

The Cost of Brain Diseases: A Burden or a Challenge?

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Brain diseases represent a considerable social and economic burden in Europe. With yearly costs of about 800 billion euros and an estimated 179 million people afflicted in 2010, brain diseases are an unquestionable emergency and a grand challenge for neuroscientists.

The Cost of Brain Disorders in Europe: The Grand Challenge

Brain research is at the forefront of science but extensive work is still needed to understand brain functioning at molecular, cellular, and system levels as well as to unravel the pathogenesis of complex brain diseases. Brain research and brain diseases are relatively new terms. The former covers neuroscience, neurological, and psychiatric research and the latter includes disorders that might be classified as neurological or psychiatric, even though they can be also cared for by other specialists and general physicians. Both terms are better understood by decision makers and the general public and were therefore proposed by the European Brain Council (EBC), an alliance of all major European organizations interested in the brain and its diseases. FENS, the Federation of European Neuroscience Societies, has been a major supporter and partner of EBC since its inception and has participated in a long and successful drive to increase the support of brain research in Europe.

There is no way to escape from the fact that brain disorders are a major public health problem in Europe and the rest of the world. The World Health Organization (WHO) global burden of disease study and two major pan-European studies on the cost of brain disorders were of seminal importance in disclosing this major challenge. They demonstrated that, beyond doubt, brain disorders are the major public health problem in Europe and all other high-income countries.

Brain diseases were included in the global burden of disease study by the WHO (World Health Organization, 2008;

Murray and Lopez, 1997), and the burden of brain disease was collected in a single article in 2003 (Olesen and Leonardi, 2003). It showed that brain diseases are responsible for 35% of Europe's total disease burden. This figure was, however, calculated in terms of so-called DALYs, or disability-adjusted life years, which is difficult for politicians and other decision makers relate to and understand.

In 2003, the EBC decided to fill this knowledge gap by providing sound estimates of the cost of as many brain disorders as data would allow for all of Europe. Since data for each disease were only available in a few countries, a health economic model was developed using the imputation of missing values. The calculations were based on the cost of a given disorder in one single person for 1 year and the 1-year prevalence of the disorder. More than 100 epidemiology and health economic experts made the best-possible estimates from existing data. Prevalence and cost values were given as a European mean using all available national data since no global European information was available. Values were then calculated for all European countries and multiplied with their population to give the total cost in each single country; these values were added up to provide the total European cost. This first cost study (Andlin-Sobocki et al., 2005) was prevalence based and it estimated the cost of a given brain disease for a single year, namely 2004. It included 12 major brain disorders, some traditionally classified as psychiatric, some as neurologic. Because data were considered too weak for the inclusion of other brain diseases at the time, several major disorders were

left out. A major category excluded for lack of accurate data was represented by child and adolescent disorders as well as mental retardation. The document included both direct and indirect costs of diseases. Two types of direct costs were analyzed. All costs related to health care, such as hospital care, doctor's visits, and drugs, regardless of who pays—the individual, a private insurer, or the public through taxes and social insurance—were intended as the direct health care cost. Costs outside the medical sector, both private and public, such as nursing home costs and assistance given through the municipality to compensate for limitations in function caused by dementia, multiple sclerosis, or schizophrenia or private costs for adapting to the disorders, in terms of services or goods, formed the direct nonmedical costs. Indirect cost included the days that can be taken off work due to illness, no matter if this means a short-term absenteeism from work or early retirement. Presenteeism, intended as limitations in one's work capability while at work, was not evaluated as it was considered too uncertain.

Following this accurate methodology, the above study already pointed out that, in 2004, 127 million European citizens were living with a brain disorder, for a total annual cost of 385 billion euro. Psychiatric disorders accounted for 62% of the total cost, while the remaining 38% were caused by neurological diseases including dementia. These data highlighted that brain disorders were more costly than cardiovascular disorders or cancer. The results of this study were made available to the European

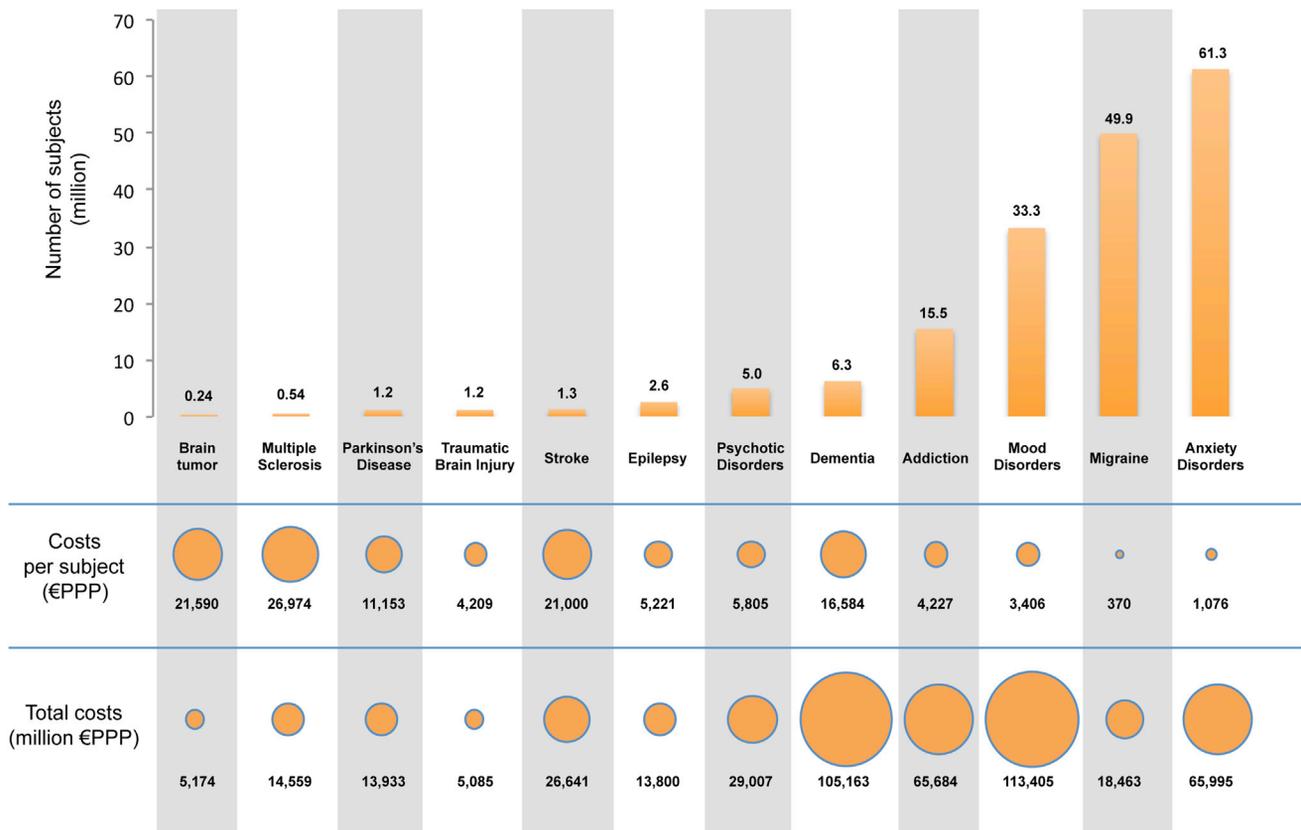


Figure 1. Cost of Disorders of the Brain in Europe in 2010

Commission before the finalization of the European framework program for research and technological development (7FP, 2007–2013), and they probably played a major role in the Commission's decision to make brain research one of the European priorities of FP7.

Given the limitation of the data that were collected in 2004, EBC committed a new report, which was published in 2010 (Gustavsson et al., 2011; Olesen et al., 2012). This new study intended to present updated, comprehensive, and accurate estimates of the costs of brain disorders in 30 European countries with a population just over 500 million. The number of disorders for which data were sufficient for inclusion increased from 12 in the 2004 study to 19 in this new study (seven disorders were newly considered, namely specific eating disorders (anorexia and bulimia nervosa), child and adolescent disorders, i.e., attention deficit and hyperkinetic disorders, conduct disorders, mental retardation, personality disorders, sleep disorders, as

well as neuromuscular). Furthermore, a number of cost items for several disorders, which were missing in the first study, became available in 2010, making the cost estimates more complete also for the previously included diseases. The methodology of the study was otherwise the same. One-third of all European citizens—179 million people—had at least one brain disorder, an astonishing figure even if many had only minor disorders such as anxiety or tension-type headache. The total European 2010 cost of brain disorders was 798 billion euro per year, of which in average direct health care costs represent 37%, direct nonmedical costs 23%, and indirect costs 40%.

Mood disorders and dementia represented the most costly diseases for European society, as demonstrated in the 2004 study. However, when compared with the latter, these disorders increased up to 113.4 and 105.2 billion euros/year, respectively. The new study showed that the cost per subject with a

certain brain disorder is highly variable. For instance, the cost per subject for brain tumors is 33,900 euros, whereas the one for migraine is about 662 euros. Indeed, neuromuscular disorders and brain tumors are low in terms of prevalence but highly costly per patient. Mood disorders and dementia are both common and costly. Migraine and anxiety are highly prevalent but at the same time the cost per subject is rather low (Figure 1).

There is a large difference in the distribution of cost categories among the 19 major brain disorders; dementia has the highest proportion of direct nonmedical cost (84%), whereas personality disorders and headache have the highest proportion of indirect costs, 78% and 79%, respectively (Figure 2).

A total amount of 798 billion euros per year represents a huge amount and some might fear an exaggeration. On the one hand, despite all efforts, the so-called double counting, i.e., counting cost of a patient with two diseases twice, may not

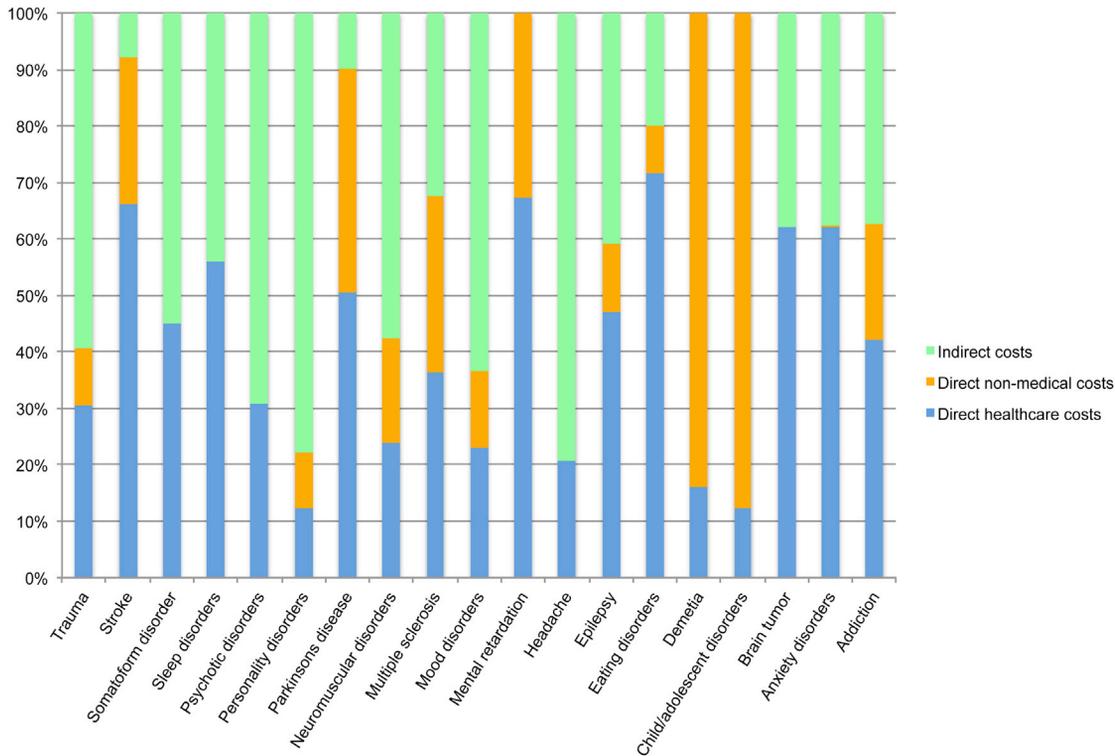


Figure 2. Relative Direct Health Care, Direct Nonmedical, and Indirect Cost in Europe of 19 Brain Disorders

have been totally avoided. On the other, there are hundreds of less prevalent brain disorders that could not be included for lack of data. Many of them are very costly per patient and the omission adds up to a considerable amount that easily offsets any double counting of included disorders. The cost estimate was thus considered a relatively conservative one. A tentative comparison with other major diseases (although not always possible or correct due to the limited data available) indicates that cardiovascular disorders account for 192 billion euro per year (The European Heart Network, <http://www.ehnheart.org>), and the cost of cancer has been estimated between 150 and 250 billion/year (Wilking et al., 2006).

Based on these cost data, which were validated with many other studies on single disorders (see, for example, Wimo et al., 2011 for dementia; Wittchen and Jacobi, 2005 for addiction; Kleinman et al., 2003 for bipolar disorders; Kotsoopoulos et al., 2001 for epilepsy; Pelham et al., 2007 for child disorders), it is clear that brain diseases are the current and

future major health economic challenge for Europe.

The Challenge: How to Change the Numbers?

Brain disorders can represent a ticking bomb under Europe's economy due to their enormous societal costs, which are set to grow with the aging of the European population. Addressing these large costs for the society requires an intensified research and novel solutions. To face this societal emergency, we need to develop a strong network for both basic and clinical brain research.

Despite these major challenges and the efforts of the scientific community in Europe, we are still struggling against the discrepancy between the huge societal impact of brain diseases and the modest financial and time resources that are allocated to brain research, teaching, and care.

Far more research than what we are currently performing is needed to get into the causes and developmental pathways of brain diseases, for their diagnosis, prevention, and treatment.

FENS, in collaboration with EBC and its partners worldwide, supports advocacy to identify brain research as a priority on all political agendas, both at national and international levels. It is our belief that only a coordinated program to increase the support to research efforts in the field can succeed in our ambitious endeavor, which is to relieve the burden of brain disorders through a better understanding of the brain. We are strongly convinced that the promotion of basic research will, in the future, provide new therapeutic and diagnostic tools to help patients with brain-related diseases. It is therefore FENS's main goal to promote neuroscience in Europe at all levels, by bringing together scientists of diverse backgrounds and by maintaining the engagement of European funding agencies in supporting basic brain research as well as research into brain-related diseases.

The EBC effort to estimate burden of disease and cost of illnesses was and still is particularly useful in this scenario. The data from the above-mentioned studies are often reported and used in the discussion of priorities, such as

decisions on access to health care and investments in research and development. It is necessary to state that such priorities are complicated and that other types of information are important. In our view, the present data can be exploited to illuminate key policy decisions, which include investment in research and development as the main instrument for reducing the burden and cost of brain diseases. It is important for Europe not only to use existing resources in an efficient and equitable manner, but also to contribute to the development of new knowledge to improve the situation. This is a long-term vision with significant implications not only for health care but also for economic development.

But are the previous and current investments in brain research not sufficient? A systematic study commissioned by EBC has provided us with seminal data to tackle this issue. The study (Sobocki et al., 2006) estimated both public and private spending on brain research and the results were depressing. Comparing the costs to research funding, brain research was clearly underfunded. An attempt was also made to analyze the possible cost/benefit ratio of increased investment in brain research and it was shown to be a highly profitable investment for society.

How would society benefit from increased funding on brain research? To answer this question, 200 experts produced a Consensus document on European brain research, which has been recently published in its second edition (Di Luca et al., 2011). The research needed to fill the gap was discussed under 45 headings in a highly structured format. Each theme was dealt with by a multidisciplinary group, consisting of a basic scientist, a neurologist or a psychiatrist, a patient representative, and a scientist from industry. Each two-page

description of a theme ended with a specific explanation of the benefits to European society.

Now, the most irrelevant question is: was all this useful? These efforts have been extremely successful. The European Commission provided extensive support for brain research in FP7. Brain research, and rightly so, was considered a priority to be endowed with the necessary, dedicated financial resources. More than two billion euros have been dedicated to brain-related research since 2007, with a yearly allocation of more than 300 million euros. Such investment supported the foundation of a novel and active community dedicated to brain research, which has joined forces to reach an unsurpassed and essential multidisciplinary effort. We are getting closer to cures, but we have not got there yet.

The challenge remains and there is the need to confront it. We can profit from the already developed highly multidisciplinary context, favoring the continuation of an active research community with high levels of collaboration and knowledge across discipline borders and respecting a fair balance between basic and applied research. With the development of new working documents of the European Commission Horizon 2020, and the start of influential European programs such as "The Human Brain Project" FET flagship and complementary international programs such as the U.S. Human Brain Initiative, we believe the intellectual capital on brain research that was previously seeded can expand and move forward, hopefully bridging the gap between knowledge and cure in the medium-term schedule.

Note: this article reflects presentations at a Special Interest Event on Global Advocacy, at the ninth FENS Forum of Neuroscience in Milan, July 8, 2014, 18:45, where we will discuss the need of

advocacy strategies for brain research in relation to the increasing cost of brain disease and the negative influence of the global financial crisis on funding.

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