Viewpoint

DISABILITY ASSESSMENT IN TRAUMATIC BRAIN INJURY – ISSUES AND CONTROVERSIES

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ABSTRACT

This viewpoint article discusses the issues and difficulties that psychiatrists face when seeing patients with traumatic brain injury. Lack of proper instruments for assessment, lack of clarity on who is the medical authority for certification, confounding effects of comorbidities, etc. are discussed.

Keywords: traumatic brain injury, disability certification, RPWD Act

In clinical practice, there are many situations in which disability due to mental dysfunction has to be quantified. Usually, these are for helping mentally ill patients to avail welfare benefits and sometimes for medicolegal purposes. Assessment for disability benefits is done based on the criteria given in the Rights of Persons with Disability (RPWD)[1] Act in these situations. But it is felt that this Act does not cover all situations needing assessment and certification. One such situation is the assessment done for deriving the compensation to be awarded in cases of road traffic and occupational accidents, who have developed mental problems following traumatic brain injury (TBI) sustained in such accidents. There are many difficulties associated with this certification. Some of these are lack of appropriate tools, confusion about the proper medical authority for issuing the certificate and the confounding effects of pre-existing medical or psychiatric comorbidities. The RPWD Act has specified the Indian Disability Evaluation and Assessment Scale (IDEAS)[2] as the tool for quantifying psychosocial disability of mental illness and chronic neurological conditions. But, for many, there is confusion about whether this is the tool to be used in this situation and whether this is appropriate for cases with TBI. It is essential to use precise tools in such settings as the issued certificates may be challenged in courts of law. Further, the way disability is conceptualized in the Act is not in line with the recommendation of the World Health Organization. This leads to many difficulties for the doctors, the patients and the legal professionals. We attempt to discuss these issues in this article using case vignettes that we came across.

1) Issues with lack of proper tools and the scoring using ideas

Unlike the assessments done for availing welfare benefits, in these settings, the decisions of the doctors are likely to be contested in court.

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Hence proper instruments are needed for assessment. The Indian Disability Evaluation and Assessment Scale (IDEAS) was prepared under the initiative of the Indian Psychiatric Society (IPS) in 1996, when the Government of India (GOI) agreed to include mental illness as a disability in Persons with Disability (PWD) Act of 1996. Later the RPWD Act was passed as GOI notified that IDEAS is the tool to be used for estimating disability for mentally ill persons for getting the benefits specified in the act. We are using a few cases to discuss two aspects of the difficulty in certification. Difficulty in using IDEAS will be discussed here and the confounding due to the presence of comorbid psychiatric disorder will be discussed later. Some data show that World Health Organization's Disability Assessment Schedule (WHODAS)[3] may be a better tool. This point also is to be discussed.

Description of IDEAS

A description of the scoring of IDEAS[2] is given below. The corresponding terms used in WHODAS[3] are given within brackets. The tool includes the following areas:

1) Understanding and communication (Cognition in WHODAS)
2) Self-care (Same in WHODAS)
3) Interpersonal activities (Getting along in WHODAS)
4) Work (Life activities in WHODAS)

The score for each of these items ranges from zero to four. Zero is nil, one mild, two moderate, three severe and four profound. This gives a total score from zero to 16. Both instruments share four domains that are important for the assessment of disability, as shown above. The WHODAS has two more domains in addition to the above. These are Mobility and Participation (joining in community activities and participating in society). IDEAS does not have these but adds a score for the duration of illness (DOI), which is the final item that ranges from one to four.

This is scored as follows:

- < 2 years: add 1
- 2-5 years: add 2.
- 6-10 years: add 3.
- > 10 years: add 4

Thus, the total score of IDEAS ranges from zero to 20. For getting disability benefits, a person should have a minimum of 40% disability according to the RPWD Act. For this, the Act specifies a minimum score of seven out of a total of 20. Some of the patients coming for disability benefits have a score of four in the item for the duration of illness. Thus, in practice, any patient who has a score of one (mild) each in three of the four other domains, will get a score of seven, just because the duration score is four. So, even if there is only mild impairment in three out of four of the core areas affecting function, the person gets disability benefits.

Using WHODAS also has its merits and demerits. The item Mobility of WHODAS leads to confusion when assessing patients with sensorimotor or musculoskeletal comorbidities. Participation, that is, joining in community activities and participating in society is an important aspect of a person's life and is likely to be impacted by mental illness. This could be due to the direct effect of the illness or due to the stigma and discrimination prevalent in society towards mentally ill persons. It is good that WHODAS has included this item. It is surprising why this item was omitted in the IDEAS.

Neuropsychologists feel it may not be fair to use IDEAS, which is a tool for assessing disability due to chronic mental illness to assess disability arising out of traumatic brain damage. They use the NIMHANS disability index for TBI[4]. This is based on the score obtained from the NIMHANS Neuropsychological Battery. Courts in different parts of the country have accepted this disability index and give compensation accordingly. Using this battery requires a qualified neuropsychologist trained in administering it.

Case 1

Mr. Y, a 47-year-old male, reported to Motor Accidents Claim Tribunal (MACT) board for certification of disability after a road traffic accident that happened on 15th May, 2019. He had been treated for TBI (subdural hemorrhage) sustained in the accident. In addition, he had a history of bipolar affective disorder for more than 15 years in the past, with multiple episodes of mania and depression, and was receiving treatment with two mood stabilizers and other psychotropics. Before the accident, he used to work, mainly handling marketing in private firms.

When presenting before the board, he had memory impairment, shivering, difficulty in work, reduced energy, low confidence and motivation, easy fatiguability, reduced self-care and a history of nausea while travelling. The patient was referred by the board for neuropsychological assessment. The neuropsychological evaluation using NIMHANS Neuropsychology Battery[4] showed 73% impairment in cognitive functioning. The patient also had bipolar disorder for the past 15 years, currently in moderate depression with a score of 28 on Beck's Depression Inventory[5].

On the assessment of disability using IDEAS, he had a total score of 11 (scores for the self-care domain was one, interpersonal domain one, communication domain one, employment domain four and duration of illness (DOI) four, taking illness duration as 15 years, indicating 55 percent disability). This is inclusive of the duration of his bipolar disorder. If the duration is taken as three years only, that is the time since the TBI, the duration of illness score will be only two. So, the total disability score will be only nine, indicating 45 percent disability. This difference may not be significant for availing disability benefits as both are above the required minimum benchmark of 40%. But in cases in which disability is due to traffic or occupational accidents, this leads to a significant change in the compensation to be awarded. Hence, this aspect is likely to be contested in the courts.

There was confusion regarding the calculation of the total illness duration in this case. Is it from the date of traumatic brain injury or the onset of bipolar disorder? As per the opinion of the Neurosurgery department, he did not have any disability from their evaluation. This made us unsure of the level of the actual dysfunction. The Orthopedics and Physical Medicine units reported a five percent disability. Such cases of multiple disabilities raise one more issue. Should we use the telescoping formula in cases where there are multiple disabilities due to the accident or not?

Our further query is how to convert this cognitive disability of 73% to functional disability, especially when the neurosurgeon says there is no disability. The Clinical Psychologist who does the assessments is not a member of the certifying board and is not likely to be called by the court to testify. Will this create difficulty? Should the certificate mention quantity of disability as 73% based on the score in neuropsychological testing or 45% (DOI three years from the date of TBI)? Or is it 55% (DOI 15 years from the onset of bipolar disorder) using the scoring of IDEAS?

The scoring of IDEAS is in contrast to a comparable scale like the WHODAS, which has all the other domains except the duration of illness. So, the same person will get different scores when this instrument is used because DOI is not considered. But the score on the other four major domains is almost the same. In our opinion, this is an anomaly. The solution would be to remove the duration criteria in IDEAS or reduce its weightage from the current 4 points to a maximum of 2 or so. Basavarajappa et al.[6] have looked at the change that can occur in disability scores when IDEAS or WHODAS is used. They say, "a score of 23 in WHODAS corresponded to the score of 7 (40%) in the Indian Disability Evaluation and Assessment Scale (IDEAS)". They argue for shifting from

IDEAS to WHODAS and state that such a "shift would better identify patients whose disability status is influenced by the degree of disability rather than by DOI".

They further comment that in contrast to WHODAS, IDEAS does not specify any time frame for assessment of disability. WHODAS assesses disability over the previous one month. There is no such time frame in IDEAS; most clinicians consider functioning over the past few weeks to evaluate disability. Moreover, while IDEAS gives 20% weightage for the duration of illness (DOI), WHODAS does not have any weightage for DOI. Further, they opine that "DOI would not be a direct measurement of a person's disability." The initial proposal of IDEAS had "months of illness in the last two years" in place of DOI. But the duration of disability might be ideal. A time frame for measuring disability would also be required.

2) Issues in cases with pre-existing psychiatric comorbidity

In addition to these confusions, there are many areas where clinicians find it challenging to assess the patients and issue certificates. These are about the confounding effect of pre-existing/current mental illness in a person who subsequently gets involved in a road traffic accident. The patient in Case 1 had pre-existing bipolar disorder for 15 years with possible cognitive decline due to this. Further, it was difficult to ascertain whether the current disability is due to TBI or the current state of moderate depression. Assessing the state of functioning before the TBI is a contentious issue. One alternative suggested was using a tool like Vineland Social Maturity Scale[7] to evaluate the level of functioning before TBI. But the validity of this tool in adults is not established. It may not be easy to justify its use for this purpose before a court of law.

While there is some data on the negative impact of DOI on functioning in schizophrenia, this effect is not conclusive for bipolar disorder. It has not been clearly described anywhere how the calculation of the actual duration of illness is to be done in a disorder with interspersed periods of illness and wellness, like bipolar disorder. Hence, treating the two at par and giving the same benefit to both is not justifiable.

Using IDEAS for assessing TBI cases seems inappropriate for another reason too. Longer duration of illness is generally considered a poor prognostic factor for most mental illnesses. But this may not be true for TBI. Many patients may improve over time in this category. Hence, adding the duration of illness as a factor that always worsens disability is incorrect for TBI cases.

3) **Issues in cases with pre-existing physical comorbidity**

Case 2

Mr. L, a 34-year-old male who studied up to SSLC, was seen by MACT Board for evaluation. This patient met with a road traffic accident which led to head injury, and he was admitted to the hospital for one week after the accident. He later improved. The patient worked as a drawing teacher in a school before the accident and had to resign from his job due to memory impairment and easy fatiguability. He complained of forgetfulness, which also affected his ability to do the job. The patient has had a previous history of osteogenesis imperfecta with a history of multiple fractures since childhood. He was in a wheelchair; his mother supervised his daily activities, and he needed support for personal care from his mother. There was no history of any other past psychiatric illness or substance use. Neuropsychological assessment was done using the NIMHANS Neuropsychological Battery, which was suggestive of the involvement of frontal and parietal lobes and there was a 38 % impairment in his cognitive functioning. While scoring IDEAS in this patient, scoring the self-care domain was complex as there was a preexisting physical disability.

Case 3

A 76-year-old male appeared before the MACT board for certification to obtain compensation

for brain injury sustained in a vehicle accident. But later, on careful history taking, it was clear that the patient also had a cerebrovascular accident after the accident but before the present assessment. Hence the whole calculation of disability due to the accident could have been wrong.

The above two cases present the difficulty in patients in whom pre-existing medical conditions impair functioning and contribute to the disability. These cases demonstrate situations where comorbid physical conditions made the assessment challenging. In Case 2, the patient had mobility issues due to a pre-existing medical condition (osteogenesis imperfecta). It is not clear what adjustment is to be made in the scoring of items 2, 3, and 4 of IDEAS, which will be impacted by the medical condition. Using WHODAS instead of IDEAS may not help to solve this issue. In Case 3, a careful review of history brought the occurrence of an episode of stroke in the period between the accident and the assessment for disability. If this part were not clarified, the whole impairment would have been attributed to the accident. Such errors are likely to creep in when a patient comes before the doctor for certification without proper evaluation and documentation. Those attending the medical boards must keep this aspect in mind while seeing patients for certification.

The above discussion highlights some of the difficulties in the certification of patients presenting before the MACT board with TBI. Some additional problems are discussed below.

4) Non-inclusion of TBI and lack of a specified medical authority.
5) Issues in the definition of disability

4) Non-inclusion of TBI and lack of a specified medical authority

Unfortunately, the RPWD Act is silent on this condition, though it has listed many disabilities, including chronic neurological conditions. Some neurological disorders have been listed in the Act as being eligible for disability benefits, but TBI is a notable exception. Math SB et al. [8] highlight the omission of TBI among the conditions eligible for disability benefits as a lacuna of the Act. This creates considerable difficulty for patients, families and professionals involved. They have also raised criticism about the description of these neurological conditions.

Medical authority who has to issue disability certificates is mentioned in the Act, except for this category. There is confusion regarding this; in some centers, it is the clinical psychologist trained in neuropsychology who issues the certificate. In our country, even clinical psychologists are in short supply. Hence, this can be difficult in most hospitals, including medical college hospitals. The other group of professionals who should be involved is neurologists. But they also may not be available everywhere and usually do not attend the medical boards. There needs to be more clarity and proper guidelines regarding this. In practice, at least in Kerala, the task of issuing these certificates has fallen on psychiatrists, who are already members of many medical boards. Though there are no clear guidelines in this area, most psychiatrists consider such patients as suffering from neurocognitive disorders and issue certificates. In the absence of any specific tool for this, they use the one they are familiar with, i.e., IDEAS.

5) Issues in the definition of disability

Another criticism about the approach of the act is that it runs counter to the spirit of the International Classification Of Functioning[9] (ICF) of WHO. The ICF views disability as etiology neutral and only looks at the impairment in structure or function, restriction in activities and limitation of participation as the aspects to be assessed for disability quantification. The WHODAS was developed for this. But the RPWD Act has ignored this and lists multiple etiologies for disabilities. The concept of ICF is not to consider the etiology of the condition that led to disability and only quantify the impairment, restriction and limitation that causes difficulty in the person. It does not

differentiate between mental or physical causes of disability. WHODAS is a tool intended to measure disability due to any conditions.

To quote from the ICF document:

"***Parity and aetiological neutrality.*** In classifying functioning and disability, there is not an explicit or implicit distinction between different health conditions, whether 'mental' or 'physical'. In other words, disability is not differentiated by etiology. By shifting the focus from health conditions to functioning, it places all health conditions on an equal footing, allowing them to be compared using a common metric. Further, it clarifies that we cannot infer participation in everyday life from diagnosis alone[9]".

"In classifying functioning and disability, there is not an explicit or implicit distinction between different health conditions. Disability is not differentiated by etiology. ICF clarifies that we cannot, for instance, infer participation in everyday life from medical diagnosis alone. In this sense, ICF is etiology-neutral**:** if a person cannot walk or go to work, it may be related to any one of several different health conditions. By shifting the focus from health condition to functioning, the ICF places all health conditions on an equal footing, allowing them to be compared, in terms of their related functioning, via a common framework".

But the RPWD Act lists the etiologies and hence stresses the causes than the loss of function, which is the real measure of disability. The WHODAS is designed to be a measure of disability and should be the standard tool to quantify both physical and psychological disability without even considering whether it is due to a physical or psychiatric cause. Only then can we stop the stigma and discrimination that mentally ill persons are being subjected to.

The following areas need urgent clarification and legal regulation if people with TBI are to get the benefit of proper certification and compensation.

- Who is the medical authority to issue these certificates? Is it the psychiatrist, the clinical psychologist, the neurologist, or the neuropsychologist?
- Is NIMHANS Neuropsychological Battery the tool for assessing cognitive functions for certification of disability/compensation in cases of TBI? If it is to be used, how to convert the score obtained to functional disability?
- What is the tool for assessing and quantifying the disability in cases with TBI? Is it IDEAS, WHODAS or some other tool?
- What adjustments need to be made in the quantification of disability in patients presenting with pre-existing physical or psychiatric comorbidity?
- How to mitigate the impact of the patient's current mental state on disability assessment?
- At a broader level, we think, the issue of how to define disability would also have to be considered, at least, in future revisions of the RPWD Act.

Conclusions

After discussion with experts working in this area, we have come to the following realizations. Certification of TBI patients has not received adequate attention from neurologists, neurosurgeons, and rehabilitation professionals in our country. There is no proper tool fixed for this purpose. But professionals faced with the day-to-day task of assessing and certifying these patients have found their own ways to prevent a stalemate, which could have led to undue difficulties for the patients with TBI and their families. In many centers, the task of issuing disability certification for TBI cases is being done by psychiatrists. Most psychiatrists are aware that there is no clear procedure for issuing disability certificates to persons with TBI in the present RPWD Act. One way out used by many of them who are faced with the task is to treat these cases as belonging to the category of chronic neurological illnesses mentioned in the RPWD Act. They assess these cases using tests of cognitive functions like the Mini-mental

State Examination (MMSE)[10], Addenbrooke's Cognitive Examination[11] or Montreal Cognitive Assessment (MoCA)[12]. Tests of lobe functions are also used. Diagnosis is based on ICD 10[13] and categories from the Organic disorders (F00) block are used. Assessment of disability is done using Indian Disability Evaluation and Assessment Scale. They have not faced any difficulty in courts accepting these certificates. As IDEAS is the tool mentioned in the Act as a tool for assessing psychosocial disability in cases of chronic neurological illnesses, this may be a practical solution till the necessary framework and procedures are in place.

Neuropsychologists recommend and continue to use the NIMHANS Battery to calculate disability in cases needing certification for claiming compensation. In their experience, many courts have accepted these certificates. Recommendations have been sent to the Government of India to amend the Act to include these recommendations.

Considering all these, we hope the government comes out with amendments to the disability Act without further delay.

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