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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