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Fatigue: Biomedicine, Health & Behavior

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/rftg20

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To cite this article: L.A. Jason & A.A. Mirin (2021): Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation, Fatigue: Biomedicine, Health & Behavior, DOI: 10.1080/21641846.2021.1878716

To link to this article: https://doi.org/10.1080/21641846.2021.1878716

Published online: 28 Jan 2021.

FATIGUE: BIOMEDICINE, HEALTH & BEHAVIOR
https://doi.org/10.1080/21641846.2021.1878716

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Updating the National Academy of Medicine ME/CFS prevalence and economic impact figures to account for population growth and inflation

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ABSTRACT

We update the US prevalence and economic impact estimates of the 2015 National Academy of Medicine report on myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), taking into account growth in population, economic inflation, and inclusion of children. We find a rough doubling of the ME/CFS prevalence and economic impact figures in the US, with low-end prevalence coming out to 1.5 million and economic impact having a range of 36–51 billion dollars per year.

ARTICLE HISTORY
Received 14 December 2020
Accepted 18 January 2021

KEYWORDS
Myalgic encephalomyelitis; chronic fatigue syndrome; prevalence; economic impact

Introduction

In 2015, the National Academy of Medicine (NAM) [1] issued a groundbreaking report on myalgic encephalomyelitis / chronic fatigue syndrome, commonly referred to as ME/CFS. This report, which is routinely cited by the healthcare community, government agencies, politicians, the press, and ME/CFS advocates, is now 6 years old. Moreover, several of the sources cited therein were from earlier studies. Hence, a number of the published statistics are now obsolete.

Herein we provide updated US prevalence and economic impact estimates, taking into account growth in population and economic inflation. These estimates are specific to the United States, as an international investigation is beyond the scope of this work. We do not attempt to carry out new studies at this time, as that would be an expensive and lengthy undertaking. Rather, we maintain the basic assumptions of the previous NAM report and merely adjust to the present-day population and economy. One exception is that we now include a study on children aged 5–17 in our prevalence and economic estimates.

Prevalence

Obtaining a reliable prevalence estimate has been a challenge, as most studies have serious methodological limitations, due largely to various methods of generating cohorts, different standards of rigor in identifying cases with comprehensive medical

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and psychiatric evaluations, and at times inappropriately broad case definitions, which has led to a wide variation of results [2,3]. Because of these conceptual and methodological challenges, Jason et al.'s [4] study reported in 1999 is generally accepted as providing one of the most reliable estimates of adult prevalence and was used by the National Academy of Medicine. We apply this estimate to the present-day population and additionally now include a pediatric component.

The NAM report [1] cites a US prevalence range of 836,000–2.5 million people. We consider here only the lower limit and address the upper limit below. The lower limit is based on the aforementioned study of Jason et al. [4] that cites an adult prevalence of 0.42%. A pediatric study by Jason et al., [5] carried out subsequent to the NAM publication, found a prevalence among 5-17-year-olds of 0.75%. The larger pediatric versus adult prevalence is due to a number of factors such as differences in screening methods, case definitions used, as well as when the data were collected.

The current US population is roughly 332 million people [6], approximately 78% of whom are adults and 22% children [7]. This works out to 259 million adults and 73 million children. Multiplying the adult population of 259 million by the adult prevalence of 0.42% gives 1.09 million adults with ME/CFS. Of the 73 million children in the US, approximately 73% are ages 5–17 [8], which works out to 53 million. Multiplying that figure by the pediatric prevalence of 0.75% gives a figure of 0.40 million children aged 5–17 with ME/CFS.

Adding the adult prevalence of 1.09 million and the pediatric prevalence of 0.40 million gives a total prevalence of 1.49 million Americans with ME/CFS (rounded off to 1.5 million). This is nearly double the lower estimate figure of 836,000 in the NAM report.

Economic impact

The NAM report cites a US economic impact factor of 18–24 billion dollars per year [1]. This figure is based on a study by Jason et al. [9] and takes into consideration both direct and indirect medical costs. The direct costs are based on separate community-based and tertiary studies, which find per-patient annual costs of $2,342 and $8,675, respectively [9]. The indirect costs are estimated to be $20,000 per patient per year, based on a study by Reynolds et al. [10], which approximates loss of household income without distinguishing between lost income of people with ME/CFS and lost income of caregivers, the latter assumed to be small. This gives a total per-patient annual direct and indirect cost range of $22,342 to $28,675. Multiplying by the low-end adult prevalence of 836,000 gives a range of 18.7–24 billion dollars. (The slight discrepancy in the lower figure is due to a typographical error plus incorrect rounding in the NAM report.)

We now adjust the direct medical costs by accounting for the per-capita increase in medical costs since 2008, the year of publication of the Jason et al. [9] paper. We do not attempt to ascertain increases in medical costs for ME/CFS specifically, as reliable information on that is not at our disposal. The increase in medical costs from 2008 to 2018 is seen to be 41.5% [11], and from 2018 to 2020 to be 12% [12], for a total increase of 58.5%. This gives a present-day range in direct per-person costs of $3,712 to $13,750 per year. We adjust the indirect costs by accounting for the 39.4% increase in inflation since 2004 [13], the year of publication of the Reynolds et al. [10] paper. Hence in today's dollars, the indirect per-person annual cost is $27,880. Summing the two

figures (direct and indirect costs) gives a range of $31,592 to $41,630 per person per year. Applying this to the updated adult prevalence of 1.09 million people gives a range of 34.4–45.4 billion dollars per year in direct and indirect medical costs.

We additionally consider the economic impact of the 0.40 million children aged 5–17 with ME/CFS. With no reliable information contrasting pediatric and adult medical costs, we approximate that a child will have similar medical costs to those of an adult. With most children not working, we ignore loss of productivity but acknowledge that there will be some lost income on the part of caretakers. Applying the range of per-person annual direct medical costs of $3,712 to $13,750 to the child prevalence of 0.40 million youth gives a range of 1.5–5.5 billion dollars per year. Adding this to the adult range of 34.4–45.4 billion dollars per year gives an overall range of 35.9–50.9 billion dollars per year in medical costs and lost productivity, which we round to 36–51 billion dollars per year. This is roughly double the economic impact range of 18–24 billion dollars per year cited in the NAM report.

Discussion and limitations

We see that using the latest population and cost figures, along with including 5-17-year-olds, results in a rough doubling of the prevalence and economic impact of ME/CFS in the US as cited in the NAM report [1]. We have not attempted to adjust the NAM upper prevalence limit of 2.5 million because we have not ascertained the origin of that figure. However, we believe the figure of 2.5 million to have originated with CDC [14] and that the intent of NAM was to use an even larger upper boundary figure. During the first decade of this century, CDC studies often made use of the operationalized Fukuda et al. case definition by Reeves et al. [15], known as the empirical criteria. It has been critiqued as having broader inclusion criteria and hence would be associated with a higher prevalence [16]. Specifically, Reeves et al. computed an ME/CFS prevalence of 2.54% among Georgian adults ages 18–59 (as compared to the Jason et al. value of 0.42% among all adults). If the NAM had applied the 2.54% prevalence figure of Reeves et al. [15] using the empirical criteria to 198.1 million adults (thus using the same population base figure used by Jason et al.'s study and assuming the over 59-year-old prevalence is similar to that of all adults), the prevalence estimate would have been 5.0 million people rather than the 2.5 million in the NAM report.

The 2.54% prevalence figure is unusually high, and as noted, the Reeves et al. [15] case definition is known to have broader inclusion criteria. Interestingly, an earlier CDC study of Reyes et al. [17] of Wichita, KS, gave a prevalence of 0.235%, over ten times smaller. Until there is an agreed-upon case definition as well as how to operationalize it, there will continue to be a wide variation of prevalence estimates. In fact, even with an agreed upon case definition, prevalence estimates will only be as good as the familiarity of health care providers and the ability to reliably diagnose with standardized methods.

While we estimated today's direct medical costs by applying the per-capita increase since 2008, that simplistic approach ignores changes in standards for diagnosis and treatment. Attaining a reliable estimate would require a new study based on today's standards of practice. A recently published Australian study [18] estimates annual direct costs of 23 thousand (Australian dollars) per person, which after applying a US currency conversion factor of 0.74 [19], comes out to 17 thousand US dollars per year. This compares to the

updated US range of 4–14 thousand dollars per year. Also, a recent US analysis of medical insurance claims [20] found those individuals with ME/CFS to have annual costs approximately 23 thousand dollars higher than that of the general population; however, that cost figure is not reflective of the full ME/CFS population in that many of those afflicted are not receiving treatment due to lack of diagnosis and lack of insurance coverage.

Similarly, the simplistic approach of estimating indirect costs by applying the degree of inflation since 2004 ignores changes to the economy and earnings patterns. It also does not adequately take into account loss of income by caregivers. Again, the actual value is likely higher. As with direct costs, a new study is required. The aforementioned Australian study [18] estimates annual indirect costs of 53 thousand (Australian dollars) per person, which works out to 39 thousand US dollars per year. This compares to the updated US value of 28 thousand dollars per year. While there are undoubtedly differences in the economies between the US and Australia, we are not surprised by the higher Australian estimates.

Conclusions

Since the 2015 NAM report, we have taken into account population increases together with inclusion of 5-17-year-olds, to estimate the prevalence of ME/CFS in the United States, and we arrive at a figure of 1.5 million people. Considering the updated prevalence and factoring in increases in medical costs and inflation, we estimate the annual economic cost of ME/CFS in the United States to be 36–51 billion dollars. The availability of these revised figures enables the community to cite the groundbreaking work of the National Academy of Medicine report while adjusting for present-day population and economics.

Disclosure Statement

No potential conflict of interest was reported by the author(s).

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References

[1] National Academy of Medicine, National Academy of Sciences. Beyond myalgic encephalomyelitis / chronic fatigue syndrome: redefining an illness. 2015. [cited 2020 Dec 5]. Available from: http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx.

[2] Brurberg KG, Fonhus MS, Larun L, et al. Case definitions for chronic fatigue syndrome / myalgic encephalomyelitis (CFS/ME): a systematic review. BMJ Open. 2014;4:e003973. doi:10.1136/bmjopen-2013-003973.

[3] Lim EJ, Ahn YC, Jang ES, et al. Systematic review and meta-analysis of the prevalence of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). J Transl Med. 2020;18:100. doi:10.1186/s12967-020-02269-0.
[4] Jason LA, Richman J, Rademaker AW, et al. A community-based study of chronic fatigue syndrome. Arch Intern Med. 1999;159(18):2129–2137. doi:10.1001/archinte.159.18.2129.
[5] Jason LA, Katz BZ, Sunnquist M, et al. The prevalence of pediatric myalgic encephalomyelitis / chronic fatigue syndrome in a community-based sample. Child Youth Care Forum. 2020;49:563–579. doi:10.1007/s10566-019-09543-3.
[6] Worldodometer. United States population. [cited 2020 Dec 5]. Available from: https://www.worldometers.info/world-population/us-population/.
[7] Kids Count Data Center. total population by child and adult populations in the United States. [cited 2020 Dec 5]. Available from: https://datacenter.kidscount.org/data/tables/99-total-population-by-child-and-adult#detailed/1/any/false/37,871,870,573,869,36,868,867,133,38/39,40,41/416,417.
[8] Kids Count Data Center. child population by age group in the United States. [cited 2020 Dec 5]. Available from: https://datacenter.kidscount.org/data/tables/101-child-population-by-age-group#detailed/1/any/false/37,871,870,573,869,36,868,867,133,38/62,63,64,6,4693/419,420.
[9] Jason L, Benton MC, Valentine L, et al. The economic impact of ME/CFS: individual and societal costs. Dyn Med. 2008;7(6). doi:10.1186/1478-7547-7-6.
[10] Reynolds KJ, Vernon SD, Bouchery E, et al. The economic impact of chronic fatigue syndrome. Cost Eff Resour Alloc. 2004;2:4. doi:10.1186/1478-7547-2-4.
[11] The Balance. The rising cost of health care by year and its causes. [cited 2020 Dec 5]. Available from: https://www.thebalance.com/causes-of-rising-healthcare-costs-4064878.
[12] Statista. Estimated annual change in medical costs in the United States from 2007 to 2020. [cited 2020 Dec 5]. Available from: https://www.statista.com/statistics/720767/medical-cost-trend-in-us/.
[13] Dollar Times. Calculate the value of $100 in 2004. [cited 2020 Dec 5]. Available from: https://www.dollartimes.com/inflation/inflation.php?amount=100&year=2004.
[14] Jason LA, Torres-Harding S, Njoku MG. The face of CFS in the U.S. *The CFIDS Chronicle*. January 2006. [cited 2020 Dec 6]. Available from: https://www.researchgate.net/publication/236995875_The_Face_of_CFS_in_the_US.
[15] Reeves WC, Wagner D, Nisenbaum R, et al. Chronic fatigue syndrome – a clinically empirical approach to its definition and study. BMC Med. 2005;3:19. doi:10.1186/1741-7015-3-19.
[16] Jason L, Fox PA, Gleason KD. The importance of a research case definition. Fatigue: Biomed, Health Behav. 2018;6:52–58. doi:10.1080/21641846.2018.1389336.
[17] Reyes M, Nisenbaum R, Hoaglin DC, et al. Prevalence and incidence of chronic fatigue syndrome in Wichita, Kansas. Arch Intern Med. 2003;163:1530–1536. doi:10.1001/archinte.163.13.1530.
[18] Close S, Marshall-Gradisnik S, Byrnes J, et al. The economic impacts of myalgic encephalomyelitis / chronic fatigue syndrome in an Australian cohort. Front Public Health. 2020. doi:10.3389/fpubh.2020.00420.
[19] Coinmill.com - The currency converter. [cited 2020 Dec 7]. Available from: https://coinmill.com/AUD_USD.html#AUD=1.
[20] Valdez AR, Hancock E, Adebayo S, et al. Estimating prevalence, demographics, and costs of ME/CFS using large scale medical claims data and machine learning. Front Pediatr. 2019;6:412. doi:10.3389/fped.2018.00412.