Compliance with appointments and medications in a pediatric neurology clinic at a University Hospital in Riyadh, Saudi Arabia

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ABSTRACT

Objective: The objectives of the study are to estimate the rate of epileptic patients' compliance with appointments and medications in a pediatric neurology clinic. Also to study the factors associated with non-compliance and to determine the parents' perceived reasons for non-compliance with appointments.

Methods: It is a prospective study in which 147 epileptic children who attended the neurology clinic during the first 12-months of the study period were included. Patients were recruited into the study after their parents were interviewed using a detailed questionnaire; their compliance with appointments was monitored prospectively over at least a one year from their recruitment into the study. The parents of the other 70 patients who did not attend the clinic were telephoned. Only 32 replied and were asked about the reasons for non-attendance to the clinic.

Results: Eighty-six percent of the patients' parents stated that they were complying with the medications while only 53% of them did not miss any appointment to the clinic during the study period. Compliers with appointments were more likely to comply with their medications too. Children with grand-mal epilepsy and absence seizures were found to be more likely to comply with taking medications than patients with febrile, rolandic and myoclonic seizures (P=0.01). Health belief model factors associated with non-compliance were 1. Children encountering side effects from their medications 2. Parents who were not satisfied with the provided services 3. Parents who thought that alternative medicine is more effective than traditional medicine 4. Parents who think that their children are not susceptible. Patients' perceived main reasons for non-compliance were wrongly registered appointments (27.5%), forgetfulness (22.5%) and busy parents.

Conclusion: Failure to keep the clinic appointment is an indicator of poor compliance with medications. A telephone call is recommended to reduce the role of clinic non-compliance. Developing a questionnaire form to investigate parents health belief model could be used routinely by social workers and then health education could be tailored for each patient and parent.

Keywords: Epilepsy, pediatric, compliance and appointment.

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Concern with the problem of non-compliance has a lengthy history. In 200 BC, Hippocrates advised physicians to consider non-compliance as a possible explanation for a patient's failure to recover

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when a typically effective treatment had been use.[1] Compliance is defined as the extent to which, the patient's behaviour in terms of taking medication, following advice, or executing lifestyle changes, coincides with the clinical prescription.[2] Non-compliance with anti-epileptic drugs (AED) is a leading cause of treatment failure.[3] Failure to comply with drug regime is prevalent among patients with epilepsy and the consequences of this is often an increased risk of further seizures,[4] and even sudden death was found to be more in poor-compliance and poor-seizures, controlled groups.[5]

It was shown in 2 extensive literature reviews that patients on average keep 75% of the appointments they make and only 50% of those made for them.[6] The compliance rate for long-term medications is only 50%.[7] The rate of non-compliance depends on the clinic being attended and the population of patients being studied. Reports from primary care centers in the USA quote non-compliance rates between 5% and 30%.[8] The problem of non-compliance of patients suffering from chronic diseases and especially epilepsy is universal with different rates. In Japan, investigators found that only 42%[9] could adhere to the follow-up appointment, in South Africa, epileptics and asthmatics non-compliance rate was found to be 63%,[10] in the United States of America, 15-39%,[11] in Netherlands, a study showed that 93% of the patients were adherent to the treatment protocol.[12] Investigating the magnitude of the problem and the factors associated with non-compliance is essential in designing an appropriate health education strategy and having a plan to reduce the impact of the problem.

The failure rates of appointments keeping in a Saudi University outpatient clinics were found to be 29.5%[13] while non-compliance with AED taking in adults' epilepsy clinic was 30.8%.[2] Local studies, that investigate the problem of noncompliance among epileptic children in the Kingdom of Saudi Arabia (KSA) are rare. This study was initiated with the following objectives: 1. To estimate the rate of compliance with appointments and medications in a pediatric neurology clinic. 2. To investigate the factors associated with non-compliance such as patients' socio-demographic (SD) characteristics, medical history, frequency of medication and their availability and health belief model (namely patients' satisfaction with services; perception of disease seriousness and efficacy of treatment) and to assess the parents' perceived reasons of non-compliance with appointments.

Methods. This study was carried out on all epileptic children who attended the neurology clinic of King Khalid University Hospital (KKUH) over a period of 12 months. No patient was excluded and none of the parents declined to participate in the study. All patients were monitored for their compliance behaviour for at least 12 months after recruitment into the study, so the study is therefore prospective in design. It lasted for 2 years. The patients were usually given appointment to the clinic every 3-4 months. At the time of recruitment into the study the parents were interviewed by a social worker using a detailed questionnaire. Compliance with medications was assessed during the interview at the first contact for each patient while appointment keeping was observed over a period of at least 12 months. Patients who did not show-up in their scheduled appointment were telephoned and asked for the reasons for non-attendance over the whole study period.

The sample size was calculated by the standard formula $n = z\ \alpha^2 \times p\ (1-p)/d^2$. As no previous local study was conducted in this age group population so 'P' was assume to be 0.3 (range 0.22 – 0.38) at 95% level of significance. The required minimal sample size = $3.84 \times 0.3 \times 0.7/(0.08)^2 = 126$ patients. For the purpose of this study, the patient is labeled non-complaint with appointment if he/she failed to attend one or more appointment(s) during the follow-up period. Similarly, the parents who admit that their child missed a total of one day dosage per week is considered to be non-complaint. This level was devised specifically for the present study as the treating physicians felt that it is likely to adversely affect the disease control. The preliminary data entry and analysis was carried out using Systat statistical program and a univariate analysis was carried out for the determinants of non-compliance.

Results. The total number of study patient was 147. The majority of the study population were Saudi (72.1%), aged 6-12 years (44.2%), living inside Riyadh city, KSA (75.9%) and males outnumbered females (1.5: 1). The most frequent types of seizures were grand-mal seizures (41%) and partial seizures (33%). Patients' fathers had higher education than their mothers (P=0.00003). Most of the study population have stable families (91.2%). While the majority of the parents (86%) mentioned that they were complying with their children drug-taking, only 53% of them did not miss any clinic appointment. Children who were attending their appointments regularly were more likely to comply with medications (92.3%) than clinic appointment non-compliers (80.3%), although statistically not significant (P=0.06). The children SD characteristics in terms of age, nationality, gender, family size and area of residence were not found significantly associated with appointments' and medications' compliance. A higher proportion of patients living inside Riyadh, KSA, complied with appointments more so than those living outside Riyadh, KSA, but not at a statistically significant value (P=0.131).

Parents' socio-demographic characteristic and frequency of medication were not associated with both appointments and medications compliance. Similarly, the medical history did not influence the compliance status significantly except the seizure type (**Appendix 1**). The type of seizures was found to be significantly associated with medication taking (P= 0.007), namely children with grand-mal seizures had higher compliance rate. Children who were reported to have side effects from their medications were less likely to comply (71%) than the other children (88%), but not at a statistically significant level (P= 0.09). Parents who were satisfied with the provided services complied more with appointments (P= 0.053). Similarly, parents who thought that alternative medicine (AM) is more effective than traditional medicine (P=0.08) and parents who thought that their kids are not susceptible were less compliant with medications (P=0.058) (**Appendix 2**). The parents' or relatives' perceived causes of non-compliance were mainly wrongly registered appointments (27.5%), forgetfulness (22.5%) and busy parents (20%).

Discussion. The study took place in a university tertiary care hospital in Riyadh city, KSA. Each patient was interviewed to assess among other things drugs' compliance over the last week; then his clinic appointment keeping behavior, at the end of the study was assessed through the medical records. This design made it possible for us to have a face to face interview with all the patients' parents included in the study (100% response rate). If the study population was selected from the records, we may have missed to interview some of the patients' parents. The finding of 47% of the patients missing one or more appointment is a cause of concern. Furthermore, children not complying with their clinic appointment were found less likely to comply with their medications. This indicates that patients who do not keep their appointments should be contacted and monitored closely as they are likely to be irregular in drug-taking which incur unnecessary morbidity and mortality.[1,7] This inevitably interferes with optimal therapy and results in reduced control of seizures. The finding of only 14% of the study population confessing non-compliance with their medications is much below reports in the national[14] and international literatures.[15] A study on Saudi adult epileptic patients found a rate of non-compliance with AED of 31%.[14] Assessment of compliance using parents' memory is a subjective method and recall bias is a high possibility. The use of a more objective method as pill count method or drug level, or both is therefore recommended. While many studies found that old age, higher education and better socio-economic status are probably the only consistently important SD influences on appointment keeping behavior,[6] the present study did not find any of these factors to be significantly associated with compliance. This could be due to the small sample size and therefore the high possibility of type II error. Parents who believed that alternative medicine is more effective than traditional medicine and children who experienced side effects of drugs were found less complaint with medications, although the difference was not statistically significant. This result goes with the findings of a Saudi study that 53% of patients' non-compliant with medications mentioned the reasons as the disbelief in the value and need of adherence while 6.3% were due to drugs' side effects.[14] Another Western study found that patients believe that it was not all that important to take prescribed AED's.[4] It was not surprising to find unsatisfied parents with the provided services less compliant with clinic appointments. While we did not find significant difference in compliance based on parents' perception of doctors' skills (P=0.206), others found that patients who believe in the diagnostic ability, thoroughness and sympathy of their physician have a lower appointment failure rate.[16,17] One possible explanation is that in interviews, like in this study, people tend to produce more socially acceptable answers than in self-administered questionnaires especially if conducted outside the hospital by non-health professionals. The parents' perception that wrongly registered appointments is a leading cause of non-compliance (27.5%) is unexpected. It goes with the finding of a Canadian study that an appreciable proportion of non-attenders could be attributed to poor communication of appointments (30%) and forgetting the appointments (14%).[18] The appointment system at KKUH is computerized and each patient receives a slip of paper indicating the date of the following appointment. The use of Gregorian plus Hijrah calendars that produce confusion may explain this finding. Written information should be simply and clearly presented using short sentences. In a study of a series of psychiatric patients' compliance with antidepressants and tranquilizers, it was found that the readability of the leaflets provided was directly related to patient compliance with the medication regimen.[1] The use of telephone reminders could reduce non-compliance due to poorly communicated appointments and forgetfulness. A randomized trial of telephone and mailed reminders among patients new to a general medical clinic found a lower non-compliance rate among the patients who received the telephone call (10%) and those who received a letter (12%) compared with the control group (20%) (P 0.05).[18] Telephone or mailed reminders also resulted in greater patients and health care personnel satisfaction.[18] Since unsatisfaction with the provided services, the presence of drugs' side effects, the belief that AM is more beneficial and the belief that other children are not susceptible had some

association with non-compliance, we recommend an intervention to tackle these health belief model (HBM) issues. Developing a short form to investigate parents' HBM may be used routinely by social workers and then health education should be tailored for each parent and patient. As parents admitted that being busy was a cause for 20% of appointments' non-compliance, they should be reminded to put a high priority for their children's health and not to let other daily trivial urgencies override important tasks in their life or their children's lives.

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Appendix 1 - Compliance status with appointments and medications in relation to patients medical history.

Medical History	Appointment		P-value	Medication		P-value
	Compliers n (%)	Non-compliers n (%)		Compliers n (%)	Non-compliers n (%)	
Family history of seizures						
No	51 (52)	47 (48)		85 (85)	15 (15)	
Yes	24 (60)	16 (40)	0.507	38 (90.5)	4 (9.5)	
Total	**75 (54.3)**	**63 (45.7)**		**123 (87.2)**	**19 (12.8)**	0.543
Type of seizures						
1. Febrile seizure	14 (66.7)	7 (33.3)		17 (81)	4 (19)	
2. Rolandic seizure						
3. Absence (petit-mal)						
4. Grand-mal (generalized)	30 (50.8)	29 (49.2)		55 (91.7)	5 (8.3)	
5. Partial seizure (simple, complex)	24 (52.2)	22 (47.8)	0.664	47 (88.7)	6 (11.3)	
6. Myoclonic	9 (60)	6 (40)		5 (50)	5 (50)	
7. Others	1 (33.3)	2 (66.7)		3 (100)	0 (0)	
Total	**78 (54.2)**	**66 (45.8)**		**127 (86.4)**	**20 (13.6)**	**0.007**
No attacks						
Free	38 (61.3)	24 (38.7)		53 (84.1)	10 (15.9)	
1-3 attacks	19 (51.4)	18 (48.6)		33 (84.6)	6 (15.4)	
4-6 attacks	5 (71.4)	2 (28.6)		7 (100)	0 (0)	
>6 attacks	16 (42.1)	22 (57.9)	0.216	34 (89.5)	4 (10.5)	0.617
Total	**78 (54.2)**	**66 (45.8)**		**127 (85.4)**	**20 (13.6)**	
Medication						
Carbamazepine	33 (58.9)	23 (41.1)		52 (92.8)	4 (7.2)	
Sodium Valproate	24 (45.3)	29 (54.7)		39 (83)	8 (17)	
Penobarbitone	22 (59.5)	15 (40.5)	0.210	22 (81.5)	5 (18.5)	
Others	4 (33.3)	8 (66.7)		7 (25.9)	20 (74.1)	0.0000
Total	**83 (52.5)**	**75 (47.5)**		**120 (76.4)**	**37 (23.6)**	
Frequency of medication						
Once daily	6 (46.2)	7 (53.8)		10 (76.9)	3 (23.1)	
Twice daily	42 (60)	28 (40)		64 (90.1)	7 (9.9)	
Three times daily	23 (50)	23 (50)	0.612	43 (93.5)	3 (6.5)	*0.342
Using > one medication	14 (50)	14 (50)		24 (85.7)	4 (14.3)	
Total	**85 (54.4)**	**72 (45.6)**		**141 (89.2)**	**17 (10.8)**	
Side effects of medication						
Yes	7 (50)	7 (50)		10 (71.4)	4 (28.6)	
No	63 (53.4)	55 (46.6)	0.966	107 (88.4)	14 (11.6)	0.0939
Total	**70 (53)**	**62 (47)**		**117 (86.7)**	**18 (13.3)**	
Response to treatment						
Cured	21 (65.6)	11 (34.4)		29 (85.3)	5 (14.7)	
Good control	29 (50.9)	28 (49.1)		52 (89.7)	6 (10.3)	
Fair control	16 (64)	9 (36)	0.379	23 (92)	2 (8)	
Poor control	11 (47.8)	12 (52.2)		18 (78.3)	5 (21.7)	
Total	**77 (56.2)**	**60 (43.8)**		**122 (87.1)**	**18 (12.9)**	**0.462**
Associated Symptoms						
No	48 (58.5)	34 (41.5)		69 (84.1)	13 (15.9)	
Yes	24 (51.1)	23 (48.9)		45 (90)	5 (10)	
Total	**72 (55.8)**	**57 (44.2)**	**0.523**	**114 (86.4)**	**18 (13.6)**	**0.491**
Focal Neurological sign						
No	66 (56.4)	51 (43.6)		102 (86.4)	16 (13.6)	
Yes	10 (45.5)	12 (54.5)		21 (87.5)	3 (12.5)	
Total	**76 (54.7)**	**63 (45.3)**	**0.475**	**123 (86.6)**	**19 (13.4)**	**0.849**
Mental Retardation						
No	49 (58.3)	35 (41.7)		75 (87.2)	11 (12.8)	
Yes						
Mild	11 (68.8)	5 (31.2)		12 (70)	5 (29.4)	
Moderate	9 (52.9)	8 (47.1)		15 (88.2)	2 (11.8)	
Severe	9 (34.6)	17 (65.4)		24 (92.3)	2 (7.7)	
Total	**78 (54.5)**	**65 (45.5)**	**0.113**	**126 (86.3)**	**20 (13.7)**	**0.216**
Last Attack						
>6 month	28 (59.6)	19 (40.4)		39 (83)	8 (17)	
>3-6 months	10 (62.5)	6 (37.5)		14 (87.5)	2 (12.5)	
>1-3 months	12 (54.5)	10 (45.5)		20 (90.9)	2 (9.1)	
>1-4 weeks	11 (52.4)	10 (47.6)		20 (86.9)	3 (13.1)	
>Within last week	17 (45.9)	20 (54.1)		32 (86.5)	5 (13.5)	
Total	**78 (54.5)**	**65 (45.5)**	**0.730**	**125 (86.2)**	**20 (13.8)**	**0.931**
Age of onset of Epilepsy						
>6 years	19 (57.6)	14 (42.4)		30 (88.2)	4 (11.8)	
>3-6 years	24 (54.5)	20 (45.5)		41 (91.1)	4 (8.9)	
>1-3 years	23 (52.3)	21 (47.7)		37 (82.2)	8 (17.8)	
≤ one year	12 (54.5)	10 (45.5)		18 (81.8)	4 (18.2)	
Total	**78 (54.5)**	**65 (45.5)**	**0.975**	**126 (86.3)**	**20 (13.7)**	**0.571**

n - number

Appendix 2 - The association of patients' health belief with medications and appointments compliance.

Parameters monitoring health beliefs	Appointment		Total	P-value	Medication		P-value
	Compilers n (%)	Non-compilers n (%)			Compilers n (%)	Non-compilers n (%)	
Patients' satisfaction with service provided							
Very satisfactory	46 (56.8)	35 (43.2)	**81**		73 (89)	9 (11)	
Satisfactory	22 (61.1)	14 (38.9)	**36**		29 (80.6)	7 (19.4)	
Not satisfactory	3 (27.3)	8 (72.7)	**11**		10 (83.3)	2 (16.7)	
Very unsatisfactory	0 (0)	3 (100)	**3**		3 (100)	0 (0)	
Total	**71 (54.2)**	**60 (45.8)**	**131**	0.053	**115 (86.5)**	**18 (13.5)**	**0.551**
Seriousness of problem							
Dangerous	35 (53)	31 (47)	**66**		60 (89.6)	7 (10.4)	
Dangerous of small degree	9 (64.3)	5 (35.7)	**14**		11 (78.6)	3 (21.4)	
Not dangerous	14 (63.6)	8 (36.4)	**22**		20 (86.9)	3 (13.1)	
Not sure	13 (43.3)	17 (56.7)	**30**		24 (80)	6 (20)	
Not sure but worried	7 (58.3)	5 (41.7)	**12**	0.573	12 (92.3)	1 (7.7)	
Total	**78 (54.2)**	**66 (45.8)**	**144**		**127 (86.4)**	**20 (13.6)**	**0.603**
Regular treatment efficiency							
Useful	44 (62.9)	26 (37.1)	**70**		64 (90.1)	7 (9.9)	
Of little use	14 (46.7)	16 (53.3)	**30**		28 (90.3)	3 (9.7)	
Useless	3 (30)	7 (70)	**10**		7 (70)	3 (30)	
Harmful	6 (46.2)	7 (53.8)	**13**		10 (76.9)	3 (23.1)	
Not sure	11 (52.4)	10 (47.6)	**21**		18 (81.8)	4 (18.2)	
Total	**78 (54.2)**	**66 (45.8)**	**144**	0.237	**127 (86.4)**	**20 (13.6)**	**0.295**
Benefit of regular attendance							
Very useful	56 (53.3)	49 (46.7)	**105**		94 (88.7)	12 (11.3)	
Of little use	18 (69.2)	8 (30.8)	**26**		24 (85.7)	4 (14.3)	
Useful	1 (50)	1 (50)	**2**		2 (100)	0 (0)	
Harmful	1 (25)	3 (75)	**4**		3 (75)	1 (25)	
Not sure	2 (28.6)	5 (71.4)	**7**		4 (57.1)	3 (42.9)	
Total	**78 (54.2)**	**66 (45.8)**	**144**	0.237	**127 (86.4)**	**20 (13.6)**	**0.175**
Cause of epilepsy (Jinni, evil eye and so forth)							
No	40 (58)	29 (42)	**69**		63 (90)	7 (10)	
Yes	28 (50.9)	27 (49.1)	**55**		47 (83.9)	9 (16.1)	
Know	9 (58.9)	8 (47.1)	**17**		14 (77.8)	4 (22.2)	
Total	**77 (54.6)**	**64 (45.4)**	**141**	0.75	**124 (86.1)**	**20 (13.9)**	**0.341**
Parents' belief that alternative medicine is better than current medicine							
No	55 (59.1)	38 (40.9)	**-**		85 (89.5)	10 (10.5)	
Yes	3 (37.5)	5 (62.5)	**-**	0.242	5 (62.5)	3 (37.5)	
Not sure	20 (46.5)	23 (53.5)	**-**		37 (84.1)	7 (15.9)	
Total	**78 (100)**	**66 (100)**	**-**		**127 (100)**	**20 (100)**	**0.08**
Physician is skillful							
Yes	50 (56.2)	39 (43.8)	**-**		79 (87.8)	11 (12.2)	
Of little skill	4 (80)	1 (20)	**-**		5 (100)	0 (0)	
No	0 (0)	2 (100)	**-**	0.206	1 (50)	1 (50)	
Do not know	22 (47.8)	24 (52.2)	**-**		40 (83.3)	8 (16.7)	
Total	**76 (100)**	**66 (100)**	**-**		**125 (100)**	**20 (100)**	**0.19**
Your other children are susceptible to epilepsy							
No	46 (50.5)	45 (49.5)	**-**		75 (80.6)	18 (19.4)	
Not sure	12 (80)	3 (20)	**-**	0.124	15 (100)	0 (0)	
Yes	13 (46.4)	15 (53.6)	**-**		27 (93.1)	2 (6.9)	
Do not know	6 (66.7)	3 (33.3)	**-**		9 (100)	0 (0)	
Total	**77 (100)**	**66 (100)**	**-**		**126 (100)**	**20 (100)**	**0.058**

n - number