



## Review

## Quality of life is social – Towards an improvement of social abilities in patients with epilepsy

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## ABSTRACT

Quality of life (QoL) for people with epilepsy is considered worse than the condition's clinical and medical prognosis would predict. Quantity and quality of social interaction considerably determine QoL. Research shows that a significant proportion of patients with epilepsy experience difficulties with social functioning that is thought to be related to impaired QoL. The aim of this review article is to provide an evidence base for conceptualising and developing interventions to improve quality of life through social functioning, for adults with epilepsy. Previous and current research is considered initially with regards to why such difficulties arise and established interventions that address social competence and functioning are reviewed and explored from the field of schizophrenia, a condition also associated with similar difficulties in social cognition, cognition and negative symptoms. The paper considers the advantages and disadvantages of these interventions, the outcomes and emerging research in this area. Positive findings are found from interventional studies in schizophrenia such as the enhancing potential and generalisation of training in social cognition, the benefits of an integrated approach to improving social functioning and proposal of 'online' interaction approaches. These findings provide interesting and exciting directions for the ultimate goal towards interventions for the improvement of social functioning and quality of life in patients with epilepsy. This is of particular significance as at present there is currently no such dedicated program for people with epilepsy.

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## 1. Background

Quality of life has been defined by the World Health Organisation [1] as a reference to a person's wellbeing and the individual's perception of their position in life. Due to the complex nature of epilepsy and its frequently chronic course, a number of factors can greatly impact on a person's perception of quality of life, happiness and life satisfaction. Improving quality of life for people with epilepsy is therefore a major challenge. This is not only on the humanist side for improving life satisfaction for the individual and those around them but also for health and societal costs due to the association between reduced health related

quality of life and higher costs in healthcare, as well as indirect costs such as unemployment [2–3]. Table 1 outlines recent studies looking at quality of life in epilepsy and the common themes highlighted. This reflects the multidimensional issues and emphasises Sherman's [4] conclusion that improving quality of life for people with epilepsy is more than just the reduction of seizure frequency with medication.

If we look back in time, more than half a century ago, epilepsy was seriously stigmatised as a disorder that imprints the personality into an epileptic personality that is surrounded by a 'social abscess' [21]. Norman Geschwind was one of the first neurologists to develop elaborated neuroscientific concepts to explain the increased prevalence of certain behavioural abnormalities, described as Waxmann Geschwind Syndrome, as symptoms of brain dysfunction. However, beginning in the 1970s, the social and psychological turn in psychiatry and related disciplines might have enforced a tendency to neglect the neurological basis and to overrate the socio-psychological causes of certain symptoms affecting social competencies. The following decades were

*Abbreviations:* QOL, quality of life; ToM, theory of mind; FLE, frontal lobe epilepsy; TLE, temporal lobe epilepsy; MTLE, mesial temporal lobe epilepsy; IGE, idiopathic generalised epilepsy; AED, anti epileptic drugs.

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**Table 1**  
Quality of life studies in epilepsy.

Author	Population	Social	Psychological	Cognitive	Psychiatric/ comorbidities	Physical health/ epilepsy specific	Miscellaneous
Viteva [5]	Refractory epilepsy		Stigma	Memory	Emotional well being	Health perception	
Gauffin [6]	Epilepsy with subjective memory complaints	Reduced social life	Self-esteem, hope for future		Hope Self esteem		Education Employment
Taylor [2]	Diagnosis of epilepsy				Depression, anxiety	Seizure frequency and severity	
Kanner [7]	Diagnosis of epilepsy requiring AED treatment				Mood and anxiety	Seizure freedom	
Whatley [8]	Diagnosis of epilepsy	Social support	Stigma		Depression		
Meneses [9]	Focal epilepsy			Language, IQ and attention			
Piazzini [10]	Diagnosis of epilepsy with good medication compliance			Cognitive impairment	Psychiatric disturbances	Seizure frequency, prognosis, number of medications, disability	
Poochikian [11]	Seizure free vs. continued seizure group					Seizure control	
Harden [12]	Woman with intractable epilepsy	Social functioning due to seizures			Anxiety	Seizure severity	
Pais-Ribeiro [13]	Diagnosis of epilepsy			Cognitive functioning	Epilepsy specific optimism		
Senol [14]	Diagnosis of epilepsy				Fatigue Depression	Seizure frequency	
Tracy [15]	Diagnosis of epilepsy				Mood state	Seizure control	
Meldolesi [16]	Temporal lobe epilepsy	Reduced independence and social support			Depression and anxiety		
Szarlarski [17]	Medication resistant	Social support	Poor coping skills		Mood states		Adverse events
Pulsipher [18]	Temporal lobe epilepsy				Psychiatric conditions	Medical	

Excludes studies of learning disability, pre and post surgery studies. Due to cross cultural differences in quality of life [19,20] studies focus on European, American, Canadian, Scandinavian and Australian studies.

characterised by tremendous efforts to de-stigmatise patients with epilepsy in the public and empower them.

Several intervention programs looking at improving quality of life and well being for people with epilepsy have been developed in recent years. These tend to be targeted approaches, focusing on aspects such as self-management (e.g. WebEase) [22], psycho-education [23,24] and mood through CBT approaches (e.g. UPLIFT for epilepsy) [25] and physical and social activation (e.g. PEARLS) [26]. These programs have shown some positive results but sample sizes have been small and they require detailed further evaluation of their outcomes and underlying models.

The Modular Service Package Epilepsy (MOSES) [23] provides a more multifaceted educational approach and has been subject to more rigorous evaluation. This group approach is a 2-day program aimed at improving patient's knowledge about epilepsy, increasing self-confidence and encouraging responsibility in self-management. The approach employs a didactic step-by-step method using workbooks and reflective practice in groups with regards to their feelings and attitudes and covers nine separate modules. The 1 h long psychosocial module focuses on aspects of different domains of everyday life and underlying statutory regulations, e.g. driving license, safety issues, etc. They also discuss self-esteem and overcoming social isolation. While MOSES overall has been found to have good treatment related effects (improved knowledge and emotional 'coping', less epileptic attacks, less side effects), it has shown small effects in social skills and only a tendency towards better social functioning [27]. Social functioning however is a key aspect in quality of life and it is frequently referenced that social relationships and networks in both professional work and personal connections are the single most important factor and predictor of well being, happiness and life satisfaction [4,28]. Therefore this aspect is paramount in the goal of improving quality of life in epilepsy.

Helliwell and Putman [29] reported that in the general population those who have close friends and confidants, friendly neighbours and supportive co-workers are less likely to experience sadness, loneliness, low self esteem and problems with eating and sleeping. In fact, this 'social capital' is found to positively impact on health, morbidity and mortality. Helgeson [30] however, concluded that it is not the size of the social support network but rather the quality of it that acts to buffer life stress, enhance respect, improve self esteem and feelings of belonging that are important for quality of life. In a population of children with autism, Bauminger and Kasari [31] found that it was the presence of friendships that had intimacy, reciprocity and emotional enrichment that most profoundly impacted on quality of life, rather than the mere structure of a social network. Quality social networks and support are also found to be of great importance in mental and physical health conditions, acting as a buffer against the impacts of stress exposure [32].

In epilepsy, Amir et al. [33] found social support to be a mediator between disease severity and mastery and thus that it helps improve ability to cope with the limitations of their condition. Whatley et al. [34] proposed that better social support improved the feeling of being 'connected' for people with epilepsy, which in turn impacted on their perceived quality of life. Promoting social relationships in this population would also likely bear a positive and indirect impact on other factors identified in Table 1, such as improving mood, vocation, health perception and ability to cope. However, people with epilepsy can suffer from communication problems and interpersonal difficulties that significantly impact on their social functioning [35]. These social deficits are not always readily apparent in the majority of patients but people with epilepsy are generally found to have fewer social supports compared to those without their condition [36–37], are less likely to marry, have fewer children [38], have lower rates of

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