Original article

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Mind the gap: health disparities in families living with epilepsy are significant and linked to socioeconomic status

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ABSTRACT – *Aims*. There is limited information on disparities of people with epilepsy (PWE) and, foremost, their caregivers. The objective of this study was to comprehensively compare between PWE and caregivers with low socioeconomic status (SES) and those with high SES for disparities in demographic and epilepsy characteristics, treatment and health care utilization, physical and psychosocial impact, and knowledge about epilepsy.
Methods. PWE and caregivers completed surveys about the aforementioned outcomes during their epilepsy clinic visit or epilepsy monitoring unit admission. Associations were evaluated using SES as a binary independent variable and the patient and caregiver related outcomes as dependent variables.
Results. Thirty-eight patients with low SES and 88 patients with high SES were recruited. Patients with low SES were more commonly non-white, uninsured, unemployed, of lower educational attainment and living in larger households. They were more likely to visit the emergency room for their seizures, were more frequently on polypharmacy and experienced more AED adverse effects. They exhibited higher depression and anxiety levels and worse quality of life. Twenty-two caregivers with low SES and 66 caregivers of high SAS were recruited. Caregivers with low SES were more likely to be non-white and single. They manifested poorer knowledge about epilepsy.
Conclusion. There are notable inequalities in demographic, treatment-related and health care utilization aspects of care of PWE, as well as in the psychosocial impact of their disease. Additional demographic and epilepsy knowledge-related disparities are recognized in caregivers of PWE. Identification of those disparities is a critical step in the creation of appropriate interventions to eliminate them.

Key words: epilepsy, seizures, disparities, socioeconomic status, caregiver

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Epilepsy is an unpredictable, often chronic and debilitating disorder that impacts people of all ages, races, social classes and ethnicities, as well as those who care for them. Epilepsy affects approximately three million people in North America and more than 50 million individuals and their families worldwide, constituting a major, universal, public health issue (Reynolds, 2000; Theodore *et al*., 2006).

In an era where the headlines are flooded with news on societal inequalities, disparities in health care between groups with different levels of underlying socioeconomic status (SES) do not come as a surprise. Disparities in health care are defined as systematic differences in the use or receipt of health care services between people who have comparable need for them (Vickrey and Shapiro, 2009). For people with epilepsy (PWE), there is limited, but growing, evidence of existing disparities (Theodore *et al*., 2006; Szaflarski *et al*., 2006; Burneo *et al*., 2009; Bautista and Jain, 2011; Avetisyan *et al*., 2013; Kroner *et al*., 2013). Prior studies have shown that patients with low SES demonstrate more frequent use of the emergency room, more hospitalizations and more visits to a general practitioner for their care. Additionally, they had greater likelihood of uncontrolled seizures, drug-related adverse effects, stigmatization and poorer quality of life (Begley *et al*., 2011). These studies are characterized by remarkable heterogeneity in terms of methodology, definitions, populations and outcomes (Burneo *et al*., 2009). They typically focus on select demographic, treatment-related and health care utilization aspects of care of PWE, often neglecting the psychosocial impact and knowledge about the disease. The literature on disparities of caregivers is even scarcer. That has been already emphasized for other neurological conditions such as dementia (Gilmore-Bykovskyi *et al*., 2018) and spinal cord injury (Walker *et al*., 2015), but not for epilepsy, despite the major burden associated with care of PWE (Karakis *et al*., 2013; Karakis *et al*., 2014a; Karakis *et al*., 2014b).

Therefore, the primary aim of this exploratory study was to comprehensively characterize any socioeconomic disparities in PWE and their caregivers with the intent to identify potential intervention targets to eliminate them.

Materials and methods

Participants

The participants provided informed consent to partake in this study that was approved by the institutional ethics committee. This cross-sectional study was conducted between August 2015 and June 2019 at Grady Memorial Hospital (GMH) and Emory University Hospital (EUH), two major teaching hospitals, in Atlanta, Georgia, United States. Adult patients attending the outpatient epilepsy clinic or being admitted electively to the Epilepsy Monitoring Unit (EMU) for continuous video-EEG monitoring for diagnostic or presurgical purposes were asked to participate by completing a series of questionnaires. Patients who were non-English speakers or unable to read and write due to mental disability were excluded. Caregivers who accompanied them were also asked to complete questionnaires. A caregiver was defined as the family member who was primarily responsible for providing unpaid every-day care for the patient. All patients were classified as PWE based on video-EEG criteria. The response rate was approximately 45%. Comparing the demographics of subjects who returned their questionnaires with those who did not, no significant differences were identified. Not all patients were accompanied by a caregiver. Comparing the characteristics of patients who had a caregiver available with those who did not, no significant differences were identified.

Questionnaires and procedures

This was a survey-based study. For patients, the following aspects of disparities were considered:

– demographic characteristics;
– epilepsy characteristics;
– health care utilization and treatment;
– physical and psychosocial impact;
– and knowledge about epilepsy.

Specifically, participating patients completed questionnaires providing demographic (age, gender, race, employment, annual household income, education, insurance, marital status and household size) and epilepsy-related (age at disease onset, disease duration, type of seizures and average number of seizures/month in the past year) information. Akin to previous literature on disparities (Teagarden *et al*., 2020), low SES was defined as annual household income below 138% of the Federal Poverty Level (FPL) for household size in the year of study participation, which is the cutoff point typically used to qualify for Medicaid (public health insurance) in the United States. Seventy-five percent of the patients cohabitated with their caregivers. Hence household income represented the aggregate of patient and caregiver income in the majority of the cases. In the minority of cases where the patients lived alone, household income pertained to their individual earnings. The patients also provided information on health care utilization (emergency room visits, hospitalizations and outpatient clinic visits related to seizures in the past year) and treatment (number of antiepileptic drugs [AEDs], compliance and medication adverse effects). Patients'

perception of AED adverse effects was measured using the Liverpool Adverse Events Profile (LAEP) (Baker *et al.*, 1993). Supplementary information was gleaned from review of medical records. Physical impact was assessed by the presence of self-reported injuries. Psychiatric impact was assessed by measuring levels of anxiety and depression with the Beck Anxiety (BAI) (Beck *et al.*, 1988) and Beck Depression (BDI) (Beck, 1993) Inventories, respectively. Social impact was evaluated by evaluation of the patients' quality of life (QOL) and stigma levels. QOL was evaluated by completing the 31-item version of the QOLIE (QOLIE-31) instrument (Cramer *et al.*, 1998). Stigma was evaluated with the Liverpool stigma scale (Jacoby, 1994; Baker *et al.*, 2000). General knowledge about medical and social aspects of seizures was evaluated using the Epilepsy Knowledge Profile-General (EKP-G) (Jarvie *et al.*, 1993).

Caregivers accompanying the patients were also asked to complete questionnaires. For caregivers, the following aspects of disparities were considered:

– demographic characteristics;
– psychosocial impact;
– and knowledge about epilepsy.

Specifically, caregivers provided demographic information (age, gender, race, relationship to the patient, employment, education, and marital and cohabitation status). Social impact was assessed by measuring the time devoted to patient care, the burden of caregiving and the caregivers' perception of stigma against the family. Time spent in patient care, in hours per week, was loosely defined as the time devoted to everyday activities where caregiver participation was indispensable to the patient. This included medication provision, outpatient and emergency room visits and hospitalizations, as well as driving for any patient-related activity. Given the lack of a disease-specific questionnaire to assess their burden, the Zarit caregiver burden inventory (ZCBI) was used instead. This is a 22-item inventory derived from the original 29-item inventory (Zarit *et al.*, 1980). It is the most widely used standardized, validated scale to assess caregiver burden, administered previously for various neurological disorders, including epilepsy (Westphal-Guitti *et al.*, 2007; Kim *et al.*, 2010; Karakis *et al.*, 2013; Karakis *et al.*, 2014a; Karakis *et al.*, 2014b). Caregiver stigma was measured with the aforementioned modification to the Liverpool stigma scale to reflect the caregivers' perception of stigma against their family. Psychiatric impact to the caregivers was measured using the aforementioned BDI and BAI. Caregivers' knowledge about epilepsy was assessed with the EKP-G mentioned above. For a detailed description of the questionnaires used both for patients and caregivers, please refer to the *supplementary material*.

Analysis

Descriptive statistics were used for all variables. Associations were evaluated using SES as a binary independent variable and the patient and caregiver-related outcomes as dependent variables. The Wilcoxon rank-sum test was used for comparisons of continuous variables and Fischer's exact test was used for comparisons of categorical variables. Given the exploratory nature of this study and the risk of missing important associations when attempting to reduce type I error, we did not adjust for multiple comparisons (Rothman, 1990). *P* value of <0.05 was considered statistically significant. Statistical analysis was performed in SAS (Cary, NC).

Results

Comparison of patients with low vs high SES

Thirty-eight patients with low SES and eighty-eight patients with high SES were recruited. From a demographic standpoint, patients with low SES were more likely to be non-white (51%) compared to those with high SES (25%) (p=0.006), uninsured (private insurance rate of 29% vs 80%; $p<0.0001$), unemployed (unemployment rate of 82% vs 52%; p=0.0025), of lower educational attainment (some college education rate of 49% vs 80%; p=0.001) and living in larger households (median number of household members of four vs three; p=0.008). From a health care utilization and treatment standpoint, patients with low SES were more likely to visit the emergency room for their seizures (mean annual visits number of 1.8) compared to those with high ES (mean annual visits number of 1.4) (p=0.01), were more likely to be on polypharmacy (rate of patients on two or more AEDs of 92% vs 73%; p=0.01) and experience more AED adverse effects (median LAEP score of 49 vs 42; p=0.01). From a physical impact standpoint, the frequency of self-reported injuries in patients of low SES (79%) compared to those with high SES (60%) did not attain statistical significance (p=0.07). From a psychosocial impact standpoint, patients with low SES exhibited higher anxiety levels (median BAI score of 21.5 vs 18; p=0.01) compared to those with high SES. That association sustained (p=0.03) when symptoms of anxiety were examined as a dichotomous variable (*i.e.* anxious or not; BAI cut-off >7 points). The association of depression levels and SES (median BDI score of 18 for low SES patients vs 13 for high SES patients) did not attain statistical significance (p=0.05) when examined as a continuous variable, but was statistically significant (p=0.02) when symptoms of depression were examined as a dichotomous variable (*i.e.* depressed or not; BDI cut-off >9 points). Patients with low SES also exhibited worse

quality of life (median QOLIE-31 overall score of 46.5 vs 50; p=0.05). These results are summarized in *table 1*.

Comparison of caregivers with low vs high SES

Twenty-two caregivers with low SES and 66 caregivers of high SAS were recruited. From a demographic standpoint, caregivers with low SES were more likely to be non-white (53%) compared to those with high SES (21%) (p=0.009) and single (rate of unmarried caregivers of 47% vs 19%; p=0.01). Age (median age of 35.5 for low SES caregivers vs 47 for high SES caregivers) and unemployment rate (50% for low SES caregivers vs 29% for high SES caregivers) differences did not attain statistical significance (p=0.07 and p=0.09, respectively). From a psychosocial impact standpoint, the association of anxiety levels and SES (median BAI score of 11.5 for low SES caregivers vs 5 for high SES patients) did not attain statistical significance (p=0.07). From an epilepsy knowledge

Table 1. Disparities in low SES patients compared to high SES patients.

Variable	Low SES patients (n=38)	High SES patients (n=88)	p value
Demographics			
Age (median, IQR)	34 (14)	34 (21.5)	0.52*
Gender (female, n, %)	20/38 (53%)	56/88 (64%)	0.32^
Race (non-white, n, %)	19/37 (51%)	21/85 (25%)	0.006^
Employment (not employed, n, %)	31/38 (82%)	44/84 (52%)	0.0025^
Education (college, n, %)	18/37 (49%)	67/84 (80%)	0.001^
Marital status (not married, n, %)	28/38 (74%)	49/85 (58%)	0.10^
Household size (median, IQR)	4 (2.5)	3 (2)	0.008*
Insurance (private, n, %)	11/38 (29%)	67/84 (80%)	<0.0001^
Annual household income (median, IQR)	$16,000 (10,000)	$75,000 (70,000)	<0.0001*
Epilepsy characteristics			
Age at epilepsy onset (years, median, IQR)	20 (11)	20 (17)	0.97*
Duration of epilepsy (years, median, IQR)	15 (21)	13 (16)	0.32*
Seizure frequency (seizures/month, median, IQR)	3 (7)	2 (4)	0.20*
Seizure type (convulsive, n, %)	14/23 (61%)	32/57 (56%)	0.80^
Treatment			
Number of AEDs (>/2, n, %)	34/37 (92%)	61/84 (73%)	0.01^
Compliance with AEDs (yes, n, %)	25/34 (74%)	66/80 (82.5%)	0.31^
Medication adverse effects (LAEP, median, IQR)	49 (16)	42 (15.5)	0.01*
Health care utilization			
Emergency room visits per year for seizures (mean, SD)	1.8 (1.9)	1.4 (2.8)	0.01*
Admissions per year for seizures (mean, SD)	0.9 (1.5)	0.7 (1.4)	0.19*
Clinic visits per year for seizures (mean, SD)	4.5 (6.3)	4.1 (4)	0.70*
Physical impact			
Injuries (yes, n, %)	27/34 (79%)	41/68 (60%)	0.07^
Psychiatric impact			
Depression (BDI, median, IQR)	18 (12)	13 (15)	0.05*
Anxiety (BAI, median, IQR)	21.5 (26)	18 (16)	0.01*
Social impact			
Quality of life (QOLIE-31 overall score, median, IQR)	46.5 (25)	50 (28)	0.05*
Stigma (Liverpool stigma scale, mean, SD)	1.3 (1.2)	1.2 (1.2)	0.98*
Knowledge			
Epilepsy knowledge (EKP-G, median, IQR)	38 (16)	41 (9)	0.12*

SES: Socio-Economic Status; IQR: Interquartile Range; SD: Standard Deviation; AEDs: Antiepileptic Drugs; LAEP: Liverpool Adverse Events Profile; BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory; QOLIE-31: Quality of Life-31 scale; EKP-G: Epilepsy Knowledge Profile-General. *Wilcoxon rank-sum test (Mann–Whitney U test). ^Fischer's exact test.

standpoint, caregivers with low SES exhibited poorer knowledge about epilepsy compared to those with high SES (median EKP-G score of 38.5 vs 42; p=0.03). These results are summarized in *table 2*.

Discussion

This study corroborates significant socioeconomic disparities in demographic, treatment-related and health care utilization aspects of care of PWE, and highlights additional inequalities in the psychosocial impact of their disease. Furthermore, demographic and epilepsy knowledge-related disparities are identified in caregivers of PWE.

Comparison of patients with low vs high SES

In the context of living with a commonly chronic and debilitating disorder, the identified social and economic disadvantages of PWE come as no surprise. In accord with prior reports mostly focusing on comparison of PWE with the general population (Theodore *et al*., 2006; Kroner *et al*., 2013; Avetisyan *et al*., 2013; Thurman *et al*., 2016), PWE of low SES were more likely uninsured, with lower educational attainment, unemployed and residing in larger households. In line with prior studies (Begley *et al*., 2011), we identified more frequent use of the emergency room and higher frequency of medication adverse effects. On the other hand, we did not identify issues with compliance in the patients dealing with financial distress as previously reported in the literature (Dodrill *et al*., 1987). In addition to the previously recognized poorer QOL in PWE of low SES (Begley *et al*., 2011), we demonstrated higher levels of anxiety in these individuals. Therefore, a patient-centered, holistic approach to PWE with low SES that addresses not only their pharmacologic management but incorporates their psychosocial well-being is paramount.

Table 2. Disparities in low SES caregivers compared to high SES caregivers.

Variable	Low SES caregivers (n=22)	High SES caregivers (n=66)	p value
Demographics			
Age (median, IQR)	35.5 (23)	47 (17)	0.07*
Gender (female, n, %)	14/22 (64%)	44/66 (67%)	0.80^
Race (non-white, n, %)	10/19 (53%)	13/63 (21%)	0.009^
Relationship to patient (n, %)			
Child	0/20 (0%)	2/63 (3%)	
Parent/sibling	4/20 (20%)	21/63 (33%)	0.43^
Spouse	15/20 (75%)	33/63 (53%)	
Friend/other	1/20 (5%)	7/63 (11%)	
Employment (not employed, *n*, %)	9/18 (50%)	18/63 (29%)	0.09^
Education (college, *n*, %)	11/19 (58%)	48/63 (76%)	0.14^
Marital status (not married, *n*, %)	9/19 (47%)	12/63 (19%)	0.01^
Cohabitation (yes, *n*, %)	13/15 (87%)	41/57 (72%)	0.32^
Psychiatric impact			
Depression (BDI, median, IQR)	10 (15)	7 (9)	0.19*
Anxiety (BAI, median, IQR)	11.5 (16)	5 (11)	0.07*
Social impact			
Time spent in patient care (hours/week,	24 (101)	14 (36)	0.12*
median, IQR)	22 (20)	19 (24)	0.61*
Caregiver burden (ZCBI, median, IQR)	0.9 (1.1)	0.8 (1)	0.80*
Stigma (Liverpool stigma scale, mean, SD)			
Knowledge			
Epilepsy knowledge (EKP-G, median, IQR)	38.5 (6)	42 (7)	0.03*

SES: Socio-Economic Status; IQR: Interquartile Range; SD: Standard Deviation; ZCBI: Zarit Caregiver Burden Inventory; BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory; EKP-G: Epilepsy Knowledge Profile-General. *Wilcoxon rank-sum test (Mann-Whitney U test). ^Fischer's exact test.

Comparison of caregivers with low vs high SES

Little attention is shown for the secret patient in a family living with epilepsy, namely the caregiver (Karakis *et al*., 2013; Karakis *et al*., 2014a; Karakis *et al*., 2014b). The findings of this study suggest that caregivers of PWE with low SES shared similar social and economic disadvantages. They were more likely to be single with a similar trend towards unemployment that nevertheless did not reach statistical significance. They also manifested a trend towards more anxiety compared to caregivers with high SES, and their epilepsy knowledge was poorer. Given the scarcity of prior literature on inequalities in caregivers of PWE, it is unclear whether these findings reflect differences in economic resources, social support, knowledge/attitudes towards epilepsy or a combination thereof (Szaflarski *et al*., 2006). Yet, if replicated in future studies, they could act as intervention targets for future trials. Specifically, mental health support and better education of caregivers with low SES may play a pivotal role in the family therapy plan (Beech, 1992; Elliott and Shneker, 2008).

Strengths and limitations

There is dire need for further research of socioeconomic disparities of PWE and, foremost, their caregivers. This exploratory study attempted to comprehensively address this knowledge gap utilizing a well-characterized cohort of adult PWE, confirmed by video-EEG, and their caregivers. The set of measures collected were broad and covered most of the outcomes examined previously in the literature on inequalities in epilepsy.

On the other hand, there are limitations to acknowledge such as the risk of response bias, recall bias and lack of generalizability to other settings and cultures. Moreover, the point-in-time comparisons performed in this study limit further insight into the evolution of these findings longitudinally as well as inference of causation.

Significance and future directions

These limitations notwithstanding, the findings of this study may have clinical, research and public health implications. From a clinical perspective, they highlight targets of tailored collaborative interventions when confronted with families of different SES living with epilepsy. Specifically, there is a need to design multidisciplinary programs comprised of epileptologists, neurosurgeons, mental health providers, primary care physicians, pharmacists, dietitians, nurse navigators, social workers, case managers and community members that ensure PWE receive "the right care, at the right time, by the right team and in the right place" (Innovation, 2013). From a research perspective, these findings call for further investigation of disparities in epilepsy that incorporates the caregivers and attempts to clarify and address the magnitude and culprits of these disparities. To accomplish these goals, collaborative efforts that ensure larger representation of diverse groups of PWE from various settings and countries are required (Szaflarski *et al*., 2006). Both patient-reported and provider-documented aspects of care should be investigated, longitudinally and with comparative groups of patients suffering from other chronic disorders, focusing on intervention trials (Avetisyan *et al*., 2013; Burneo *et al*., 2009; Begley *et al*., 2011). From a public health perspective, providers, administrators, advocates and policy makers should include the care takers into their agenda and promote actions that eliminate inequities for families living with epilepsy. Specifically, high impact and sustainable educational programs can enhance epilepsy self-management within the family living with the disease (Elliott and Shneker, 2008), but also address misbeliefs, negative stereotypes and discriminating attitudes in the community (Karakis *et al*., 2020). International, multi-society collaborations have the power to raise political and public awareness and narrow the knowledge, advocacy and public education gap about the burden of epilepsy to the family and to the society as a whole (Spiciarich *et al*., 2019).

Conclusion

There are notable inequalities in demographic, treatment-related and health care utilization aspects of care of PWE as well as in the psychosocial impact of their disease. Furthermore, there are noteworthy demographic and epilepsy knowledge-related disparities in caregivers of PWE. Identification of those disparities is an important step in the creation of appropriate interventions to eliminate them. □

Supplementary data.
Summary didactic slides and supplementary material are available on the www.epilepticdisorders.com website.

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None of the authors have any conflict of interest to declare.

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TEST YOURSELF

(1) Compared to PWE with high SES, PWE with low SES:
A. are more commonly non-white
B. visit more frequently the emergency room
C. experience more AED adverse effects
D. exhibit higher anxiety levels
E. all of the above

(2) Compared to caregivers of PWE with high SES, caregivers of PWE with low SES:
A. are more commonly white
B. are more commonly married
C. exhibit lower anxiety levels
D. exhibit better knowledge about epilepsy
E. none of the above

(3) To tackle socioeconomic disparities in epilepsy in the future:
A. tailored multidisciplinary interventions are needed for the whole family
B. further research is needed that incorporates the caregivers
C. advocacy groups and policy makers should include the care takers in their agenda
D. all of the above

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".