



Relationship between optimism, disease variables, and health perception and quality of life in individuals with epilepsy [☆]

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Abstract

Epilepsy is a relatively frequent chronic condition with an important impact on the health perception and quality of life (QOL) of patients. The aim of the present study was to identify variables related to health status perception and QOL in persons with epilepsy. Participants were 200 persons with epilepsy, 53.5% of whom were males. The mean age was 39.6; 95% had seizures, and 99% were taking antiepileptic medication. The self-report questionnaire administered assessed four types of variables: demographic, disease, epilepsy-specific optimistic attitude, and outcome variables. Results demonstrated that an optimistic orientation is related to better perception of physical and mental health status and better perception of QOL. The variables that best predict positive outcomes are optimistic orientation, perception of cognitive functioning, and perception of seizure control. These results question the importance attributed to seizure characteristics for everyday functioning and everyday life of individuals with epilepsy, and stress the importance of facilitating an epilepsy-specific optimistic orientation.

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1. Introduction

Epilepsy is the world's most common serious neurological disorder [1,2], and it is often surrounded by prejudice and myth, which can be overcome only with enormous difficulty. Between 5% [1] and about 9% [3] of people experience at least one seizure at some point, but not all of those who have an epileptic seizure develop epilepsy. Seizures are episodic, unpredictable, uncontrollable, aversive events, and are the main feature, or the most evident characteristic, of this disorder.

Research into epilepsy tends to be focused largely on neurobiological issues. However, over the years, a body of empirical research indicates that seizure disorders are often associated with a variety of psychological and social problems, as well as malaise [4–6] and social and political isolation. The fear patients have about their seizures (or possible seizures) is seldom assigned a significant role in adjustment to everyday life. Many people with epilepsy do not know others with their condition [7]. Patients have many concerns about what they believe are the potentially destructive effects of epilepsy (i.e., brain damage, mental deterioration, loss of intelligence, mental illness). Additionally, epilepsy is a disorder traditionally associated with a significant amount of stigma [8]. Despite advances in the understanding and treatment of epilepsy within the past several decades, people with this disorder continue to be

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stigmatized by it [2], and the stigma associated with epilepsy has been related to poor psychosocial health outcomes, such as low self-esteem, worry, negative feelings about life, and depression [8].

Mittan and Lock [9] report that two-thirds of the people with epilepsy they studied believed that other peoples' reactions contributed more to their social problems than the seizures themselves, and half of them considered others' reactions worse than seizures. Stigma is still pervasive and is manifested in various forms of social discrimination (e.g., difficulties in obtaining a driver's license, employment, and health insurance) [10]. There are three erroneous beliefs related to public ignorance and misconceptions [11]. First, lay people tend to characterize epilepsy in terms of *tonic-clonic* (grand mal) seizures, when in fact there are many different forms of epilepsy and seizures. Second, epilepsy is still classified as a "mental disorder" rather than a physical one. Finally, there is the association of epilepsy with numerous negative, namely, antisocial, personality traits.

Today, the new generation of antiepileptic drugs and treatment adherence (i.e., proper use of pharmacological agents and compliance with lifestyle orientations) guarantee that the majority of patients do not have seizures and can maintain a normal life, with a low cognitive impact of the disease. Nevertheless, epilepsy therapy may be prolonged, and a cure is not always attainable.

For these reasons, health status perception and quality of life (QOL) are important health care outcomes. This notion has been readily accepted, and has resulted in an increased amount of research investigation into health status perception and QOL in epilepsy [2,12,13]. In fact, one of the main health outcomes is health status perception [14–16], and the main tools used to assess health status perception are short form measures based on those developed for the Medical Outcomes Study [17], with SF-36 as a valid and reliable health status measure for descriptive studies of people with epilepsy [15].

QOL is also an important end-point reference for evaluation of outcomes, being assessed by a multitude of different approaches [18].

Because subjective experience of disease is an important feature of epilepsy, psychological variables, namely, positive variables, can play an important role in coping with the condition and in determining the outcome of disease. Optimism is an important personality variable with respect to behavioral health outcomes [19]. Scheier and Carver [19] define optimism as "general expectations that good things will happen" (p. 172). It is a relatively stable, generalized expectation that positive outcomes will occur across important life domains. Optimism also benefits people's actions and their potential to achieve in times of adversity, according to Scheier and Carver [20]. It is a personality disposition approach to resilience derived from expectancy-value models of motivation. These models assume that people who have favorable expectations about outcomes that are important to them respond to difficulties with continued efforts, and people with unfavorable expectations are more

likely to stop trying. Peoples' actions are greatly affected by their beliefs about the probable outcomes of those actions [19].

Scheier and Carver [19] explain that expectation judgments in many stressful encounters can range from very general to very specific—dispositional optimism and situational optimism. *Dispositional optimism* refers to generalized outcome expectations that good things, rather than bad things, will happen (in opposition, pessimism refers to the tendency to expect negative outcomes). *Situational optimism* refers to the expectations an individual generates over a particular situation. Situational optimism is the expectation of a positive outcome in a specific situation.

Because specific expectations are more proximal to specific events than dispositional expectations, they may be important predictors of psychological and biological responses to specific stressors. Situational and dispositional optimism measures have been found to be only modestly correlated; Taylor [21] reported the highest and only significant correlation between specific outcome expectations and generalized optimism (0.1), and studies that have employed both measures have found that they predict different patterns of psychological and physical health outcomes. Another study [22] determined that situational optimism was a stronger predictor of mood than dispositional optimism and predicted immune changes when dispositional optimism did not.

It is recognized that optimistic attitude, that is, the expectation that good things will happen, seems to promote a higher level of physical and psychological well-being [23]. Segerstrom et al. [22] explain that there exists a growing body of evidence that elucidates the relationship of optimism and other psychosocial factors to biological processes associated with physical health. Research also suggests that more frequent seizures are related to worse health status perception, worse global QOL, and/or worse QOL in specific domains [6,24,25]. The same holds true for another seizure-related variable: perception of seizure control. Smith et al. [24], for example, verified that when psychological variables are excluded, the perception of seizure control contributes significantly to anxiety in refractory epilepsy. Additionally, results from neuropsychological tests and self-reports of cognitive functioning, being predictors of global QOL, affect the QOL of persons with epilepsy [26,27].

The aim of the present study was to identify the relationship between epilepsy-specific optimistic orientation and disease variables (seizure frequency, perception of seizure control, and perception of cognitive functioning) and outcome variables (physical and mental health status perception and QOL).

2. Methods

Participants comprised a sequential sample of 200 outpatients with epilepsy from a General University Hospital, in Porto, Portugal, with a mean age of 39.6 and mean level of education of 8.1 years; 53.5% were males, 63% were married or cohabitating, 95% had seizures (4.5% with >1 seizure

per week, 7.5% with ≤1 seizure per week, 9.5% with >1 seizure per month, 13% with ≤1 seizure per month, 24.5% with >1 seizure per year, 36% with ≤1 seizure per year, and 5% without seizures), 70.5% had only one type of seizure, and 99% were taking antiepileptic drugs (49% monotherapy, 33.5% bitherapy, and 16.5% polytherapy). Table 1 is a cross-tabulation of type and frequency of seizures.

A self-report questionnaire was developed to evaluate four types of variables: demographic variables (age, education), disease variables (seizure frequency, number of years with the disease, perception of seizure control, and perception of cognitive functioning), epilepsy-specific optimistic attitude, and outcome variables (QOL and mental and physical components of health status perception).

Seizure frequency was self-reported as daily, more than once per week, once or less often week, more than once per month, once or less often per month, more than once a year, once or less often per year, or no seizures.

Perception of seizure control was assessed with four questions from the Liverpool Seizure Severity Scale [28]. With this scale, patients classify their seizures on the basis of their subjective experience. The scale was designed as a measure of outcome in the evaluation of treatment of intractable epilepsy. The four items explore perception of control over seizures (“When your attacks occurred, how often have you been able to tell when you will have them?” “How often have you been able to fight off your attacks?” “How often have you had an impending sense or warning with your attacks?” “How much control have you had over your attacks?”). Patients answer on a four-item Likert-type scale; the higher the score, the more severe the seizures. For this sample, the internal consistency of the four items, as measured with Cronbach’s α , is 0.90.

Perception of cognitive functioning was assessed with the questionnaire developed by Vickrey et al. [29] for epilepsy, the ESI-55. It includes five items: difficulties in concentrating and thinking, difficulties in maintaining focused attention for prolonged periods, difficulties in problem solving and reasoning, memory difficulties, and difficulties with speech and language. Patients answer on a five-item Likert-type scale, with higher scores reflecting more favorable perceptions. The internal consistency for this sample, as measured with Cronbach’s α , is 0.8.

Epilepsy-specific optimistic orientation was evaluated with a questionnaire developed for the present study. It includes seven items that assess optimistic expectations regarding future health status, some of them inverted items, as outlined in Table 2. Based on the classification of Scheier and Carver [20], it is a moderately general judgment of expectation. The seven-item questionnaire has satisfactory internal consistency (Cronbach’s $\alpha = 0.8$, with corrected item–total correlation mainly in the 0.7’s, between 0.5 and 0.7). Lower scores on optimistic orientation represent a higher optimistic orientation.

Health status perception was measured with the SF-8, which is based in the SF-36 [17]; the Portuguese version was developed by Pais-Ribeiro [30]. It includes eight items grouped under two dimensions (four items each) of health status perception mental and physical health perception. Higher scores represent better health status perception. QOL was measured with one item: “Overall, how do you classify your QOL during the last 4 weeks?” Patients answered on a five-item Likert-type scale ranging from “weak” to “excellent.” Higher scores indicate worse QOL. According to Idler and Benyamini [31], global assessment of health and QOL with one item is recognized as valid and reliable.

Table 1
Types and frequency of seizure

Seizure type	>1/week	>1/month	>1/year	≤1/year	No seizures	Total
Simple partial	0	0	2	1	1	4
Complex partial	6	22	28	25	0	81
Partial secondarily generalized	1	1	6	5	0	13
Generalized tonic-clonic	0	10	30	29	2	71
Tonic	2	0	0	2	2	6
Absence	0	0	6	3	0	9
Myoclonic	0	1	3	7	5	16
Total	9	34	75	72	10	200

Table 2
Epilepsy-specific optimistic orientation scale

	Definitely true	Mostly true	Mostly false	Definitely false
My epilepsy will last for a short time				
I will probably be sick a lot in the future				
I believe I will live with this disease for the rest of my life				
I believe I will recover from my epilepsy with time				
I try to see my disease in a positive way				
I believe my disease will last for my entire life				
I expect my health to get worse				

Participants answered the questionnaire after providing informed consent, in accordance with the Helsinki Declaration, Portuguese law, and hospital rules. A trained psychologist helped patients, mainly those with a lower educational level, complete the questionnaire.

3. Results

Inspecting differences based on demographic and disease variables, we found that based on gender, patients exhibit a statistically significant difference with respect to optimism ($t(198) = 2.2, P < 0.03$), with males manifesting a higher optimistic orientation ($M = 13.2$) than females ($M = 14.8$).

With respect to type of seizure, no statistically significant differences were noted in the following outcomes and intermediate variables: optimistic orientation, mental health perception, physical health perception, quality of life, and number of years with the disease. There were no statistically significant differences between number of years with the disease and the principal variables.

To answer the research question, we investigated the relationship between disease variables, epilepsy-specific optimistic orientation, health status perception, and QOL. Because age and educational level are correlated with some of the variables: age with optimistic orientation [$r(200) = -0.2, P = 0.001$], physical health perception [$r(200) = -0.2, P = 0.0001$], perception of cognitive functioning [$r(200) = -0.2, P = 0.001$], and QOL

[$r(200) = 0.1, P = 0.04$]; and educational level with optimistic orientation [$r(200) = -0.1, P = 0.01$], physical health perception [$r(200) = 0.2, P = 0.003$], perception of cognitive functioning [$r(200) = 0.1, P = 0.01$], QOL [$r(200) = -0.1, P = 0.01$], and perception of seizure control [$r(200) = -0.1, P = 0.01$], we tested partial correlations controlling these two variables. Partial correlations are coefficients that describe the linear relationship between two variables, while controlling the effects of one or more additional variables. Table 3 outlines the correlations between the variables studied. In this table are listed statistically significant and important correlations between epilepsy-specific optimistic orientation and components of health status perception, especially the physical component of health perception.

Higher optimistic orientation is correlated with better perception of cognitive functioning (items from ESI-55), better perception of physical and mental health (measured with the SF-8), and better QOL. (Higher scores are not “better” for all indicators.)

Optimistic orientation is correlated with perception of cognitive functioning, but not with perception of seizure control nor with seizure frequency. Perception of cognitive functioning seems to play a central role in the correlation matrix, and does not appear to be related to seizure features.

A standard multiple regression estimates the coefficients of the linear equation that best predict the value of the dependent variable. This is a reliable technique when independent variables are correlated with one another and with the dependent variable to varying degrees. We performed three separate regression analyses, considering physical health perception, mental health perception, and QOL as dependent variables for each regression, and epilepsy-specific optimistic orientation, perception of cognitive functioning, perception of seizure control, and seizure frequency as predictors. Results are reported in Table 4.

The results highlight three variables that contribute significantly to prediction of the physical component of health status (physical health perception, $R_a^2 = 0.5$), two for the mental component of health status (mental health perception, $R_a^2 = 0.2$), and two for QOL ($R_a^2 = 0.1$). From the

Table 4

Standard multiple regression analysis to estimate the magnitude of variance of prediction of physical and mental health perception and QOL by psychological and disease variables

	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>P</i>
<i>Dependent variable: physical health perception</i>					
Intercept	11.6				
Optimism	-0.2	0.02	-0.3	-7.05	0.0001
Cognitivef	0.2	0.03	0.4	7.5	0.0001
Seizurec	-0.1	0.03	-0.1	-3.04	0.003
Seizuref	0.06	0.08	0.03	0.7	ns
$F(4, 195) = 59.8, P < 0.0001$					
Model adjusted $R^2 = 0.54$					
<i>Dependent variable: mental health perception</i>					
Intercept	12.2				
Optimism ^a	-0.1	0.04	-0.2	-3.6	0.0001
Cognitivef	0.1	0.05	0.2	3.6	0.0001
Seizurec	-0.001	0.05	-0.002	-0.02	ns
Seizuref	0.1	0.12	0.09	1.5	ns
$F(4, 195) = 14.1, P < 0.0001$					
Model adjusted $R^2 = 0.20$					
<i>Dependent variable: quality of life</i>					
Intercept	2.3				
Optimism	0.05	0.01	0.2	3.9	0.0001
Cognitivef	-0.03	0.01	-0.1	-2.1	0.03
Seizurec	0.01	0.01	0.04	0.6	ns
Seizuref	0.02	0.04	0.03	0.5	ns
$F(4, 195) = 10.03, P < 0.0001$					
Model adjusted $R^2 = 0.15$					

^a Optimism, epilepsy-specific optimistic orientation; Cognitivef, cognitive functioning; Seizurec, perception of seizure control; Seizuref, seizure frequency.

variables studied, optimism and perception of cognitive functioning are the best predictors of each dependent variable. Optimism is the variable that best contributes to mental health status perception and QOL, whereas perception of cognitive functioning is the variable that best predicts physical health status. Seizure control contributes significantly to the prediction of physical health status perception but not to the prediction of mental health status perception or QOL, and seizure frequency does not contribute to the prediction of any outcome or dependent variable.

Table 3

Partial correlations between the components of health status perception, quality of life, perception of cognitive functioning, perception of seizure control, and seizure frequency, controlling for age and educational level

	Optimism ^a	Mntcomp	Physicomp	QOL	Cognitivef	Seizurec	Seizuref
Optimism		-0.3 ^b	-0.6 ^b	0.3 ^b	-0.4 ^b	0.10	0.001
Mntcomp			0.6 ^b	-0.6 ^b	0.3 ^b	-0.03	0.09
Physicomp				-0.5 ^b	0.6 ^b	-0.19 ^b	0.005
QOL					-0.2 ^b	0.07	0.05
Cognitivef						-0.06	-0.0001
Seizurec							0.1
Seizuref							

^a Optimism, epilepsy-specific optimistic orientation; Mntcomp, mental component of health perception; Physicomp, physical component of health perception; QOL, quality of life; Cognitivef, cognitive functioning; Seizurec, perception of seizure control; Seizuref, seizure frequency.

^b $P < 0.0001$.

4. Discussion

One of the most interesting conclusions of the present study is that seizure frequency does not contribute to the prediction of everyday functioning and everyday life, similar to the findings of Gilliam et al. [25], where linear regression analysis confirmed that mood had the strongest association with subjective health, independent of seizures, driving status, medication requirement, or employment, and Smith et al. [32], who found that seizure frequency contributed little to psychological status. In Portugal, Meneses [33] also found that individuals with different seizure frequencies did not differ in a statistically significant manner on any of the SF-36 scores. Conversely, Jacoby et al. [6] reported that “individuals with frequent seizures have significantly poorer psychosocial profiles than those with infrequent or no seizures” (p. 158). These authors found that seizure activity was the most important predictor of poorer psychosocial status. Similarly, Buck et al. [34] reported that seizure frequency was one of the three most important variables explaining the variation of all SF-36 scale scores.

Nationality may play a role. In fact, Buck et al. [34], studying Europeans with epilepsy and controlling clinical and demographic variables, noted statistically significant differences between countries on all SF-36 scales except Physical Functioning.

The results concerning perception of seizure control are also worth stressing, as this variable was statistically significantly correlated only with physical health status perception, and this correlation was a weak one. Consequently, our study demonstrates that perception of seizure control is a poor predictor of health perception and QOL, in opposition to the findings of Collings [5] and Smith et al. [24], where perception of seizure control was related to anxiety. Thus, our results do not support efforts to change the perception of seizure control as a first-line intervention to improve individuals' health status perception and QOL. Rather, our results indicate that perception of cognitive functioning is a good predictor of physical and mental health status perception and QOL [26,27]. Furthermore, our results suggest that epilepsy-specific optimistic orientation is an important psychological variable in prediction of positive epilepsy outcomes, namely, the physical and mental components of health status perception and QOL, which is, as far as we are aware, a new finding. Therefore, multidisciplinary intervention strategies with an impact on perception of cognitive functioning and/or epilepsy-specific optimistic orientation can have a profound effect on the lives of individuals with epilepsy.

We can consider a possible overlap between variables in the sense that the majority of psychosocial variables are positive variables. However when we inspect Table 3, we see that the overlap between variables is reduced, with higher shared variance between pairs of variables around 35% for physical component of health perception and optimism and 9 and 16% for mental health perception and per-

ception of cognitive functioning respectively, and optimistic orientation. We can say that we are in the presence of different constructs.

The clinical implications of the findings are that it is important to organize support groups for individuals with epilepsy, with the aim of developing positive expectations (optimism, self-efficacy, hope), because there exists a growing body of evidence that elucidates the relationship of these variables and other psychosocial factors to biological processes associated with physical health [22], health perception, disease adjustment, and everyday life and, probably, to improved quality of life and epilepsy outcomes.

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