

Brain disorders and treatment gaps—non-treatment carries the greatest cost burden

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Up to eight out of 10 people living with a brain disorder remain untreated or inadequately treated, even though effective therapies exist. What are the barriers to optimal treatment? Is it really unaffordable to grant people with brain disorders access to the best medical and psychosocial care? These questions were at the heart of the Value of Treatment study of the European Brain Council (EBC) which has been under discussion at the 4th Congress of the European Academy of Neurology (EAN) in Lisbon.

"The Value of Treatment puts a valuable resource in the hands of political decision-makers that contains the background information they need to reach conclusions on and analyse the return on investment for various treatments – as well as pinpointing cost-effective policy recommendations for treating [brain disorders](#) in their countries," explained Prof Wolfgang Oertel (Marburg), Vice President of the EBC, who participated in the study. But it is not only a case of diagnosis and [treatment](#) of certain brain disorders, the study also sets out a vision for a more patient-centred and seamless, integrated care model for these conditions.

Brain disorders cost 800 billion a year

According to the European Brain Council brain disorders – including both neurological and psychiatric conditions – currently affect around one third of all European citizens or 179 million people, with steadily

increasing numbers. And the costs of these conditions are enormous: the European Brain Council estimates the total at EUR 800 billion a year in Europe, with around 40 percent accounted for indirect costs such as incapacity, and lost earnings and tax revenues. But the huge amounts of money invested in treatment are often failing to deliver the desired outcomes, as Prof Oertel explained: "Healthcare and welfare systems are often inadequately organised and have trouble keeping up with the rapid pace of medical advances."

Long-term misdiagnosis and inadequate treatment are the best examples of this. If a patient is unlucky, they can end up waiting a very long time before receiving specialist care. Many treatments have only been studied for a few years in neurological diseases a patient may suffer from for decades and may waste precious resources. At the same time, valuable time is lost – and particularly in the case of neurological disorders: 'time is brain'. "When it comes to many brain disorders, the medical profession is increasingly pushing up against its limits. However, early recognition, starting treatment as soon as possible and preventive measures would serve to minimise the risks or may even in some instances slow the progression of the disease," reported Prof Oertel.

Recommendations for patient-centred care

Following two years of research, The Value of Treatment (VoT) delivers recommendations to provide better and more cost-effective care for people with brain disorders. It contains nine case studies, which look into the situation regarding Alzheimer's disease, epilepsy, headache, multiple sclerosis, normal pressure hydrocephalus, Parkinson's disease, restless legs syndrome, schizophrenia and stroke. Hundreds of experts from representing European professional societies such as the EAN, EPA, ECNP, ENSA, FENS and patients' associations like EFNA and GAMIAN which are all members of the European Brain Council were involved in the study which was based on data sets from different

countries of the WHO Europe region, including the Czech Republic, France, Germany, Great Britain, Italy, Luxembourg, Russia, Sweden, Switzerland and Spain. The report used clinical indicators and patient data to assess the value of individual treatments for specific patient groups. This involved comparing the best possible treatment with the standard treatment offered or – if applicable – non-treatment and analysed the health, social and economic costs. "We clearly saw that an early start to treatment and optimal care costs the least over the long term. Non-treatment is the most expensive variant for diseases such as [restless legs syndrome](#) or multiple sclerosis and epilepsy, which affect people from a young age," said Prof Maura Pugliatti (Ferrara).

Case management instead of acute treatment alone

The Value of Treatment uses case studies to value specific healthcare interventions – and identifies where they often fall short of what they set out to achieve. In one such case study, a stroke patient in the prime of her life describes how she felt abandoned after receiving acute therapy. Nobody talked to her or her relatives about what should happen next. No steps were taken to initiate a course of rehabilitation or find out more about her situation at home and in the workplace. "This is something that simply wouldn't happen with better case management," noted Prof Oertel. "Everything possible would have been done to get this lady back on her feet and provide her with the necessary support. Perhaps she would have even been able to keep her job. But it is a time-consuming processes. That said, in overall economic terms it is still more cost effective than early retirement and permanent incapacity at the age of 45."

Other case studies analysed the situation of patients suffering from restless leg syndrome (RLS), a highly prevalent neurological disease. Around 2,7 percent of the European population suffer from moderate to severe forms of this uncontrollable urge to move the legs due to pain-like

sensations, leading to chronic sleep deprivation. "RLS is among the five most important disorders with respect to economic disease burden", Prof Oertl reported. The report describes a 67-year old RLS patient who received the diagnosis only after years of suffering. Subsequently medication was given at a too high dosage as a consequence of which her symptoms further worsened. "When translating RLS costs and the impact of RLS inadequate treatment to the general population, we foresee substantial economic impacts well beyond what may be anticipated from current epidemiological figures in the literature", said Vinciane Quoidbach, a research associate at EBC herself strongly involved in the VoT study. Joke Jaarsma from Amsterdam, herself a sufferer of RLS and the president of EFNA added: "Education about RLS is urgently needed to increase expertise of health care professionals on how to diagnose and manage RLS. Also the search into the causes of RLS and for new treatment strategies has to be intensified."

Another example from the VoT study looked at the issues surrounding the care gap: a migraine patient had been creeping out to her garage at night for years to scream so that her children would not be affected by her cries of pain. "This clearly illustrates the consequences of a lack of specialist facilities and a lack of defined treatment paths for certain diseases and patient groups, and shows what happens when insufficient social support is put in place for patients and their relatives," said Prof. Oertel. But it is specialist outpatient clinics that are likely to fall victim to cost cutting measures in times of financial austerity. "The ongoing economic and financial crises have seen an overall deterioration in access to neurological care in some cities and rural areas due to cut backs or the introduction of excesses payable by patients. It often takes too long to come up with the right diagnosis and initiate personalised therapies – if at all," concluded Prof Oertel. But this is a false economic strategy. As a fact-based study, The Value of Treatment highlights how important prevention and early detection are, while showing that an early start to treatment makes sense both from a healthcare and an economic

point of view: "Measurable health gains are linked to early intervention such as better survival rates, fewer complications, lower incidence of disability, improved quality of life and, ultimately, lower treatment costs – all of that would be possible!" Prof Oertel explained. Given the right medication, 70 percent of epilepsy patients could lead fit-free lives without any restrictions, and the remaining 30 percent could be offered access to other viable treatment options including surgical intervention. "But that calls for suitable treatment from the occurrence of the first fit onwards – by a suitably qualified specialist. And this is where there are major – yet surmountable – treatment gaps to be filled. We have a humanitarian duty to bridge them to the best of our ability when it comes to neurological conditions.

More information: [www.braincouncil.eu/activities ... e-value-of-treatment](http://www.braincouncil.eu/activities...e-value-of-treatment)

Olesen et al, The economic cost of brain disorders in Europe, *EurJNeurol* 2012, 19(1); DiLuca et al. The cost of brain diseases: a burden or a challenge? *Neuron* 2014, 82(6)

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