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Headache disability evaluation and impairment assessment in the Italian Health Care and Welfare System

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Abstract. Headache is a public health problem concern to impairment of physical, social and emotional functioning, both in everyday life and in work activities, with a significant economic impact in terms of direct and indirect costs. The diagnosis of headache is often difficult, as it is based on the patient's subjectivity and objective signs can sometimes be lacking. Several specific questionnaires have been developed to measure its severity, associated disabilities, the effects on quality of life, disability and the overall impact of chronic headache (HRQoL, MIDAS, HIT-6). In Italy, the citizens who suffer from headaches may relate to certain forms of social protection as the Law 68/1988 ("employment of people with disabilities"), the Law 104/92 ("framework law for the assistance, social integration and rights of disabled people") and the recognition of disability (Ministerial Decree of 5 February 1992 "approval of new tables of disabling diseases").

Key words: disability, headache, law, migraine

Valutazione della disabilità della cefalea nel sistema di salute e welfare italiano
Riassunto. La cefalea è un problema di salute pubblica che porta alla compromissione del funzionamento fisico, sociale ed emotivo, sia nella vita di tutti i giorni e nelle attività lavorative, con un significativo impatto economico in termini di costi diretti e indiretti. La diagnosi di mal di testa è spesso difficile, in quanto è fondata molto sulla soggettività del paziente e i segni oggettivi possono essere a volte carenti. Diversi questionari specifici sono stati sviluppati per misurarne la gravità, la disabilità associata, gli effetti sulla qualità della vita, sulla disabilità e l'impatto complessivo della cefalea cronica (HRQoL, MIDAS, HIT-6). In Italia, i cittadini che soffrono di mal di testa possono riferirsi ad alcune forme di protezione sociale come la Legge 68/1988 ("occupazione delle persone con disabilità"), la Legge 104/92 ("Legge quadro per l'assistenza, l'integrazione sociale e i diritti delle persone disabili") e il riconoscimento della disabilità (Decreto Ministeriale del 5 febbraio 1992 "Approvazione delle nuove tabelle di malattie invalidanti").

Parole chiave: disabilità, emicrania, legislazione, mal di testa

Clasificación de la discapacidad del dolor de cabeza en el sistema de salud y bienestar italiana
Resumen. La cefalea es un problema tanto a nivel de salud publica tanto a nivel de funcionamiento fisico, social ed emocional, tanto en la vida diaria come por el trabajo, que tiene un impacto considerable en el ambito economico, en materia de costos directos y indirectos. El diagnostico de la cefalea usualmente es dificil porque fundada en la subjetividad y porque signos obiectivos a menudo carecen. Se han desarrollado diferentes cuestionarios para medir la severidad, la discapacidad y las consecuencias en la calidad de vida de la cefalea cronica (HRQoL, MIDAS, HIT-6). Los ciudadanos de lo Estado Italiano que sufran de cefalea cronica pueden beneficiar de unas medidas de proteccion social, como la Ley 68/1988 ("empleo de las personas con discapacidad"), la Ley 104/92 ("Ley marco de ayuda social por la asistencia, la integración social y los derechos de las personas con discapacidad") y el reconocimiento de la discapacidad (Decreto Ministerial de 5 de febrero 1992 "La aprobación de las nuevas tablas de enfermedades discapacitantes").

Palabras claves: cefalea, discapacodad, la legislación, la migraña

Introduction

Headache is a chronic pain disorder representing a major global health problem, affecting 50 milions persons in Europe, leading to impaired physical, social and emotional functioning, both in the everyday life and in the work activicties, with significant economical impact in term of direct and indirect costs.

Globally, the percentage of the adult population with an active headache disorder is 46% for headache in general, 11% for migraine, 42% for tension-type headache and 3% for chronic daily headache.

Despite the high prevalence of headache in the general population the real impact on quality of life is often underestimated.

The World Healthcare Organization (WHO) brings headache disorders into the 10 most disabling conditions for the two genders, and into the five most disabling for women.

The few Italian population-based studies confirm the high prevalence of this disorder and its severe impact on quality of life in our Country, with relevant implications for health-care policy, planning and resource allocation (1).

Diagnosis of headache is complicated by the fact that it is founded on patient's subjectivity and objective signs are lacking and the consultations in general practice rarely take place during a migraine attack so that diagnosis it's substantially based on symptoms experiences remotely by the patients.

Discussion

Direct and indirect costs of headach

Headache is a public-health concern given the large amount of associated disability and estimated financial costs to society.

The World Health Organisation have pointed out that the world's economical impact of headache is about £ 140 billion a year.

Several studies have quantified overall costs associated with migraine, ranging from 581 to 7089 dollars per year (2).

The greatest costs of headache have to do with "direct costs", related to the use of medical care resources (hospital admissions, diagnostic tests and therapies).

The individual "indirect costs" concern the loss of workplace productivity, of workdays or reduced productive time spent during a workday, due to headache.

There is general consensus that indirect costs are predominant over the direct costs, amounting to the 93% of the total economic burden of headache (3).

Infact, workers with headache stay on the workplace, but use to work at a lower level with significative loss of productivity.

Absenteism from tension-type headache alone is the equivalent of 0.4 to 1.2 days per year for every person in the workforce; migraine causes the average sufferer to lose approximately 4.6 work days annually.

Thus, all form of headache together are estimated to produce at least the equivalent of 1 lost workday per year for every employed person.

Recently, an italian study have compared the impact of chronic migraine and episodic migraine on the individual, in terms of costs and on the National Health System (NHS), confirming the higher economic toll of chronic migraine respect to episodic migraine (4).

Headache continue to be under diagnosed, misdiagnosed, and mistreated as it's not perceived by the population as a serious disease, since it's mostly episodic, do not cause death, and it's not contagious.

Generally, patients are reluctant to go to primary care physicians with complaints about recurrent headache as they can get relief by using symptomatic medications.

Therefore, although headache is clearly a major significant health problem, the public and many health care professionals use to see as somewhat trivial complaint and not as an organic debilitating disease.

As a result, the physical, emotional, social and economic burdens of headache are poorly acknowledged compared with those of other, less prevalent, neurological disorders.

The low consultation rates in developed countries may indicate that many subjects are unaware that effective treatments exist and 50% of people with headache are estimated to be self-treating.

It is important to underline that headache is not only painful, but also disabling, as it produces impairment of productivity at work and school as well as of family and leisure time.

The World Health Organization, in the Global Burden of Disease Study, updated in 2004, pointed out

that migraine on its own account for 1.3% of years lost due to disability.

Headache disorders impose a recognizable burden on sufferers including sometimes substantial personal suffering, impaired quality of life and financial cost.

Repeated headache attacks, and often the constant fear of the next one, deeply damage family time, social life and employment, relationships, recreation activity.

A cross sectional telephone survey, conducted on 1810 woman, between 18 and 35 years, from Israel and 8 European Countries, with a self-report of migraine or severe headache (5), showed that nearly one half (46%) of participants missed at least 1 day of work or school because of migraine during the prior 6 months of observation; 74% of participants was prevented from functioning fully at work or school because of migraine; 39 % of participants indicated that migraine had negatively affected their job or school performance.

The same study showed that migraine has a substantial detrimental impact on the family life and leasure time: 62% of participants reported one or more occurences of being unable to spend time with family or friend because of migraine and the 67% admitted to be unable to enjoy recreational or leisure activities as a consequence of migraine.

Not only patient's life is affected during the migraine attack, but also in the illness free period.

For these reasons patients frequently show avoiding conducts (avoiding some food or drink, not sunbath or sleeping to much).

Anxiety and depression are often associated with migraine.

The long-term effort of coping with a chronic headache disorder may also predispose the individual to other illnesses.

Although patients tend to think that depression is the normal response to the chronic pain, the association between headache and psychological diseases is well known (6-9).

For example, depression is three times more common in people with migraine or severe headaches than in healthy individuals.

Assessment of disability in patients with headache

A lot of specific instruments have been developed to measure severity, associated disability, effects on quality of life, related disability and overall impact of chronic headache.

Assessment of disease burden focused on health-related quality of life (HRQoL) has become an important component of the evaluation of patients with headache.

Health-related quality of life is one component of overall quality of life and encompasses an individual's health status, functional status, and well-being.

Patients with primary chronic headache have a reduced HRQoL measured by the Medical Outcomes Study Short Form (SF- 36) generic health-related quality of life profile questionnaire (10).

In particular, quality of life has been shown to be negatively associated with headache severity, impacted more by migraine headaches than by other forms of episodic headache, and diminished to a similar degree in migraine and in other chronic disorders such as depression.

The impact of chronic headache on HRQoL depends more on the frequency than on the severity of the headache attacks (11).

Population-based studies demonstrated that HRQoL scores in the migraine population were significantly lower than those in the control population. These studies also described the relationships between HRQoL and migraine frequency and disability. As migraine frequency and disability increased, HRQoL decreased (12,13).

Another approch to assess headache impairment is based on disability evaluation.

The Migraine Disability Assessment (MIDAS) is the most frequently tool used to measure headache disability. It consists of 5 questions that focus on lost time in three domains: schoolwork or work for day; housework or chores; and family, social, or leisure activities (14).

Migraine and other headaches are associated with significant limitations in all measured dimensions of patient well-being and functioning compared to the general population and to patients with other chronic diseases [10]. Bigal et al confirmed this concept, showing the direct relationship between migraine chronicity and disability (15).

Moreover, the global impact of headaches is measured using the HIT-6 questionnaire, which discriminates between different headache types.

Italian social protection policies in patients with headache

Italian citizens with medical diseases and, so, the ones with headache, can long for some forms of social protection:

1. Law 68/1988 ("*employment of people with disability*").

Headache is a highly prevalent on the young and productive population with significant socio-economical consequences (direct and indirect costs).

The law 68/1988 is addressed to:

- people with a permanent or a progressive physical, mental or sensory impairment with reduction of the ability to work greater than 45%;
- industrially disabled people with a degree of handicap of more than 33%, certified by the National Institute for the Insurance against Accidents at Work (INAIL);
- deaf or blind people;
- disabled ex-servicemen, registered disabled civilians and legally disabled persons with impairment as per DPR 915/78.

The law establishes special lists of people with disabilities who are looking for a job according to their abilities.

Employers, both in the public and private sector, are obliged to guarantee the workplace to people in these categories.

The Law obliges both public and private employers with at least 15 workers, to hire disabled workers in accordance with reserve quota.

This mandatory hiring, limited to new workers and valid for technical/executive staff only, also concerns political parties, trade unions and no-profit associations operating in the field of social solidarity, assistance and rehabilitation.

In our opinion, the law can be applicable to citizens with headache, with the aim of employment and re-employment of the worker with reduction of the ability to work greater than 50%, considering stress-related trigger factors in the workplace (for example, noises, computer, ripetitive movements).

2. Law 104/92 ("Framework Law for assistance, social integration and rights of the disabled people").

The aim of this law is guaranteeing the respect for human dignity, the rights to freedom and the autonomy of persons with disabilities, promoting the integration (in the familiar, scholastic and social context); preventing and removing negative conditions that stop the human development, the highest possible level of autonomy and participation in social life, as well as the enjoyment of civil, political and patrimonial rights; achieving a functional and social rehabilitation of people with physical and sensory impairment, while ensuring adequate services and prevention, care and rehabilitation measures, as well as a legal and economic protection; preparing adequate initiatives to overcome marginalization and social exclusion (art. 1 a), b), c) and d)).

Article 2, law 104/92 dictates the basic principles in order of disabled person's rights, social integration, care and assistance.

Article 3, law 104/92, defines a "disabled person" as someone «having a permanent or a progressive physical, mental or sensory impairment that determines difficulties in learning, social relations and work integration, in such a way as to determine a process of social disadvantage or marginalization». This notion stresses the limitations of faculties (impairments) and the social disadvantage (handicap), that is, on the elements that have a negative impact on the life of persons with disabilities. The idea according to which, handicap is a consequence of the impairment, is a potentially critical aspect overcome by the most recent perspectives on disability, such as the idea promoted by the World Health Organization (WHO) through the ICF (International Classification of Functioning, Disability and Health), on which the Government has been working for years in order to include the ICF, among others, in the job system, while considering environment as a key factor. A handicap is considered as severe when it determines a reduction of personal autonomy and requires permanent, global and continuous assistance, both in the individual sphere and in social life. However, the normative indication aimed at distinguishing "handicap" from "severe handicap" has not been followed by any specific evaluation instrument or national guidelines.

The quantification of the social and economical handicaps caused by headache is a complex problem, especially given the great variability of headache patients clinical pictures.

For example, patients with headache, which is a disabling disease, must have the possibility, by the

recognition of the handicap status, of the workplace nearing, as the headache trigger factors include sleep deprivation.

The patient suffering from headache must have the possibility to easily gain access to social and healthcare services and enhance their individual abilities, involving families and communities.

3. Ministerial Decree of 5th february 1992 ("*Approval of new tables of disabling diseases*").

The definition of registered disability ("*invalidità civile*") can be found in a law dated 1971 (law 118/71), amended in 1988, according to which "mutilated and disabled people are those people affected by congenital or acquired disability, even of a progressive nature, including mental disability caused by organic or dysmetabolic oligophrenia, mental insufficiency caused by sensory or functional impairment having reduced permanently the ability to work by one third at least, or, if under 18 years old, persons with permanent difficulties to carry out their tasks and activities.

In order to claim socio-sanitary assistance and attendance allowance, mutilated and disabled people shall be over the age of 65, with permanent difficulties to carry out the activities and tasks of their age".

In the category of patient between 18 and 65 years, the main reference is the reduction of the ability to work.

However, the scientific idea establishing a link between a disease and the reduction of the ability to work (which is referred to very generically) is very weak, and appears to be more the consequence of multiple compromises than a series of clearly explicable principles. In addition, the definition of the "ability to carry out the daily activities" is even vaguer; the evaluation of this ability does not rely on any methodological indication for the entire National territory. Other evaluation methods are applied to sensory impairment (deaf and blind persons), but with the same rationale.

The Local Health Units ("*ASL*") Medical Commissions are aimed at evaluating disabling diseases generally refer to specific tables, approved in 1992, based on the ICIDH (International Classification of Impairments Disabilities and Handicaps), that include, for each "pathology, disease, impairment", a fixed or a variable score.

Unfortunately, these specific tables do not include headache disorders, so that Medical Commissions must refer to generic chronic pain diseases for the attribution of precise scores.

In this contest, the approach to patients with headache is really complex, as, in most cases, there are no laboratory and radiologically findings or clinical signs to substantiate the presence of headache and the diagnosis is usually established through patients' reported symptoms (pain, photophobia, nausea, etc..).

Socio-sanitary assistance and attendance allowance are reserved for those suffering from conditions so severe that they are unable to work.

But, given that headache can range from mild to severe forms, it is not always easy to determine whether a headache sufferer is impaired to such a level as to be entitled to Social Security Disability benefits.

As with most other conditions that are not included in the table system, there is a lengthy process to access to disability benefits.

- first, the condition must be medically documented (headache diaries, nuclear magnetic resonances, neurological examinations, ecc..) and chronic;
- secondly, the documentation must show the impairment of the everyday life and of the work activity.

4. Regional proposal.

Recently, Lombardy, with the intention of better apply the social protection national system to people with headache, has spread an orientative table (table 1) for the specific evaluation of people with headache (Circolare regionale 14 dicembre 2006, n. 30, "Indicazioni operative per la valutazione delle cefalee nell'ambito dell'invalidità civile").

This table, that graduates headache from mild forms (15%) to chronic and therapy-resistent headache (46%) can be an useful tool of the Medical Commission in the evaluation of this disease.

However, this approach, based on attacks frequency, duration and intensity doesn't reflect the real impact of headache on the everyday activicties (working activity included) and appear insufficient for the evaluation of the person with headache disability.

Morever, referring to these tables, the higher score accessible to people with headache is 46%, precluding economical benefits (with are for scores greater than 74%).

The maximum score for people with headache neither is sufficient to rilieve from the payment of sanitary supply or therapies.

Table 1. Evaluation of people with headache. Circolare regionale 14 dicembre 2006, n. 30, “Indicazioni operative per la valutazione delle cefalee nell’ambito dell’invalidità civile”.

0-15%		**16-30%**	**31-46%**
A) episodic headache with low-medium frequency of attacks and good response to therapy	B1) episodic headache with medium-high frequency of attacks and poor response to therapy	B2) chronic forms with poor response to therapy	C) chronic forms refractory to treatment
1) migraine with or without typical aura	1) migraine with or without typical aura	1) chronic migraine	1) chronic migraine
2) tension-type headache	2) tension-type headache	2) chronic daily headache with or without medication overuse	2) chronic daily headache with or without medication overuse
3) episodic cluster headache	3) episodic cluster headache	3) chronic cluster headache	3) chronic cluster headache
4) episodic recurrent migraine	4) episodic recurrent migraine	4) chronic recurrent migraine	4) chronic recurrent migraine
		5) Short-lasting Unilateral Neuralgoform headache attacks with Conjunctival injection and Tearing (SUNCT)	5) Short-lasting Unilateral Neuralgoform headache attacks with Conjunctival injection and Tearing (SUNCT)
		6) continuous migraine	6) continuous migraine
		7) new daily persistent headache (NDPH)	7) new daily persistent headache (NDPH)
8) Trigeminal cephalalgias and facial pains	8) Trigeminal cephalalgias and facial pains	8) Trigeminal cephalalgias and facial pains	8) Trigeminal cephalalgias and facial pains

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