

How to label someone treated for epilepsy?

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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. **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, and 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:** In total, 328 responses were analysed. Mean age was 35 ± 9.6 years, 85% were female. Fifty-three percent of subjects had epilepsy; 31% were parents of someone with epilepsy, and the remainder stated other kind of relationship with someone with epilepsy. The majority of subjects preferred the label "person having epilepsy" (28%) followed closely by "person with epilepsy" (27%). Parents were more likely to mind the term "epileptic" (71.6 %), while the opposite was true for patients (43.4%). **CONCLUSION:** 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.