

What do caregivers of persons with rare, epilepsy-related disorders need to know?

Merete Kristin Tschamper* (nurse/PhD-student), Silje Systad (special educator/PhD), The National center for rare, epilepsy-related disorders, department for children and adolescent, Oslo university hospital, Norway

Summary: Persons with rare, epilepsy-related disorders often have intellectual disability and a need for long-term care. Caregivers, both informal and formal, need information in order to take care of the person with rare epilepsies. **Aims:** 1) to obtain an overview of research on caregivers' information needs; 2) to explore if the need for information differed between caregivers of persons with rare diagnosis compared to caregivers of other epilepsies with intellectual disability. **Method:** A scoping review. **Results:** Out of 3900 articles, only 17 met the inclusion criteria, of which 5 described information needs identified by caregivers of persons with rare epilepsies. Five categories of information needs were identified. **Conclusion:** There are few studies concerning the information needs for caregivers of persons with rare epilepsies in general and for formal caregivers in particular. Diagnosis- specific medical information needs seems unique for caregivers of persons with rare epilepsies.

Introduction

Rare, epilepsy-related disorders are associated with early onset epilepsy, which is difficult to treat, along with intellectual disability (1-3). The caregivers, responsible for persons with such complex conditions, need information and education, in order to ensure optimal treatment and care (1,2).

The caregivers' need for comprehensive information has been acknowledged; legal rights and clinical guidelines have been developed in order to ensure optimal treatment for the persons (4,5). **Aims:** We wanted to get an overview of primary research of both formal and informal caregivers' need for information from their point of view. We also wished to explore if the need for information differed between caregivers of persons with rare epilepsies compared to caregivers of other epilepsies with intellectual disability.



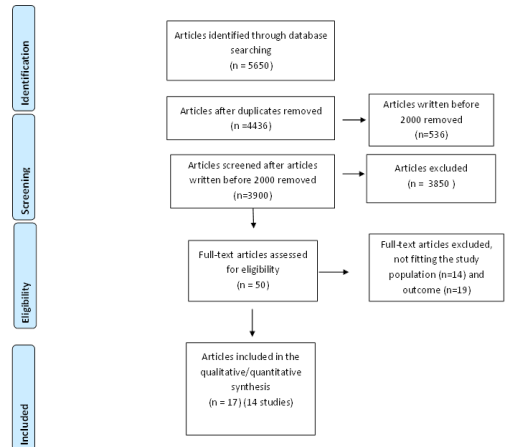
Shutterstock

Results

- 17 out of 3900 articles met the inclusion criteria of which 5 described information needs identified by caregivers of persons with rare epilepsies (see flow chart).
- Only 4 out of 17 articles described formal caregivers need for information.
- Categories of information needs reported by the caregivers were:
 - 1) Medical information
 - 2) Information on how to cope with emotional distress
 - 3) Experiential information from peers
 - 4) Information in transition to adulthood
 - 5) Interdisciplinary information exchange
- The information need that seemed unique for the caregivers of persons with rare epilepsies was diagnosis-specific, medical information. This need seems to be related to the fact that the public knowledge of the disorders is limited. Furthermore it was emphasized by the risk of severe health consequences for the person when caregivers are not informed about the symptoms.

Method

A protocol was developed and implemented following the scoping review framework outlined by Arksey and O'Malley, and the preferred reporting items outlined by PRISMA Extension for scoping reviews (PRISMA-ScR): Checklist and explanation (6,7). The databases Medline (Ovid), Cinahl, Embase (Ovid), Psycinfo (Ovid) were searched for primary studies. Two researcher screened articles and identified articles that fit the inclusion criteria: formal/informal caregivers of persons with epilepsy and intellectual disability and descriptions of information needs.



Flow chart of the inclusion and exclusion of studies

Conclusion

- There are a limited number of studies concerning the information needs for caregivers of persons with rare epilepsies in general and for formal caregivers in particular.
- A need for diagnosis- specific, medical information seems to be unique for caregivers of persons with rare epilepsy-related disorders due to the limited public knowledge of the disorders.
- There is a need for further studies regarding the information needs for caregivers. Particularly, there is a need for studies concerning rare epilepsies and formal caregivers.

References:

1. McTague A, Cross JH. Treatment of epileptic encephalopathies. 2013;27(3):175-84.
2. Camfield C, Camfield P. Most adults with childhood-onset epilepsy and their parents have incorrect knowledge of the cause 20-30 years later: a population-based study. *Epilepsy Behav.* 2014;37:100.
3. Brincicotti M, Matricardi M. *Epileptic Encephalopathies of Infancy and Childhood.* Clinical Electroencephalography: Springer; 2019. p. 413-30.
4. NICE, clinical guideline 137: The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. 2012.
5. Scottish Intercollegiate Guidelines Network (SIGN). A national clinical guideline 143, 2015: Diagnosis and management of epilepsy in adults. 2015.
6. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. 2005;8(1):19-32.
7. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Annals of internal medicine.* 2018;169(7):467-73.