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STIGMA AND SELF-STIGMA IN ADOLESCENTS WITH EPILEPSY PSYCHO-SEოANTIC APPROACH

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Introduction: Over 50 million people worldwide have epilepsy and 80% of them live in developing countries. [7]. According to the international statistics, although the complete seizure control is achieved in considerable part of the patients, the majority of them are suffering the enormous influence of social stigma and self –stigmatization [1]. Level of stigma awareness in patients with epilepsy is relatively high. It turns out that, 50% of them consider themselves stigmatized, while 15% has strong feeling of being an object of stigmatization. Furthermore, young people face stigma more often than the old ones. [5]. Considering psychological issues of adolescence, stigma-related problems of chronic disease should be of biggest importance for this age group among population with epilepsy. Problems of stigmatization in adolescents with epilepsy are less explored nowadays though.

Researches about adolescents with epilepsy involve youngsters between the ages 11-21. It should be noted, that researches are mostly based on data obtained from questionnaires and scales [8], [6], [4], [3]. One of the limitations associated with the study of stigma is, that it is difficult to narrow it down to specific variables. Because of that, most of the studies about stigma are correlative and quantitative. Although recently in a scientific study of the stigmatization of people with epilepsy, qualitative, phenomenological approaches have become more common 11]. On the one hand, the reason is that quantitative researches do not provide enough data about the subject, because individuals might not be conscious of some of the components of self-stigmatization and these components may unconsciously affect their important attitudes. On the other hand, qualitative approaches are far more relevant for studying phenomena, such as stigma and stigma perception. Psycho-social aspects of epilepsy has not been studied on Georgian population until recently, therefore the number of researches is few. The most part of the studies involve only adult patients and comprises general information about the quality of their life and public awareness [13].

Stigma, either in a form of social discrimination or any other kind of action, expressed in behavior towards the group of people with epilepsy is obvious, observable, exteriorized and conscious. It's far more difficult to study the phenomena of stigma perception and self-stigmatization. The patient's values and attitudes to self-perception and self-stigmatization are not obvious, observable and very often are unconscious. It should be noticed that less conscious attitudes and beliefs are very hard to reveal and assess because of psychological defense mechanisms (denial, regression, rationalization etc.) affecting such types of phenomenon. Therefore attitudes and values of patients with chronic disease, related to self-perception and self-stigmatization are hard to reveal and require

specific approach. The best way to accomplish this is to use a procedure that would allow phenomenological analysis of the issues of self-perception, self-stigmatization and help to unveil true values and believes of patients with epilepsy, while avoiding the defense mechanisms mentioned above.

Objective of the research is to reveal the subjective picture of self-stigmatization.

Methodology: To expose the picture of self-stigmatization of adolescents with epilepsy, we considered using psycho-semantic experiment to be most valid, to study important attitudes for individual consciousness.

The paradigm of psycho-semantic experiment originates from Osgood's semantic space model (semantic differential technique) and personal construct theory of Kelly. Psycho semantics, although a discipline of psychology, is of apparent interdisciplinary nature and is linked with other fields of study such as sociology and philosophy. Psycho-semantic experiment gives opportunity to study knowledge, connotation and constructs of individual in action and not introspectively. Experimental psycho-semantic paradigm allows modeling the real forms of action of speech and reasoning, especially reconstructing the system of connotative meaning of individual or group consciousness by building up the semantic space [12]. Semantic spaces reconstructed with psycho-semantic experiment, describes the perception of the disease and related social and psychological aspects perceived by the adolescents with epilepsy (as an integrated group), as well as "true", unveiled meanings of the phenomena mentioned above, and relations between them.

For the research, we used non-probability sampling method while recruiting participants from epilepsy program of state health service, on their informed consent. Participants group included 55 adolescents: 26 females and 29 males.

Criteria for Selecting Participants: 1. diagnosis of epilepsy; 2. the length of the diagnosis at least 2 years; 3. the age of the participants 14-18 years.

Criteria for Excluding Participants: 1.intellectual disability; 2. specific language impairment; 3. severe organic brain syndrome; 4. physical disability.

Control group included: 30 healthy adolescent of both gender (16 male, 14 female).

In this research we use the combination of different categories of words with connotations describing disease-related, psychological or social phenomena. Materials for experiment were selected with the expert of the field. 126 words/connotations where selected in total. Several categories have been outlined (See Table 2). During experiment participants were given a stack of cards with notions and were asked to group them together as it made sense to them (no right or wrong answers).

Table 1

General notions:	Notions describing individual characteristics	Notions describing psychological feelings	Notions associated to the disease	Notions describing social function
Light	Independence	Learning	Epilepsy	Support
Darkness	Activeness	Anger	Seizure	Respect
Beauty	Indifference	Tormenting	Patient	Power
Hope	Self-control	Grief	Healthy	Friendship

Results: Data have been processed in SPSS-16. Cluster analysis refers to categorize the variables in different groups (clusters). In the given case, hierarchical cluster analysis was used, that considers visual analysis of dendrogram and determining the maximum distance of cluster agglomeration. Clusters of analyzing level are semantic system reconstruction of the group consciousness. Each cluster of patients with epilepsy represents significant semantic unities. These integrities create the picture of relations of their consciousness. Thus we named the clusters according to their connotations.

Cluster "Family and Love"

It is one of the biggest clusters in semantic space of patients with epilepsy. The central construct of this cluster is "fate". The cluster describes traditional family: man and woman united in marriage with their children. The same cluster includes the notions, such as "reproduction", "love", "happiness" and "respect". Unification of these notions indicates that the group of patients considers family as source of social respect and happiness. Merging "reproduction" and "child" with the cluster of family suggests that reproduction and having children is considered obligatory in family, while having children without marriage is precluded. All these factors represent the understanding of family in context of tradition and culture. The family cluster also includes the notions of "past" and "future". Having a family is considered a stable, strong value and is a consistent unit through the past and future. In case of control group, "fate" is associated with "infertility" and is in the same sub-cluster together with "hope" and "future". This difference suggests that for healthy adolescents, infertility is considered in context of fate, but in positive and optimistic perspective. Unlike to patient group, where family is related to past as well as future, for healthy participants family is merely connected to future.

Cluster "Hope"

The given cluster contains two sub-clusters. The first sub-cluster gathers the notions "friendship" and "support", which is considered similar by the adolescents with epilepsy. Thus support and friendship for adolescents with epilepsy is related to compassion while friendship is associated with kindness and hope. Friendship considers support, compassion and gives hope and optimism to patients. Hope is hereby related to psychological comfort, compassion, support, that on its hand is associated with joy and delight. The data reveals that unlike patients healthy adolescents connect "hope" with family.

Cluster "Human"

Central constructs of the cluster are "beauty" and "health". Concept of "human" is related to "life" and "health", while "health", on its hand, is related to "attractiveness" and "beauty". In fact, for the patients, healthy person is beautiful and attractive as well. Therefore, person with disease is neither beautiful, nor attractive. This fact must have an important influence on their self-esteem. In case of control group the notion of "beauty" appeared to be associated with "sympathy" and "friendship". Thus for healthy participants, beauty and the resulting sympathy are prerequisites of stable social connections and friendship. Healthy adolescents unified the notion of "human" with

"life" and "viability" in separate cluster, showing that they see this concept in more general context and do not attribute it to health and beauty.

Cluster"psychological self-affirmation in society"

The cluster describes self-affirmation in society. The basic semantic construct is "distinctiveness". The cluster also comprises "fight", "competitiveness", "public opinion" and "sociability". For patients being different means fighting competing and considering the public opinion. Other important notions in this cluster include "strength" and "sociability". Supposedly, for the victorious fight, they consider "strength" and "sociability" as most important traits. Considering the context, sociability is possibly the way to prove to "others" that they are not "different". Thus, self-affirmation in society and reducing difference may be achieved with sociability. As for "distinctiveness", being the basic construct of self-affirmation in society for patients, it is standing separately in the dendrogram of the control group, in the same cluster with "respect" and "self-confidence". For the patients "distinctiveness" has a significant role on their way of self-affirmation, while for healthy participants it is not connected to "competitiveness", "public opinion", "strength" and "sociability".

Cluster "ego-regulation and situation control"

This is one of the most important clusters with central construct of "regime compliance". This construct turns out to be connected with "prudence", "motivation", "and ability to work". Regime compliance is the most important constructs for epilepsy patients which means keeping regime – systematic and timely use of medicine, getting enough sleep and reducing the factors that trigger seizure (e.g. exhausting, prolonged computer use etc.) Having seizure refers to losing control over one's body and regime compliance means controlling seizures that gives them opportunity to maintain control over oneself and situation. For this group, this makes person prudent, motivated, purposeful and able to work. The concept of "regime compliance" is connected to "safety" – this shows more connection between regime compliance and controlling seizures. Very often, seizure is the cause of injure, moreover, impairment of consciousness during seizure endangers their life – for example, losing consciousness during swimming or getting serious brain injury after falling may be life-threatening. For the control group, "regime compliance" is located with "profession", "high salary", "power" and "success". Therefore, healthy adolescents see the regime compliance in different, mainly in social context.

Cluster "Illness"

The cluster describes medical condition. It contains more of description than emotional characteristics. Presumably, the emotions related to the situation are suppressed. The main constructs in the cluster are "curable" and "incurable". Besides, "incurable" is linked with the notion of "disability". Therefore, inability to cure the disease equates to disability. The notions given are connected with "infertility", referring to the fact that fertility (and therefore having family, as we have argued above) is associated with good outcome of their disease. It is noteworthy that notions "spells" and "seizure" are located in different clusters. "Spells" is more connected to "anxiety", while "seizure" is associated to "epilepsy", "patient" and "curable". Therefore, adolescents with epilepsy do not

consider the two notions ("seizure" and "spells") similar. Furthermore, if "seizure" is connected to the notion of "curable" and this connection has optimistic orientation, "spells" is associated to "anxiety" and has rather negative sense. Unlike the group of patients, disease-related notions, such as "anxiety" and "spells" are classified in totally different clusters. More specifically, "anxiety" is together with "fear" and "victim" in the cluster of negative emotional experience, like notions of "frustration", "failure", and "grief". For the control group, "spells" unifies the large cluster, containing disease-related notions: "clinic", "medical personnel", "epilepsy", "seizure", "patient" etc. Thus, for healthy participants "spells" is the construct that generalizes epilepsy and related medical context.

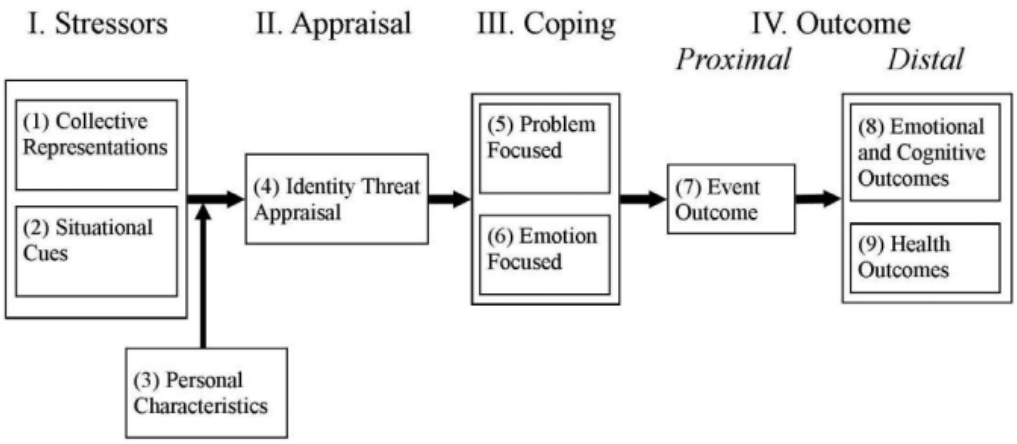
Cluster "Self-stigmatization"

Separate cluster of stigmatization and stigma-related concept describe the phenomenon of stigma very well: for the adolescents with epilepsy stigma is connected with "ugliness", "mockery", "isolation" and "frustration". All these notions are unified together with the notion of "flattery". Connection of flattery with these notions is particularly interesting, because these notions are directly related to discrimination and stigmatization. Therefore absence of mocking, isolation, and humiliation is perceived by patients as flattery, emphasizing the fact that the adolescents with epilepsy consider themselves stigmatized. This cluster shows that accepting people with epilepsy as an equal and alike, is an expression of stigma, because patient with epilepsy knows, that he or she is different and is not accepting this fact by others, is regarded as not sincere.

"Flattery" and "damaging", which patients located in self-stigmatization cluster, are connected to "disablity", "fault" and "label" for the control group. Healthy patients see the disability as a fault and the reason of stigma. Logically, the cluster contains separate group of "mockery", "antipathy" and "humiliation". It, in fact, describes all actual attributes of stigmatization. While for group of patients stigma is connected to the notions describing self-stigmatization and related emotional state (isolation, mockery, frustration, and ugliness). "Isolation" and "ugliness" were located by the control group in separate cluster with notions of "aggressiveness", "irritation", "confusion" and "shame". Here "shame" is part of stigma-cluster.

Discussion: Human cognitive processes tend to categorize objects, events and society members. Our perception of the universe is based on such cognitive processes as categorization, generalization, or division into smaller sub-groups, creating of subordinate systems. The mentioned process is then followed by stereotyping. This means granting a separate category with a stereotype or prejudice. Adolescents with epilepsy have obvious manifestations (epileptic seizure) of their condition which is associated with different stereotypes and prejudices in almost every culture of the world, including Georgian society. The participants with this disease experience stigmatization from the members of the society and are in conditions of suffer from constant pressure and stress. Considering the mentioned characteristics of the target population, for interpreting data obtained from a research we chose "identity disturbance model" [9].

According to the model of the threat of identity caused by stigma, stigma is a source of stress. And as a result of stress, the physical, cognitive and emotional welfare of the adolescents with epilepsy can be disturbed. According to the identity disturbance model, the main sources of stress,



for the participants with epilepsy, are collective stereotypes, situational cues and individual characteristics.

Collective stereotypes : The effect of illness-related collective stereotypes can be clearly seen from the clusters such as "human", in which the notions of "life", "beauty", "attractiveness" and "health" reflect the widespread opinion that a human is beautiful and attractive and subsequently, a person with illness cannot be perceived as beautiful or attractive. Thus, belonging to the category of not-healthy participants shall have an important impact on the self-esteem of the adolescents with epilepsy! For the epilepsy patients of both genders, the concept of "family" is connected to the notions of "reproduction" and "child". This connection reflects the stereotype established in Georgia, that family without a child is not a family. The influence of collective stereotypes is also evident in the cluster of "illness". To be more specific, the notions "infertility" and "disability" appeared to be united in the cluster that assembles the illness-describing notions. The mentioned indications represent the opinion spread in the society about the possibilities of a person with epilepsy to have a child. So, for the adolescent with epilepsy, the diagnosis of epilepsy includes the following threats: infertility, problems in getting married, diminished self-assessment (I am not healthy – I am not attractive).

Situational cues: The most important from the situational cues is discrimination. In the given case, these are the situations where the person with epilepsy perceives his/her distinctiveness acutely. The results make it clear that the adolescents with epilepsy clearly see their distinctiveness. This is well described in the cluster "psychological self-affirmation in society". The patients with this diagnosis are exposed to threat of discrimination in plenty of situations. This may be a necessity to take anticonvulsants, some limitations (driving a car, swimming etc.), special regime and hyper-caring from the family members and friends.

Individual characteristics: This factor gathers the characteristics of the adolescents with epilepsy that differentiates them from their healthy peers, such as diagnosis of epilepsy and probability of seizure occurrence. The diagnosis of epilepsy itself considers discrimination and stigma while the threat of the seizure occurrence exacerbates the feeling of one's "distinctiveness". Because of these factors, patient has a permanent expectation of discrimination and stigmatization that

causes the reevaluation of the possible threat. In addition, patients with epilepsy are aware of the above-mentioned stressors, accept and share the collective representations that lead to self-stigmatization. The obtained data shows that the adolescents with epilepsy experience self-discrimination have low self-esteem and are ashamed of their diagnosis. The cluster "self-stigmatization" outlined on the dendrogram of the adolescents with epilepsy, shows that even the equal treatment towards the adolescents with epilepsy is perceived by them as a negative attitude – flattery.

Having the influence of collective stereotypes, situational cues and individual characteristics, the adolescents with epilepsy are in permanent state of expecting threat and thus, they permanently feel the pressure of the above-mentioned stereotypes. The influence of stress threatens the social identity of the adolescents with epilepsy.

The analysis of the research data shows all types of identity disturbances that are included in the given model. Particularly, the **categorization threat**– division of the society according to the criteria: healthy, non-healthy. For the adolescent with epilepsy, disclosure of the illness means accepting the identity of the epilepsy group against his or her will. This considers the devaluation of his/her identity in the eyes of the healthy people (either in reality, or in the imagination of the patient). Therefore, the adolescent is unintentionally enrolled in group of the stigmatized people. The adolescents with epilepsy are always exposed to the **distinctiveness threat**. This is the obligation to take drugs, be in a special regime, probability of seizure occurrence, different limitations because of the illness that differentiates them from healthy peers. From the dendrogram of the adolescents with epilepsy it is clearly seen that the members of the group have a severe sense of the **acceptance threat**. For example, they think that others are always flattering; they have an increased need of friendship and support. In addition to this, the analysis of the data reveals that the adolescents with epilepsy perceive themselves as an object and never as the subject of compassion.

One of the most obvious examples of identity threat is the **threat of stereotyping**. In this case, the patient has emotional, behavioral and cognitive responses not only to the obvious behavior (discrimination), but also on to potential behavior. The adolescents with epilepsy acknowledge the stereotypes connected with this illness and they believe that their social identity is in threat. In such situation, the responsive reaction to the stress is initiated without any stressor. According to identity disturbance model, the expectancy of the above-mentioned threats and the assessment of probability of their occurrence is the process of primary appraisal. The primary appraisal is followed by the secondary appraisal that means the assessment of the resources of the adolescents with epilepsy for overcoming the stereotypes (possible threats). The strategies of overcoming stress are the most changeable aspect of the process caused by the stigma. Although, the analysis of the results revealed that the adolescents with epilepsy have a quite wide range of stress coping strategies. The analysis of data shows that one of the problem-focused strategies is regime compliance. In case of adolescents with refractory seizures, situation control and self-control is connected with overcoming "distinctiveness". In this case, "regime compliance" is not included in the process of problem solving, because for this group of patients the seizures and their frequency are not related to regime compliance. Social support was outlined from the emotion-focused strategies, this is shown in the cluster "hope" – the adolescents with epilepsy think of friendship and social support as a psychological comfort. The mentioned connection indicates that tension and distress is not present in this case.

Prolonged Stress Outcome: The processes related to stress have adaptive functions. Although the permanent state of stress has a negative impact on the physical, cognitive and emotional conditions, as well as immune system, attention, memory functions, learning productivity. The stress coping strategies such as suppression, regression and enhanced control, cause the overloading of working memory. The allostatic load caused by stress is the reason of anxiety and depression, emotional exaltation (Phelan, 2010). Therefore, the high level of depression and reduced self-esteem of the adolescents with epilepsy showed in different studies are supposedly results of the negative impact of stigma-induced identity threat.

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