

# LSE Research Online

M. Leonardi, E. Ruiz De La Torre, T. J. Steiner, M. Tinelli, A. Raggi, D. D'Amico, L. Grazzi, K. Paemeleire and

D. Mitsikostas

Value of treatment of headache patients and need to improve headache patients' journey

## **Article (Accepted version)** (Refereed)

#### Original citation:

Leonardi, M. and Ruiz De La Torre, E. and Steiner, T.J. and Tinelli, M. and Raggi, A. and D'Amico, D. and Grazzi, L. and Paemeleire, K. and Mitsikostas, D. (2018) Value of treatment of headache patients and need to improve headache patients' journey. Neurological Sciences, 39 (1). pp. 115-116. ISSN 1590-1874

DOI: <u>10.1007/s10072-018-3366-6</u>

© 2018 Springer-Verlag Italia S.r.I., part of Springer Nature

This version available at: http://eprints.lse.ac.uk/89384/

Available in LSE Research Online: July 2018

LSE has developed LSE Research Online so that users may access research output of the School. Copyright © and Moral Rights for the papers on this site are retained by the individual authors and/or other copyright owners. Users may download and/or print one copy of any article(s) in LSE Research Online to facilitate their private study or for non-commercial research. You may not engage in further distribution of the material or use it for any profit-making activities or any commercial gain. You may freely distribute the URL (http://eprints.lse.ac.uk) of the LSE Research Online website.

This document is the author's final accepted version of the journal article. There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

#### Value of treatment of headache patients and need to improve headache patients' journey

Leonardi M <sup>1,2</sup>, Ruiz De La Torre E<sup>3</sup>, Steiner TJ<sup>2,4</sup>, Tinelli M<sup>5</sup>, Raggi A<sup>1</sup>, D'Amico D<sup>1</sup>, Grazzi L<sup>1</sup>, Paemeleire K<sup>6</sup>, and Mitsikostas D<sup>7</sup>

- 1. 1. Foundation IRCCS Neurological Institute Carlo Besta; MilanItaly
- 2. 2.Lifting The BurdenLondonUK
- 3. 3.European Headache AllianceBrusselsBelgium
- 4. 4.NTNU Norwegian University of Science and TechnologyTrondheimNorway
- 5. 5.London School of EconomicsLondonUK
- 6. 6.Ghent University HospitalGhentBelgium
- 7. 7. National and Kapodistrian University of AthensAthensGreece

The European Brain Council recently unveiled the report "The Value of Treatment for Brain Disorders," which highlights the need for more investment into research on neurological and mental diseases and the wide disparities between and within countries relating to treatments, detection, and intervention. More than 165 million Europeans are living with brain disorders such as epilepsy, headache, Alzheimer's disease, depression, and multiple sclerosis; the burden on national health budgets is staggering—rising to more than 800 billion euro a year in direct and indirect costs such as lost earnings and lost tax revenues.

Governments and politicians concerned over the cost of headache care for very large numbers of people fail to recognize a fundamentally important aspect of the economics of headache disorders: untreated, they are a huge financial drain. The high disability leads to massive losses in productivity. The costs of treating headache may be high, but would be dwarfed by the savings made from recovered lost work time if the resources were allocated to treat headache disorders appropriately [1, 2]. For this reason, implementation of good headache healthcare is likely to be cost-saving. Our first priority to improve patients' care should be to demonstrate the value of treating headache in these terms, so that policy will recognize the benefits of addressing these healthcare and educational failures.

The "care pathway" for most European people with headache is a series of dead ends. Many who would benefit from professional care find it unavailable, fragmentary, or difficult to access. Where headache services exist, they tend to be focused in specialist headache clinics, delivering high-end multidisciplinary care with very limited capacity. Such clinics are needed by the minority with complex disorders, but cannot serve this purpose when inundated by people who could be effectively treated in primary care—as most people needing headache care require neither specialist expertise nor investigations. Contrariwise, one in every three people receiving care for migraine in Russia and Spain, and one in every four in Luxemburg, does so from specialists [3].

Lack of knowledge among healthcare providers is a problem sewn in medical schools: worldwide, only four hours are committed to headache disorders in formal undergraduate medical training lasting 4–6 years. Poor awareness of headache disorders exists similarly among the general public: headache disorders are not perceived by the public as serious as they do not cause death and are not contagious. Consequently, headaches are often trivialized as "normal" and seen in those who complain of them as merely an excuse to avoid responsibility. On a political level, many governments, even if aware of it, do not acknowledge the substantial burden of headache on society. Healthcare for headache obviously comes at a cost: large numbers of people need treatments, together with advices on correct usage, and delivery of these requires organized healthcare. Good healthcare can greatly reduce the burden of headache, but it persists—principally because healthcare systems that should provide this care do not exist or fail to reach many who need it [3]. The roots of this failure mostly lie in education failure, at every level, but also in limited accessibility to appropriate care. Headache disorders are consequently under-recognized in society, under-prioritized in health policy, underdiagnosed in the population, and undertreated in

healthcare systems. People with headache fail to seek healthcare that is inadequate, and adhere poorly to it.

Policy and system gaps for headache patients result in two principal service gaps: (a) 50% who could and should manage themselves do not have the knowledge or receive the educational and practical support to do so and therefore misdiagnose, fail to capitalize on potential gains from lifestyle change, undermedicate or over-medicate, and/or use inappropriate medication, and are at risk of aggravating their disorder. (b) Fifty percent who need (would benefit from) structured headache services find they do not exist, or are fragmentary with no clear route through, and are provided inexpertly by doctors who are uneducated and uninterested and often promote overtreatment with inappropriate drugs.

Headache care for the large numbers who need it requires structured headache services together with public education on how to make correct use of them. Implementation of good headache healthcare is likely to be cost-saving and headache patients' journey can be improved worldwide. The solution is implementation of structured headache services through education of professionals at primary care level: based in primary care to provide sufficient reach, and supported by educational initiatives that will enable to reduce the underdiagnosis of headache disorders. Structured headache services at second or third level of care should provide adequate diagnosis and treatments to the more complex situations, such as high-frequency and chronic headaches or headaches complicated by comorbidities, that require tailored multidisciplinary care.

#### References

- 1) Vos T, Flaxman AD, Naghavi M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990- 2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet;
- 2) Linde M, Gustavsson A, Stovner LJ, et al. The cost of headache disorders in Europe: the Eurolight project. Eur J Neurol 2012;
- 3) Ayzenberg I, Katsarava Z, Sborowski A, Chernysh M, Osipova V, Tabeeva G, Steiner TJ. Headache-attributed burden and its impact on productivity and quality of life in Russia: structured healthcare for headache is urgently needed. Eur J Neurol. 2014;21:758-765.

### **Corresponding Author**

Matilde Leonardi

Neurology, Public Health, Disability Unit, Neurological Institute C. Besta

Via Celoria 11, 20133 – Milano (Italy)

Phone: +39.02.2394.2511;

E-mail: matilde.leonardi@istituto-besta.it

**Acknowledgements:** The current study was part of the Value of Treatment Project coordinated by the European Brain Council. The value of treatment of headache was supported by Novartis AG and Teva Pharmaceuticals

**Conflict of interest:** We certify that there is no actual or potential conflict of interest in relation to this article.