

Original Article

Factors Affecting Quality of Life in Adults with Epilepsy in Turkey: A Cross-Sectional Study

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Abstract

Background: In order for effective healthcare services to be offered by health professionals, the quality of life of epileptic individuals and the factors that affect them should be identified.

Objective: The aim of this study was to determine the quality of life and affecting factors for epileptic patients in the east of Turkey.

Method: This research was descriptive in nature, and conducted with 150 patients of epilepsy who fit the criteria of inclusion in the study, registered in the neurology clinic of a university hospital located in the east of Turkey, between the dates of June-December 2015. A descriptive information form and a life quality scale specific for epilepsy (OQLIE-31) were used to collect the research data.

Results: It was detected that the total QOLIE-31 score of the epilepsy patients was 54.65 ± 7.85 , and that among the subscales, the lowest mean score was with the subscale of emotional well-being (45.55 ± 11.02) while the highest mean score was with the subscale of social function (60.78 ± 15.28).

A significant relationship was found with the mean score of total life quality according to where the patients lived and the duration of diagnosis ($p < 0.05$); a significant correlation was found between the mean scores of subscales of seizure worry and cognitive functioning in accordance with income perception; a significant difference was found between the mean scores of the subscales of emotional well-being in relation with the presence of additional chronic disease (Comorbid disease) ($p < 0.05$). At the same time, there was a significant negative correlation between the number of seizures/attacks throughout the year and the scores of total quality of life ($r = -0.201$, $p < 0.05$) and energy/fatigue ($r = -0.196$, $p < 0.05$).

Conclusion: As a result of the study, it was determined that the life quality of epilepsy patients was moderate and some of their descriptive characteristics (income status, place of residence, duration of diagnosis, additional disease status) were related to quality of life. At the same time, it was established that as the number of attacks increased, the quality of life and energy of the patients decreased. It is recommended to consider socio-demographic characteristics in the planning of nursing applications for epilepsy patients.

Keywords: Epilepsy, quality of life, nursing

Introduction

Epilepsy is a clinical syndrome emerging as a result of sudden onset and abnormal discharges by conglomerates of neurons which have particular functions within the central nervous system, and generally characterized by recurrent seizures (Fisher, Van Emde Boas & Blume, 2005). Epilepsy is the most common chronic neurological disease after headache. Worldwide prevalence of epilepsy varies between 3-42/1000 (Iser & Tekgul, 2010) whereas in Turkey

epilepsy prevalence is reported as 6.1-10.2 per thousand (Durna, 2013).

Direct effects of epilepsy such as loss of consciousness, falls, and accidents can affect one's daily activities and reduce the professional and social independence of the individual (Suurmeijer, Reuvekamp & Aldenkamp, 2001). In the meantime in epilepsy, threatening factors such as the unpredictable nature of the disease and fear of social exclusion may cause the patients to experience many psychosocial

problems (Au, Li & Chan, 2002). Seizures that develop with sudden onset in epilepsy may also negatively affect self-esteem by creating loss of control in patients. Recurrent seizures interfere with the ability of the patients for education, business life, marriage, and establishment of social relations (Fisher, Vickrey & Gibson, 2000).

Epilepsy negatively affects the quality of life of patients as a chronic and neurological disease that adversely affects human life in terms of personal care, safety, social relations, and issues related with social life (Degirmenci, et al., 1996). The quality of life is defined as "well-being" and is described as the way one perceives his own situation within the scope of his own values. As a multidimensional concept, the quality of life depends upon physical and mental health status, level of addictions, social relationships, environmental factors, and personal beliefs (Mollaoglu, Durna & Kazan, 2001; Jacoby, 2002).

Recent studies in a variety of geographic regions revealed that the quality of life of epilepsy patients was in worse condition than that of individuals with other chronic diseases (Stevanovic, 2007; Hermann et al., 1996; Quintas, 2016; Yue, et al., 2011; Grant, Prus & Nakhutina, 2013).

At the same time; the spectrum of factors that may affect the quality of life in epilepsy includes a wide variety of demographic characteristics. These demographic factors that directly or indirectly affect the quality of life are revealed to be: age, gender, marital status, education, income level (Giovagnoli, Meneses & Silva, 2006; Kubota & Awaya, 2010; Alanis-Guevara et al., 2005; Auriel et al., 2009; Chen et al., 2016; Zhao et al., 2011), additional diseases (comorbid disease), psychiatric conditions (Cramer et al., 2003; Agrawal et al., 2016; Eddy et al., 2010), the amount of anti-epileptic medications that are used, and therapeutic issues such as the frequency of recurring attacks and their levels of severity (Yue, et al., 2011; Kubota & Awaya, 2010; Thomas et al., 2005; Kwan et al., 2009).

Modern epilepsy management focuses on enhancing the quality of life of epilepsy patients as well as seizure control (Theodore, 2006). The main purpose of this treatment is to control seizures altogether or to increase the quality of life of patients by reducing seizure recurrence to the minimum possible level. As symptoms

arising in relation with the treatment modalities that are applied affect the patient's quality of life and treatment process, healthcare professionals providing patient care are responsible for predicting, preventing, and controlling these emerging symptoms (Misirli, 2003).

Determining the quality of life and affecting factors for individuals with epilepsy is important in the planning and application of nursing care. The planned care must be individualized and monitored. In order to achieve this individualization, it is necessary to primarily determine the particular variables of quality of life for each of the patients (Blac & Hawks 2009). Recognition of factors related to the quality of life will provide opportunities for the improvement of diagnosis and intervention strategies for individuals with epilepsy (Tedrus et al., 2013).

Although there is a limited number of studies in various regions of Turkey evaluating the quality of life of epilepsy patients (Mollaoglu, Durna & Kazan, 2001; Demirci, 2017), no study has been conducted upon the subject in the Eastern region. Therefore, (the present study); was conducted to determine the quality of life and related factors for individuals with epilepsy in the East of Turkey.

Research Questions;

- What is the level of quality of life of the epilepsy patients in the east of Turkey?
- What are the factors that affect the quality of life of epilepsy patients in the east of Turkey?

Materials and methods

Research design and sampling; The research was carried out as an identifier to highlight the quality of life and affecting factors thereof for epilepsy patients in the east of Turkey. The universe of the research consisted of patients receiving diagnosis of epilepsy during at least 1 year, registered in the neurology outpatient clinic of Ataturk University Research Hospital, between June - December 2015. The sampling consisted of 150 epilepsy patients in accordance with the research criteria who applied to the neurology outpatient clinic between these dates. Epilepsy was diagnosed on the basis of the 1981 and 1989 Classifications of Epileptic Seizures and Epilepsies and Epileptic Syndromes (ICE) of the International League Against Epilepsy (ILAE, 1981; ILAE, 1989).

Criteria for inclusion in the study were as

follows:

- 18 years of age and above,
- Those who had seizure within 1 year,
- Those capable of verbal communication,
- Those who did not receive a psychiatric diagnosis,
- Those with sufficient cognitive competence to answer questions,
- Those who accepted the research voluntarily were included.

Atatürk University research and application hospital is the largest hospital facility in the Eastern Anatolian region of Turkey and accepts patients from many provinces in the region of eastern Anatolia. 3 faculty members, 4 assistants, and 1 nurse serve in the neurology outpatient clinic of the hospital. In this outpatient clinic, epilepsy patients are examined only on Wednesdays of each week.

Data collection: Research data were collected with Introductory Information Form developed by the researchers and with the QQLI-31 Epilepsy Life Quality Scale in order to identify the level of quality of life. Appointments were set by the researcher with epilepsy patients who applied to the neurology outpatient clinic, pre-examination or post-examination, during Wednesday that was designated as the specific date of examination in the Atatürk University Research Hospital. Epilepsy patients were evaluated in terms of eligibility for criteria of inclusion in the research. Data collecting forms were filled with the epilepsy patients who had the criteria of eligibility through face-to-face interview technique. Literate patients read and filled the forms by themselves, while illiterate patients had their forms read to and filled for them by the researcher. The implementation of data collecting forms to each patient took between 15-30 minutes.

Introductory Information Form: Introductory information form consisted of a total of 13 questions, 8 of which were about the demographic properties of the patients (age, gender, marital status, location of settlement, educational status, occupation, perception of income, family structure) while 5 of them were about the properties of the disease (duration of diagnosis, frequency of seizure recurrences during the last year, type of seizures, presence of any additional chronic disease, antiepileptic treatment modality).

Scale of Quality Of Life In Epilepsy (QOLIE-31): The QOLIE-31 scale consists of 7 subscales.

These subscales consist of: seizure worry (5 items), emotional well-being (5 items), energy/fatigue (4 items), social function (5 items), cognitive function (6 items), medication effects (3 items), overall quality of life (2 items), and an additional item covering overall health, comprising a total of 31 items. The scale is scored from 0 to 100, and high scores point to a high quality of life. Validity and reliability of the scale in our country was provided by Mollaoglu et al. (2015), total Cronbach alpha value of the scale was 0.91, and in the subscales the alpha value was found to be shifting between 0.67 and 0.84. In this study the cronbach alpha coefficient is 0.70.

Statistical analysis; In percentage distributions, mean, independent groups, t test, Mann Whitney-U test were used while in one way variance analysis, Kruskal Wallis and Sperman correlation analysis were used for the evaluation of the data. In the one-way analysis of variance, the LSD advanced analysis was used in cases where the variances were homogeneous in order to determine the groups from which the significance was derived. The statistical significance level was accepted as $p < 0,05$. The data was resolved in SPSS 18 package program.

Ethics: Ethics Committee permission was taken before the start of the investigation from Atatürk University Faculty of Health Sciences, and institutional permission was obtained from Atatürk University Research Hospital. Verbal permissions were obtained from participating patients after providing explanation regarding the objective of the study.

Results

Demographic background: The mean age of the participating patients in the study was detected as $30.29 \pm 9,67$, and the age range was found to vary between 18 and 64. Of the patients with epilepsy, it was found that 61.3% were female, 58.7% were married, 52.7% resided in the city, 18.7% were college graduates, % 46.7 were housewives, 62.7% had their income equal to their expenditure, and 62% lived in a nuclear family.

It was established that 38.7% of the patients had a duration of diagnosis of 3 years and above, 46% experienced 1 seizure within the last one year, 51.3% of these seizures were of generalized tonic clonic type, 89.3% of them had no other accompanying disease, all of them used antiepileptic drugs, and 28% of them received treatment with a single type of drug

(monotherapy). At the same time, the frequency of seizures during the past year varied between 1-5 and their mean value was 2.25 ± 1.39 .

Scoring for the Quality of Life Scale and Its Subscales: The mean total QOLIE-31 score of the participating patients with epilepsy was found to be 54.65 ± 7.85 . Among the subscales of the quality of life scale, the mean score of the seizure worry was found as 59.88 ± 13.21 , that of total quality of life was found as 59.88 ± 17.78 , that of emotional well-being was found as 45.55 ± 11.02 , that of energy/fatigue was found as 56.33 ± 12.96 , that of cognitive functions was found as 49.38 ± 12.96 , that of the effects of drugs was found as 59.45 ± 25.57 , and that of social functions was found as 60.78 ± 15.28 (Table 1). It was detected that the total QOLIE-31 score of the patients with epilepsy was 54.65 ± 7.85 , and while the lowest mean value among the subscales was with the emotional well-being subscale (45.55 ± 11.02), the highest mean value was with the social function subscale (60.78 ± 15.28) (Table 1).

Factors Affecting the Quality of Life: In this study a statistically significant difference was detected with the mean total life quality subscale of the OQLIE-31 scale according to where the patients lived ($p < 0.05$). In the advanced statistical analysis (LSD), it was determined that those who reside in a village had higher total quality of life scores than those living in a city (Table 2). The points of the seizure worry subscale and the cognitive function subscale of the participating patients varied significantly according to the revenue perception ($p < 0.05$). In the advanced analysis (LSD) to determine which group the differences originated from, it was detected that those who had their incomes equal to their expenditures had a higher score of seizure worries than those who had their incomes less than their expenditures, and that those with less income than expenditure had the highest score of cognitive function (Table 2). A the mean score of total quality of life according to the duration of diagnosis of the patients ($p < 0.05$). A statistically significant difference was detected in Advanced statistical analysis (LSD) revealed that individuals with 7-12 months of duration of diagnosis had the highest score of total quality of life (Table 2). Those with an additional chronic disease (comorbid conditions) were found to have a significantly higher mean score of emotional well-being than those with none ($p < 0.05$). Those who encountered epilepsy

seizures were found to have significantly higher mean score of attitude than those who did not ($p < 0.05$) (Table 2). A negatively significant correlation was found between the number of seizures experienced by the patients within the last one year, the mean scores of total quality of life ($r = -0.201$, $p < 0.05$), and of energy/fatigue ($r = -0.196$, $p < 0.05$). It was observed that the patients have diminishing energy and decreasing quality of life as the number of their seizures increase (Table 3). No significant difference was detected between the mean scores of general OQLIE-31-P quality of life and overall quality of life according to the age, gender, marital status, educational status, profession, family type, seizure type, and the modality of anti-epileptic treatments of the patients ($p > 0.05$).

Discussion

In this study, levels of quality of life of epilepsy patients were tried to be determined with a small sampling consisting of Turkish participants. Additionally, factors affecting the quality of life of the participants were investigated. According to the results of the study, the quality of life of individuals with epilepsy were detected to be of moderate (54.65 ± 7.85) level (0 points, indicating the lowest quality of life, 100 points; indicating the highest quality of life). In a different region of Turkey, Mollaoglu et al. 82. reported that also in their study where they evaluated the validity and reliability of the OQLIE-31-P scale, similar to the result of this study, the quality of life of the epilepsy patients was at moderate level. When compared with the results of many prior studies abroad, the quality of life of the individuals with epilepsy in this sampling was found to be lower (Quintas, 2016; Yue, et al., 2011; Grant, Prus & Nakhutina, 2013). It is regrettable that the mean scores of quality of life of the patients in our study were at a low level. This result may be partially due to cultural differences and the low socio-economic level in the east of Turkey. As a result of the study, the mean score of emotional well-being (45.55 ± 11.02) was found to be the lowest among the subscales of the quality of life scale of the epilepsy patients. Epilepsy is a chronic disease that negatively affects the quality of life and general health status of individuals. In epilepsy, threatening factors such as the indeterminate nature of the disease, recurrent seizures, and fear of social exclusion may cause the patients to face many psychosocial problems (Au, Li & Chan, 2002). Recurrent seizures may interfere with the ability of the patients for

education, business life, marriage, and establishment of social relations. Additionally, society exhibiting attitudes such as prejudice, social stigma, and discrimination may also lead to emotional problems experienced by individuals with epilepsy (Morrell, 2002; De Boer, Mula & Sander, 2008; Aydemir, 2011). In many studies, depression was reported as one of the most prominent determinants that affect the quality of life (Cramer et al., 2003; Agrawal et al., 2016; Eddy et al., 2010).

In our study, epilepsy patients living in the village were found to have a higher overall quality of life score than those living in the city. The lifestyle of the village-dwelling people that is surrounded by nature, the way they consume many products in their natural state, their lower exposure to unfavorable physical and chemical factors, and their distance away from the stress of the city are thought to be positively affecting their general health status. A statistically significant difference was found between the points of the subscales of seizure worry and cognitive function, in relation to the variable of income status of the patients with epilepsy. It was detected that patients with equal amounts of income and expenditure experienced seizure worry less than those who had less income than expenditure. Similarly, also in previous studies a positive relationship was found between the level of income and the quality of life, and it was observed that the quality of life improved as the level of income increased (Chen et al., 2016; Zhao et al., 2011). This result may be indicative of an increase in the quality of life in our country due to increased income levels of epileptic individuals and greater use of treatment options.

When the mean quality of life scores were examined according to the duration of diagnosis, it was determined that the mean overall quality of life scores of the individuals with epilepsy who received diagnosis for 7-12 months was higher. Similarly, Gordon et al. (2011) also found that as the duration of epilepsy increased, the mean quality of life scores decreased. This result can be explained by the addition of comorbid conditions depending on the chronicization of the disease. Interestingly, in this study, individuals who developed additional chronic diseases other than epilepsy had higher mean scores of emotional well-being than those who did not. Unlike this study, Cramer et al. (2003) found that the quality of life of epileptic individuals with additional chronic disease was worse. In our study, those

with additional chronic disease being in better mood can be explained by their improved sense of self-confidence over increasing experience with the other chronic disease and quicker adaptation to the new development of disease. Moreover, the presence of an additional chronic disease can provide effective disease management.

In our study, a negative correlation was detected between the attack frequency and the mean score of energy/fatigue subscale of the quality of life. Not surprisingly, it is observed that as the number of seizures increases, the energy of epileptic patients decreases. Similar to the result of the study, Scevola et al. (2017) detected a significant relationship between the frequency of attacks and the quality of life. In some previous studies, a negative correlation was reported between the severity of attacks and the quality of life (Cramer, Hammer, Kustra, 2004; Cramer, 2001; Harden, Maroof, Nikolov, 2007).

In a different region of Turkey, Mollaoglu et al. (2001) detected in their study that the physical, social, and emotional dimensions of the quality of life were adversely affected as the frequency of seizures increased, and that these individuals experienced higher social exclusion. Similarly, it was reported in different previous studies that seizure control improved the status of psychological well-being (Auriel et al., 2009; Reid, Herbert, Baker, 2004; Velissaris et al., 2007).

It was reported in the literature that increased seizure frequency is one of the important determinants that increased the overall burden of the disease, caused difficulty in coping, and created serious problems in daily life (Mollaoglu, Durna & Kazan, 2001). When the quality of life and gender variables were examined, there was no significant difference between the mean values of all subscales of the QOLIE-31 scales of men and women (Yue et al., 2011; Tlusta et al., 2009; Bala et al., 2016), in accordance with previous studies. Unlike our study findings, in other studies (Alanis-Guevara et al., 2005; Auriel et al., 2009; Chen et al., 2016) women with epilepsy were reported to experience worse quality of life than men.

However, in the study of Mollaoglu et al. (2001) it was reported that the quality of life of women with epilepsy was better than that of men. This inconsistency may be due to cultural differences, such as the fact that men and women in different

countries have different social support and different functional roles. For example, in Turkish society, women's individual coping styles and emotional sharing are thought to be stronger than men's.

There was no significant difference between the general and subscale scores of the quality of life according to the marital status of the participants, but in married individuals the seizure worry, overall life quality, emotional well-being, and cognitive function subscales of the quality of life were found to be higher than those in single individuals. Zhao et al. (2011), Pascale et al. (2002) reported that marital status and having children had a positive effect on the quality of life by influencing the functioning of the individual. This finding supports the conclusion of the study. However, in a previous study with a different result, it was determined that married epileptic patients had lower quality of life than single patients (Mollaoglu et al., 2001).

Among subscales of the quality of life, the mean scores of seizure worry, total quality of life, social function, emotional well-being, energy/fatigue, cognitive function, the effects of drugs, social function subscales and overall mean scores exhibit no statistically significant difference in relation to the educational status. Yaşar et al.⁴⁶ also found no correlation between the quality of life and level of education in the results of their study on patients with epilepsy. Contrary to this study, Fisher et al. (2000), Zhao et al. (2011) found a positive relationship between the level of education and the quality of life. They detected that the quality of life was found to increase as the level of education increased.

No significant relationship was detected between the mean scores of general and overall subscales of the quality of life according to the occupations of the patients. The level of unemployment is higher in patients with epilepsy, the rate of which is about two to three times greater than that in the general population (Clarke, Upton & Castellanos, 2006). In a UK study, the unemployment rate for the control group was 19%, while for epileptic patients it was 46% (Raguraman & Wadoo 2006). In some European countries, there are legal barriers that restrict epilepsy patients in the workplace. These institutional and social limitations often result in poor performance of epileptic patients compared to the general population at work (Baker et al., 1997).

When we investigated the relationship between seizure type and quality of life in our study, there was no statistically significant difference between patients with partial type seizures and those with other seizure types, although the mean score of general quality of life was lower with the latter. Unlike these study findings, Mollaoglu et al. (2001) and Baker et al. (1997) found that patients with partial seizures had a higher mean score of quality of life.

In this study it was found that all epilepsy patients used antiepileptic drugs regularly and the majority (72.0%) received multiple drug treatment. It was reported in the literature that in 70-80% of individuals who regularly used antiepileptic drugs, the seizures were controlled and the quality of life increased (Baker et al., 1997). Another finding from the study was that the mean overall and subscale scores of the quality of life of epileptic individuals who used monotherapy were higher than those who used polytherapy. As a matter of fact, previous studies also reported that the quality of life of patients taking multiple medicines was worse. (Yue, et al., 2011; Zhao et al., 2011; Thomas, 2005). This result can be explained by the fact that the frequency of seizures is lower in the individuals using single drugs and that it is easier to control them, which affects the quality of life positively. In the meantime, it is estimated that polytherapy might increase the side effects of antiepileptic drugs and disrupt the quality of life of patients with epilepsy.

Conclusion: This study demonstrated that the quality of life of epileptic individuals is moderate and there is a relationship between certain descriptive characteristics (income status, place of residence, duration of diagnosis, additional disease status) and the quality of life. At the same time, it was established that as the number of attacks increased, the quality of life and energy of the patients decreased.

It is very important to know the quality of life determinants in order to design patient-centered treatment methods in individuals with epilepsy. In this direction, the level of quality of life of epileptic patients should be assessed at specific time intervals and demographic characteristics should be considered when nursing applications are planned.

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Characteristics (N=150)	N	X±SD P value	X±SD P value	X±SD P value	X±SD P value	X±SD P value	X±SD P value	X±SD P value	X±SD P value
Place of residence									
City	79	59.27±14.94	56.74±16.61	46.58±11.57	57.66±14.02	50.29±14.32	59.71±25.36	60.89±16.12	54.75±8.87
Town	42	59.23±11.07	61.37±18.18	44.48±11.56	52.62±11.96	48.36±11.39	61.91±22.88	61.81±13.92	54.21±6.91
Village	29	62.49±10.93	66.29±18.86	44.28±8.48	58.10±10.39	48.37±11.29	55.17±29.88	59.00±15.17	55.00±6.18
		F=0.697 p >0.05	F=3.369 p<0.05	KW=2.264 p >0.05	KW=4.197 p >0.05	F=0.410 p >0.05	KW=0.521 p >0.05	F=0.291 p >0.05	F=0.100 p >0.05
Income level									
Income<expenditure	40	63.45±13.57	63.00±17.99	48.90±12.50	57.63±12.76	51.62±11.69	60.84±25.22	61.73±13.64	56.87±6.64
Income=expenditure	94	57.70±13.25	58.01±16.99	44.94±9.93	55.53±3.35	49.79±13.21	60.11±25.85	60.90±16.16	54.18±8.15
Income>expenditure	16	63.79±9.29	63.13±21.24	40.75±11.52	57.81±11.40	41.39±12.17	52.09±25.09	57.69±14.32	51.84±7.88
		F=3.560 p<0.05	F=1.413 p >0.05	KW=4.592 p >0.05	KW=0.463 p >0.05	F=3.824 p<0.05	KW=1.856 p >0.05	F=0.404 p >0.05	F=2.865 p >0.05
Duration of disease									
0-6 month	36	60.47±12.52	56.81±20.32	44.11±11.61	56.53±13.62	47.41± 14.69	56.10±26.74	58.64±16.63	52.99±9.07
7-12 month	23	62.22±9.50	69.67±17.73	45.57±10.63	55.87±12.67	47.38± 10.21	66.91±21.48	63.87±14.33	56.48±6.08
1-3 years	33	60.75±14.53	54.32±15.54	46.91±11.01	54.55±11.62	48.90± 14.50	55.05±24.30	59.52±15.00	53.40±7.32
Over 3 years	58	58.09±14.16	61.08±15.87	45.66±10.99	57.41±13.58	51.67± 11.77	61.07±26.77	61.60±15.06	55.65±7.82
		F=0.664 p >0.05	F=4.088 p<0.05	KW=0.698 p >0.05	KW=0.960 p >0.05	F=1.079 p >0.05	KW=4.267 p >0.05	F=0.676 p >0.05	F=1.571 p >0.05
Comorbidity status									
Yes	16	61.46±15.45	54.84±13.59	53.50±14.30	51.25±18.12	49.65±15.03	51.91±25.61	56.56±12.60	53.61±8.16
No	134	59.69±12.97	60.49±18.16	44.60±10.22	56.94±12.15	49.35±12.75	60.35±25.51	61.28±15.54	54.77±7.83
		t=0.505 p >0.05	t=-1.201 p >0.05	MWU=722.000 p<0.05	MWU=917.000 p >0.05	t=0.088 p >0.05	MWU=849.000 p >0.05	t= -1.169 p >0.05	t=-0.557 p >0.05