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والصيدلة - مراكش  
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## Quality of life in children with epilepsy

### THESIS

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BY

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#### KEY-WORDS :

Quality -Domains -Epilepsy -Child

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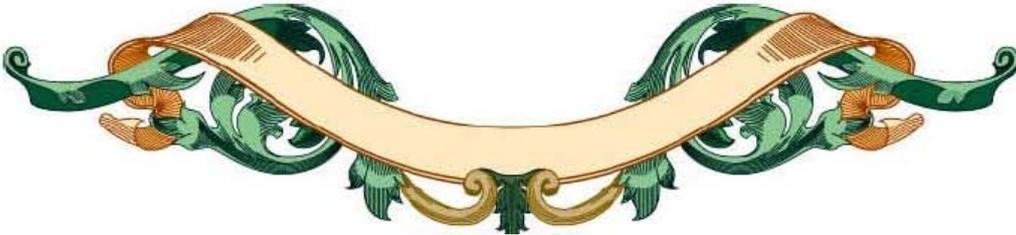
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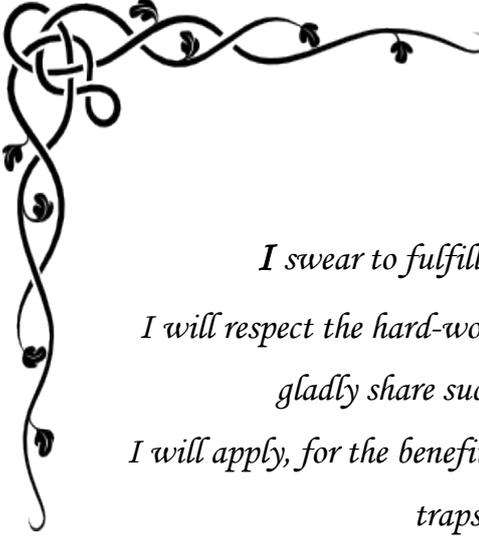
JUDGES



بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

"رب أوزعني أن أشكر نعمتك  
التي أنعمت عليّ وعلى والديّ  
وأن أعمل صالحاً ترضاه  
وأصلح لي في ذريّتي  
إني تبنت إليك و إني من المسلمين"  
صدق الله العظيم





# hippocraticoath

*I swear to fulfill, to the best of my ability and judgment, this covenant:*

*I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.*

*I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism.*

*I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.*

*I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.*

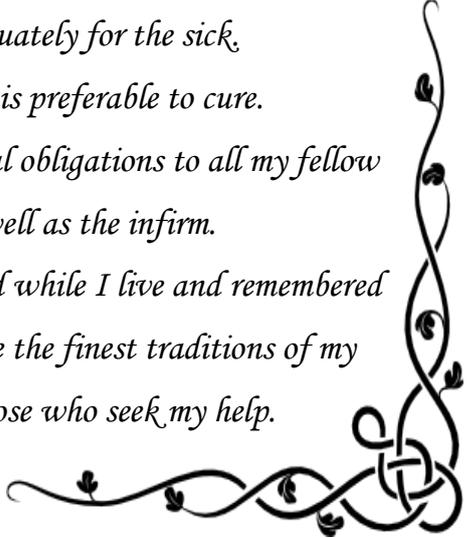
*I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.*

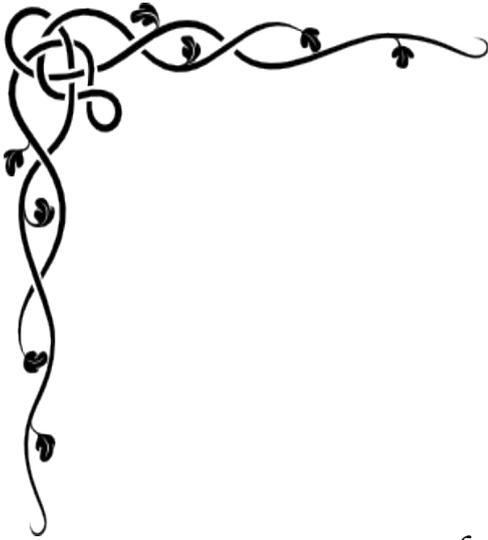
*I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick,*

*I will prevent disease whenever I can, for prevention is preferable to cure.*

*I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.*

*If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.*





*awareness of my own frailty .Above all, I must not play at God.*

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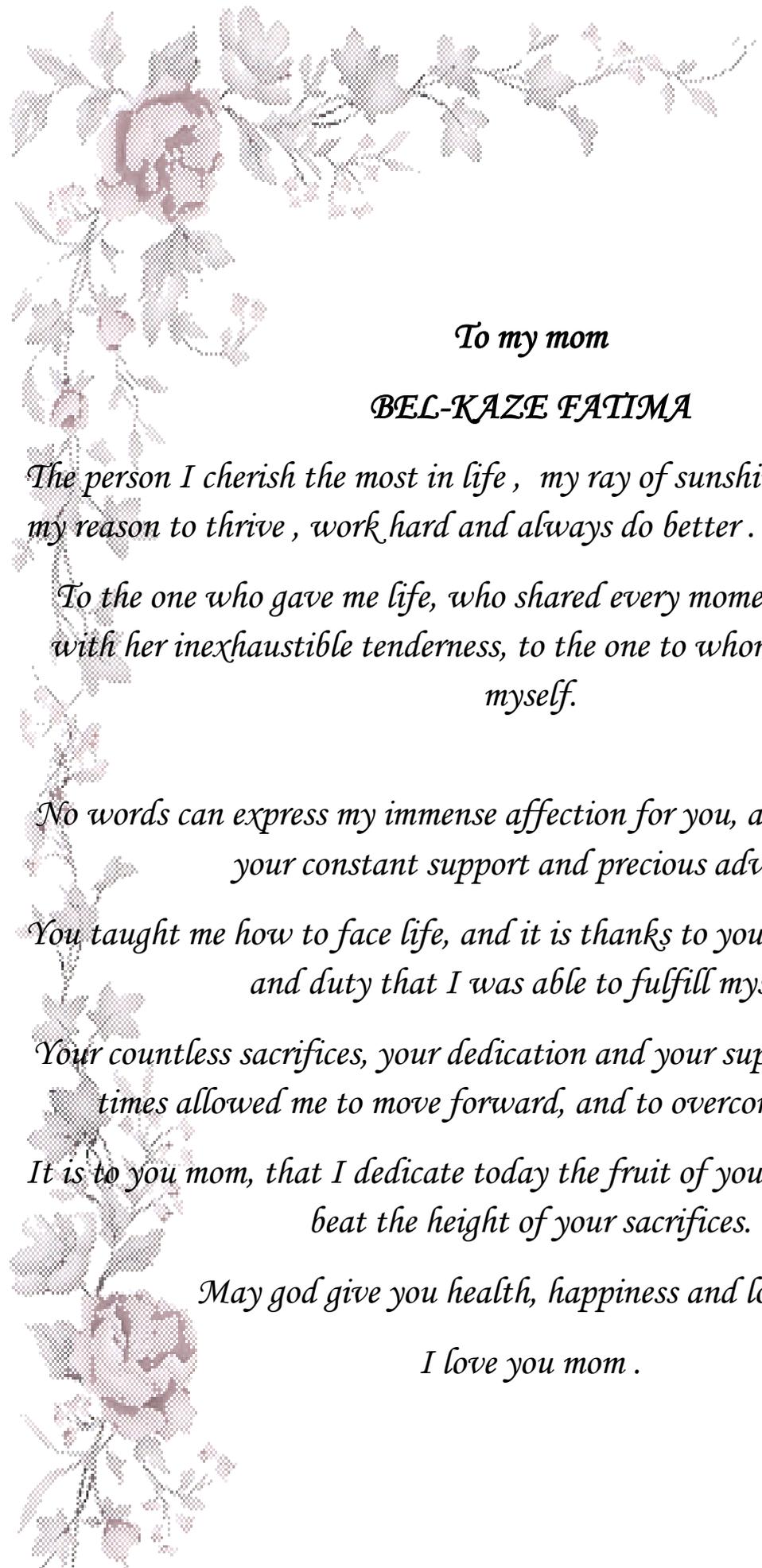
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*DEDICATIONS*





*To my mom*

***BEL-KAZE FATIMA***

*The person I cherish the most in life , my ray of sunshine , my best friend , my reason to thrive , work hard and always do better .*

*To the one who gave me life, who shared every moment of my existence with her inexhaustible tenderness, to the one to whom I owe the best of myself.*

*No words can express my immense affection for you, and my gratitude for your constant support and precious advices .*

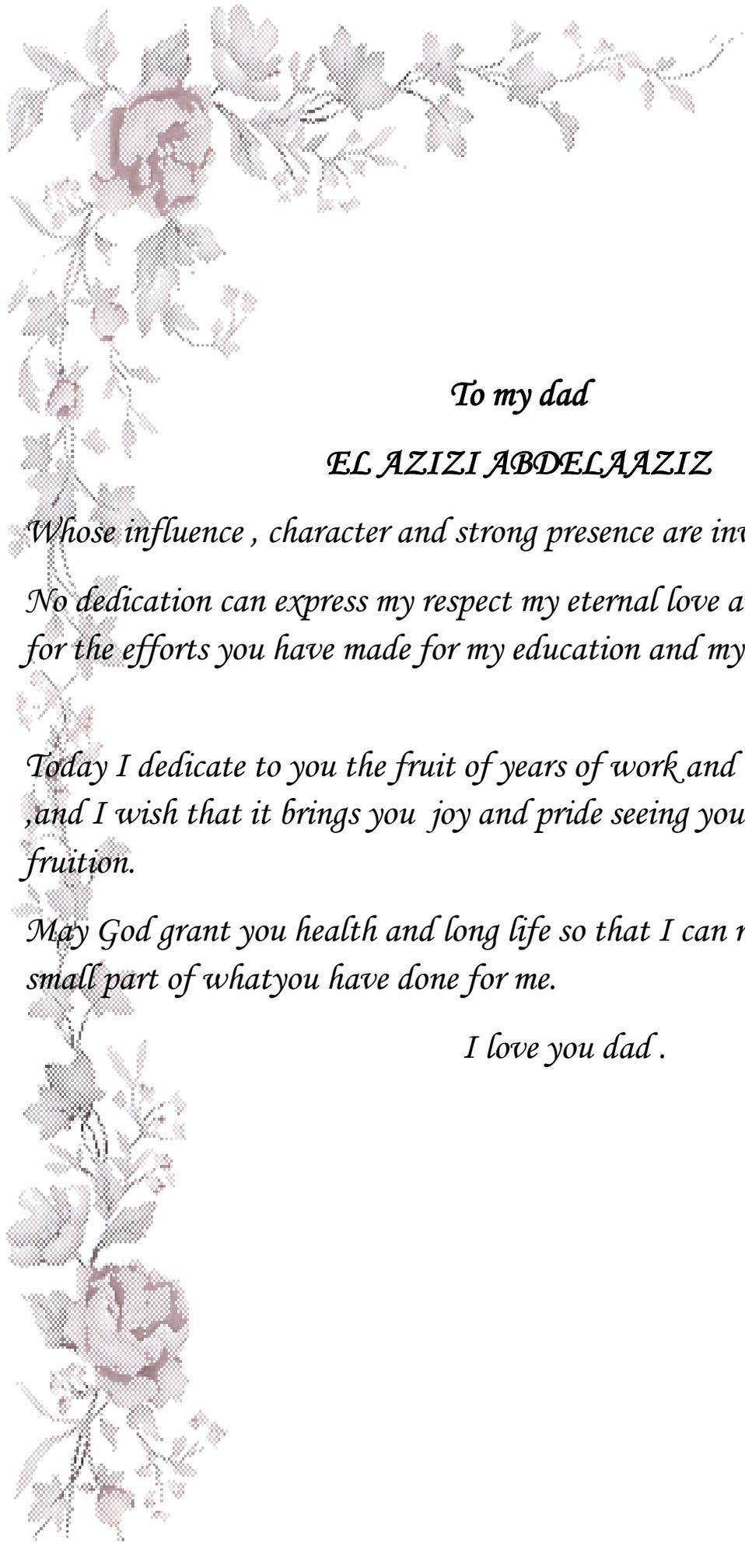
*You taught me how to face life, and it is thanks to your teaching of values and duty that I was able to fulfill myself.*

*Your countless sacrifices, your dedication and your support in my difficult times allowed me to move forward, and to overcome all the tests.*

*It is to you mom, that I dedicate today the fruit of your devotion hoping to beat the height of your sacrifices.*

*May god give you health, happiness and long life.*

*I love you mom .*



*To my dad*

*EL AZIZI ABDELAAZIZ*

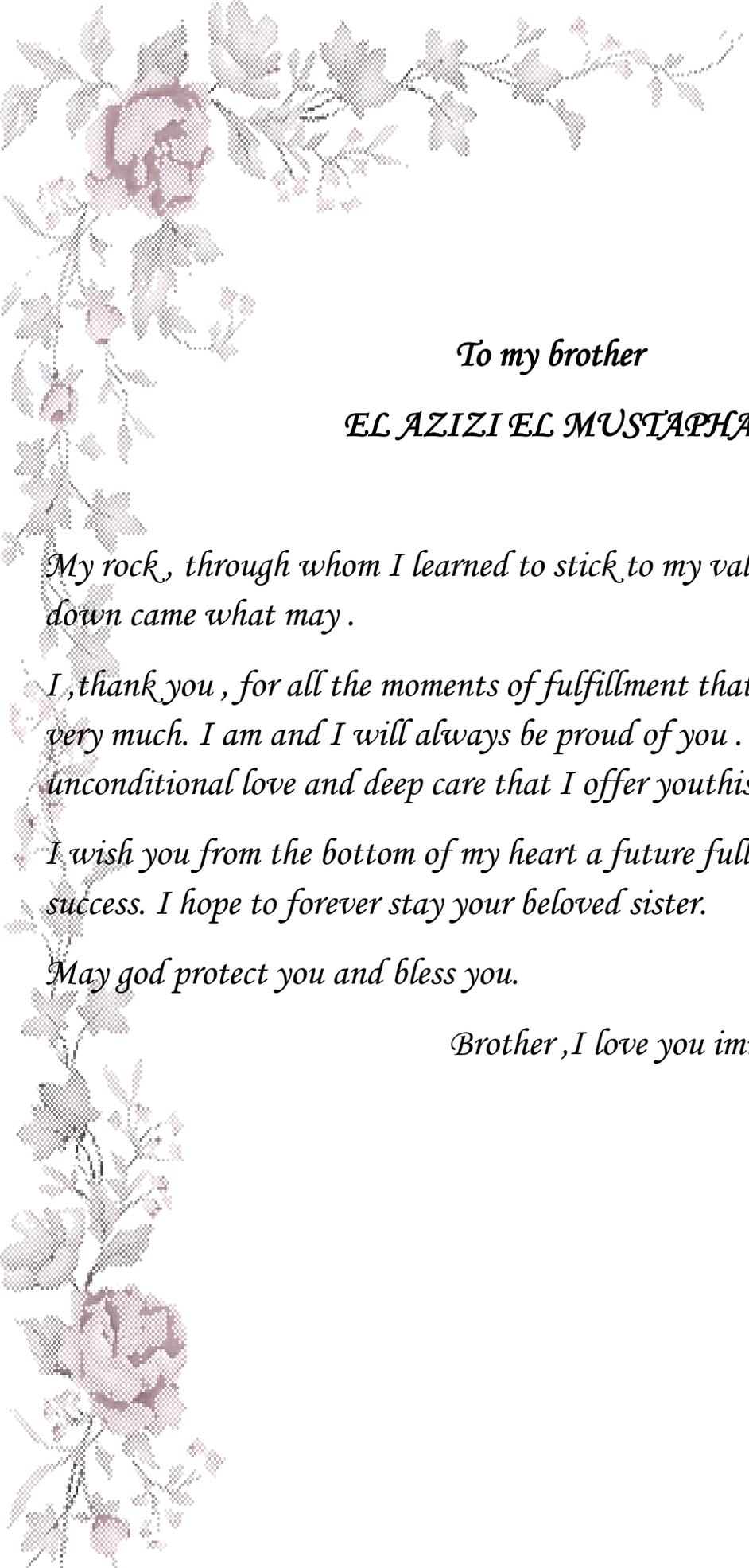
*Whose influence , character and strong presence are invaluable to me .*

*No dedication can express my respect my eternal love and my consideration for the efforts you have made for my education and my well-being .*

*Today I dedicate to you the fruit of years of work and continuous efforts ,and I wish that it brings you joy and pride seeing your hopes come to fruition.*

*May God grant you health and long life so that I can render you even a small part of what you have done for me.*

*I love you dad .*



*To my brother*

*EL AZIZI EL MUSTAPHA*

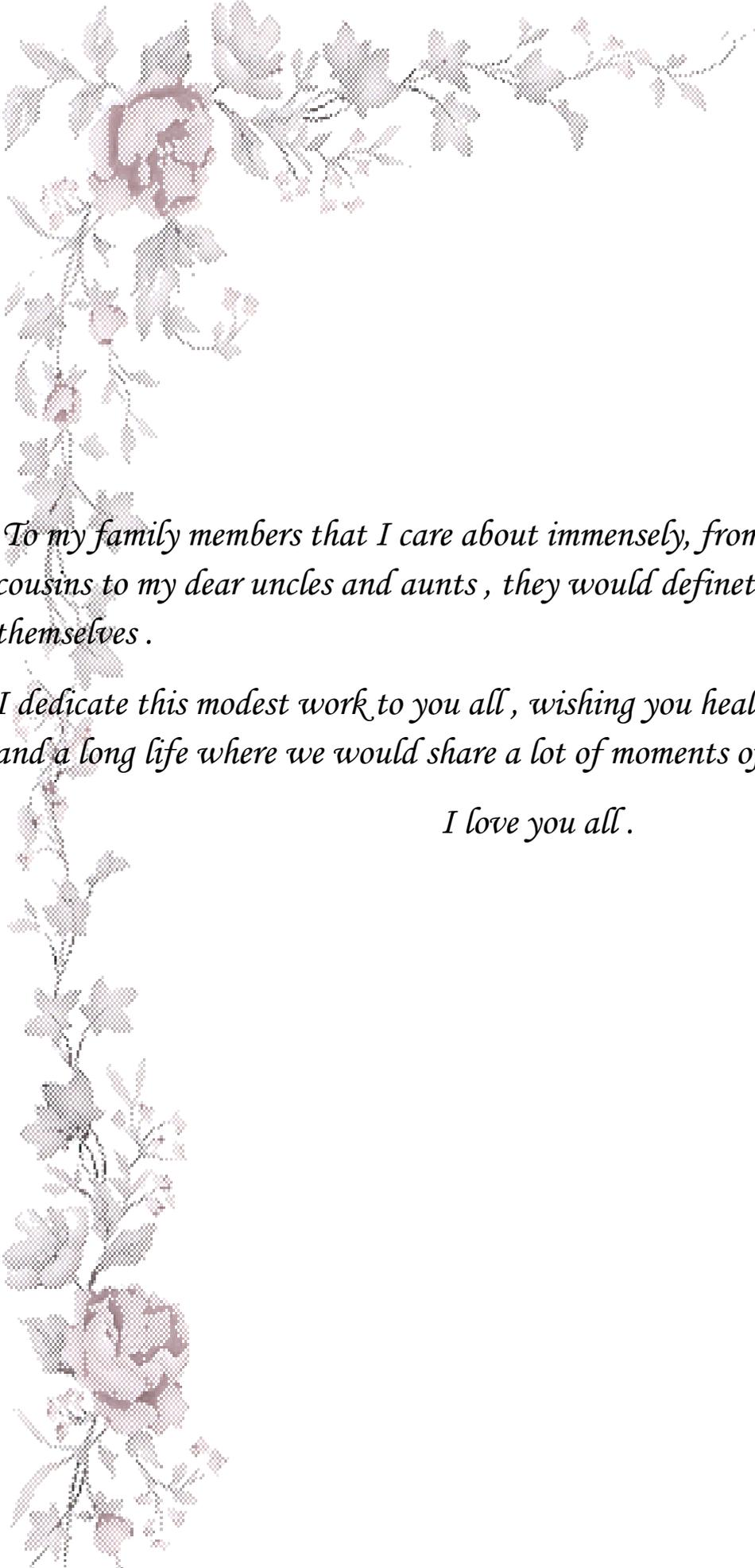
*My rock, through whom I learned to stick to my values , and never bow down came what may .*

*I ,thank you , for all the moments of fulfillment that we shared, I love you very much. I am and I will always be proud of you . It is with unconditional love and deep care that I offer you this modest work,*

*I wish you from the bottom of my heart a future full of happiness and success. I hope to forever stay your beloved sister.*

*May god protect you and bless you.*

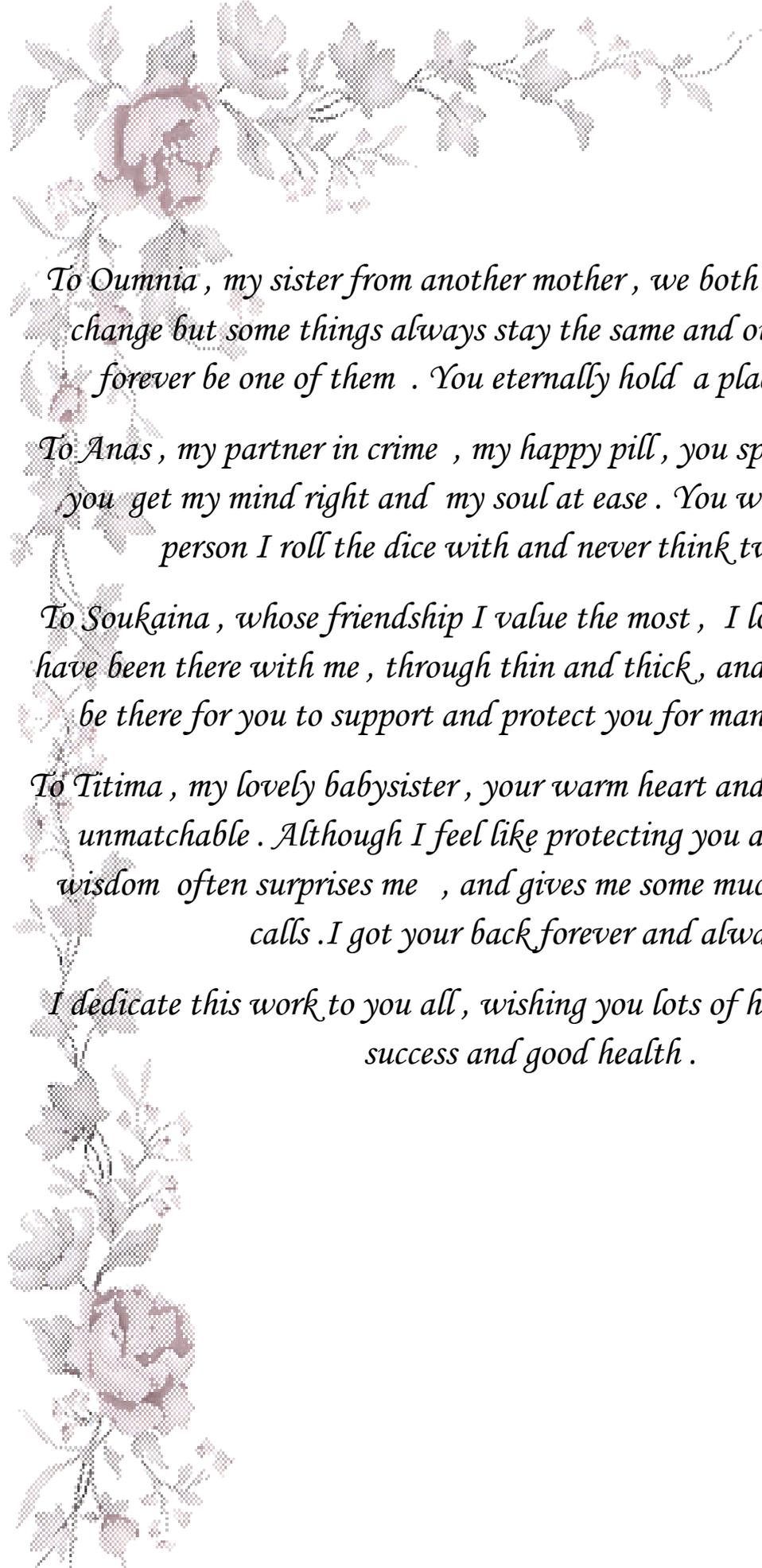
*Brother ,I love you immensely .*



*To my family members that I care about immensely, from my close cousins to my dear uncles and aunts , they would definetly recognize themselves .*

*I dedicate this modest work to you all , wishing you health , peace of mind, and a long life where we would share a lot of moments of pure happiness .*

*I love you all .*



*To Oumnia , my sister from another mother , we both know that seasons change but some things always stay the same and our sisterhood will forever be one of them . You eternally hold a place in my heart .*

*To Anas , my partner in crime , my happy pill , you speak my language so you get my mind right and my soul at ease . You will always be that person I roll the dice with and never think twice with .*

*To Soukaina , whose friendship I value the most , I love you dearly , you have been there with me , through thin and thick , and I will undoubtedly be there for you to support and protect you for many years to come .*

*To Titima , my lovely babysister , your warm heart and unique presence are unmatched . Although I feel like protecting you all the time , your wisdom often surprises me , and gives me some much needed wake up calls .I got your back forever and always .*

*I dedicate this work to you all , wishing you lots of happiness , immense success and good health .*

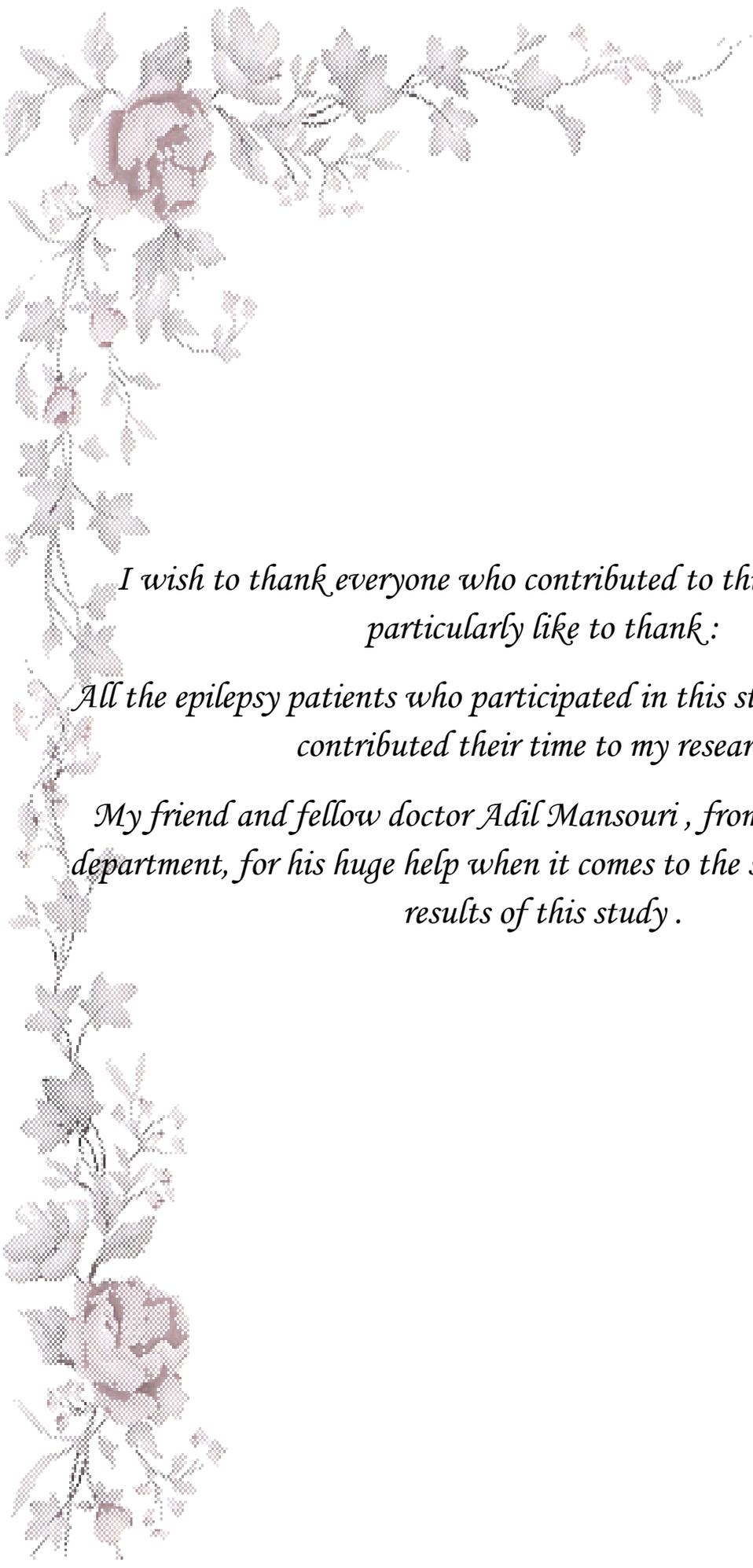
اللَّهُمَّ

*Praise be to Almighty God,  
which allowed me to see this long awaited day.*



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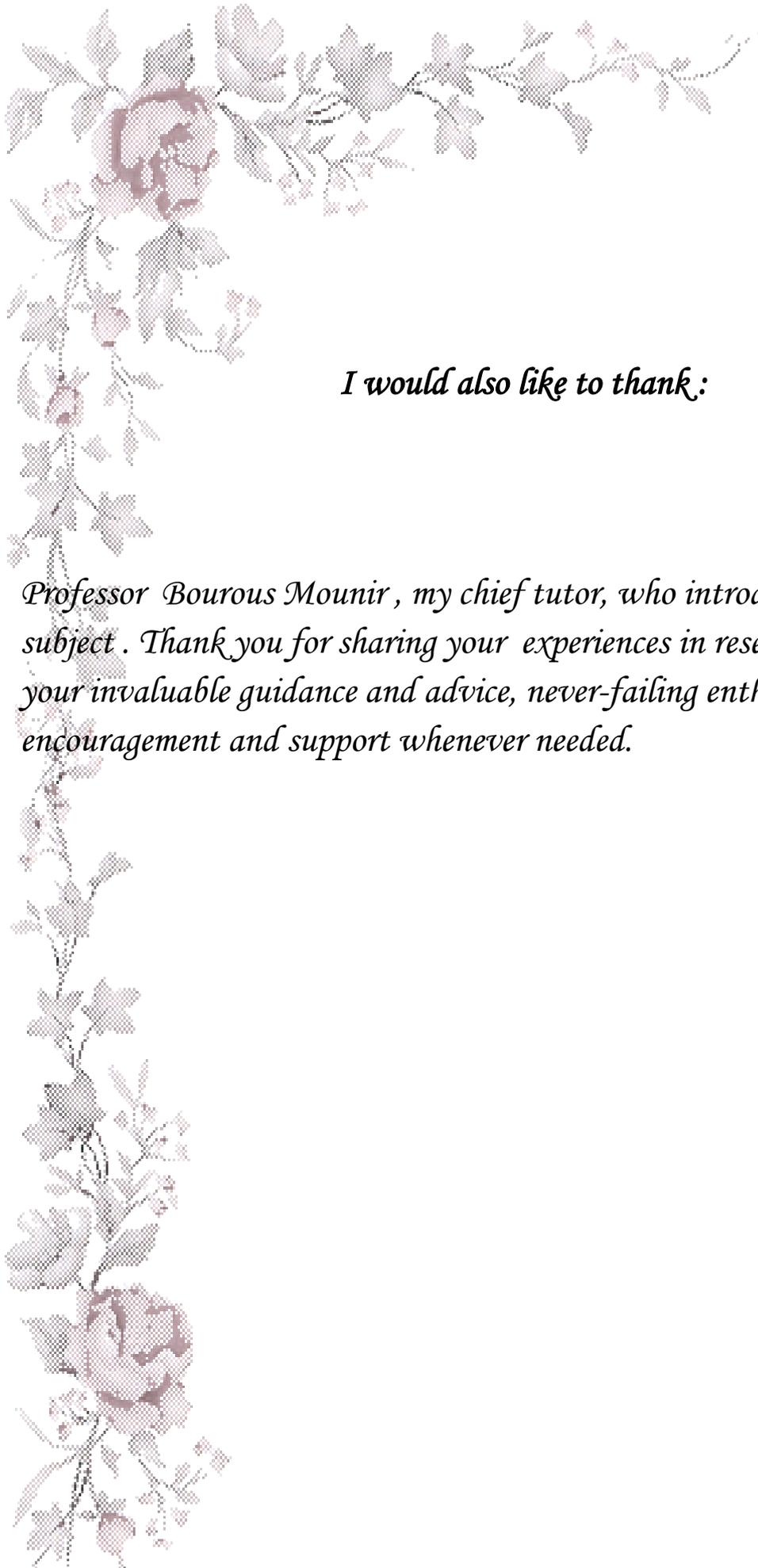




*I wish to thank everyone who contributed to this thesis. I would particularly like to thank:*

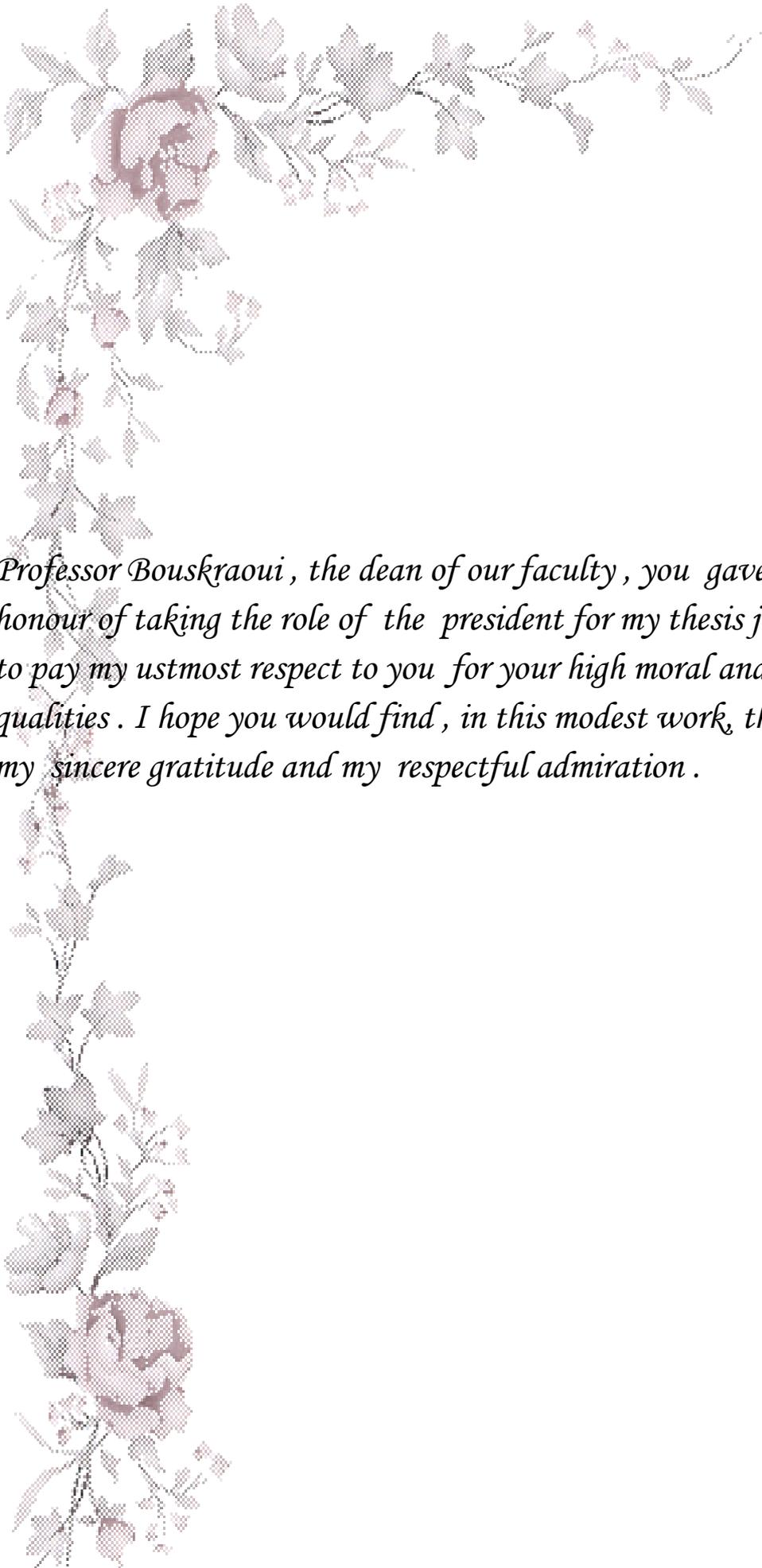
*All the epilepsy patients who participated in this study and generously contributed their time to my research.*

*My friend and fellow doctor Adil Mansouri, from the epidemiology department, for his huge help when it comes to the statistical work and results of this study.*

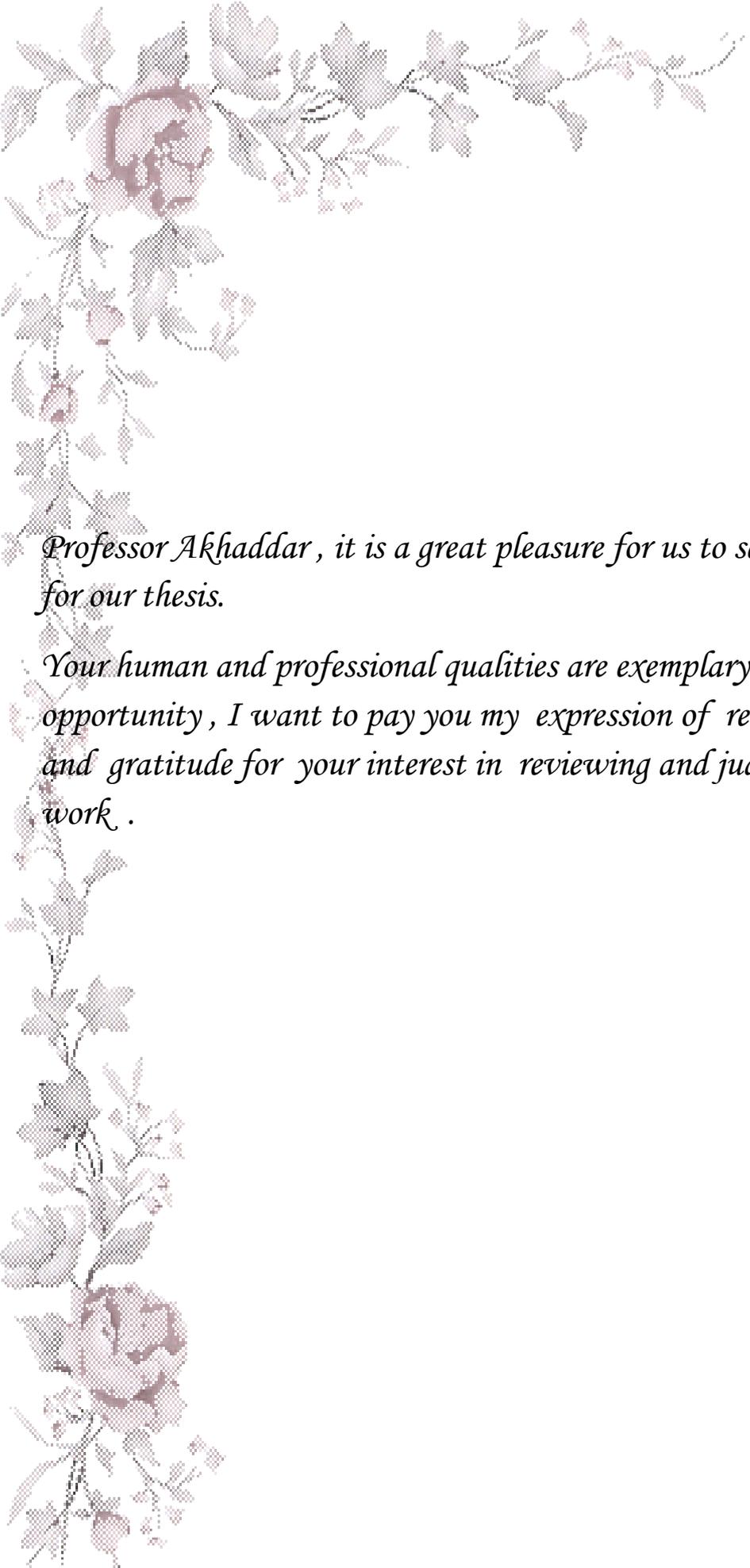


*I would also like to thank:*

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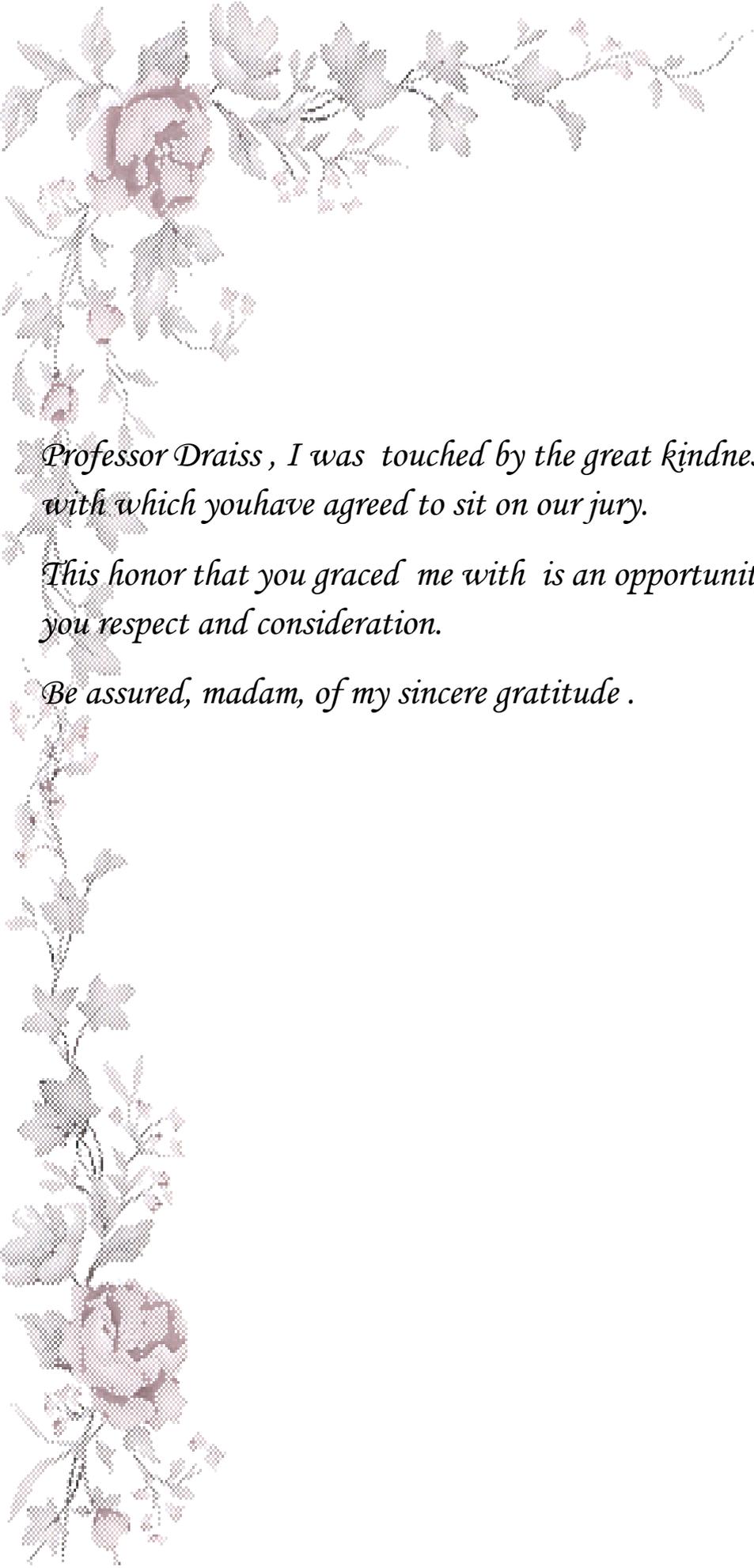
*Professor Bouskraoui , the dean of our faculty , you gave me the huge honour of taking the role of the president for my thesis jury . I would like to pay my utmost respect to you for your high moral and professional qualities . I hope you would find , in this modest work, the expression of my sincere gratitude and my respectful admiration .*



*Professor Akhaddar, it is a great pleasure for us to see you sit on the jury for our thesis.*

*Your human and professional qualities are exemplary. Through this opportunity, I want to pay you my expression of respect, appreciation and gratitude for your interest in reviewing and judging my modest work.*





*Professor Draiss , I was touched by the great kindness and spontaneity with which you have agreed to sit on our jury.*

*This honor that you graced me with is an opportunity for me to testify to you respect and consideration.*

*Be assured, madam, of my sincere gratitude .*



*ABBREVIATIONS*



AED : anti-epileptic drug

CWE : children with epilepsy

EEG : electroencephalogram

HR-QOL : health related quality of life

ILAE : international league against epilepsy

QOL : quality of life

SE : status epilepticus

SPSS : statistical package for the social sciences

CEQ-P : child epilepsy questionnaire parental form



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*INTRODUCTION*



Epilepsy is a chronic disease of the brain that affects people of all ages. It is one of the most common neurological diseases globally with approximately 50 million people worldwide suffering from it .

It is a common chronic illness of childhood and evaluating the epileptic children's quality of life in its globality is hard to obtain .

WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (1) .

Traditionally, clinicians have focused on treating the physical aspects of epilepsy; however, there are other factors, including psychological facets, which can also affect the health-related quality of life (HR-QOL). Research using HR-QOL assessments in chronic disease has had important implications for epilepsy management and overall outcomes. It has been found that children and adolescents with epilepsy have a lower HRQOL than healthy counterparts and an increased risk for maladjustment and poor quality of life (QOL) in different domains than children with other chronic health problems, such as diabetes or asthma. Psychological or psychosocial problems, such as emotional, behavioral, or environmental problems and social stigma, are faced by children and adolescents with epilepsy (1) .

Therefore QOL should be an important outcome measure in the management of children with epilepsy , rather than only seizure control .

-Goals of the study :

Taking the fact that our study is the first of its kind in Morocco into consideration , the purpose of this work is to analyse the overall QOL of children with epilepsy in order to identify the contributing factors amenable to change, therefore helping clinicians and researchers to envision opportunities and improve manageable aspects of epileptic children and adolescent's

## **Quality of life in children with epilepsy**

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QoL. In addition to shaping clinical activities in engagement with children and families, these factors can be the focus of specific intervention studies for better management of their chronic illness. Thus enabling the child and his/her family to lead a life as close to normal as possible and avoid a lot of the medical and psychosocial complications of epilepsy .



*PATIENTS  
AND METHODES*



### **I. Type of the study :**

This is a descriptive cross sectional study .

### **II. Definition of the target population :**

This study was conducted in the pediatric emergency department of the Mohamed VI university Hospital of Marrakech. It targeted epileptic children attending consultations and check ups .

### **III. Sampling :**

The sample consisted of 104 patients .

#### **1. Inclusion criteria :**

Epilepsy was defined by the presence of two or more unprovoked seizures . Children aged between 5 and 16 years with a minimum seizure duration of 1 year that had been receiving antiepileptics for at least one year were the cases .

#### **2. Exclusion criteria :**

Children with severe disabilities, global developmental delay or other known chronic illnesses were excluded from the study. Children whose primary caregiver was not available to answer the questionnaire were also excluded .

### **IV. Progress of the study :**

The study was conducted for a period of one year.

#### **1. Recruitment of patients :**

Parents of epileptic children from the pediatric emergency department during consultations, were interviewed using the questionnaire chosen for our study , after ethical

approval and an informed consent. Some were contacted through a phone call interview for an ulterior consultation .

### **2. Data collection :**

Every patient with his/her caregiver were seen individually in their follow up consultation , a researcher was present during the completion of the questionnaire and clarified any queries , and thereby ensured that the questionnaire items were not misunderstood .

Then a physical examination was conducted .

### **V. Questionnaire, variables and measurement indicators :**

The instrument used consisted of two parts . Part one contains items assessing demographic profile , and informations on the disease . Part two contains items specifically assessing the QOL of CWE (QOLCE 16) . The QOLCE is a specific measure for quality of life in children with epilepsy. The QOLCE 16 that we 're using in our study is a brief recently validated version, and given the short estimated completion time, it is an appropriate measure for clinicians looking to capture HR-QOL (2) .

- The QOLCE 16 was divided into 4 sections :
- Section 1 : the child's cognitive functioning
- Section 2 : the child's emotional functioning
- Section 3 : the child's social functioning
- Section 4 : the child's physical functioning
- Each section consisted of 4 items .
- The scoring consisted of recoding all items such that higher scores indicate higher well being .
- The full score is 100. The higher the score, the better the QOL of the children.

## **VI. Ethical considerations :**

To protect the patient's confidentiality, the questionnaire was anonymous. The goals of this study were thoroughly explained to them. The questionnaire was filled after obtaining the caregiver's consentment . For illiterate patients , the author completed the questionnaire .

## **VII. Statistical methods used in our study :**

The statistic analysis was done using SPSS software .



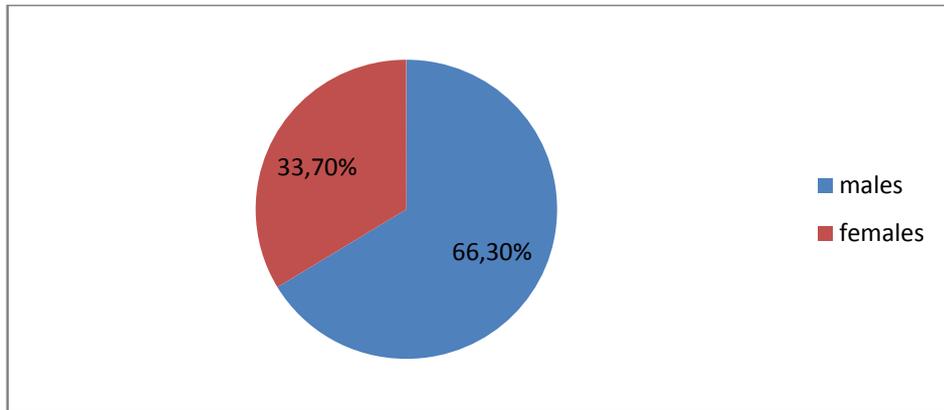
*RESULTS*



## I. Socio-demographic variables among children with epilepsy :

### 1. Gender :

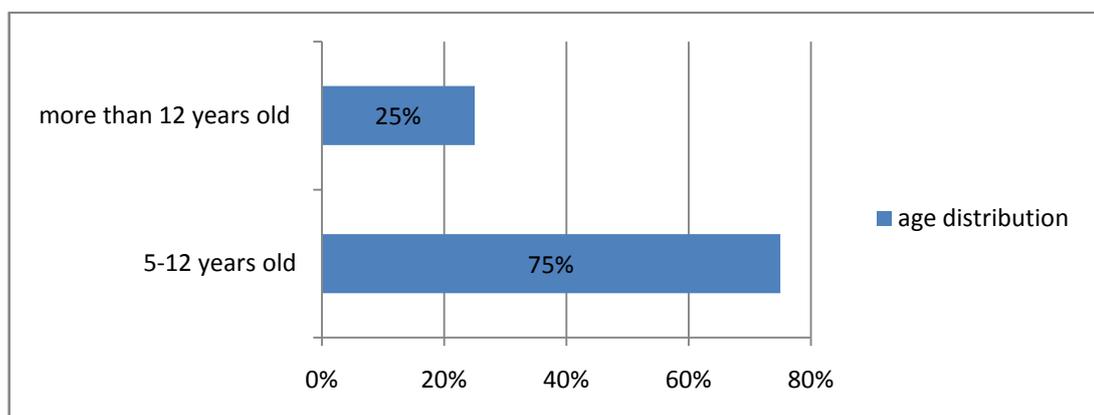
The sex ratio in this study's sample is 1.94 .



**Figure n° 1 : The gender distribution in children with epilepsy**

### 2. Age :

The age range of epileptic children during our consultation was between 5 and 16 years old .

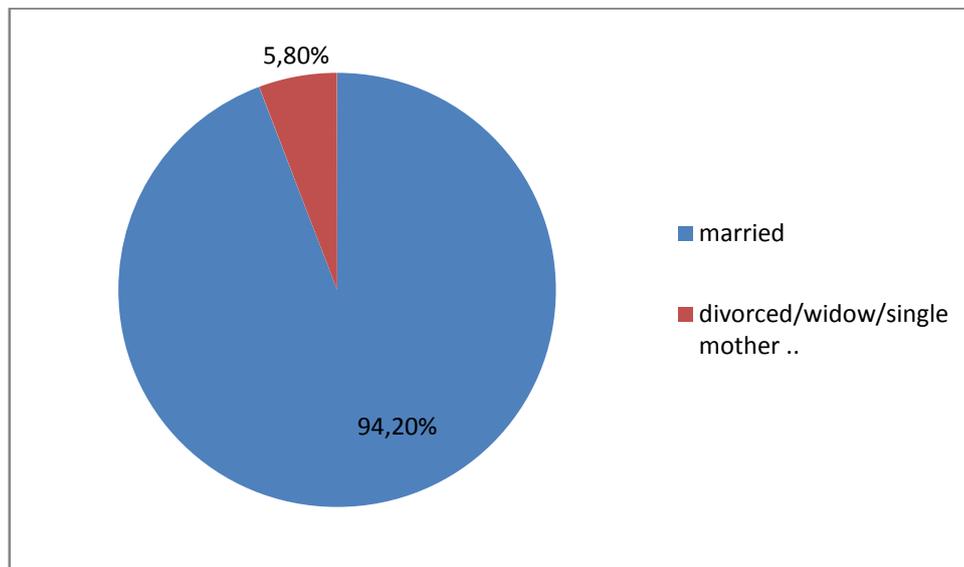


**Figure n°2 : The age distribution in children with epilepsy**

**3. Areas of residence :**

52.9 % of patients lived in urban areas while 47.1% lived in rural areas .

**4. Marital status distribution :**



**Figure n°3 : The parents' marital status**

**5. Consanguinity :**

The notion of consanguinity was found in 24 % of the patients .

**6. Parents' income :**

In this study, 55.8% of children's parents had decent income while 44.2 % had low income.

**7. Schooling :**

Only 6.7 % were out of school due to their illness . 93.3 % children were attending school.

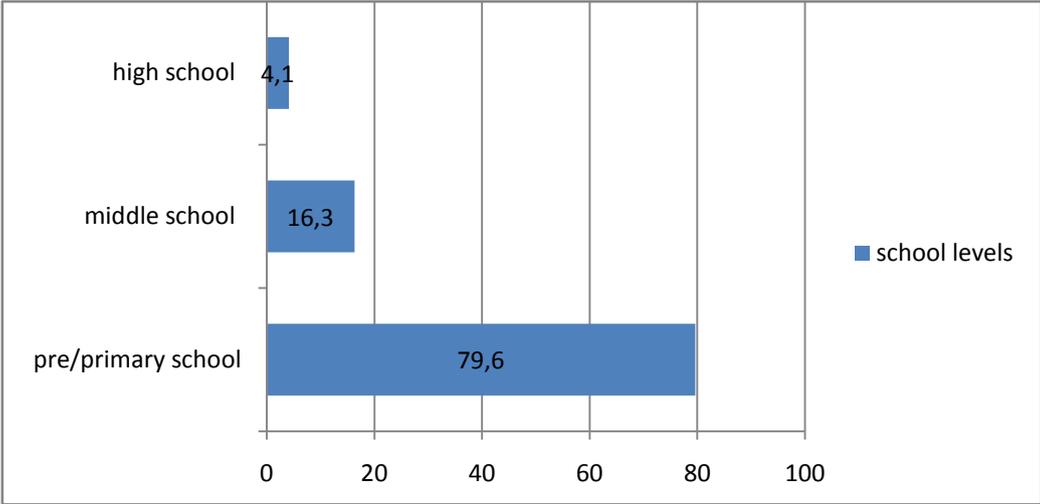


Figure n°4 :Distribution of the schooling levels of children with epilepsy

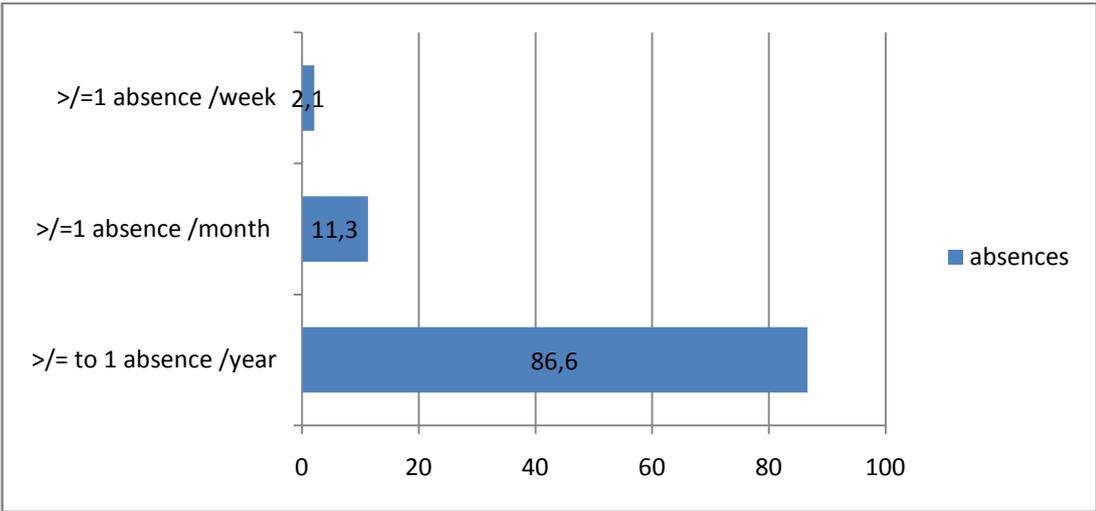
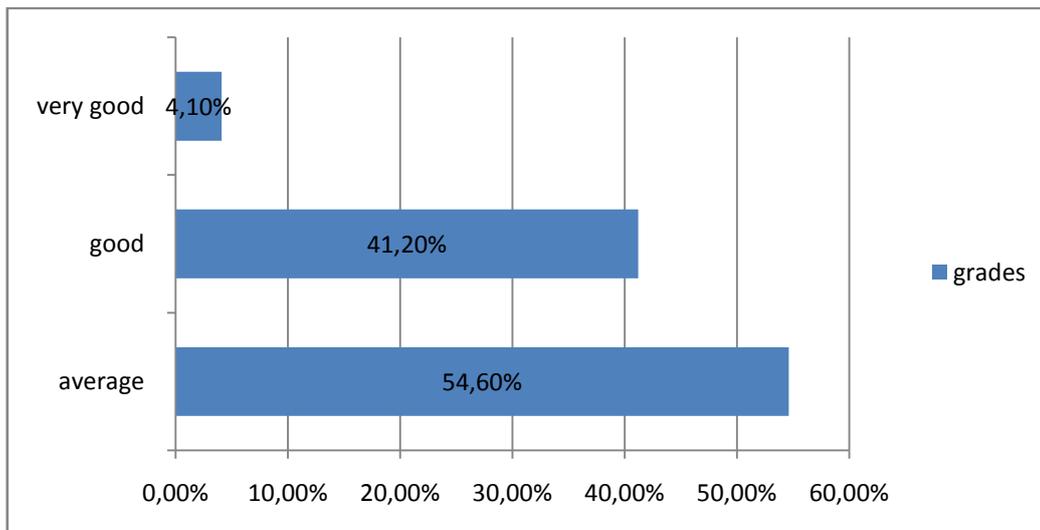


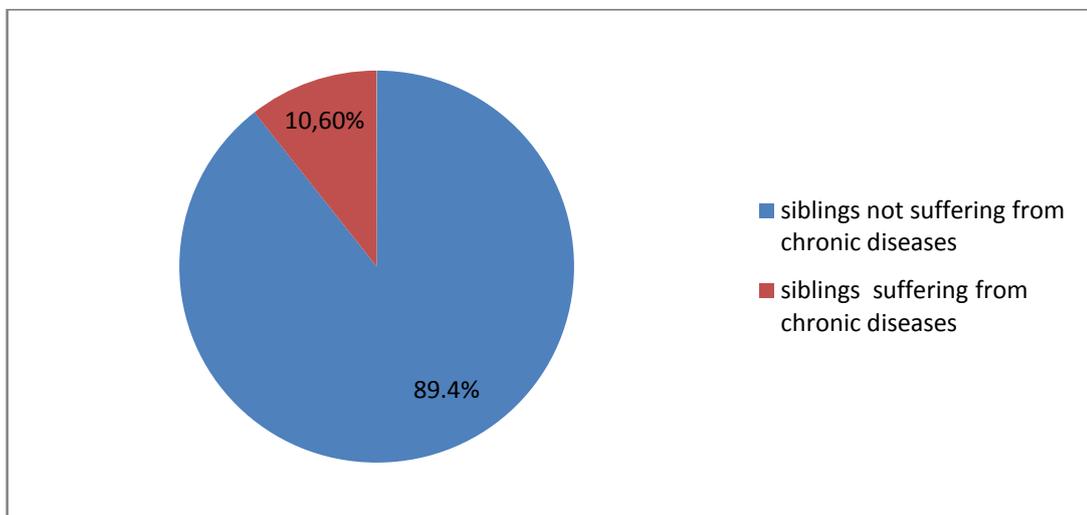
Figure n°5 : Distribution of the presences/absences at school



**Figure 6 : Distribution of the grades at school**

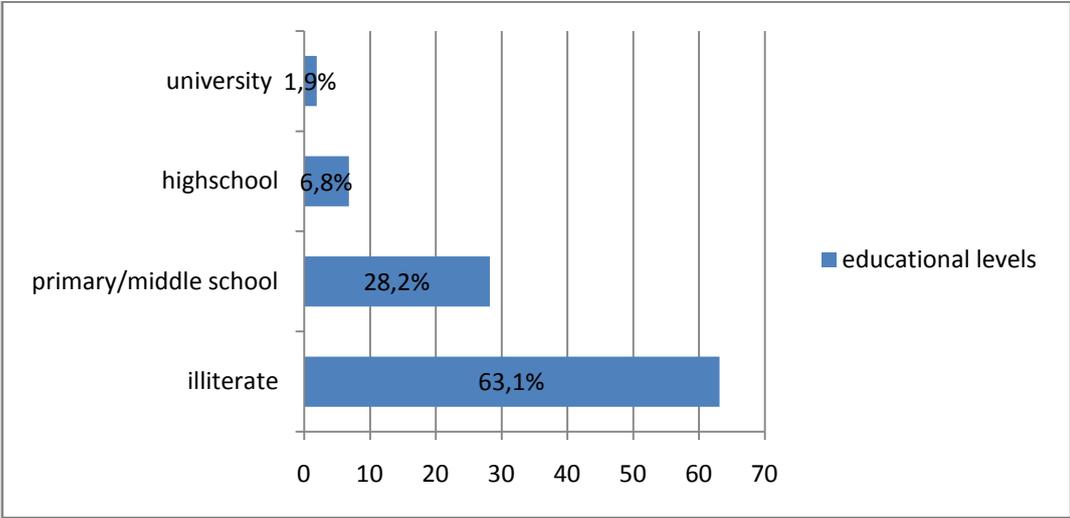
### **8. Siblings :**

The majority of patients had siblings (90.4%) , of whom only 10.6% suffered from chronic diseases .



**Figure n°7 : Distribution of chronic diseases in siblings**

**9. The mother's level of education :**



**Figure n°8 : Distribution of the educational levels of the caregivers**

**10. Caregivers :**

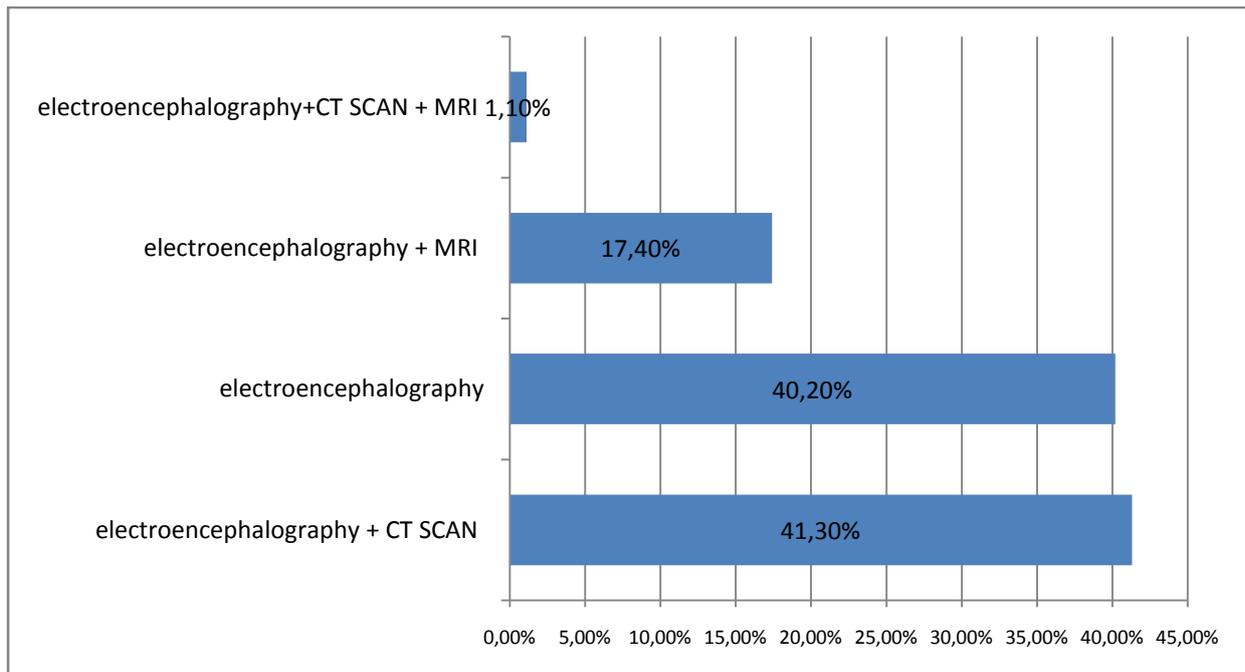
All caregivers were mothers except one case where the caregiver was a grandmother.

## II. Epileptic variables among study group :

### 1. Diagnosis of epilepsy :

Epilepsy was diagnosed in the majority of our patients based on history + neuroimaging (88.5 %), while only 11.5 % of the patients had a diagnosis based on history alone.

### 2. Means of neuroimaging :



**Figure n°9 : distribution of the diagnostic techniques :**

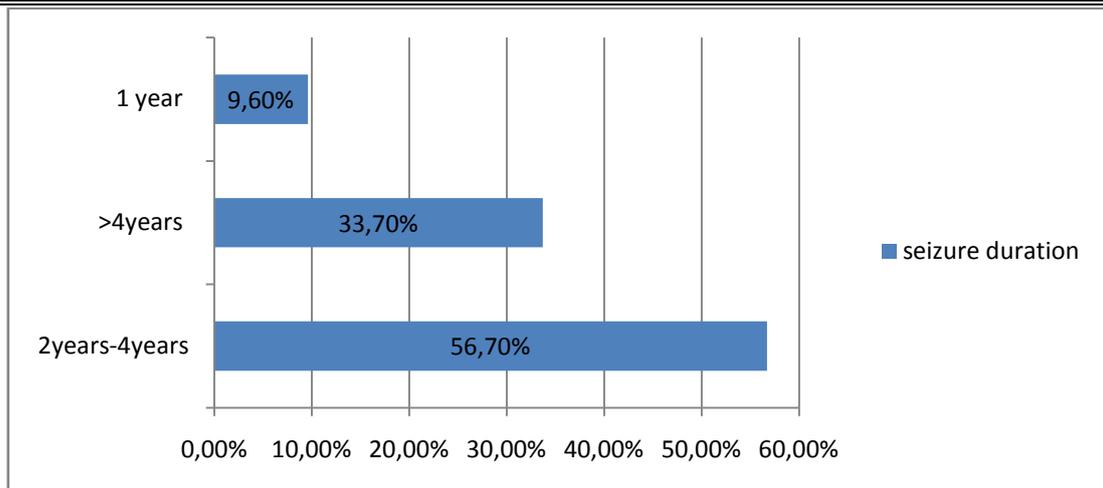
### 3. Types of seizures :

79.8% of the children had generalised epilepsy while 20.8% of them had partial seizures .

### 4. Seizure duration distribution :

Only 9.6% of the patients had a seizure duration of 1 year. The majority of children had a seizure duration of more than 1 year 90.4%.

## Quality of life in children with epilepsy

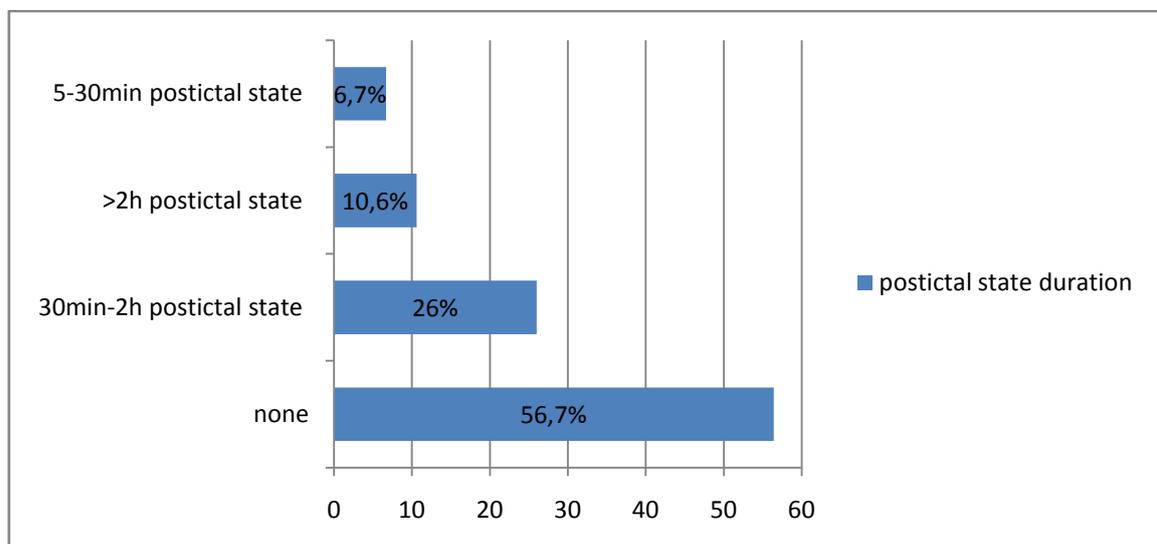


**Figure n°10 : Distribution of the seizure duration in children with epilepsy**

### 5. Last seizure :

58.7% of patients had their last seizure less than one year ago ; 41.3% had their last seizure 1 year ago or more .

### 6. Postictal state distribution :



**Figure n°11: Distribution of the postictal state duration in children with epilepsy**

### 7. Seizure frequency distribution :

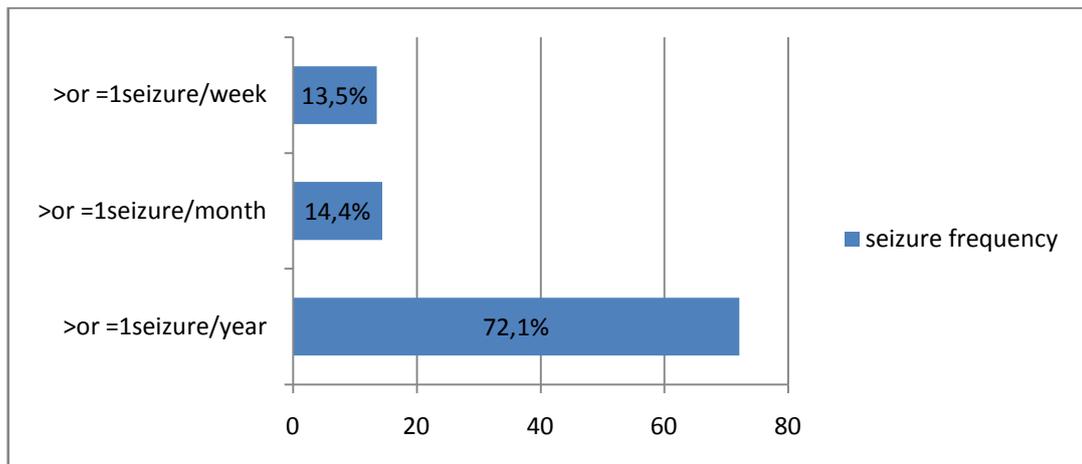


Figure n°12 : Seizure frequency distribution in children with epilepsy

### 8. Therapy :

90.4% of epileptic children in our study were placed on monotherapy while only 9.6% were under polytherapy .

➤ **Anti epileptic drugs prescribed to our patients :**

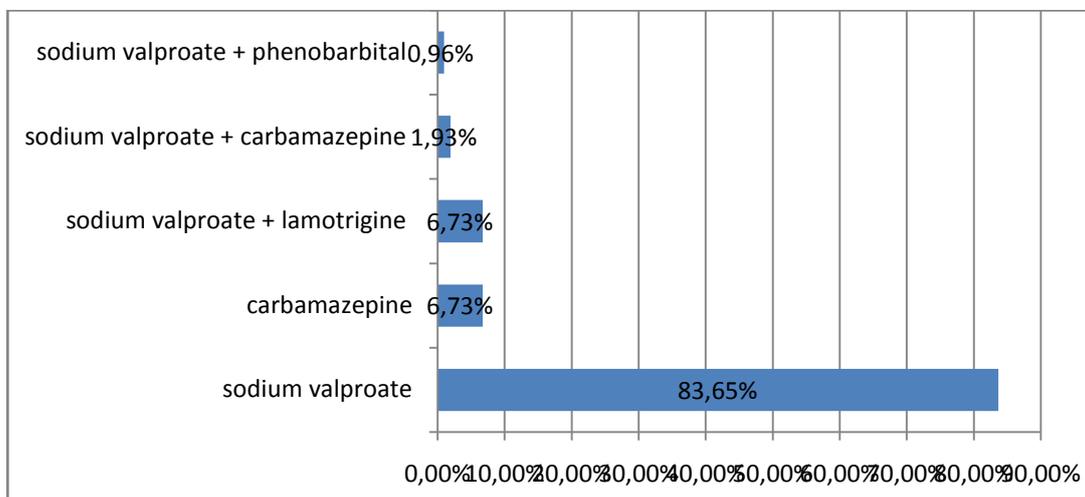
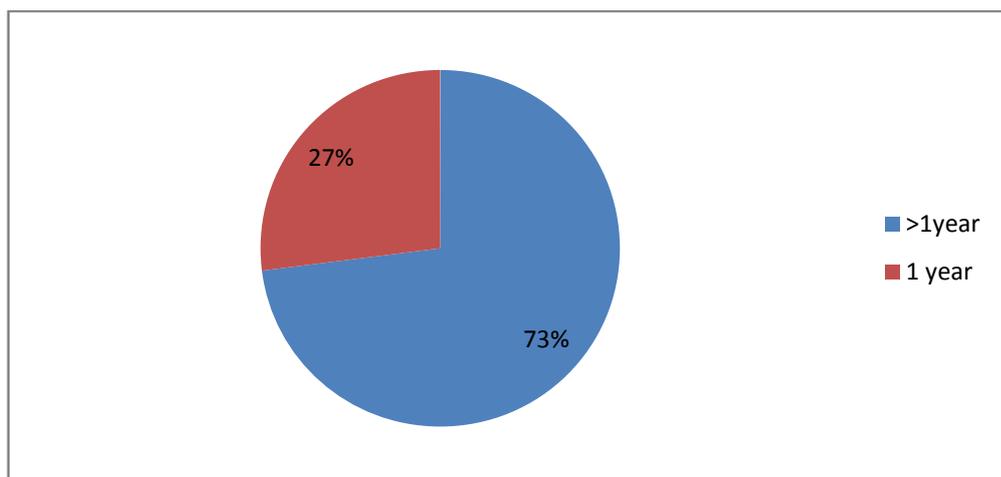


Figure n°13 :Distribution of AEDs that children with epilepsy were placed on

➤ Treatment duration :



**Figure n°14 : Distribution of the AED treatment duration of children with epilepsy**

**Univariate study results :**

The relationship between overall QOL and various patient and disease characteristics is shown in Table 3 and table 4 respectively .

The overall QOL of each domain was shown in table 1.

The mean score of each subscale was shown in table 2.

The mean overall QOL score was  $83,70 \pm 21.88$ . The physical section was found to be affected the most with the lowest mean score of  $78.84 \pm 14.99$ . Its lowest mean Item was about parental supervision with a 44.95 (table 2).

**Table n°1**

Domains of QOL	QOLdomain score
Cognitive	$88.52 \pm 18.68$
Emotional	$80.76 \pm 16.60$
Social	$86.71 \pm 21.02$
Physical	$78.84 \pm 14.99$

## Quality of life in children with epilepsy

**Table n°II**

Items of each domain :	Mean score of each item
Cognitive functioning :	
Q1	91.35
Q2	82.45
Q3	92.79
Q4	87.50
Emotional functioning :	
Q5	87.02
Q6	86.06
Q7	81.01
Q8	68.99
Social functioning :	
Q9	86.30
Q10	85.34
Q11	87.74
Q12	87.50
Physical functioning :	
Q13	94.23
Q14	93.99
Q15	82.21
Q16	44.95

**Table n°III**

Variable	Cohort	Mean QOL scores +/-SD	Significance (P value )
Age	>12 (n=26)	79.86 ± 14.26	0.10 (>0.05)
	5-12 (n=78)	84.99 ± 13.74	
Gender	Male (n=68)	84.60 ± 13.11	0.40 (>0.05)
	Female (n=35)	82.01 ± 15.77	
Residence	Urban (n=55)	81.81 ± 14.00	0.14 (>0.05)
	Rural (n=49)	85.84 ± 13.80	
Marital status of the parents	Married (n=97)	83.86 ± 13.96	0.51 (>0.05)
	Single (n=6)	79.94 ± 16.42	
Mother's level of education	Educated (n=38)	85.81 ± 13.78	0.24 (>0.05)
	Illiterate (n=65)	82.42 ± 14.15	
Children attending school	Yes (n=97)	84.40 ± 13.04	0.06 (>0.05)
	No (n=7)	74.11 ± 22.78	

**Table n°IV**

Variable	cohort	Mean QOL scores +/-SD	Significance (P value)
Type of epilepsy	Partial (n=21)	80.58 ± 15.89	0.26
	Generalised (n=82)	84.43 ± 13.51	0.31
Seizure duration	1 year (n=10)	88.28 ± 9.80	0.28
	>1 year (n=94)	83.22 ± 14.31	0.16
Seizure frequency	Once in a week/month (n=29)	76.72 ± 17.06	0.01 (<0.05)
	Once in a year (n= 75)	86.41 ± 11.64	
Therapy	Monotherapy (n=94)	84.87 ± 13.14	0.09 (<0.05)
	Bi/polytherapy (n=10)	72.81 ± 17.51	
Therapy duration	1 year (n=28)	87.16 ± 12.81	0.12
	>1 year (n=76)	82.44 ± 14.26	

**Table n°V : Relationship of demographic factors with the QOL domains**

	Age		Residence		Parents marital status		Maternal education	
	5-12 y P value	>12 y P value	Urban P value	rural P value	Married P value	single P value	Yes Pvalue	no Pvalue
Cognitive section	87,90 ±19,84 0.56	90,38 ±14,81	85,90 ±21,15 0.13	91,45 ± 15,13	89,49 ±16,72 0.25	71,87 ± 38,27	89,30 ±21,00	87,88 ±17,43 0.71
Emotional section	84,45 ±14,96 0.00 (S)	69,71 ± 16,64	78,29 ±15,95 0.10	83,54 ±17,05	81,05 ±16,47 0.47	76,04 ± 21,07	85,03 ±16,34	78,46 ±16,46 0.05
Social section	88,38 ±18,64 0.24	81,73 ±26,74	86,70 ±19,72 0.99	86,73 ±22,59	86,01 ±21,53 0.02 (S)	95,83 ± 7,56	90,29 ±18,01	84,51 ±22,59 0.15
Phisical section	79.08 ±16.60 0.63	80.24 ±15.85	76,36 ±15,76 0.73	81,63 ±13,70	78,86 ±15,02 0.65	76,04 ±15,52	78,61 ±15,62	78,84 ±14,81 0.94

## Quality of life in children with epilepsy

**Table n° VI : The relationship of the patients characteristics with the domains of QOL :**

	Type of epilepsy		Seizure frequency		Seizure duration		Therapy		Therapy duration	
	focal	generalised	F1	F2	1y	>1y	Mono	poly	1y	>1y
	P value		P value		P value		P value		P value	
Cognitive section	83,03 ±19,97	89,78 ± 18,28	89,50 ±18,18	85,99 ± 20,02	97,50 ± 6,03	87,56 ± 19,32	89,49 ±18,40	79,37 ±19,77	95,31 ± 11,73	86,01 ± 20,15
	0.14		0.39		0.01 (S)		0.10		0.005 (S)	
Emotional section	82,14 ±17,48	80,25 ± 16,50	83,58 ±15,67	73,49 ±17,00	85,00 ± 12,56	80,31 ± 16,97	81,78 ±16,18	71,25 ± 18,4	82,58 ± 14,46	80,09 ± 17,37
	0.64		0.005 (S)		0.39		0.05		0.50	
Social section	79,16 ± 21,04	88,49 ± 20,79	91,58 ± 15,29	74,13 ± 27,93	90,62 ± 20,25	86,30 ± 21,16	88,56 ± 19,21	69,37 ± 29,52	89,95 ± 21,26	85,52 ± 20,94
	0.07		0.03 (S)		0.53		0.04 (S)		0.343	
Physical section	77,97 ± 16,95	79,19 ± 14,60	78.5 ± 17.90	74.99 ± 19.98	72.6 ± 13.40	73.7 ± 16.80	79,65 ± 14,31	71,25 ± 18,58	77,80 ± 16,90	76,40 ± 17,02
	0.74		0.018 (S)		0.79		0.92		0.422	



*DISCUSSION*



## I. Concept of quality of life :

### 1. Historical background :

Philosophers have through all ages been occupied with the immense questions and seemingly unsolvable problems related to the quality of human life. For half a century grand thinkers have been reflecting on the meaning of life and how to improve it (3).

This was a propulsion to start researches on subjective well-being and quality of life.

As philosophy is the basics of science, a new theory emerged where the purpose is to take a close view of life as a unique entity, which mechanical models are unable to do. This means that things considered to be beyond the individual's purely biological nature, which was what traditional medical science has often been inspired by, notably the quality of life, meaning in life, and aspirations in life, are included under this perspective (4).

### 2. Definition of QOL :

Many approaches to define quality of life exists , and setting one unanimous definition has proven to be challenging, as it can refer both to the experience an individual has of his or her own life and to the living conditions in which individuals find themselves. The term's subjectivity can simply be portrayed if we compare a person who may define quality of life according to wealth or satisfaction with life, while another may define it in terms of capabilities, as an exemple, a disabled person may report a high quality of life, whereas a healthy person who recently lost a job may report a low quality of life.

Therefore quality of life comprises both subjective and objective indicators to evaluate different aspects of an individual's well being together with his own set of values . It is viewed as a multidimensional concept, encompassing physical, psychological and social well being . According to WHO the physical domain includes independence in activities of daily living and symptoms of disease, the psychological domain involves emotional, cognitive and behavioral

## **Quality of life in children with epilepsy**

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statuts, and the social domain, how people perceive their role and relationship with other people (5). When it comes to epilepsy, which is a common chronic illness of childhood, it was hypothesized that psychological co-morbidity, child characteristics, and environmental factors influence epileptic outcomes more than epilepsy-specific variables. It has also been found that children and adolescents with epilepsy have a low HR-QOL than healthy controls and have more risk of maladjustment than children with other chronic diseases. Overall these children do not only have a reduced QOL but also a poor epilepsy outcome. Therefore the necessity of assessing the QOL in epileptic children and adolescents should be a major part of the treatment process (1) .

### **3. Quality of life measurements :**

There are several broad categories of quality-of-life measurements. These include generic indicators, which assess function, disability and distress resulting from general ill health; it also allows comparisons with healthy population. Disease-specific measures, such as those designed to evaluate health-related quality of life in specific illness groups; and individualized measurements, which allow the inclusion of aspects of life that are considered important by individual patients. Examples of quality-of-life measurements include the pediatric quality of life inventory, the child health and illness profile, and the youth quality of life. These measures have been shown to correlate with disease severity, discriminate between health and chronically ill populations, and can be used to compare across adolescents with different chronic illnesses. However, because they are general, they lack precision and sensitivity to change. In contrast, disease-specific HR-QOL measures focus on the domains of functioning most relevant for a particular disease and its treatments. For example, there are Several disease-specific HR-QOL measures for adolescents with chronic diseases that have been developed for adolescents with a range of illnesses including, diabetes, obesity, cystic fibrosis, cancer, asthma, epilepsy, and HIV/AIDS (6).

#### **4. Reasons to measure quality of life :**

There are many uses for quality of life measures in clinical practice, such as:

Identifying and prioritizing problems, because the measurement records information on a range of problems allowing the patient and the doctor or nurse to identify which problems are most important. They can thus agree on priorities. This is particularly useful when patients have multiple problems. Additionally, these measures can be used to capture information that superficially seems to have no clinical relevance but might explain disease severity or coping problems.

Facilitating communication, because the measure presents clear information on a range of problems. If correctly applied it may speed the clinical encounter and help staff to focus on the patient's main concerns.

Screening for hidden problems. Some patient's problems can be overlooked unless specifically inquired about, especially psychological and social problems. For example, a measure that asks, "Would you describe your mood as depressed most of the time," is a sensitive and specific screening tool for depression .

Facilitating shared clinical decision making. Used in this way, assessments help identify the patient's preferred outcome or treatment goals. If these are not known, then the treatment may not meet the patient's expectations, and this may affect adherence to treatment and the patient's satisfaction with care.

Monitoring changes or responses to treatment, because change is usually monitored through laboratory or clinical tests rather than the patient's perception of change. Inability to bring out improvements that are seen as relevant to the patient may affect adherence to treatment(7) .

## **Quality of life in children with epilepsy**

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The challenge in measuring quality of life lies in its uniqueness to individuals. Questions arise as to what extent the standardized QOL measures are actually representing the quality of life of individual patients or groups of patients (8) .

## **II. Epilepsy :mechanismn , diagnosis , managment :**

### **1 – Epidemiological profile**

Epilepsy affects 0.5% to 1% of children and is the most frequent abstract chronic neurologic condition in childhood. Incidence rates appear to be declining in high income countries (9) . The validity of epilepsy diagnoses from different data sources varies, and contemporary population–based incidence studies are needed.

Based on the epidemiological profile of a study held in the pediatric department in the university hospital of Marrakech, children with Epilepsy represented 5.8% of the children seen in the pediatric daily hospital and 2.61% of children hospitalised in the pediatric department from january 2008 to december 2012. The majority were males, which is consistant with our study (10) .

### **2 – Definitions :seizure and Epilepsy**

Little common agreement exists on the definition of the terms seizure and epilepsy. A definition is a useful tool for communication, diagnosis, and differential diagnosis. Consequently, the representatives of the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy set a proposal that presents practical and operational definitions applicable both in medical and non medical settings.

Therefore, an epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain.

## **Quality of life in children with epilepsy**

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On the other hand, Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (11).

### **3- Elements of a definition of epileptic seizure :**

First of all, mode of onset and termination. An epileptic seizure is demarcated in time, with a clear start and finish. Termination of an epileptic seizure often is less evident than is the onset, because symptoms of the postictal state can blur the end of the seizure. They can be determined on behavioral or EEG grounds .

The second element consists of clinical manifestations. Seizure presentation depends on location of onset in the brain, patterns of propagation, maturity of the brain, confounding disease processes, sleep-wake cycle, medications, and a variety of other factors. Seizures can affect sensory, motor, and autonomic function; consciousness; emotional state; memory; cognition; or behavior, sensory manifestations are taken to include somatosensory, auditory, visual, olfactory, gustatory, and vestibular senses, and also more complex internal sensations consisting of complex perceptual distortions. Not all seizures affect all of these factors, but all influence at least one.

The third element consists of an abnormal enhanced synchrony. This is the most difficult feature of the definition to apply in practice, because the electrical discharge is visible only under some circumstances of testing. Patients with recurrent seizures may have a normal scalp EEG between seizures and even during seizures (11).

### **4- Elements of a definition of Epilepsy:**

History of at least one seizure is required to establish the presence of epilepsy; a predisposition, as determined, for example, by a family history, or by the presence of

## **Quality of life in children with epilepsy**

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epileptiform EEG changes, is not sufficient to determine epilepsy. The definition does not include a requirement that the seizure be unprovoked, instead, the definition requires, in addition to at least one seizure, the presence of an enduring alteration in the brain that increases the likelihood of future seizures.

At times, epilepsy must be defined by more than just the recurrence, or a potential for recurrence, of seizures. For some people with epilepsy, behavioral disturbances, such as interictal and postictal cognitive problems, can be part of the epileptic condition (11) .

## **5-Status epilepticus :**

Seizures can begin in one or both hemispheres of the brain, alter an individual's awareness of their surroundings, or cause an individual to experience motor symptoms . An early diagnosis, treatment, and specific medical support must be performed to prevent Status Epilepticus (SE). Status epilepticus (SE) is a condition where seizures are abnormally prolonged (for a time period of 5 min or more) either due to the failure of the mechanisms leading to seizure termination or from the initiation of a mechanism. It is a condition, which can have long-term consequences (especially if its duration is more than 30 min) including neuronal death, neuronal injury, and alteration of neuronal network, depending on the type and duration of seizures (12).

## **6-Classification of seizures :**

Classification of pediatric epilepsies follows the ILAE's still-valid 1989 revised Classification of Epilepsies and Epileptic Syndromes approach. It uses etiology and seizure localization to classify epilepsies. This classification is still the current classification system, and all subsequent updates have been proposals. The seizure localization component divides seizures into three categories: partial (focal,local), generalized(convulsive or nonconvulsive), and unclassified. The partial seizures were divided into simple, complex, and secondarily generalized, while the generalized seizures included absence, atypical absence, myoclonic,

## **Quality of life in children with epilepsy**

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clonic, tonic, tonic-clonic, and atonic. The etiological categories include idiopathic, symptomatic, and cryptogenic (characterizing epilepsies with a presumed but unknown cause) (13).

Once a child experiences a first unprovoked seizure the risk of recurrence ranges from 30 to 50 % within the following 2 to 5 years. Although the immediate treatment after a first unprovoked seizure may reduce the risk of recurrence within the first 1–2 years, it does not modify the long term outcome. Therefore antiepileptic drugs (AED) are rarely used after the first seizure unless the risk of injury and harm from seizures is prominent. Treatment is rather initiated after the second unprovoked seizure as per recommendation (14).

## **7– Risk factors for childhood epilepsy:**

Risk factors of childhood epilepsy varied depending on demographic characteristics, for example in a study from Irbid in Jordan (15) showed that history of febrile convulsions, head trauma, abnormal perinatal history and family history showed a statistically significant increase risk for developing epilepsy.

While another study in Iran (16) showed that a positive family history of epilepsy and residence in rural areas were the two major risk factors associated with epilepsy in this study.

On the other hand, a study in Oran in Algeria (17), found that consanguinity, family history of epilepsy, history of febrile seizures, severe head trauma and mental retardation are risk factors for epilepsy.

## **8– Children’s difficulties due to their illness:**

More often than not, Children with epilepsy who reside in the African continent are faced with some of the greatest challenges of receiving adequate care. The burden of disease is exacerbated by the high incidence of acquired causes and the large treatment gap. Skilled teams to identify and care for children with epilepsy are lacking (18). These difficulties inevitably impact the child’s well being and daily activities. As it happens, it has been reported

## **Quality of life in children with epilepsy**

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that 15 % of the school-age senegalese children were excluded from school because of their seizures (19).

In a study of epileptic children's characteristics that were followed in the Marrakech University Hospital from 2003 to 2007 , more than one third of the school-age children's scholasticity was perturbed (20). A later study found that 18 % abandoned school while 23 % had school difficulties (10).

In fact, Wakamoto et al (21) in his study where he showed the long-term medical, educational, and social outcomes in individuals with a history of childhood-onset epilepsy aged 20 years or older, in a defined area of Japan with a mean follow-up period of 18.9 years, that these patients had lower levels of educational backgrounds .

However, in our study only 6.7 % of the children were out of school, but 53 % of them had average and below average grades reflecting their difficulties.

### **III. Measurements of the QOL in children with epilepsy :**

QoL instruments for children and adolescents with neurodisabilities were reviewed and described based on their purpose, conceptual focus, origin of domains and items, opportunity for self report, clarity (lack of ambiguity), potential threat to self-esteem, cognitive or emotional burden, number of items and time to complete, and psychometric properties. Several generic and condition-specific instruments were identified for administration to children and adolescents with neurodisabilities, such as: cerebral palsy, epilepsy and spina bifida, and hydrocephalus. Many have parent-proxy and self-report versions and adequate reliability and validity (22).

## **Quality of life in children with epilepsy**

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The generic scales used to measure the QOL like child health questionnaire are insufficiently sensitive to epilepsy (6).

A number of epilepsy-specific health-related quality of life (HRQL) scales for children have been developed with the aim to include and measure accurately the impact and burden of epilepsy. Specific measures, Similarly to generic measures, address areas such as physical and emotional functioning. They also cover issues that may be predominant among patients with epilepsy (e.g, perceptions of social stigma...). Only a few studies to date have utilized these or generic HRQL measures to assess the HRQL of specific populations with epilepsy (23). In this category we find parental form like CEQ-P, or the patient reported questionnaire such as quality of life in childhood epilepsy (QOLCE-76/55/16).

In our study, we used a two sections questionnaire. The first section holds the patient's and the disease's characteristics, while the second part holds a brief version of the quality of life in childhood epilepsy questionnaire (QOLCE 16). It is a multidimensional measurement of health related quality of life (HR-QOL) with good psychometric properties and a short-estimated completion time (2).

## **IV. Confronting our results with literature :**

Epilepsy is a disease that has an important repercussion on children's psychological development and social life. It interferes with their personal and professional relationships due to the many stigmas that are hovering around it. Therefore affecting their quality of life on various levels. Through years, multiple studies showed either a negative public attitude towards epilepsy or a barely acceptable one with misconceptions still strongly present [24, 25]. Opposed to some studies in western Europe that reflected a mainly positive attitude (26).

From the children's perspective, QOL is not related to seizure severity but is associated with mental health and peer and parental support (27). A study that examined the relationship

## **Quality of life in children with epilepsy**

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between parent-child communication and psychosocial well-being showed Open communication was associated with positive illness attitude, positive self-perception and greater health-related quality of life for children living with epilepsy (28) .

However, addressing the question why some children with epilepsy report a relatively good quality of life while others do not requires a deeper understanding of the determinants of quality of life.

In our cross-sectional study to identify various factors affecting the QOL in CWE, we tried to establish the association of demographic and epilepsy variables with QOL. Overall QOL was not significantly affected by demographic characteristics . On the other hand it was affected by disease characteristics, with a poorer QOL in children with higher seizure frequency (1 seizure/week and 1 seizure/month categories ) and in those receiving polytherapy .

The major strength of this study was the large sample size, much more than that of other similar studies .

### **1. Relationship of demographic variables with overall quality of life :**

In our study, demographic factors such as age, area of residence, the mother's level of education, the child's educational status, socio economic status, were not significantly associated with overall QOL, as opposed to some studies like Devinsky et al (29) that found that overall QOL was affected in older children as compared to younger age group. Nadkarni et al (30) observed a better QOL in younger children living in urban areas and of literate mothers. Hussain et al found that caregivers with little education were associated with a poor QOL (31).

**Table n°VII : significant patients characteristics affecting overall QOL in literature**

Studies	country	Number of patients	age	residence	The mother's level of education	Parents' marital status	SES
Devinsky et al (29)	USA	197	0.03 (S)	-	-	-	0.05
Nadkarni et al (30)	India	102	<0.01 (S)	<0.0001 (S)	<0.0001 (S)	-	<0.05 (S)
Yong et al (32)	China	418	<0.05 (S)	-	-	-	<0.05 (S)
Sherman et al (33)	Canada	163	NS	-	NS	0.02	NS
Zeinab M et al (34)	Egypt	50	0.007 (S)	NS	NS	0.01 (S)	-
Our study	Morocco	104	0.10	0.14	0.24	0.51	0.14

## **2. Relationship of various disease characteristics with overall QOL**

Consistent with other studies like Yong et al (32) and Sanjeev et al (35), Overall QOL was compromised in the group of children with higher seizure frequency and those on polytherapy. Abbas Z et al (5), Nadkarni et al (30) and Devinsky et al (29) also reported a negative effect of polytherapy on QOL in CWE .

**Table n° VIII : The significant disease characteristics affecting overall QOL in literature**

### Quality of life in children with epilepsy

Studies	Country	Number of patients	Seizure type	Seizure duration	Seizure frequency	Therapy	Therapy duration
Abbas Z et al (5)	Sudan	100	-	<0.05 (S)	-	<0.001(S)	<0.05 (S)
Nadkarni et al (30)	India	102	<0.05 (S)	-	<0.05 (S)	<0.05 (S)	<0.05 (S)
Devinsky et al (29)	USA	197	<0.05 (S)	<0.05 (S)	<0.05 (S)	<0.05 (S)	-
Yong et al (32)	China	418	NS	NS	<0.05 (S)	<0.05 (S)	-
Zeineb M et al (34)	Egypt	50	0.000 (S)	-	0.000 (S)	0.000 (S)	0.001 (S)
Our study	Morocco	104	0.26	0.16	0.001 (S)	0.009 (S)	0.11

### 3. Relationship of various patient and disease characteristics with the domains of qol :

The main areas that are affected in children with epilepsy are the cognitive, the emotional, the social and the physical domain. These domains were assessed in our study to determine which one were affected by the various patient and disease characteristics.

The emotional domain was affected more in older children (>12 years old ). Devinsky et al (29) reported that this may be due to the fact that older children are more likely to perceive a greater negative impact on life and general health and have more negative attitude toward epilepsy. Kariuki et al (36) studied the association of epilepsy by age 7 years with the development of childhood emotional/behavioral problems at age 7, 11, and 16 years, after adjusting for fetal risk indicators and social disadvantage at birth and found that the risk of

## Quality of life in children with epilepsy

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emotional/behavioral problems after epilepsy was greater at 16 years than at 7 years, suggesting an increasing risk over time possibly related to the cumulative effects of living with the illness .

We found that this domain was also affected by seizure frequency. Austin et al (29) major finding was that children who had recurrent seizures had significantly higher total and internalizing behavior problems scores compared to healthy siblings and with children who did not have that seizure recurrence significantly predicted behavior problems which is possibly due to different explanations one of which is that children have a negative psychological response to seizures.

**Table n° IX : The factors affecting the emotional domain in literature**

Studies	Country	Age	gender	residence	SES	Mother's level of education	Seizure frequency	Therapy
Nadkarny et al (30)	India	<0.05	-	<0.05	-	<0.05	<0.05	-
Kariuky et al (36)	UK	<0.05	-	-	-	-	-	-
Austin et al (37)	USA	-	-	-	-	-	0.001	-
Devinsky et al (29)	USA	0.01	0.0002	-	0.05	-	0.01	0.02
Our study	Morocco	0.000(S)	0.53	0.10	0.12	0.53	0.005 (S)	0.56

We also found that Seizure frequency had a negative impact on the social aspect. Viteva EL (38) in her study assessed the impact of the seizure severity and frequency on the QOL of Bulgarian patients with refractory epilepsy and found higher seizure frequency had a negative impact on most social aspects.

As opposed to Pal et al who showed that there was no significant reciprocal association between the frequency of seizures and social integration (39) .

In our study, the social aspect was significantly affected by polytherapy too. Nagarathnam et al (40) explained this correlation with the fact people with epilepsy suffered

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from stigmatisation and that polytherapy and seizure frequency were predicting factors of stigma.

We also found that the social aspect was affected by the marital status of the parents meaning that children with epilepsy coming from homes where parents are either divorced, separated or being raised by single mothers, or where one of the parent is deceased, have a more compromised score in the social section. Sherman et al (33) reported lower overall HRQOL in children from families characterized by parental separation/divorce. He also pointed out that this demographic variable was of negligible importance in severe epilepsy where epilepsy-related factors and comorbid behavioral conditions take precedence over demographic variables when it comes to the impact they have on the HRQOL. Nonetheless, marital harmony reflects the degree of parental adjustment, which is an important target for intervention because it influences outcomes for the child when it comes to developmental gains, social adaptation and behavioral problems (41).

**Table n° X : The factors affecting the social domain in literature**

Studies	country	Number of patients	age	Residence	Mother's level of education	SES	Seizure frequency	therapy
Nadkarni et al (30)	India	102	<0.05	<0.05	<0.05	<0.05	<0.05	-
Devinsky et al (29)	USA	197	-	-	-	<0.05	-	-
Nagarathnam et al (40)	India	170	-	-	-	-	<0.05	<0.05
Viteva et al (38)	Bulgaria	70	-	-	-	-	<0.05	-
Our study	Morocco	104	0.16	0.99	0.18	0.23	0.000 (S)	0.006 (S)

Our finding of a significant correlation between longer duration of epilepsy and the cognitive aspect of QOL is consistent with literature and has been well documented over the

## Quality of life in children with epilepsy

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years [42, 43]. Devinsky et al (29) stated that longer duration of epilepsy was associated with lower scores in the memory and concentration domain, with a higher risk of academic and other school related problems.

We found that the cognitive section was significantly affected by antiepileptic drugs too. This may be explained by the fact that Antiepileptic drugs decrease membrane excitability, which leads to a slowed motor and psychomotor speed, poorer attention and mild memory impairment. Due to these global changes in the excitation levels in the central nervous system, cognitive and behavioral deficits may occur. Although a number of consistent risk factors which increase the risk for cognitive side effects have been established such as Polytherapy, high blood levels of an antiepileptic drug (AED), patient's age and type/frequency of seizures, different effects –positive or negative–have been demonstrated for AEDs, with an incomplete comparative data across all of them [44,45] .

**Table n° XI : The factors affecting the cognitive domain in literature :**

Studies	Country	Number of patients	Residence	Mother's level of education	Seizure frequency	Seizure duration	Therapy duration
Devinsky et al (29)	USA	197	-	-	-	<0.05	<0.05
Nadkarni et al (30)	India	102	<0.05	<0.05	<0.05	-	-
Yong et al (32)	China	418	-	-	-	<0.05	-
Our study	Morocco	104	0.131	0.71	0.39	0.001 (S)	0.005 (S)

The physical aspect, in our study, was not found to be affected by the demographic factors. This finding is consistent with previous studies such as Nadkarni et al (30) and devinsky et al (29). In our finding, the physical aspect was only affected by the seizure frequency, same as the study of Abbas Z et al (5) where it shows that children with high seizure

frequency experienced limitations in their activities which was the main concern of their caregivers .

#### **4. The most affected domains of QOL :**

On the other hand, the physical functioning was the most affected domain in our study. Although it was not consistent with most of the other reports [46, 47], and we do not have a clear explanation for this phenomenon, Because factors affecting the children's QoL were multifaceted, many factors were interactional. So our finding may reflect the fact that the majority of the children that participated in our study were <12 years old (75 % ) with 25% who were only 5 years old; combined with the fact that a large majority of the caregivers are illiterate, and tend to perceive higher risks for their children and misinterpret information about their children's condition. Essentially because they didn't fully grasp their children's state or weren't informed well enough. Therefore they can be more restricting to their children's different activities. As a matter of fact, we found that the lower score in all 16 items corresponded to the last question about parents supervision (mean=44.95). In fact, Prahbhjot et al (48) reported that 39% of the parents opined that their epileptic child needed more supervision than before from them while playing.

That being said, Miller et al (49) in his study where he compared the HRQOL of children with epilepsy with that of a healthy control group, indicated that children with epilepsy had a diminished HRQOL in both the physical and emotional domain compared to healthy children .

In our study, we found that seizure frequency is the factor that affects not only the overall quality of life, but also two of its domains, the emotional/behavioural aspect and the social one. These three areas were found to be significantly improved in children whom were rendered seizure free after undergoing surgery for their intractable epilepsy. This suggests the effectiveness of epilepsy surgery in improving a child's quality of life and draws, in foresight, a circumspect observation of the possible counseling of families to explain the potential benefits of surgery beyond seizure reduction in fitting cases (50).

**table n° XI : The most affected domains of QOL in literature**

Study	country	Number of patients	The most affected domain
Nadkarni et al (30)	India	102	Emotional functioning
Momen et al (47)	Iran	104	Social functioning
Nagesh et al (46)	India	104	Cognitive functioning
Arya et al (51)	India	40	Emotional functioning
Our study	Morocco	104	Physical Emotional

### LIMITS:

The limitations of this study include:

In this study, QOLCE scores were used to identify relationship association trends of various factors affecting QOL, more so than calculating the exact global QOL score. The QOLCE has not been validated for Moroccan patients, we translated it only for use in this study. Though we had a glimpse of where we stood compared to other studies. By the end of our research, we had an idea of the factors that needed to be modified and domains that had to be prioritised for a better QOL in children with epilepsy in our region .

The QOLCE-16 used in our study was a parent reported questionnaire. Therefore the reports made by parents may not reflect the views of the children.

Parents who were reluctant to participate in our study were excluded. Only one of the parents took part in the survey. We did not make comparisons between the reports of both parents. This may also have introduced selective bias. In addition, similar to most prior studies we did not include control groups in our evaluation of the QOL in pediatric epilepsy.

Despite all the limitations, our study still demonstrates some new suggestions. First, in our environment the physical aspect seems to be the most affected compared to others .Secondly, in addition to the demographic and clinical characteristics of the children that affected the overall QOL, many of them had a significant impact of the 4 domains of QOL individually. This suggests that, to improve QoL of the children with epilepsy - with the exception of AED, surgery and some interventions intended for children - there is much to be done if we take these modifiable and non-modifiable factors into consideration. Recognition of this will be helpful for professionals in treating and improving the QoL of children with epilepsy.



*CONCLUSION*



Epilepsy is one of the most common neurologic disorder in children, known to have significant adverse effects on child development and quality of life (52).

Apart from unpredictable seizures and consequent injuries, children with epilepsy (CWE) are confronted with psychosocial problems. Quality of life (QOL) varies with culture and socio-economic standing .

Despite all the limitations, our study still demonstrates some new suggestions. First , we highlighted a more compromised QOL in the physical domain followed by the emotional one.

Second, we also identified a handful of demographic and disease related factors ( age , parents marital status, therapy , seizure frequency , therapy duration ,seizure duration ) that significantly had an impact on either the overall QOL or on some of the subscales .

This suggests that, to improve QoL of the children with epilepsy - with the exception of AED, surgery and some interventions intended for children - there is much to be done if we include sections of the QOL and these factors in the treatment. Recognition of this will be helpful for professionals enabling comprehensive and effective care of children with epilepsy.



*RECOMMENDATIONS*



Epilepsy treatment has traditionally focused on medical therapy, sometimes to the exclusion of psychosocial and quality of life issues. Yet epilepsy can affect many factors that influence patients' quality of life. Therefore, children with epilepsy have a comparatively weakened quality of life and focusing merely on control of seizures insufficient. In our study, we evaluated that several factors impact significantly the overall QOL (seizure frequency, polytherapy) and each section separately (age, parents marital status, polytherapy, therapy duration, seizure duration, seizure frequency). So the patient should be monitored regularly and treated appropriately. Necessary measurements for improvement of QOL while taking into consideration these factors are also essential and should be an important index in the management of epileptic children, in addition to regular drug treatment.

In our finding the physical domain was the most affected, consequently we deduced that parental knowledge about epilepsy would affect their attitude, educational style toward their children. That means that parents with little knowledge about their children's illness tend to have more of a restricting parenting style when it comes to their children's activities. Accordingly, the QoL of children decreases especially in its physical aspect. Therefore educating parents about epilepsy and its effects on the different dimensions of QOL and the interaction of the different factors with these areas should be an important step taken by the child's doctor in the treatment protocol.

When it comes to future research, the present findings suggest several recommendations. Future studies should employ both epilepsy specific and generic measurements of HRQOL. As noted in our study, epilepsy specific indicators may be more sensitive in identifying specific illness-related predictors of HRQOL in children with epilepsy and may contain items that are more relevant for children with cognitive or physical limitations. However, generic measurements are useful for comparing children with epilepsy with other groups, such as healthy children and children with other chronic diseases. The inclusion of both

## **Quality of life in children with epilepsy**

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types of indicators may provide a more comprehensive picture of the HRQOL of children with epilepsy.

To cope with the illness, people with epilepsy need information coupled with psychological and social support. The physician can supply some of each, such as providing support, being an informed, empathetic listener, alleviating fear of the unknown, encouraging compliance, and providing information about epilepsy, available drugs, alternative approaches to control, to the people with epilepsy, their family and the community. The physician should therefore refer the child to a psychologist or a psychiatrist when it's needed, who can also facilitate the establishment of contacts and self-help groups to boost self-esteem and confidence.

The side effects of AEDs, as well as the physical and emotional issues related to epilepsy can all have detrimental effects on quality of life. Moreover Stigma, can impact self-esteem and the social functioning of children suffering from epilepsy. It can also negatively affect family stability , hence , the physician should encourage open communication between the family members to avoid any disruptions in interfamilial relationships.



*SUMMARIES*



### Summary:

Epilepsy is a chronic disorder that causes recurrent seizures. These seizures can occur on a daily basis leading to an impact on the four aspects of quality of life in epileptic children, citing the cognitive, emotional, social and physical dimensions.

Therefore, the aim of the present study was to accurately determine and investigate the different factors that affect quality of life in children with epilepsy; using the QOLCE-16. For this reason, we led a descriptive prospective study over 1 year.

Followed-up in consultation with the pediatric emergency and the pediatric department (A) of the CHU Mohammed VI of Marrakech.

We recruited 104 patients suffering from epilepsy. Their age range was between 5 and 16 years old, with a female predominance (66.3% were males, 33.7 % were females). 52.9% of the patients were from the rural areas of the region of Marrakech. When it comes to the marital status of the parents, 94.2% were married with only 5.8% who were either divorced, widow or single parent. Slightly more than half of the parent's SES was decent (55.8%). The majority of the caregivers were mothers except one, with most of the caregivers being illiterate (63.1 %).

The physical section was found to be affected the most with the lowest mean score of  $78.84 \pm 14.99$ . The factors that affected the overall QOL were seizure frequency and the number of AEDs that the patient was under.

The cognitive section was affected by seizure duration and the number of AEDs. while the emotional section was affected by age and seizure frequency. On the other hand, the parent's marital status had a significant impact on the social section. In our finding, the physical domain was not found to be affected by neither the demographic factors nor the patients characteristics.

## Quality of life in children with epilepsy

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Our study is the first of its kind concerning QOL in children with epilepsy in Morocco. We can even name it the first in the Maghreb region, because –based on our resarch – only one study about QOL in epileptic patients was carried out in the past in Morocco (fez precisely). However the mean age was around 30 years old.

## RESUME :

L'épilepsie est une maladie chronique qui provoque des crises récurrentes. Ces crises peuvent avoir des effets au quotidien entraînant un impact sur les quatre aspects de la qualité de vie des enfants épileptiques, en citant la dimension cognitive, émotionnelle, sociale et physique.

Par conséquent, le but de la présente étude était de déterminer et d'étudier avec précision les différents facteurs qui affectent la qualité de vie des enfants atteints d'épilepsie; à l'aide du QOLCE-16.

Pour cette raison, nous avons mené une étude prospective descriptive sur 1 an. Suivi en concertation avec l'urgence pédiatrique et le service pédiatrique (A) du CHU Mohammed VI de Marrakech. Nous avons recruté 104 patients atteints d'épilepsie, leur tranche d'âge était entre 5 et 16 ans, avec une prédominance féminine (66,3% étaient des garçons / 33,7% étaient des filles). 52,9% des patients étaient originaires de zones rurales de la région de Marrakech. En ce qui concerne l'état matrimonial des parents, 94,2% étaient mariés et 5,8% seulement étaient divorcés, veuves ou monoparentaux. Un peu plus de la moitié du SSE des parents était décent (55,8%). Le parent responsable du suivi de l'enfant était dans La majorité des cas la mère, la plupart d'entre elles étant analphabètes (63,1%).

La section physique s'est avérée la plus affectée avec le score moyen le plus bas de  $78,84 \pm 14,99$ . Les facteurs qui ont affectés la qualité de vie globale étaient la fréquence des crises et le nombre des antiépileptiques que prenait le patient. La section cognitive était affectée par la durée des crises et le nombre des antiépileptiques . Tandis que la partie émotionnelle était affectée par l'âge et la fréquence des crises.

## Quality of life in children with epilepsy

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Par contre, l'état matrimonial des parents avait un impact significatif sur la partie sociale. Dans notre série, le domaine physique ne s'est pas révélé affecté par les facteurs démographiques ni les caractéristiques des patients.

Notre étude est la première du genre concernant la qualité de vie chez les enfants épileptiques au maroc. On peut même la nommer la première au Maghreb, car, en se basant sur notre recherche, une seule étude sur la qualité de vie chez les patients épileptiques a été réalisée auparavant au Maroc (fès précisément) cependant l'âge moyen était d'environ 30 ans.

## ملخص

الصرع مرض مزمن يسبب نوبات متكررة. يمكن أن يكون لهذه النوبات آثار على الحياة اليومية فتأثر على الجوانب الأربعة لجودة حياة الأطفال المصابين بالصرع ، مستشهدة بالأبعاد الإدراكية المعرفية والعاطفية والاجتماعية و الجسدية البدنية.

لذلك ، كان الهدف من هذه الدراسة هو تحديد ودراسة بدقة العوامل المختلفة التي تؤثر على نوعية حياة الأطفال المصابين بالصرع ؛ باستخدام QOLCE-16.

لهذا السبب ، أجرينا دراسة وصفية مستقبلية لمدة عام واحد تتمثل في المتابعة بالمعاينة في مصلحة المستعجلات للأطفال و مصلحة الأطفال (أ) بمستشفى محمد السادس الجامعي بمراكش. قمنا بمعاينة 104 طفل مصاب بالصرع ، وكانت أعمارهم تتراوح بين 5 و 16 سنوات مع أغلبية من الذكور ذ (66.3%) ! (33.7%)

52.9% من المرضى هم من المناطق الريفية في منطقة مراكش. وفيما يتعلق بالحالة الزوجية للوالدين، فإن 94.2% كانوا متزوجين و 5.8% فقط كانوا مطلقين أو أرامل أو آباء غير متزوجين. فيما يخص الوضع الاجتماعي والاقتصادي للوالدين لانقاً في 55.8%. غالبية مقدمي الرعاية هن الأمهات باستثناء واحدة ، ومعظم مقدمي الرعاية أمين (63.1%).

تم العثور على القسم الجسدي ليكون الأكثر تأثراً مع أدنى متوسط درجة  $14.99 \pm 78.84$ . كانت العوامل التي أثرت على نوعية الحياة بشكل عام هي النوبات وعدد مضادات الصرع التي يتناولها المريض. تأثر القسم المعرفي بمدة النوبات وعدد الأدوية مضادات الصرع. بينما تأثر الجزء العاطفي بعمر وتواتر النوبات. من ناحية أخرى ، كان للحالة الزوجية للوالدين تأثير كبير على الجانب الاجتماعي. في سلسلتنا ، لم يتأثر المجال الجسدي بالعوامل الديموغرافية أو خصائص المريض.

دراستنا هي الأولى من نوعها في نوعية حياة الأطفال المصابين بالصرع في المغرب. يمكننا حتى تسميتها الأولى في المنطقة المغربية. لأنه ، بناءً على بحثنا ، تم إجراء دراسة واحدة فقط على جودة الحياة لدى مرضى الصرع سابقًا في المغرب (على وجه التحديد فاس) ، ولكن متوسط العمر كان حوالي 30 عامًا.





## Quality of life in children with epilepsy

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The caregiver's education : primary/middle school  highschool  university  ill ate

### Informations on the disease :

Diagnosis of epilepsy : history  history+/-neuroimaging..

Type of epilepsy : partial  generalised

Seizure duration : 1year  >1year

Duration of the postictal state : 5 to30min  30 to2hours: more than 2h: none :

Seizure frequency :>/=once a week  >/= once a month  >/=once a year

Last seizure : less than 1 year :  1 or more than one year :

Therapy :monotherapy  polytherapy

Duration under 1year  >1year

### treatment :

#### Section 1 : The child's Cognitive functioning

very often   fairly often   sometimes   almost never   never   not applicable

- |  |                          |                          |                          |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Had trouble understanding directions?               | <input type="checkbox"/> |
| 2. Had difficulty following complex instructions?      | <input type="checkbox"/> |
| 3. Had difficulty following simple instructions?       | <input type="checkbox"/> |
| 4. Had trouble remembering things people told him/her? | <input type="checkbox"/> |

#### Section 2: The child's Emotional functioning

All of the time   most of the time   some of the time   a little of the time   none of the time   not applicable

- |                                    |                          |                          |                          |                          |                          |                          |
|------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Felt nobody understood him/her? | <input type="checkbox"/> |
| 2. Felt down or depressed?         | <input type="checkbox"/> |
| 3. Felt frustrated?                | <input type="checkbox"/> |

## Quality of life in children with epilepsy

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4. Felt confident?

### Section 3: The child's Social functioning

very often   fairly often   sometimes   almost never   never   not applicable

- |   |                          |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. How limited are your child's social activities compared with others his/her age? | <input type="checkbox"/> |
| 2. Affected his/her social interactions at school or work?                          | <input type="checkbox"/> |
| 3. Isolated him/her from others?  | <input type="checkbox"/> |
| 4. Made it difficult for him/her to keep friends                                    | <input type="checkbox"/> |

### Section 4: The child's Physical functioning

very often   fairly often   sometimes   almost never   never   not applicable

- |   |                          |                          |                          |                          |                          |                          |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Played freely in the house like other children his/her age?            | <input type="checkbox"/> |
| 2. Been able to do the physical activities other children his/her age do? | <input type="checkbox"/> |
| 3. Played freely outside the house like other children his/her age?       | <input type="checkbox"/> |
| 4. Needs more supervision than other children his/her age?                | <input type="checkbox"/> |



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# قسم الطبيب

## أقسم بالله العظيم

أن أراقب الله في مهنتي.

وأن أصون حياة الإنسان في كافة أطوارها في كل الظروف  
والأحوال باذلاً وسعي في استنقاذها من الهلاك والمرض

والألم والقلق.

وأن أحفظ للناس كرامتهم، وأستر عورتهم، وأكتم سرهم.

وأن أكون على الدوام من وسائل رحمة الله، باذلاً رعايتي الطبية للقريب والبعيد،  
للصالح والطالح، والصديق والعدو.

وأن أثار على طلب العلم، أسخره لنفع الإنسان .. لا لأداه.

وأن أوقر من علمني، وأعلم من يصغرني، وأكون أخاً لكل زميل في المهنة الطبية

متعاونين على البر والتقوى.

وأن تكون حياتي مصداق إيماني في سرّي وعلانيتي، نقيّة مما يشينها تجاه

الله ورسوله والمؤمنين.

والله على ما أقول شهيدا

أطروحة رقم 170

سنة 2020

## جودة الحياة عند الأطفال المصابين بمرض الصرع

### الأطروحة

قدمت ونوقشت علانية يوم 2020/10/02  
من طرف

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المزودة في 04 يناير 1994 بالراشيدية

**لنيل شهادة الدكتوراه في الطب**

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- ميادين - مرض الصرع - الطفل جودة

### اللجنة

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الحكام

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أستاذ في طب الأطفال

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أستاذ مبرز في طب الأطفال .

**ع. أخضار**

أستاذ في جراحة الدماغ و الأعصاب

**ع. الدرايس**

أستاذة مبرزة في طب الأطفال .

السيد

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