our Society

This document was elaborated by a coalition of experts in cerebrovascular diseases, including researchers and health economists, under the coordination of Associação Brasil AVC (Stroke Brazilian Association), with the endorsement of the following stroke support associations:

Associação Brasil AVC

JOINVILLE/SC

MACEIÓ/AL

LAGOA SANTA/MG

CUIABÁ/MT

BRUSQUE/SC

MONTES CLAROS/MG

STROKE IS YOUR PROBLEM...

Mr(s). businessman, as Stroke is a cause of long periods of work leave.

Mr(s). trader, as Stroke is a cause of impoverishment of families, and this reduces consumption.

Mr(s).health manager, as Stroke is a cause of increased public health costs.

STROKE is OUR problem, as a society!
Considering that **1 in 4 people around the world** will have a Stroke, and it is the most disabling disease in Brazil, we must implement solutions to avoid or lessen its consequences on the families and the community.

Abstract:

Stroke is a chronic condition with significant social and economic implications, requiring an holistic care model that goes beyond the acute phase treatment. This approach must include prevention strategies, emergency treatment and rehabilitation, in addition to social and professional reintegration, all supported by a rigorous quality and outcome monitoring system. It is imperative that government agencies, healthcare providers and healthcare managers help in the implementation of integrated, patient centered policies to ensure an effective and truly humanized care.

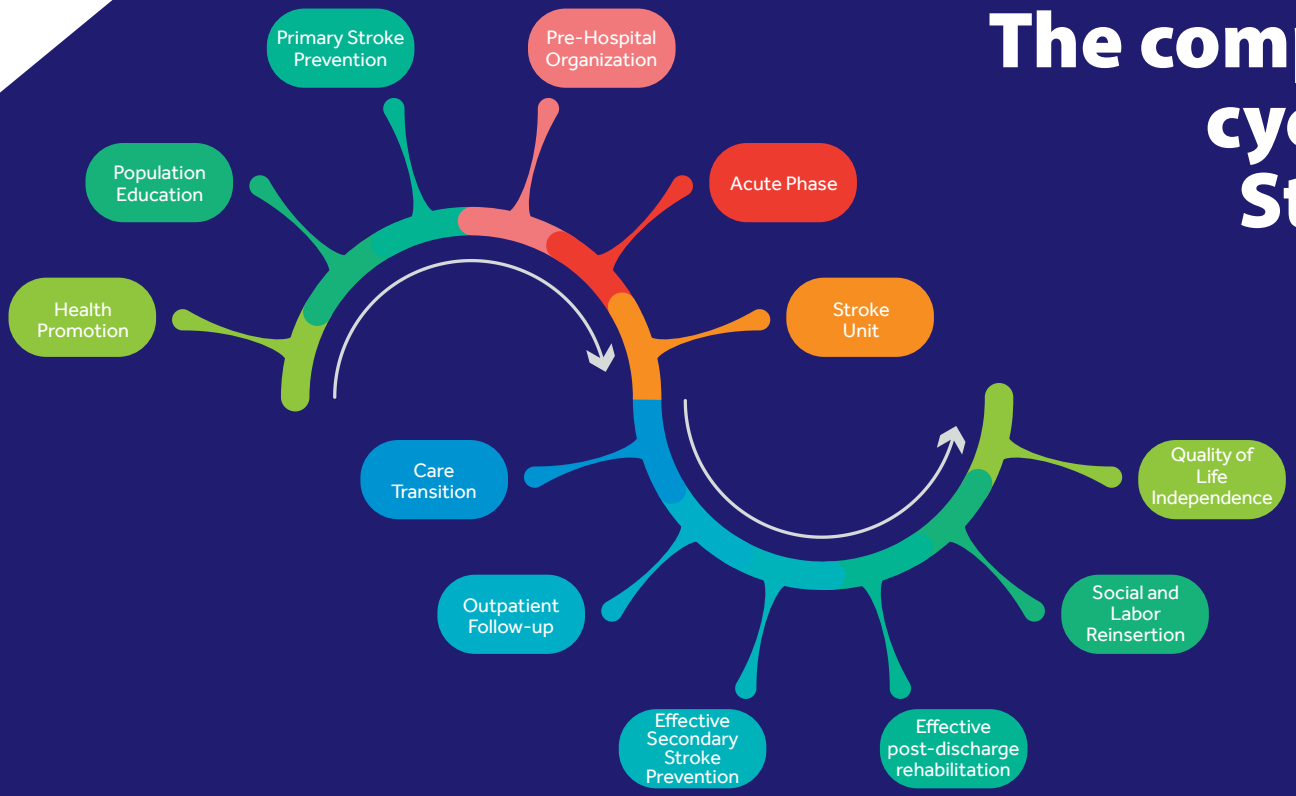
Introduction:

Despite significant advances in the treatment of stroke over the last three decades, this condition remains the second leading cause of death and disability worldwide. Approximately a quarter of the population will be affected by a stroke during their lifetime, and half of survivors will face some type of chronic disability[1].
In the Brazilian context, the situation is even more complex. Stroke care is hampered by multiple factors, including faulty health education[2], access limitations, variable quality of care in different places, treatment fragmentation throughout the patient journey, lack of robust data, and unsustainable resource allocation.
Amid significant advances in the structuring of emergency services for the treatment of the acute phase of stroke, we still face worrying gaps that transcend the hospital environment and permeate the sphere of prevention, post-discharge monitoring and patient life quality. The alarming fact that stroke has resumed its position as the main cause of death in Brazil in 2022, according to the National Civil Registry, is not a mere statistical indicator; it is a wake-up call that resonates as a public health crisis and a blunt reflection of our social reality.

The stroke care cycle must be integrated and continuous, pertinently applying the best evidence-based practices that are also cost-effective. This wide-ranging strategy goes from primary prevention — with interventions aimed at modifiable risk factors — to the use of multidisciplinary stroke units and acute phase therapeutic approaches. Furthermore, it extends to secondary prevention and ensures patient access to effective rehabilitation programs, aimed at restoring functionality and improving life quality.

This wide-ranging approach is crucial for meeting the complex needs of each person affected by the disease, providing care that is both humanized and rigorously based on best health practices.

The complete cycle of Stroke care



This transformation is not just desirable; it is necessary to maximize the health value delivered to the population and to effectively address one of the greatest health challenges of our time.
Recent studies by Joinvasc indicate that a stroke is associated with a reduction of almost 9 years in life expectancy and a total cost of R$ 134.000 (One hundred thirty-four thousand reais). What makes the situation even more serious is that around 70% of these costs are indirect, that is, they are under the responsibility of patients and their families.

Stroke is not just a medical statistic or a hospital cost; it is a human tragedy that reverberates through individuals, families, and communities. This white paper proposes to shed light on the tangible and intangible costs of this growing crisis, with special attention to the impacts on quality and life expectancy, transcending the limited vision that focuses only on the "acute phase" of the disease.

The Growing Stroke Crisis[3] in the World:

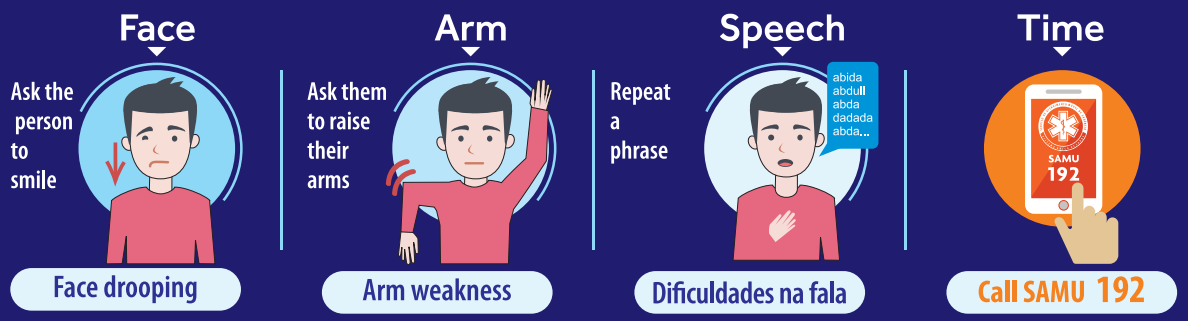
- **Incidence:** Increase of **70%**
- **Prevalence:** Increase of **85%**
- **Mortality:** Increase of **43%**

These numbers underscore the critical need to address the stroke crisis that worsens with each passing year.

Acute Stroke: An Emergency That Requires a Larger view

In stroke management, one of the mottos is "time is brain". In a case of an ischemic stroke with occlusion of a large artery, for every minute without treatment, around 2 million neurons, on average, are lost[4]. This data emphasizes the urgency of diagnosis and intervention. It is crucial that the general population and healthcare professionals immediately recognize symptoms suggestive of stroke: crooked mouth indicating facial paralysis, weakness on one side of the body denoting hemiparesis or hemiplegia, and difficulty speaking, whether due to dysarthria or aphasia. The presence of any of these symptoms require an emergency evaluation at a specialized center for the diagnosis and treatment of stroke.

Signs and symptoms indicative of an acute stroke.



Acute Stroke Management is Essential, But an Effective Strategy Goes Beyond and Requires Health Policies that Cover the Entire Cycle of Care:

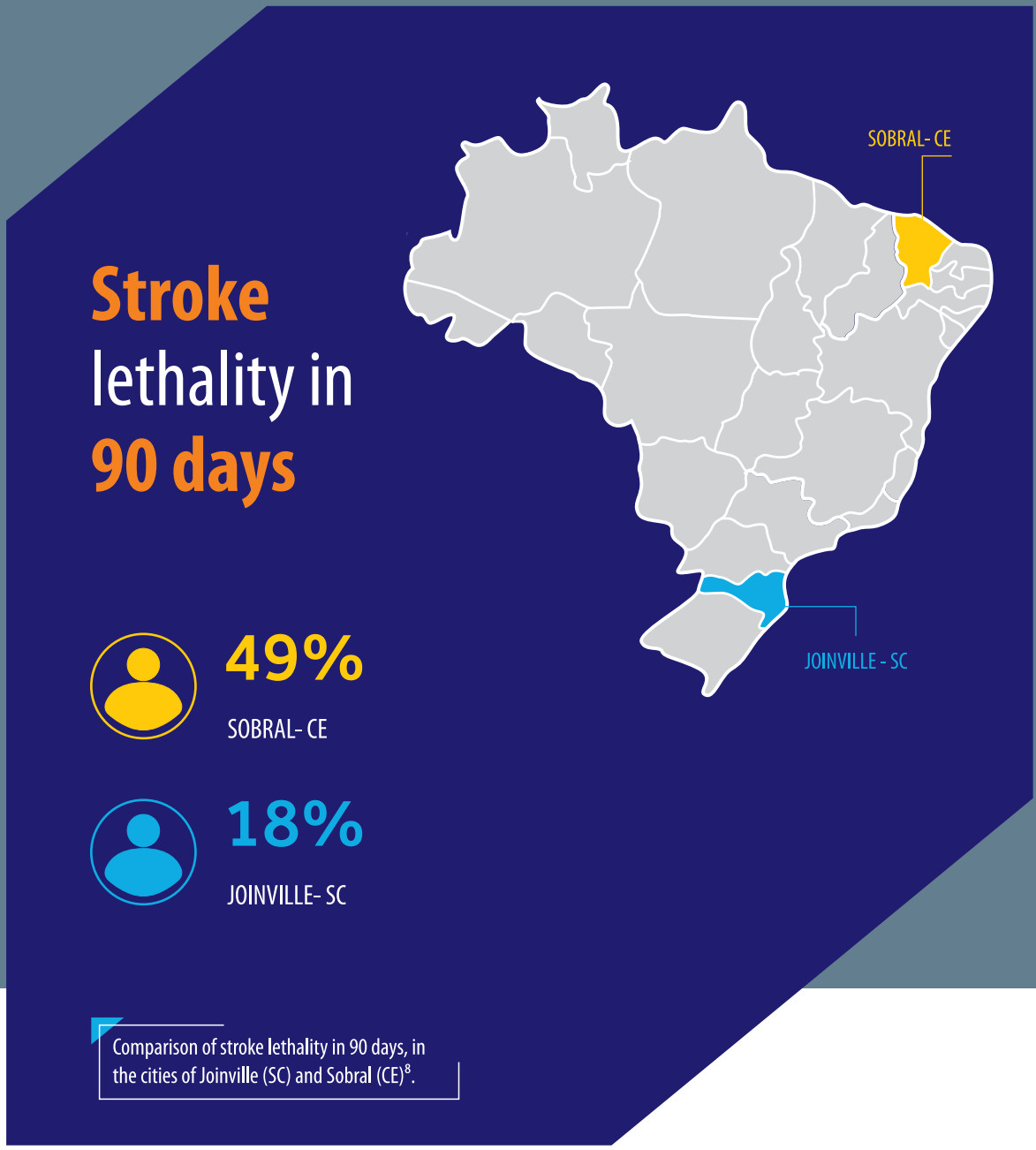
In Brazil, recent advances in the organization of state of the art services for acute phase management, unfortunately, did not take into consideration the challenges faced by the population in the prevention of stroke, in the transition of care after hospital discharge, in the access to rehabilitation and in strategies of secondary prevention[5,6]. These gaps, that have most often been beyond the scope and responsibility of stroke centers, operators and healthcare professionals, reduce the possibilities of prevention and full recovery.

Disability caused from a stroke often stays with an individual for the rest of their lives. However, current assessment of success in stroke treatment tends to focus on in-hospital clinical results or in the first 90 days post-event. This approach is insufficient. To truly understand the impact of stroke, it is essential that we look beyond the acute phase and consider the long-term outcomes that really matter to those affected by the disease. This means evaluating the journey of all individuals affected by a stroke, regardless of where or whether they were treated. Only such an inclusive perspective will give us a clear vision of the efficiency of our healthcare systems in tackling cerebrovascular diseases.

In Stroke, Geography is Destiny

An innovative study conducted by "Academia VBHC" illustrates the big disparity in access to acute-phase stroke treatment in Brazil (Atlas of Variation in Health: Brazil[7]). Although since 2012 the country's public health policy has encouraged the use of acute phase therapies, including differentiated remuneration for hospitalizations and administration of thrombolytic treatment, the reality is disturbing. The study reveals that an alarming number of around 154 (One hundred fifty-four) million people (or 87.6% of Health Regions) live in areas where intravenous thrombolysis is applied in less than 1% of stroke cases.

The inequity in access to stroke care in Brazil is highlighted by recent data from the Joinvasc program, which reveals striking disparities in mortality rates in different regions. In Joinville, Santa Catarina, the post-stroke mortality rate in a period of 90 days is 18%, while in Sobral, Ceará, this number jumps to 49%[8].



Comparison of stroke lethality in 90 days, in the cities of Joinville (SC) and Sobral (CE)[8].

The negligence in updating SUS stroke care policies, established in 2012, is reflected in a cruel reality for the population. Around 30% of patients, those with cerebral ischemia caused by occlusions of large arteries, remain without treatment alternatives. In 2023, we still lack a policy that ensures access to mechanical thrombectomy, one of the most significant advances in medicine, with proven effectiveness in improving outcomes and reducing mortality. The most severe cases of stroke, without the intervention of mechanical thrombectomy, present seriously increased rates of mortality and neurological disability, imposing an economic and social burden of an alarming magnitude in the society and in the health system. Currently, only around 1.4% of stroke victims who require mechanical thrombectomy have access to the procedure in Brazil[9], with most of these procedures being carried out in the private sector. This gap amplifies the population catastrophe of stroke, becoming a portrait of inequality and the urgency of rethinking our public health policies.

The Cost of Stroke:

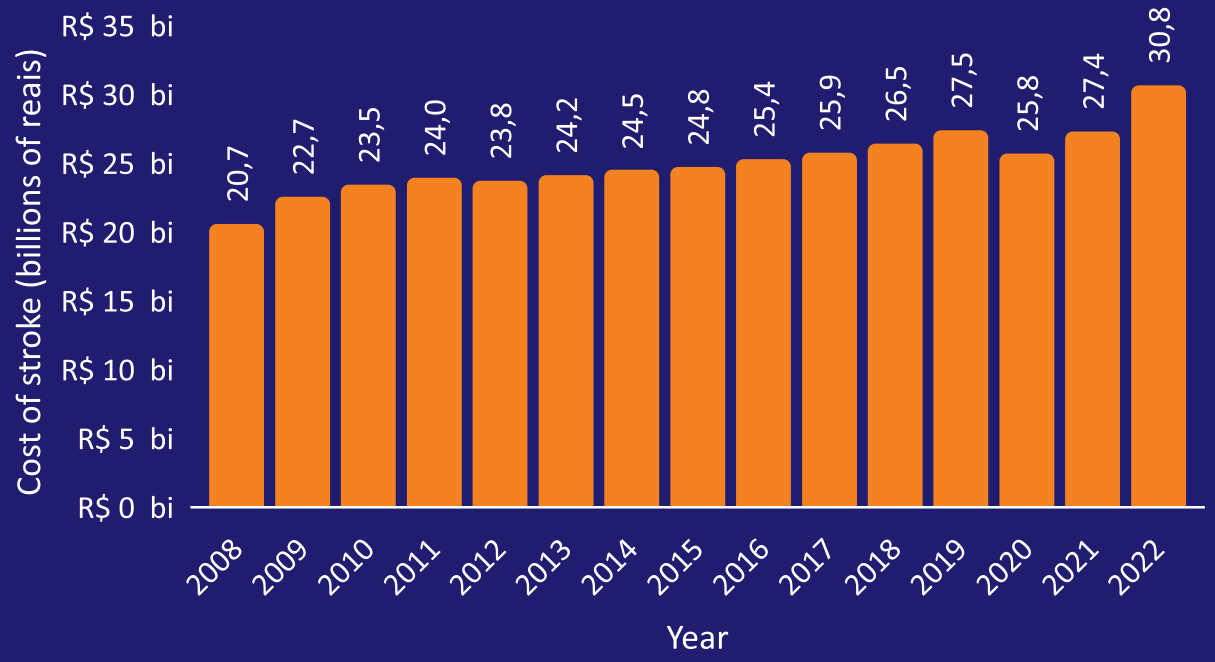
Understanding the true cost of stroke requires a multidimensional approach that considers the financial, social and emotional impact of the disease in the individuals and their families. This emphasizes the need for comprehensive policies that aim not only at the treatment, but also at prevention and rehabilitation, contributing to improve the population's life quality.

Economic studies on the financial impact of stroke reveal that, in Western countries, the costs associated with the disease can consume 3 to 4% of the total health budget[10], percentage of which, with the aging of the population, tends to increase[11]. In the USA, the annual cost is predicted to jump from US$ 105.2 (one hundred and five point two billion dollars) in 2012 to US$ 240.7 (two hundred and forty point seven billion dollars) by 2030[12]. In 2017, Europe spent approximately € 60 (sixty) billion euros on stroke[13].

The financial cost and social impact of cerebrovascular diseases in Brazil are on an alarming rise. Annually, SUS records 113 hospitalizations for stroke per 100,000 (one hundred thousand) inhabitants. It is worth noting that this statistic does not consider data from private hospitals or unregistered cases and deaths. This reality translates into a devastating burden: in 2022 alone, the direct and indirect costs of stroke in Brazil were estimated as an impressive 30.8 (thirty point eight) billion reais.

The cost of stroke in Brazil

The true tragedy of stroke, however, manifests itself in an individual level. A pioneer study of the Joinvasc program revealed that the average cost of stroke per patient reaches R$ 134,050.00 (one hundred thirty-four thousand fifty reais). This amount is not just a figure: it hides personal stories full of struggles, suffering and admirable human resilience. To fully understand the personal and economic impact of stroke, it is vital to analyze these costs into their individual components.



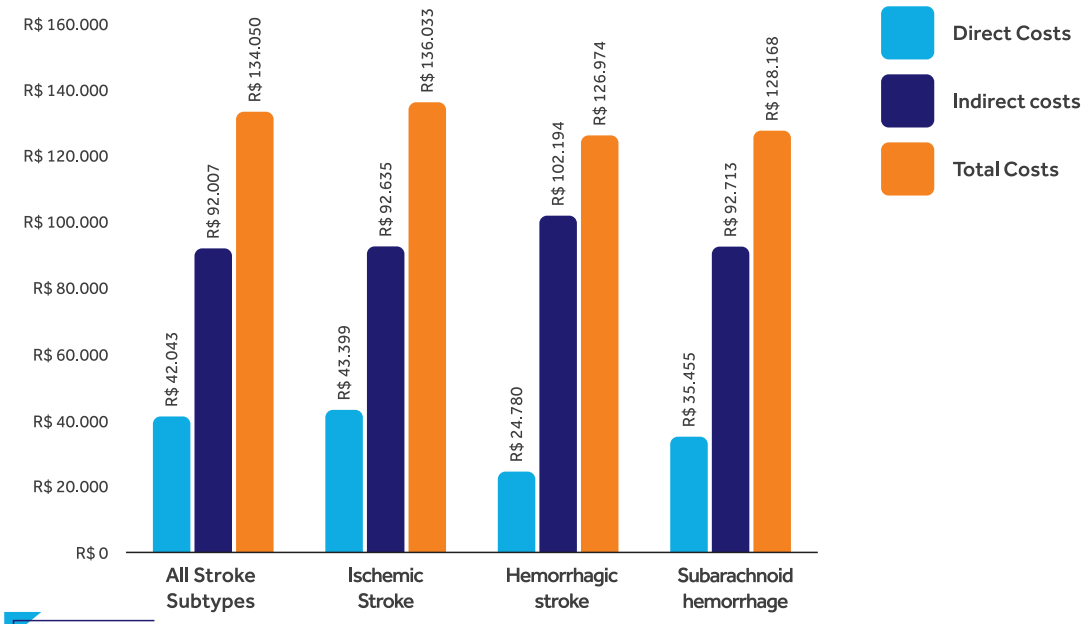
Escalation of total stroke costs in Brazil, source "Academia VBHC"

The True Personal and Economic Cost of Stroke : R$ 134.050,00

(one hundred thirty-four thousand and fifty reais).

Cost Breakdown:

- → **Direct Costs (supplied by the health system): 31,4%**
  - → First Hospital Admission: 10.6%
- → **Indirect costs (paid by the patient): 68.6%**
  - → Loss of Productivity: 56.2%



Comparison of direct costs (provided by the health system), indirect costs (paid by the person) and total costs of different stroke subtypes.

About 70% of the total cost related to stroke is on the patient, their family and their community

These are indirect costs. Of this percentage, 56.2% are linked to loss of productivity throughout the patient's life. This burden not only affects the individual's ability to contribute economically to society, but also has significant impacts on the social context and family structure.

The Decrease of Life Quality and Expectancy:

Stroke not only impacts the economy, but also causes a considerable reduction in Quality-Adjusted Life Expectancy, or QALY. In concrete terms, each occurrence of ischemic stroke, which is the most common type, causes an average loss of 7.48 QALY and a decrease of 8.88 years in the individual's life expectancy.[14]

How Much Does a Stroke REALLY Cost?

JOINVASC Stroke Program

The outcome that really matters to those who suffer a stroke is hidden from us.

We rarely witness the impact on patients, their families and communities.

Loss of QALY and years of life after ischemic stroke, hemorrhagic stroke and subarachnoid hemorrhage.

*QALY (Quality Adjusted Life Expectancy): An indicator used to measure the impact of a disease on the quality and expectancy of life of an individual.

The Hidden burden of Stroke

In addition to the tangible economic impacts, there is a "hidden cost" of stroke, which permeates deeper aspects of human existence, revealing a face of suffering and anguish that cannot be quantified monetarily.

The pain of human suffering, isolation, loss of independency, family breakdown. These are lives interrupted and dreams shattered. These intangible costs are rarely quantified in economic studies, but they are what most affect the patient and their loved ones.

The biggest impact of stroke,is often intangible:

- Anxiety and pain
- Social isolation
- Depression
- Worsen in life quality
- Prejudice and social stigmas
- Disruption of family bonds

Main Recommendation:

To significantly improve access to stroke prevention, treatment and ongoing care, we directly call on government agencies, healthcare providers and healthcare managers, to develop and implement integrated and holistic policies aiming comprehensive stroke care. These policies must go beyond the mere provision of acute phase treatments, covering the entire spectrum of care — from effective prevention to rehabilitation and reintegration into the social and professional sphere. To ensure high-quality care, it is crucial to establish a robust system for monitoring the quality of care. This system must meticulously track and evaluate outcomes that are directly relevant to affected individuals, thus promoting the incremental improvement of humanized care, which is centered on the patient's needs and sustainable.

To achieve a truly transformative approach, we propose the following actions:

- **Ensuring Equitable Access:** Structure policies and resource allocation that ensure universal and equitable access to all phases of stroke care, regardless of geographic location, socioeconomic status or any other barriers.
- **Continuous Care Approach:** Implementing strategies that cover all stages of stroke — from effective prevention, treatment in the acute phase, to rehabilitation and social and professional reintegration.
- **Strengthening Prevention Strategies:** Launching educational campaigns and awareness programs to rigorously control risk factors and promote healthy lifestyles, with a focus on underserved or at-risk communities.
- **Optimization of Treatment in the Acute Phase:** It is essential to institute evidence-based protocols to ensure that patients receive immediate treatment in specialized hospital centers, capable of stroke management. These institutions should offer dedicated multidisciplinary teams, stroke units, and rapid access to reperfusion therapies for ischemic stroke, such as intravenous thrombolysis and mechanical thrombectomy. Furthermore, they must be able to provide surgical and endovascular management of hemorrhagic stroke. The adoption of these practices not only improves patients' life quality, but also demonstrates a significant reduction in the costs associated with stroke.
- **Investing in Full Rehabilitation:** Creating rehabilitation programs dedicated to meeting patient's needs during the transition from the hospital environment to chronic outpatient treatment is crucial. These programs must use a multidisciplinary and humanized approach, aiming at functional recovery and improving life quality.
- **Institute Monitoring for Patient-Relevant Outcomes:** Developing a robust monitoring system that meticulously evaluates both clinical outcomes and patient experience and satisfaction in order to continually improve the standard of care.

Conclusion:

In this white paper, our goal is more than simply instigating deep reflection; it is fostering collective action to face the emerging stroke crisis in Brazil. It is crucial to understand that stroke is not just a matter of statistics and diagnoses; it has a devastating impact on human lives, disrupting families and seriously compromising the quality and life expectancy of millions of people. Furthermore, most of this financial burden falls precisely on those affected by the disease. This is a direct call to recognize the urgent need for more effective preventive and therapeutic measures that can mitigate both the human suffering and the economic burden associated with stroke.

To overcome this crisis, we need an holistic and integrated approach. This ranges from acute treatment to proven preventive actions, including individualized rehabilitation plans and support mechanisms for reintegration into professional and community life. This is not only a medical and social imperative, but also a moral and economic one.

Therefore, we call on all sectors—governments, the healthcare industry, healthcare professionals, communities and every citizen—to gather forces in joint and immediate action against stroke. Together, we have the power to not only ease the overwhelming impact of this condition, but also to build a healthier and more resilient future for our country.

The need is pressing; The time to decisively act is now.

References:

1. Collaborators TG 2016 LR of S. Global, Regional, and Country-Specific Lifetime Risks of Stroke, 1990 and 2016. New Engl J Med 2018;379(25):2429–37. 10.1056/nejmoa1804492
2. Cabral NL, Longo A, Moro C, et al. Education Level Explains Differences in Stroke Incidence among City Districts in Joinville, Brazil: A Three-Year Population-Based Study. Neuroepidemiology 2011;36(4):258–64. 10.1159/000328865
3. Owolabi MO, Thrift AG, Mahal A, et al. Primary stroke prevention worldwide: translating evidence into action. Lancet Public Heal 2021;7(1):e74–85. 10.1016/s2468-2667(21)00230-9
4. Saver JL. Time Is Brain--Quantified. 2005;37(1):263–6. 10.1161/01.str.0000196957.55928.ab
5. Brasil M da S do. PORTARIA No. 665, DE 12 DE ABRIL DE 2012. 2012; https://bvsms.saude.gov.br/bvs/saudelegis/gm/2012/PRT0665_12_04_2012.html.
6. Brasil M da saúde do. PORTARIA No 664, DE 12 DE ABRIL DE 2012. 2012; https://www.saude.go.gov.br/images/imagens_migradas/upload/arquivos/2014-05/linha-cuidado-iam-rede-atencao-urgencia2012-portaria-664.pdf.
7. VBHC A. Atlas de Variação em Saude Brasil - Academia VBHC. 2022. https://www.academiavbhc.org/atlas.
8. Santos E dos, Wollmann GM, Nagel V, et al. Incidence, lethality, and post-stroke functional status in different Brazilian macro-regions: The SAMBA study (analysis of stroke in multiple Brazilian areas). Front Neurol 2022;13:966785. 10.3389/fneur.2022.966785
9. Asif KS, Otite FO, Desai SM, et al. Mechanical Thrombectomy Global Access For Stroke (MT-GLASS): A Mission Thrombectomy (MT-2020 Plus) Study. Circulation 2023;147(16):1208–20. 10.1161/circulationaha.122.063366
10. Katan M, Luft A. Global Burden of Stroke. Semin Neurol 2018;38(02):208–11. 10.1055/s-0038-1649503
11. Kolominsky-Rabas PL, Heuschmann PU, Marschall D, et al. Lifetime Cost of Ischemic Stroke in Germany: Results and National Projections From a Population-Based Stroke Registry. Stroke 2006;37(5):1179–83. 10.1161/01.str.0000217450.21310.90
12. Ovbiagele B, Goldstein LB, Higashida RT, et al. Forecasting the Future of Stroke in the United States: A Policy Statement From the American Heart Association and American Stroke Association. Stroke 2013;44(8):2361–75. 10.1161/str.0b013e31829734f2
13. Luengo-Fernandez R, Violato M, Candio P, Leal J. Economic burden of stroke across Europe: A population-based cost analysis. European Stroke J 2019;5(1):17–25. 10.1177/2396987319883160
14. Diegoli H, Magalhães PSC, Makdisse MRP, et al. Real-World Populational-Based Quality of Life and Functional Status After Stroke. Value Heal Reg Issues 2023;36:76–82. 10.1016/j.vhri.2023.02.005

TECHNICAL RESPONSIBILITIES:

PEDRO MAGALHÃES CRM/SC 12558

HENRIQUE DIEGOLI CRM/SC 19824

PRODUCED BY:

Associação Brasil AVC

Find out more about **ABAVC!**

www.**abavc.org**.br

@abrasilavc

@abavcoficial

ACADEMIA VBHC®

Find out more about **ACADEMIA VBHC!**

www.**academiavbhc**.org

@company/academiavbhc

@academiavbhc/