



Topic Brief: Social and Structural Determinants of Health in Epilepsy

Date: 9/14/2022

Nomination Number: 1009

Purpose: This document summarizes the information addressing a nomination submitted on June 3, 2022, (<https://effectivehealthcare.ahrq.gov/get-involved/nominated-topics/health-disparities>) through the Effective Health Care Website. This information was used to inform the Evidence-based Practice Center (EPC) Program decisions about whether to produce an evidence report on the topic, and if so, what type of evidence report would be most suitable.

Issue: The nominator, the American Epilepsy Society, is a clinical society requesting a systematic review to understand social and structural determinants of health for children and adults with epilepsy. They plan to incorporate findings from a review into guidance and/or member education activity and program opportunities.

Findings: The scope of this topic met all EHC Program selection criteria and was considered for a systematic review. However, it was not selected.

Background

Approximately 3 million U.S. adults and 470,000 children have active epilepsy¹. Previous studies indicate that persons with epilepsy are more likely to experience barriers or delays in receipt of certain types of care, including epilepsy specialty care, and that these delays are often associated with individual factors or social determinants of health. Social determinants of health are environmental conditions that can affect health, function, and quality of life. These are grouped into 5 domains: economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context². These can contribute to health disparities and inequities.

Adults with epilepsy were more likely to have Medicaid or other public insurance coverage and to report an inability to afford prescription medicine, specialty care, or vision or dental care. Adults with epilepsy were more likely to take less medication than prescribed to save money, to be in families having problems paying medical bills, and to report delaying care because of insufficient transportation³.

The nominator is clinical society that plans to develop guidance based on the AHRQ systematic review. They were consulted to provide additional detail around the population, exposure types and outcomes of interest. They had interest in a review similar to the in-progress systematic review on “[Social and Structural Determinants of Health Risk Factors for Maternal Morbidity and Mortality: An Evidence Map.](#)”

Scope

1. What risk indicators have the greatest prediction of poor health outcomes for adult with epilepsy?
2. What risk indicators have the greatest prediction of poor health outcomes for children with epilepsy?

Population	1. Adults with epilepsy	2. Children 18 years and younger with epilepsy and their caregivers
Exposure/Comparator	Include biological, social, and environmental factors from the individual (e.g., patient factors such as education/health literacy/cultural beliefs, trust, socioeconomic resources), family/family structure, provider factors (e.g., cultural competency, bias, fluency in languages other than English), health care system/geographical and community levels (e.g., systemic factors such as availability of health insurance, quality of health insurance, training for providers, appointment duration), with a special interest in predictors related to access to quality care, patient-provider dynamics, and social and structural determinants of health, including racism (e.g., race/ethnicity, acculturation, socioeconomic status, insurance status, adherence, education/health literacy, English proficiency)	Include biological, social, and environmental factors from the individual (e.g., patient factors such as education/health literacy/cultural beliefs, trust, socioeconomic resources), family/family structure, provider factors (e.g., cultural competency, bias, fluency in languages other than English), health care system/geographical and community levels (e.g., systemic factors such as availability of health insurance, quality of health insurance, training for providers, appointment duration), with a special interest in predictors related to access to quality care, patient-provider dynamics, and social and structural determinants of health, including racism (e.g., race/ethnicity, acculturation, socioeconomic status, insurance status, adherence, education/health literacy, English proficiency)
Outcomes	Health outcomes related to epilepsy (such as seizure control), Health status outcomes such as health-related quality of life, patient satisfaction, resource utilization (such as emergency department use), harms	Health outcomes related to epilepsy (such as seizure control), Health status outcomes such as health-related quality of life, patient satisfaction, resource utilization (such as emergency department use), harms
Setting	Non-U.S. excluded	Non-U.S. excluded

Assessment Methods

See Appendix A.

Summary of Literature Findings

We identified five reviews partly addressing the scope. Two focused on adults: a scoping review that focused on factors associated with treatment adherence in adults⁴, and a systematic review on rural people with epilepsy⁵. The three reviews on children focused on factors associated with utilization of surgery in children⁶; scoping review on socioeconomic factors on prevalence, adherence and outcomes⁷; and an in-progress scoping review on disparities in pediatric epilepsy broadly (expected completion in 3-6 months)⁸. Searches for all reviews end in 2020.

We identified four relevant studies⁹⁻¹² from the nomination that were published in the last five years. In addition, we identified 18 studies in our targeted search, most not included in the five

scoping reviews and systematic reviews. Factors examined in studies included race/ethnicity, insurance status and type, age, socioeconomic status/poverty, and geography.

Key question	Systematic reviews (August 2019-August 2022)	Study publications (September 2017-September 2022)
KQ 1: Adults	Total-2 <ul style="list-style-type: none"> • Pubmed-1⁴, 5 	Total-12 <ul style="list-style-type: none"> • Surgery^{11, 13, 14} • Treatment^{12, 15} • Quality of care¹⁶ • Mortality¹⁷ • Discharge against medical advice^{18, 19} • Adherence²⁰ • Quality of life²¹ • Access³
KQ 2: Children and Caregivers	Total-3 <ul style="list-style-type: none"> • Pubmed-3⁶⁻⁸ 	Total-11 <ul style="list-style-type: none"> • Quality of life^{22, 23} • Treatment^{24, 25} • Adherence^{26, 27} • Emotional well-being²⁸ • Remission⁹ • Resource utilization¹⁰ • Surgery^{11, 29}

KQ=key question.

Summary of Selection Criteria Assessment

We identified five systematic and scoping reviews that cover the nomination, but searches end in 2020. The evidence base is likely small based on our targeted search and examination of previous reviews.

References

1. Epilepsy Fast Facts. Atlanta, GA: Centers for Disease Control and Prevention; 2020. <https://www.cdc.gov/epilepsy/about/fast-facts.htm>. Accessed on 6 September 2022 2022.
2. 2030 HP. Social Determinants of Health. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>.
3. Tian N, Kobau R, Zack MM, et al. Barriers to and Disparities in Access to Health Care Among Adults Aged ≥ 18 Years with Epilepsy - United States, 2015 and 2017. MMWR Morb Mortal Wkly Rep. 2022 May 27;71(21):697-702. doi: 10.15585/mmwr.mm7121a1. PMID: 35617131.
4. von Gaudecker JR, Buelow JM, Miller WR, et al. Social determinants of health associated with epilepsy treatment adherence in the United States: A scoping review. Epilepsy Behav. 2021 Oct 7;124:108328. doi: 10.1016/j.yebeh.2021.108328. PMID: 34628091.
5. Duke SM, Gonzalez Otarula KA, Canales T, et al. A systematic literature review of health disparities among rural people with epilepsy (RPWE) in the United States and Canada. Epilepsy Behav. 2021 Sep;122:108181. doi: 10.1016/j.yebeh.2021.108181. PMID: 34252832.
6. Beatty CW, Lockrow JP, Gedela S, et al. The Missed Value of Underutilizing Pediatric Epilepsy Surgery: A Systematic Review. Semin Pediatr Neurol. 2021 Oct;39:100917. doi: 10.1016/j.spen.2021.100917. PMID: 34620465.
7. Huber R, Weber P. Is there a relationship between socioeconomic factors and prevalence, adherence and outcome in childhood epilepsy? A systematic scoping review. Eur J Paediatr Neurol. 2022 May;38:1-6. doi: 10.1016/j.ejpn.2022.01.021. PMID: 35248913.

8. Wagner J, Bhatia S, Marquis BO, et al. Health Disparities in Pediatric Epilepsy: Methods and Lessons Learned. *J Clin Psychol Med Settings*. 2022 Aug 5. doi: 10.1007/s10880-022-09898-1. PMID: 35930105.
9. Gregerson CHY, Bakian AV, Wilkes J, et al. Disparities in Pediatric Epilepsy Remission Are Associated With Race and Ethnicity. *J Child Neurol*. 2019 Dec;34(14):928-36. doi: 10.1177/0883073819866623. PMID: 31502509.
10. Grinspan ZM, Patel AD, Hafeez B, et al. Predicting frequent emergency department use among children with epilepsy: A retrospective cohort study using electronic health data from 2 centers. *Epilepsia*. 2018 Jan;59(1):155-69. doi: 10.1111/epi.13948. PMID: 29143960.
11. Sanchez Fernandez I, Stephen C, Loddenkemper T. Disparities in epilepsy surgery in the United States of America. *J Neurol*. 2017 Aug;264(8):1735-45. doi: 10.1007/s00415-017-8560-6. PMID: 28702686.
12. Szaflarski M, Wolfe JD, Tobias JGS, et al. Poverty, insurance, and region as predictors of epilepsy treatment among US adults. *Epilepsy Behav*. 2020 Jun;107:107050. doi: 10.1016/j.yebeh.2020.107050. PMID: 32294594.
13. Mandge V, Correa DJ, McGinley J, et al. Factors associated with patients not proceeding with proposed resective epilepsy surgery. *Seizure*. 2021 Oct;91:402-8. doi: 10.1016/j.seizure.2021.07.007. PMID: 34303161.
14. Sharma K, Kalakoti P, Henry M, et al. Revisiting racial disparities in access to surgical management of drug-resistant temporal lobe epilepsy post implementation of Affordable Care Act. *Clin Neurol Neurosurg*. 2017 Jul;158:82-9. doi: 10.1016/j.clineuro.2017.05.001. PMID: 28500925.
15. Sirven J, Sprout GT, Speer M, et al. The influence of social determinants of health on epilepsy treatment delays in an Arizona Medicaid population. *Epilepsy Behav*. 2022 Jan;126:108473. doi: 10.1016/j.yebeh.2021.108473. PMID: 34920347.
16. Bensken WP, Navale SM, Andrew AS, et al. Markers of Quality Care for Newly Diagnosed People With Epilepsy on Medicaid. *Med Care*. 2021 Jul 1;59(7):588-96. doi: 10.1097/mlr.0000000000001541. PMID: 33797505.
17. Blank LJ, Acton EK, Willis AW. Predictors of Mortality in Older Adults With Epilepsy: Implications for Learning Health Systems. *Neurology*. 2021 Jan 5;96(1):e93-e101. doi: 10.1212/wnl.0000000000011079. PMID: 33087496.
18. Agarwal P, Xi H, Jette N, et al. A nationally representative study on discharge against medical advice among those living with epilepsy. *Seizure*. 2021 Jan;84:84-90. doi: 10.1016/j.seizure.2020.11.018. PMID: 33307465.
19. Raja A, Trivedi PD, Dharmoon MS. Discharge against medical advice among neurological patients: Characteristics and outcomes. *Health Serv Res*. 2020 Oct;55(5):681-9. doi: 10.1111/1475-6773.13306. PMID: 32578887.
20. Honnekeri B, Rane S, Vast R, et al. Between the Person and the Pill: Factors Affecting Medication Adherence in Epilepsy Patients. *J Assoc Physicians India*. 2018 Jul;66(7):24-6. PMID: 31325256.
21. Scrivner B, Szaflarski M, Baker EH, et al. Health literacy and quality of life in patients with treatment-resistant epilepsy. *Epilepsy Behav*. 2019 Oct;99:106480. doi: 10.1016/j.yebeh.2019.106480. PMID: 31465909.
22. Ferro MA, Avery L, Fayed N, et al. Child- and parent-reported quality of life trajectories in children with epilepsy: A prospective cohort study. *Epilepsia*. 2017 Jul;58(7):1277-86. doi: 10.1111/epi.13774. PMID: 28485850.
23. Phillips NL, Widjaja E, Smith ML. Family resources moderate the relationship between seizure control and health-related quality of life in children with drug-resistant epilepsy. *Epilepsia*. 2020 Aug;61(8):1638-48. doi: 10.1111/epi.16602. PMID: 32640091.

24. Baker M, Olsen JC, Wilkes J, et al. Similar antiseizure medication refill characteristics in Hispanic and White pediatric patients. *Epilepsy Res.* 2022 Aug;184:106970. doi: 10.1016/j.eplesyres.2022.106970. PMID: 35779465.
25. Baumer FM, Mytinger JR, Neville K, et al. Inequities in Therapy for Infantile Spasms: A Call to Action. *Ann Neurol.* 2022 Jul;92(1):32-44. doi: 10.1002/ana.26363. PMID: 35388521.
26. Gutierrez-Colina AM, Wetter SE, Mara CA, et al. Racial Disparities in Medication Adherence Barriers: Pediatric Epilepsy as an Exemplar. *J Pediatr Psychol.* 2022 Jun 7;47(6):620-30. doi: 10.1093/jpepsy/jsac001. PMID: 35024854.
27. Smith AW, Mara CA, Modi AC. Adherence to antiepileptic drugs in adolescents with epilepsy. *Epilepsy Behav.* 2018 Mar;80:307-11. doi: 10.1016/j.yebeh.2017.12.013. PMID: 29429909.
28. Goodwin SW, Wilk P, Karen Campbell M, et al. Emotional well-being in children with epilepsy: Family factors as mediators and moderators. *Epilepsia.* 2017 Nov;58(11):1912-9. doi: 10.1111/epi.13900. PMID: 28948997.
29. Jackson HN, Gadgil N, Pan IW, et al. Sociodemographic Factors in Pediatric Epilepsy Surgery. *Pediatr Neurol.* 2020 Jun;107:71-6. doi: 10.1016/j.pediatrneurol.2019.09.002. PMID: 32284204.
30. Moura L, Karakis I, Zack MM, et al. Drivers of US health care spending for persons with seizures and/or epilepsies, 2010-2018. *Epilepsia.* 2022 Aug;63(8):2144-54. doi: 10.1111/epi.17305. PMID: 35583854.
31. Hussain SA, Ortendahl JD, Bentley TKG, et al. The economic burden of caregiving in epilepsy: An estimate based on a survey of US caregivers. *Epilepsia.* 2020 Feb;61(2):319-29. doi: 10.1111/epi.16429. PMID: 31953846.

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Appendix A: Methods

We assessed nomination for priority for a systematic review or other AHRQ Effective Health Care report with a hierarchical process using established selection criteria. Assessment of each criteria determined the need to evaluate the next one. See Appendix B for detailed description of the criteria.

Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

Desirability of New Review/Absence of Duplication

We conducted a search for existing systematic reviews. We searched for high-quality, completed or in-process evidence reviews published in the last three years August 2019 to August 2022 on the questions of the nomination from these sources:

- AHRQ: Evidence reports and technology assessments
 - AHRQ Evidence Reports <https://www.ahrq.gov/research/findings/evidence-based-reports/index.html>
 - EHC Program <https://effectivehealthcare.ahrq.gov/>
- US Department of Veterans Affairs Products publications
 - Evidence Synthesis Program <https://www.hsrd.research.va.gov/publications/esp/>
 - VA/Department of Defense Evidence-Based Clinical Practice Guideline Program <https://www.healthquality.va.gov/>
- Cochrane Systematic Reviews <https://www.cochranelibrary.com/>
- PROSPERO Database (international prospective register of systematic reviews and protocols) <http://www.crd.york.ac.uk/prospéro/>
- PubMed <https://www.ncbi.nlm.nih.gov/pubmed/>

Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc).

Feasibility of New Evidence Review

We conducted a limited Medline search of primary literature published within the last five years from September 2017 through September 2022. We reviewed the entire search yield for relevance to the nomination questions.

History and Search Details

Search	Actions	Detail	Query	Results	Time
#5		s	Search: #4 AND (Systematic Review[pt] OR Meta-Analysis[pt] OR Clinical Study[pt] OR cohort OR systematic) Filters: from 2017 - 2022	690	14:26:31
#4			Search: #2 AND #3 Filters: from 2017 - 2022	1,295	14:26:18
#3			Search: Outcome and Process Assessment, Health Care[MeSH:noexp] OR Outcome Assessment, Health	1,267,565	14:26:07

	<p style="text-align: center;"> Care[MeSH:noexp] OR Patient Outcome Assessment[MeSH] OR Treatment Outcome[MeSH] OR Treatment Failure[MeSH] OR outcomes OR Health Status[mesh:noexp] OR Functional Status[MeSH] OR Psychosocial Functioning[MeSH] OR Health Inequities[MeSH] OR Health Status Disparities[MeSH] OR Quality of life[MeSH] OR Patient Satisfaction[MeSH] OR Patient Harm[MeSH] OR "seizure control" OR Health Care Costs[MeSH] Filters: from 2017 - 2022 </p>		
#2	<p>Search: #1 AND Epilepsy[mesh] Filters: from 2017 - 2022</p>	3,833	14:24:51
#1	<p>Search: Social Determinants of Health[MeSH] OR "social determinants of health" OR "social determinant of health" OR Sociological Factors[MeSH:No exp] OR Prejudice[MeSH] OR Gender Equity[MeSH] OR Racism[MeSH] OR Sexism[MeSH] OR Ethnic and Racial Minorities[MeSH] OR racism OR racial OR ethnicity OR Sex Factors[MeSH] OR Gender Identity[MeSH] OR sexism OR "gender equity" OR "gender bias" OR Social Stigma[MeSH] OR Social Isolation[MeSH] OR Social Support[MeSH] OR "social support" OR culture OR acculturation OR Communication Barriers[MeSH] OR Limited English Proficiency[MeSH] OR Digital Divide[MeSH] OR "language barrier" OR "language barriers" OR "language fluency" OR Health literacy[MeSH] OR "health literacy" OR Health Services Accessibility[MeSH] OR Health Equity[MeSH] OR accessibility OR accessible OR Insurance Coverage[MeSH] OR Medically Uninsured[MeSH] OR uninsured OR availability OR Unemployment[MeSH] OR Socioeconomic Factors[MeSH] OR Economic Factors[MeSH] OR Economic Stability[MeSH] OR Housing Instability[MeSH] OR Economic Status[MeSH] OR Poverty Areas[MeSH] OR poverty OR Income[MeSH] OR Educational Status[MeSH] OR uneducated OR Social Environment[MeSH] OR Community Networks[MeSH] OR Home Environment[MeSH] OR Housing Quality[MeSH] OR Social Support[MeSH] OR Community Support[MeSH] OR Geography, Medical[MeSH] OR "geographical isolation" OR Rural Health[MeSH] OR rural OR Urban Health[MeSH] OR urban OR Adverse Childhood Experiences[MeSH] Filters: from 2017 - 2022</p>	1,496,035	14:24:31

<https://clinicaltrials.gov/ct2/results?cond=epilepsy&term=disparity&cntry=&state=&city=&dist>

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Value

We assessed the nomination for value. We considered whether or not the clinical, consumer, or policymaking context had the potential to respond with evidence-based change, if a partner

organization would use this evidence review to influence practice, and if the topic supports a priority area of AHRQ or the Department of Health and Human Services.

Appendix B. Selection Criteria Assessment

Selection Criteria	Assessment
1. Appropriateness	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the U.S.?	Yes
1b. Is the nomination a request for an evidence report?	Yes
1c. Is the focus on effectiveness or comparative effectiveness?	No; it is focused on association with outcomes
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	Yes, over 3 million people in the US have active epilepsy
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes.
2c. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2d. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes. According to an analysis using MEPS the aggregate cost of epilepsy care was \$24.5 billion ³⁰ . In another analysis annual costs of caregivers of children with epilepsy were estimated at nearly \$48 billion when including both direct and indirect costs ³¹ .
3. Desirability of a New Evidence Review/Absence of Duplication	
3. A recent high-quality systematic review or other evidence review is not available on this topic	We found five evidence reviews that partly cover the nomination. However the search dates end in 2020.
4. Impact of a New Evidence Review	
4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)?	Yes
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Yes
5. Primary Research	
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies)	We identified 22 publications through a targeted literature search and the nomination. Of these 12 focused on adults, and 11 focused on children. They assessed the association of a variety of factors with health outcomes.
6. Value	
6a. The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change	Yes there is increased interest in addressing disparities and understanding how social determinants of health affect outcomes.

6b. Identified partner who will use the systematic review to influence practice (such as a guideline or recommendation)	The American Epilepsy Society plans to use this review to inform guidance and dissemination materials.
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