

## To tell or not to tell? Perceptions about stigma of patients with epilepsy in different situations

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**Introduction:** Epilepsy imposes a major psychosocial burden. Challenges faced by the person with epilepsy include fear of revealing the condition, unpredictability of seizures and stigma. Stigma comes from an unmet expectation, a prejudice or a standard defined by society [1]. Self-esteem, self-confidence, responsibility are feelings that are associated with the individual's ability to feel free, loved and take initiatives [2]. This study explores whether patients report epilepsy depending on the context of social situation.

**Materials and Methods:** We performed a qualitative and quantitative research at the Hospital of Clinics at University of Campinas, using a questionnaire adapted from Troster [3]. This questionnaire describes eight scenarios for possible disclosure: (a) a random contact with a stranger on a bus, (b) a pleasant evening with an old friend, (c) a social event to meet new members of an association (d) a family gathering to meet future in-laws, (e) a job interview with a superior, and (f) an extended visit of a close relative, (g) social media (h) school [3]. In these scenarios, patients were questioned about the likelihood of disclosing their condition to the specific interaction partner; ranking on a 6-point scale: 1 is the lowest and 6 is the highest probability for disclosure.

**Results:** Participants included 86 people with epilepsy (47 women), aged between 18 and 70 years; 28% had their first seizure after the age of 20 years old, 62% had no seizures in the last month, 75% used more than one type of medication for epilepsy, 25% were employed and 41% completed High School. There is a significant difference between scenarios (ANOVA, followed by pairwise comparisons Tukey,  $p < 0.05$ ), as depicted in figure.

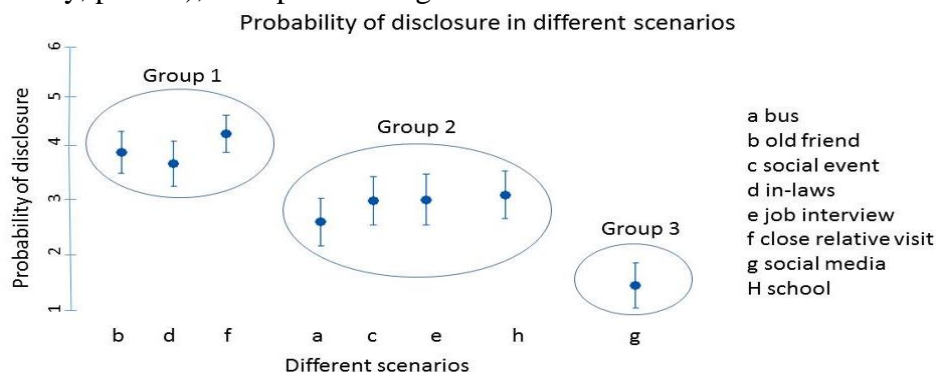


Fig.1. Situations that are not in the same group (1, 2 or 3) are significantly different.

**Discussion:** According to Troster [3], when patients perceive or feel stigma related to their disease in specific scenarios, they tend to predict disadvantages in disclosing their condition once they find themselves in the same situation. Different situations may corroborate with a different behavior depending of the functional classes established between stimuli and experience [4]. In scenarios within the same group (1, 2 or 3) chances of disclosure are similar, since stimuli related to this scenario also present a similarity (1- family or friends, 2- social interactions, 3- social media). In this sense, variables applied directly on stimuli may have a similar behavior on the same group [4]. Positive or negative experiences have a direct influence in probability of disclosing about the disease in similar situations. Among situations in group 2, patients reported a higher probability of disclosure to ensure that there would be a person to help in the case of having a seizure.

**Conclusion:** Situations that bring greater discomfort when talking about epilepsy may also be related to a greater felt and enacted stigma. This study showed that probability of disclosure is higher in situations related to family and friends, when compared to scenarios of social interaction in other environments and in social media.

**References:** [1] Goffman E. Stigma: Notes on the Management of Spoiled Identity. Prentice-Hall, 1963. [2] Guilhard, H.J. Human behavior, 63-98, 2002. [3] Troster, Epilepsia, 38(11): 1227-1237, 1997. [4] De Rose, J. Psicologia teoria e pesquisa, 9(2): 283- 303, 1993.