# Self-Esteem in Idiopathic Epilepsy

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People with etiologically unknown (idiopathic) epilepsy may have their self-esteem compromised to a certain extent, particularly the females. These results validate our position that people with epilepsy are “more than their mere symptomatic illness”, and that there is a worth in capturing wider patient-reported outcomes, beyond mere seizure frequency and severity. We consider that the usual epilepsy care must go beyond the mere prescription of ASMs.

Unknown epilepsy | Idiopathic | Epilepsy | Bhalla | Self-esteem | Epidemiology | Intergovernmental Research and Policy Journal | irpj.academia.edu

## 1. Introduction

People with epilepsy are more than their mere symptomatic illness. By this, we mean that the patient’s cognitive, behavioural or emotional perceptions may also factor for the favourable clinical outcomes and social situation of the affected patients [1]. One such factor would be the patient’s self-esteem. Self-esteem is defined as a perception of inner-self in determining relation to oneself. It is an essential concept in chronic conditions, like epilepsy, for numerous reasons. Theories have held that what we believe about ourselves strongly influences our choices, decisions, level of effort and persistence, and how we subsequently perform [1]. For instance, low self-esteem is related to procrastination, delay and avoidance [2] as an excuse for adverse outcomes. Others have shown that those who report low self-esteem feel vulnerable and discouraged from seeking help [3]. On the other hand, higher the self-esteem, the more motivated would be the patient to engage in self-care and coping [4], which, in turn, means the reduced impact of illness on one’s life [5]. Self-esteem and self-efficacy are distinct constructs, but, increasing self-esteem could subsequently increase willpower in changing the negative health-related behaviours, which, in turn, builds self-efficacy [6].

In case of epilepsy, reducing self-perception of epilepsy as something devaluating and shameful is an important goal of treatment strategy [7] because a poor sense of self-esteem contributes to the feelings of being different, which may counteract positive effects of treatment. For instance, others have shown that people with epilepsy feel like a burden on their family, which, in turn, increases their risk of self-injuries and death [8]. Similarly, low self-esteem is a barrier against learning of how to live with symptoms and being accustomed to the resultant identity change, which is essential for well-being in epilepsy [9]. In contrast, high self-esteem protects against falling into a negative, doubtful state regarding one's ability to cope with or overcome their illness [10].

The risk of poor self-esteem may vary depending upon the cultural context of the patients. For instance, in many cultures, epilepsy is seen as a possession by evil spirits [11]. In another example, in the 6$^{th}$ century BC Persian

Textbook of Avesta, [12] the “God states that the persons with epilepsy should not make an offering in honour of him”. So, people with epilepsy may feel the devaluation, shame, secrecy and withdrawal triggered by such negative stereotypes, [13] which may marginalize the patients, and their families and community. In addition, epilepsy is not a single and homogeneous disease condition, which means that the patient's own sense of esteem may differ with the type of epilepsy and seizures. For instance, etiologically unknown (hereafter referred as idiopathic) epilepsies, by definition, are those for which the underlying cause is not known (i.e., lack of causal inference). So, this ambiguity of identifiable external cause of the illness may mean that patients would perceive themselves as the internal locus of causality, i.e. recognizing oneself as the cause of events, something which is associated with low self-esteem [14]. Moreover, the causal ambiguity goes against the theory of locus of control in the sense that others (e.g., medical professionals) are controlling life's decisions (e.g., medication uptake) rather than the individual himself. Furthermore, confusion about one's identity arising from the idiopathic nature of epilepsy may lead one to maladaptive coping responses of escapism or avoidance of current issues [9].

Furthermore, many epilepsy patients never achieve (or maintain) clinical remission despite several therapeutic options, [15] which means that adverse psychosocial sequelae would possibly be affecting their therapeutic outcomes in epilepsy [16]. Thus, with such a vision, the primary aim of this study was to look into the frequency and correlates of poor self-esteem in persons affected with idiopathic epilepsy in Demavend, Iran. The secondary aim of our study was to estimate the psychometric properties and factor structure parameters of a brief Gharagozli-Bhalla Self-Esteem in Epilepsy (GB-SEEQ) Questionnaire. We believe our work would help to provide means for rapid assessment of self-esteem in usual clinical settings as a way to improve the outcomes of epilepsy for the patient’s wholesome and sustained well-being.

## 2. Self-Esteem and Idiopathic Epilepsy

Self-esteem is a clinically relevant parameter in epilepsy. For instance, by improving self-esteem, one may reduce the symptomatology and have improved quality of life [14][15]. Low self-esteem is a possible obstacle in effective self-management and coping, such as by negatively affecting one’s willpower to adhere. Low self-esteem may also lead to mental health issues such as depression or anger, which may further compound the negative impact of epilepsy on one’s life [17].

In our study, the mean self-esteem was poorer among females than males, but, upon logistic regression, there was no association between sex and self-esteem components. These results are consistent with current data from numerous countries that have shown that males display higher self-esteem than females.[18] Any pattern of sex difference in self-esteem is possibly the result of multiple macropsychological mechanisms and a broad set of social, economic, demographic and cultural value indicators that guide culture-specific self-esteem development in males and females [18]. Another possible explanation for a sex difference in self-esteem could be related to the fact that females are more likely to have neurotic traits than males [19], which was found to be strongly related to being “displeased with myself” in our study. Neuroticism is the most studied personality trait in the health literature, and its association with poor self-esteem is not unexpected [20]. So, from these results, we may infer the need to include personality trait assessment as a part of usual epilepsy care, more so since therapy may alter negative

personality traits, [21] which may help the patients in their day-to-day management of epilepsy [22]. Moreover, treating physicians may also consider complementing behaviour-modifying positive body image interventions [23] that help to trounce unhealthy beliefs to ensure one's acceptability to oneself. The association of hand tremors with self-esteem can also be understood through possible subjective alternation in body image and self-concept among the patients due to their epilepsy or its treatment [24]. Thus, active engagement of theory-based behaviour-modifying positive body image interventions, such as persuasive cognitive dissonance, [23] within usual epilepsy care may help to trounce unhealthy patient beliefs to ensure one's acceptability to oneself.

The personal component of self-esteem was associated with unemployment and the side-effect of difficulty in finding words, names and appointments. Being gainfully employed allows one to feel content in personal, familial and social aspects of life [25]. But, unemployment contributes towards ill health and influence peoples' development, life's pleasures, quality of life and self-esteem in a negative way [25]. The association of self-esteem with unemployment in our study is reasonable since economic inactivity is strongly related to self-esteem [26]. Unlike many other conditions, epilepsy could be more disruptive and poorly acceptable socially, which may interfere with the epilepsy patient’s chances of being employed [27]. So, based on these results, we may infer the need for health agencies to improve the unfair prejudices and stereotypes (e.g., related to accidents and absenteeism from work [28]) of possible employers towards epilepsy [29]. Also, the health agencies should focus on creating job quota system for people with epilepsy or develop occupations that are adapted to epilepsy, such as the micro-franchisee program designed by the last author. In this micro-franchisee program, the recovered (or well-controlled) epilepsy patients work as “local advocacy, support, and domestic health visiting agent” in their own rural settings in exchange for an honorarium and a bicycle [30][31][32].

Another factor related to the personal component of self-esteem was the difficulty in finding words, names and appointments. Mild cognitive restrictions are common for people with epilepsy [33]. So, we may infer that treating physicians should make use of cognitive training interventions to deal with such anticipated issues, either from the prolonged use of ASMs or from seizure-induced brain injuries and neurodegeneration [34]. Others have also shown that those who undergo cognitive training achieve improved functional connectivity [35]. Similar could be the strategies for other side-effect issues that were found to be associated with self-esteem, for instance, hand tremor, which is an established side-effect [36] with ASMs, especially with valproate. Thus, instead of vague follow-ups, the health agencies should seek to develop a system of periodic follow-up contact with the patients to help issues identified early-on, through, for instance, domestic health visitors [30][31][32]. This way, treating physicians would have the possibility to optimize doses or change ASMs in an appropriate time and manner [36].

The factors that affected the home/family component of our patient's self-esteem were headache, having been insulted due to epilepsy, always thinking about epilepsy, and illiteracy. People with epilepsy are less likely to follow their mandatory education well or be adequately employed, which is a risk for their adequate self-esteem. There is a substantial overlap between illiteracy and one's self-esteem through, for instance, unhealthy concepts and evaluations [4][7][10]. For instance, people with low literacy levels are often viewed as unintelligent, unproductive and deficient, which may or may not be true though [37]. Illiteracy is also associated with increased dependence upon others, poor coping and mental health [38]; which may affect one’s esteem through internalizing and externalizing

ways. Unfortunately, illiteracy is not a factor that can be modified at the patient level, but, high levels of health literacy may translate into less harmful psychological elements [39]. Furthermore, the association of insult due to having epilepsy with self-esteem is not unexpected either. Feeling offended is a self-conscious emotion [40] like shame, and is typically trigged by a blow to a person's honour, hence to one's public face.

Another factor related to low self-esteem was "always thinking about epilepsy". Always thinking about epilepsy may precipitate into a constant state of anxiety or fear, which is relatively reasonable since epilepsy is a long-term illness, and the onset of seizures is sudden, unpredictable and unprovoked. A variety of cognitive-behavioural therapies are available, which can help patients confront the pervasive effects of epilepsy or its treatment (e.g., headache) through self-responsibility, self-acceptance, and self-assertiveness [41]. For instance, cognitive-behavioural therapies may help epilepsy patients to overcome anxiety attacks, feelings of having no control over one's life and being completely helpless.

We also estimated the psychometric properties of our B-GEQ questionnaire. The alpha coefficient of internal consistency was considerably higher than the usual criteria of 0.70. High alpha coefficient means that all our elements were in line with each other to measure a common underlying construct together. Also, our questionnaire was not biased to raise one particular type of participant response since the group alpha coefficient for responding a yes to an item (a0.85), and no to an item (a0.93) was sufficiently high and similar to each other. Besides these, our factor structure was also adequate, for instance, 90.0% coefficient of determination, 86.9% cumulative variance, and 0.09 as the standardized residual. For factor analyses, we used conventional parameters, such as eigenvalue ≥1.0 and factor loading ≥0.40.

### 3. Conclusions

To conclude, we found that people with etiologically unknown (idiopathic) epilepsy in a non-western context may have their self-esteem compromised to a certain extent, particularly the females. These results validate our position that people with epilepsy are "more than their mere symptomatic illness", and that there is a worth in capturing wider patient-reported outcomes, beyond mere seizure frequency and severity. By taking upfront the epilepsy patients as "more than their mere symptomatic illness", we might be in a better position to reduce the compound impact of epilepsy on one's physical, mental, and social well-being through complementing behavioural therapies with usual ASMs. However, it is necessary to estimate the effect one, and who, may obtain from such complementary therapeutic approaches in epilepsy.

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