

Diagnostic and neuropsychiatric considerations in epilepsy and intellectual disability

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Valorization

Epilepsy and intellectual disability (ID) relatively often co-occur.¹ The epilepsy among those with ID is often more severe, chronic, and refractory to treatment, which can have a pervasive impact on their quality of life.^{2,3} Moreover, epilepsy and ID have each been linked to a variety of behavioral, affective, and psychiatric comorbidities.⁴⁻⁶ A better understanding of the complex associations between neuropsychiatric comorbidities and epilepsy and ID has important implications for good clinical practice and treatment of these individuals.

Relevance of findings

Diagnostics are an important aspect within the care for people with epilepsy and ID. The comprehensive diagnostic processes can be time-consuming, intensive, and a burden for patients. Reliable screening instruments can be helpful if comprehensive diagnostics are too demanding or time-consuming for patients or caregivers. In this dissertation, the reliability and validity of multiple screening instruments are investigated (see chapter 3 and 4). Chapter 3 showed that abbreviated versions of two intelligence tests (WISC-III and WAIS-IV) provide an accurate estimation of global intellectual functioning. These short forms take significantly less time than a full examination, which can reduce the burden for patients and the psychologist assessing the patient. In chapter 4, the Anxiety, Depression And Mood Scale (ADAMS) appeared to be a reliable screening instrument for detection of early signs of depressed mood or anxiety disorder for adults aged below 50 years. The instrument was already validated among adults aged 50+ years,⁷ but evidence for younger adults was lacking. Early detection of such symptoms is relevant for all age groups, as it can help to guide individual treatment plans and therefore prevent from developing a severe affective disorder.

With respect to the classification of ID, a methodology to assess three domains of adaptive functioning is described in this dissertation. This was based on DSM-5 criteria of ID,⁸ which is legally implemented in the Dutch mental health care system since January 2017. Chapter 2 focusses particularly on the concept and assessment of an ID domain discrepancy, in which one domain is significantly more deficient than another. As the studies described in chapter 6, 7 and 8, this ID domain discrepancy appeared to be associated with aggression, anxiety, depressive symptoms and psychogenic nonepileptic seizures. These findings emphasize the relevance of this concept and should, therefore, be implemented in the care for people with ID. Addressing an ID domain discrepancy in daily clinical practice could, for example, have implications for the treatment strategies to meet both the strengths and needs of the individual,

which might minimize the risk of overestimating or underestimating an individual. The instruments and methodology can be applied to adults with all levels of ID and can be adapted to children with ID. Other instruments to assess domains of adaptive functioning that are available might be suitable as well.

The second part of this dissertation provides information on the associations between neuropsychiatric outcomes and (independent) epilepsy and ID characteristics. The findings illustrate the wide variety of neuropsychiatric comorbidities among patients with epilepsy and ID and the complexity of associations between many factors. It is important for health care professionals working with patients with both epilepsy and ID to be aware of the prevalence of neuropsychiatric comorbidities (especially depressive symptoms), by being sensitive to early signs. Also, the complex interplay with associated factors, with positive and negative directions, should be taken into account.

The role of epilepsy (characteristics) in general on neuropsychiatry among people with ID seems to be modest compared to ID characteristics, which indicates that other factors beyond epilepsy should be considered at all times. Therefore, a multidisciplinary approach is highly recommended.

Target groups

The findings described in this dissertation are relevant for multiple target groups. The main target group consists of patients with epilepsy and ID and their relatives. Some of the findings are relevant to other patient populations as well, for example the ID population in general or to patients with neurological disorders. Another important target group includes health care professionals, such as psychologists and behavioral scientists, physicians (specialized in the care for people with ID), neurologists, nurses and direct support staff working in the field of ID and/or epilepsy. Finally, the results are very relevant for scientists, as the findings require validation in other study populations and multiple recommendations for future research are described.

Activities for innovation and implementation of knowledge

The studies described in this dissertation are also published or submitted as scientific articles in peer-reviewed journals. In order to expand the readership to as many target populations as possible, several findings have been published in Dutch journals as well. In addition, many of the findings were presented and discussed during oral and poster presentations at national and international symposia and congresses in the fields of epilepsy or ID, and the aim is to continue this in the (near) future. Another aim is to include the findings in educational materials on this topic and to embed these in the

Study Center of Epilepsy (in Dutch: Leerhuis Epilepsie), which is an initiative of the two main epilepsy centers in The Netherlands: Kempenhaeghe and SEIN. This Study Center of Epilepsy provides teaching courses (tailor-made if required) on epilepsy to health care professionals in all regions of The Netherlands. In this way, multiple attempts are made to reach health care professionals and scientists of various fields.

Future plans also include a special effort to reach patients and their relatives and non-academic health care professionals. By using a standardized format, a series of short videos will be created in the form of a co-production by Kempenhaeghe and CCE ("Centrum voor Consultatie en Expertise"). Each video will focus on a specific element of epilepsy, ID and neuropsychiatry and will be supported by documented experiences of a patient and his/her (professional) caregivers. By using simple language, subtitles and visual elements, the video will be made suitable for a wide audience. Funding for this project is being requested. If this succeeds, the video series will be made available for free on the Internet, and may be used for educational purposes as well.

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