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Quality of life in adult patients with epilepsy and their family members

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ABSTRACT

Purpose: Epilepsy is not only a neurological disorder but may also have negative psychosocial consequences on people with epilepsy (PWE) and their relatives. Epilepsy has a major impact on quality of life (QoL) in PWE and family members. However, less is known about the impact of family support and family functioning on quality of life for PWE and family members and their interaction. Therefore, the study aimed to investigate factors that influence QoL in hospitalized adult patients with epilepsy and their relatives.

Method: An explorative cross-sectional study has been conducted in a tertiary clinic in Switzerland. Hospitalized adult patients with epilepsy and their relatives were enrolled in the study. Subjective QoL as well as family support and family functioning were measured with patients and family members. Patients and their relatives assessed the patients' support need and their satisfaction with the care provided. In addition, patients were administered a disease-related HRQoL measure (QoLIED-36, Version 2).

Backward stepwise multivariate linear regression analysis was used to explain variances in patients and relatives' subjective QoL.

Results: One hundred and four dyads of patient and family member participated. Subjective QoL in patients and family members differed significantly, as did satisfaction with care delivery. In both groups family support contributed significantly to QoL. In the models 40% of the variance in QoL in patients and relatives could be explained. While the quality of life of the family members was affected by the patients' knowledge about the disease and the reason for their current hospitalization, patient QoL scores had no influence on the QoL of family members. The patients' QoL, however, depended significantly on the QoL of the family members.

Conclusion: Interventions should address both PWE and family members and focus on the self-care improvement of PWE and the well-being and coping of family members. A patient-centred approach needs to include both the PWE and the relatives and address family support in order to alleviate stress in the patients and relatives alike.

1. Introduction

Epilepsy is a common chronic neurological disorder which is characterized by recurrent seizures. Epilepsy has been reported to affect between 5 and 10 people per 1000 and the incidence in developed countries is around 50/100,000/year.[1–3]

Classifying epilepsy merely as a neurological disorder is inadequate, since it is also a disorder with negative social consequences.[4] To an affected person, the burdens of epilepsy include physical hazards from unpredictable seizures, but also social exclusion as a result of negative attitudes towards people with epilepsy (PWE).[5] Stigma may even preclude adults from marrying or PWE can be denied employment even when seizures would not render their work unsuitable or unsafe.[5–7] Although 75–85% of PWE in developed countries reach seizure control through individually tailored antiepileptic drug (AED) therapy and live a self-reliant life, up to 25% of all patients suffer from refractory forms of epilepsy.[8] Hence, the disease may prevent those PWE from living a completely self-reliant life.[9] Seizure frequency, age at time of onset, and chronicity of the disease influence quality of life and can hinder the ability to make psychosocial adjustments.[10,11]

In the last two decades, the number of research articles that focus on epilepsy as a disease associated with psychological consequences

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like anxiety, depression, or low self-esteem has increased and demonstrated the detrimental impact of epilepsy on the individuals' health-related quality of life (HRQoL).[12–17] Quality of life (QOL) is a broad, multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life.[18] The concept of health-related quality of life (HRQoL) and its determinants encompass the aspects that can be clearly shown to affect health – either physical or mental.[19] On the individual level they include physical and mental health perceptions and their correlates, notably health risks and conditions, functional status, social support, and socioeconomic status.

A study showed that patients with a good awareness, knowledge, and attitude towards the disease had better HRQoL scores and the authors suggested that epilepsy treatment should also focus on enhancing these components in order to improve health outcomes.[20] Impaired HRQoL and low self-esteem, however, seem to be intensified by the seizures themselves and the clinical trajectories of the disease.[21–23] A recent study assessed HRQoL in both patients with psychogenic, non-epileptic seizures and patients with epilepsy, and showed that HRQoL scores were reduced in patients regardless of their diagnoses.[24] Familial support, however, was also shown to influence HRQoL in both groups. After controlling for illness duration, seizure frequency, and depression, subscales on the role of family predicted reduced HRQoL in patients with pseudo seizures, while communication and affective involvement subscales scores also predicted HRQoL in patients with epilepsy.

Thompson and Upton[25] suggested that negative consequences are likely to extend to families as well, since PWE do not live in a vacuum. A literature review from Ellis et al.[13] revealed that little research has been undertaken to show the possible impact of epilepsy on the family. The majority of articles pertained to the impact of childhood and adolescence epilepsy on the family and only few studies investigated families of adult PWE. While family has been shown to be a major resource to adjust to the illness in adulthood,[26] the illness per se can also be considered a stressor to the entire familial structure, since it can jeopardize the family system and the general quality of life of its members.[27] In this study, general quality of life is seen as the degree to which a person enjoys the important possibilities offered by her life. It includes well-being as global judgement of life satisfaction and feelings ranging from depression to joy.[28,29] It has been shown that the illness puts major strains on individual relatives.[30–33] Depression and anxiety of family members are highly correlated with the severity of tonic-clonic seizures in the PWE.[30,33] Espie et al.[9] found that family members did not have distinguished concerns compared to healthcare professionals but had significantly higher scores in worrying for their intellectually handicapped relative ($p < .00$). A study showed that relatives of adult PWE required more information about epilepsy from healthcare professionals as well as more opportunities to talk about stigmatization and lifestyle changes.[34] The consequences for the family member has been shown to depend on the required amount of change and the support needs of the PWE.[35,36] Westphal-Guitti et al.[37] demonstrated that caregivers of adolescent and adult patients with juvenile myoclonic epilepsy and temporal lobe epilepsy had similar mild to moderate burden and that the QoL was significantly compromised in both groups of caregivers. The authors concluded that nurses can carry out psycho-educative programmes aimed at diagnosing the impact of epilepsy in the family, decreasing the burden, and improving the QoL of caregivers. Since HRQoL in caregivers was not linked to objective disease and patient characteristics but seemed related to the self-perceived burden of care or coping styles,[38,39] the QoL of family members who remain confronted with repeated hospitalizations of patients with refractory epilepsy might be highly affected due to the perceived burden. A qualitative study showed that parents of adult patients with refractory epilepsy were still in charge of the well-being of their children with epilepsy. While some considered this fact to be completely "normal," other felt burdened because they had to juggle the safety and the desired autonomy of the child.[40] The perceived burden might be alleviated by familial social support.

Although many previous studies claimed to examine the effects of epilepsy on the family as a whole, most of them investigated PWE and obtained information about the perception by the individual of the family unit and its functioning as well as the impact of the illness on QoL.[41–43] Only few investigated the family as the unit of analysis and collected data from both PWE and family members.[33] Therefore, we conducted an explorative study to identify disease and family related factors that influence the QoL of PWE and their family members.

This study simultaneously enrolled hospitalized patients and relatives to investigate general QoL in both groups and to explore family functioning as well as family social support and their correlation to QoL in the patient/relative dyad. We assumed that clinical characteristics, low HRQoL, and support needs of the patients in their daily activities would have a negative influence on the subjective QoL of both patients and relatives. Additionally, we hypothesized that satisfaction with health service delivery, balanced family functioning, and familial support would influence QoL positively.

2. Methods

The results presented herewith are based on a study with an explorative cross-sectional design to assess individual QoL in adult patients with epilepsy and their main care-giving family member. Those enrolled in the study were adult patients that were hospitalized in a Swiss tertiary epilepsy clinic for further diagnostic or readjustment of their medication between September 2008 and June 2010, along with their family members.

All hospitalized patients were asked to participate if they were (a) older than 18 years of age; (b) had idiopathic, cryptogenic, or symptomatic epilepsy; (c) able to sign an informed consent and to understand the study questions. Patients were asked to indicate a person considered a relative providing care for them and who was willing to equally participate in the study. Nurses were also asked to identify main caregivers among visiting family members and to invite them to participate. "Relative" was defined as person who may be a next of kin, but also a close friend or carer; a person that engages in supporting the patient on a regular basis, who is emotionally close, and committed to the patient's well-being.

Relatives were included if they were (a) over the age of 18; (b) identified themselves as providing social support to the patient on a regular basis; and (c) signed an informed consent and were able to read and understand the study questions.

We were able to enrol a total of 137 patients and 137 family members, of which 104 patients and their relatives participated as a dyad.

The questionnaires were distributed to patients and family members. Quality of life was assessed with a semi-structured interview using the SEIQoL-DW measure (see below) for both the patients and their families. The family characteristics (composition and network size) were obtained during the interviews and a genogram was drawn with each participant. Questionnaires on family support and family functioning and satisfaction with healthcare delivery within the prior 6 months were distributed to patients and family members. When the patient asked for assistance with the questions, the questionnaires on family support and family functioning were administered to the patients by an experienced research nurse. Socio-demographic information and disease characteristics for the patients were retrieved from

medical records. The socio-demographic characteristics of the family members were obtained by trained interviewers in person or over the phone. The study was approved by the Zurich Ethics Committee.

2.1. Measurement

Disease-related parameters were extracted from the patients' medical records. These included type of epilepsy, time elapsed since diagnosis, numbers and form of seizures, medication, and reason for recent hospitalization. Additionally, psychosocial characteristics of patients and relatives were assessed such as gender, age, knowledge of the patient about her medication, employment, marital status, and perceived support needs of the patients.

Quality of life in patients and family members (the respondents) was measured with the Schedule for Evaluation of Individualized Quality of Life-Direct Weighting (SEIQoL-DW). The semi-structured interview procedure takes 10–20 min and allows the individual to identify the most important areas of her quality of life.[44] The instrument is also suitable to assess QoL over time.[45] For this study the SEIQoL-DW was administered to patients as well as to family members. First, the interviewer elicited the five areas of life considered most important for QoL by the patients and relatives. Second, the level of satisfaction/functioning of the five cues was recorded on a vertical, visual analogue scale ranging from 0 to 100 (0 = worst possible to 100 = best possible) for each cue. Third, the direct weighting procedure was applied by asking the participants to determine the relative importance of the five areas of life in relation to each other. The weights were constrained to add up to a total of 1.0. Finally, each cue level was multiplied by the corresponding cue weight. The products were summed up across the five cues to determine a global QoL score. The index score can range from 0 to 100, with higher scores indicating greater perceived QoL. The instrument has been used in diverse patient populations and has shown good validity and reliability. Test–retest reliability has been reported with Pearson's correlation to be $r > .70$ and Cronbach's α between .72 and .88.[46–49]

For the *health-related quality of life in patients*, a disease-specific measure was used. The Quality of Life in Epilepsy (QoLIE-31 Version 2) consists of 31 items comprising the following subscales: emotional well-being, general quality of life, seizure worry, level of activities, cognition, medication side effects, and social functioning. The epilepsy-related quality of life can be assessed between 0 (worst possible) and 100 (best possible). The German version of the questionnaire has shown construct validity to have high correlation with the SF 36. Cronbach's α of the QoLIE-31 was .94 and varied between .76 and .90 for the seven subscales.[50]

With regard to the *familial network structure*, a genogram and eco-map were drawn with every participant. These features allowed the family characteristics and social network to be visible and discussed with the participants. These instruments were used to assess the number of persons in the network, gender distribution, relational patterns, age, and spatial arrangement within the network.[51]

The perceived *family support* was measured with the short version of the Freiburg Social Support Questionnaire (F-Sozu, K-14), a 14-item questionnaire comprising four domains: the emotional (8 items) and practical support (3 items) as well as social integration and social burdens within the family (3 items). The answers in the five-step scale ranged from "do not agree at all" to "totally agree," adding up to a mean of the sum score between 1 and 5. The internal consistency (Cronbach's α) of F-Sozu short form is .94. Test–retest reliability carried out at an interval of one week has been reported with $r > .96$.[52]

Family functioning was measured with the German version of the Family Adaptability and Cohesion Scale (FACES III). The questionnaire is based on Olson's Circumplex Model and consists of 20 items.[53] The questionnaire assesses family cohesion and family adaptability with a five-point response option which ranges from "almost never" (scoring 1) to "almost always" (scoring 5). Cohesion is defined as the emotional bonding that exists between family members, whereas adaptability is the family's ability to change its power structure, role relationships, and rules to respond to situational or developmental needs. The FACES III questionnaire consists of 20 statements to comment on relationships and attitudes in family life. Of the two major parameters of family functioning that are explored, the essence of cohesion is evaluated through statements such as "family members know each other's close friends" and "our family does things together," while adaptability is explored through affirmatives like "when problems arise we compromise" and "family members say what they want." The questions contrast positive and negative aspects of family life such as "it is easier to discuss problems with people outside the family than with other family members," compared to "family members discuss problems and feel good about the solutions."

Whereas cohesion represents the bonding between relatives by defining four distinct qualities – (a) detached or low bonding; (b) independent; (c) bonded; or (d) enmeshed – adaptability defines the family's capacity to manage changes in power, roles, and relationships, along with their ability to adjust to new situations. The categories range from rigid to chaotic functioning. The two dimensions range from low to high. Medium scores in both dimensions mean that the family is "well balanced," while low and high scores mean that the family is "dysfunctional." The FACES III has satisfactory statistical markers with good reliability (Cronbach's α .62 for adaptability and .77 for cohesion) and validity.[53–55]

Satisfaction with care delivery in the healthcare setting was assessed with the Patient Assessment of Chronic Illness Care (PACIC). The questionnaire evaluates satisfaction with regard to the care provided during the prior six months through 20 items on a five-point Likert scale. The score ranges between 20 and 100. Internal consistency is very good, with a Cronbach's α of .91.[56,57] In this study, PACIC question wording was modified to reflect the caregivers' perceptions of the quality of chronic illness care, as opposed to the patients'. Rather than the patient having to say, "Over the past six months, when I received care for my chronic illness, I was…," it was the caregiver who was asked, "Over the past six months, when the patient received care for her chronic illness, I was…" The questionnaire for the relatives has not been tested for its properties yet.

The *support needs of patients in self-management* were assessed through the Activities of Daily Living and Instrumental Activities of Daily Living (ADL/IADL). Activities of Daily Living consisted in bathing, dressing, toileting, ambulation at home, urinary continence as well as eating, while Instrumental Activities were evaluated based on support needs in using a telephone, shopping, cooking, housekeeping, transportation, medication taking, and organizing financial matters. The scale ranged from 1 (no support need) to 3 (completely dependent). A total score of 42 indicates the highest support need.[58,59]

2.2. Analyses

The analyses were conducted with the IBM SPSS Statistics 19 software. In addition to the descriptive analysis of patients and family members data, backward stepwise multiple linear regression was applied using $p \geq .10$ as exclusion and $p \leq .05$ as inclusion criteria to explore the variables explaining the variance in the subjective QoL in adult patients and their relatives, and to explore which variable was the most important to determine their

subjective QoL. In the first model, predictors that have been described in literature as having a correlation with QoL were entered in the model and complemented by socio-demographic factors.

The following predictor variables from patients and family members were included in the model: socio-demographic variables (gender, employment, number of relatives in the same household, pets in the household), perceived social support within the family (F-Sozu), family functioning (FACES III) using reference categories such as dysfunctional family (low and high values) and well-balanced family (medium values), satisfaction with delivery of patient treatment and care (PACIC), and network size.

In the patient analysis, the predictor variables were the health-related QoL measured with the QoLIE-31 comprising emotional well-being, intensity of concerns about seizures, energy level, cognitive abilities, medication side effects, social functioning, and support needs in ADL/IADL's. Disease-related variables were included into the model such as number of seizures, reason for hospitalization, as well as form of epilepsy. Self-reported employment status was also included in the model, as were variables of the family member such as their subjective QoL measured with the SEIQoL-DW.

In the analysis of the family members, the following patient predictors were entered: patient subjective QoL (SEIQoL-DW), patient health-related QoL, along with medical variables such as absence seizures, number of seizures, form of epilepsy, and reason for current hospitalization. Patient employment, support need in ADL/IADL perceived by the family member along with patient perception and knowledge about the treatment (medication) were also included. Variables of the family members such as network size and employment status were entered into the model, too.

Boxplots were used to visually identify the outliers. In the variable "number of daily seizures" two outliers were replaced with the mean number of the remaining sample. The values of these two outliers were more than three box lengths from the end of the box (extreme outlier), i.e. these cases reported 30 and 40 seizures a day while in the whole sample the mean value of reported seizures was 1.57 (SD = 5.2; median = 0) and in the remaining sample the mean value of reported seizures was 0.9 (SD = 1.9; median = 0). In addition to the basic inspection of data distribution (box plots), we used stem and leaf plots for studentized residuals and stem and leaf plots for leverage in order to visually identify observations with potential great influence. Cook's distance measure (Cook's influence statistics) which combines information on residual and leverage was calculated for patients and caregivers regressions. Cook's distance values above cut-off ($d > 4/n$) were found for both data points which had been previously suspected to be influential cases by visual inspection. Therefore, these data points were replaced with the mean value in the further analyses.

The internal consistency (Cronbach's α) was measured for all scales: SEIQoL-DW (.64 for patients and .72 for caregivers), PACIC (.89 for patients and .94 for caregivers), ADL/IADL (.77 for patients and .79 for caregivers), F-Sozu short Version (.91 for patients and .93 for caregivers), FACES III, subscale adaptation (.73 for patients and .60 for caregivers), subscale cohesion (.55 for patients and .57 for caregivers), and QoLIE-31 German Version 2 (.82 for patient). All seven subscales were in the range between .63 and .87. This means that in all questionnaires, Cronbach's α was lower than but still close to the values reported in literature. On the FACES III cohesion subscale, the internal consistency values were lower in patients and families than in literature. In other words, the family relations might be more burdened by the disease than in other populations.

The assumptions for both multiple linear regression models conducted with backward stepwise methods have been proved and were met. White-Test for homoscedasticity was conducted in STATA 11.

3. Results

The data pertaining to 104 patients and 104 family members who paired up as dyads were entered into the analytical tools. Demographic and clinical findings are presented in Table 1.

The patients with epilepsy were younger than their relatives ($p = .000$). For both patients and relatives, the majority of the study participants were women.

A high percentage of the patients with epilepsy were not partnered (67%), but the majority of the patients lived with at least one other person (78%). Family members were married in 71% of the cases. The predominant relational status between patients and relatives was parenthood (41%), followed by partnership (33%).

Table 1
Demographic and clinical characteristics of patients with epilepsy and their family members.

	Patients ($n = 104$)	Family members ($n = 104$)
Gender, *n* (%)		
Female	54 (51.9)	68 (65.4)
Age (years), mean ± SD (range)	37.0 ± 13.5 (18–68)	49.7 ± 13.7 (19–85)
Marital status, *n* (%)		
Married/in partnership	34 (32.7)	74 (71.2)
Single	65 (62.5)	17 (16.3)
Divorced/separated	5 (4.8)	10 (9.6)
Widowed		2 (1.9)
Living situation, *n* (%)		
Living alone	23 (22.1)	8 (7.7)
Relation to the patient, *n* (%)		
Parent		42 (40.8)
Spouse		34 (33)
Sibling		15 (14.6)
Friend		5 (4.9)
Carer		5 (4.9)
Child		2 (1.9)
Employment, *n* (%)		
Employed full-time	39 (37.5)	68 (65.4)
Part-time employment	9 (8.7)	12 (11.5)
Part-time employment due to disability	45 (43.3)	3 (2.9)
Retired/disability pension	5 (4.8)	19 (18.3)
Unemployed	5 (4.8)	1 (1.0)
Type of epilepsy, *n* (%)		
Symptomatic	89 (85.6)	
Idiopathic	15 (14.4)	
Type of seizures, *n* (%)		
Absence	20 (19.2)	
Tonic-clonic	48 (46.2)	
Myoclonic	5 (4.8)	
Clonic	2 (1.9)	
Tonic	5 (4.8)	
Atonic	1 (1.0)	
Form of epilepsy		
Focal simple	5 (4.8)	
Focal complex	42 (40.4)	
Generalized	47 (45.2)	
Mixed	10 (9.6)	
First diagnosed, *n* (%)		
Days ago	2 (1.9)	
Weeks ago	6 (5.8)	
Years ago, *n* (%), mean ± SD	96 (92.3), 18.1 ± 15.3	
Number of seizures,[a] mean ± SD (range)		
Daily	0.9 ± 1.9 (0–10)	
Last week	5 ± 10.7 (0–70)	
Last month	15.7 ± 30.1 (0–140)	
Last year	136.7 ± 315.9 (0–1500)	

[a] Two extreme outliers removed.

Table 2
Differences in between patients and family members.

Mean (SD)	Patient ($n = 104$)	Family member ($n = 104$)	Statistics	95% $CI_{difference}$	p-Value
Quality of life (SEIQoL-DW)	73.41 (18.59)	80.26 (12.78)	$t_{183} = -3.09$	−11.22; −2.48	.002
Support need ADL/IADL	14.68 (2.46)	15.08 (2.35)	$t_{205} = -1.18$	−1.05; .265	.239
Satisfaction with care delivery	49.92 (15.26)	37.52 (16.55)	$t_{204} = 5.59$	8.03; 16.77	.000

The majority of patients were employed part-time with a disability pension (43%), followed by those with full employment (38%). The majority of the family members were fully employed (65%).

The majority of the patients (86%) had been diagnosed with symptomatic epilepsy for several years. Generalized seizures were present in 59% of the patients. Although seizure frequency varied widely among the participants, 26% of the patients had daily seizures. Of the patients with seizures, 10% had focal epilepsy with secondary generalization and 45% had focal epilepsy (simple or complex).

Subjective QoL was significantly lower in patients than in family members ($p = .002$), whereas satisfaction with healthcare delivery was significantly higher in patients than their relatives. Moreover, the support needs in ADL and IADL reported by the patients were, on average, lower than when assessed by the family members. However, the difference between the two groups was not significant (Table 2).

A minority of patients and family members reported well-balanced cohesion within their families. While well-balanced adaptation skills were claimed only by a minority of the patients, they were reported by the majority of the family members (Table 3).

3.1. Quality of life in patients with epilepsy

Patient subjective QoL was influenced by the subjective QoL of the family member, perceived social support within the family, emotional well-being, and lack of concern about the seizures, along with age, gender, and full employment. The model explained 40% (R^2 adjusted: 35%) of the variance of the "patient subjective QoL" independent variable (Table 4).

In the model, 40% of the variance of QoL in patients was explained. Perceived social support by family turned out to have the highest significance, followed by emotional well-being. The QoL of family members had more influence on the QoL of patients when the patients were not worried about their seizures.

Table 3
Family functioning in patients and family members.

	Patients ($n = 104$)	Family members ($n = 104$)	Test
Cohesion, n (%)			
Detached	57 (54.8)	55 (52.9)	$\chi^2_{(3)} = 4.965$
Independent	34 (32.7)	43 (41.7)	$p = .174$
Bonded	12 (11.5)	5 (4.8)	
Enmeshed	1 (1)	0 (0)	
Adaptation, n (%)			
Rigid	10 (9.6)	8 (7.8)	$\chi^2_{(3)} = 7.517$
Structured	16 (15.4)	25 (24.3)	$p = .057$
Flexible	24 (23.1)	34 (32.7)	
Chaotic	54 (51.9)	36 (35.0)	
Categorized family function as well balance and dysfunctional			
Cohesion, n (%)			
Well balanced	46 (44.2)	48 (46.6)	$\chi^2_{(1)} = .117$
Dysfunctional	58 (55.8)	55 (53.4)	$p = .732$
Adaptation, n (%)			
Well balanced	40 (38.5)	59 (57.3)	$\chi^2_{(1)} = 7.346$
Dysfunctional	64 (61.5)	44 (42.7)	$p = .007^*$

* $p < .01$.

3.2. Quality of life in family members of patients with epilepsy

The model also explained 40% of the variance (respectively 35% R^2 adjusted) in the QoL of the family members (Table 5). Perceived social support within the family and network size were key factors to explain the QoL of relatives. The variable of the family functioning scale examining whether problems were better discussed outside of the family influenced the QoL of the relative negatively but not significantly when the patient agreed with this statement. The QoL of the family members was influenced positively – although not significantly from a statistical standpoint – when the family members were retired as opposed to fully employed and when the patients were at least employed part-time in spite of their disability. Other variables that influenced QoL in family members positively and significantly were high patient knowledge about medication, patient activity level, and when medication adjustment was the reason for hospitalization.

The parameter with the highest significance and the biggest influence was the perceived social support within the family, followed by the patients' knowledge about medication. The activity level of the patients ranked third, followed by medication adjustment as the reason for hospitalization and the size of the relatives' network. The most important predictor for QoL in family members was the perceived social support within the family.

4. Discussion

We were able to find several indicators to gauge the influence of family variables on the QoL of patients and their family members. Family characteristics influenced QoL in both patients and family members. Perceived high family support played an important role in the QoL of patients and family members, whereas social relationships within the family (network size) had a positive impact on family members only. Several variables that we hypothesized to influence QoL such as disease parameters, satisfaction with service delivery, support needs in ADL/IADL and family functioning did not correlate with QoL neither in patients nor in family members.

Table 4
Multiple linear regression model for the "Subjective Quality of Life of Patient with Epilepsy".

Independent variables	Standardized B	p-Value
Subjective Quality of Life of Family Member	.208*	.017
Family support	.428***	.000
Emotional well-being	.216*	.026
Not worried about seizures	.190*	.049
Age	.078	.376
Sex (reference: woman)	.127	.153
Employed full-time[a] (reference: unemployed)	−.114	.214

$R^2 = 0.40$, adjusted $R^2 = 0.35$. Dependent variable: Subjective Quality of Life of Patient with Epilepsy.

[a] Categories: employed full-time, part-time employment, part-time employment due to disability, retired/disability pension, unemployed.

* $p < .05$.
** $p < .01$.
*** $p < .001$.
$n = 94$.

Table 5
Multiple linear regression model for the "Subjective Quality of Life of Family Member of Epilepsy Patient".

Independent Variables	Standardized *B*	*p*-Value
Support within family	.339***	.000
Number of social relationships of family member	.176*	.039
Patient discusses more often problems outside of family[a] (reference: almost never)	−.125	.145
Knowledge of patient regarding the medication[b] (reference: little or no knowledge at all)	.293**	.001
Medication adjustment as reason for hospitalization[c] (reference: no reason)	−.216*	.015
Energy level of the patient	.209*	.017
Patient is employed part-time due to disability[d] (reference: unemployed)	.120	.171
Family member is fully retired[d] (reference: full employment)	.087	.300

$R^2 = 0.40$, adjusted $R^2 = 0.35$. Dependent variable: Subjective Quality of Life of Family Member of Epilepsy Patient.
[a] Categories: nearly always, more often, quite often, seldom, almost never.
[b] Categories: a lot of knowledge, little or no knowledge.
[c] Categories: it was a reason, it was no reason.
[d] Categories: employed full-time, part-time employment, part-time employment due to disability, retired/disability pension, unemployed.
* $p < .05$.
** $p < .01$.
*** $p < .001$.
$n = 96$.

The regression model for the patients showed that family support influenced QoL of patients significantly. These findings are consistent with studies that had revealed that patients with seizures exhibited improved emotional adjustment when they perceived social support as sufficient.[60] The feelings of being loved and wanted contribute to provide a supportive environment and to nurture the PWE, which helps to adjust to the illness. The patients need encouragement and seek supportive personal relationships to improve their QoL.[61,62] Family members who are able to adjust to the illness situation themselves can cheer up the patients and empower them to cope with the illness. Saburi et al.[72] reported that family reactions such as openness, acceptance, and support, while discouraging fear, isolation of the individual, secrecy, concealment, and overprotection were positively correlated with the quality of life in PEW ($r = .39$, $p \leq .01$). In their study, the effect of the "perceived family reactions" independent variable explained 15% of the variance in QoL. Based on these findings and our own, we conclude that in order to enhance the quality of life in adults with epilepsy, health professionals need to encourage positive family reactions to alleviate stress and worries in patients.

Perceived HRQoL as a patient-related factor also carried major importance. As expected, subscales of the HRQoL measure correlated with the subjective QoL measure. In particular, the model showed that the patients' emotional well-being and their worry or not about the seizures influenced their subjective QoL significantly. This points to higher self-efficacy in these patients who were convinced they were equipped to cope with the illness.[63] Age and gender contributed to explain the variance in QoL, as did full-time employment, although none of these factors were significant. We assume that full-time employment was strenuous for the patients. They had had to be hospitalized due to the deterioration of their health, causing them to be on sick leave during that time and eventually jeopardizing the workplace.[64] These concerns were also reported in a most recent study that showed that PWE were preoccupied about maintaining employment or being able to attend educational courses.[65] The impact on QoL might therefore not be a consequence of seizures, but rather a result of discrimination and misconception about the epileptic disorder.[66] These issues might explain the negative impact of full-time employment of patients on their subjective QoL.

In the regression model for relatives, family support and a high number of relationships within the family system positively influenced the family members' QoL. Patient characteristics impacted QoL negatively as well as positively. Patient situation influenced the relatives' QoL negatively when the patients were hospitalized due to refractory epilepsy, causing AED medication to be adjusted. This might have increased the stress in family members, as they tried to protect the patients from stigmatization of epilepsy and its negative social consequences.[4] The patients' knowledge about the disease and its treatment had a positive influence on the QoL in relatives, as did the patients' energy level to manage their everyday life. These factors might point to the patients' self-efficacy and their conviction to manage their illness self-reliantly. This might have relieved the relatives of their caregiver burden and responsibility for disease management.

The fact that family members who were retired had higher QoL than their fully employed counterparts was linked to more time and less strains in everyday life. The employment status of the patients had less influence, although part-time employment with a disability pension influenced the QoL of family members positively. This might be due to the fact that patients benefitting from a disability pension along with a part-time job were themselves more satisfied with their life situation and could rely on the social support of co-workers in addition that of their relatives. This might exonerate family members, although subjective QoL of the patients did not influence the QoL of the family members. This is in contrast to the findings for patients that showed that the latter depended on their relatives' well-being in order to report a higher QoL.

Our study showed that a higher number of relationships positively influenced the QoL of family members. Therefore, the familial network and support beyond the relationship with the patient need to be assessed. Family members should be encouraged to balance their support with the patient and to seek and maintain relationships in the extended family or with friends. Health professionals and nurses in particular are predestined to address this issue with the relatives.

Unfortunately, our sample in the regression analyses ($n = 94$ patients and $n = 96$ caregivers) lacked the necessary degrees of freedom to explore interactions among the factors. We feel that limiting the initial number of interactions among factors a priori would have also been in conflict with our explorative approach to subjective QoL in both patients and family members.

Since HRQoL measures focus on disease-specific issues that limit answers by family members, we used the SEIQoL-DW instrument. This measure allows assessing domains of individual importance for QoL, but prohibits us from directly comparing the scores with other populations of PWE and relatives[38] and limits the study, as it does not allow conclusions on the burden these particular patients and families had to bear compared with other study participants. Nevertheless, further family centred research should use generic and subjective QoL such as the SEIQoL-DW. This

would enable to measure determinants contributing to the individual QoL and lead to distinguishing different clinical and life trajectories among groups of PWE and their relatives.

In our study, the disease parameters correlated with neither the patients', nor the family members' subjective QoL, in spite of the fact that more patients (54.8%) in our study reported seizures. Patients and family members who have been accustomed to chronic condition for a long time might not experience disease features as major stressors. Although many studies showed that seizure frequency, form of epilepsy, time since last seizure, and antiepileptic drug (AED) side effects were important variables influencing the HRQoL among PWE,[67,68] our findings are in accordance with those of other studies[37–39,69,70] that showed little or no correlation between disease characteristics and QoL.

While patients were more satisfied with healthcare service delivery, family members criticized the system for being less open to their involvement. These findings were in accordance with the yearly survey of the clinic that reported higher satisfaction with services in patients than in family members.[71] Despite our assumption that satisfaction with healthcare delivery could influence QoL, this variable did not contribute to the variance, neither in patients, nor in family members.

Furthermore, we found differences between the patients and the relatives' evaluation of the patients' support needs in ADL/IADL. Patient support needs were deemed more significant by the family members than by the patients. The difference did not contribute to the variance of QoL, neither in family members, nor in patients. However, anecdotal accounts let us assume that the different assessments can contribute to conflicts within the family system.

According to previous studies, family functioning can be often be poor in patients suffering from epileptic or psychogenic non-epileptic seizures.[24,42] In our study, the majority of both patients and family members reported dysfunctional cohesion. However, on the adaptability subscale, family members assessed the adaptation skills as well-balanced. Patients reported more chaotic adaptation than family members. Given that in our study, the majority of family members were parents of the patients, these relatives might be more in charge of everyday life and might have hence developed well-structured and flexible behaviours. Patients, on the contrary, might be affected in their role-functions.[72] Therefore, family adaptability might not be equally comprehensible by the patients and the relatives. Despite the differences between patients and relatives, family functioning influenced neither the patients', nor the family members' QoL. Even in those patients who reported chaotic adaptation, no correlation to QoL patterns was found.

A qualitative study showed that PWE and family members focused on the on-going search for services and help and were concerned with the experiences related to life with epilepsy.[73] Their struggle is focused on dealing with the everyday challenges to their well-being. Alleviating stress and enhancing family support and self-efficacy of both patient and family member are utterly important, since family systems tend to stabilize over time and provide pivotal support to each member.[74]

5. Conclusions

Family characteristics such as family support, network size, and family functioning and their respective influence on the quality of life of both patients and family members have to be understood as a complex, intertwined system. In addition to family support, patient QoL was highly impacted by the well-being of the family member. Family member QoL was impacted by patient knowledge about the disease and its treatment. Interventions should address both PWE and family members and focus on the self-care improvement of PWE and the well-being and coping of family members. A patient-centred approach needs to include both patients and family members and address family support in order to alleviate stress in all stakeholders.

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