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## Are Acoustic Neuroma Association Patients Characteristically Different than the General Population Patients? The Benefits and Drawbacks of Survey-Based Studies

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### Dear Editor,

We read with great interest the article entitled “Influence of selection bias in survey studies derived from a patient-focused organization: a comparison of response data from a single tertiary care center and the acoustic neuroma association” by Prummer et al (1). The authors compare a population of 802 acoustic neuroma association (ANA) responders with 258 acoustic neuroma (AN) patients presented at their tertiary academic center regarding their demographics, baseline symptoms, treatment modalities, and post-treatment quality of life outcomes and satisfaction. They demonstrated that ANA patients had larger tumors, suffered from more baseline associative symptoms, received higher rates of active management *vs.* observation, and had lower quality of life scores in almost all categories. Thus, they concluded that the ANA population is significantly different from the general AN patients presenting to an academic center. We admire the authors’ achievements in presenting such important results and agree with their conclusion, and we would like to add a few insights from our experience with ANA survey-based projects (2, 3).

In addition to the study’s observed differences between the ANA and general AN population, we detected additional ANA characteristics that deviated from the average U.S. population and thus can further contribute to the authors’ conclusion. Notably, our ANA cohort’s insurance affiliation, income, education level, travelling capacity for quality care, and treatment seeking at academic *vs.* private institutions seemed potentially skewed from the general population. More than 70% of our responders had completed a college or graduate degree, different than the 2016 census bureau report of 33% U.S. adults with a bachelor’s degree (4). This can play a role in decision making, physician discussion, personal research, and expectations. For instance, we observed that patients of a higher educational background had higher recalls of the risks associated with their treatment complications being discussed with them (3). Around 60% of our participants had PPO

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insurance, whereas Medicare and Medicaid representing only 13% of the cohort. This is different from the general U.S. population with a combined 36% benefiting from the latter two providers (5). Less than 10% of our cohort had annual household income below \$25,000 even though 20% of U.S. households fell below this threshold in 2017 (6). Many of our ANA cohorts also sought care by traveling great distances, with around 1/4 of the cohort traveling out-of-state for parts of the management. These are potentially important distinctions in patients' accessibility to quality care, proper follow-up, and outcome satisfaction between ANA and the general AN population. As the authors appropriately discussed, there is also a strong component of selection bias from patients whose relatively superb or suboptimal outcomes may make them more likely to be an active member of such a nonprofit organization and participate in time-consuming voluntary research projects.

Though we agree that there are substantial differences between the two populations, we believe that such national organization survey-based studies can still provide value in the appropriate settings. One advantage is the ability to collect instant data from an extensively heterogeneous cohort with wide ranges of location and treatment facility type, income and insurance affiliation, as well as long follow-up years averaged more than 7 years. This level of heterogeneity is extremely difficult to attain even if done in a single-institutional prospective setting. Limiting a cohort to a treatment center may result in unintentional patient inclusion barriers based on the center and attendings' treatment type preferences (active *vs.* conservative) as well as the encountered level of disease severity. There may also be unintended patient exclusion based on insurance partnerships and surrounding community's demographics, as opposed to a nation-wide survey-based study which acquires data directly from all patients who desire to participate. It should be noted that the population of any academic tertiary care center will be somewhat skewed and not represent the general population given that the majority of those patients at a single center will be drawn from the same geographic area. Collecting data from ANA allowed us potential comparisons between decade of diagnoses, diagnosing physicians, U.S. region of residence, insurance plans, and academic *vs.* private centers. This would have been nearly impossible in a prospective study performed at a tertiary academic center which might itself be influenced by certain guidelines and oversights, possibly rendering it slightly different than the general AN population at large. That being said, to the authors' points with which we totally agree, great care must be taken when attempting to generalize the results of such studies to the general population.

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