

Assessment of quality of life among the elderly with epilepsy

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Abstract

As the elderly represent the most rapidly growing population in the United States, it is critical that physicians are capable of managing their chronic illnesses, including epilepsy. Optimal treatment of epilepsy integrates an understanding of health-related quality of life (HRQOL), yet limited information is available to guide HRQOL issues among the elderly. This study found that seniors with epilepsy do not have poorer HRQOL compared with general epilepsy populations. However, when compared with general populations without epilepsy, seniors with epilepsy report a significantly lower HRQOL across all domains. Multiple factors may uniquely affect HRQOL among elderly populations with epilepsy: aging, comorbid conditions, and epilepsy variables. However, to our knowledge, no one instrument addresses all of these aspects. The development of HRQOL instruments specifically for an elderly population with epilepsy may be useful and needed.

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1. Introduction

Epilepsy, a chronic condition characterized by recurrent unprovoked seizures, affects two to three million people in the United States [1], with more than one-third being 65 years or older [2,3]. The incidence and prevalence of epilepsy rise sharply after age 60, and its incidence is the highest of any age group [1,4]. Etiology of epilepsy among the elderly is idiopathic in nearly 50% of cases, and among the known causes, the most common is stroke, which accounts for 30 to 50%, followed by degenerative disease and neoplasm [5–7]. The most common type of epilepsy is partial complex seizures, but unlike in the general population in whom seizures typically arise from the temporal lobe, partial seizures in the elderly often originate from extratempo-

ral regions or the frontal lobe in areas frequently affected by stroke [8]. Vague complaints and a lack of typical presentations among the elderly lead to common misdiagnoses of seizures as being syncope, dementia, or altered mental status [8,9]. Moreover, multiple factors complicate the treatment of epilepsy in this population: altered drug metabolism or clearance, cardiovascular and cerebrovascular comorbidity [10], and concomitant medications that interact with antiepileptic drugs (AEDs) adversely [11].

Because the elderly represent the most rapidly growing population in the United States, understanding optimal care of epilepsy among the elderly is critical. However, limited information is available concerning the impact of epilepsy and its treatment on quality of life among the elderly [12]. Quality of life is an essential element of pharmaceutical clinical trials and medical treatment that refocuses medical intervention on the issues relevant to patients and their perspectives, but is rarely incorporated into routine clinical care practice [12]. Current AED studies involve adults younger than 60 years of age, and few studies examine

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health-related quality of life (HRQOL) among the elderly with epilepsy [13].

Previous research on HRQOL using a generic, non-epilepsy-specific instrument (e.g., Short Form 36 Health Survey) suggests that older patients with epilepsy cope better with their epilepsy than their middle-aged peers [14]. Other research using an unstructured instrument (e.g., blank piece of paper), focusing on epilepsy patient-derived quality-of-life concerns, concludes that HRQOL issues among the elderly are similar to those of younger populations [15]. Because of the high morbidity and mortality among this population, selecting a useful and meaningful method to quantify quality of life for an elderly epileptic population is a challenge [16]. Current instruments that measure quality of life for people with epilepsy have been developed and tested exclusively among patients younger than 65 years, and limited empirical data are available to guide quality-of-life issues in elderly populations [12]. The goal of this study was to assess quality-of-life issues among the elderly population with epilepsy, using both seizure-specific and generic HRQOL instruments, the Quality of Life in Epilepsy Inventory–31 and Short Form 36 Health Survey.

2. Methods

2.1. Instruments

The Short Form 36 Health Survey (SF-36) is a widely used measure of HRQOL [17]. Respondents rate their ability to function and their level of pain in various areas using Likert scales ranging from two to six levels. Items are scored in the following eight domains: Physical Functioning, Role Limitations due to Physical Health Problems, Bodily Pain, Social Functioning, General Mental Health (including psychological distress and well-being), Role Limitations due to Emotional Problems, Vitality/Energy/Fatigue, and General Health Perceptions.

The Quality of Life in Epilepsy Inventory–31 (QOLIE-31) is a disease-specific tool that is used to assess quality of life in epilepsy populations [18]. The QOLIE-31 was normed on adults with simple and complex partial, grand mal, absence, or myoclonic seizures of mild to moderate severity. It prompts patients to rate how they feel and how well they are functioning, using Likert scales from three to ten levels. It measures HRQOL across seven domains: Emotional Well-Being, Social Functioning, Energy–Fatigue, Cognitive Functioning, Seizure Worry, Medication Effects, and Overall Quality of Life.

2.2. Participants and procedure

Surveys were sent to 56 patients who did not experience significant cognitive impairment, dementia, or psychiatric illness, were 60 years or older, and had an established diagnosis of epilepsy from the Via Christi Comprehensive Epilepsy Center. The two quality-of-life surveys were accompanied by a cover letter (explaining the purpose of the research, the risks and benefits of participation, and their right to refuse participation) and a self-addressed, stamped envelope to return completed surveys. No protected health information or identifiers were collected or recorded. Surveys returned between February and March 2007 were collected and analyzed.

3. Results

Of the 56 people to whom surveys were sent, 23 responded, for a 41% response rate. Of the respondents,

56.5% ($n = 13$) reported being female, and 43.5 ($n = 10$) reported being male. The mean age of respondents was 66 years, with a range from 60 to 82 (SD = 6).

3.1. QOLIE-31

The QOLIE-31 provides a scale from 0 to 10, with 10 representing the best possible quality of life and 0 representing the worst possible quality of life, as bad as or worse than being dead. The average number reported for Overall Quality of Life within this sample was 6.6, the median was 6.0, and the mode was 5.0 (Fig. 1).

On the QOLIE-31, respondents reported how they had felt during the past 4 weeks with respect to 12 items, using a 6-point Likert scale ranging from “all of the time” to “none of the time.” Respondents reported a generally positive quality of life. Specifically, 53% reported feeling happy all or most of the time, 70% reported feeling “so down in the dumps that nothing could cheer you up” a little or none of the time, and 61% reported feeling limited in social activities as a result of their health a little or none of the time. Two items on the QOLIE-31 address epilepsy-specific determinants of QOL: Seizure Worry and Difficulty Reasoning. Sixty-five percent (65%) reported worrying about having another seizure a little or none of the time, and 48% reported having difficulty reasoning and solving problems a little or none of the time.

3.2. Comparison of QOLIE-31 results from this sample with results from other studies

The scores from this sample’s QOLIE-31 were not significantly different from those of the general populations with epilepsy for which the QOLIE-31 was standardized (Fig. 2) [18]. Though it was not significantly different, Seizure Worry was the scale with the most disparity between this older sample and other younger samples. Seizure Worry tended to be less of a concern (the higher the score, the less seizure worry) among the elderly population compared with other studies’ younger populations with epilepsy.

3.3. Comparison of QOLIE-31 with SF-36

The QOLIE-31 and SF-36 were compared to see if they are equivalent measures of quality of life in this elderly

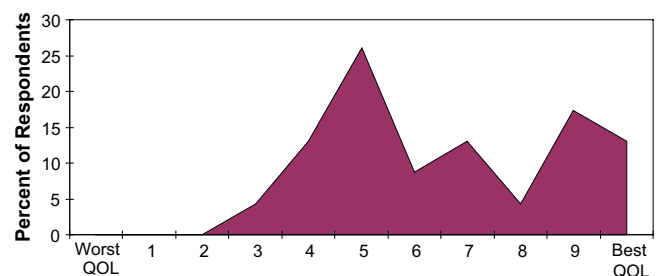


Fig. 1. Respondents’ self-reported quality of life as assessed by the QOLIE-31.

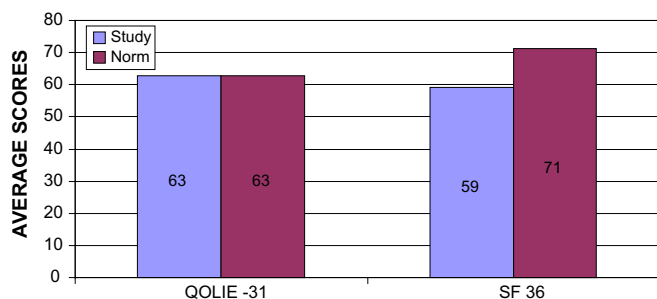


Fig. 2. Comparison of the QOLIE-31 and SF-36 average scores from this study with norms.

population. Weighted means were calculated for each domain (Table 1). The Total Quality of Life score derived from the SF-36 was not significantly different from that of the QOLIE-31 for this study's sample or the normative sample (Fig. 2) [18].

3.4. SF-36

The analyses were conducted using a *t* test and weighted scores based on the QOLIE scoring manual [19]. SF-36 scores derived from this study were significantly lower than the scores derived from the general adult population, $t(22) = -2.228$, $P = 0.036$ (Fig. 2) [17]. All eight of the subscale average scores were lower than the norms, and five were significantly lower. The subscales with significantly lower means from the norm include: physical function, $t(22) = -3.641$, $P = 0.001$; role-physical, $t(22) = -3.517$, $P = 0.002$; general health, $t(22) = -2.541$, $P = 0.019$; social functioning, $t(22) = -2.861$, $P = 0.009$; and role-emotional, $t(22) = -2.909$, $P = 0.008$ (Table 2).

Table 1
Weighted means, standard deviations, and ranges for SF-36 and QOLIE-31 domains

	Mean	SD	Min	Max
SF-36				
Physical Function	59.1	33.0	0.0	100.0
Role—Physical	48.9	43.6	0.0	100.0
Body Pain	66.6	28.1	2.0	100.0
General Health	58.1	26.1	10.0	100.0
Vitality	56.5	24.6	5.0	90.0
Social Functioning	64.7	31.2	13.0	100.0
Role—Emotional	52.2	48.0	0.0	100.0
Mental Health	67.3	19.7	24.0	96.0
Total	59.2	26.0	21.0	98.0
QOLIE-31				
Seizure Worry	69.9	26.6	10.7	100.0
Overall QOL	64.6	20.3	27.5	100.0
Emotion	66.6	19.5	24.0	96.0
Energy	51.9	23.0	10.0	90.0
Cognitive	61.4	23.7	10.0	100.0
Medication	65.6	25.5	25.0	100.0
Social Functioning	65.6	28.4	14.0	100.0
Total	62.7	20.5	16.8	95.5

Table 2

Comparing SF-36 subscale scores of elderly patients with epilepsy in this study with those of the general population

SF-36 subscale	This Study	Norm	Difference
Physical Function ^a	59.1	84.2	-25.1
Role—Physical ^a	48.9	80.9	-32.0
Body Pain	66.6	75.2	-8.6
General Health ^b	58.1	71.9	-13.8
Vitality	56.5	60.9	-4.4
Social Functioning ^a	64.7	83.3	-18.6
Role—Emotional ^a	52.2	81.3	-29.1
Mental Health	67.3	74.7	-7.4

^a Statistically significant difference at the 0.001 level.

^b Statistically significant difference at the 0.01 level.

4. Discussion

Our study highlights the impact of epilepsy among the elderly population and the need for effective assessment of HRQOL in this group. Consistent with previous studies, seniors with epilepsy do not necessarily have poorer quality of life than the general epilepsy population [14,15,20]. Advanced aging was not shown in the current study to negatively impact overall quality of life among the epilepsy population. Although seniors were more likely to have limited physical reserve and report more fatigue and loss of energy, their emotional and social well-being was not necessarily less than that of younger populations with epilepsy. Although a similar study suggests that epilepsy chronicity and age of onset relate to patients' HRQOL [14], another study suggests that the "causes" (e.g., stroke or dementia) of new-onset seizures among the elderly are more devastating to quality of life than epilepsy itself [21].

Seizure worry tends to be less of a concern among the elderly population in the current study than with younger populations with epilepsy in other studies. This may be explained by the fact that seizures among the elderly are relatively well controlled [16,22]. Additionally, some researchers reason that the elderly adapt to changes in their health over time and that their perceived social expectations are less demanding compared with those of young/middle-aged adults [14].

When compared with general populations without epilepsy, elderly patients with epilepsy report a significantly lower quality of life across all domains. As seizure worry appears to be less problematic, and seizures are well controlled among elderly patients, it is possible that AED side effects and/or the presence of depression may be playing a role in lowering HRQOL. The relationship between mood disorders and epilepsy is complex and multifactorial, including: AED side effects, high risk of affective disorder in focal epilepsy, altered endocrine system and metabolism, and psychological burden of having epilepsy [23,24]. Although 70% of this study's participants reported that "they feel so down in the dumps that nothing could cheer you up" a little or none of the time, our participants' reported limitations (due to their poor emotional and phys-

ical problems) were significantly greater than those of the general population.

QOLIE-31 epilepsy-specific items indicate that 74% of our participants are somewhat worried about the long-term side effects of their AED(s); 61% reported some bothersome physical side effects of AEDs, and 65% reported at least some bothersome mental side effects of AEDs. Recent studies comparing quality-of-life outcomes of immediate and deferred treatment with AEDs among individuals with new-onset seizures imply that there is a trade-off between adverse effects of seizures and adverse effects of taking AEDs [25]. Shifting from polypharmacy to monotherapy or the use of second-generation AEDs with fewer side effects may result in favorable HRQOL outcomes [26,27]. Among the elderly, who often rely on government insurance, cost of medication is an additional issue. Further research on AED cost–benefit analysis is needed.

We acknowledge limitations to our study. First, although this was the first study of its kind to our knowledge, we had a small sample size. The population was older than in most patient studies, and there are limitations associated with this, such as impaired vision and reduced fine motor abilities. Second, there is a potential sampling bias as patients with high morbidity may not have responded to our survey, and respondent bias is a relative weakness of the study as well. This could be controlled in future studies by administering additional surveys to nonresponders and completing surveys via telephone. Additionally, our data were derived from community-dwelling elders treated by a specialist and excluded nursing home residents and patients treated by primary care physicians. As a result, our participants may not accurately reflect the general elderly population in the United States with epilepsy. Rather than attributing differences between our elderly patients and standard QOLIE controls solely to age, it is possible that other factors such as the absence of a local control group could have a possible impact on the differences found. Other factors could include the general health of Kansans, patients' comorbid conditions, and local patterns of treatment. A final limitation to this study was that data concerning type/chronicity of AED use and concomitant medications were not collected. Future research with a larger sample size including elderly patients treated by primary care physicians and stratification by AED type will be beneficial.

Our study indicates that the SF-36 score is not significantly different from the QOLIE-31 score. However, the SF-36 does not include items on cognitive function or medication effects, which affect multiple quality-of-life domains in patients with chronic AED use. Additionally, the SF-36 does not address issues related to driving, employment, and seizure worries, which are critical issues for most patients with epilepsy. Hence, a generic instrument may not reflect important changes attributable to specific disease in epilepsy.

5. Conclusion

We conclude that seniors with epilepsy do not necessarily have poor quality of life compared with the general epi-

lepsy populations. However, when compared with general populations without epilepsy, seniors with epilepsy report a significantly lower quality of life across all domains. Though seizures are generally easily controlled among the elderly with epilepsy, it is possible that AED side effects and depression may be indirectly affecting their HRQOL. HRQOL instruments used for the elderly with epilepsy must be reliable, valid, comprehensive, and sensitive to change to assess the impact of epilepsy and treatment. In this article, we have discussed multiple factors that may uniquely affect quality of life among elderly populations with epilepsy: aging variables (dementia, stroke, change in expectation), comorbid conditions (mood disorder), and epilepsy variables (independence issues, AED side effects, unpredictability of seizures). To our knowledge, there is no one instrument that addresses all of these aspects. The development of HRQOL instruments specifically for an elderly population with epilepsy may be useful and needed.

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