PatientsLikeMe® Epilepsy Community: Factors Affecting Quality of Life

Simon Borghs¹, Christine de la Loge¹; Svetlana Dimova¹; Tracy Durgin²; George Phillips³; Knut Mueller⁴; Candice Lafosse⁵; Paul Wicks⁶

¹UCB Pharma, Brussels, Belgium; ²UCB Pharma, Smyrna, GA, USA; ³UCB Pharma, Raleigh, NC, USA; ⁴UCB Pharma, Levallois-Perret, France; ⁶PatientsLikeMe Inc, Cambridge, MA, USA

Introduction

- PatientsLikeMe, which hosts a free online community for patients with epilepsy, was developed in partnership with UCB and launched in January 2010
- Previous data analyses (March 2010¹, September 2010², and May 2011^{3,4}) provided insights into the characteristics and experiences of users with epilepsy

Objective

• To assess the impact of epilepsy on the quality of life of members of the PatientsLikeMe Epilepsy community

Methods

Study Population

 Community members who logged in between January 2010 – November 2011 and reported diagnosis of epilepsy and multiple seizures

Data Collected

- Demographics, epilepsy characteristics, symptoms (preset symptoms checklist; Table 1; Figure 1), and side effects patients perceived to be related to their treatment
- Patient-Reported Outcomes
- QOLIE-31/P (Quality of Life [QoL] in Epilepsy) total score⁵: Epilepsy-specific quality of life instrument (score range = 0-100; 100 represents best health status)
- HADS (Hospital Anxiety and Depression Scale): Anxiety and depression instrument⁶ (score range = 0-21; 0 represents best anxiety or depression status)
- EQ-5D (Euro-QoL 5 dimensions) utility score⁷: Generic health status instrument (score range = 0-1; 1 represents best health status)

Logistic Regression Analysis

 Multivariate logistic regression analysis to identify variables associated with poor HRQoL (<Quartile 1 [Q1] of QOLIE-31/P total score or EQ-5D utility score; Table 1)

Table 1 Variables Included in Multivariate Logistic Regression Analysis

Variable	Levels (vs <i>reference level</i>)	
Sociodemographic		
Age	>25–50, >50 years vs <i>0–25 years</i>	
Gender	Female vs Male	
Body mass index	0–18.5, >25 vs > <i>18.5</i> –25	
Epilepsy-related		
Duration since diagnosis	0-1, >1-10 years vs >10 years	
Type of epilepsy syndrome	Focal, Unidentified vs Generalized	
Seizures		
Occurrence of seizures in 4 weeks preceding PRO assessment	TC, Non-TC, Missing vs None	
Symptoms		
Severity of each symptom from the symptom checklist (anxiety, depression, fatigue, headache, insomnia, memory problems, pain, problems concentrating, and somnolence)	Moderate & severe vs None & mild	
AED treatment		
Type of current AEDs	Combination of older ^a & newer ^b , Newer monotherapy, Newer polytherapy, Older monotherapy, Missing vs <i>Older polytherapy</i>	
Side effects		
Moderate and severe side effects in 4 weeks preceding PRO assessment	Yes vs No	
Co-morbidities		
Number of co-morbidities	1, 2+, Missing vs 0	

Older AEDs: acetazolamide, benzodiazepines, carbamazepine, ethosuximide, methsuximide, phenobarbital, phenytoin, sultiame, valproic acid

bNewer AEDs: felbamate, gabapentin, lacosamide, levetiracetam, lamotrigine, oxcarbazepine, pregabalin, rufinamide, retigabine, tiagabine, topiramate, vigabatrin, zonisamide

Results

Parameter^a

Demographic and Epilepsy Characteristics

- 3,073 registered patients recorded a diagnosis of epilepsy and had multiple seizures (Table 2):
- 69.5% completed the preset symptoms checklist
- 36.2% completed a patient-reported outcomes (PROs) assessment
- 20.8% patients reported ≥1 side effect they perceived as being treatment-related

Table 2. Patient Demographic and Epilepsy Characteristics

	N=3,073	n=2,135	n=1,113
Gender, n	2,929	2,107	1,113
Female, %	71.5	73.2	72.3
Age, n	2,909	2,095	1,112
Mean (SD), years	37.8 (12.7)	37.6 (12.6)	37.8 (12.3)
Age class, %			
0–20 years	7.3	7.1	6.2
21–50 years	76.3	76.8	77.6
>50 years	16.4	16.2	16.2
Time since diagnosis, n	3,044	2,130	1,113
Mean (SD), years	17.7 (14.1)	17.4 (13.8)	17.7 (13.6)
Age at first seizure, n	2,906	2,095	1,112
Mean (SD), years	17.2 (13.5)	17.1 (13.3)	16.5 (13.0)
Seizure type ^b , n	3,073	2,135	1,113
Generalized, %	23.7	28.3	30.7
Partial, %	23.7	29.1	33.6
Mixed, %	28.0	33.4	35.0
Unknown, %	24.7	9.2	0.6
AED treatment ^{c,d} , n	1,773	1,593	1,009
Monotherapy, %	51.4	50.3	47.7
Polytherapy, %	48.6	49.7	52.3
Newer AEDs only, %	56.4	56.4	56.3
Older AEDs only, %	19.8	19.4	17.9
Combination of newer and older AEDs, %	23.8	24.2	25.8
Co-morbidities ^e , n	2,271	1,769	986
Patients with ≥1 co-morbid condition, %	53.9	54.8	55.7
Migraine, %	28.1	28.6	28.4
Anxiety disorder, %	17.6	17.9	18.1
Major depressive disorder, %	13.9	14.6	15.4
Hypertension, %	10.5	10.7	11.4

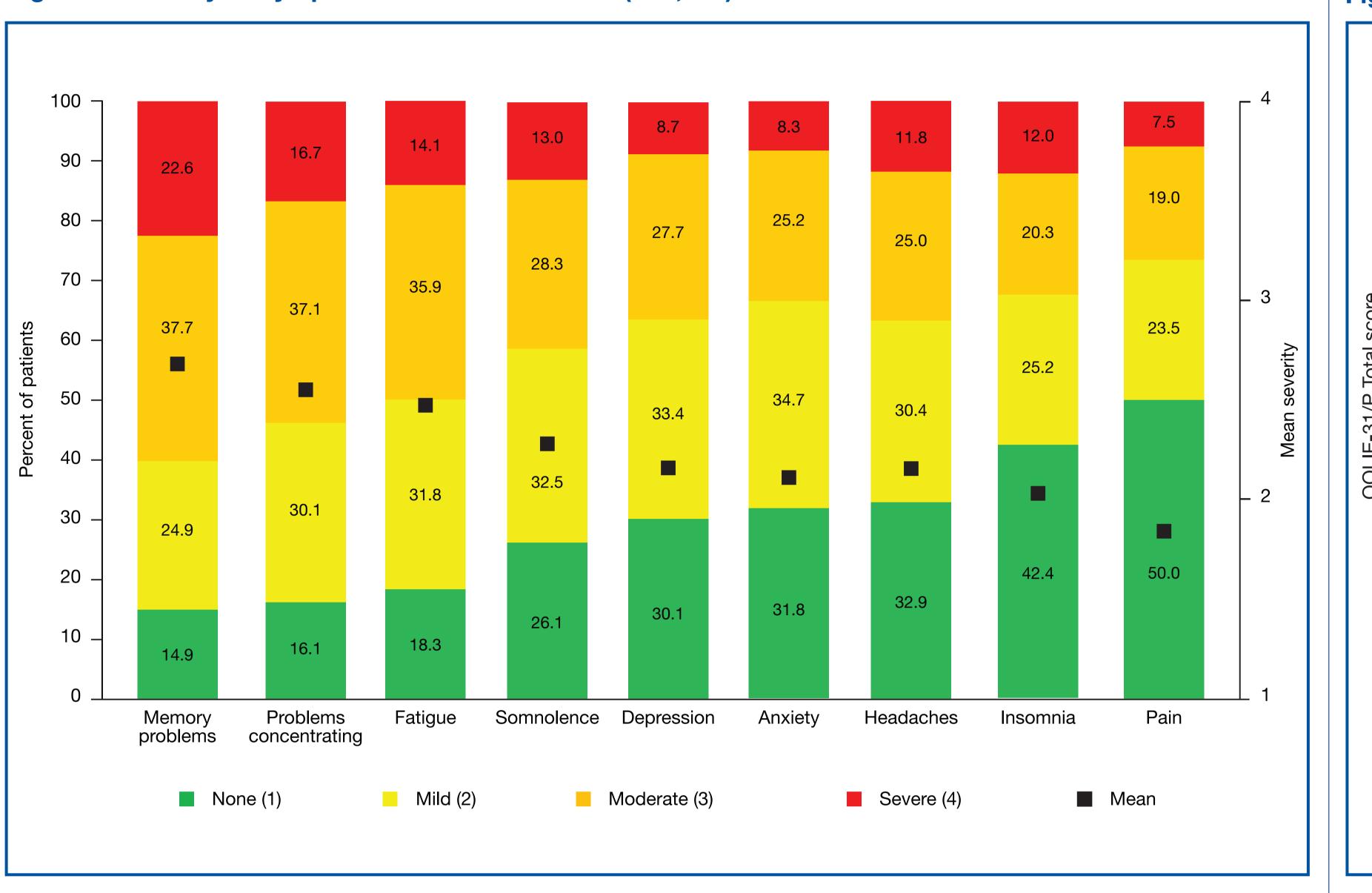
Members of the PatientsLikeMe Epilepsy Community who do not self-report AED treatment may take no AED(s) or may have not reported their treatment

co-morbidities recorded by ≥10% of the patients from a preset co-morbidity checklist

Symptoms

 Symptoms most frequently recorded as moderate or severe were memory problems, problems concentrating, fatigue, and somnolence (Figure 1)

Figure 1. Severity of Symptoms at First Evaluation (n=2,135)



Side Effects

A single patient may have reported more than one perceived side effect

 The most frequently recorded side effects perceived by the patients as associated with their treatment were somnolence, fatigue, and memory impairment (Table 3)

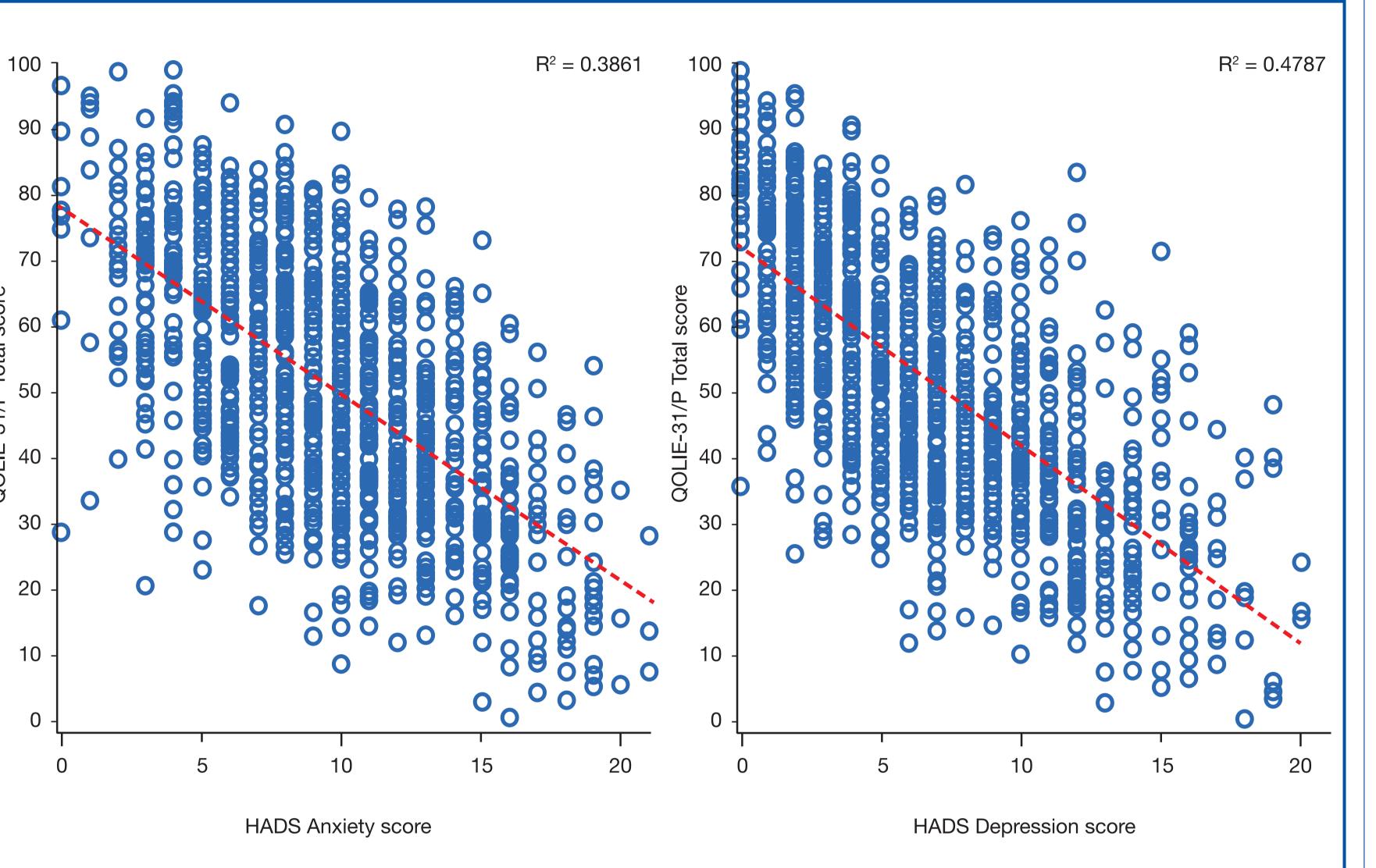
Table 3. Side Effects Perceived to be Associated with Any Treatment (Recorded by ≥5% Patients; n=639)

Side effect (MedDRA preferred term)	Patients n (%)
Somnolence	148 (23.2)
Fatigue	110 (17.2)
Memory impairment	88 (13.8)
Dizziness	74 (11.6)
Abnormal weight gain	67 (10.5)
Depression	48 (7.5)
Insomnia	39 (6.1)
Nausea	36 (5.6)
Headache	35 (5.5)
Balance disorder	32 (5.0)
MedDRA, Medical Dictionary for Regulatory Activities Side effects due to medication and emerging symptoms of disease are often difficult to distinguish and therefore must be careful	ly evaluated

Correlation Between QOLIE-31/P Total Score and HADS Subscores

 QOLIE-31/P total score was highly correlated to HADS Anxiety (R=0.6214) and Depression (R=0.6919) scores (Figure 2)

Figure 2. Correlation Between QOLIE-31/P Total Score and HADS Anxiety and Depression Scores (n=1,113)

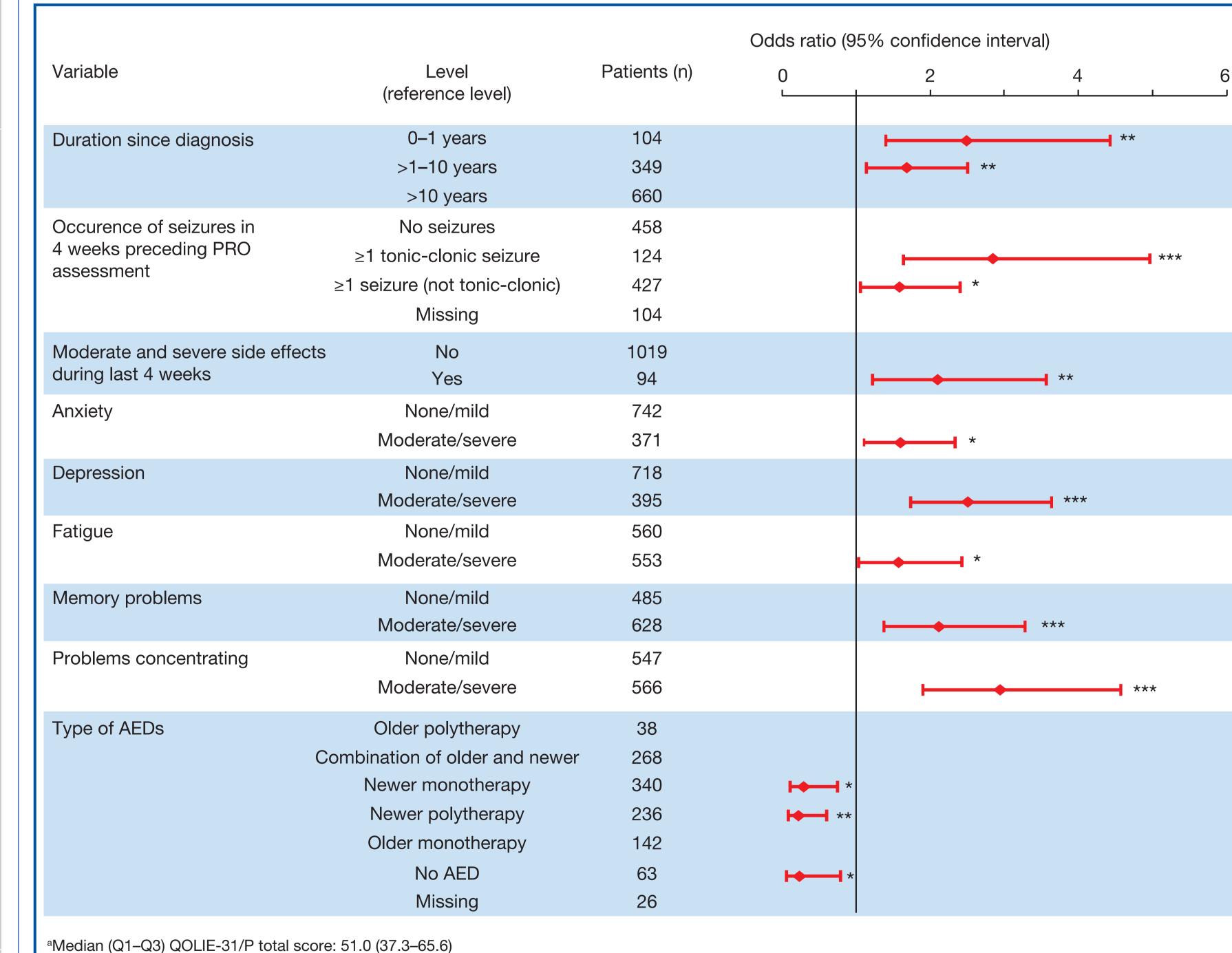


Predictors of Poor Health-Related Quality of Life

QOLIE/31P

• 279/1,113 (25.1%) patients included in the multivariate logistic regression analysis were classified as having poor HRQoL (QOLIE-31/P total score <Q1) (Figure 3)

Figure 3. Predictors of Low QOLIE-31/P Total Score (<Q1)^a

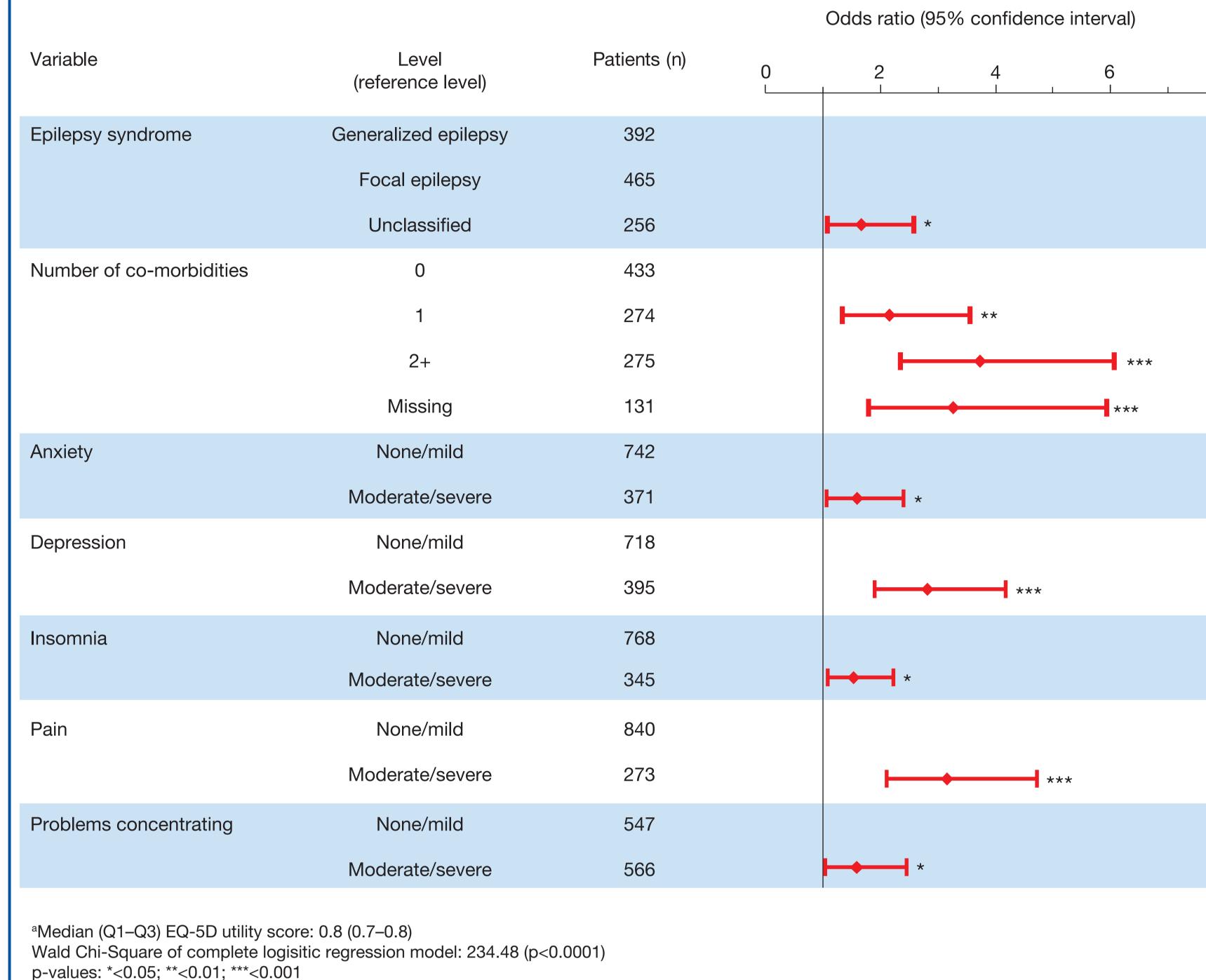


Wald Chi-Square of complete logisitic regression model: 235.41 (p<0.0001) p-values: *<0.05; **<0.01; ***<0.001 AED, antiepileptic drug; PRO, patient-reported outcome

EQ-5D

• 263/1,113 (23.6%) patients included in the multivariate logistic regression analysis were classified as having poor HRQoL (EQ-5D Utility Score <Q1) (Figure 4)

Figure 4. Predictors of Low EQ-5D Utility Score (<Q1)^a



Conclusions

- Based on reports by users of the PatientsLikeMe Epilepsy Community, memory problems, fatigue and somnolence were the most frequently occurring symptoms and perceived treatment-related side effects
- The most predictive factors for poor HRQoL (odds ratio >2; p<0.05) differed according to the instrument used:
- QOLIE-31/P: moderate/severe problems concentrating, depression, memory problems, and side effects; occurrence of generalized tonic-clonic seizures and epilepsy duration ≤1 year

EQ-5D: pain, depression and co-morbidities

- Variations in the predictors highlight differences in the content of QOLIE-31/P and EQ-5D - each covers different dimensions of patient health and uses different weighting to derive their summary score
- These results suggest that a holistic approach not limited to seizure control should be considered when treating people with epilepsy

The authors would like to thank all the patients who have contributed to this work by sharing their data Sally Cotterill, PhD (QXV Communications) assisted with poster development, which was funded by UCB Pharma Artwork was supported by QXV Communications, part of the InforMed group

Simon Borghs, Svetlana Dimova, Tracy Durgin, George Phillips and Knut Mueller are employees of UCB Pharma Svetlana Dimova owns stock/stock options in the company Christine de la Loge was an employee of UCB Pharma at the time that the study was carried out

Candice Lafosse is an employee of Keyrus Biopharma, Levallois-Perret, France Paul Wicks is an employee of PatientsLikeMe and owns stock options in the company. The PatientsLikeMe R&D team has received research support from Abbott.

1. de la Loge et al. AES 2010, Abstract 1.305, www.aes.org 2. de la Loge et al. AES 2011, Abstract 2.271, www.aes.org 3. Dimova et al. Abstract P01.062, AAN 2012, Neurology 2012;78(Suppl.1); www.neurology.org

4. de la Loge et al. Value Health 2012;15:A147-A148 5. Cramer JA, et al. Epilepsia 1998;39:81-8

6. Zigmond AS, Snaith RP. Acta Psychiatr Scand. 1993;67:361-70 The EuroQol Group. Health Policy 1990;16:199–208

Acorda, Avanir, Biogen, Johnson & Johnson, Merck, Novartis, Sanofi and UCB