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Master Thesis

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Epilepsili hastalara bakım verenlerdeki zihinsel sıkıntı düzeyinin belirlenmesi

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KABUL VE ONAY

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We testify that the Master student (Mohanad Mahdi Abd ullah Al-Maawari

- Student ID :198205304) at Çankırı University - Institute of Health Sciences - Department of Public Health Nursing has been examined and defended his thesis entitled (Determining the Level of Mental Distress among Caregivers of Patients with Epilepsy) and after fulfilling all the necessary conditions determined by the relevant regulations, We saw, as jury members whose signitures below, that the thesis (is sufficient to obtain a master's degree in public health nursing).

Date Members of discussion committee:

Thesis supervisor:	**Doç. Dr. Huri Seval Gönderen Çakmak Çankırı Karatekin University**	**……** **Signature**
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I confirm the above result

Signature

ETİK BEYANNAMESİ

Yüksek Lisans/Doktora tezi olarak hazırlayıp sunduğum "Epilepsili hastalara bakım verenlerdeki zihinsel sıkıntı düzeyinin belirlenmesi" başlıklı tez; bilimsel ahlak ve değerlere uygun olarak tarafımdan yazılmıştır. Tezimin fikir/hipotezi tümüyle tez danışmanım ve bana aittir. Tezde yer alan araştırma tarafımdan yapılmış olup, tüm cümleler, yorumlar bana aittir.

Yukarıda belirtilen hususların doğruluğunu beyan ederim.

İmza
Tarih 18/2/2021
Öğrencinin Adı Soyadı
Mohanad Mahdi
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ETHICAL DECLARATION

I present to you, my Master's thesis entitled (Determining the Level of Mental Distress among Caregivers of Patients with Epilepsy) under the supervision and guidance of my research supervisors including idea and hypothesis and certify that I have written it according to ethics and scientific values, upon which scientific research is based in writing the thesis.

Signature

Date **: 18 / 2 / 2021**

Student

Mohanad Mahdi Abd ullah Al-Maawari

THE REVIEW OF THE LINGUISTICS EXPERT

This is to hereby that the thesis entitled (Determining the Level of Mental Distress among Caregivers of Patients with Epilepsy) has been reviewed in terms of stylistics and linguistics (grammar and spelling). To the Iraqis candidate (M.Sc. student) (Mohanad Mahdi Abd ullah Al-Maawari) passport NO. (A15023653). Therefore, after the modification of all recommended notes thesis has become free of all linguistics errors and ready to be defended and used as a scientific method to award the degree of M.Sc. in (Public Health Nursing).

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ABBRAVIATIONS AND SYMBOLS

GSQ **:** General Health Questionnaire

AEDS **:** Antiepileptic Drug

CDs **:** Chronic Diseases

One-Way ANOVA : One –Way Analysis of Variance

M: Mean

SD: Standard Deviation

N:Number

%:Percentage

Min: minimal

Max: Maximal

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Epilepsili hastalara bakım verenlerdeki zihinsel sıkıntı düzeyinin belirlenmesi

Al-Maawari, Mohanad Mahdi Abd ullah. Epilepsili Hastalara Bakım Verenlerdeki Zihinsel Sıkıntı Düzeyinin Belirlenmesi, (Yüksek Lisans), Çankırı, 2021.

ÖZET

Giriş/Amaç: Epilepsi yönetiminde bakım verenler önemli bir rol oynarlar. Epilepsili hastaların bakımı, bakım verenlerde duygusal sıkıntıya neden olabilir. Bu çalışmada, epilepsi hastalarının aileleri/ bakım verenlerde ruhsal sıkıntının demografik özelliklerinin ve boyutlarının etkisi araştırılmıştır. Bu çalışmanın amacı epilepsi hastalarına bakım verenlerde ruhsal sıkıntı düzeyini belirlemektir.

Yöntem: Çalışmaya Diwaniyah Eğitim Hastanesi Nörodejeneratif Hastalıklar Uzmanlık Merkezinde takip edilen 100 epilepsi hastasının bakım verenleri dahil edildi. Çalışmanın örneklem grubu olasılıksız örnekleme yöntemi ile belirlenmiştir. Veriler 10/5/2020 ile 10/11/2020 tarihleri arasında toplanmıştır. Çalışmada veriler Hasta ve Bakım verici bilgi formu ve Genel Sağlık Anketi (GSA-28) ile toplandı. Veriler Microsoft Excel versiyon 2010 ve SPSS versiyon 20 kullanılarak analiz edildi. İstatistiksel anlamlılık% 5 olasılık seviyesinde belirlendi.

Bulgular: Bakım vericilerin ,% 48.0'ı kadın ve% 52.0'ı erkek olmak üzere 100 kişiden oluşuyordu. Hasta bakıcılarının GSQ-28 ortalama puanı 11,36 ± 2,505 idi. Ortalama ölçek puanları, genç yaştaki bakım vericilerde, eğitim düzeyi yüksek, gelir düzeyi yetersiz olanlar, kırsalda yaşayanlar ve hastanın ebeveynleri için istatistiksel olarak anlamlı derecede yüksekti ($p < 0,05$).

Sonuç: Bakım verenler arasında epilepsi hastalarında duygusal sıkıntı mevcuttu ve bakım verenlerin psikolojik bakım faktörlerini iyileştirmek için dikkat edilmesi gerektiğine dikkat çekildi.

Anahtar Kelimeler: Bakım verenler, epilepsi, genel sağlık, ruhsal sıkıntı

Determining the Level of Mental Distress among Caregivers of Patients with Epilepsy

Al-Maawari, Mohanad Mahdi Abd ullah. Determining the Level of Mental Distress among Caregivers of Patients with Epilepsy, (Master degree), Çankırı, 2021.

SUMMARY

Background / objective: Caregivers play an important role in the management of epilepsy in the community. Caring for patients with epilepsy can cause emotional distress in caregivers. This study investigated the effect of demographic characteristics and dimensions of mental distress among family caregivers of epilepsy patients. The purpose of this study was to determine the level of mental distress in those who care for patients with epilepsy.

Method: A total of 100 caregivers of patients with epilepsy in the Specialist Center for Neurodegenerative Diseases at Diwaniyah Teaching Hospital were included. Non-probability sampling was performed. Data were collected from 10/5/2020 to 10/11/2020. Data in the study were collected with an information form and the General Health Questionnaire (GSQ). The data were analyzed using Microsoft Excel version 2010 and SPSS version 20. Statistical significance was set at 5% level of probability.

Results: The caregivers consisted of 100 people comprising 48.0% females and 52.0% males. Patient caregivers had mean total GSQ-28 points of 11.36 ±2.505. The mean scale points were high by a statistically significant degree for patient caregivers with young age, high educational level, inadequate income level, those living in rural areas and who were parents of the patient ($p<0.05$).

Conclusion: Emotional distress was present among caregivers for patients with epilepsy and the need for attention to improve the psychological care factors of the caregivers is noted.

Key words: Caregivers, epilepsy, general health, mental distress

1.INTRODUCTION

Epilepsy is one of the most common chronic neurological diseases in which repeated multiple seizures occur. Epilepsy occurs as a seizure that affects some people due to a disorder affecting the nervous system (Srivastava, Tripathi, Tiwari, Singh, & Tripathi, 2016). It is concentrated in the brain and affected people face many problems that persist throughout their lives.

People with epilepsy suffer from many problems that continue throughout their life during the period of injury. This type of nervous system disorder not only affects the psyche of the affected person but goes beyond this and affects the family. Therefore, people with epilepsy suffer from a state of tension, anxiety, depression and frustration, and they are afraid of the unknown future. The question arises whether one day the patient will heal and become a normal person able to function like other healthy people. This disease accounts for 1% of the global burden of disease in the world and affects people around the world. The World Health Organization also estimates that 80% of people with epilepsy live in low and middle income countries, meaning poor countries (Mbuba & Newton, 2009). It is believed that epilepsy and its prevalence are higher in low- and middle-income countries, while the incidence of epilepsy is lower in high-income and developed countries. A new study found that about 3-4 million African people suffer from epilepsy, with an estimated treatment gap of 80% (Srivastava et al., 2016; Yusuf, Nuhu, & Olisah, 2013).

The prevalence of epilepsy among people around the world is from 6 to 7, with approximately 70 million people affected by epilepsy. The prevalence of epilepsy was 9.17 in the United States, affecting 2.5 million people, including 325,000 children under the age of 15. The prevalence of epilepsy among children is 1.43 to 7.98. People who provide health care to patients with epilepsy differ, and it has medical, psychological, educational, personal and social implications in all age groups (Gupta & Sharma, 2013; Manjunatha, Pateel, & Shah, 2010; Tabeleão, Tomasi, & Quevedo, 2014).

The resulting anxiety disorders in caregivers for epilepsy patients not only affect the person's emotional state, but they may also cause physical symptoms such as tremors and increased heart rate. Numerous previous studies evaluated the resulting state of anxiety among parents of children with epilepsy.

Caregivers are people who care for others often parents, spouses, or children with special medical needs or disabilities, and caregivers play an active role in caring for patients with epilepsy. The provision of health care to patients with epilepsy is a large and widespread responsibility in this case, which includes not only practical assistance and care provided to the patient with epilepsy, but also emotional support provided to people with

epilepsy. Care is often very important and very stressful and creates significant social, emotional, behavioral and financial challenges for caregivers of epilepsy patients (Manjunatha et al., 2010; Yusuf et al., 2013).

Caregivers for those who suffer from epilepsy are more likely to develop severe mental depression, anxiety, and physical problems disorders while caring for epilepsy patients (Bello-Mojeed, Omigbodun, Ogun, Adewuya, & Adedokun, 2013; Manjunatha et al., 2010).

Diagnosed mental illness (anxiety or depression) affects not only the primary individuals who are diagnosed, but also families, friends, and important people around them (Crowe & Brinkley, 2015). Different levels of depression, anxiety and mood disorders including loss of hope feelings of sadness, loneliness, isolation, fear, irritability, and nervousness and physical symptoms such as headache, fatigue, and insomnia result from caregiving for a person with problems (Bao Giang, Viet Dzung, Kullgren, & Allebeck, 2010). Caregiving is a large, time-consuming responsibility that creates social, emotional, behavioral and financial problems for caregivers and causes various restrictions on their personal lives. Caregivers in the family are often described as forgotten patients. Caregivers for those with epilepsy suffer from psychological distress, including mood swings, fatigue, headache, joint and muscle pain, and marital and familial conflicts (Manjunatha et al., 2010; Tabeleão et al., 2014; Yusuf et al., 2013).

Some studies confirmed that caregivers for epilepsy patients suffer from great emotional distress (Al-Kattan, Afifi, Shamloul, & Mostafa, 2015; Seekles, van Straten, Beekman, van Marwijk, & Cuijpers, 2009). Caregivers with a significant burden are at risk of developing clinical disorders including depression and anxiety (Nuhu et al., 2010).

A single seizure does not mean that a person has epilepsy (10% of people around the world have one seizure during their lifetime). Epilepsy is defined as experiencing two or more seizures. Epilepsy is one of the first health conditions known to man, as indicated by writings recorded in 4000 BC. Fear, discrimination and social stigma surrounded epilepsy for centuries. This stigma persists in many countries to this day, and may affect the quality of life of people with this disorder and their families (Yusuf et al., 2013). The plan was to determine the level of mental distress in those who care for patients with epilepsy.

1.1 Objective of the study

It is planned to determine the level of mental distress in those who care for patients with epilepsy, relationship between mental distress and sociodemographic characteristics.

1.2 Statement of the problem

Determining the level of mental distress among caregivers of patients with epilepsy**.**

1.3 Hypothesis of the study

The main hypothesis of the research are;

H_0: There is no a relationship between mental distress and certain variables.

H_1: There is a relationship between mental distress and certain variables.

1.4 Limitation of the study

Lack of generalization due to the sample (accidental) and considered a weak sample considered.

1.5 Assumption of the study

The assumptions of this study are that there is an influence between demographic information and mental disorder, and the participants will understand the questions and be honest in their answers, and the criteria for inclusion in the sample are appropriate and thus ensure that all participants.

2. LITERATURE OF REVIEW

2.1 Overview

2.1.1 Epilepsy

Epilepsy is a common chronic disorder caused by mutations or disorder in the electrical functioning of the brain. These storms or disorders cause seizures and can alter certain actions, movements, thoughts, speech, and emotions during these seizures. The reason is never found in most people with epilepsy. However, research suggests a combination of environmental factors such as genetics and head injury. There are many different types of seizures ranging from almost imperceptible to severe. Among the most common and best-known seizures are color enhancing seizures, previously known as "grand mal". These begin with hard limbs, followed by involuntary jerking of the body. However, seizures can occur as a variety of changes in mental, behavioral and emotional states, as well as motor and muscle control. They can serve as a warning for an upcoming seizure.

Any factor causing disruption of the nerve cell membrane may play a role in epilepsy etiology. There are four main headings in the etiologic classification. These are; idiopathic epilepsy, symptomatic epilepsy, provoked epilepsy and cryptogenic epilepsy (Banerjee, Filippi, & Hauser, 2009; İşler & Bir, 2010).

1. Idiopathic epilepsy: this type of epilepsy emerges due to congenital brain defects in newborns and infants, brain injuries or hypoxia, or metabolic causes linked to hypoglycemia or hypocalcemia.

2. Symptomatic epilepsy: this generally is due to genetic causes or later developing anatomic or pathologic situations.

3. Provoked epilepsy: no definite neuroanatomic pathology is identified, while a specific systemic situation or environmental factor is effective in the occurrence of seizures.

4. Cryptogenic epilepsy: There is no definite cause found for epilepsy; however, it is thought to be due to an acquired cause outside of genetic factors.

Providing health care to patients with epilepsy is a great and time-consuming task that creates social, emotional, behavioral and financial problems in caregivers for epilepsy patients and causes various restrictions on their personal lives. Caregivers for patients with epilepsy in the family are often described as forgotten patients. The caregivers for patients with epilepsy experience severe psychological distress, including mood swings, fatigue, headaches, joint and muscle pain, and marital and family disputes (Manjunatha et al., 2010; Yusuf et al., 2013).

There are many studies that confirmed that people who provide health care for epilepsy patients suffer from great emotional distress (Al-Kattan et al., 2015; Seekles et al., 2009). People who provide health care to epileptic patients with a high burden are at risk of developing clinical disorders including depression and anxiety (Nuhu et al., 2010).

2.1.2 Caregiver

A caregiver is a person who helps another person individually, whether paid or unpaid, who has a problem with completing their activities in daily life. Anyone with impaired health can seek help from caregiving services to address their problems. Caregiving is often used to treat problems related to the elderly, impotence, disease and mental disorders.

2.1.3 General Effects of Caring on Caregiver

Caregiving has multidimensional effects on health, socioeconomic and psychological status, indicators of quality of life, in a long and difficult process. The burden as a result of caregiving may lead to mental problems like depression, anxiety and burnout syndrome, in addition to reductions in physical health, social isolation and financial difficulties (Malak, 2008).

Depression and anxiety are normal results of caregiving. The lowering of quality of life of caregivers is a situation which worsens functioning and indirectly affects the patient. The caregiver being a partner, previous relationships between the caregiver and patient, and health problems in the caregiver may trigger depression (YILMAZ & TURAN, 2008).

2.1.4 Mental illness (mental disorder)

This is a term given to a group of mental health disorders that affect the way a person thinks. feels, their moods, and behavior. This may be symptomatic and chronic, and it may affect a person's ability to interact with others and their ability to perform daily tasks. Examples of mental illness are: depression, anxiety disorders, schizophrenia, eating or appetite disorders, and addictive behaviors (Yusuf et al., 2013).

2.2 Previous studies

This chapter tries to shed light on some relevant Previous studies

2.2.1 The first study:

Chunsong Yang and others, in this study they touched on the topic of assessing anxiety among people who provide health care for children with epilepsy disease.

And they examined factors associated with anxiety. Where the study included 334 participants, and the study found that 25.7% (86/334) of people who provide health care to children with epilepsy have symptoms of anxiety, with an average SAS score of 44.31 10,558. he results in this study indicate that people who provide health care for epilepsy patients should pay more attention to the psychological and emotional symptoms among caregivers of children with epilepsy. As for the factors that have a significant impact on symptoms of anxiety that appeared on health care providers for children with epilepsy. With epilepsy, where multiple linear regression revealed that SAS scores were significantly related to children's age, attitude toward seizures, and payment of medical expenses. It was found in this study that there are several possible reasons for these results:

1. Parents of young children with epilepsy may be more anxious about the health of their children, Disease diagnosis, and the effect of the disease on study and work, which makes people who provide health care for patients with epilepsy more likely to have anxiety.

2.The behavior of people who provide health care towards the seizures that epilepsy suffer from have a significant and important effect on anxiety disease. Health care providers for epilepsy patients who have greater knowledge about more about seizures may have more confidence in the treatment.

3.Patients are not treated in outpatient medical clinics in general by the state, and treatment of epilepsy requires a very long period of time, and therefore the cost of treating epilepsy represents a heavy burden of disease for most families who have a patient with epilepsy.

The inability of the families of a patient with epilepsy to bear the costs treatment may lead to the emergence of anxiety among caregivers.

The onset of anxiety disease symptoms among health-care subjects for epilepsy patients in this study was consistent with a range of 9% to 58% reported in a systematic review by jones and Riley. However, the influencing factors that were studied and identified in this study differed from those mentioned and studied in some previous studies, such as Yong et al, who found that an anxiety disease affecting parents who provide health care for a epilepsy is significantly related to the recurrence of epileptic seizures. Children, monthly

household income per capita, and parents' knowledge of epilepsy (P= 000). In addition, in a study on this topic.

Chapski and colleagues reported that higher levels of maternal anxiety disease were associated with lower socioeconomic status, more family stress, and higher generalized anxiety disease. However, the household income factor was more likely to

related to the medical expense payment factor of a family with a patient with epilepsy. because people with lower incomes were expected to have more difficulty paying medical expenses for treating an epilepsy patient. In a study they conducted, Williams et al. Reported that parental anxiety disease did not differ with the type of seizure or the level of seizure control in a patient with epilepsy, consistent with current findings.

This study had several limitations, including:

1.The people who participated were samples taken from the hospital, which may not be representative of the entire population of children with epilepsy.

2.The current study used a type of cross-sectional study design, and this design allows only conclusions related to correlation and not causation.

3. People who provide health care who attend hospital may have a relatively greater economic Status than the general population of health care providers, and they may show more interest in the disease and suffer from a higher level of anxiety

2.2.2 The second study

In a study by Jones and others, this study aimed to systematically review previous studies that focused on symptoms of anxiety. Reported by parents of children with epilepsy (0-18 years), PubMed was used to locate relevant studies. The research selected was reviewed regarding the prevalence of threshold scores above and comparisons were made with controls on standard measures of anxiety disease. Previous research has also been reported regarding factors associated with the anxiety of parents caring epilepsy, the impact on child outcomes, and comparisons with previous research that included equivalent measures of depression symptoms. Fifteen studies were identified that met the inclusion criteria, None of the research was population-based. The percentage of parents who scored above the cut-off limits on the standard measures of anxiety was 9-58%. compared with parents of healthy controls. parents of children with epilepsy had higher average scores in two of the three studies within the selected studies where this was measured. The potential associations with health-care parental anxiety in childhood epilepsy have varied widely across studies. Factors such as recurring seizures and use antiepileptic drugs (AEDS), have

been associated with parental anxiety in some but not all studies. Regarding child outcomes, increased parental anxiety disease was associated with lower quality of life and lower scores in areas of adaptive behavior. Symptoms of anxiety are common among parents of children with epilepsy. More regular, representative research is needed to determine the prevalence of clinically significant anxiety disease and to track the cose of common symptoms. Where such research and studies will help us in identifying the associated with parental anxiety and the effect of symptoms on the outcome of the child and the parents very clearly. Intervention studies are needed to assess approaches aimed at reducing symptoms and the potential impact on child and parent labor. Moreover, there is a need to evaluate the effect of antiepileptic interventions and therapies that focus on diseases associated with children's neurobehavioral behavior on parental anxiety.

2.2.3 The third study

In a study conducted by the scientist Young, the most important results were reached: Parental anxiety disease (of any degree of severity) was found in 191 people in the interview that was conducted, which gives a prevalence rate of 56.2%. Of the 191 subjects, 24.4% reported mild anxiety, and 13.2% reported severe anxiety, 18.5% reported mild anxiety.

Factors associated with parental anxiety included recurring epileptic seizures in children with epilepsy, the average monthly income of each person in this study and the knowledge of the parents who care for a child with epilepsy ($P < 0.05$). Parental anxiety was significantly associated ($P = 0.000$) with the type of life of children with epilepsy.

Study Summary including male parents who provide healthcare to children with epilepsy are at risk of developing anxiety. Parental anxiety disorder results from children and parents. Parental anxiety is closely associated with children's QOL. It is necessary for expert persons involved in the topic to be familiar with and identify such a relationship to develop the quality of life for children with epilepsy and for parents who provide health care for children with epilepsy.

2.2.4 The fourth study

It is a study conducted by the scientist Williams and others and reached results, the most prominent of which are:

Parents' beliefs and attitudes regarding epilepsy may mainly depend on the adaptation, temperament and quality of life of both the child and his family. The main aim of this study was to examine the relationship between parental anxiety disease and the type of

life in children with persistent epileptic disease. The subjects in the study sample were from Parents (n = 200) of children between the ages of 6 and 16 who have been diagnosed and treated for epilepsy for a period of time of at least one year. Parents were given questionnaire questions about quality of life and anxiety during the child's visit to the medical clinic. The study suggested a progressive regression analysis that parental anxiety, severity of co-morbid conditions, control of seizures (epileptic seizures), and the number of drugs taken by patients were significantly related to the quality of life of these children with epilepsy. Where parents with high anxiety disease and whose children were diagnosed with epilepsy, suffered from poorly controlled epileptic seizures and subjected to pathological disabilities accompanying the deterioration and poor quality of life.

2. 2.5 The Fifth Study:

This study was done by the scientist Jones and Riley, where the most important finding was that the family of a child with epilepsy I have experienced stress, anxiety, and disruptions in their family life, more and more painful than other families face compared to them.

The results of research and studies that investigated the knowledge of seizures and familial variables that occur as predictors of children's behavior have shown that familial variables are GABA and often have a greater impact. A systematic review of the study estimated that up to 50% of mothers of infants with epilepsy are at risk of developing depression. While parents of children with epilepsy may also overcome an increased risk of symptoms of anxiety disorder. Anxiety disorder is the most common mental health disorder today. Women are more likely than men to develop anxiety disorder throughout their lives compared to men. Adult anxiety disorders include social anxiety disorder, specific phobias, panic disorder, agoraphobia, and generalized anxiety disorder. It is very likely that there will be an impact of epilepsy in children on the family, no matter what and has an effective role As well as exposure to their epileptic seizures, the conditions that are inherent and associated with a set of cognitive and behavioral difficulties and problems that are often unrecognized and not provided treatment for them and have a very significant impact on the quality of life related to health (HRQOL). Sanctions in the school also include an increased risk of poor educational attainment and problems with commitment to attend school, which may directly affect the comfort and well-being of parents.

3. MATERIAL AND METHOD

3.1 Study Design

A quantitative design (a descriptive study) was used to determine the level of mental distress among caregivers of patients with epilepsy. This study was completed from 10/5/2020 to 10/11/2020.

3.2 Study Setting

The study was completed in the Specialist Center for Neurodegenerative Diseases at Diwaniyah Teaching Hospital. Al-Diwaniyah teaching hospital is the largest regional general hospital and represents the main medical therapeutic services in Al-Diwaniyah city which includes 18 operation rooms with specialized medical departments and centers. It was established by a Japanese company and opened in 1986. The capacity is 466 beds, with about 2368 patients hospitalized each month, and about 21147 clients visit the hospital for treatment each month. The hospital contains four recovery care units with 25 nurses employed, and there are 44 nurses working in anesthesia. The hospital performs 1965 surgical procedures under general anesthesia each month.

3.3 Study Sample

The population for the study comprised relatives of patients attending the neurology clinic of Al-Diwaniyah hospital. The sample comprised 100 patient relatives attending the neurology clinic within a 6-month period. As the full number is unknown, the sample was calculated on a time basis.

2.4 Inclusion Criteria for the Study

- Caring for the patient for at least two months
- Being related to the patient
- Being literate
- No obstacle to communication
- Accepting participation in the study

2.5 Exclusion Criteria for the Study

- Receiving any psychiatric diagnosis or treatment
- Caring from someone outside of informal care (paid caregiver, nurse, etc.)

2.6 Research variables

The dependent variable was general mental health. The independent variables were age, gender, degree of closeness, marital status, number of children, educational status, occupation, caregiving duration, previous caregiving, disease status of caregiver and patient, patient age and gender.

2.7 Data collection tools

2.7.1 Personal information form

This form was created by the researchers by screening the literature and included demographic and social information like age, gender, educational status, disease of patient relatives, etc.

2.7.2 General health questionnaire

The **GSQ identifies** general psychopathology level and is used to find psychiatric cases in public screening. The 60-item version was first developed by David Goldberg in 1972. Later forms containing 12, 28, 30 and 60 items were created. These adaptations had high correlations with each other (Banks et al., 1980).

The scale is used mainly in environments outside of psychiatry and was developed with the aim of social screening to identify psychiatric problems and mental health comprising 28 items. Each item questions symptoms in the last few weeks and has four-point Likert responses (never, as much as usual, more frequently than usual, very frequently) which are coded from 1 to 3 or responses to the scale are coded when read aloud by the implementor. Individuals receiving points above 5 are determined to have mental problems (anxiety and depression). Points use the method called GHQ type pointing for assessment. Accordingly, 0 points are given for the first two responses, with 1 point given for the last two responses. Those receiving points below 5 on the scale are accepted as 'normal'. Those receiving 5 points or more are assessed as the 'risky' group. As points increase, the risk of disrupted mental health increases. Points on the scale are minimum 0 and maximum 28. The GSQ-28 comprises 4 dimensions. Each subdimension comprises 7 items; somatic symptoms (A1-A7), anxiety and insomnia (B1-B7), disorder of social functions (C1-C7) and severe depression (D1-D7). Validity-reliability studies by Kılıç found the Cronbach alpha reliability coefficient for the GSQ-28 was 0.94. With cut-off point of 5, sensitivity was 73.7% (KILIÇ, 1996). Reliability of the scale was confirmed for an Iranian population with Cronbach's alpha 0.97 (Brahimi et al., 2007). In this research, the Cronbach alpha reliability coefficient

for the GSQ-28 was calculated as 0.739. When the Cronbach alpha coefficient is assessed, the scale has acceptable reliability.

2.8 Statistical analysis

Data obtained in the research were statistically assessed with the SPSS (IBM SPSS Statistics 22) program. Frequency tables and descriptive statistics were used to interpret findings. To identify which group was the source of statistical significance between groups, the Tukey corrected two-way comparison was performed. Parametric test methods were used for measurement values abiding by normal distribution. Comparison of measurement values between two independent groups used the T test, with comparisons of measurement values between three or more independent groups using the one-way analysis of variance (ANOVA). The findings were assessed in 95% confidence interval and 5% significance level.

4. RESULTS

Of patient relatives, 52% were male, 38% were unemployed and 35% were married. Of individuals, 36% had children and 28% had 3-4 children. Of participants, 39% were primary school graduates and 80% lived in the city (Table 1).

Table 4.1: Demographic distribution characteristics of caregivers (n:100)

Property		N	%
Age	**15-24** **25-34** **35-44** **45-54**	**41** **25** **28** **6**	**41.0** **25.0** **28.0** **6.0**
Gender	**Male** **Female**	**52** **48**	**52.0** **48.0**
Occupation	**Self-employed** **Housewife** **Employee**	**38** **35** **27**	**38.0** **35.0** **27.0**
Marital status	**Married** **Single** **Divorced**	**35** **30** **35**	**35.0** **30.0** **35.0**
Children	**Yes** **No**	**63** **37**	**36.0** **37.0**
Number of Children	**1-2** **3-4** **Higher** **No Children**	**14** **28** **27** **31**	**14.0** **28.0** **27.0** **31.0**
Educational Status	**Primary** **Secondary** **BSc** **Postgraduate**	**39** **29** **27** **5**	**39.0** **29.0** **27.0** **5.0**
Family Income	**Excellent** **Medium** **Poor**	**24** **33** **43**	**24.0** **33.0** **43.0**
Cardiovascular disease	**No** **Yes**	**40** **60**	**40.0** **60.0**

Physical Activity	**Very Active** **Active** **Irregular Active** **Inactive**	**5** **25** **49** **21**	**5.0** **25.0** **49.0** **21.0**
Relationships (Patient-you)	**Father** **Mother** **Brother** **Wife** **Son**	**30** **23** **29** **7** **11**	**30.0** **23.0** **29.0** **7.0** **11.0**
Place of residence	**City** **Rural**	**80** **20**	**80.0** **20.0**

The mean total GSQ-28 points for patient relatives were 11.36 ±2.505. The points for the subdimensions of somatic symptoms, anxiety and insomnia, disorder of social functions and severe depression were 2.97±1.275; 2.78 ± 1.236; 3.28±1.400; and 2.67±1.272, respectively (Table 2).

Table 4. 2: Mean GHQ-28 Points of Patient relatives

Scale	n	Mean	Std	Min	Max
GHQ-28 total	**100**	11.36	2.505	4	18
Somatic symptoms	**100**	2.97	1.275	0	6
Anxiety and insomnia	**100**	2.78	1.236	0	7
Disorder of social functions	**100**	3.28	1.400	0	6
Severe Depression	**100**	2.67	1.272	0	6

Table 4.3: Findings about Comparisons of GHQ-28 and subscale points in terms of caregiver descriptive characteristics

Independent Variables		GHQ-28	Somatic symptoms	Anxiety/insomnia	Social function disorder	Depression
		Mean ±Sd	Mean±Sd	Mean±Sd	Mean±Sd	Mean±Sd
Age	**15-24 (n:41)**	2.27±0.70	2.26±0.38	2.27±0.38	2.29±0.41	2.19±0.39
	25-34 (n:25)	2.10±0.63	2.31±0.37	2.27±0.35	2.22±0.30	2.30±0.40
	34-43 (n:28)	1.95±0.60	2.36±0.44	2.10±0.38	2.38±0.42	2.21±0.37
	44-54 (n:6)	1.89±0.65	2.26±0.56	2.40±0.55	2.30±0.58	2.21±0.55
Test value*	**F/p**	**2.059/0.028**	0.351/0.788	1.738/0.164	0.690/0.561	0.425/0.735
Gender	**Male (n:52)**	1.46±2.783	2.35±0.42	3.43±0. 40	2.27±0.37	2.26±0.42
	Female (n:48)	1.27±2.241	2.26±0.38	2.29±0.37	2.32±0.43	2.26±0.42
Test value**	**t/ p**	0.376/0.708	1.089/0.299	2.193/0.142	0.339/0.561	0.531/0.468
Occupation	**Self-employed (n:38)**	2.24±0.66	2.36±0.43	2.18±0.41	2.30±0.40	2.31±0.41
	Housewife (n:35)	1.98±0.58	2.21±0.36	2.26±0.37	2.26±0.41	2.20±0.39
	Employee (n:27)	2.00±0.68	2.34±0.40	2.28±0.39	2.35±0.40	2.14±0.38
Test value*	**F/p**	0.622/0.818	0.402/0.257	0.621/0.539	0.399/0.539	1.422/0.246
Marital status	**Married (n:35)**	1.73±0.73	2.22±0.395	2.25±0.400	2.32±0.345	2.25±0.376
	Single (n:30)	2.01±0.55	2.33±0.434	2.23±0.408	2.24±0.412	2.15±0.414
	Divorced (n:35)	1.93±0.93	2.36±0.389	2.21±0.380	2.32±0.457	2.27±0.414
Test value*	**F/ p**	1.592/0.109	1.055/0.352	0.094/0.911	0.374/0.689	0.755/0.473
Children Found	**No (n:37)**	1.16±2.872	2.35±0.453	2.21±0.392	2.24±0.423	2.18±0.390
	Yes (n:63)	1.48±2.278	2.28±0.376	2.24±0.394	2.33±0.393	2.26±0.406
Test value**	**t/p**	-0.603/0.548	1.157/0.250	-0.813/0.418	-0.648/0.522	-0.453/0.652
Educational Status	**Primary (n:39)**	1.62±0.41	2.33±0.389	2.22±0.373	2.17±0.346	2.28±0.416
	Secondary (n:29)	1.53±0.37	2.18±0.375	2.30±0.360	2.29±0.386	2.25±0.335

	BSc (n:27)	2.07±0.56	2.36±0.457	2.15±0.432	2.45±0.468	2.13±0.407
	Postgraduate (n:5)	2.50±0.67	2.51±2.342	0.29±0.520	2.48±0.312	2.17±0.592
Test value*	**F/ p**	**52.418 /0.000**	1.617/0.190	0.735/0.434	2.995/0.893	0.035/0.448
Family Income	**Excellent (n:24)**	2.63±0.60	2.37±0.414	2.22±0.408	2.21±0.408	2.22±0.414
	Medium (n:33)	2.73±0.83	2.23±0.455	2.18±0.427	2.43±0.386	2.20±0.393
	Poor (n:43)	3.02±0.81	2.32±0.358	2.28±0.357	2.24±0.404	2.25±0.415
Test value*	**F/ p**	**4.690 /0.001**	0.918/0.403	0.618/0.541	0.925/0.158	0.117/0.890
Physical Activity	**Very Active (n:5)**	1.62±0.41	2.28±0.303	2.14±0.364	2.17±0.234	2.25±0.528
	Active (n:25)	1.53±0.37	2.40±0.422	2.14±0.422	2.17±0.488	2.25±0.419
	Irregular active (n:49)	2.07±0.56	2.27±0.423	2.22±0.337	2.32±0.389	2.19±0.372
	Inactive (n:21)	2.50±0.67	2.40±0.369	2.30±0.450	2.25±0.378	2.28±0.432
Test value*	**F/ p**	**52.418/0.000**	0.582/0.628	1.996/0.120	0.239/0.869	0.309/0.819
Relationships (Patient-you)	**Father (n:30)**	2.52±0.84	2.33±0.408	2.30±0.460	2.33±0.350	2.25±0.479
	Mother (n:23)	2.60±0.56	2.27±0.452	2.20±0.330	2.21±0.471	2.27±0.352
	Brother (n:29)	1.51±0.41	2.39±0.384	2.29±0.332	2.36±0.363	2.15±0.396
	Wife (n:7)	2.01±0.50	2.14±0.349	2.24±0.441	2.24±0.604	2.32±0.356
	Son (n:11)	1.53±0.40	2.15±0.369	1.96±0.367	2.24±0.389	2.23±0.321
Test value*	**F/ p**	**62.401/0.000**	1.076/0.373	1.812/0.133	0.573/0.683	0.451/0.771
Place of residence	**City (n:80)**	1.82±0.68	2.29±0.403	2.25±0.382	2.28±0.400	2.24±0.403
	Rural (n:20)	2.03±0.46	2.36±0.420	2.15±0.432	2.36±0.428	2.17±0.395
Test value**	**t/ p**	**6.986/0.001**	0.493/0.484	1.003/0.319	0.600/0.441	0.432/0.512

*ANOVA (one-way analysis of variance) **T test

5. DISCUSSION

This research was performed with the aim of determining the mental distress levels of caregivers for patients with epilepsy. In the literature, the care burden of relatives of patients with chronic diseases (CDs), is mostly assessed. Very few studies related to mental distress were encountered.

In our study, the total mean points for GSQ-28 for patient relatives were 11.36 ±2.505. In the study by Doğan et al. the mean total GSQ-28 points for relatives of patients receiving care services in the home were found to be 5.76±4.07 (DOĞAN, 2019). A study of relatives of patients with dementia observed that 41.7% of patient relatives were above the GSQ-28 cut-off (Kamalzadeh et al.). In the present study, the cut-off value for the GSQ-28 scale was 5. When assessed from this aspect, relatives of patients with epilepsy are at risk for disrupted mental health.

In our study, as the age interval of patient relatives fell, the mean total points on the GSQ-28 scale showed increased risk of mental discomfort at statistically significant levels. This situation may be connected with the inadequate coping methods of individuals with very young ages.

As the educational level of patient relatives increased in our study, GSQ-28 total mean points increased by a statistically significant level. Similarly, we found higher psychological distress and physical disease comorbidities than comorbidity studies of psychological and physical disorders performed with the GSQ-28 in high-income countries (33%) (Meader et al., 2011). Individuals with high educational level have increased probability of being employed. This situation may cause mental stress due to responsibilities related to both caregiving and working life.

Additionally, the fall in income level in the present study increased risk by significant levels. Studies found an association between low educational levels and low socioeconomic status with increasing major depression (Tomlinson, Grimsrud, Stein, Williams, & Myer, 2009). However, it appears that somatic symptoms are frequently associated with social and economic conditions (Shidhaye, Mendenhall, Sumathipala, Sumathipala, & Patel, 2013).

The CDs of epilepsy may cause economic distress in families. The patient being forced to leave work, occasional hospitalization, medical follow-up, treatment and medication costs, families living distant from treatment centers and special expenditure may

disrupt the family in economic terms (Durna & Akın, 2012). This situation may negatively affect the mental status of patient relatives.

In our study, low physical activity increased GSQ-28 mean total points. A study of university students found a negative correlation between physical activity and mean total points for the GSQ-28 scale. Additionally, development of health may stimulate the individual toward healthy life and adherence and this may increase the person's energy and is simultaneously stated to lower the rate of mental problems (İlhan, BAHADIRLI, & Toptaner, 2014).

In the present study, being the mother or father (parent) appeared to increase the risk of mental discomfort compared to other degrees of relatedness. Similarly, a study observed that nearly 65.7% of parents had psychological problems and 91.4% of parents had weak or mistaken knowledge levels about epilepsy. There was a significant correlation between parental knowledge levels and mental health ($p<.001$) (Behrouzian & Neamatpour, 2010). However, acceptance of epilepsy diagnosis for children in families is a difficult process. Families of epilepsy patients experience psychological stress and burden due to topics like the uncertain nature of epilepsy, prognosis of epilepsy, side-effects of antiepileptic medications, and effects on the future life of the patient (marriage, career, etc.) (Clarke & Critchley, 2016). A study by Zararsız (2009) found that education given to children with epilepsy and parents about ensuring safety in epilepsy reduced anxiety and depression and for this reason recommended that continuous education be given about epilepsy to children and parents (Zararsız, 2009). Additionally, a study by Baker et al. (2005) determined that epilepsy had significant effect in psychosocial terms among adolescents and that adolescents with epilepsy experienced higher levels of depression and social anxiety compared to adolescents without epilepsy. The same study reported that high seizure frequency in adolescents with epilepsy was associated with low self-esteem, while tonic-clonic seizures were associated with high depression levels. Additionally, they stated that low levels of knowledge about epilepsy were significantly associated with high depression levels, low self-esteem and high social anxiety levels (Baker, Spector, McGrath, & Soteriou, 2005). Reduced social interaction reduces the chance to develop friendships and this situation is reflected in the marital status/partner compatibility of epilepsy patients. A study determined that men and women patients with epilepsy had lower rates of marriage and higher rates of divorce compared to the general population. Additionally, the onset age of epilepsy and seizure frequency affect marital status with those with younger age of onset for epilepsy found to have lower probability of marriage (Agarwal et al., 2006; Azuma & Akechi, 2014; MOLLAOĞLU, BOLAYIR, & TAŞ, 2003). All these processes may increase anxiety and stress in families and cause mental distress.

5. CONCLUSION and RECOMMANDATIONS

In our study, relatives of patients with epilepsy were found to have very high mental distress levels according to the GSQ-28 scale. Young age of patient relatives, high educational level, inadequate income level, living in rural areas and being mother-father of the patient increased the risk of mental distress by significant degrees.

In line with this, we recommend that;

- Patient relatives be given coping strategies and psychological support from the time the patient receives epilepsy diagnosis.
- Counseling services and cognitive behavioral therapy methods may increase self-efficacy of relatives of epilepsy patients, supporting development of positive attitudes about epilepsy and additionally management of anxiety and depression.
- Nurses are recommended to assess the care burden and mental distress of caregivers for epilepsy patients, determine the problems of caregivers in education and counseling services, develop coping strategies for these problems and create awareness about the topics where caregivers require support.

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APPENDICES

Appendix 1. Questionnaire (by English languish)

Title Questionnaire: Determine the level of mental distress among caregivers of patients with epilepsy.

Purpose of Questionnaire :

-To determine the level of mental distress among caregivers of patients with epilepsy

-To find all the relationship between the level of mental distress of caregivers and their social and demographic characteristics.

DIRECTIONS: To know is there a statistically significant relationship between the levels of mental distress in epilepsy patients. Please respond to each item as accurately as possible, and try not to skip any item. Indicate the frequency with which you engage in each behavior by circling.

Researcher: Mohanad Mahdi Abd ullah

Part1: Personal information form

1. Your age ☐

2. gender: 1) Female ☐ 2) Male ☐

3. Your marital status: 1) married ☐ 2) Single ☐ 3) Divorced ☐ 4) Widowed ☐

4. Do you have children?. 1) Yes ☐ 2) No If yes, please indicate a number ☐

5. Your educational level: 1) Primary school / high school ☐ 2) High school and its equivalent ☐

3) Collectors ☐ 4) Postgraduate studies ☐

6. Family income :1) Excellent family ☐ 2) Middle income family ☐ 3) Poor family ☐

8. What is the level of your physical activity? 1) Very active ☐ 2) Active ☐

3) Irregular active ☐ 4) Stable (stable) ☐

9. What is the relationship between you and the patient 1) father ☐ 2) mother ☐

3) brother ☐ 4)wife ☐ 5) son ☐ 6) other ☐

10. Housing 1) city ☐ 2) countryside ☐

Part 2: psychological Aspects Scale (General Health Questionnaire. GHQ)

Q	Description	The statement				dimensions
		Never	Some time	Most time	Always	
1A	Been feeling perfectly well in good health?					**Physical symptoms**
2A	Been feeling in need of a good tonic?					
3A	Been feeling run down and out of sorts?					
4A	Felt that you are ill?					
5A	Been suffering any pains in your head?					
6A	Been getting a feeling of tightness or pressure in your head?					
7A	Been having hot or cold spells?					
8B	Lost much sleep over worry?					**Anxiety**
9B	Had difficulty in staying asleep once you are off?					
10 B	Felt constantly under strain ?					
11 B	Getting edgy and bad-tempered?					
12 B	Been getting scared or panicky for no good reason?					
13 B	Found everything getting on top of you ?					
14 B	Been feeling nervous or strung-up all the time?					
15 C	Been managing to keep yourself busy and occupied?					**social dysfunction**
16 C	Been taking longer time over the things you do?					
17 C	Felt on the whole you were doing things well ?					
18 C	Been satisfied with the way You're carried out your tasks?					
19 C	Felt that you are playing a useful part in things?					
20 C	Felt capable of making decisions about things?					
21 C	Been able to enjoy your normal Were you daily activities?					
22 D	Been thinking of yourself as a worthless person?					**Depression**
23 D	Felt that life is entirely hopeless?					
24 D	Felt that life inset worth living?					
25 D	Thought of the possibility that you might make					
26 D	Found at times you couldn't do anything because your nerves were too bad?					
27 D	Found yourself wishing you were dead and away from it all?					
28D	Found that the idea of taking your own life kept coming into your					

Appendix 2. Questionnaire (by Arabic languish)

استبيان العنوان: تحديد مستوى الاضطراب العقلي بين مقدمي الرعاية لمرضى الصرع.

الغرض من الاستبيان:

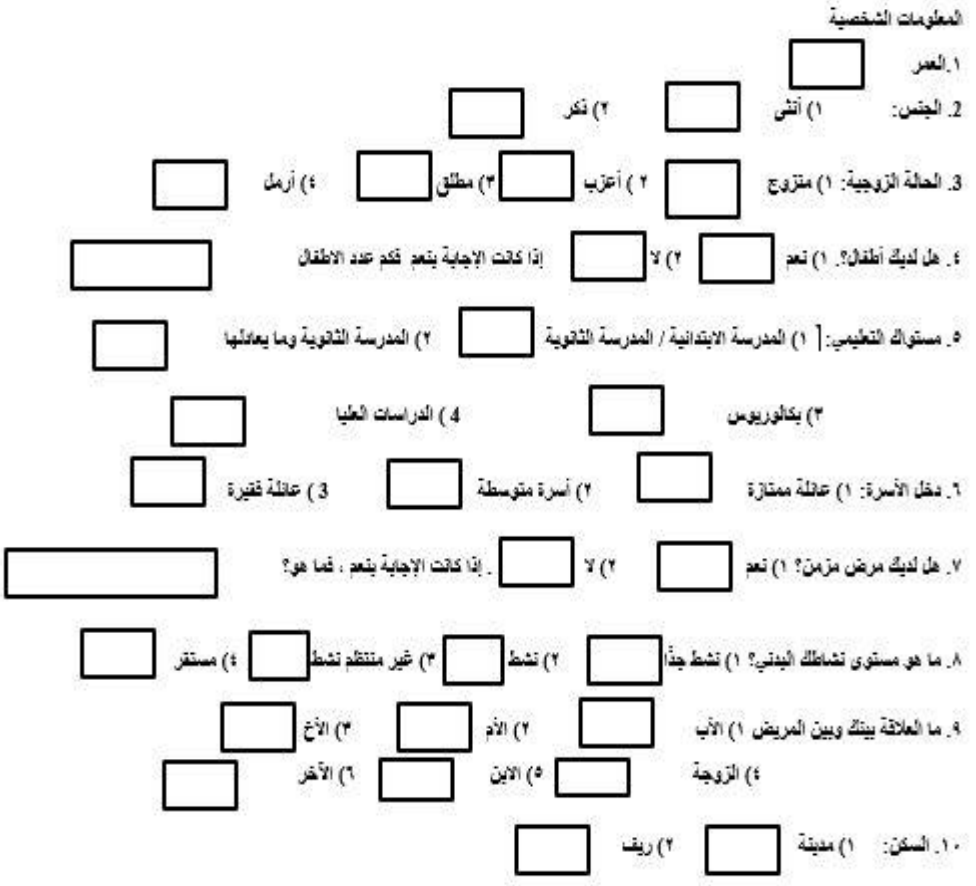
- **تحديد مستوى الاضطراب العقلي لمقدمي الرعاية لمرضى الصرع**

-إيجاد كل العلاقة بين مستوى الضائقة النفسية لمقدمي الرعاية وخصائصهم الاجتماعية والديموغرافية.

الاتجاهات: لمعرفة هل هناك علاقة ذات دلالة إحصائية بين مستويات الاضطراب العقلي لدى مرضى الصرع. يرجى الرد على كل عنصر بأكبر قدر ممكن من الدقة ، وحاول عدم تخطي أي عنصر.

الباحث: مهند مهدي عبد الله

الجزء الاول : المعلومات الشخصية



الجزء الثاني: مقياس الجوانب النفسية (استبيان الصحة العامة)

ت	وصف	البيان				أبعاد
		أبدا	بعض الاحيان	معظم الوقت	دائما	
1أ	هل تشعر انك على ما يرام عندما تكون في صحة جيدة؟					الأعراض الجسدية
2أ	هل تشعر بالحاجة إلى منشط جيد؟					
3أ	هل تشعر بانك بحاجة الى الركض والخروج نوع ما؟					
4أ	هل شعرت أنك مريض؟					
5أ	هل كنت تعاني من أي آلام في رأسك؟					
6أ	هل شعرت بضيق أو ضغط في رأسك؟					
7أ	هل كان لديك نوبات ساخنة أو باردة؟					
8ب	لا تستطيع النوم بصورة طبيعية بسبب القلق المفرط؟					القلق
9ب	هل واجهت صعوبة في النوم عندما تكون في الخارج؟					
10ب	هل تشعر بانك باستمرار تحت ضغط واجهاد؟					
11ب	هل تعاني من الانفعال والمزاج السيء؟					
12ب	هل تشعر بالخوف أو الذعر بدون سبب وجيه؟					
13ب	هل وجدت كل شيء يسيطر عليك؟					
14ب	هل تشعر انك عصبي او متوتر طوال الوقت ؟					
15ج	هل تشعر انك تمكنت من إبقاء نفسك مشغولاً ومنهمك؟					الخلل الاجتماعي
16ج	هل تستغرق وقتًا أطول على الامور التي تفعلها؟					
17ج	هل شعرت بشكل عام بأنك تقوم بأمور جيدة؟					
18ج	هل أنك راضٍ عن الطريقة التي تنفذ بها مهامك؟					
19ج	هل شعرت ان لك دور في جزء مفيد من الامور ؟					
20ج	هل شعرت انك قادر على اتخاذ قرارات بشأن الأمور؟					
21ج	هل تمكنت من الاستمتاع بنشاطاتك اليومية العادية؟					
22د	هل تفكر في نفسك كشخص لا قيمة له؟					الكآبة
23د	هل شعرت بأن الحياة ميؤوس منها تمامًا؟					
24د	هل شعرت أن الحياة لا تستحق العيش؟					
25د	هل فكرت في إمكانية أن تفسد نفسك					
26د	هل وجدت في بعض الأحيان أنك لا تستطيع أن تفعل أي شيء لأن أعصابك كانت سيئة للغاية؟					
27د	هل وجدت نفسك تتمنى لو كنت ميتا وبعيدا عن كل ذلك؟					
28د	هل وجدت أن فكرة أخذ حياتك الخاصة لا تزال تأتي في حساباتك					

Appendix 3. Approval of the sample research

THE VITAE CURRICULUM

Name : Mohanad Mahdi Abdullah

Educational status: University

Bachelor's degree: 2009 Baghdad University - College of Nursing. General nursing.

Professional Experience: Clinical Nursing - Medical Surgery Nursing
Nursing Administration - Pediatric Nursing
Nursing process - college and institute lecturer
Nursing.

The scientific institutions to which he belongs: Al Hussein Children's Hospital -
Higher Institute of Health

Fields of scientific study: Public Health Nursing

Scientific activities: participation in seminars and scientific training
Medical programs and conferences in the Ministry of Health
Scientific and nursing workshops

Other information: Ministerial certified trainer in the following fields (health care, First Aid - Pediatric Nursing), instructor at the Higher Institute of Health - Diwaniyah Ministerial certified trainer in the following fields (health care- First Aid - Pediatric Nursing),instructor at the Higher Institute of Health - Diwaniyah