

An Assessment on Epilepsy in Children and Their Parents Adaptation to Epilepsy Medications and Their Knowledge Level



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Epilepsili Çocukların ve Ebeveynlerinin Epilepsi Tedavisine Uyum Düzeyinin Belirlenmesi

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Summary

Objectives: Epilepsy is one of the most common chronic neurological diseases seen in childhood. Compliance with treatment is the key factor of success in treatments. Non-compliance with epilepsy treatment is frequently encountered, and it is a significant problem that may necessitate the re-hospitalization of patients. It is very important for children with epilepsy in Turkey to grow into an adult with an improvement in their compliance with treatment. This study aims to determine parents' opinions on the compliance with the treatment of their children with epilepsy and their knowledge level of epilepsy. This study used a prospective design with a cross-sectional analysis.

Methods: The present study was conducted at the Ankara Training and Research Hospital with the involvement of 125 children diagnosed with epilepsy who were undergoing follow-up care and their parents. For data collection, a study questionnaire, which included 19 questions, 11 of which were related to descriptive characteristics of the children with epilepsy and their plans, was used. In addition, the "Epilepsy Knowledge Test for Parents" was applied to assess the level of knowledge the parents of the children with epilepsy had on this disease.

Results: Non-pharmacological treatment applications were found to differ according to the mother's education level ($p=0.001$), as well as to the father's education level ($p=0.002$). The mean score obtained by the parents on the epilepsy knowledge test was 12 (minimum-maximum: 6–17).

Conclusion: Treatment compliance of the study group was high, and the parents' education level was shown to affect the status of their non-pharmacological treatment application. It was further found that in cases where the parents' education level was not high, great care was still shown to their children's treatment plan. This finding can be attributed to the importance given to children in the Turkish family structure.

Keywords: Child; compliance with treatment; epilepsy; nursing; parents.

Özet

Amaç: Bu araştırma, ebeveynlerin epilepsili çocuklarının tedaviye uyumlarına ilişkin görüşlerini ve hastalığa ilişkin bilgi düzeylerini belirlemek amacıyla planlanmıştır.

Gereç ve Yöntem: Çalışmanın evrenini Ankara Eğitim ve Araştırma Hastanesi, Çocuk Nöroloji Polikliniği'nde epilepsi tanısıyla takip edilen 125 epilepsili çocuk ve ebeveynleri oluşturmaktadır. Araştırmada veri toplama aracı olarak araştırmacı tarafından literatür taranarak hazırlanan; epilepsili çocukların ve ebeveynlerin tanıtıcı özelliklerini sorgulayan 11 soru; tedaviye uyumlarını değerlendiren 19 sorudan oluşan anket formu oluşturulmuştur. Epilepsili çocuğa sahip ailelerin epilepsiye yönelik bilgilerini değerlendirmek 'Ebeveyne Yönelik Epilepsi Bilgi Ölçeği' kullanılmıştır. Verilerin değerlendirilmesinde sayı, yüzde ve ortalama, Mann-Whitney U Testi (Demografik bilgiler ve hastalığa ilişkin özellikler-ölçek puanları), Shapiro-Wilk testi ile Kruskal Wallis 20 Testi (ölçek puanları) analizi testi kullanılmıştır.

Bulgular: Bu araştırma doğrultusunda, 125 epilepsili çocuğun yaş ortalaması 11 (minimum-maksimum: 2–19), ebeveynlerin yaş ortalaması 37 yıl (minimum-maksimum: 22–56) dir. Hasta çocukların %56.8'si ($n=71$) erkektir. Çalışmamızda ebeveynlerin %24.2'sinin ($n=30$) tedavi için ilaç dışı yöntemlere başvurdukları belirlenmiştir. Annenin eğitim düzeyine göre ilaç dışı yöntemlere başvurma durumunun farklılık gösterdiği tespit edilmiştir ($p=0.001$). Babanın eğitim düzeyine göre ilaç dışı yöntemlere başvurma durumunun farklılık gösterdiği tespit edilmiştir ($p=0.002$). Nöbetler bitince ilaçları bırakmayan ebeveynlerin bilgi puanı bırakan ebeveynlere göre daha yüksek olsa da aradaki fark sınırdan anlamsız çıkmıştır ($p=0.055$).

Sonuç: Ebeveynlerin epilepsi bilgi ölçeği puan ortancası 12 (minimum-maksimum: 6-17) olarak bulunmuştur. Çalışma grubumuzun tedavi uyumları yüksek bulunmuştur.

Anahtar sözcükler: Çocuk; tedavi uyumu; epilepsi, hemşirelik; ebeveyn.

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Introduction

Compliance with treatment, in effect, involves the cooperation that exists between the patient and the caregiver concerning the latter's ability to administer the prescribed treatment plans. Going for a checkup, starting and completing a treatment programs, using medication in recommended doses and at recommended times, and complying with required changes to attitudes and diets are factors of treatment.^[1,2] Compliance with treatment is the key factor in the successful outcome of treatments. Effectiveness of and advancement in treatment for diseases have been shown to have a positive relationship with patients' compliance with and commitment to treatment.^[3] Non-compliance with treatment can take on many forms, including failure to use or irregular use of prescribed medications, using medications that are not prescribed, missing appointments, and not following through with the controls.^[3]

Epilepsy is one of the most common chronic neurological diseases seen in childhood.^[1] Non-compliance with epilepsy treatment is frequently encountered in clinical practices, and it is a problem that may require the re-hospitalization of patients. Not using or irregularly using prescribed medications, using medications that are not prescribed, missing appointments, and not following the controls constitute the majority of non-compliance with treatment cases.^[4,5] Non-compliance with treatment also may result in seizures continuing, re-hospitalization, morbidity, a rise in mortality, and increased health care costs.^[5]

To this end, it is important that families know the effects and side effects of medications used in treatment, the safe dosage amounts and correct use of the medications, and the necessity of using the medications regularly. The neurology/internal disease nurses of healthcare staff can provide more effective nursing care and positively contribute to a child's disease treatment management and the process of getting through the disease. A literature review showed that many studies had been conducted on the life quality of families with an epileptic child, safety measures for epilepsy, and knowledge level on epilepsy.^[6-8] However, to our knowledge, there were no studies found that assessed children's compliance with treatment. This study was conducted to provide evidence through the analysis of data on the necessity of epilepsy nursing, whereby the results obtained through assessment of the situation in Turkey can serve as a

guide for planning the health care and ensuring treatment compliance of epilepsy patients.

Research questions

What is the level of treatment compliance of children receiving epilepsy treatment? What are the related factors?

Materials and Methods

Participants

The sample of this study consisted of 125 epileptic children between the ages of 0 and 18 who were receiving follow-up care at the Children's Neurology Outpatient Clinic of the Ankara Training and Research Hospital.

Participants' demographical and disease-related characteristics

A study questionnaire of 35 questions was developed to assess the participant children's descriptive characteristics and their compliance. This questionnaire was prepared with reference to a literature review.

Epilepsy knowledge scale

The Epilepsy Knowledge Scale (2002), developed by Austin et al.,^[9] was used to determine parents' knowledge about epilepsy. The validity and reliability of the scale were performed by Ünal (2011).^[7] The scale includes 20 questions on the causes of seizures, emergency care, seizure-related complications, and cognitive and psychosocial results and the limitations they impose.^[10] On the scale, (0) and (1) indicate incorrect and correct, respectively, and the range of possible scores is between 0 and 20, with higher scores meaning that the family's knowledge level is high. The study by Austin et al.^[9] calculated the Cronbach's alpha coefficient to be 0.69, while the study conducted by Ünal^[7] found the Cronbach's alpha coefficient to be 0.72 and 0.78 for the pre-test and post-test, respectively, in Turkey. For this study, the Cronbach's alpha coefficient was determined to be 0.66.

Statistical analysis

Distribution of continuous variables, such as age, was examined using the Shapiro-Wilk test. In this study, discrete variables, such as the number of hospitalizations, are shown in the form of the median (min-max), while categorical variables, like sex and education level, are presented in percentage (%) form because the continuous variables did not show normal distribution.

Limitations of this study

The data for the study were collected only from the patients who presented to the Children's Neurology Outpatient Clinic of the Ankara Training and Research Hospital between March 8, 2016, and February 6, 2017. Therefore, the findings based on the data obtained from these patients who presented to the outpatient clinic between these dates were limited to this indicated period alone.

Results

Basic characteristics of disease epileptic child/parents

Among the children with epilepsy, 44% (n=55) had a seizure within the last six months, while 26.4% (n=33) had a seizure within the last one year. The primary reasons parents did not administer their children their medications on time were because of their job schedule (42.4%, n=22), followed by failure to remember (28.8%, n=15).

When the parents' opinions on epilepsy medication were analyzed, the findings showed that 75.4% (n=94) of them thought that medication use was required, and 97.6% (n=122) thought that medication use was necessary and beneficial for their children's recovery and that the medications must be taken regularly for the success of treatment. On the negative side, 35.2% (n=44) of the parents believed that the medications were addictive, while 15.2% (n=19) believed that the medications had too many side effects.

Among the participants who experienced side effects from the medications, 52.3% (n=23) waited for the side effects to disappear, whereas 25.0% (n=11) called the doctor to learn what to do. Of the parents who forgot to administered medications, 56.1% (n=69) stated that they administered the dosage when they remembered, and 26.0% (n=32) stated that they never gave the dosage when they failed to remember.

Parental level of education according to applications

Finally, the findings showed that the children's mothers who graduated from high school used a non-pharmacological treatment application less. On the other hand, illiterate fathers of the children applied non-pharmacological treatment applications at a higher rate than the fathers who had graduated from high school and/or university.

It was observed that the parents did not administer the drugs in due time, mostly due to the intensity of housework

(42.4%, n=22), and the second place due to forgetfulness (28.8%, n=15) (Fig. 1).

The findings showed that 38.3% (n=46) of the parents saw the side effects of the drugs, and 24.2% (n=30) used another method for treatment instead of medicine.

When the distribution of the side effects of children with epilepsy due to drug treatment was examined (Fig. 2), it was determined that the most sleepiness (n=15), the least respiratory distress, hair loss and hyperactivity (n=1) were observed.

It was observed that 44.0% (n=55) of children with epilepsy had seizures in the last six months and 26.4% (n=33) in the last one year (Fig. 3).

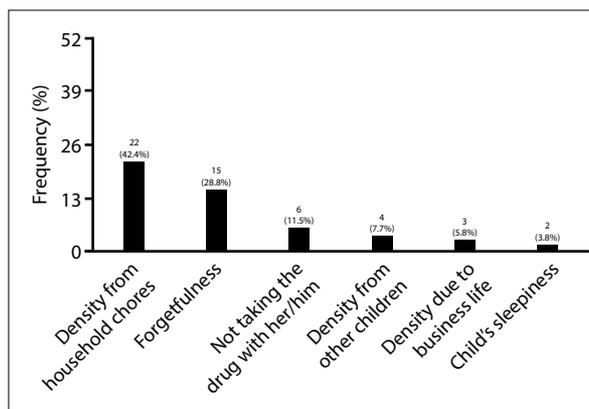


Fig. 1. One a day with epilepsy children sometimes have not remember the reason parents' lack of medication.

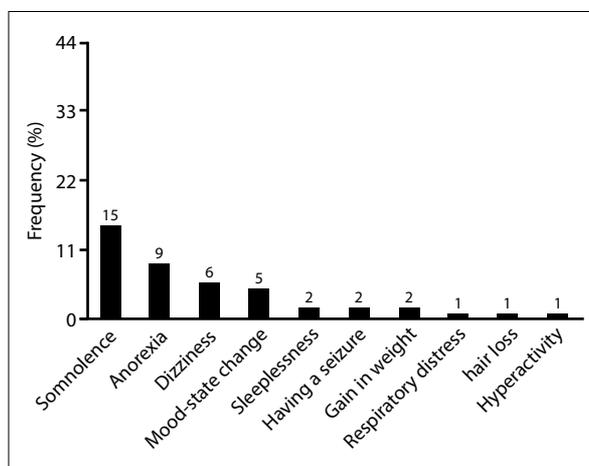


Fig. 2. Distribution of the side effects of anti-epileptic treatment seen in children with epilepsy.

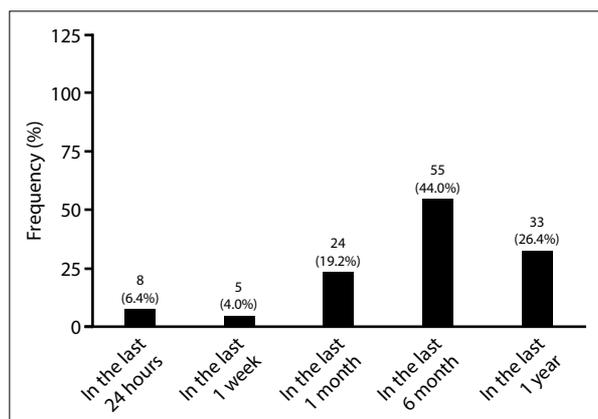


Fig. 3. Time distribution of the latest seizure of children with epilepsy.

Discussion

The effectiveness of treatment for diseases and advancements in treatment has been shown to have a positive relationship with patients' compliance with and commitment to treatment. There are many reasons to account for non-compliance with treatment, including the complexity of the treatment plan, side effects of medications, loss of belief in the benefit of the medications, previous negative experiences with medication, fear of getting addicted to medication and communication problems with treatment staff.^[11] Non-compliance with treatment can, however, increase treatment costs and disrupt an individual's functionality, as the disease would become chronic, which would result in loss of workforce, give rise to an economic burden on society and lead to loss of time and energy, making the provision of health care services inefficient.

The medical history of families with epileptic children showed that 36% of them had a member or members who had seizures. A study by Güner^[12] performed in 2015 found that 22.9% of epileptic patients had a history of epilepsy in their family. Additionally, a study conducted by Al Rajeh et al.^[13] found that there was at least one person with epilepsy in the family in 24% of epilepsy cases. Regarding the parents of epileptic children, 36.8% could not provide a description of epilepsy disease when they were asked. A study by Avci,^[14] which examined the effects of training provided to epileptic children and their parents on disease management, found that among the mothers who participated in the study, 57.7% of the mothers in the study group and 51.9% of the mothers in the control group did not know what kind of disease epilepsy was. These stud-

ies showed that the awareness level of these neurological diseases was quite low among families with a child who has epilepsy or similar neurological disease. If there is a history of epilepsy in the family, even a primary fever in childhood may trigger an epileptic seizure. Studies have found that the education provided to families is effective.^[15] The parents approach to the disease plays a key role in critical situations in terms of the disease diagnosis. To this end, symptoms and findings should be explained to parents who visit healthcare institutions or take part in routine vaccination programs.

The median diagnosis age and first seizure age were seven years (min-max: 0–17) and six years (min-max: 0–17). A study by Caplin et al.^[16] conducted with 173 children with epilepsy found that the mean age of initial seizure was 6.5 ± 3.7 years. According to the study conducted by Asadi-Pooy^[17] with 181 children with epilepsy whose mean age was 7.0 ± 4.6 , the initial seizure was at the age of 4.9 ± 4.2 years. In a study conducted by Ersun^[10] (2012) on 130 children with epilepsy, it was reported that the children's seizures had started between the ages of five and 10 in 43.1% of the children. Haşlak^[18] examined the characteristics of 173 patients under the care of the neurology department and found that age of initial seizure of 110 (63.6%), 32 (18.5%), 18 (10.4), and 13 (7.5%) of the patients were 1–6 months, 7–12 months, 13–24 months and 25 months and over, respectively. The data on epilepsy diagnosis in Turkey differ from those reported in different countries around the world. These data on Turkey show that the symptoms in question start to appear at early ages and that parents are late in bringing their children to neurology outpatient clinics, with the reason being that epilepsy is stigmatizing in traditional Turkish culture.

A study conducted by Ersun^[10] with 130 children found that 50% had had epilepsy for between one and three years and that 49.2% had one or none epileptic seizures in the last one year.^[10] According to the study by Wagner et al.^[19] which assessed seizure management of young epilepsy patients, 40%, 38%, and 22% had been epileptic for less than five years, for 5 to 10 years and 11 to 15 years, respectively, and 38%, 43% and 20% had had a seizure in the last one month, in the last one year or longer than one year, respectively. In studies examining the frequency of seizures in children, it had been reported that over time seizures had relatively decreased, as in line with the findings from the present study.

Overall, the results in this study were compatible with the studies reported in the literature.

Among the children who were receiving epilepsy treatment, 89.6% (n=112) followed the regular controls according to the assessment made on their continuity with controls. Zararsız^[20] found in his study conducted in Mersin on epilepsy children and their parents that 93.3% of the children diagnosed with epilepsy went to regular check-ups. Another study performed in Turkey by Güner^[12] reported that 93% went to check-ups whenever they wanted.

A study conducted on adults with epilepsy by Acaroğlu (2016)^[21] showed that compliance with medication treatment affected life quality, and further reported that 59.1% of the patients in the study used their medications regularly, and that among these patients, 63.2% stated that being provided with sufficient knowledge about the treatment is what made them use the medications regularly and comply with the treatment plan. Şenol et al.^[15] emphasized this when they analyzed the factors affecting compliance with anti-epileptic medication treatment. In Turkey, diseases like epilepsy, which are highly stigmatized in society,^[22] have become easy to follow because even patients whose socio-economic status is low are included in health care service. Informing individuals and parents about epilepsy, using medications regularly, and going to controls on time will boost quality of life and help patients to fight the disease effectively.

Almost half of the patients [48.8% (n=61)] found the epilepsy treatment to be understandable and easy to follow, while 7.2% (n=9) found the treatment to be complicated and 25.6% (n=32) found it to be difficult. Previous studies have reported different findings on individuals with different chronic diseases who were undergoing treatment involving multiple drugs.^[22-24] On the other hand, when compliance with treatment is low for those who find treatment difficult, the results may be re-hospitalization and high costs.

Among the parents, 58.1% (n=72) stated they administered medications on time, and 81.4% (n=103) reported that they did not obtain any information about the medication. A study conducted by Alçı^[22] assessed the difficulties that children with epilepsy experienced in school life and found that 50% of the children misused or did not use the medications regularly because of side effects, were unwilling to

use medication or forgot to take the medication. One of the key factors of compliance with treatment is the use of medication on time. Informing parents, especially the parents of children with chronic diseases, is significant in terms of raising awareness in taking medication on time.

Regarding the resources from which the patients obtained information about the medication treatment, 59.2% (n=61), 22.3% (n=23), and 9.7% received information from the doctor, the internet, and the nurse, respectively. Nurses in pediatric and adult clinics should be encouraged to use their autonomy more during this period, especially given that managing patient outcomes independent from nurses leads to non-compliance and increases patient care costs.^[9] Conducting patient training on treatment management in clinics would be an example.

According to research findings (Table 1), patients whose compliance was high had higher compliance with the treatment protocol and prescription use than patients whose knowledge level was high.

In studies on cultural comparisons, the amount of medication use, the number of medications, nutritional treatment, and attitudes of the society have been analyzed.^[23,24] Based on the results of these studies and data compiled in the present study, it was concluded that the epileptic medication experiences of individuals and their life experiences in the past affected their compliance with treatment.

In examining the parents' knowledge scale scores, the score median was determined to be 12 (min-max: 6-17). Avcı^[14] reported that the mean knowledge score of the mothers in the study group was 10.23±4.77 and 9.48±4.85 for the mothers in the control group in a study conducted with children with epilepsy and their mothers. The difference in these reported results was statistically significant, and the provision of education was shown to raise mothers' knowledge level.^[14] Parents' knowledge level, emotional status, socio-economic conditions, and other variables affect medical treatment and remission in diseases that require continuous follow-up and treatment, such as epilepsy. A specific study model must be developed for children with epilepsy and their parents.

In this study, the use of a non-pharmacological treatment application changed according to the mother's education

level ($p=0.001$) (Table 2). Specifically, the mothers who graduated from high school used a non-pharmacological treatment application less, while the fathers who were illiterate used a non-pharmacological treatment application

at a higher rate than that of the fathers who graduated from high school and/or university ($p=0.002$) (Table 2). It is important that the health care staff should know the parents' background, education level and health-disease

Table 1. Distribution of the socio-demographic characteristics and illness-related characteristics of epilepsy child/parents

	Median	Min.-Max.		Median	Min.-Max.
Parents age	37	22–56	Parents story of epilepsy		
Child age			No	80	64.0
Median	11	2–18	Yes	45	36.0
2 age and ↓	2	1.6	Know the definition of epilepsy		
2.1.- 7 age	36	28.8	Yes	79	63.2
7.1.- 12 age	43	34.4	No	46	36.0
12 and ↑	44	35.2	Number of children	2	1–6
Child sex			First seizure age	6	0–17
Female	54	43.2	Age of starting to use medication	7	0–1
Male	71	56.8	Diagnostic age	7	1–17
Mothers of educational status			Number of hospitalization		
Literate	7	5.6	Once	22	17.6
Primary school	60	48.0	Twice	6	4.8
High school	49	39.2	3 times	4	3.2
Graduate and over	9	7.2	4 times and ↑	93	74.4
Fathers of educational status			Number of seizures in the last year (n=122)	2	1–52
Literate	57	4.0	Go to the controls regularly		
Primary school	43	34.4	Yes	112	89.6
High school	67	52.6	No	13	10.4
Graduate and over	10	9			
			n	Median	Min.-Max.
General			124	12	6–17
Parents assessment of treatment			**		0.673
Complex			9	11	9–13
Hard			32	12	8–14
Complex and challenging			23	112	8–17
Clear and easy to understand			61	12	6–17
Parents give drugs on time**					0.306
Yes			72	12	6–17
No			20	12	10–17
Sometimes			32	11.5	8–15
Parents getting information about medicines*					0.884
Yes			103	12	6–17
No			21	12	8–14
Having side effects of drugs*					0.885
Yes			46	12	6–15
No			74	12	7–17
Applying methods other than medication					0.135
Yes			30	12	10–15
No			94	12	6–17

*Mann-Whitney U test result; **Kruskal-Wallis test result; Min: Minimum; Max: Maximum.

Table 2. Parental attitudes towards non-medication for treatment according to education level

	Yes		No		p
	n	%	n	%	
Mothers of educational status					0.001
Literate	5	71.4	2	28.6 ¹	
Primary school	19	31.7	41	68.3 ²	
High school	4	8.3	44	91.7 ^{1,2,3}	
Graduate and over	2	22.2	7	77.8 ³	
Fathers of educational status					0.002
Literate	4	80.0	1	20 ^{1,2}	
Primary school	14	32.6	29	67.4	
High school	12	18.2	54	81.8 ¹	
Graduate and over	0	0.0	10	100.0 ²	

^{1,2,3}p<0.05.

practices to improve the efficacy of the service provided. Nurses are in a position where they have the opportunity to easily determine the health care needs and health care practices, as they tend to have the most face-to-face interaction with the children and their parents. Fear of traditional medical treatment, distrust of institutions, feelings of hopelessness, knowledge level, and the moral dimensions of these methods all contribute to the decision of applying a non-pharmacological treatment. Patient attitudes and their behaviors affect the course of the disease in children.

In Turkish society, raising a child and meeting their requirements are generally considered the mother's responsibility. As a result, 90% of the interviews conducted for data collection are conducted with mothers. It, therefore, can be argued that the course of the disease can be affected positively and patient costs and re-hospitalization numbers can be decreased if the knowledge level of mothers with children suffering from a chronic disease increases. To accomplish this, integrated learning models and anti-epileptic medication applications can be developed with information systems that involve the mother, father, children, teacher, pharmacist, and doctor, along with individual training to make them open to new information.

Recommendations

- It is recommended that parents be given education on care, treatment and child development, and that social support groups, where parents and children can receive training together and talk about their problems, be established

- For future studies, a randomized control design should be used.

Ethical dimension of the study

Approval to perform this study was received from the ethics committee of Yildirim Beyazit University with the decision no. 78033166/673, dated 12/25/2015. Written approval was also obtained from the Ankara Training and Research Hospital, where this study was conducted. Written consent was obtained from all parents of the children with epilepsy who participated in this study.

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Ethics Committee Approval

Ethics committee approved.

Peer-review

Externally peer-reviewed.

Conflict of interest

The authors declare that they have no conflict of interest.

Authorship Contributions

Concept: S.S.M., A.K.; Design: S.S.M., A.K.; Supervision: S.S.M., A.K.; Materials: S.S.M., A.K.; Data collection &/or processing: S.S.M., A.K.; Analysis and/or interpretation: S.S.M., A.K.; Literature search: S.S.M., A.K.; Writing: S.S.M., A.K.; Critical review: S.S.M., A.K.

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