

The Impact of Pharmacist's Counselling on Knowledge of Epilepsy and Its Treatment among Caregivers of Paediatric Patients with Epilepsy

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Abstract

Introduction: Parent health literacy is a predictor of adherence-related outcome among children with epilepsy.

Objective: The aim of this study was to evaluate the impact of pharmacist's counselling on paediatric patient's caregivers' knowledge on epilepsy and antiepileptic drugs (AED). This study also assessed the caregivers' confidence status before and after pharmacist's counselling and to evaluate their satisfaction on the counselling.

Methods: A pre and post interventional study was carried out from July to December 2017. The intervention was one to one counselling session to caregiver by pharmacist. The first set of questionnaire assessing the knowledge on epilepsy and AED (Part A) and confidence level (Part E) were administered to the caregivers prior to the counselling session. The caregivers had to complete the second set of questionnaire, consisting of Part B, which has the same questions as Part A but in reverse order, and Part G that measure caregivers' satisfaction level on the counselling, immediately after the counselling session. Caregivers were then follow-up a month later during their medication refill with the third set of questionnaire which consisted of Part E that assessed their confidence level.

Results: A total of 18 caregivers received the interventions and completed all three sets of questionnaires. The mean score on knowledge on epilepsy post counselling was significantly higher than pre counselling (16.6 ± 2.8 vs 9.2 ± 4.3 , $p < 0.001$). There was a marked increment in patients' confidence in managing their children's epilepsy condition (median score 5.0, IQR 0.25, vs 3.0, IQR 0.0, $p < 0.001$). Overall, the caregivers rated the pharmacist counselling from very good to excellent.

Conclusion: A comprehensive counselling session tailored to epilepsy disease and its management by pharmacist increased caregivers' knowledge on epilepsy and AED and their confidence in managing children with epilepsy.

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Introduction

Epilepsy is a neurological disorder operationally defined as two or more episodes of unprovoked seizures occurring at least 24 hours apart. It is one of the most common, disabling neurological conditions. It was estimated that around six to seven children per 1,000 population in the United States have epilepsy (1). It increases the morbidity and symptomatic epilepsy reduces life expectancy by 18 years at maximum (2). The commencement of antiepileptic drug (AED) is recommended if there is more than one episode of unprovoked seizure to reduce the recurrence risk.

Parent health literacy has been associated with child health outcomes and medical treatment. Adherence is defined as the extent to which a patient's treatment-related behaviours (e.g., taking medication, following a prescribed diet, modifying health habits, and attending clinic appointments) correspond to a health professional's advice or treatment plan (1). Of those diagnosed with epilepsy, the vast majority are treated with AEDs and approximately 70% can become seizure free once the most effective regime is followed (3-4). Unfortunately, evidence suggested that adherence to medications among patients with

epilepsy was sub-optimal (5-8). Therefore, to address this matter, caregivers' knowledge towards epilepsy and AEDs is crucial to reduce seizures among children apart from increasing patient's adherence.

Nonadherence has been associated with increased seizure risk of 21%, morbidity, mortality and higher health care costs (9,10). Increased frequency of seizure can have serious repercussions on an individual's perceived quality of life (11). Pharmacists play an important role in the care of epileptic patients by educating patients on their condition, appropriate use of medication and advocating importance of adherence (12). It was found that the total first-year medical care cost for epilepsy patient was MYR 1690.13 per patient per year (13). Therefore, it is vital for the pharmacists to highlight the importance of optimising seizure control. Previous research has shown that factors contributing to adherence were patients' knowledge, education, satisfaction with medical care and complexity of treatment regimens (14-18). Knowledge on medication could significantly reduce drug related events such as misinterpretation of directions, side effects and nonadherence (19). Nevertheless, paediatric patients' adherence to treatment is largely dependent on their caregivers. A study suggested that additional counselling helped to improve caregivers' knowledge regarding the condition which may lead to better adherence (17). Counselling services provided by pharmacists to patients with chronic conditions have shown positive impact on patients' outcomes (18). Pharmacists emphasise on rationale drug use and management of patients' medical condition which improves knowledge and subsequently may positively influence adherence to medication. To our knowledge, there was no local published data regarding the impact of pharmacist's counselling on knowledge among caregivers of paediatric patients with epilepsy. Therefore, this study aimed to investigate caregivers' knowledge on epilepsy and AEDs as well as patient's caregiver confidence status and satisfaction upon counselling by pharmacists.

Method

Study Design

A prospective study was performed in Hospital Melaka, Malaysia. Hospital Melaka is a state hospital which covers patients from Melaka state. Ethical approval for this study was obtained from the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (NMRR ID: NMRR-17-639-35402). This study adhered to strict information governance and security protocols.

Study Setting and Study Population

This study was conducted from July to December 2017, in Satellite 5 Outpatient Pharmacy of Hospital Melaka. The study population consisted of caregivers who accompanied epileptic paediatric patients aged below eighteen years old that attended the paediatric neurology follow up visits which was scheduled on every Thursday morning. The inclusion criteria were parents or caregivers of children aged below eighteen years old who were diagnosed with any forms of seizure, patients whom AED(s) are administered by their caregivers at home. The exclusion criteria were inadequate data / missing data, patients who just started taking AED(s) or had a new AED regime for less than one month from the recruitment date and parents or caregivers who could not understand Malay and English or illiterate.

Sample size calculation was done based on $N = 2 + C(s/d)^2 + 20\%$ drop off (20). In which, the constant for significance level of 0.05; power of study of 0.8, $C=7.85$; standard deviation of knowledge score, $s=3.4$; difference detected, $d = \text{post knowledge score} - \text{pre knowledge score} = 4.3$ (21). Hence, a minimum of eight subjects was required to show a significant result at 95% confidence interval and power of study at 80%.

All epileptic patients' caregivers who went to the Satellite 5 Outpatient Pharmacy after neurology clinic follow up on Thursday morning were screened and recruited via convenient sampling. All caregivers that met the inclusion and exclusion criteria were approached for study details explanation. Caregivers who agreed to join the study were required to sign the informed consent form. Patients and caregiver's demographic data were collected.

Before the pharmacist's counselling, the baseline knowledge on epilepsy and AED and confidence of caregivers in managing epilepsy were assessed using the first set of questionnaires (Part A knowledge and Part E confidence). Then, a counselling session by pharmacist was conducted for approximately 30 minutes. After counselling, the knowledge on epilepsy and AED of caregivers and caregivers' satisfaction towards pharmacist counselling were assessed using the second set of questionnaires consisting of Part B and Part G. Part B had the same questions as Part A but the questions were in reverse order. The caregivers were followed up at one-month interval during their medication refill and their confidence in managing

epilepsy was reassessed using the third set of questionnaires which consisted of Part E. The detailed workflow of the study was shown in Figure 1.

The counselling session was conducted with the aid of presentation slides and leaflets that were prepared by the pharmacists and checked by specialists in charge of paediatric neurology clinic. All counselling materials were prepared in English and Malay. The types of seizures, how to take care of paediatric epilepsy children, what to do during seizure attack, common side effects of AED and importance of compliance were some of the contents included in the counselling tools. The caregivers will receive the counselling leaflets at the end of the counselling session for further reference to improve their knowledge. Throughout the study period, the counselling was carried out by three pharmacists who had been trained by a senior pharmacist and a counselling checklist was used. These approaches were taken to ensure the counselling sessions were consistent, of good quality and effective.

Study Instrument

The questionnaires used were researcher-assisted questionnaires. The questionnaires were developed by Chen *et al.* (21) and permission to use had been obtained. There were four parts of questionnaires used in this study (Part A, B, E and G), as summarised in Table 1.

Questionnaire Part A consisted of 21 questions. Part A was a 10-minute researcher-assisted questionnaire used to assess caregivers' baseline knowledge on epilepsy and AED before counselling. In Part A, the scoring for answers followed a negative grading system. There were three responses for each question: 'true', 'false' and 'not sure'. The correct responses were assigned one point, the incorrect responses were assigned negative one point whereas the 'Not Sure' responses were given zero point. As such, a maximum of 21 points and minimum of negative 21 points were possible for questionnaire Part A. After the counselling session by pharmacist, questionnaire Part B (same questions as Part A but in a reverse order), was used to evaluate caregivers' knowledge on epilepsy. The knowledge scores pre-counselling (Part A) and post-counselling (Part B) was compared.

Caregivers' confidence in managing of epilepsy was evaluated using questionnaire Part E. In this Part of questionnaire, the answers were in five-point Likert scale and scores were assigned to the responses as follow: 'very confident' (five points), 'confident' (four points), 'a little confident' (three points), 'a little not confident' (two points), and 'no confidence' (one point). Confidence was assessed pre-counselling and one-month post-counselling to enable caretakers to incorporate their newly acquired knowledge into their daily care for patients. The one-month lapse will give a better insight into caregivers' confidence as compared to if the evaluation of confidence was done immediately post counselling.

Caregivers' satisfaction on pharmacist's counselling was assessed using questionnaire Part G that consisted of seven questions with five-point Likert scale answers. In Part G, 'excellent' ratings were assigned five points, followed by four points for 'very good', three points for 'good', two points for 'satisfactory', and one point for 'poor'.

Statistical analysis

All data was entered into a Microsoft Excel 2003 spreadsheet. Data was analysed with SPSS (version 18.0.0) software. The mean scores and the mean differences between Part A and B were calculated. Paired sample t test was used to compare the means of sets A and B. The proportion of caregivers giving correct answer for each question was calculated. The proportion of pre- and post-counselling was compared using McNemar test. The median scores of confidence status pre- and post-counselling were compared using Wilcoxon Signed-Ranked test. Statistical significance was defined as $p < 0.05$.

Table 1: Summary of questionnaires used

Part	Measurement	Remarks
A	Caregiver's knowledge on epilepsy and AED	-
B	Caregiver's knowledge on epilepsy and AED	Same questions as Part A but in reverse order
E	Caregiver's confidence	-
G	Caregiver's satisfaction on pharmacist counselling	-

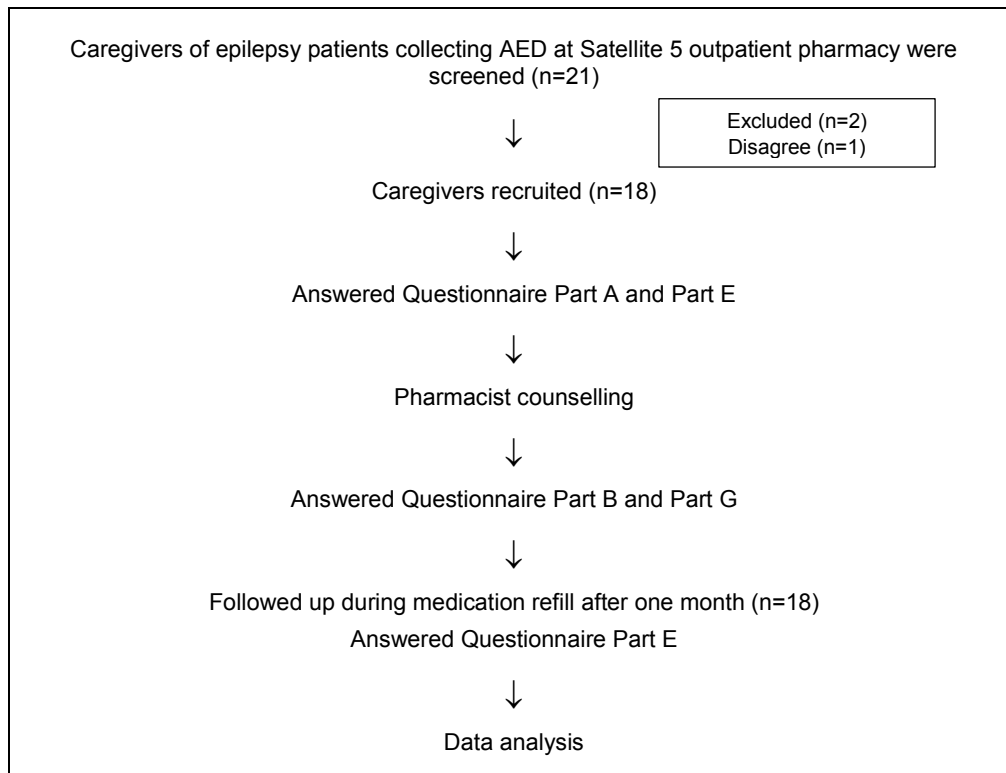


Figure 1: Workflow of study

Results

Twenty-one caregivers were screened. Among these caregivers, one declined participation and two participants were excluded. Among the 18 caregivers included, sixteen (88.9%) of the patients under their care had generalised seizures and two (11.1%) had focal seizure. The characteristics of caregivers and epilepsy patients were presented in Table 2 and Table 3 respectively.

Caregivers' knowledge on epilepsy

After counselling, the mean score of caregivers' knowledge on epilepsy was significantly higher than pre-counselling (16.6 ± 2.8 versus 9.2 ± 4.3 , $p < 0.001$) (score range = -21 to 21). After pharmacist counselling, there was an increment of the proportions of caregivers answering correctly for 20 out of the 21 questions. The distribution of proportion of caregivers with correct answer for each question before and after counselling was presented in Table 4. Among the 20 questions, there was significant improvement in proportion of caregivers answering correctly post-counselling for three questions (question 9, 10c and 11b).

Caregivers' confidence and satisfaction towards pharmacist's counselling

The median score of confidence of caregivers improved after counselling (5.0, interquartile range (IQR) 0.25 versus 3.0, IQR 0.0, $p < 0.001$). Overall, the caregivers rated the counselling provided by the pharmacist as very good to excellent with median satisfaction score ranging from 4.5 (IQR 1.0) to 5.0 (IQR 0.0) for each component assessed. The details were tabulated in Table 5.

Table 2: Characteristics of caregivers of paediatric epilepsy patients (n=18)

Characteristic	n (%) / mean \pm SD
Age of caregivers, mean \pm SD	35.8 \pm 4.8
Gender of caregivers, n (%)	
Female	14 (77.8%)
Male	4 (22.2%)
Education level, n (%)	
Primary	1 (5.6%)
Secondary	9 (50%)
Pre-university *	3 (16.7%)
Diploma	4 (22.2%)
Degree	1 (5.6%)
No. of children under their care, n (%)	
1	0 (0%)
2	5 (27.8%)
3	8 (44.4%)
\geq 4	5 (27.8%)

Abbreviation: SD – standard deviation

* Pre-university refers to caregivers with advanced level certificate or underwent matriculation programme

Table 3: Characteristics of paediatric epilepsy patients under the care of respondents (n=18)

Characteristic	n (%) / mean \pm SD
Age of epilepsy patients, mean \pm SD	5.1 \pm 3.0
Types of seizure, n (%)	
Generalised	16 (88.9%)
Focal	2 (11.1%)
No. of AEDs prescribed, n (%)	
1 AED	11 (61.1%)
2 AEDs	5 (27.8%)
3 AEDs	2 (11.1%)
Duration of taking AED, n (%)	
< 1 year	4 (22.2%)
1-5 years	9 (50.0%)
> 5 years	5 (27.8%)
Ever dispensed with rectal diazepam, n (%)	
Yes	5 (27.0%)
No	13 (73.0%)
Keep a seizure diary, n (%)	
Yes	14 (77.8%)
No	4 (22.2%)

Abbreviation: SD – standard deviation; AED – antiepileptic Drug

Table 4: Percentage of caregivers with correct answer for questions regarding epilepsy pre- and post-counselling

No.	Question	Pre (%)	Post (%)	p-value*
2a	Epilepsy is a disorder caused by abnormal electrical activity in the brain.	66.7	100.0	-
2b	Epilepsy is a curable disease.	38.9	66.7	0.231
3a	My child may have more seizures if he/she does not get enough rest.	55.6	100.0	-
3b	My child may have more seizures if he/she develops a fever or falls sick.	44.4	100.0	-
3c	My child may have more seizures if he/she misses taking their seizure medication(s).	55.6	88.9	0.109
4	If my child stops having seizures while taking the seizure medication(s), I can stop the medication(s).	77.8	100.0	-
5	If my child missed a dose(s) of the medication(s), I should ignore the missed dose and double the next dose.	83.3	100.0	-
6	I can bring the child to see other doctors but I must inform them my child is on seizure medication(s).	94.4	94.4	1.000
7	If my child is drowsy and/or dizzy after taking the seizure medication(s), I should continue with the medication(s), but inform the doctor at the next appointment.	72.2	83.3	0.727
8	If my child has a body rash, fever and mouth ulcers after starting seizure medications, I should bring the child to the Accident and Emergency Department immediately	77.8	100.0	-
9	There is no need to inform the doctor if I want to give herbal supplements or other medicines to my child.	61.1	94.4	0.031
10a	If your child is having a convulsive seizure (whole body is stiff and jerking uncontrollably), turn the child's body to recovery position (Body lying on the side, head tilted upwards).	83.3	94.4	0.625
10b	If your child is having a convulsive seizure (whole body is stiff and jerking uncontrollably), put a spoon or finger into the child's mouth to prevent him/her from biting his/her own tongue.	61.1	100.0	-
10c	If your child is having a convulsive seizure (whole body is stiff and jerking uncontrollably), give rectal diazepam if the seizure lasts longer than 5 – 10 minutes.	27.8	77.8	0.008
10d	After the seizure, let your child sleep for up to 60 minutes.	16.7	22.2	1.000
11a	I should bring my child to seek medical attention immediately every time a seizure occurs.	44.4	77.8	0.109
11b	I should bring my child to seek medical attention immediately if he/she is remains confused or sleepy 5 minutes after a seizure episode.	33.3	66.7	0.031
11c	I should bring my child to seek medical attention immediately if seizure continues for more than 10 minutes after giving rectal diazepam.	61.1	94.4	0.070
12	Children with seizures may swim alone.	72.2	100.0	-
13a	A seizure diary is a diary epilepsy patient or the caregiver use to record their seizure frequency.	72.2	100.0	-
13b	A seizure diary can help the doctor to know if the seizure medication(s) your child is taking helps your child's fits.	72.2	100.0	-

* *Mc Nemar test*

Analysis was not done for question 2a, 3a, 3b, 4, 5, 8, 10b, 12, 13a and 13b due to small sample size in the respective categories

Table 5: Scores of caregivers' satisfaction towards pharmacist counselling (n=18)

No.	Question	Score, median (IQR)
1	Pharmacist's knowledge	5.0 (0.3)
2	Pharmacist's explanation of medications	5.0 (0.3)
3	Pharmacist's instructions on administration	5.0 (1.0)
4	Pharmacist's courtesy and respect	5.0 (1.0)
5	Amount of time pharmacist offers to spend	5.0 (0.0)
6	Usefulness of information provided	5.0 (0.3)
7	Overall rating of service	4.5 (1.0)

Score scale 1: poor, 2: satisfactory, 3: good, 4: very good, 5: excellent

Abbreviation: IQR – interquartile range

Discussion

The educational counselling provided by the pharmacist was effective at improving caregiver knowledge on epilepsy and antiepileptic treatment. This result is in accordance with the results from a study done in Singapore by Chen *et al.* (21) and another study in Taiwan by Liu (22).

This study reported that the general knowledge regarding AED among our population was satisfactory for some questions. In our study, more than 80.0% of the caregivers correctly answered missed dose management and not to double dose. Whereas only 59.0% and 70.0% of caregivers in the Thailand and Singapore studies responded that double dosing to replace a missed dose was incorrect (19,21). The higher percentage in our study reflected that our population of study has a better understanding of missed dose management. However, this study highlighted that attention need to be paid to some of the AED knowledge questions. More than one-fifth of the caregivers were not aware of the symptoms of hypersensitivity reaction that need immediate medical attention. In addition, almost one third of the caregivers was not aware of the drug-drug and drug-herb interactions thus would not inform prescribers regarding the initiation of herbal supplements or other medications. After counselling, the knowledge of both aspects improved among caregivers. Therefore, it is crucial to highlight this information in the epilepsy counselling session in the future.

Nonetheless, our findings showed that the less than half of the caregivers was aware that epilepsy is not curable. Even after counselling, around one third of the caregivers was still not aware that epilepsy cannot be cured. Although all caregivers answered that they will not stop the AED if the child stops having seizure, not all of them was aware that missing AED is one of the contributing factors of seizure. Therefore, they still need to be educated that epilepsy cannot be cured but can be controlled well with AED and hence compliance towards AED is important.

There were three questions pertaining to knowledge on acute management during seizure attacks presented with the lowest score before counselling. Only five out of 18 of them were prescribed with rectal diazepam previously and all of them could answer correctly on the use of rectal of diazepam. This result was higher than the population studied in Singapore and Thailand whereby 44.0% and 95.0% of the respective population know how to use rectal diazepam (19,21). Knowledge on the correct use of rectal diazepam is essential to terminate prolonged convulsive seizures and clusters of repeated seizures in children with epilepsy. The management of acute seizures usually demands immediate administration of appropriate antiepileptics for avoiding status epilepticus (23). Therefore, more effort could be focused onto improving patient's knowledge on the correct use of rectal diazepam.

Prior to counselling, only one third of the caregivers were aware that they need to seek immediate medical attention if a child remained confused or sleepy for five minutes after a seizure episode. Similarly, caregivers in Singapore also shared a low level of awareness as only 7.4% of caregivers were able to give a correct response to the similar question prior to counselling (21). In our study, there was significant improvement after counselling, whereby about two third of the caretakers were able to answer the questions correctly. Counselling sessions provided were able to address caregiver's wrong perception on when to seek medical attention after seizure episode and educate caregiver on the correct use of rectal diazepam.

As for seizure diary, approximately 70.0% population of our study kept seizure diaries, which was higher than the respondents in Taiwan (22). This showed that caretakers in this study were aware on the importance of recording frequency of seizure to assist doctors in assessing their children's epilepsy control and thus help to optimise the treatment.

Earlier study done by Galleti recognised the importance of counselling for paediatric patients in order to identify any knowledge deficits but did not explore the effects of counselling on parameters such as knowledge (24). Our study showed that counselling by pharmacist could improve the knowledge of caregivers.

Almost all caregivers were more confident in managing their children's epilepsy conditions after the counselling session. This coincided with the improvement in most of the questions post counselling. This finding was similar to the study done in Singapore (21). The mean score of caregiver satisfaction towards pharmacist's knowledge and pharmacist's explanation of medications was rated between very good to excellent. This implied that the caregivers in our study were generally satisfied with the service provided the pharmacists.

This study gave an insight into the impact of pharmacist's counselling on knowledge of epilepsy and its treatment among caregivers of paediatric patients with epilepsy in local setting. It provided preliminary data on what element to be focused in the counselling to improve the knowledge on epilepsy and its treatment among the caregivers. However, we were unable to explore how improved knowledge on epilepsy

as well as knowledge on AED may affect the compliance in this population of study. Therefore, future studies could further explore the impact of pharmacist's counselling on patient's adherence to antiepileptic treatment.

Conclusion

Pharmacist-based counselling improved caregiver's knowledge on epilepsy, AEDs and confidence in managing epilepsy. Caretakers were highly satisfied with counselling services given by pharmacists. A protocol should be generated with involvement of pharmacists in education service for better care of paediatric epilepsy patients. On the other hand, future study could be conducted to explore the association between caregiver's knowledge and patients' compliance to treatment.

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Conflict of Interest Statement

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