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HOW TO LABEL SOMEONE TREATED FOR EPILEPSY?

INTRODUCTION: The debate on how a person with diagnosed epilepsy should be referred to still continues, but views of those living with epilepsy are rarely researched. Publications on the topic of appropriate labels for someone diagnosed with epilepsy have so far almost exclusively consisted of views of professionals in this field.

OBJECTIVES: To identify which label patients treated for epilepsy and persons close to them prefer.

METHODS: For one month, starting from 28th May 2017, an anonymous online questionnaire was offered to all visitors of the Croatian Association for Epilepsy's website.

The first question was “*What do you think is the most appropriate label when talking about someone treated for epilepsy?*”, with 5 possible answers:

1. *Epileptic*
2. *Person with epilepsy (or depending on the context child/older person/woman with epilepsy)*
3. *A person having epilepsy (or depending on the context child/older person/woman having epilepsy)*
4. *Patient with epilepsy/diseased with epilepsy*
5. *I think all the suggested labels are equally appropriate*

The second question was a yes/no question: “*Would you mind if someone called you (or your child/family member/friend/acquaintance) an ‘epileptic’?*”

The remainder of the questionnaire collected demographic data (age, gender, country of residence, level of education) and the relationship with a person with epilepsy, which was then checked for associations with label preference.

RESULTS: The total number of respondents was 417, but when excluding criteria described in Methods were applied, number of subjects was 328. Age range was 16-66, with a mean of 35±9,6 years, and the vast majority of subjects were women (85%). About half of the respondents were subjects with epilepsy (53%), further 31% were parents of someone with epilepsy, and the remainder stated other kind of relationship with someone with epilepsy (Table 1.).

Table 1. Subject characteristics. N=328.

| | N (%) |
|-------------------------------------|-----------|
| Age (years) | 35±9,6* |
| Gender | |
| Male | 50 (15%) |
| Female | 276 (85%) |
| Level of education | |
| Elementary School | 11 (3%) |
| Secondary School | 189 (58%) |
| College/School of higher education | 45 (14%) |
| University | 82 (25%) |
| Relation with someone with epilepsy | |
| Myself | 173 (53%) |
| Parent | 102 (31%) |
| Partner | 12 (4%) |
| Other family member | 30 (9%) |
| Friend | 11 (3%) |

*Mean±SD. Missing data: age 6, gender 2, level of education 1, relation 0

The majority of subjects preferred the label “person having epilepsy” (28%) followed closely by “person with epilepsy” (27%) (Table 2.).

Table 2. Most appropriate label when talking about someone treated for epilepsy.

| | N (%) |
|---|-----------|
| Epileptic | 10 (3,0) |
| Person (or depending on the context child/older person/woman) with epilepsy | 87 (26,5) |
| Person (or depending on the context child/older person/woman) having epilepsy | 92 (28,0) |
| Patient with epilepsy/diseased with epilepsy | 65 (19,8) |
| I think all the suggested labels are equally appropriate | 74 (22,6) |

Characteristics related to labels: Regression model between age and the preffered label was not significant, and there were also no association with either gender or level of education (Table 3.).

Neither age, gender, or level of education were significantly related with the disapproval of the term “epileptic”. However, the disapproval of the term was significantly different among the different categories of relation with someone with epilepsy, with a post-hoc analysis revealing a significant difference in the patient and parent categories, i.e. parents were more likely to mind the term “epileptic”, while the opposite was true for patients (Table 4.).

Table 3. Association of subjects’ characteristics with the preferred label for someone treated for epilepsy.

| | Most appropriate label for someone with epilepsy | | | | | χ ² | p |
|-------------------------------------|--|----------------------|------------------------|-----------------------|---------------|----------------|-------|
| | Epileptic | Person with epilepsy | Person having epilepsy | Patient with epilepsy | No preference | | |
| Gender | | | | | | 3,74 | 0,442 |
| Male | 1(2,0) | 9(18,0) | 13(26,0) | 12(24,0) | 15(30,0) | | |
| Female | 9(3,3) | 77(27,9) | 78(28,3) | 53(19,2) | 59(21,4) | | |
| Level of education | | | | | | 7,95 | 0,093 |
| Secondary school or less | 6(3,0) | 57(28,5) | 47(23,5) | 38(19,0) | 52(26,0) | | |
| Post-secondary education | 4(3,1) | 30(23,6) | 45(35,4) | 27(21,3) | 21(16,5) | | |
| Relation with someone with epilepsy | | | | | | 10,48 | 0,033 |
| Myself | 8(4,6) | 48(27,7) | 38(22,0) | 37(21,4) | 42(24,3) | | |
| Parent | 1(1,0) | 29(28,4) | 38(37,3) | 15(14,7) | 19(18,6) | | |

Bold values denote cells where counts were statistically different than expected.

Table 4. Association of subjects’ characteristics with the disapproval of the label “epileptic”.

| | Do you mind the label “epileptic”? N(%) | | OR (95%CI)/ χ ² | p |
|-------------------------------------|---|-----------------|----------------------------|---------|
| | Yes | No | | |
| Age | | | 0,99 (0,97-1,01) | 0,351 |
| Gender | | | 0,094 | 0,759 |
| Male | 26(52,0) | 24(48,0) | | |
| Female | 150(54,3) | 126(45,7) | | |
| Level of education | | | 0,868 | 0,833 |
| Elementary School | 7(63,6) | 4(36,4) | | |
| Secondary School | 99(52,4) | 90(47,6) | | |
| College/School of higher education | 26(57,8) | 19(42,2) | | |
| University | 44(53,7) | 38(46,3) | | |
| Relation with someone with epilepsy | | | 21,799 | <0,0001 |
| Myself | 75(43,4) | 98(56,6) | | |
| Parent | 73(71,6) | 29(28,4) | | |
| Partner | 5(41,7) | 7(58,3) | | |
| Another family member | 17(56,7) | 13(43,3) | | |
| Friend | 7(63,6) | 4(34,3) | | |

Bold values denote cells where counts were statistically different than expected.

DISSCUSION: We believe our study has brought an additional insight from those living with epilepsy into the language debate. These results can help with shaping future recommendations for terminology in epilepsy.

REFERENCES:

- [1] Hatcher JL. Replacing the stigma of “epileptic” with a tasteless acronym and coming full circle. Seizure 2014;23:408. doi:10.1016/j.seizure.2014.01.023.
- [2] Noble AJ, Marson AG. Should we stop saying “epileptic”? A comparison of the effect of the terms “epileptic” and “person with epilepsy.” Epilepsy Behav 2016;59:21–7. doi:10.1016/J.YEBEH.2016.03.016.
- [3] Reuber M. “Epileptics”, “people with epilepsy”, “PWE”, “epilepsy patients”--what is the best label? Seizure 2014;23:327. doi:10.1016/j.seizure.2014.01.014.