

Revision articles

Applicability of Burden of Disease methodology in human communication disorders

Aplicabilidade dos estudos de carga de doença nos distúrbios fonoaudiológicos

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ABSTRACT

The burden of disease methodology is composed by the calculation of specific indicators, and proposes to measure the effects of diseases on the physical, emotional and social welfare, either from the effects of premature death and morbidity, as well as comorbidities on the health conditions of the population. This study aimed to verify the possibility of application of the concept of the burden of disease in the study of human communication disorders in an attempt to introduce new methodologies and better characterize the setting of these diseases. This study involved an integrative literature review in Scielo, Lilacs and Pubmed bases, with presentation of concepts and a critical analysis of burden of disease's indicators and their potential applications in the field of speech, language and hearing sciences. The findings indicate a lack of studies using the concepts related to burden of disease as applied to human communication and its disorders as well as their implications on the life of the subject according to the methodology proposed by the World Health Organisation. There are opportunities to apply the burden of disease concept and methodology in the field of communication disorders, both, to identify the impact of diseases on the individual, as for the evaluation of the quality and also to measure the effectiveness of interventions in the field of speech-language disorders.

Keywords: Speech, Language and Hearing Sciences; Quality-Adjusted Life Years; Prevalence; Incidence; Review

RESUMO

A metodologia de mensuração da carga de doença, composta pelo cálculo de indicadores específicos, propõe mensurar os efeitos de agravos (ou de doenças) sobre o bem estar físico, emocional e social, seja a partir dos efeitos da morte prematura e da morbidade, bem como de comorbidades sobre as condições de saúde da população. O estudo teve como objetivo verificar a possibilidade de aplicação dos conceitos de carga de doença no estudo das metodologias e melhor caracterização do cenário de agravos fonoaudiológicos. O estudo envolveu revisão integrativa da literatura nas bases Scielo, Lilacs e Pubmed, com apresentação de conceitos e uma análise crítica dos indicadores de carga de doença e suas potenciais aplicações no campo da fonoaudiologia. Os achados indicam que existe uma carência de estudos utilizando os conceitos relacionados à carga de doença aplicados à comunicação humana e seus distúrbios, bem como às implicações destas na vida do sujeito a partir da metodologia proposta pela Organização Mundial da Saúde. Há oportunidades de aplicação da metodologia foco da pesquisa, tanto para que forneça o impacto dos agravos no indivíduo, como para a avaliação da qualidade de vida e para a mensuração da efetividade das intervenções no campo dos distúrbios fonoaudiológicos.

Descritores: Fonoaudiologia; Anos de Vida Ajustados por Qualidade de Vida; Prevalência; Incidência; Revisão

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INTRODUCTION

Human communication comprises encoding and decoding capability of the written and spoken system of a language through language, motor and auditory skills. The speech-language disorders are characterized as any restriction or lack of ability (resulting from a limitation in communication) to carry out a normal activity and are associated with several factors: environmental, biological and also appear as pathological events. It is therefore of paramount importance to study these disorders, their understandable background as well as to identify possibilities of detection, prevention and treatment for the different populations.

In the 90s the World Health Organization (WHO) initiated the use of disease burden estimates (burden of disease) through the project "Global Burden of Disease and Risks Factors", providing global estimates of this indicator, and preliminary results published in 1993 in which Murray was the head researcher¹. The measurement methodology of disease burden, comprising the calculation of specific indicators, proposes to measure the effects of diseases (or diseases) on the physical well-being, emotional and social development of an individual, whether from the effects of premature death and morbidity and comorbidity on the health conditions of the population². Studies of this type of measurement include five main measures: prevalence, incidence, Disability Adjusted Life-Years (DALYs), Quality-adjusted life year (QALY) and years of life lived with disability (YLD).

A recent study compared the global burden of a list of 291 diseases between the years 1990 and 2010 and in this role, there are listed the speech disorders in the description of diseases. Although not listed, communication disturbances observed clearly the burden of cardiovascular disease, which clearly have as one of its consequences the Communication disorders³.

Studies of communication disorders, in most cases, have been used epidemiological methods for easier access and lower costs, as prevalence studies in specific population groups. With the perspective of chronic events, however, the analysis of YLD may be the most effective measure to describe the phenomenon of speech disorders, but research that compared YLD considering consequences on the communication disorders have not been cited, even these are relevant from the point of view of cardiovascular post-event comorbidity, for example, strokes⁴.

Given this context, it is clear that the indicators of the methodology of the disease burden studies can be used to study the occurrence of speech disorders, being isolated or concomitant, enabling the analysis of its consequences (comorbidities), limitations and disabilities. This study aims to determine, from the literature, the possibility of application of the burden of disease concepts in the study of human communication disorders, in an attempt to increase new methodologies and provide better characterization of the setting of these diseases.

METHODS

From an integrative review of the literature on disease burden in Scielo, Lilacs and Pubmed bases, concepts and a critical analysis of disease burden indicators and their potential applications in the field of phonology will be presented. An integrative review consists of a review method literature that allows the search, selection, critical evaluation and synthesis of scientific evidence, allowing the inclusion of studies which adopt different methodologies; identifies gaps and directs the development of future research on certain subject^{5,6}. Bibliographical survey was conducted in June 2015 without minimum limitation date, using the search strategies described in Figure 1.

Search strategy	Initial result	Result after analysis
("dysphonia"[MeSH Terms] OR "dysphonia"[All Fields]) AND (Burden[All Fields] AND ("disease"[MeSH Terms] OR "disease"[All Fields]))	8	0
("language disorders"[MeSH Terms] OR ("language"[All Fields] AND "disorders"[All Fields]) OR "language disorders"[All Fields]) AND (burden[All Fields] AND ("disease"[MeSH Terms] OR "disease"[All Fields]))	81	1
(dysphagia[Title/Abstract]) AND burden of disease[Title/Abstract]	2	0
(voice disorders) AND burden of disease	18	2
Carga de Doença [Título]	15	1
DALY[Title]	71	4
(qalys[Title/Abstract]) AND burden[Title/Abstract]	205	10
(yld [Title/Abstract]) AND burden[Title/Abstract]	118	3

Figure 1. Description of Search strategy of articles

After the search of articles and following the rules of the integrative review inclusion and exclusion criteria were established. Inclusion criteria: (a) research investigating burden of disease versus communication disorders; (B) articles without limitation publication date and court date in June 2015 (in general revisions close to a period between 5 and 10 years, and all the studies found, regardless of their date of publication); (C) articles in English, Portuguese or Spanish; (D) articles with DALY measures of disease; (E) QALY measures of disease; (F) conceptual articles on the subject. Exclusion criteria: (a) items which not treat exclusively of disease burden and its variables.

Initially 518 articles were identified: pre-sorting was performed by headings, eliminating the repeated

ones. With the reading of abstracts (and application of predefined inclusion and exclusion criteria 86 articles were selected. With the subsequent reading of the studies it was possible to refine the further search, leaving 21 articles for this article reference composition.

LITERATURE REVISION

The focus of this work is an analysis of the concepts of the methodology for measuring the global burden of disease, through its indicators and verifying their implementation in the field of communication disorders, enabling better use of this methodology in future studies. A summary of the survey can be found in Figure 2.

Study	Journal year of publication	Authors	Title of the article	Description
1	Journal of Health Economics 1997	Murray CJL; Acharya AK.	Understanding DALYs	Review of the method to quantify the burden of disease using the measure of years lost due to disability - DALY. It highlights the advantage of the measure differ only in sex and age, for non-fatal health events.
2	Journal of Public Economics 1993	Broome J.	QALYs	Theoretical survey of the QALY measure, pointing out some difficulties as the generalization of the measure for all disabilities.
3	Annu. Rev. Public Health 2002	Gold RM, Stevenson D, Fryback GD.	HALYs and QALYs and DALYs, oh my: similarities and differences in summary measures of population health	Review of the methods used for the disease burden measures (DALY, Haly and QUALY) and it notes that such measures help to understand the impact of diseases in specific populations and enables the economic analysis of health programs.
4	Bulletin of the World Health Organization 1994	Murray CJL.	Quantifying the burden of disease: the technical basis for disability-adjusted life years	It brings important considerations for a new load condition indicator, thereby providing a formula for calculating DALY. It emphasizes the variables of the calculation, and discusses advantages and disadvantages of the method.
5	Social Science & Medicine 2003	Allotey P, Reidpth D, Kouamé A, Cummins RD.	Context and the determinants of the severity of disease: an exploratory comparison of paraplegia in Australia and Cameroon.	The study shows the Burden of Disease with DALY in paraplegia, demonstrating that these measures may vary according to the context in which the affected individual is.
6	Journal of Health Economics 1997	Arnard S, Hanson K.	Disability-adjusted life years: a critical review	It mentions that the DALY has emerged to measure the burden that the disease imposes a certain population affected by a particular disease. The paper considers that the technical basis of the measure is flawed because it considers so the age factor the age factor in variables as well as the measure does not distinguish the way of measuring the burden and the capacity.
7	Revista Portuguesa de Saúde Pública 2003	Ferreira LNE.	Utilities, QALYs and measurement of quality of life	It reviews QALY measurement method and cites the instrument measuring the quality of life using the EQ-5D questionnaire generic health status.
8	Relatório da Fundação Oswaldo Cruz (FIOCRUZ) 2005	Leite CI, Joaquim GV, Scramm AMJ et al..	Final report of the Global Burden of Disease project in Minas Gerais State	The report shows the results of the burden of disease study in Minas Gerais in 2005, reporting the effects of the disease both in mortality and disability by disease group and age group.

Study	Journal year of publication	Authors	Title of the article	Description
9	Revista de Saúde Pública 1999	Nedel BF, Rocha M, Pereira J.	Years of life lost due to mortality: one of the components of Burden Disease	Initially, the paper reviews the DALY method; then shows measures of years of life lost due to premature death, one of the components of Disease Burden in the states of Rio Grande do Sul and Santa Catarina, compared to some results in Brazil.
10	Social Science & Medicine 1989	Carr-Hill RA.	Assumptions of the QALY Procedure	It mentions that the measure of QALY is a useful measure for health care management, it allows a better decision on what the most effective program to be followed is. It emphasizes theoretical assumptions that underpin the technique.
11	Acta Neurologica Taiwanica 2007	Tseng MC, Lin HJ.	Health-related quality of life after stroke: review of the literature and implications for future research	The article provides a review of the methods used to assess DALYs, QALYs and Halys, it considers the economic and medical technology assessment for these resources.
12	Revista de Psiquiatria Clínica 2007	Daltio SC, Mari JJ, Ferraz BM.	Studies on pharmacology and Burden Disease in schizophrenia.	Review on publications in Medline database on main studies on pharmacology in schizophrenia.
13	Journal of Voice 2015	Roy N, Tanner K, Merrill RM, Wright C, Miller KL, Kendall KA.	Descriptive Epidemiology of Voice Disorders in Rheumatoid Arthritis: Prevalence, Risk Factors, and Quality of Life Burden.	It estimates the prevalence of communication disorders and checks the relation to the quality of life in specific group (Rheumatoid arthritis patients). Discusses the risk factors relating to QALY, although not applying the concept directly.
14	Ann Otol Rhinol Laryngol. 2015	Tanner K, Pierce JL, Merrill RM, Miller KL, Kendall KA, Roy N.	The Quality of Life Burden Associated With Voice Disorders in Sjögren's Syndrome.	It estimates the prevalence of communication disorders and the relation with the quality of life in specific group (Patients with Sjogren syndrome). It discusses the risk factors relating to QALY, although not applying the concept directly.
15	Lancet 2012	Vos T 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	Comparative analysis of years lived with disability in the decades of 90 and 2000. There 1160 sequelae of 289 diseases and speech disorders are not included in the list.
16	Lancet 2012	Murray CJ et al.	Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010.	Comparative analysis of DALY in the decades of 90 and 2000

Study	Journal year of publication	Authors	Title of the article	Description
17	HealthPolicy Plan. 2006	Sassi F.	Calculating QALYs, comparing QALY and DALY calculations	Methodological discussion, describing the technical aspects of the calculations with positive and negative weighting
18	Eur J Health Econ. 2015	Tilling C, Krol M, Attema AE, Tsuchiya A, Brazier J, van Exel J, Brouwer W.	Exploring a new method for deriving the monetary value of a QALY.	Methodological discussion of alternative proposition to calculate the monetary value of QALY.
19	Int J Stroke. 2009	Bersano A, Burgio F, Gattinoni M, Candelise L	Aphasia burden to hospitalized acute stroke patients: need for an early rehabilitation programme	It estimates the prevalence of aphasia in specific group. (Stroke patients). It discusses some ideas of disease burden, although not applying the concept directly
20	Int J Public Health. 2014	Devleeschauwer B, Havelaar AH, Maertens de Noordhout C, Haagsma JA, Praet N, Dorny P, Duchateau L, Torgerson PR, Van Oyen H, Speybroeck N.	DALY calculation in practice: a stepwise approach.	Systematization of the methodology, making a critical reflection on the difficulties for a closer estimate of the real number.
21	Ciênc. saúde coletiva [online]. 2004	Schramm, JMA et al.	Epidemiological transition and the study of burden disease in Brazil.	Study on Burden Disease in Brazil

Figure 2. Description of the selected studies on Burden Disease (methodological focus and disturbances).

According to the literature, in the late twentieth century, the World Health Organization (WHO) launched the Global Burden of Disease initiative, which has compiled a set of simple measures of overall health. These measures seek to contemplate at one time the effects of premature death and morbidity on the health conditions of the population, the so-called studies disease burden^{7,8}. These studies analyze the measures described below.

Prevalence: defined as the ratio of a group of people who have an endpoint (clinical condition or injury) at a specific point in time⁹.

Incidence defined as the ratio of a first group free of a clinical condition that develops over a certain period of time. That is, the incidence refers to new cases occurring in a first population free of disease or new outcomes such as disability or death, occurring in patients with a specific disease⁹.

Disability Adjusted Life-Years (DALY) - year of healthy life lost – it is an indicator that considers the impact of measures of disease, both in terms of morbidity and in relation to mortality. The DALY considers the total years of healthy life lost due to a disease (or a risk factor) and calculation includes both the age at death, and the duration and severity of any current inability².

For example, its application can show the conditions with the potential to become chronic, depicting the expectations of an unhealthy state in a population. A comprehensive study on 306 diseases in 188 countries (GBD2013¹⁰) pointed out that the five leading causes of DALYs were ischemic heart disease, lower respiratory infections, cerebrovascular disease, lumbar diseases, sore throat and traffic accidents.

Quality-Adjusted Life Years (QALY) - adjusted life years for quality of life - captures in a single measure gains in quantity and in quality of life. It is a generic tool for assessing the health status by providing objective measures of quality of life and interventions¹¹. For example, this measurement can be used for results verification in interventions. In study¹² to evaluate the effectiveness of interventions for the management of cardiovascular risk, the comparability of cost-effectiveness measurements was performed from this indicator, and the findings showed that the money was greater for actions performed by women (compared to actions with the male audience), with greater gain in QALYs versus pounds invested in the female audience.

Years Lived with Disability (YLD) - years of life lost due to illness and / or disability - is the quantification of years lived with disability from a grievance¹¹.

For example, this indicator can be used for survival demonstration. In GBD2013¹⁰ the increasing socio-demographic status was associated with a change in Years of Life Lost (YLL) - for YLD, driven by declines in YLLs and YLD increases of musculoskeletal disorders, neurological diseases and mentally disorders caused by the use of chemicals.

It can be seen that the mapping initiative of global burden occurred after two decades of the first publications on the subject. Date of 1976 the first time that the methodology was employed, Zeckhauser and Shepard used it to check health outcomes compared to quality life issues¹³.

The interest in quantifying not only morbidity but also quality of life can be attributed to the increased life expectancy, which leads people affected by diseases to remain more time exposed to them and hence to use longer service health, leading to the need for development of more specific and effective health policies and programs, so that the costs are rationalized and minimized.

The object of some Studies^{14,15} has been the method of review that seeks to check the impact of the disease, retaking its manifestation and its limitations to the application of measures to burden disease. These measures are mentioned in other studies^{7,14,16-18}, and the authors, unanimously, put the best indicator to express the disease burden is the DALYs (Disability Adjusted Life-years) which shows a broadening of the concept of years lost due to non-fatal events. Thus, the DALYs for a disease or condition, consists of the sum of years lost due to premature death (YLL- Years of Life Lost) and years of life lost due to disability (YLD- Years Lost due Disability), resulting in the formula of disease burden $DALY = YLL + YLD$.

Considering the speech disorders, it is worth the reflection that the abovementioned measure (YLD), from which it appears the years of life lost due to disability is a very important tool to be used in cases of people suffering from communication disorders, such as example, those associated with the hearing loss. The YLD measures the ratio between how much living with disabilities generates disabilities in the individual and brings the information for the years of life with which the subject lives with the limitations imposed by the disability. Data on hearing impairment charge and communication disorders associated with it have the potential to support and aggregate information for monitoring actions, aimed at investment in early detection as well as in improving the techniques

for minimizing the effects of hearing loss in communicative, educational, social and psychological aspects.

Among the surveyed studies, a literature review¹⁹ on the method of measuring disease burden specifies some disadvantages: lack of theoretical sedimentation and the fact that this is such a global measure to generalize variables for all diseases. However, since the initiative of the World Health Organization to measure the global burden of disease, this is the method that has been used for a general mapping of illness.

Inferring in the field of speech therapy, it must be considered that an involvement as complex as the communication disorders, implications of large measurements and individual variable to individual, can not get as many generalizations to obtain objective measures of their consequences. However, the method is currently the only proposed to measure disease burden.

Considering the disadvantages of the method and adding the fact that the prevalence of hearing loss is high in the context of human communication disorders, studies that intend to carry out such measures would be of great impact as objective measures can quantitatively translate states that often are only described qualitatively. Numbers, as objectively measure, add to that descriptor greater impact, facilitate the development of databases for studies and aim reporting for raising health resources, in other words they are able to optimize curative interventions of certain diseases.

In the panorama of national literature, one study⁸ conducted disease burden measures in the state of Minas Gerais, being the only one to perform the burden of disease measures specified by disease group and age group, by specifying each component of the DALY measures. This study points out that there are limitations on the quality of the information for estimating the required parameters, i.e., in its conclusions it highlights the importance of studies of this type, but includes data limitations. The speech-language disorders were not analyzed, however, when the study explains the weight of occurrence, hearing loss is one of the aspects considered. Thus, the analysis of that aspect raises a reflection on future research in relation to hearing impairment, in case necessary information is available for implementing the measures or even, if possible, include a survey on the variables involved in the measures of disease burden in hearing impairment.

In the selected international literature, it was found a study²⁰ that measured the burden of disease from DALY in paraplegia, bringing the effects of these data

in the country, the environment, gender and the socio-economic conditions. In this study, there is a relevance of the impact of disease in individuals with different realities, indicating how each operation is changed face to an involvement. This study highlights the importance of developing indicators for the burden of disease in intervention actions in order to seek a common denominator in interventions for different realities. As authors discuss¹⁸ to find a guiding covering the different realities, whether of gender, age or social status, is of paramount importance in speech disorders, since accessing and obtaining curative actions could be more uniform, prioritizing the individuality that each affected person has, emphasizing especially how they live with the impacts inherent in the grievance. Once again, one can understand the importance of these studies as guidelines for research of people suffering from disabilities of any kind and degree. It is through them that you can set priorities as necessary as they relate to health policy to understand any degree of complexity.

Among the studies that emerged from this research, the studies relating to QALYs measures^{11,15,21} are highlighted as it is a simple utility, but effective for understanding the consequences of the individuals' bad quality of life of. An individual's healthy year corresponds to one QALY. In this sense, a year of life with a low level of health, for example x , where $x < 1$, applies to x QALYs. Adjusting the value of a year of future life to a current value at one rate r , it is possible to calculate the current value of expected QALYs by an individual, considering their health profile and their future life¹¹.

An important aspect regarding the application of the QALY is the basic notion that permeates that for any individual the prospect of Y living year with less than full health can be equated with the prospect of X living years in full health when $x < Y$ ²². Given the hypothesis that different settings (profiles) of survival duration in many health states may be converted to their equivalent "full years of healthy life," the QALY measures can be used to assist in cases of decision which different therapeutic options can produce different combinations of survival and diverse qualities of life²². On the other hand, although it is possible to aggregate and compare the valuations in relation to health and quality of life in different scenarios, it must be considered that the perception of health, disease and limitation involves the subjectivity of each subject and each context.

In two of the studies^{23,24} there is an attempt to approach some variables of disease burden by proposing to verify associations between human

communication disorders and levels of quality of life. However, it is observed that studies are not made in the general population, i.e., they are targeted to specific groups. In Brazil, disease information systems and health problems such as those of violence, reportable diseases, chronic diseases do not include communication disorders, possibly because they are comorbidities resulting from diseases and disorders, preventing more global analysis, making those studies targeted to specific audiences (clinics, hospitals, health centers).

A possibility of using QALY tool in the field of speech disorders is the generation QALYs with or without intervention, relating, for example, the amount of QALYs gained by intervention on conditions such as dysphagia, dysphonia, labyrinthine or rehabilitation. The comparison of the QALY under the conditions with and without intervention in these cases would identify when and which applied intervention would lead to a state of better health in the individual, implying even when lack of intervention would result in faster deterioration of activities and quality of life of the individual.

The indicators that estimate the disease burden become relevant in the grounds scenario for health investment plans: an article²⁵ reports the literature review with the economic approach of disease burden, especially in schizophrenia, highlighting the high load rates disease in this disorder to society, demonstrating the importance of these findings in the economy and health policies. In Holland²⁶, for example, a survey explored an alternative approach to estimate the monetary value of a QALY, and the results were evaluated as promising, but without neglecting the possible methodological weaknesses.

It is observed^{24,27} an initiative of approaching disturbances studies of speech and the methodology to estimate the burden of disease, but as previously discussed, attempts apply to specific groups of individuals with a given disease, where the disorder human communication is a result of the injury. An Italian²⁷ survey estimated aphasia burden in patients who suffered stroke, in order to establish parameters for early rehabilitation, suggesting the importance of checking the burden of aphasia in a broad population of patients hospitalized with acute stroke, for forming impairment residual estimates and the consequent impact on the definition of specific programs for early rehabilitation.

The magnitude of the use of disease burden estimation methodology is clear, just quickly check the latest publications in high impact journals, yet

the Speech Therapy needs to appropriate of their measures. The practicality and applicability of DALYs were evidenced in study²⁸ which established steps for the calculation: (1) definition of the population; (2) conceptual model of outcomes; (3) data collection; (4) analysis of the data; (5) calculation of the DALY. Despite the simplistic systematization, difficulties in quality of data access are placed as the greatest difficulty in using the methodology.

Brazil is on the scene of major studies on burden disease²⁹ with an overview of chronic degenerative diseases, parasitological, external causes, among others. It is evident therefore, the challenge of implementing the methodology for assessing the burden of speech disorders.

CONCLUSION

With this scenario, the application of the tools to establish the burden of disease provides an opportunity to assess the impact of intervention actions to minimize the impact of the limitations and implications of speech disorders, providing not only data on the effects of interventions on this grievance, but allowing also featuring a gold standard measure to measure the results of the actions in this field. It can be inferred that the methodology draws an important overview for planning and evaluation of intervention, however, it is necessary that the researcher becomes aware of its limitations and be able to evaluate what better indicator applies to their studies.

It is possible to infer that there is a lack of studies using the concepts related to disease burden applied to human communication and its disorders, as well as their implications in the life of the subject from the methodology proposed by the World Health Organization. Thus, there are opportunities of application of QALYs, DALYS and its variants, both to provide the impact of injuries on the individual, and for the evaluation of quality, and for measuring the effectiveness of interventions.

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