

# Profile of neurologists in Brazil: a glimpse into the future of epilepsy and sudden unexpected death in epilepsy

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The main focus of a nation's health system revolves around the development of effective strategies and new options of treatment, with the aim of preventing or even reversing human diseases (1). The spectrum of disorders of the brain, part of the central nervous system (CNS), is large, covering hundreds of disorders that are listed in either the mental or the neurological disorder chapters of established international diagnostic classification systems. Brain disorders account for the majority of short- and long-term impairments and disabilities (2). As such, the best available estimates of the prevalence and cost per person for 19 groups of brain disorders in Europe have been reported (2). In brief, the total cost of brain disorders is estimated at €798 billion (2). Furthermore, the European per capita cost of brain disorders is €1550 on average but varies by country (2). The costs (in billion €PPP 2010) of the included brain disorders are as follows: mood disorders €113.4; dementia: €105.2; psychotic disorders: €93.9; anxiety disorders: €74.4; addiction: €65.7; stroke: €64.1; headache: €43.5; mental retardation: €43.3; sleep disorders: €35.4; traumatic brain injury: €33.0; personality disorders: €27.3; child/adolescent disorders: €21.3; somatoform disorder: €21.2; multiple sclerosis: €14.6; Parkinson's disease: €13.9; epilepsy: €13.82; neuromuscular disorders: €7.7; brain tumor: €5.2 and eating disorders: €0.8 (2).

Leading scientific journals and primary funding agencies suggest that neuroscience is the most rapidly growing field within the biomedical sciences in the world (1). For Latin American countries, especially Brazil, these assertions are especially relevant. For example, Nitrini conducted a study in 2006 that assessed the evolution of scientific production by 295 Brazilian clinical neuroscientists from 1995 to 2004 (3). The author showed that more than 40% of the Brazilian papers were published in *Arquivos de Neuro-Psiquiatria*, the official journal of the Brazilian Academy of Neurology, and that epilepsy was one of the sub-areas with the highest scientific production (3). The growing number of publications on epilepsy detected in this study may be a

consequence of several well-established factors. By definition, epilepsy is a transient occurrence of signs and/or symptoms due to abnormal, excessive, or synchronous neuronal activity in the brain (4). Furthermore, epilepsy is considered to be the most common serious neurological condition. Epilepsy knows no geographic, social, or racial boundaries, it occurs in both men and women, and it affects people of all ages, though it more frequently affects young people in the first two decades of life and people over the age of 60 (5,6). Epilepsy has a prevalence of approximately 1% in developed countries; each year, 24 per 100,000 persons suffer from this neurological condition in Europe and 53 per 100,000 in North America (1,3,7-9). The incidence of epilepsy is higher in developing countries compared to industrialized countries, with up to 190 affected individuals per 100,000 people (10,11). Epilepsy is considered a serious chronic disease, with a number of factors that negatively affect the quality of life of these individuals. Stigma and exclusion have become common global features of epilepsy (5,12,13). In addition, physical, psychological, and social consequences are very severe, as seizures may cause fear, misunderstanding, secrecy, stigmatization, and social isolation (5,12,13).

Additionally, we must not fail to mention that, unfortunately, epilepsy is associated with a high rate of premature death compared with the general population (14,15). Sudden unexpected death in epilepsy (SUDEP) is the most common epilepsy-related category of death, accounting for 7.5% to 17% of all deaths in people with epilepsy and 1:500 to 1:1,000 patient-years among adults (14-18). The main risk factors described thus far are the presence or number of generalized tonic-clonic seizures (GTCS), nocturnal seizures, young age at epilepsy onset, long duration of epilepsy, dementia, the absence of cerebrovascular disease, asthma, male gender, the symptomatic etiology of epilepsy, and alcohol abuse (14,15,18-21). Regarding epilepsy causal factors, experimental and clinical studies suggest that respiratory and cardiovascular abnormalities during and after seizures and genetic factors likely contribute to SUDEP risk (19,20,22-27). Obviously, it is extremely difficult to estimate SUDEP occurrence. However, discovery and careful evaluation of new risk factors, greater specificity regarding mechanisms, and the development of effective preventive measures may help prevent the occurrence of fatal events in affected individuals. Along these lines, proposals for future research that expand on existing clinical, genetic, and basic science research and that support the education of health care practitioners and people with

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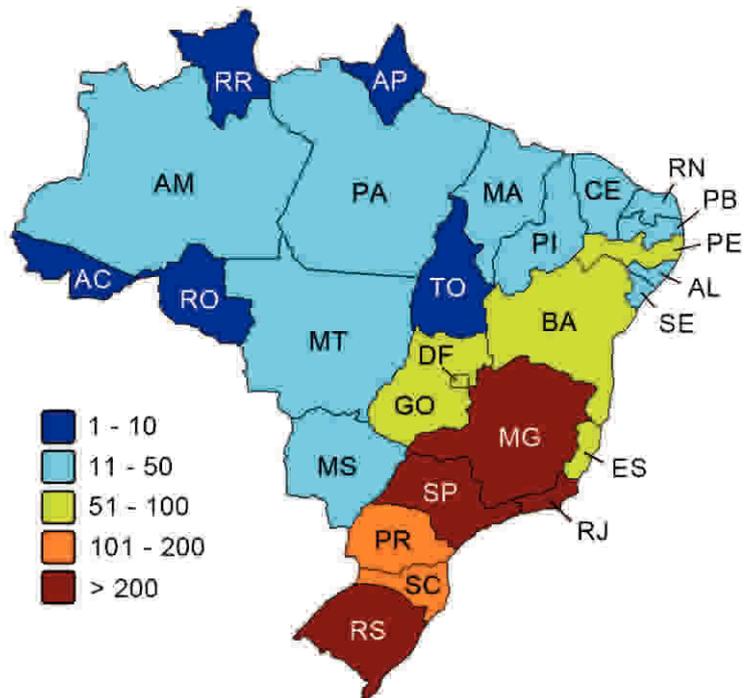
epilepsy will be of great value for advancing our understanding of SUDEP and, ultimately, our capacity to prevent it (28,29).

Despite the effort, dedication, and enthusiasm of all neuroscientists, we are not yet fully prepared to implement all of the proposals suggested thus far. For example, one area that merits further consideration is whether and when to talk about SUDEP with patients, family members, and caregivers. Although epileptologists have not yet established a global consensus on this subject (30,31), recent studies suggest that providing information about SUDEP to individuals, relatives, and caregivers is most likely more beneficial than harmful in most cases (32). We recently evaluated a survey of the current practice of all 293 epileptologists officially accredited at the Brazilian League of Epilepsy (LBE) (33). Unfortunately, the participation rate was very low, as only 44 professionals answered the questions (33). Of these, 14% of epileptologists discussed SUDEP risk with the majority of their patients, 76% with a minority of their patients, and 10% with none (33).

Interestingly, of all such professionals who discuss SUDEP with a minority of their patients, approximately half of them (44%) discussed the possible occurrence of SUDEP when patients asked about it (33). It should be noted that although the data obtained in our study are consistent with the current literature, the low participation of Brazilian epileptologists in our assessment is an issue that should be reviewed and discussed. This disinterest becomes more worrisome when we evaluate the report recently developed by the Brazilian Federal Council of Medicine (34) (Figure 1). In brief, the report notes that Brazil has a total of 2629 neurologists, the vast majority of whom (approximately 80%) are concentrated in the south and southeast parts of Brazil. Thus, a number of questions must be answered: 1 – How can individuals with epilepsy in regions with extremely low numbers of neurologists be monitored and treated? 2 – How can campaigns be created in these regions to demystify and reduce the stigma that exists against people with epilepsy? 3 – Is it possible to create tertiary epilepsy centers in regions with low numbers of neurologists? 4 - How

**Absolute number of neurologists in Brazil, 2011**

Abbrev.	States	Nr.
AC	Acre	1
AL	Alagoas	21
AP	Amapá	2
AM	Amazonas	14
BA	Bahia	97
CE	Ceará	50
DF	Distrito Federal	83
ES	Espirito Santo	57
GO	Goiás	80
MA	Maranhão	13
MT	Mato Grosso	21
MS	Mato Grosso do Sul	27
MG	Minas Gerais	270
PA	Pará	22
PB	Paraíba	25
PR	Paraná	177
PE	Pernambuco	92
PI	Piauí	14
RJ	Rio de Janeiro	324
RN	Rio Grande do Norte	19
RS	Rio Grande do Sul	251
RO	Rondônia	6
RR	Roraima	1
SC	Santa Catarina	111
SP	São Paulo	828
SE	Sergipe	20
TO	Tocantins	3
<b>TOTAL</b>		<b>2629</b>



Regions	Nr.	Percent
North	49	1.86%
Northeast	351	13.35%
Midwest	211	8.03%
Southeast	1479	56.26%
South	539	20.50%

**Figure 1 - Absolute numbers of neurologists in Brazil; obtained from the Report of Medical Demography in Brazil - General Data and Descriptions of Inequalities, Volume 1 (Brazilian Federal Council of Medicine; Regional Council of Medicine of São Paulo, December 2011).**



can we create research institutes in these regions? 5 – Can discussions regarding SUDEP take place with these professionals? Despite the existing difficulties, the vast majority of epileptologists located in the south and southeast actively participate in experimental and clinical epilepsy studies, including SUDEP. In this regard, this series of questions and proposals could stimulate the 293 accredited epileptologists in LBE to create an intense task force in poorer regions. We realize that this venture is not easy, but it is certainly feasible. We have qualified and credentialed professionals that are ready to initiate and invest in collaborations. With sustained focus and fundraising for epilepsy and SUDEP research in both children and adults, the future is very promising (28). As the American physicist Robert Hutchings Goddard said: “Just remember - when you think all is lost, the future remains”.

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### AUTHOR CONTRIBUTIONS

Scorza F, Amorim H, Scorza C, Cavalheiro E, and Albuquerque M drafted the manuscript, reviewed for English grammar and spelling, designed the study, interpreted the text, and drafted the manuscript. All the authors read and approved the final submitted version for publication.

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