

# Stigma and socioeconomic outcomes in epilepsy

Akademisk avhandling

Som för avläggande av filosofie doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i Kammaren, Vita stråket 12, Sahlgrenska Sjukhuset, Göteborg, den 27 januari 2023, klockan 09.00.

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## Avhandlingen baseras på följande delarbeten

- I. Andersson K, Ozanne A, Edelvik Tranberg A, Chaplin JE, Bolin K, Malmgren K, Zelano J. Socioeconomic outcome and access to care in adults with epilepsy in Sweden: A nationwide cohort study. *Seizure: European Journal of Epilepsy*. 2020; 74: 71-76.
- II. Andersson K, Ozanne A, Zelano J, Malmgren K, Chaplin JE. Perceived stigma in adults with epilepsy in Sweden and associations with country of birth, socioeconomic status, and mental health. *Epilepsy & Behavior*. 2022; 136: 108886.
- III. Andersson K, Strang S, Zelano J, Chaplin JE, Malmgren K, Ozanne A. Multiple stigma among first-generation immigrants with epilepsy in Sweden. *Epilepsy & Behavior*. 2021; 115: 107638.
- IV. Andersson K, Zelano J, Chaplin JE, Malmgren K, Ozanne A. Challenges in epilepsy care and the importance of multidisciplinary teams: The perspectives of adult patients and their health providers in Sweden. *Manuscript*.

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# Stigma and socioeconomic outcomes in epilepsy

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## Abstract

Epilepsy influences all aspects of life. While the treatment of seizures is the natural starting point in epilepsy care, social aspects of epilepsy need consideration for successful outcomes. The purpose of this doctoral thesis is to investigate the impact of stigma and socioeconomic status in epilepsy. The thesis is based on four studies with different methodological designs. By using data from national registers (Paper I), self-report questionnaires (Paper II), individual face-to-face interviews (Paper III) as well as focus group interviews (Paper IV), stigma and socioeconomic outcomes in epilepsy are investigated from both a quantitative, population level and a qualitative, individual experience level.

The results indicate that higher education and better income levels are not only associated with less severe epilepsy but also to greater access to a neurologist (Paper I). A higher educational level also appears protective against low income and unemployment in epilepsy compared to healthy controls (Paper I).

Within the Swedish population foreign-born people with epilepsy report higher levels of stigma compared with Swedish-born persons with epilepsy (Paper II). Factors that predict higher levels of stigma are seizure frequency, higher levels of anxiety and lower levels of mental health (Paper II). People with epilepsy born outside of Sweden were found to experience multiple stigma that may increase the risk of social isolation and present barriers to epilepsy care (Paper III). Social barriers, stigma and complex medical situations increase the need for support in specialized epilepsy care. A multidisciplinary team that facilitates communication, education, psychological support, and cooperation with external sectors is crucial to support vulnerable persons with epilepsy (Paper IV).

This thesis contributes to our knowledge of stigma, stigma-associated factors, and socioeconomic disparities in epilepsy care in Sweden. The results from Paper I-IV highlight the importance of an individual approach acknowledging patients' social circumstances and the need for multidisciplinary teams in epilepsy care. They further underscore the need for targeted interventions aiming to reduce stigma and improve the support for vulnerable persons with epilepsy.

**Keywords:** Epilepsy, Stigma, Socioeconomic status