



MASTERARBEIT / MASTER'S THESIS

Titel der Masterarbeit / Title of the Master's Thesis

„The impact of epilepsy influenced self-esteem on the perceived quality of
life“

verfasst von / submitted by

Amir Hodzic', BSc.

angestrebter akademischer Grad / in partial fulfilment of the requirements for the degree of

Master of Science (MSc.)

Wien, 2015 / Vienna 2015

Studienkennzahl lt. Studienblatt /

A 066 840

degree programme code as it appears on

the student record sheet:

Studienrichtung lt. Studienblatt /

Psychology

degree programme as it appears on

the student record sheet:

Betreut von / Supervisor:

PhD. Giorgia Silani

Acknowledgement

First of all I would like to thank my family for everything they have made possible for me so far. Thanks to my girlfriend and sister who picked me up and dusted me off when something went wrong. My heartfelt thanks goes to my parents, who supported me in every decision and situation ever encountered, who made my life as easy as possible and who made me the person I am today.

Special thanks go out to my supervisor PhD. Giorgia Silani as well, who supported and encouraged me throughout the process of this thesis with patience, competence and always a little bit of fun to make it as comfortable as possible.

Index:

Abstract (English).....	3
Abstract (Deutsch).....	4
1. Introduction and theoretical background.....	5
1.1 Self-esteem.....	7
1.2 Epilepsy.....	14
1.3 Quality of life.....	22
2. Hypothesis.....	28
3. Methods.....	29
3.2 Participants.....	29
3.3 Recruitment.....	33
3.4 Questionnaires.....	33
3.4 Statistical analysis.....	40
4. Results.....	41
5. Discussion.....	47
6. References	
7. Appendix	

ABSTRACT (English)

Research literature to date has focused mainly on the influence of epilepsy related factors like seizure frequency, seizure duration or medication on quality of life, but almost no research investigated how epilepsy influenced self-esteem effects the perceived quality of life. Therefore this study investigates the relationship between epilepsy, self-esteem and quality of life. The total population consists of N = 274 (female = 185, male = 89) with age ranged from 16 to 66. Of the total population 163 have epilepsy. To assess self-esteem and quality of life two questionnaires were used, first the Multidimensionale Selbstwertkala (MSWS) by Schütz & Sellin (2007) and the WHOQOL-BREF, a quality of life assessment by the World Health Organization. Both these questionnaires were integrated in an online survey and filled out by an experimental group (epilepsy) and a control group (no epilepsy). The results indicate that having epilepsy has a rather great effect on self-esteem, leading to a possible lower psychological well-being and thus to a lower quality of life. It was further tested how self-esteem impacts the quality of life and resulted in great effects in all domains of the WHOQOL-BREF, especially in the psychological domain. Researchers have found that knowledge about epilepsy significantly correlates with self-esteem, ergo the more is known about epilepsy by an individual, the higher the self-esteem, making knowledge about this illness one of the top priorities in coping with low self-esteem and baring the possibilities for prevention in this area.

ABSTRACT (Deutsch)

Die Forschungsliteratur hat bis dato vorwiegend den Einfluss von Epilepsie relevanten Faktoren (z.B. Anfallshäufigkeit, Anfallsdauer, Dauer der Medikamenteneinnahme) auf die Lebensqualität untersucht. Stark vernachlässigt wurde dabei der Einfluss von Epilepsie beeinflusstem Selbstbewusstsein auf die wahrgenommen Lebensqualität. Um diese Lücke zu schließen wurde eine Gesamtstichprobe von N = 274 (weiblich = 185, männlich = 89) mit einer Altersspanne von 16 – 66 erhoben. 163 Personen der Gesamtstichprobe leiden an Epilepsie. Um Selbstbewusstsein und Lebensqualität zu erheben wurden die Multidimensionale Selbstwertkala (MSWS) von Schütz & Sellin (2007), sowie der WHOQOL-BREF, ein Messinstrument für Lebensqualität der Weltgesundheitsorganisation (WHO) in einem Onlinefragebogen verwendet. Dieser Onlinefragebogen wurde von zwei Gruppen ausgefüllt, der Experimentalgruppe (Epilepsie vorhanden) und der Kontrollgruppe (Keine Epilepsie vorhanden).

Die Ergebnisse deuten darauf hin, dass Epilepsie einen Effekt auf das Selbstbewusstsein hat, was zu einem niedrigeren psychischen Wohlbefinden führen kann und in weiterer Konsequenz zu einer niedrigeren Lebensqualität. Weiters wurde untersucht wie Selbstbewusstsein die Lebensqualität beeinflusst und resultierte in beachtlichen Effekten in allen Domänen des WHOQOL-BREF. Die Kontrolle von Alter und Beschäftigung zeigte das Alter in der Kontrollgruppe und Beschäftigung in beiden Gruppen einen mediierenden Effekt haben. Forscher fanden eine signifikante Korrelation zwischen dem Wissen über Epilepsie und Selbstbewusstsein, die besagt, dass um je mehr Wissen man über Epilepsie verfügt, das Selbstbewusstsein auch gesteigert wird. Diese Beziehung macht Wissen über Epilepsie zur obersten Priorität im Umgang mit niedrigem Selbstbewusstsein und leitet mögliche Präventionsstrategien ein, um niedrigem Selbstbewusstsein und niedriger Lebensqualität entgegen zu wirken.

1. Introduction and theoretical background

About 10% of the world population has a certain vulnerability to develop epilepsy at some point in their life. Regarding the expert groups around Gauffin, Landtblom and Rätys' (2010) as well as Sung, Muller, Ditchman, Phillips and Chans' (2013), self-esteem is the most crucial factor contributing to our psychosocial well-being and people who get diagnosed with a chronic illness are in need of a certain amount of time and effort to deal with the changes in their health condition and their whole life as well. Therefore it is no surprise at all that people who get diagnosed with epilepsy (as well as any other serious disease) are prone to low self-esteem and thus are at risk for poor psychosocial well-being. Common psychosocial problems in patients who suffer from epilepsy are unemployment/underemployment, social isolation and psychological distress.

Current literature suggests that self-esteem is negatively correlated with a number of epilepsy-related variables. Numerous studies show that seizure severity is the most important factor in predicting the self-esteem in epilepsy patients (Gauffin et al., 2010; Sung et al., 2013; Lee, Hamiwka, Sherman & Wirrell, 2008; Rätty, Söderfeldt, Larsson & Larsson, 2004; Smith, Baker, Dewey, Jacoby & Chadwick, 1991). Furthermore self-esteem seems to be correlated negatively with seizure frequency (Sawangchareon, Pranboon, Tiamkao & Sawanyawisuth, 2013; Gauffin et al., 2010; Rätty et al., 2004; Baker, Spector, McGrath & Soteriou, 2005), length of intake and number of anti-epileptic-medication (Sawangchareon et al., 2013; Gauffin et al., 2010; Lee et al., 2008), and the stigmatization that goes hand in hand with epilepsy (Lee et al., 2008; Viteva, 2013; Hills & Baker, 1992; Baker et al., 2005; McLaughlin, Pachana & Mcfarland, 2008; Baker, 2002).

Through this combination of epilepsy and diminished self-esteem, the perceived quality of life (QOL) can seem rather off grade. It has been shown in a vast number of studies that the QOL is reduced if the person suffers from epilepsy. The main epilepsy-related factors influencing the QOL are seizure frequency, duration of illness and effectiveness of antiepileptic therapy (e.g. Sung et al., 2013; Guekht et al., 2007; McLaughlin et al., 2008). Another factor influencing QOL is the stigmatization because of the condition (McLaughlin et al., 2008). Viteva (2013) found perceived stigma in 43.6% of patients with refractory epilepsy and in 28.7% of patients' severe stigmatization. The study showed that the perceived stigmatization had a negative effect on the overall QOL, because the seizures occur unpredictably, and because of occurrence of social exclusion due to no knowledge about and negative attitude towards epilepsy of the society, patients with epilepsy hide their condition from family, partners and friends. This can lead to low self-esteem, anxiety and depression (Sung et al., 2013).

This leads to the issue of comorbidity in patients who suffer from epilepsy. Sawangchareon et al. (2013) found that 60% of patients with epilepsy suffer from anxiety and depression. Smith et al. (1991) found that 33% of their subjects could be classified as clinically anxious and 15% as clinically depressed. Stigmatization can cause increased levels of anxiety and depression as well, as Baker, Brooks, Buck and Jacoby stated 1999.

It has been shown that knowledge about epilepsy and its consequences significantly correlates with self-esteem (Hills et al., 1992; Baker et al., 2005; Baker, 2002), still the majority of people with epilepsy do not seek professional help for their diminished self-esteem and increased levels of anxiety or depression, instead they rely on their own internal and external resources to cope with those psychological consequences themselves.

1.1 Self-esteem

According to Murk (2008), three definitions of self-esteem have dominated the field for quite some time. First there was James (1890/1983), who stated that success in certain areas of life increase the individuals' self-esteem, whereas failure diminishes self-esteem. Soon this theory was exposed to criticism, since if success predicts self-esteem, constant attention, vigilance and a need to respond to chance of failure is needed. Therefore the probability for psychological maladjustment rises immensely, leaving the individuals able to develop overachievement, perfectionism, anorexia (mainly in female individuals) and antisocial behaviour.

A widely accepted point of view on the definition of self-esteem was phrased by Rosenberg (1965). He said that self-esteem needs to be seen as a feeling, as an attitude concerning ones worth as a person. Critics did not wait a long time to speak their minds about Rosenberg definitions – they said if high self-esteem only consists of a good feeling about oneself, there would be huge difficulties differentiating between high self-esteem, excessive pride, self-centeredness and narcissism, which all consist of the main factor of feeling good about oneself.

Branden (1969) stated a new definition of self-esteem in combining the two dimensions competence (the degree to which people see themselves as capable) and worthiness (feeling of being a person of value).

Self-esteem has two interrelated aspects: it entails a sense of personal efficacy and a sense of personal worth. It is the integrated sum of self-confidence and self-respect. It is the conviction that one is competent to live and worthy of living. (S. 110)

With this multidimensional view he offered a “two factor” approach which combines the best aspects of both competence and worthiness to create a new dimension called self-esteem. Cast and Burke (2002) took up Brandens’ (1969) definition and added some factors and information. The main addition consists of their results of the research on self-esteem, which brought up three main conceptualizations or functions of self-esteem: (1) self-esteem as an outcome, (2) as a self-motive and as a (3) buffer for the self, protecting from harmful situations. According to identity theory, self-esteem is a positive outcome of successful self-verification which develops through a match between the ideal self of an individual and the perceived self of the surroundings. Though it is not yet clarified if self-esteem is an actual consequence or a cause of certain situations in life. If it turns out to be a cause, improving self-esteem would benefit the outcomes associated with self-esteem, such as relationships, physical health, etc. and reduce the probability for psychological maladjustment. When distress in form of depression or anxiety occurs, self-esteem can act as a buffer for the individuals self, by processing feedback in a self-serving way thus maintaining a positive self-view. Other researchers argue that high self-esteem gives you a more stable sense of the self as well as more cognitive resources, enabling individuals with high self-esteem to cope in a better way with unpleasant situations. Self-esteem as a self-motive is seen as a goal in itself, motivating people to strive just for the sake of a high self-esteem. To achieve it, they act in more positive ways and alter situations in their favour.

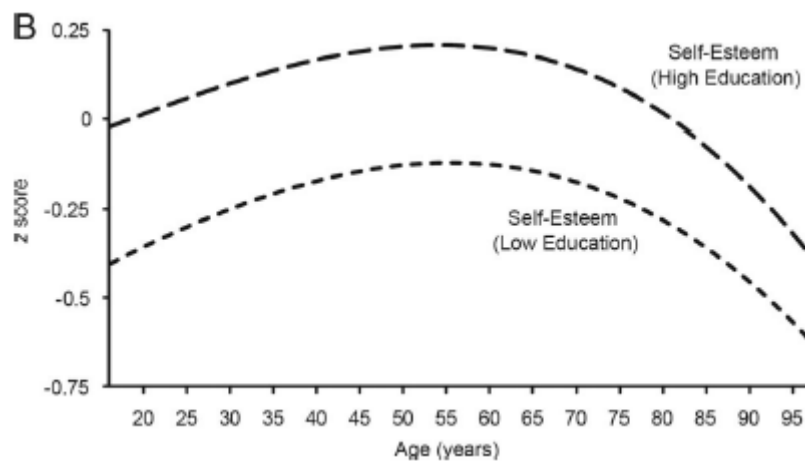
Leary, Terdal, Tambor and Downs (1995) as well as Sowislo and Orth (2013) describe self-esteem in association with the sociometer theory. In this theory self-esteem serves as an instrument to measure or evaluate someone’s interpersonal relationships.

In more detail the self-esteem works as a marker which shows the individual to what degree it is being included or excluded by other people.

Being included had a massive survival value back in the day, this instinct is still intact today and so being in the in-group and being accepted boosts your self-esteem, by being excluded the exact opposite happens.

Orth, Robins and Widaman (2011) suggested a certain progression of self-esteem, saying it increases during young and middle adulthood, peaking at about 60 years and then slowly declining in old age. Studies about self-esteem show that it is associated with a number of different aspects. For example self-esteem is positively correlated with relationship satisfaction, suggesting people with high self-esteem show more relationship enhancing behaviour, whereas people with low self-esteem tend to behave in the opposite direction. Self-esteem is also positively correlated with job satisfaction, occupational status and salary. This correlation could be explained in two different ways, either a satisfying job, a good status and salary influence the perception of one's value, therefore increasing self-esteem, or high self-esteem is the cause for the motivation to get a better education and qualification, resulting in a better paid job. As for correlation between self-esteem and education, Orth et al. (2011) showed that high education results in a higher self-esteem at all ages (see Figure 1).

Figure 1



Note: The impact of education on self-esteem. Taken from “Life-span development of self-esteem and its effects on important life outcomes” by Orth, U., Robins, R. W. & Widaman, K. F., 2011, *Journal of Personality and Social Psychology*, 102 (6), 1271 – 1288.

Either way, this matches with the suggestion of Orth et al. (2011) about the peak of self-esteem, since we can assume that a normally developing life sees an individual employed from young adulthood, peaking in experience and confidence at around 60, where retirement is not far away. People with high self-esteem also seem to report a better physical health. A reason for this association could be a greater amount of social support, less stress and more positive coping behaviours. Feeling healthy may as well make them feel more independent and able to contribute more to their families and society, thus increasing self-esteem.

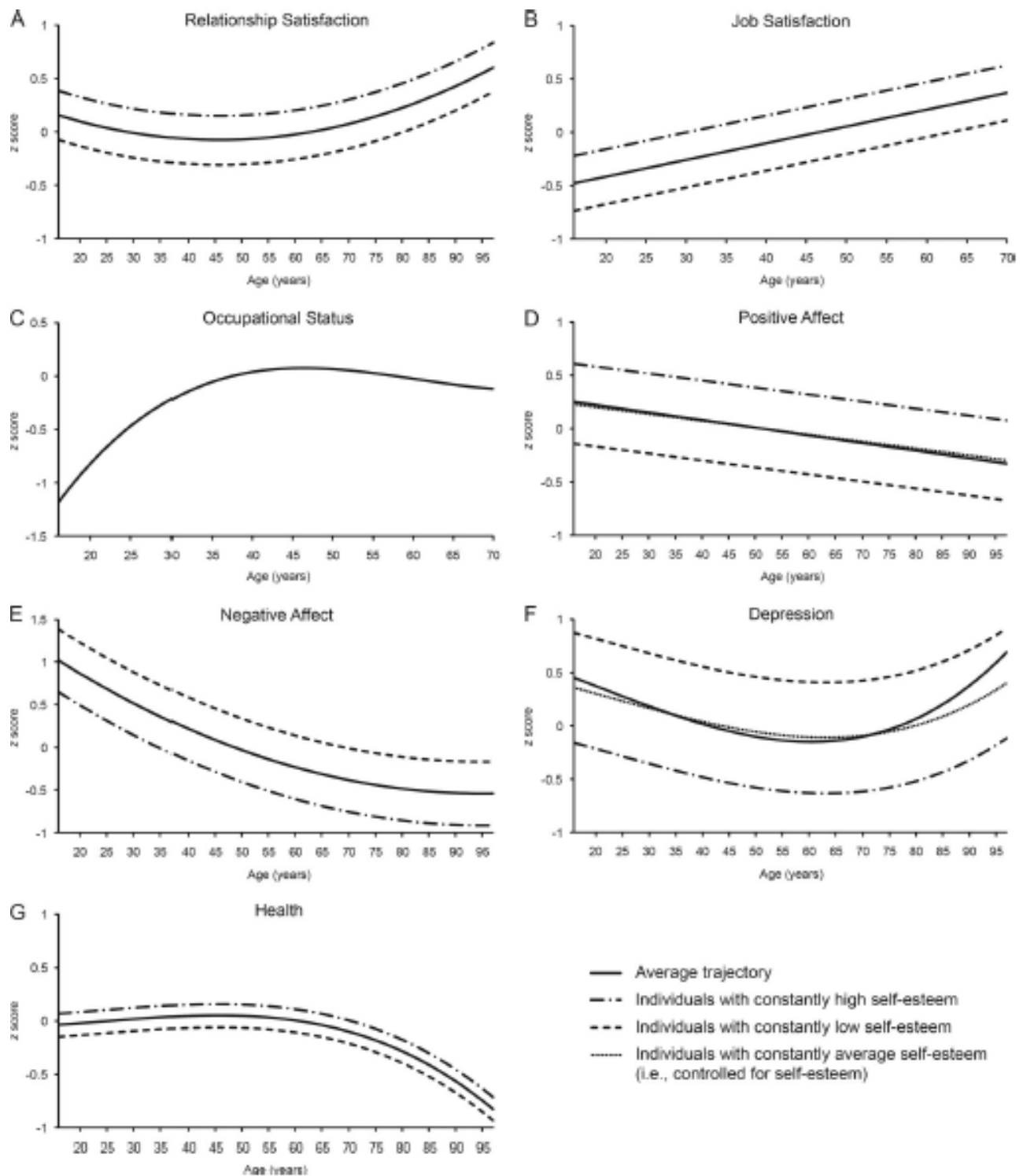
Unfortunately self-esteem is not only associated with positive factors, but correlates also with a low number of psychological symptoms such as depression, anxiety, bulimia, etc. Sowislo et al. (2013) suggests that such symptoms may develop in individuals with low self-esteem, because they tend to be more sensitive to criticism, focus their attention on how others see them, tend to avoid people by whom they feel their self-esteem might be threatened and to conceal their inner thoughts and feelings from others.

This leads consequently to a lack of spontaneity, shyness, feelings of loneliness and exclusion from others. Sowislo et al. (2013) postulated two theories which describe how self-esteem may be linked to depression and anxiety. The tripartite model postulates that depression should have a stronger relation to self-esteem than anxiety. Though depression and anxiety both share the feature of high negative affectivity, depression is related with low positive affectivity as well, whereas anxiety is not. Hence depression should be more related with self-esteem, because self-esteem as well contains positive and negative affectivity. The second theory, so called cognitive content hypothesis, states that depression and anxiety can be distinguished by specific cognitive vulnerabilities. Depressive cognitions reflect negative evaluations of the self, the world and future, whereas anxious cognitions reflect the anticipation of a physical or psychological threat, accordingly depression should have a stronger relation to self-esteem.

Orth et al. (2011) published an overview of certain areas of life and there progression with average, high and low self-esteem (see Figure 2), In Panel A we can see that high self-esteem is maintained throughout the whole time span, slightly decreasing at the age of 50, but then again increasing at old age again above the score at the beginning, panel B shows the progression of self-esteem in job satisfaction, showing a constant increase in self-esteem throughout the years, reaching a maximum at 70. Interestingly panel C shows only the line for the average self-esteem, probably meaning that self-esteem does not have much or any impact at all on the occupational status. In panel D high self-esteem decreases constantly, reaching towards zero. Panel E and F are the only two where low self-esteem is dominant over high self-esteem, meaning that negative affect and depression are dominated strongly by low self-esteem, whereas in depression low self-esteem is at a constant high, with a immense gap between low and high self-esteem.

Panel G shows the progression of self-esteem in combination with health, where high and low self-esteem scores are not far apart. Summarizing Figure 2 high self-esteem is present and dominating at almost every area except for the negative ones such as negative affect and depression, leading to the assumption that the higher the self-esteem, the better the situation in the corresponding area.

Figure 2



Note: Overview of certain areas of life and there progression with average, high and low self-esteem. Taken from "Life-span development of self-esteem and its effects on important life outcomes" by Orth, U., Robins, R. W. & Widaman, K. F., 2011, *Journal of Personality and Social Psychology*, 102 (6), 1271 – 1288

1.2 **Epilepsy**

According to Fischer (2014) epilepsy is a disease of the brain, which can be defined as followed: (1) At least two unprovoked (or reflex) seizures occurred more than 24 hours apart, (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years and (3) diagnosis of epilepsy syndrome. Until recent years there was an ongoing debate whether epilepsy is a symptom of an underlying neurological disorder or a condition per se, when the International League against Epilepsy (ILAE) and the International Bureau of Epilepsy (IBE) have agreed upon regarding to epilepsy as a disease.

Although it seems there is a definite system and criteria with which epilepsy can be diagnosed, Sander and Shorvon (1996) mentioned early that there are methodological difficulties in diagnosing epilepsy accurately. Syncope or psychogenic attacks are conditions, which commonly lead to misinterpreting them as epilepsies. Furthermore syncope and psychogenic attacks are more likely in females, leading to a higher rate of misdiagnosis in females. To stress out the unfortunate possibility of misdiagnosing epilepsy, Sander and Shorvon (1996) said that 10% - 20% of cases referred to epilepsy units with seemingly intractable seizures do not have epilepsy. On the other hand, a lot of people have epilepsy an uncertain amount of time before they even get diagnosed for sure. To get an overview of epilepsy, here is a rough classification of the main epilepsy groups according to Shorvon (2011), considering that there are a lot of specific epilepsy types which belong to these main groups:

- (1) Idiopathic epilepsy: predominantly genetic or presumed genetic origin and in which there is no gross neuroanatomic or neuropathologic abnormality
- (2) Symptomatic epilepsy: acquired or genetic cause, associated with gross anatomic or pathologic abnormalities, and/or clinical features, indicative of underlying disease or condition
 - a. Acquired epilepsy: used to refer to symptomatic epilepsies excluding the predominantly genetic and developmental causes. The term includes those epilepsies due to external or environmental causes as well as internal pathologic processes, which have no known pathological component (e.g. tumor, neurodegenerative disorder, autoimmune disorders)
- (3) Provoked epilepsy: specific systemic or environmental factor is the predominant cause of the seizure in which there are no gross causative neuroanatomic or neuropathologic changes
- (4) Cryptogenic epilepsy: presumed symptomatic nature in which the cause has not been identified

In the most recent ILAE classification report it was suggested that the term idiopathic, symptomatic and cryptogenic are replaced by the terms genetic, structural/metabolic and unknown. These suggestions were never implemented for the following reasons: Idiopathic epilepsies are probably the consequences of combination of genetics and environmental influences, although genetic influence is probably predominating.

Changing symptomatic into structural/metabolic does not make much sense either, for many of the symptomatic conditions are neither structural nor metabolic. Another distinction can be made in terms of seizures itself, dividing them into two forms, generalized and partial (or focal) seizures (see Table 1).

Originally this categorization was first described by Hughling Jackson, but officially recommended by the ILAE in 1964 (Gastaut et al., 1964). The ILAE defined partial seizures in which the first clinical and electroencephalography (EEG) changes indicate initial activation of a system of neurons limited to a part of one cerebral hemisphere. Whereas generalized seizures cannot be attributed to one hemisphere, for actually there are both cortical and subcortical circuits and both hemispheres involved in the onset, but not necessarily the entire cortex. However, “secondarily generalized” is a similar term that can contribute to confusion to some extent, but which basically refers to the subsequent spread of a seizure. Further generalized seizures are either symmetrical or asymmetrical.

Table 1

Classification of seizures

Generalized seizures

Tonic-clonic (in any combination)

Absence

Typical

Atypical

Absence with special features

Myoclonic absence

Eyelid myoclonia

Myoclonic

Myoclonic

Myoclonic atonic

Myoclonic tonic

Clonic

Tonic

Atonic

Focal seizures

Unknown

Epileptic spasm

Note: Adapted from “Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE commission on classification and terminology, 2005 – 2009” by Berg, A. T., Berkovic, S. F., Brodie, M. J., Buchhalter, J., Cross, H. J., van Emde Boas, W. et al., 2010, *Epilepsia*, 51 (4), 676 – 685.

Individuals can be seizure free for a vast time because of many reasons, e.g. they remaining seizure vulnerability can be successfully controlled by medication therapy, children can outgrow epilepsy or individuals have a definitive treatment such as brain surgery. Unluckily there is no definite cure, because the term cure implies that individuals who have a history with epilepsy have the same risk or probability for a future seizure as the population unaffected by the vulnerability for epileptic seizures. Unfortunately such a low risk for a potential seizure in the future can never be achieved nor guaranteed. Another term that can be found in medical literature regarding chronic diseases is “remission”, which can be found in Sander and Shorvon (1996) for example. They stated that epilepsy besides other factors has been defined in terms of its activity – an active case of epilepsy was defined as a person who has had at least one seizure in the last five years regardless of the treatment. An inactive case was defined as remission with treatment (without epilepsy for more than five years and receiving treatment) or remission without treatment (without epilepsy for more than five years and not receiving any treatment). However, the term “remission” implies that epilepsy is easing down, but it does not mean that the disease is absent. As a solution to this problem concerning terminology the term “resolved” has been adopted, implying that an individual is free from epilepsy at the moment, but it is not guaranteed that it will never return again (recurrence risk depends on the type of epilepsy, age, syndrome, etiology, treatment and many other factors). Most relapses occur early, e.g. after a single unprovoked seizure 80 – 90% of those who had a second one did so within 2 years.

Fischer (2014) precisely defined when epilepsy is resolved:

Epilepsy is considered to be resolved for individuals who either had an age-dependent epilepsy syndrome but are now past the applicable age or who have remained seizure free for the last 10 years and off anti-seizure medicines for at least the last 5 years. (P. 1)

In the more recent definition of Fischer (2014) we can see some adaptations as for when epilepsy is resolved. First they took into consideration age-dependent epilepsy syndrome, which is usually active only in a certain lifespan.

The time someone has to remain seizure free to be classified “epilepsy resolved” has been prolonged, now needing to be 10 years without a single seizure occurring, which is not sufficient yet. Fischer (2014) stated that a person suffering from epilepsy has to be off anti-seizure medicine for at least five years as well.

Regarding the causes of epilepsy it is safe to say that it is multifactorial, mainly being the result of simultaneously genetic and environmental influences, as well as provoking factors (e.g. light, etc.), though the latter is not predominant. Sander and Shorvon (1996) wrote that congenital, developmental and genetic conditions are associated with epilepsy in childhood, adolescence and young adults. For the older population, cerebrovascular disease is a common cause for epilepsy. Other risk factors are head traumas, sporadic CNS (central nervous system) infection and tumours which can occur at any age, though tumours are more likely after the age of 40. Sander and Shorvon (1996) reported that sex is an influencing factor as well, with studies showing higher rates of epilepsy in males than in females. Socioeconomic status seems to have an impact on epilepsy, showing higher rates of prevalence in lower socioeconomic classes, although to this date not a lot of studies have been considered.

Besides the burden of the probability of epileptic seizures occurring, epilepsy entails a number of other consequences the individual and often their families may have to deal with, e.g. stigma, psychological, social, cognitive and economic maladjustments.

O'Donoghue, Goodridge, Redhead, Sander and Duncan (1999) found that one-third of their sample (N = 309) with active epilepsy were significantly handicapped by epilepsy. Their surveys showed that people who suffer from epilepsy experience difficulties with work and social activities, even more when they have frequent seizures.

If seizures occur more than once a month people suffer two to three times more from psychiatric disorders compared with those in remission. Taking a closer look at the analysis, it can be seen that 34% of the sample were unemployed or off work due to their condition, despite the fact that they are in working age. In comparison 11% of those who were in remission were unemployed. One-third expressed a suspicion that they have not been offered the job because of their epilepsy, one-quarter even thought that they lost their job due to their condition. In terms of psychiatric symptoms, 124 subjects (34%) consulted their primary physician at some point during the illness. The most common symptoms in these subjects were depression (23%), anxiety (6.5%) and overdose (6%).

Baker (2002) said that a number of studies have undertaken research on the impact epilepsy has on the quality of life with the result that the condition compromises people's quality of life by creating difficulties in driving, employment and even limitations in insurance provisions. Baker (2002) found that the unpredictability of epilepsy is the essential factor when it comes to psychological consequences and maladjustments. Consistent with O'Donoghue et al. (1999), Baker (2002) described that people with epilepsy are more likely to suffer from depression and anxiety and low self-esteem.

These psychosocial maladjustments could lead to social withdrawal and isolation, which can very well explain or at least contribute to un- or underemployment, lower academic achievements as well as lower rates of marriage in people with epilepsy. In addition people who suffer from epilepsy often suffer from side effects of anti-epileptic drugs (AEDs), which are often cognitive and physical. Major cognitive consequences include reduced attentiveness, impoverished memory and mental slowing, thus possibly leading to even more psychological problems. In the following table is a listing of major consequences (see Table 2).

Table 2

Impact of seizure frequency on certain domains of everyday life

	Seizure frequency			p Value ^a
	None in last year	Fewer than one per month	At least one per month	
Felt epilepsy affected a lot/some				
Relationship with spouse/partner	19% (n = 1,304)	28% (n = 720)	38% (n = 982)	p < 0.0001
Relationship with other close family members	16% (n = 1,884)	23% (n = 1,180)	37% (n = 1,787)	p < 0.0001
Social life and activities	26% (n = 1,878)	39% (n = 1,179)	57% (n = 1,785)	p < 0.0001
Ability to work in paid employment	23% (n = 1,862)	33% (n = 1,170)	54% (n = 1,766)	p < 0.0001
Nature of paid work	27% (n = 1,367)	38% (n = 824)	57% (n = 1,052)	p < 0.0001
Health overall	22% (n = 1,874)	31% (n = 1,177)	47% (n = 1,782)	p < 0.0001
Relationship with friends	15% (n = 1,884)	25% (n = 1,186)	40% (n = 1,789)	p < 0.0001
Feelings about self	29% (n = 1,879)	39% (n = 1,176)	51% (n = 1,768)	p < 0.0001
Plans/ambitions for the future	33% (n = 1,878)	44% (n = 1,177)	63% (n = 1,774)	p < 0.0001
Standard of living	23% (n = 1,877)	34% (n = 1,182)	50% (n = 1,774)	p < 0.0001

^a Test of significance was χ^2 test. From Baker et al., 1997 (5).

Note: Taken from "The Psychosocial Burden of Epilepsy" by Baker, G. A., 2002, *Epilepsia*, 43, 26 – 30

1.3 Quality of life

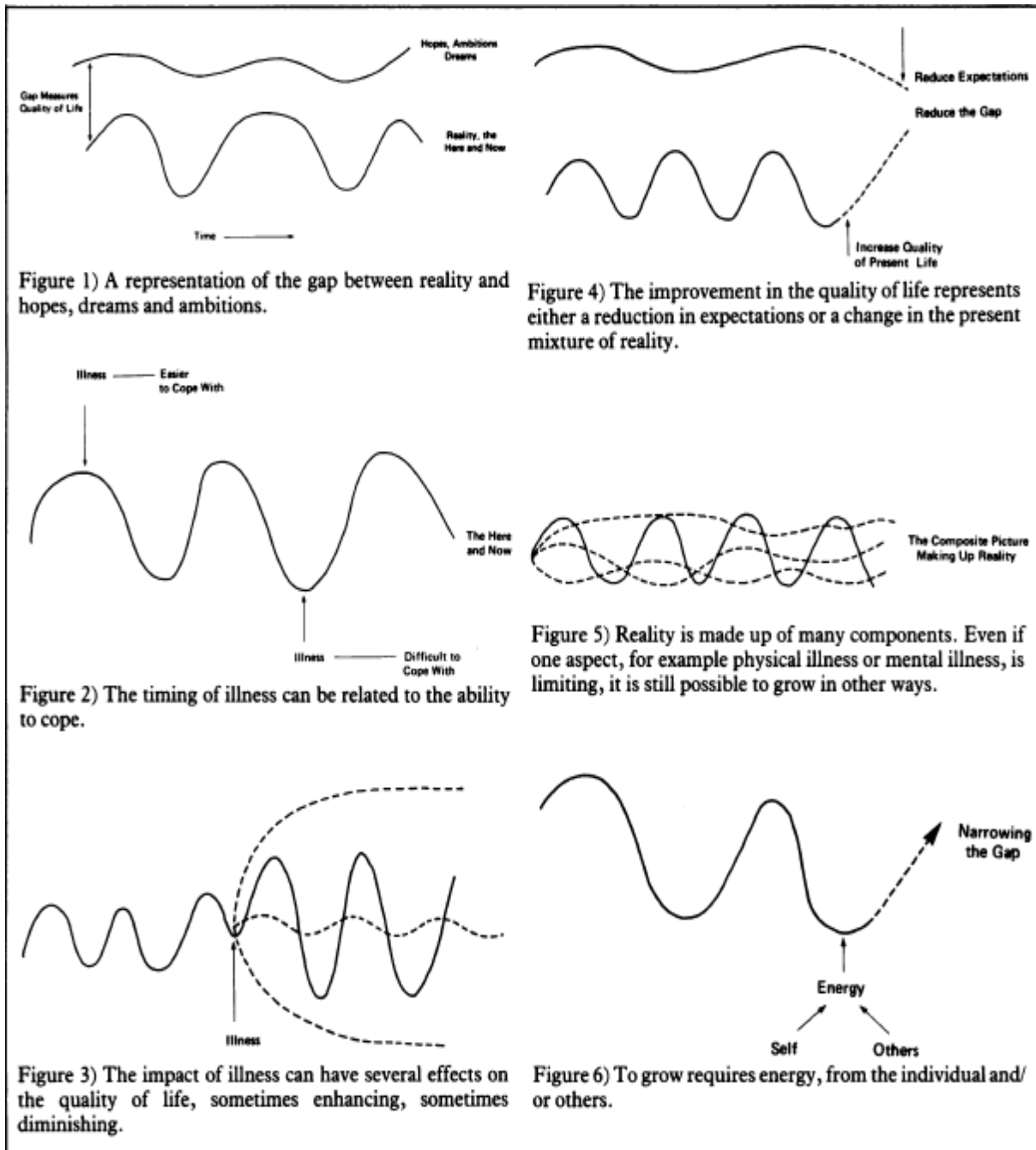
Discussions and thoughts about the quality of life date as far back as Aristotle, who invented the concept of *eudaimonia*, where individuals were encouraged to realize their full potentials to achieve a 'good life'. Across thousands of years many philosophers and scientists tried to define the phrase quality of life, with more or less success. To date there is still no consistent definition of the term, thus there are a few concepts within those theories existing, that overlap with one another. Calman (1984) emphasized that quality of life can only be defined and even measured concerning individuals and their experiences in the past, their ambitions, hopes, fears and thoughts.

Quality of life must contain all areas of life, including the negative ones such as illness, deaths of loved ones, etc. Calman (1984) described good quality of life as hopes of an individual being met by the experience they encounter in life. For poor quality of life the exact opposite is the case – hopes and dreams are not matched with the individuals' experience. Calman (1984) also stressed out that those hopes and ambitions have to be realistic, which implies that with getting older these expectations will change over time. However, this has led Calman (1984) to the following implications in terms of defining quality of life.

- It can only be assessed and described by the individual.
- It must take in account many aspects of life.
- It must be related to individual aims and goals.
- Improvement is related to the ability to identify and achieve these goals.
- Illness and treatment may well modify the goals.
- The goal must be realistic.
- Action is required to narrow the potential gap. This may be by the patient alone or with the help of others.
- The gap between the expectation and the reality may be the driving force for some individuals.
- As each goal is achieved new ones are identified, opening the gap again. It is a constantly changing picture.

Calman (1984) illustrated certain progressions and situations of quality of life during a lifetime in form of diagrams (Figure 3).

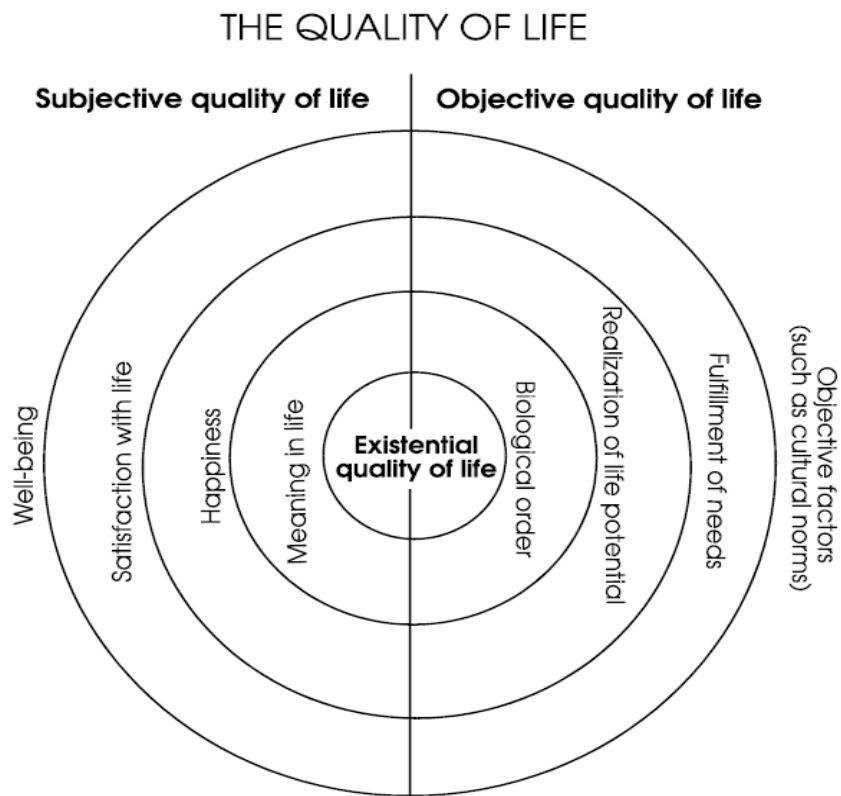
Figure 3



Note: Taken from "Quality of life in cancer patients – an hypothesis" by Calman, K. C., 1984, *Journal of medical ethics*, 10, 124 – 127

Ventegodt, Merrick and Andersen (2003) stated an integrative theory of quality of life, where they distinguish between three dimensions of quality of life – *subjective* quality of life, *existential* quality of life and *objective* quality of life. Calman (1984) described his theory as a kind of subjective quality of life, therefore Ventegodt et al. (2003) added two dimensions, because they say that quality of life can't be solely defined on inner feelings, thoughts and ambitions of the individual, there has to be objective measures which are as important to quality of life as the personal emotions. Subjective quality of life is precisely what Calman (1984) already stated – the individuals' personal feelings and point of view on how things stand in their current life situation. The existential quality of life contains the evaluation of life at a deeper level. In this dimension our biological needs need to be fulfilled, such as growth, as well as a spiritual and religious ideals. The objective quality of life revolves around the perception of one's own quality of life by the outside world. This dimension is highly influenced by the culture in which the society lives in. Examples for the objective quality of life are social status and symbols you need to have to be a good member of society. Ventegodt et al. (2003) then created a spectrum of quality of life, which goes from subjective to objective quality of life, in the centre you can find the existential quality of life. This spectrum contains various existing quality-of-life-theories, which can be seen in Figure 4.

Figure 4



Note: Taken from "Quality of life theory I. The IQOL theory: an integrative theory of the global quality of life concept" by Ventegodt, S., Merrick, J. & Andersen, N. J., 2003, *TheScientificWorldJOURNAL*, 3, 1030 – 1040.

Well-being is the outer most factor of the subjective quality of life side. Ventegodt et al. (2003) say that it is the most natural aspect of subjective quality of life, which is some kind of evaluation of one's own quality of life, because the question about one's well-being is always followed by an explanation. Well-being is situated on the outside of the circle because when we think about being well and feeling good, we don't think about the deeper meaning of life, fulfilling of needs, etc. Satisfaction in life is not the same as well-being, because someone can feel good but not be satisfied with his life.

If someone is satisfied with his or her life, it means that someone is feeling that his or her life is the way it should be. The expectations are met by the reality, which provides us with satisfaction. Therefore satisfaction is mental state or cognitive entity.

Ventegodt et al. (2003) see happiness as a struggle for what really is important for someone. If you achieve what you strive for, you feel happy. Happiness is usually associated with nonrational constructs such as love, relationship, etc. Not surprisingly happiness can't be achieved only with money, state of health and other objective factors. In the most inner of the circle we can find the factors meaning of life, biological order and the dimension existential quality of life. Since our whole perceptions, experiences and emotions are biologically conditioned, this implicates that if life has meaning or not could be tied to the state of our biological system. If our biological system is not working properly, all of our perceptions, experiences and emotions can't work optimally either. Hence the existential quality of life is related to meaning of life and our biological system. Realizing of one's life potential is located on the right half of the circle, the objective quality of life. If we look at the very beginning of a human life, it starts with a fertilized egg which contains a vast amount of information. All of this contained information must develop and manifest itself in a human being. As life goes on the human being develops itself according to those information the fertilized egg contained until it realized its life potential. This life potential can be everything from a bartender to a scientist. If we consider this, realizing one's life potential becomes a indispensable factor in the quality of life concept. Fulfillment of needs is a rather superficial and culturally conditioned factor. If someone fulfills his or her needs, his or her quality of life will be high(er) and vice versa. On the very right side of the circle are the objective factors, which form the most superficial factor of the objective quality of life. 7Objective factors include income, marital status, state of health, etc. Therefore the objective factors are associated greatly with the culture we live in.

2. Hypothesis

As seen in the introduction section, not much research has been conducted on the overall effect of epilepsy on the patients' self-esteem, and further on how self-esteem affects the perceived quality of life. A vast majority of studies concentrated on the effect of seizure frequency, severity or antiepileptic medication, which all play an important role in the relationship between epilepsy and self-esteem, but there is nothing on how self-esteem may changes the perceived quality of life of people who suffer from epilepsy. The hypothesis has been developed in order to minimize that knowledge gap. The general question that has to be answered in this study is "How does the (assumably) diminished self-esteem as a consequence of the epileptic condition influence the perceived quality of life of the patient?" Again a number of studies have shown that some epilepsy-related factors cause a reduced QOL in the patients' eyes, e.g. seizure frequency, duration of illness and effectiveness of antiepileptic therapy (e.g. Sung et al., 2013; Guekht et al., 2007; McLaughlin et al., 2008). Again there has not been research on how self-esteem directly influences perceived QOL. Consequently this leads to the following hypothesis:

Hypothesis: Perceived quality of life is reduced as a result of epilepsy related low self-esteem

3. Methods

3.3 Participants

Overall 258 (female = 173, male = 85) participants took part in the study and filled out the online questionnaire. Of the total sample 163 participants (male = 31, female = 132) have epilepsy, 95 (male = 54, female = 41) do not have epilepsy. Mean age in the epilepsy sample is 29,9 years, in the no epilepsy sample 23,19. Main registered residences were in Germany (N = 146), Austria (N = 100), Switzerland (N = 9) and others (N = 3). The educational status of the participants is shown in table 3/3a.

Table 3

Educational status in epilepsy participants

	<i>Frequency</i>	<i>Percentage</i>
Finished school without graduation	3	1,8
Primary-, Main school graduation	26	16
Completed vocational training	54	33,1
Higher education entrance qualification	8	4,9
University degree	22	13,5
Still pupil	21	12,9
Graduated otherwise	29	17,8

Table 3a

Educational status in no epilepsy participants

	<i>Frequency</i>	<i>Percentage</i>
Finished school without graduation	-	-
Primary-, Main school graduation	2	2,1
Completed vocational training	8	8,4
Higher education entrance qualification	48	50,5
University degree	31	32,6
Still pupil	2	2,1
Graduated otherwise	4	4,2

Table 4/4a shows the occupational status.

Table 4

Occupational status in epilepsy participants

	<i>Frequency</i>	<i>Percentage</i>
Pupil	20	12,3
In training	16	9,8
Student	6	3,7
Employee	50	30,7
Official	-	-
Self-employed	2	1,2
Unemployed/Seeking employment	29	17,8
Other	40	24,5

Table 4a

Occupational status in no epilepsy participants

	<i>Frequency</i>	<i>Percentage</i>
Pupil	2	2,1
In training	2	2,1
Student	56	58,9
Employee	27	28,4
Official	3	3,2
Self-employed	2	2,1
Unemployed/Seeking employment	1	1,1
Other	2	2,1

Concerning the financial situation of the participants, the questionnaire contained a question regarding the income. A total of 227 participants answered that question, the rest did not fill it out. In the participants with epilepsy condition 80 earned up to 1000€, 48 up to 2500€ and 6 up to 5000€. In the no epilepsy condition participants 61 earned up to 1000€ and 32 up to 2500€.

Table 5 is a brief overview of the most frequent indications in terms epilepsy type, seizure frequency and seizure duration.

Table 5

Epilepsy type, seizure frequency and seizure duration

Epilepsy type	Seizure frequency	Seizure duration
Grand Mal	15 times/day (maximum in the data)	1 – 5 minutes (average time in the data)
Absences	2 – 3 times/day	10 – 45 minutes
Focal seizures	1 – 2 times/week	
Generalized epilepsy	1 – 2 times/month	
Frontal lobe epilepsy	1 – 2 times/year	
Temporal lobe epilepsy		
Idiopathic epilepsy		
Juvenile myoclonic epilepsy		
Kryptogenic epilepsy		
Symptomatic epilepsy		

3.2 Recruitment

For the recruitment of the subjects the link for the online questionnaire was posted on several social media platforms, where both people with epilepsy (online support groups, etc.) and healthy subjects were found. The subjects were informed through a statement written by the author of the study explaining what the study and the questionnaires are about, to what they can contribute and that filling out the questionnaire was absolutely anonymous. The subjects then had the choice to participate in the study or not.

3.4 Questionnaires

Multidimensionale Selbstwertkala (MSWS)

The MSWS is a questionnaire to estimate self-esteem in young adolescences (from 14 years) to adults. The version from Schütz and Sellin (2008) is a german adaptation of the english Multidimensional Self-Concept Scale (MSCS) from Fleming and Courtney (1984) and is designed for the patients to fill it out themselves.

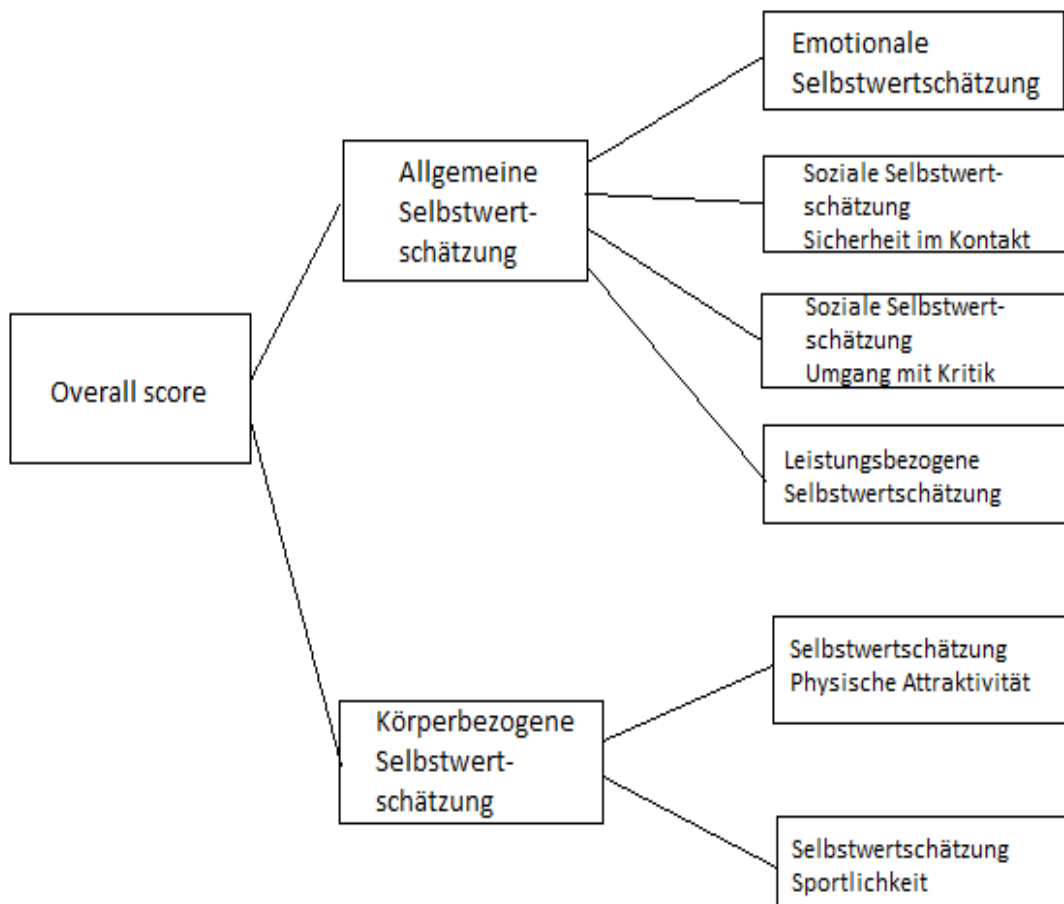
The MSWS is hierarchically structured (see Figure 5) – the overalls score contains the two dimensions *Allgemeine Selbstwertschätzung* and *Körperbezogene Selbstwertschätzung*. Furthermore the two dimensions consist of overall six sub scales, four belonging to *Allgemeine Selbstwertschätzung* and two to *Körperbezogene Selbstwertschätzung*. The former consists of the sub scales:

- (1) *Emotionale Selbstwertschätzung*: consisting of overall self-acceptance, self-satisfaction and the attitude towards oneself
- (2) *Soziale Selbstwertschätzung (assurance in contact to others)*: consisting of social skills, attitude towards social skills and emotions in dealing with other people
- (3) *Soziale Selbstwertschätzung (handling criticism)*: consisting of perceived opinion of others about oneself, perceived appreciation by others and sensitivity for criticism
- (4) *Leistungsbezogene Selbstwertschätzung*: consisting of the evaluation of the capability in the workplace and the conviction of work qualifications

Körperbezogene Selbstwertschätzung consists of the following sub scales:

- (1) *Selbstwertschätzung physische Attraktivität*: consisting of the attitude towards ones' own physical attractiveness and the satisfaction with the own body
- (2) *Selbstwertschätzung Sportlichkeit*: consisting of attitudes towards ones' own sport and coordination abilities

Figure 5



Note: Hierarchy of the MSWS. Adapted from Daig, I., Gunzelmann, T. & Brähler, E. (2008). *Diagnostica* (Zeitschrift für Psychologische Diagnostik und Differentielle Psychologie, 54, 3). Göttingen: Hogrefe.

Overall the MSWS consists of 32 items, each sub scale containing five items, except for the sub scale *Emotionale Selbstwertschätzung* which consists of seven items. The sub scales are rated on two different 7-point Likert-scales - the first 15 items are rated on an intensity scale (“not at all” to “very”) and the last 17 items on a frequency scale (“never” to “always”). Principal components analysis was carried out and six factors that explain 60% of the variance.

Regarding the psychometric criteria the MSWS is overall a solid questionnaire to evaluate a person's self-esteem. They were tested on a general population (N = 453) and a population of students (N = 125). Through the standardization of the questionnaire the MSWS has a high objectivity regarding execution and analysis.

Morina and Stangier (2007) as well as Daig, Gunzelmann and Brähler (2008) reported almost identical results concerning the psychometric criteria. Morina and Stangier (2007) reported an internal consistency (Cronbachs' α) for the sub scales in the general population between .85 and .93 and for the population of students between .80 and .89. For the two main dimensions they found Cronbach α to be between .75 and .87 in the general population and .80 and .89 in the student population.

For measuring the Re-test reliability they tested a new population of students (N = 52), Morina and Stangier (2007) found a re-test reliability of $r = .73$ for *Allgemeine Selbstwertschätzung* and $r = .77$ for *Körperbezogene Selbstwertschätzung*.

For four sub scales the re-test reliability was between $r = .70$ and .86, the remaining two were rather weak with $r = .46$ for *Leistungsbezogene Selbstwertschätzung* and $r = .62$ for *Selbstwertschätzung physische Attraktivität*. Daig, Gunzelmann and Brähler (2008) report the exact same results for the re-test reliability as Morina and Stangier (2007), though they provide the four sub scales which range between $r = .70$ and .86, which are *Emotionale Selbstwertschätzung*, *soziale Selbstwertschätzung* (as well as *in assurance in contact with others and handling criticism*) and *Selbstwertschätzung Sportlichkeit*.

Construct validity was assessed as well, gaining an $r = .26 - .68$ for the sub scales in the general population, $r = .21 - .57$ for the student population. There is a relatively high intercorrelation, since the corresponding sub scales correlate to $r = .73 - .86$ with *Allgemeine Selbstwertschätzung*, the two sub scales of the *Körperbezogene Selbstwertschätzung* correlate only to $r = .41 - .60$ with the *Allgemeine Selbstwertschätzung* though.

Whereas the sub scales of the *Körperbezogene Selbstwertschätzung* are correlating with and $r = .82$. Intercorrelation between the sub scales and the overall score is between $r = .57$ and $.82$, for the two main dimensions $r = .82$ to $.95$. Regarding the sensitivity of the MSWS, it was tested on a clinical population ($N = 114$), which was divided into three separate groups (depression, anxiety and eating disorder). The average scores of the overall scores allow a good distinction between patients and non patients with an effect of $d = .68$ to 1.21

WHOQOL – BREF

The WHOQOL – BREF is a quality of life assessment developed and approved of the World Health Organization. Its primary use is in epidemiological surveys, clinical settings and trials and can be used in ill as well as healthy populations.

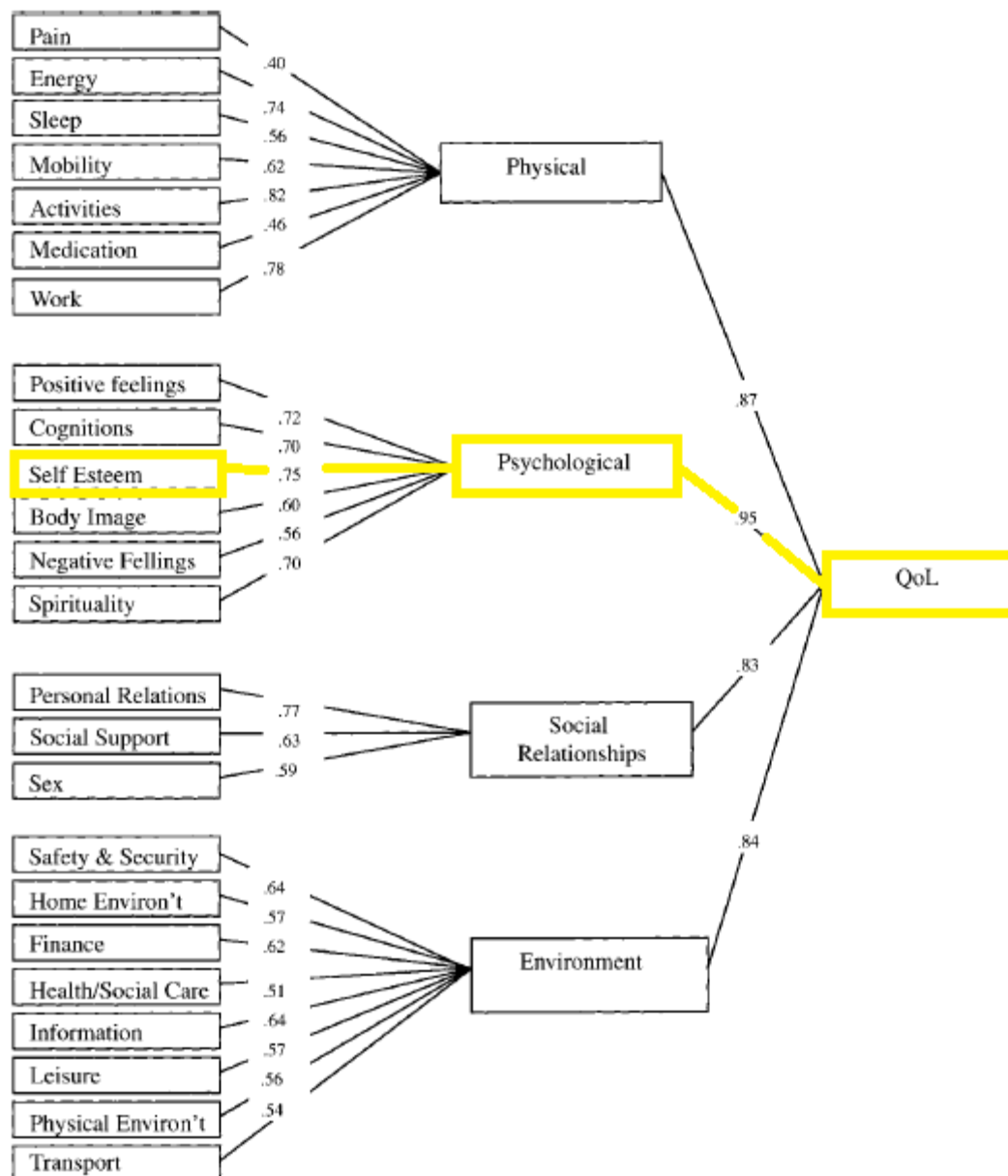
The questionnaire is a shortened version of the WHOQOL – 100 and consists of 26 items, spread over four domains (1) physical, (2) psychological, (3) social and (4) environment. The item response scales inquire the categories “how much”, “how completely”, “how often”, “how good” and “how satisfied” the respondent felt in the last two weeks. The WHOQOL Group around Skevington, Lofty and O'Connell (2004) reported that the psychometrical properties of the WHOQOL – BREF were analysed from data obtained from a survey of adults carried out in 23 countries, with a total of $N = 11\,830$.

The internal consistency (Cronbach α) was measured for the total sample, reaching acceptable values ($> 0,7$) for the physical ($\alpha = 0.82$), psychological ($\alpha = 0.81$) and environment ($\alpha = 0.80$) domains. Cronbach α for the social domain was rather marginal, reaching $\alpha = 0.68$, but Skevington et al. (2004) explained the low internal consistency of the social domain with the fact that the domain is based on only three items, the other three on six to eight items per domain.

Therefore the lower values in this domain were expected. As for the validity of the WHOQOL – BREF, Skevington et al. (2004) reported that the discriminant validity was significant for each domain in the total population, meaning that the instrument is able to discriminate between ill and healthy populations. The best values concerning discriminant validity were found in the physical, followed by the psychological, social and environment domain.

Construct validity is the measure of how good items correlate with the intended domain and if the construct validity is of high value, the domain concept is clearer and the scores are more easily interpreted. Skevington et al. (2004) stated that the analysis of the correlations showed that only seven items had strong correlations ($p > 0.5$) with domains other than their intended. The most interesting aspect of this correlation analysis in terms of this study is that the self-esteem item in domain two correlates strongly with all four domains, implying that self-esteem is an essential factor in major life domains, as for example represented in the WHOQOL – BREF. The importance of self-esteem for QOL can be seen on the confirmatory factor model in Skevington et al. (2004) as well (see Figure 6).

Figure 6



Note: 4-domain confirmatory factor model. Taken from “The World Health Organization’s WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial” by Skevington, S. M., Lofty, M. & O’Connell, K. A., 2004, *Quality of Life Research*, 13, 299 – 310

3.5 Statistical analysis

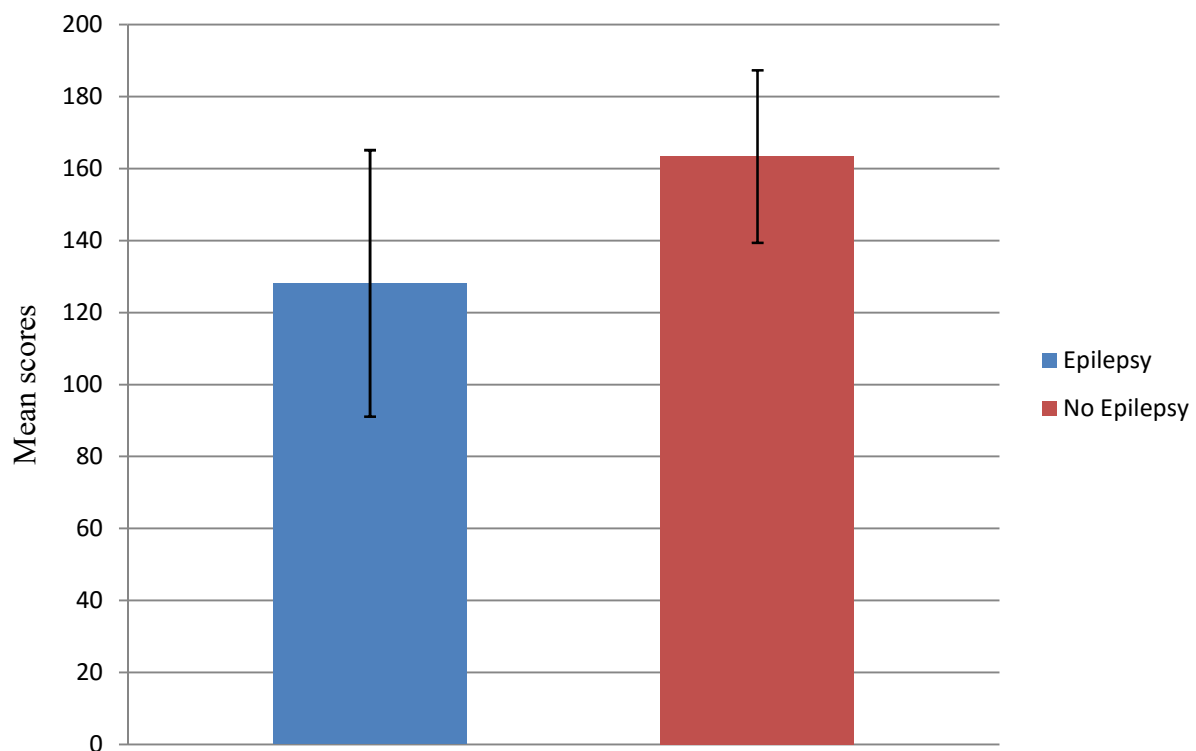
Analysis was conducted with SPSS 21 (Statistic Package for Social Siences). To test for normal distribution Kolmogorov-Smirnov test was conducted before any analysis took place. The Kolmogorov-Smirnov test showed that none of the data is distributed normally. For the comparison of the experimental and control group regarding differences in age, occupation, income, overall self-esteem and quality of life domains the Mann-Whitney-U-Test was used. The decision to take the non-parametric Mann-Whitney-U-Test was based on the testing for normal distribution, which indicated that data is not normally distributed and therefore does not meet the criteria for the t-Test for independent samples. Partial correlations were conducted to see if significant differences could be accounted for the differential results in quality of life. Regression analysis was used to take a look how the overall self-esteem influences quality of life, as well as a mediator analysis to see if self-esteem mediates the effect of epilepsy on quality of life. To deal with missing values list wise deletion was used.

4. Results

The mean values for the overall self-esteem between having epilepsy and not having epilepsy are $MV = 128,10$ ($SD = 36,99$) for the former and $MV = 163,34$ ($SD = 23,96$) for the latter. The mean score was further tested for significance, to see if the difference in the two groups is not a coincidence. The result is significant with $p \leq 0,05$, which means that there is a significant difference between subjects who suffer from epilepsy and the ones who don't. Therefore the null hypothesis H_0 is rejected.

Figure 7

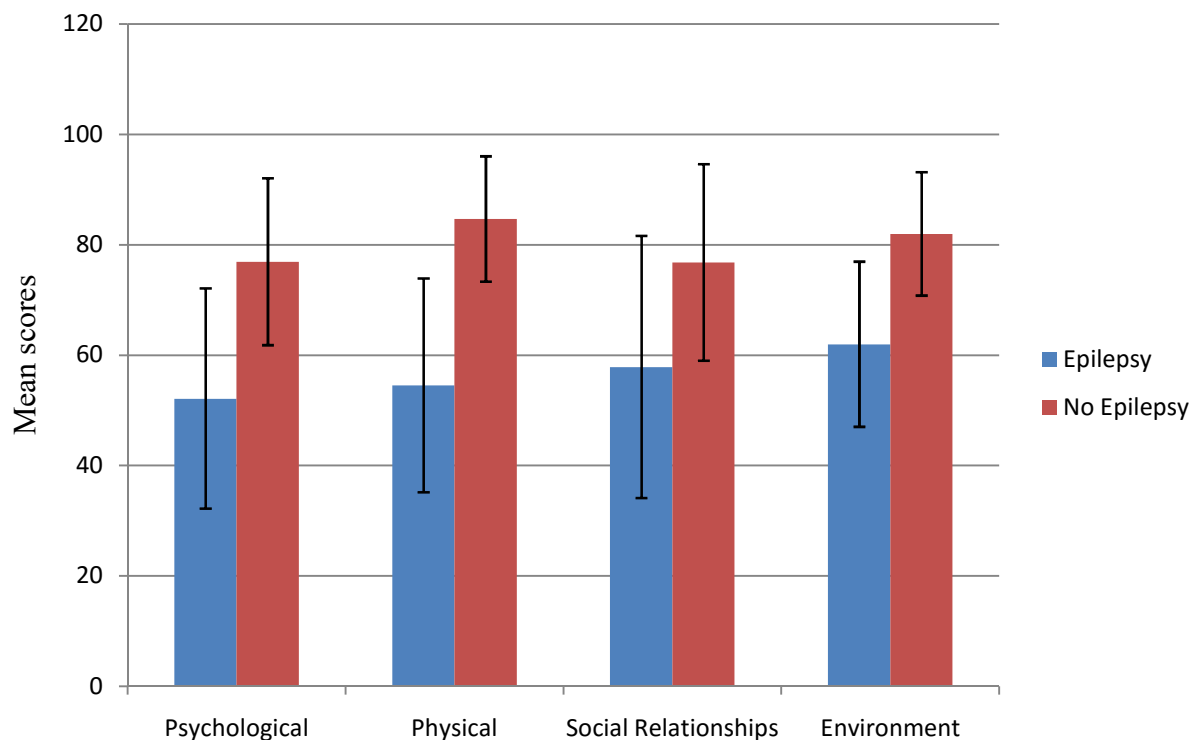
Mean scores of overall self-esteem in subjects with epilepsy and no epilepsy



Moreover it was compared how the two groups differ in their perceived quality of life. Mean scores in the psychological domain were 52,1104 (SD = 19,95) for subjects who suffer from epilepsy and 76,9060 (SD = 15,13) for those who don't. Regarding the rest of the domains we can find similar differences – (1) physical: 54,4991 for epilepsy (SD = 19,36) and 84,6505 for no epilepsy (SD = 11,35); (2) social relationships: 57,8463 for epilepsy (SD = 23,75) and 76,7730 for no epilepsy (SD = 17,79); (3) environment: 61,9521 for epilepsy (SD = 14,96) and 81,9481 for no epilepsy (SD = 11,18) (see Figure 8). Testing for difference between the mean scores showed significance ($p \leq 0,05$) in all four domains.

Figure 8

Mean scores in quality of life domains regarding having epilepsy and not having it



In terms of how overall self-esteem influences quality of life, a regression analysis was conducted, concluding that self-esteem has an enormous effect on some quality of life domains. As seen in figures 9 to 12 down below, self-esteem has a great effect on every domain of the WHOQOL-BREF, with its greatest effect on the psychological domain ($F(1, 152) = 202,749, p < .000$, with an adjusted $R^2 = .569$) for the epilepsy condition and $F(1, 92) = 69.163, p < .000$, with an adjusted $R^2 = .423$ for the no epilepsy condition. In descending order self-esteem effects the physical domain with $F(1, 152) = 41,061, p < .000$, with an adjusted $R^2 = .208$ for the epilepsy condition and $F(1, 92) = 29,625, p < .000$, with an adjusted $R^2 = .235$. The environment domain results in $F(1, 152) = 35,726, p < .000$, with an adjusted $R^2 = .185$ for the epilepsy condition and $F(1, 92) = 16,869, p < .000$, with an adjusted $R^2 = .146$ for the no epilepsy condition. Results in the social relationship domain were $F(1, 152) = 30,224, p < .000$, with an adjusted $R^2 = .160$ for the epilepsy condition and $F(1, 92) = 8,116, p < .01$, with an adjusted $R^2 = .071$ for the no epilepsy condition. To see if maybe self-esteem is just a mediator variable between the relationship of epilepsy and quality of life, a mediator analysis has been conducted. Seizure frequency was taken as an indicator for the severity of the epilepsy, coded "0 = not otherwise specified", "1 = seizure free for over a year", "2 = seizures appear multiple times a year", "3 = seizures appear multiple times a month", "4 = seizures appear multiple times a week" and "5 = seizures appear multiple times a day". Results for the physical quality of life are significant ($p < 0,05$), indicating that seizure frequency/severity influences physical quality of life as well as self-esteem, although not to the same extent. For the remaining quality of life domains the effect was not significant, therefore self-esteem remains the primary variable influencing quality of life.

Significant differences in age and occupation between the two groups were found, therefore overall-self-esteem and the quality of life domains were partially correlated with these two variables, to systematically control for their influence.

Influence of age and occupation in the correlations of overall self-esteem and the physical domain of the WHOQOL-BREF

Correlations with self-esteem are $r = .461$ ($p < 0, 01$) for the epilepsy condition and $r = .494$ ($p < 0, 01$) for the no epilepsy condition. Controlling for age and occupation, the former made the correlations for the epilepsy condition go up to $r = .464$ ($p < 0, 01$) and sink for the no epilepsy condition to $r = .488$ ($p < 0, 01$). As for the control variable occupation, correlations in the epilepsy condition went down to $r = .446$ ($p < 0, 01$) and in the no epilepsy condition to $r = .480$ ($p < 0, 01$)

Influence of age and occupation in the correlations between overall self-esteem and the psychological domain of the WHOQOL-BREF

Self-esteem and the psychological domain correlated with an $r = .756$ ($p < 0, 01$) in the epilepsy condition and with $r = .655$ ($p < 0, 01$) in the no epilepsy condition. Controlled for age, the correlation increased to $r = .761$ ($p < 0, 01$) in the epilepsy condition and stayed exactly the same in the no epilepsy condition. As far as the occupation goes, correlation changed to $r = .755$ ($p < 0, 01$) for the epilepsy condition and $r = .644$ ($r < 0, 01$).

Influence of age and occupation in the correlations between overall self-esteem and the social relationships domain of the WHOQOL-BREF

In the uncontrolled correlations the results were $r = .407$ ($p < 0, 01$) for the epilepsy condition and $r = .285$ ($p < 0, 01$) for the no epilepsy condition. Controlling for age resulted in an increase in $r = .417$ ($p < 0, 01$) for the epilepsy condition and a decrease in $r = .278$ ($p < 0, 05$) for the no epilepsy condition. Regarding the control variable occupation a decrease was found for the epilepsy condition with $r = .395$ ($p < 0, 01$) and a decrease as well for the no epilepsy condition with $r = .241$ ($p < 0, 05$).

Influence of age and occupation in the correlations between overall self-esteem and the environment domain of the WHOQOL-BREF

The correlation between the two variables resulted in an $r = .436$ ($p < 0, 01$) for the epilepsy condition and in an $r = .394$ ($p < 0, 01$) for the no epilepsy condition. After controlling for age and occupation, the former did not influence the correlation in the epilepsy group at all, but decreased the correlation to an $r = .387$ ($p < 0, 01$) in the no epilepsy condition. The occupation variable on the other hand decreased the correlation in both conditions, in the epilepsy condition to an $r = .419$ ($p < 0, 01$) and in the no epilepsy condition to an $r = .343$ ($p < 0, 01$).

Figure 9

Scatter plot of the relationship between overall self-esteem and the psychological domain of the WHOQOL-BREF in the epilepsy and no epilepsy condition

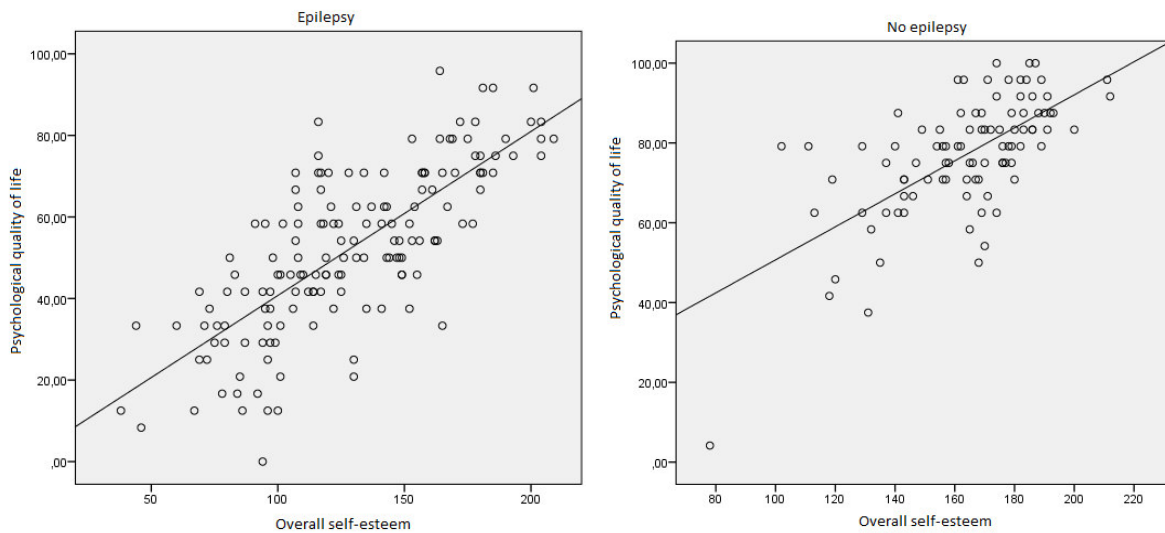


Figure 10

Scatter plot of the relationship between overall self-esteem and the physical domain of the WHOQOL-BREF in the epilepsy and no epilepsy condition

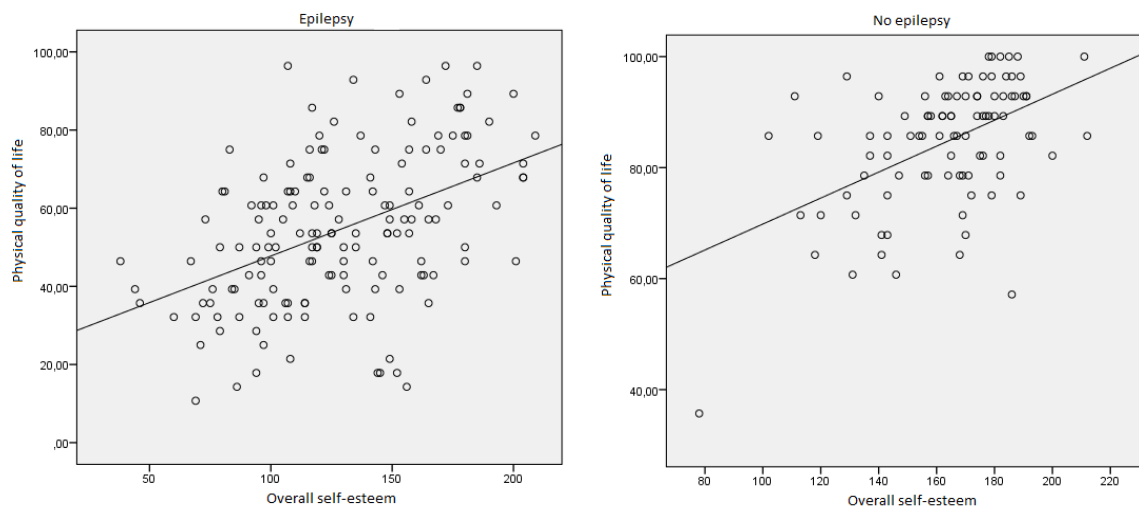


Figure 11

Scatter plot of the relationship between overall self-esteem and environmental domain of the WHOQOL-BREF in the epilepsy and no epilepsy condition

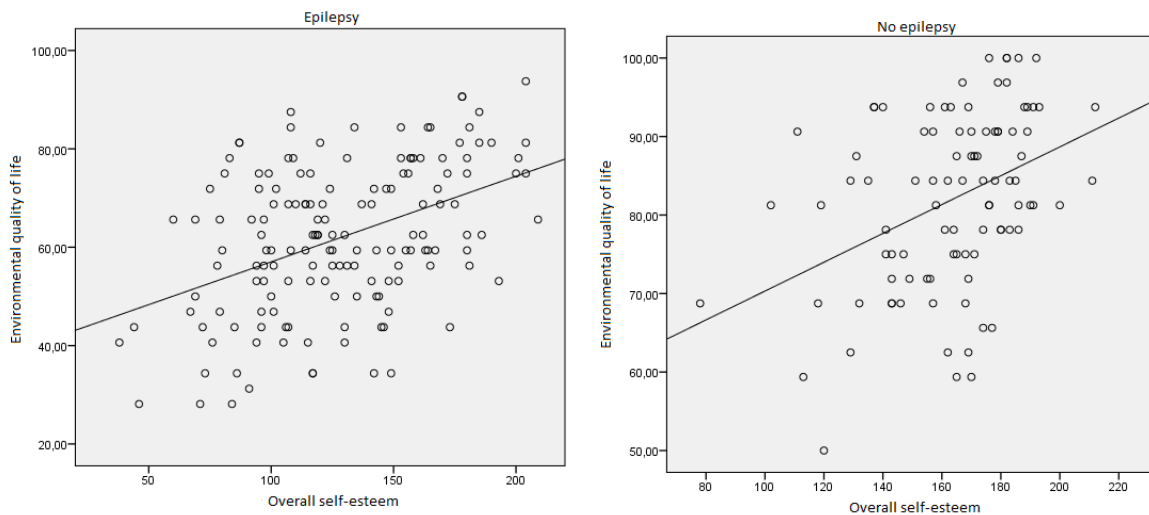
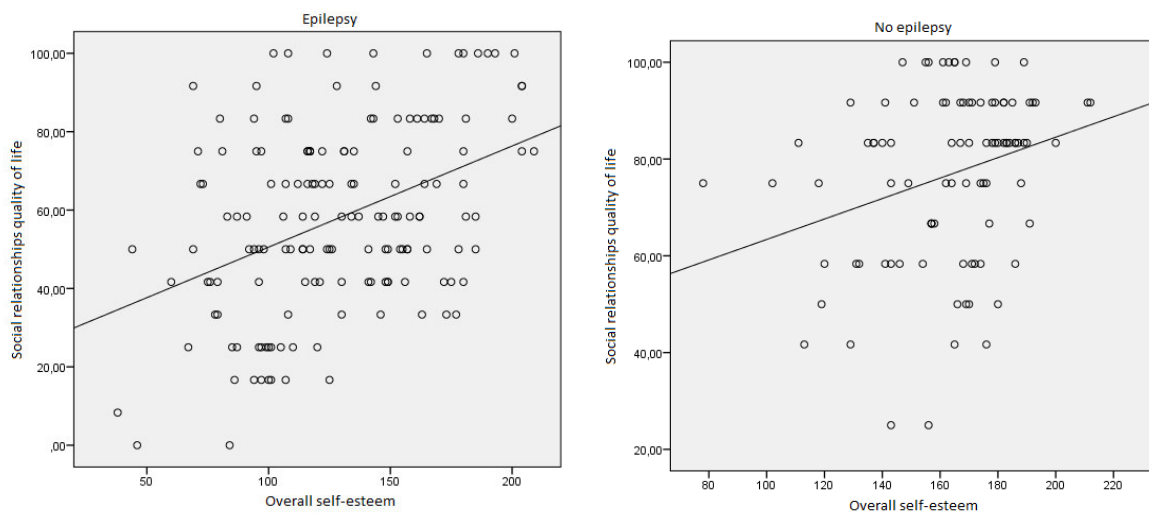


Figure 12

Scatter plot of the relationship between overall self-esteem and social relationship of the WHOQOL-BREF in the epilepsy and no epilepsy condition



5. Discussion

The aim of this study was to investigate how epilepsy influences self-esteem of individuals who suffer from it, further how this influenced self-esteem impacts the perceived quality of life. First it was tested if the subjects with epilepsy and those with no epilepsy differ significantly in their self-esteem and quality of life. With both being significant, it has to be concluded that people who suffer from epilepsy differ from healthy people in terms of self-esteem and quality of life. It was then investigated to what extent self-esteem influences quality of life and the results were quite expressive. As the epilepsy condition resulted in a higher R^2 for every quality of life dimension of the WHOQOL-BREF than the no epilepsy condition, it has to be established that self-esteem plays an important role in perceiving one's quality of life, especially if you suffer from epilepsy (and other chronic diseases as well). Since significant differences were found between the two groups in age and occupation, the two variables were partially correlated with self-esteem and quality of life. The results implicate that age does not seem to mediate the correlation between self-esteem and quality of life in neither domain in the epilepsy condition, though it appears that for the no epilepsy condition, the contrary occurred. A possible explanation for the non existing effect of age in the epilepsy group comes probably from the fact that age does not matter when it comes to quality of life, thus a serious illness affects every individual and consequently their self-esteem, regardless the age. On the other hand age seems to mediate the correlation of self-esteem and quality of life in the no epilepsy group, which could be explained in the different definitions and expectations younger and older individuals have when it comes to quality of life.

Younger generations define quality of life in the job opportunities, income, travel opportunities and leisure time they have, older generations are mainly concerned with their quality of life concerning their health. Thus both generations care for quality of life in different aspects, explaining the effect of age on the relationship between self-esteem and quality of life. As for the occupation variable, the results indicate that occupation seems to mediate the correlation between self-esteem and quality of life for both the epilepsy and the no epilepsy condition. This result is no surprise, as Orth et al. (2011) mentioned a number of studies which reported a positive correlation between self-esteem and job satisfaction, occupation status and salary. Occupation can be a source of self-esteem for a person, hence increasing quality of life. This can certainly be applied for both conditions in this study, as well as on every population regardless of the presence of an illness.

However, according to the data the assumed hypothesis can be fully confirmed, which leads us to the insight of how epilepsy influences self-esteem and in further consequence quality of life. According to Gauffin et al. (2010) and Sung et al. (2013) self-esteem is the most important factor when it comes to psychosocial well-being, which is confirmed throughout this study if only the psychological domain of the WHOQOL-BREF is to be considered, where we have differences in the effect self-esteem has on the psychological quality of life between the two groups. The greater effect of self-esteem in the epilepsy condition has to be taken seriously, for low self-esteem could have strong negative consequences considering its importance for every single domain of the WHOQOL-BREF. Therefore people with epilepsy and assumingly lower self-esteem are more likely to have a poor psychological well-being, which leads to a poorer quality of life consequently.

However, concerning Brandens' (1969) definition of self-esteem, the lack of competence (e.g. getting and keeping a job, working, fear of completing tasks sufficiently, etc.) which people with epilepsy may feel because of their condition can lead to a low self-esteem as well. Regarding Cast and Burkes' (2002) conceptualization of self-esteem as a buffer for the self which protects from harmful situations, people who suffer from epilepsy and therefore have a low self-esteem are much more likely to encounter harmful situations, because the self-esteem does not protect them from it. This function is represented in the self-esteem questionnaire used in this study by the dimension 'Soziale Beziehungen – Umgang mit Kritik', where it is important how you cope with criticism and such harmful situations. Consequently these harmful situations may very well lead to than even lower self-esteem, further to poorer psychological well-being and thus to a lower quality of life. Cast and Burke (2002) also described the identity theory, where self-esteem is seen as a positive outcome of successful self-verification. This means, that the ideal self, which the individual imagines, matches with the self that is perceived by the surroundings. This is in accordance with the gap theories of quality of life, where the expectations and ambitions have to match the experience to narrow the gap and increase the quality of life. Now if we take a person with epilepsy which assumingly has low self-esteem because of the condition, we would assume that the ideal self would hardly ever match the perceived one by the surroundings, meaning self-verification was not successful and therefore self-esteem results in a negative outcome. The negative outcome then will probably not allow experiencing the expectations and ambitions the individual has set for itself, ergo widening the gap between them and simultaneously decreasing quality of life.

As far as the limitations are concerned, the sample size could be higher to achieve more representativity, as well as the distribution of male and female in the two groups. Further the data collection on depression and anxiety showed some difficulties leading to a non consideration for this study, although depression and anxiety are the most frequent comorbidities in epilepsy and every other serious, chronic disease. The difference in sample size could also account for some found differences in the variables, therefore this study does not claim to have found causal relationships or effects, rather some tendencies towards how epilepsy, self-esteem and quality of life interact.

The main results of this study are very informative considering that a large number of people suffer from some type of epilepsy and that induced low self-esteem influences the quality of life. Referring to Hills et al. (1992), Baker et al. (2005) and Baker (2002) knowledge about epilepsy and its consequences significantly correlates with self-esteem. If only this is to be considered, this study has a great value to try to diminish the negative influence epilepsy has on self-esteem and therefore on the quality of life, or at least to be an informative paper about how epilepsy, self-esteem and quality of life are associated. Unfortunately the majority of people with epilepsy do not seek professional help for their diminished self-esteem and psychological maladjustments, instead they rely on their own internal and external resources to cope with those psychological consequences themselves. Besides the psychological quality of life the study has shown that self-esteem influences the remaining domains, physical, social relationships and environment as well, thus it can be concluded that self-esteem definitely has an effect on perceived quality of life, at least to some extent, although further research to verify and replicate the results would be necessary.

As for clinical implications there should be an offer for people with epilepsy, either stationary or in the ambulance, for courses and seminars or at least a conversation with the responsible physician (in case of an in-patient stay), where professionals and experts teach people medical facts about epilepsy as well as psychological, physical, social and environmental consequences of it. Such courses could eliminate or at least diminish the self-esteem issues and stigma to a certain amount. In combination with a therapy or program to boost patients' self-esteem, a normal life without self-esteem, anxiety and depression issues could be achieved. For future researches in this field, it should be considered to take in anxiety and depression as variables to test the impact of. As described above anxiety and depression are the most frequent comorbidities in epilepsy and probably every other serious illness. Another aspect worth taking a look at would be the gender question between those two groups, if they differ, to what degree and if explanations can be found for that.

References

- Baker, G. A. (2002). The psychosocial burden of epilepsy. *Epilepsia*, 43 (6), 26 – 30.
- Baker, G. A., Brooks, J., Buck, D. & Jacoby, A. (1999). The stigma of epilepsy: a European perspective. *Epilepsia*, 41, 98 – 104.
- Baker, G. A., Spector, S., McGrath, Y. & Soteriou, H. (2005). Impact of epilepsy in adolescence: a UK controlled study. *Epilepsy & Behavior*, 6, 556 – 562.
- Berg, A. T., Berkovic, S. F., Brodie, M. J., Buchhalter, J., Cross, H. J., van Emde Boas, W. et al. (2010). Revised terminology and concepts for organization of seizures and epilepsies: report of the ILAE commission on classification and terminology, 2005 – 2009. *Epilepsia*, 51 (4), 676 – 685.
- Branden, N. (1969). *The psychology of self-esteem*. New York: Bantam.
- Calman, K. C. (1984). Quality of life in cancer patients – an hypothesis. *Journal of medical ethics*, 10, 124 – 127.
- Cast, A. D. & Burke, P. J. (2002). A theory of self-esteem. *Social Forces*, 80 (3), 1041 – 1068.
- Chung, M. C., Killingworth, A. & Nolan, P. (1997). A critique of the concept of quality of life. *International Journal of Health Care Quality Assurance*, 10 (2), 80 – 84.
- Daig, I., Gunzelmann, T. & Brähler, E. (2008). *Diagnostica* (Zeitschrift für Psychologische Diagnostik und Differentielle Psychologie, 54, 3). Göttingen: Hogrefe.
- Diener, E. & Suh, E. (1997). Measuring quality of life: economic, social and subjective indicators. *Social Indicators Research*, 40, 189 – 216.
- Fischer, R. S., Acevedo, C., Arzimanoglou, A., Bogacz, A., Cross, H., Elger, C. H. et al. (2014). A practical clinical definition of epilepsy. *Epilepsia*, 55 (4), 475 – 482.
- Gastaut, H., Caveness, W. F., Landolt, H., Lorentz de Haas, A. M., Mc, Naughton, F. L., Magnus, O. et al. (1964). A proposed international classification of epileptic seizures. *Epilepsia*, 5, 297 – 306.
- Gauffin, H., Landtblom, A. M. & Rätys, L. K. A. (2010). Self-esteem and sense of coherence in young people with uncomplicated epilepsy, a five-year follow-up. *Epilepsy and Behavior*, 17, 520 – 524.
- Guekht, A. B., Mitrokhina, T. V., Lebedeva, A. V., Dzugaeva, F. K., Milchakova, L. E., Lokshina, O. B. et al. (2007). Factors on influencing quality of life in people with epilepsy. *Seizure*, 16, 128 – 133.
- Hills, M. D. & Baker, P. G. (1992). Relationships among epilepsy, social stigma, self-esteem and social support. *J. Epilepsy*, 5, 231 – 238.
- James, W. (1983). *The principles of psychology*. Cambridge, MA: Harvard University Press. (Original work published 1890).

Leary, M. R., Terdal, S. K., Tambor, E. S. & Downs, D. L. (1995). Self-esteem as an interpersonal monitor: the sociometer hypothesis. *Journal of Personality and Social Psychology*, 68 (3), 518 – 530.

Lee, Hamiwka, Sherman & Wirrell, 2008

McLaughlin, D. P., Pachana, N. A. & McFarland, K. (2008). Stigma, seizure frequency and quality of life: the impact of epilepsy in late adulthood. *Seizure*, 17, 281 – 287.

Morina, N. & Stangier, U. (2007). Klinische Untersuchungsverfahren (Zeitschrift für Klinische Psychologie und Psychotherapie, 36, 3). Göttingen: Hogrefe.

Murk, C. J. (2008). The psychology of self-esteem: a potential common ground for humanistic positive psychology positivistic positive psychology. *The Humanistic Psychologist*, 36, 143 – 158.

O'Donoghue, M. F., Goodridge, D. M. G., Redhead, K., Sander, J. W. A. S. & Duncan, J. S. (1999). Assessing the psychosocial consequences of epilepsy: a community-based study. *British Journal of General Practice*, 49, 211 – 214.

Orth, U., Robins, R. W. & Widaman, K. F. (2011). Life-span development of self-esteem and its effects on important life outcomes. *Journal of Personality and Social Psychology*, 102 (6), 1271 – 1288.

Räty, L. K. A., Söderfeldt, B. A., Larsson, G. & Larsson, B. M. W. (2004). The relationship between illness severity, sociodemographic factors, general self-concept, and illness-specific attitude in Swedish adolescents with epilepsy. *Seizure*, 13, 375 – 382.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.

Sander, J. W. A. S & Shorvon, S. D. (1996). Epidemiology of the epilepsies. *Journal of Neurology, Neurosurgery, and Psychiatry*, 61, 433 - 443

Sawangchareon, Pranboon, Tiamkao & Sawanyawisuth, 2013

Schütz, A. & Sellin, I. (2008). *Multidimensionale Selbstwertkala (MSWS)*. Göttingen: Hogrefe.

Shorvon, S. D. (2011). The etiologic classification of epilepsy. *Epilepsia*, 52 (6), 1052 - 1057

Skevington, S. M., Lofty, M. & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. *Quality of Life Research*, 13, 299 – 310.

Smith, D. F., Baker, G. A., Dewey, M., Jacoby, A. & Chadwick, D. W. (1991). Seizure frequency, patient-perceived seizure severity and the psychosocial consequences of intractable epilepsy. *Epilepsy Res.*, 9, 231 – 241.

Sowislo, J. F. & Orth, U. (2013). Does low self-esteem predict depression and anxiety? A meta-analysis of longitudinal studies. *Psychological Bulletin*, 139 (1), 213 – 240.

Sung, Muller, Ditchman, Phillips and Chans' (2013)

Ventegodt, S., Merrick, J. & Andersen, N. J. (2003). Quality of life theory I. The IQOL theory: an integrative theory of the global quality of life concept. *TheScientificWorldJOURNAL*, 3, 1030 – 1040.

Viteva, E. (2013). Impact of stigma on the quality of life of patients with refractory epilepsy. *Seizure*, 22, 64 – 69.

Curriculum Vitae

Name: Amir Hodzic

Academic Degree: Bachelor of Science (BSc.)

Date of Birth: 13.12.1990

School

09/1996 – 07/2000: Volksschule I Freistadt

09/2000 – 06/2009: Bundesgymnasium Freistadt: Graduation
(Matura)

University

10/2010 – 07/2013: Psychology on the University of Vienna:
Graduation (Bachelor of Science (BSc.))

Other Qualifications

- Fluently speaking German, English, Bosnian and Spanish (basic)
- European Computer Drivers License (ECDL)