ADVOCACY for RECOGNISING VESTIBULAR DISORDERS AS A DISABILITY

Contents

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Vestibular Disability

Introduction

Balance disorders also referred to as vestibular disorders which include instability, dizziness, and head spinning or vertigo are a subjective disorder that causes physical, functional, psychological and social impairment that is not compatible with normal life and imposes severe restrictions on the patient. Most balance disorder patients have a very poor quality of life with restricted mobility, persistent fear of losing balance and falling and a constant apprehension of impending vertigo. Many of them get sudden unprovoked attacks of very incapacitating head spinning with nausea and vomiting. Even when they are not getting the vertigo attacks most of them cannot walk about freely, need support or the help of a care-giver to move about, cannot sit at a place for a long time and are often unable to mentally concentrate on the work they do as they always feel insecure. The handicap that includes psychological impairment induced by dizziness is tremendous and many balance disorder patients are so very much incapacitated that they cannot earn their livelihood; many such patients are forced to stay indoors and cannot lead a normal productive life. Many studies suggest that about 50% of persons who present to clinics for dizziness have psychological disorder too as a result of the disease[(1)]. Balance disorders can make a subject unable to perform any physical labour. Even light work as defined by the Social Security Administration of USA (SSA)'s guidelines for Social Security Disability applicants requires walking, a function that can become nearly impossible for those suffering with vertigo / imbalance. Sedentary work, defined by the SSA as work that requires sitting for up to six hours a day may be very challenging in patients who suffer from many types of vestibular disorders like Meniere's disease, Vertiginous Migraine etc. Vertigo causes dizziness and confusion; conditions that prevents the patient from mentally concentrating, and jeopardise the faculty of responding, thinking and acting quickly. For patients suffering from common vestibular disorders like Meniere's disease, Vestibular neuritis, Vertiginous Migraine etc. even getting in and out of a chair can be dangerous, and communicating on the phone and with others can be difficult due to impaired hearing esp. in conditions like Meniere's disease and labyrinthitis. This prevents them from living a normal life and earning a livelihood. Quite often they become social outcasts and professionally castrated. Hence vestibular disorders should be recognized as a cause of disability and such patients should be entitled to disability benefits. The

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functional or psychological impairment and the impairment in quality of life induced by the balance disorders is tangible, is measurable and is documentable. Since balance disorders are subjective sensations, it is difficult for others to figure out how much inconvenience such patients are experiencing and how much the patient is incapacitated and hence it often goes unnoticed and the physical and psychological impact unrecognised but there is no doubt that balance disorder patients are crippled and are severely handicapped physically, socially and psychologically.

Vestibular disability jeopardise day-to-day tasks of the patient leading to unsteadiness , increased risk of fall ,decreased independence, social isolation, diminished self-confidence, low self-esteem along with socioeconomic and employment handicaps. In the West, particularly in the United States of America and Europe, vestibular disability is covered by laws that govern handicap and disability just as that of hearing impairment, and gets covered under several social security schemes [(2)(3)] to promote equality and prohibit discrimination against vestibular disabled people[(4)(5)(6)(7)]. India, on the other hand, does list hearing impairment as a disability but does not include vestibular disability in the Persons with Disability (PwD) Act, 1995[(8)]. The impact on the day-to-day life on account of the latter are far more negative than the former (i.e., hearing disorders) and this policy paper advocates on why it should be listed under the PwD.

Definition and scope

As per the WHO International Classification of Impairments, Disabilities, and Handicaps publication [(9)], in the context of health, an '**impairment**' is any loss or abnormality of psychological, physiological, or anatomical structure or function and a '**disability**' is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Disorders of the vestibular system lead to vestibular disability. Vestibular system is responsible for controlling human balance. The balance / vestibular system provides us the faculties of what in medical parlance is described as gaze *stabilisation* (due to which the visual surroundings appear stable and in defects of which the surroundings appear to be moving and the subject feels vertiginous), *postural stabilisation* (due to which the subject can stand stable and erect without falling and in defects of which the subject cannot stand erect and tends to fall) and a *sense of verticality* (by which we perceive in our minds what is vertical). This sense of verticality has to be identical with the gravitational vertical and if this does not occur the visual field

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appears tilted which is psychologically very traumatic for the patient. Patients of vestibular disorders have one or more of the sensations of head spinning/ instability and the visual surroundings appearing tilted. All of them singly or combined together is very traumatic and very unpleasant for the sufferer and most if not all of them are incapable of carrying out important functions required for normal execution of day-to-day tasks [10] and consequently have a very poor quality of life and fear to go outdoors and as already mentioned hence are unable to earn their livelihood. A balance disorder can profoundly impact daily activities and cause psychological and emotional hardship.

Disorders causing balance/ vestibular dysfunction as encountered in clinical practice in the Indian subcontinent

- **Spinocerebellar Ataxia (SCA)**
- **Parkinson's disease (PD)**
- **Muscular Dystrophies**
- **Ménière's disease**
- **Migrainous Vertigo**
- **Vestibular Paroxysmia**
- **Benign Paroxysmal Vertigo of Childhood(BPVC)**
- **Persistent Perceptive Postural Dizziness(PPPD)**
- **Phobic Postural Vertigo(PPV)**
- **Wallenburg's syndrome**
- **Cerebellar stroke**
- **Labyrinthitis and Vestibular Neuronitis**
- **Secondary Endolymphatic Hydrops**
- **Sensorimotor Neuropathy**
- **Neurotoxic Vestibulopathy from quinolines (antimalarials) / heavy metals**
- **Multiple Sclerosis (MS)**
- **Alzheimer's disease (AD)**
- **Psychomotor disadaptation syndrome**
- **Benign Paroxysmal Positional Vertigo (BPPV)**
- **Perilymph Fistula (PLF)**
- **Mal de Débarquement Syndrome(MdDS)**
- **Vestibular-ocular Reflex (VOR) dysfunction**
- **Superior Semicircular Canal Dehiscence (SSCD)**
- **Acoustic Neuroma**
- **Enlarged Vestibular Aqueduct Syndrome**
- **Ototoxicity**
- **Post Concussion Syndrome**
- **CANVAS syndrome**
- **Presbyataxia**
- **Autoimmune Inner Ear Disease (AIED)**
- **Cervicogenic Vertigo**

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Symptoms and impairments caused by balance disorders

- **Vertigo and dizziness** – Sensation of spinning, imbalance or unsteadiness, falls
- **Spatial disorientation or imbalance** – Poor postural control, clumsiness, poor coordination, problem in gait., difficulty in walking
- **Psychological changes** – Depression, anxiety, feeling of insecurity, loss of self-confidence.
- **Visual impairment** – Focusing on objects becomes difficult, difficulty seeing in the dark, difficulty in focussing on moving the head.
- **Hearing impairment** – Decreased hearing, buzzing/ ringing noise in ear, sensitivity to loud noises, trouble focusing on sounds may accompany vertigo or imbalance.
- **Cognitive changes** – Difficulty in remembering, processing information and concentrating on tasks. Most balance disorder patients are now known to have cognitive impairments also

Prevalence of vestibular disability

Unlike today when balance disorders can be very easily identified and documented by the modern vestibulometric tests, in the past there were problems in accurately diagnosing and reporting vestibular disorders and hence worldwide statistics are scant. But based on some epidemiological studies, the high prevalence in the US and some other nations gives an idea of its extent through rest of the developed and developing world. An epidemiological study from the US reveals that the country has approximately 69 million people affected by vestibular dysfunction at any given point in time [(11)]. That forms 35 percent of adults more than 40 years of age. A report from the National Institute on Deafness and Other Communication Disorders (NIDCD), nearly 8 million Americans have chronic problem balancing themselves and an additional 2.4 million have dizziness alone. Surveys in the US show that as many as 80 percent of people above 65 years of age have experienced dizziness. Furthermore vestibular vertigo is more common in elderly (up to 3 percent) and nearly three-fold in females [(12)(13)]. Incidence is the number of new cases / persons without disease at baseline. The overall incidence of dizziness is 5-7% of the population and is as high as 35% in patients older than 40 years [(14)]. Hence this indicates that 5-10% of the population presents to the doctor with vertigo / imbalance as a new case every year. The incidence of falls is 25% in subjects older than 65 years

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[14]. Falls in the elderly are a major cause of morbidity. Vertigo and dizziness accounted for 2.5% of presentations in emergency rooms in US [15]. The estimated number of visits to the emergency dept of hospitals in the year 2011 for dizziness or vertigo was 3.9 million in the US [16].

Prevalence is the number of people who have the disease at one particular point of time and is calculated as follows:-

Prevalence % = no. of people with the disease / total population X100

Many studies regarding prevalence of dizziness have been carried out in the Western world giving different figures. As a rough estimate by analysis of different studies, the figure from Wiltink [17] of 15% prevalence (not incidence) of dizziness in middle aged adults seems reasonably likely to be correct [18]. Indian statistics are not available but averages of published studies of prevalence of vertigo in different countries shows that 15% of the general population suffer from balance disorders. Prevalence is 1.8% in young adults and more than 30% in the elderly [19][20]. 65% of individuals (older than 60 years of age) experience dizziness or loss of balance; often on a daily basis [20][21]. In the US, the estimated cost of medical care for patients with balance disorders exceeds $1 billion annually [20][22]. All these facts and figures related to incidence and prevalence does show the enormity of the problem and that this requires a special attention of health care providers.

Impact of vestibular /balance disorders on day-to-day life and long-term effects

Vestibular disability has a negative impact on the quality of life. The impact can be summarized as the following [23]:

- Recurrent falls and a statistically significant increased risk of falls
- Whirling or spinning sensation off and on sometimes persistent also and /or swaying sensation even while sitting and lying down
- Light-headedness
- Feeling of getting pulled or pushed to one direction and recurrently requiring to hold on to some support

Difficulty in attaining balance and spatial orientation

- Stumbling and falling
- Walking straight when turning
- Inability in maintaining erect posture on turning or on tilting the head

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- Looking downwards to confirm ground location and stamping on the ground while walking to anchor foot firmly on the ground
- Holding on to something when standing
- Problems of walking in darkness

Problems with vision

- Trouble tracking objects
- Trouble focusing and localising objects in three dimensional space
- Uneasy feeling in busy environments e.g., in crowds , in street crossings etc

Some such patients also have problems with hearing

- Hearing loss
- Fluctuating hearing
- Roaring, ringing, whooshing, buzzing of ears
- Intolerance to loud sounds
- Increased vertigo, imbalance and dizziness and even falls due to sudden loud sounds

Cognitive issues

- Lack of attention and concentration
- Memory lapses
- Disorientation and confusion
- Problem in understanding
- Physical or mental fatigue

Psychological issues

- Loss of self-confidence, self-esteem and self-reliance
- Social isolation, panic and anxiety
- Depression
- Agoraphobia i.e., fear of going outdoors

Other issues

- Nausea and vomiting
- Feeling of being 'seasick'
- Motion sickness i.e., difficulty in travelling in cars/ buses/ trains etc

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Problems with working at heights

Acrophobia or fear of heights –Recent research has established the link between vestibular dysfunction and fear of heights, endorsing the fact that vestibular patients who are construction workers and have never been diagnosed of the disability are at continuous peril of falling from construction sites. A research has stated that fear of heights has a strong correlation with vestibular dysfunction [24][25][26][27].

Measurement and Documentation of Vestibular impairments and quality of life issues

Vestibular impairments are very precisely measurable and the impact of balance disorders on quality of life is easily documentable; not only that the grade or degree of impairment can be accurately scored. All diseases that cause balance disorders have definite and very clear diagnostic criteria. Neurotology – the medical speciality that diagnoses and treats balance disorders is no longer an occult discipline that it used to be many years back and neurotology today is a complete evidence based medical science. To identify, measure and document the disability caused by a medical disorder involving a biological system:-

a) The disorder has to have definite and clear cut diagnostic criteria of the diseases that comprise disorders of that biological system,
b) The functional status of the different organs constituting the involved biological system must be precisely measurable and
c) The social /psychological and physical impact of the disorder measurable and documentable by a definite score.

Disorders of the balance system can be very accurately diagnosed and the degree of handicap very precisely measured and documented by the contemporary vestibular function tests. The impact of the vestibular disorder on the patient's social, professional or private life can be scored by the Dizziness Handicap Inventory[28]. The diagnosis of a vestibular disorder requires a comprehensive neuro-otologic examination with a detailed description of the vertiginous episodes, including notation of frequency, severity, and duration of the attacks which are analysed in the light of the findings of the vestibular function tests. Vestibular function is evaluated very objectively by clinical tests and by some very standardized computerized investigations. The balance organ called the vestibular labyrinth which is situated deep inside the ear is a very special organ which comprises of three semicircular canals and two otolith

organs called utricle and saccule to detect any form of movement. After these organs have sensed any change in the position of the body, the central nervous system restores balance by different neural reflexes called the vestibulo-ocular and the vestibulo-spinal reflexes. We now have a full battery of very sophisticated vestibular function tests available at our disposal which can pinpoint the site of lesion in the vestibular labyrinth and can document the exact extent of functional impairment. The tests are so very precise that the degree of functional impairment of the different organs that comprise the system can be expressed as a percentage of the normal function of that organ. These tests (called vestibular function tests) include the Videonystagmography / Electronystagmography that can very precisely document the functional status of the oculomotor system and the lateral semicircular canal; the Cervical & Ocular Vestibular Evoked Myogenic Potentials (cVEMP & oVEMP) for evaluating the otolith organs namely the Saccule and Utricle respectively; the Video Head Impulse Test (VHIT) for the three semicircular canals. The perception of visual vertical plays important role in maintaining balance and keeping a person erect which can be assessed by the Subjective Visual Vertical test. Similarly the functional integrity of the Vestibulo Spinal reflex system can be checked by various tests like Craniocorporography (CCG); Static Posturography – Stabilometry, Dynamic Posturography etc . The Vestibulo Ocular Reflex is accurately assessed by some of the tests above and can be re-confirmed by Dynamic Visual Acuity (DVA). Even the functional status of the nerves that constitute the reflexes can be tested by the nerve conduction studies; hence each and every part of the balance system can be tested and the functional and structural integrity of each part can be very precisely documented. The correctly performed tests interpreted by doctors with an insight and knowledge of the vestibular system in reference to the history and clinical can help us to accurately measure and score the disability caused by impairment of Vestibular function. The net functional impairment and the quality of life of a balance disorder patient can be very well measured and documented by the time-tested Dizziness Handicap Inventory (DHI)[28] and by it the extent of functional disability as well as the psychological impact of the balance disorder on the patient can be very precisely scored[28] .Hence the extent of impairment induced by the balance disorder can be very precisely documented by the tests available today and there is no reason to suggest that the damage induced by the balance disorder is intangible or that it cannot be measured. Since it can be measured we can definitely have parameters to grade the disability and hence provide disability benefits on the basis of the exact grade of disability.

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Policy in the West

United States of America and Europe

In the United States vestibular disability is covered under Americans with Disabilities Act (42 U.S.C. 12101(a)). Passed in 1990, it covers a very broad spectrum of disabilities including those with hearing and vestibular disorders [4][6][5]. Europe has a well laid-out human rights approach to disability issues [7]. It is not a matter of discretion there, but a rights issue, thus putting it at the core of the UN Convention on the Rights of People with Disabilities (UNCRPD), to which European Union is a signatory [29].

In the countries like USA, UK some severe cases of Vertigo especially Meniere's disease are recognized as a cause of disability.[2][3][30][31]. The reason why Meniere's disease is mentioned everywhere in describing balance disorders is because in the past, Meniere's disease was one of the very few causes of vertigo that could be easily diagnosed and the incapacity caused by it could be easily documented, but with the advent of all modern investigations in neurotology, today most, if not all, diseases causing balance disorders are easily diagnosable and the induced impairment measurable and documentable. The Social Security Administration (SSA) of The United States of America (USA) recognizes vestibular /balance disorder as a disability that in some cases qualifies for benefits[3]. In Disability Evaluation under Social Security Administration (SSA-USA), s*ection 2.00* deals with disabilities related to **Special Senses and Speech in Adult. Of this, 2.07 is related to Disturbance of labyrinthine-vestibular function** [3] (Including Ménière's disease).

In USA various benefits available of Vestibular Disability through Employer, Government and Private Insurance Firms is as follows[30]

1. Short-term disability insurance benefits through the employer (these usually last for 6 months).

2. Long-term disability insurance benefits through the employer (these usually start after 6 months and can last until retirement age).

3. Private disability insurance plans (insurance purchased for self that can last through retirement age or beyond).

4. State disability insurance (usually lasts for a year, such as through California's Employee Development Department "EDD").

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5. Social Security Disability benefits (available after being disabled for 6 months and lasting through retirement age).

6. Workers' Compensation benefits (only if the disability is due to a work-related injury).

Relevant framework for India

In India the act governing the disabilities is known as Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. It received the assent of the President on January 1, 1996. The act covers the following, ***but not vestibular disability***[8]:

- Blindness
- Low vision
- Leprosy-cured
- Hearing impairment
- Loco motor disability
- Mental retardation
- Mental illness

Summary

Various studies suggest that early referral to a specialist balance unit for patients with persistent dizziness are associated with better outcome in terms of limiting the disability [32]. But if the balance disorder has occurred and the balance organ(s) has been damaged, the patient is invariably in poor shape and is severely disabled if not totally crippled. The disability and functional impairment comprises of physical, psychological and cognitive handicaps and induce a very poor quality of life for the huge magnitude of unfortunate victims of vestibular /balance impairments.The vestibular labyrinth which is the special sense-organ for balance (like the retina is for vision and the cochlea is for hearing), is non-mitotic which means that the constituent cells if damaged are damaged for life and cannot be regenerated. Hence the disability cannot be corrected by medical /surgical treatment which means that the condition is irreversible. Disorders of the balance system therefore definitely calls for disability benefits and all stake-holders be they health care-givers like neurotologists, neurologists and otologists, public health workers, health adminstrators and vestibular disorder patient bodies need to work hand in hand to ensure that balance disorder is recognised as a disability and such patients are not deprived of disability benefits in all countries.

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