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Knowledge gap exists among caregivers of adults compared to caregivers of children with epilepsy: A comparative analysis from a low resource setting

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ABSTRACT

Caregivers of adults (CG-A) and caregivers of children (CG-C) may differ in their knowledge, attitude and behavior and hence their education requirements during epilepsy counseling could vary. This study compares the current knowledge, attitudes, behavior during a seizure, presence of myths surrounding epilepsy and ability to recognize seizures among a sample of CG-A and CG-C. Caregivers of children and adult patients with minimum 6 months history of epilepsy were enrolled. Information was collected using a questionnaire about clinical and demographic details and five domains (KAP-plus); knowledge, attitude, behavior, presence of myths and a video data for identification of focal impaired awareness seizures (FIAS) and generalized tonic-clonic seizures (GTCS). There were 132 CG-A and 127 CG-C. CG-C were younger and better educated compared to CG-A (formal education of 64.6% vs 44.7% $p = 0.001$). CG-A and CG-C were comparable in the knowledge and attitude domains. CG-A scored less than CG-C in the domains of behavior (15.5 vs 16.8 $p = <0.001$), myths (15.4 vs 16.2 $p = 0.002$), video recognition of FIAS and GTCS (0.7 vs 0.94 $p = 0.001$) and KAP-plus score (22.9 vs 24.6 $p = 0.017$). The knowledge-behavior or knowing-doing gap, knowledge-faith gap and knowledge-recognition gaps existed more among CG-A compared to CG-C. Focused education strategies are required to bridge the gap among CG-A.

1. Introduction

It is estimated that 10–12 million people living with epilepsy (PWE) reside in India, contributing to almost one-sixth of the worldwide disease burden [1]. Although previous incidence of epilepsy in India was reported to be highest among children and older adults [2,3], recent studies have shown a higher prevalence in adults [1]. Most of the PWE in India are cared for by their families; responsibilities include ensuring medication compliance, providing safety during seizures, giving first-aid or emergency medications and accompanying patients for medical appointments among others [4]. They also play a significant role in identifying and providing description of seizures to the physician for correct diagnosis and appropriate treatment. It is well known that caregivers adjust poorly to recurrent seizures and hence are at greater risk of depression and have poorer quality of life than the general population [5]. Considering their roles in shaping the lives of PWE and considering the burden produced by caring, it is imperative for the caregiver to show a supportive knowledge, attitude and practice with regard to epilepsy. In India, caregiver education delivered via epilepsy counseling would be as important as patient education in providing a safe environment for PWE.

A significantly higher incidence and prevalence of epilepsy is observed in rural rather than urban India [1] where many superstitious beliefs prevail. People attribute epilepsy to the wrath of evil spirits and witchcraft and prefer approaching faith healers, exorcists and black magic practitioners than a practitioner of modern medicine. It is also believed that PWE are intellectually disabled and can never occupy higher positions in society. This has been reported in 51% of participants from a hospital-based study in South India [6] and 44% of children with epilepsy in a study in rural India [7]. Some people adopt medical treatment and then add complimentary spiritual forms of treatment [8]. These myths and beliefs are associated with a extension from reality and are responsible for practices which may harm patients' health. Despite improving knowledge, people still struggle to strike a balance between science and faith.

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Though caregivers play a significant role in the life of PWE, very few studies use a standardized questionnaire as a survey model to assess information on knowledge, attitude, and practices (KAP theory) which would have a bearing on the quality of care for PWE. A review of all published literature using PubMed found only six studies on this topic, none of which was performed in India. In the available studies, either the caregivers of adults (CG-A) and the caregivers of children (CG-C) were grouped together [9–11] or the CG-C alone were studied [12–14]. We hypothesized that CG-C would be more apprehensive and would put greater effort into gaining knowledge about the disease and its treatment to facilitate parenting their children diagnosed with epilepsy. There could be differences in the knowledge and healthcare-seeking behavior between the two groups. Because of a paucity of specialist services in India, physicians and neurologists care for both adults and pediatric PWE. Different counseling strategies may need to be adopted for their respective caregivers. It would thus be worthwhile studying the CG-A and CG-C separately and understand their similarities and differences.

We conducted this cross-sectional study to: (1) assess the current knowledge, attitudes, behavior during a seizure, presence of myths surrounding the disease and ability to recognize seizures among a sample of caregivers of adults and caregivers of children with epilepsy (2) compare the two groups with the ultimate goal of identifying their specific educational needs and plan appropriate counseling strategies.

2. Methodology

2.1. Study site and subjects

This prospective cross-sectional study was conducted at our Comprehensive Epilepsy Care Center attached to a tertiary hospital at Coimbatore, Western Tamil Nadu, South India. The study was approved by the ethics committee of the hospital. Caregivers of both children (age $\leq$ 15 years) and adult patients (age > 15) were recruited from the out-patient department of our epilepsy clinic from September 2020 to March 2021. All the patients were seen by the epilepsy specialist (RSI). The inclusion criteria were individuals who: (1) self-identified as a caregiver of a PWE living in their home (2) provided care for a PWE diagnosed according to the International League Against Epilepsy (ILAE) guidelines [15] (3) provided care for a PWE diagnosed at minimum 6 months previously and (4) were willing to participate and able to provide informed consent. The exclusion criteria consisted of (1) caregivers of PWE with history of epilepsy surgery (since they are likely to seek or get exposed to more epilepsy specific information) and (2) caregivers who had previous exposure to epilepsy-specific educational sessions or themselves were diagnosed with epilepsy.

2.2. Questionnaire

Information was collected from the participants using a questionnaire, which in addition to the clinical and demographic details included items across five domains; knowledge, attitude, practice or behavior, belief in myths and video recognition of seizures. All caregivers gave informed consent before participating in the study. Data were collected through face-to-face interviews by the epileptologist (RSI) or the trained clinical pharmacist (AAS) or physician assistant (NJ) in a separate room in neurology outpatient services. A structured interview approach was followed, each lasting 25–30 min.

We developed appropriate questions for assessment of caregivers' KAP using results from previous studies [10,12,14,16]. Some questions which the authors felt pertinent to the study population were also included. The final version of the questionnaire was determined following the incorporation of results from a pilot study of 10 caregivers (5-adult, 5-paediatric). Because the majority of caregivers in the feasibility pilot expressed difficulty in answering a 5-point Likert scale, a 3-point scale was used since it is sufficient to meet the criteria of test–retest reliability, concurrent validity and predictive validity [17]. A group of adult and pediatric neurologists and public health experts evaluated the content validity and helped in generating the final version of the questionnaire easily understandable to the Tamil speaking population. Test-retest reliability over a two-week period had a correlation coefficient of 0.92. Adequate internal reliability was indicated by a KR-20 coefficient of 0.76 for the knowledge section and a Cronbach's alpha of 0.8 for the attitude and 0.74 for the practice and myth portions.

2.2.1. Demographic and disease related variables

Age, sex, urban or rural residence, number of members in the household, marital status and family income details were collected from the participants. Family percapita income was calculated as total family income divided by the number of members in the household. Employment status was noted as currently employed or not. Educational status was considered as formal if they had completed tenth grade or more and informal if completed less than tenth grade. Details of epilepsy including age at onset, duration and family history of epilepsy were noted. Seizure frequency over the past six months was classified using the Engel seizure frequency scoring system [18]. They were divided into 2 groups of low seizure frequency or well-controlled epilepsy with score $\leq$ 4 (seizure-free or those with auras only or nondisabling nocturnal seizures) and high seizure frequency or poorly controlled epilepsy with score > 4. The epilepsy type according to the latest classification by the ILAE was noted [15].

2.2.2. Knowledge related variables

The knowledge section consisted of 18 items which included questions on the characteristics, cause, cure, investigations, antiseizure medications (ASM), traditional ideas on epilepsy, proper behavior of PWE including carrying identity card and maintaining seizure diary and an enquiry regarding whether they know any PWE living happily following treatment. Specific questions on ASM non-adherence [19] and familiarity with surgical treatment were included. The format offered yes/no answers with the correct answer receiving 1 point. The total knowledge score ranged between a minimum of zero points and a maximum of 18 points. Caregivers with scores equal to and greater than the mean score were considered having good knowledge and those with scores less than the mean were considered having poor knowledge. The caregivers' source of information about epilepsy was also enquired into.

2.2.3. Attitude, behavior and myth related variables

The attitude section consisted of six questions. Caregivers' behavior during seizures of the respective patients was assessed with seven questions including whether they witnessed any seizures while caring and six additional questions related to first-aid measures during a seizure. We included questions on six commonly prevailing myths in our population including whether epilepsy was due to evil spirits or the result of sins committed during the previous births. Answers in these three domains were graded using a 3-point Likert scale where 1 = Disagree, 2 = Uncertain and 3 = Agree. The order of scoring for negative statements was reversed. The scores were calculated as the sum of scores for each statement. This could range from 6-18 for attitude, 7–21 for behavior and 6–18 for myths. Caregivers with scores equal to and more than the mean score were considered having positive attitude, appropriate behavior and scientific beliefs respectively for the three domains. Those with scores less than the mean were considered having negative attitude, inappropriate behavior and unscientific beliefs respectively.

2.2.4. Video recognition of seizures

We showed two videos, each lasting 40 seconds, one showing the classical focal impaired awareness seizures (FIAS) of temporal lobe epilepsy exhibiting behavior arrest, stare and mild hand automatisms and the other demonstrating generalized tonic-clonic seizures (GTCS). Answers were graded using a 3-point scale where 0 = don't know/uncertain, 1 = seizure and 2 = mental disease. They were scored 1 = correct answer (seizure) and 0 = either of the two remaining responses. The seizure recognition score was calculated as the sum of scores for each statement and thus could range from 0 to 2. Caregivers who could identify one or both seizure types were considered having good seizure recognition whereas those who could identify neither were considered having poor seizure recognition.

2.2.5. Overall performance analysis using KAP-plus score

The two caregiver groups were also compared for each individual question in all five domains by dichotomizing them into right and wrong and an overall score (KAP-plus score) which was calculated based on the number of right answers to all 39 questions. The KAP-plus score could range from 0 to 39. Caregivers with scores equal to and more than the mean score were considered to have shown excellent performance and the rest with scores less than the mean were considered to have shown poor performance.

2.3. Statistics

The IBM Statistical package of social sciences, version 24 was used to analyze the data. For descriptive statistics, mean and standard deviation were calculated for continuous variables whereas frequency distribution and percentage were used for categorical variables. The Student's t-test was used to determine significant differences in the means for variables since they were normally distributed. Chi-square analysis was performed to determine significant associations between categorical variables. Multiple linear regression models were designed to assess the predictive value of socio-demographic characteristics of caregivers and the clinico-demographic features of their respective PWE (independent variables) on the 5 KAP-plus domains and on the overall performance of the CG-A and CG-C represented by the KAP-plus score (dependent variables). Statistical significance was set at $p < 0.05$.

3. Results

3.1. Response rate

There were 264 caregivers who met the study criteria of which 259 agreed to participate and completed the study (98.1% response rate). There were 132 caregivers of adult and 127 caregivers of pediatric PWE.

3.2. Demographic and clinical characteristics

This is detailed in Table 1. The mean duration of epilepsy was more in adults than children. Focal epilepsy type was more frequent in children whereas generalized epilepsy type was more common in adults. There was no difference in the seizure frequency between the groups. Caregivers of children were younger than the caregivers of adults. Parents were the predominant caregivers for children (95.3%) whereas parents (59.8%) and spouses (36.4%) represented the adults with epilepsy. Both the groups were equally distributed according to gender, employment status and percapita income. However, CG-C were better educated with 64.6% receiving formal education compared to 44.7% of CG-A (p = 0.001).

3.3. Comparison of KAP-plus domains between the caregiver groups

This is detailed in Table 2 and discussed under individual domains. Though CG-A and CG-C were comparable in the knowledge and attitude domains, CG-A scored significantly less than CG-C in the domains of seizure response, recognition, myths and KAP-plus score.

3.4. Performance of caregivers in KAP-plus domains (Table 2 & Table 3)

3.4.1. Knowledge scores

The average caregiver knowledge score of 11.2 and 11.8 for CG-A and CG-C respectively was comparable. Good knowledge score was achieved by 62.1% of CG-A and 66.9% of CG-C. Compared to CG-A, CG-C were more aware of the usefulness of recording seizures using smartphones at home to diagnose and treat epilepsy and knew PWE living happily with treatment.

3.4.2. Attitude towards epilepsy among caregivers

Caregivers' attitudes towards PWE were positive. The average caregiver attitude score of 13.4 and 13.1 for CG-A and CG-C respectively was good and comparable. Positive attitude score was obtained by 65.2% of CG-A and 59.1% of CG-C. Caregivers of adults were more confident than caregivers of children that PWE can marry and can have normal sexual relationship.

3.4.3. Behavior response to seizure among caregivers

Response to witnessing a seizure was better with CG-C than CG-A. Appropriate response was seen in 68.5% of CG-C compared to 62.9% of CG-A. Though both the groups had similar opportunity to witness seizures in PWE whom they care, only 53.8% of CG-A were aware of the first aid at the time of a seizure compared to 70.9% of CG-C (p = 0.009). Only 40.2% of CG-A were sure about restraining the arms and legs of the patient during a seizure compared to 59.8% of CG-C (p=<0.001).

3.4.4. Myths about epilepsy among caregivers

The six common myths prevailing in our community are detailed in Table 3. Caregivers of adults scored significantly less in the myth score compared to CG-C, indicating their belief in superstitions and myths. Scientific beliefs were seen in 70.1% of CG-C and 67.4% of CG-A. When compared to CG-C, CG-A were more of the belief that epilepsy was the result of sins committed during the previous birth.

3.4.5. Seizure recognition by video among caregivers

The CG-C recognized seizures better than CG-A. Good seizure recognition was seen in 75.6% of CG-C when compared to 57.6% of CG-A. Both the caregiver groups struggled to identify FIAS when compared to GTCS. Interestingly GTCS was recognized as mental disease by 32.6% of CG-A and 21.3% of CG-C whereas FIAS was identified as mental disease by 40.2% of CG-A and 33.1% of CG-C.

3.4.6. KAP-plus score

The CG-C gained higher mean KAP-plus scores than CG-A (p = 0.017). However, CG-A (60.6%) had higher percentage of excellent performers than CG-C (54.3%).

Table 1
Clinico-demographic characteristics of people with epilepsy & their caregivers.

Variables	People with epilepsy			Caregivers		
	Adults	Children	*p*-value	Adults	Children	*p*-value
Age (years)	30.9 ± 12.6 (15–76)^{a}	8.28 ± 4.4 (0.5–16)^{a}	–	44.7 ± 13 (15–85)^{a}	35.6 ± 7.7 (21–67)^{a}	<0.001
Gender						
Male	79 (59.8)^{b}	89 (70.1)^{b}	NS	52 (39.4)^{b}	49 (38.6)^{b}	NS
Female	53 (40.2)^{b}	38 (29.9)^{b}		80 (60.6)^{b}	78 (61.4)^{b}	
Place of residence						
Urban	–	–	–	69 (52.3)^{b}	52 (40.9)^{b}	NS
Non-urban				63 (47.7)^{b}	75 (59.1)^{b}	
Marital status						
Married	68 (51.5)^{b}	-	-	-	-	
Unmarried/separate/divorce						
Married	64 (48.5)^{b}	-	-	-	-	-
Education						
Informal	68 (51.5)^{b}	-	-	73 (55.3)^{b}	45 (35.4)^{b}	0.001
Formal	64 (48.5)^{b}			59 (44.7)^{b}	82 (64.6)^{b}	
Employment status						
Employed	50 (37.9)^{b}	-	-	66 (50)^{b}	72 (56.7)^{b}	NS
Unemployed	82 (62.1)^{b}			66 (50)^{b}	55 (43.3)^{b}	
Per capita income (INR)	-	-	-	4999.2 ± 6803^{a}	4242.7 ± 4067.1^{a}	NS
Relation						
Parent	-	-	-	79 (59.8)^{b}	121 (95.3)^{b}	<0.001
Spouse				48 (36.4)^{b}		
Other				5 (3.8)^{b}	6 (4.7)^{b}	
Age at onset of epilepsy (years)	19.6 ± 14.4 (1–76)^{a}	3.9 ± 4.0 (0–14)^{a}	-	-	-	-
Family history						
Yes	27 (20.5)^{b}	24 (18.9)^{b}	NS	-	-	-
No	105 (79.5)^{b}	103 (81.1)^{b}				
Duration of epilepsy (years)	11.1 ± 8.9 (0.2–40)^{a}	4.5 ± 3.8 (0.25–14)^{a}	<0.001	-	-	-
Epilepsy type						
Focal	86 (65.2)^{b}	97 (76.4)^{b}	0.048	-	-	-
Generalized	28 (21.2)^{b}	13 (10.2)^{b}				
Combined focal & generalized	6 (4.6)^{b}	11 (8.7)^{b}				
Unknown	12 (9)^{b}	6 (4.7)^{b}				
Seizure frequency						
Well controlled	43 (32.6)^{b}	43 (33.9)^{b}	NS	-	-	-
Poorly controlled	89 (67.4)^{b}	84 (66.1)^{b}				

a - Mean ± SD (range); b - Number (%); NS – not significant.

Table 2
Outcome comparison between caregivers of adults and children.

Domains (score range)	CG – adults	CG – children	*p*-value	Performance	CG – adults	CG – children
Knowledge (0–18)^{A}	11.2 ± 2.8^{a}	11.8 ± 2.9^{a}	NS	Good knowledge^{E}	82 (62.1)^{b}	85 (66.9)^{b}
				Poor knowledge^{F}	50 (37.9)^{b}	42 (33.1)^{b}
Attitude (6–18)^{B}	13.4 ± 2.6^{a}	13.1 ± 2.7^{a}	NS	Positive attitude^{E}	86 (65.2)^{b}	75 (59.1)^{b}
				Negative attitude^{F}	46 (34.8)^{b}	52 (40.9)^{b}
Behavior (7–21)^{B}	15.5 ± 2.7^{a}	16.8 ± 2.6^{a}	<0.001	Appropriate bahavior^{E}	83 (62.9)^{b}	87 (68.5)^{b}
				Inappropriate behavior^{F}	49 (37.1)^{b}	40 (31.5)^{b}
Myth (6–18)^{B}	15.4 ± 2.2^{a}	16.2 ± 1.9^{a}	0.002	Scientific belief^{E}	89 (67.4)^{b}	89 (70.1)^{b}
				Unscientific belief^{F}	43 (32.6)^{b}	38 (29.9)^{b}
Seizure recognition (0–2)^{C}	0.7 ± 0.7^{a}	0.94 ± 0.7^{a}	0.001	Good recognition^{G}	76 (57.6)^{b}	96 (75.6)^{b}
				Poor recognition^{H}	56 (42.4)^{b}	31 (24.4)^{b}
KAP-plus (0–39)^{D}	22.98 ± 5.4^{a}	24.65 ± 5.8^{a}	0.017	Excellent performance^{E}	80 (60.6)^{b}	69 (54.3)^{b}
				Poor performance^{F}	52 (39.4)^{b}	58 (45.7)^{b}

A – scoring based on yes/no answers; B – score calculated based on 3 point likert scale; C – score based on correct identification of FIAS and GTCS; D- overall score of right answers to 39 questions; E – scoring above mean; F – scoring below mean; G – recognition of either FIAS or GTCS or both; H – wrong recognition of both FIAS and GTCS; a – mean ± SD; b – number (%); CG-caregiver; NS – not significant.

3.5. Source of knowledge

This is detailed in Table 4. More than 80% of caregivers from both the groups gained information about epilepsy from health care professionals. Internet was more frequently used by CG-C when compared to CG-A (51.2% vs 26.5% $p < 0.001$).

3.6. Predictors of individual KAP-plus items among caregivers

This is shown in Table 5. Duration of epilepsy of PWE and caregiver educational status positively predicted the knowledge of CG-A and CG-C respectively. The socio-economic indicators of education and percapita income positively predicted the KAP-plus score of CG-C.

4. Discussion

We present the outcome from a comparative analysis between the CG-A and CG-C regarding their knowledge, attitude, first-aid response to seizures, presence of epilepsy myths and recognition of seizure from a video demonstration. Various clinico-demographic variables, including employment, per-capita income

Table 3
Caregivers with appropriate response to questions in the five domains.

Knowledge	CG - adults[a]	CG - children[a]	*p*-value
1. Epilepsy is a mental disease	64 (48.5)	77 (60.6)	NS
2. Epilepsy is a disorder of the brain	111 (84.1)	109 (85.8)	NS
3. Epilepsy is a contagious disease	101 (76.5)	106 (83.5)	NS
4. Epilepsy may run in families	56 (42.4)	61 (48)	NS
5. Repeated seizures cause further damage to the brain	67 (50.8)	66 (52)	NS
6. EEG & MRI are tests used to diagnose epilepsy	119 (90.2)	119 (93.7)	NS
7. Home recording of seizure with a smartphone is useful for treatment	100 (75.8)	110 (86.6)	0.027
8. Epilepsy can always be cured with medications	33 (25)	39 (30.7)	NS
9. Seizure can sometimes be sensed before it happens	76 (57.6)	75 (59.1)	NS
10. Epilepsy can affect any age group	116 (87.9)	106 (83.5)	NS
11. Missing anti-seizure medications for 1 or 2 days is okay	83 (62.9)	79 (62.2)	NS
12. PWE can safely consume alcohol	63 (47.7)	64 (50.4)	NS
13. It is beneficial for PWE to carry epilepsy ID card	113 (85.6)	109 (85.8)	NS
14. Maintaining seizure diary is useful for managing epilepsy	122 (92.4)	118 (92.9)	NS
15. Certain PWE needs to take AEDs lifelong	78 (59.1)	76 (59.8)	NS
16. Alternative systems of medicine control epilepsy better than modern medicine	32 (24.2)	24 (18.9)	NS
17. Surgery can cure epilepsy in some PWE	79 (59.8)	74 (58.3)	NS
18. I know PWE living happily following proper treatment	62 (47)	82 (64.6)	0.006
Attitude			
1. PWE can swim / drive	21 (15.9)	26 (20.5)	NS
2. PWE can marry	91 (68.9)	67 (52.8)	0.014
3. PWE cannot have normal sexual relationship	79 (59.8)	69 (54.3)	0.01
4. PWE can get good education	91 (68.9)	81 (63.8)	NS
5. PWE can be employed in all jobs	74 (56.1)	57 (44.9)	NS
6. Epilepsy is socially unacceptable	60 (45.5)	52 (40.9)	NS
Practice			
1. I have witnessed seizures in my children or relatives	118 (89.4)	115 (90.6)	NS
2. I have given first aid at the time of a seizure	71 (53.8)	90 (70.9)	0.009
3. I will give keys to the patient to control seizure	68 (51.5)	76 (59.8)	NS
4. I will hold the arms & legs of the patient tightly during a seizure	53 (40.2)	76 (59.8)	<0.001
5. I will give emergency medicines to control seizures at home.	41 (31.1)	56 (44.1)	NS
6. I will panic on seeing a seizure	46 (34.8)	51 (40.2)	NS
7. I will put something into the mouth of the patient during a seizure	99 (75)	95 (74.8)	NS
Myths			
1. Epilepsy is due to evil spirits	98 (74.2)	103 (81.1)	NS
2. Epilepsy is the result of sins committed	86 (65.2)	105 (82.7)	0.005
3. Epilepsy can be treated with religious activities	98 (74.2)	103 (81.1)	NS
4. PWE are intellectually disabled	104 (78.8)	105 (82.7)	NS
5. You can't die from epilepsy	84 (63.6)	92 (72.4)	NS
6. PWE cannot occupy higher positions in society	89 (67.4)	97 (76.4)	NS
Seizure recognition			
1. Generalized Tonic Clonic Seizure	73 (55.3)	88 (69.3)	0.022
2. Focal Impaired Awareness Seizures	19 (14.4)	32 (25.2)	0.027

a – number (%); CG = caregiver; NS – not significant.

Table 4
Caregivers' source of information about epilepsy.

Source of information	CG – adults (*n* = 132)	CG - children (*n* = 127)
Healthcare providers (doctors, nurses, paramedical staff etc)	110 (83.3)	106 (83.5)
Audio visual media	20 (15.2)	24 (18.9)
Print media	25 (18.9)	30 (23.6)
Internet	35 (26.5)	65 (51.2)
Others (friends, family members, teachers etc)	15 (11.4)	10 (7.8)

CG - Caregiver

of the caregivers and seizure frequency of the patients were comparable between the groups. As expected, our population of adults with epilepsy was suffering from a longer duration of disease compared to the children. Similarly, CG-C were significantly young and better educated compared to CG-A. Performance of both the caregiver groups overall as well as in the five tested domains was good. However, CG-C performed better than CG-A in the overall scores as well as in the domains of first-aid measures adopted on witnessing a seizure, dispelling myths surrounding epilepsy and recognizing FIAS and GTCS.

Knowledge-wise both the groups exhibited good awareness about epilepsy. Three specific findings require mention. First, involves the caregivers' awareness regarding medication adherence and maintenance of seizure diaries. The caregiver is expected to support the patients with their routine of taking ASMs. Additionally, consciousness may be impaired during a seizure, calling for caregiver assistance in the maintenance of seizure diary [20]. Second, is the caregivers' understanding of the usefulness of epilepsy surgery. At a time when India is struggling to bridge the surgical treatment gap wherein only 2 in 1000 eligible candidates undergo epilepsy surgery, our findings indicate improving awareness [21]. Third, includes the caregivers' understanding regarding the usefulness of home video recording of seizures using smartphones for the diagnosis and management of epilepsy. Caregiver reporting of events is mostly inaccurate and does not help differentiate between focal and generalized seizures [22,23]. Smartphone recordings have been shown to be useful in this regard [24]. However, belief of caregivers in alternative systems of medicine for the treatment of epilepsy is a matter of concern as very little research into their usefulness is available. Similarly, the overall attitude towards epilepsy of both the caregiver groups has been positive and comparable. Population-based studies have shown that people with good knowledge tend to have positive attitude [25]. The CG-A group was more positive than CG-C group

Table 5
Predictors of high scores in the KAP-plus domains among caregivers of adults and children.

Domains	CG – adults	*β*	*p*-value	CG – children	*β*	*p*-value
Knowledge	Duration of epilepsy	0.278	0.003	CG education	0.247	0.011
Attitude	Patients with no formal education	0.313	<0.001	-	-	-
	High seizure frequency	−0.23	0.011			
Behavior	Per capita income	0.229	0.010	-	-	-
	Non-urban residence	−0.190	0.028			
Myth	Employed CG	0.257	0.027	Having focal epilepsy type	0.194	0.036
	Age of patients	0.312	0.023			
Seizure recognition	-	-	-	-	-	-
Overall performance (KAP-plus score)	Non-urban residence	−0.189	0.032	CG education	0.214	0.025
				PCI	0.192	0.041

CG – Caregiver.

regarding successful marriages and sexual relationships for PWE; the majority of adult PWE cared for by them being married would have helped them develop this positive attitude.

In contrast to our observations about knowledge and attitude, the CG-A fared poorly when compared to CG-C in the domains of behavior response to a patient while having a seizure, myths surrounding epilepsy and seizure recognition. Though both the groups had witnessed seizures in their respective patients, CG-C responded better with first-aid measures. Restraining the patient during the seizure was practiced more frequently by CG-A which could result in joint dislocations and injuries. Majority in both the groups would however panic during a seizure and would not use rescue medications. Similarly, CG-A were less successful in dispelling myths surrounding epilepsy compared to CG-C and believed that epilepsy resulted from sins committed in the previous life. They could not balance between science, spiritualism and faith. Additionally, CG-A fared poorly in recognizing GTCS and FIAS compared to CG-C. The fact that a good number of PWE is unaware of their FIAS would make self-reported seizure frequency unreliable [26]. The caregiver should be in a position to identify both FIAS and GTCS whenever they witness them to help improve the accuracy of seizure counts. This is essential for dosage adjustments or adding new ASMs. Underdiagnosis is an issue with our patients; it could lead to unnecessary complications. As evidenced from our study, FIAS especially the ones with behavioral arrest and subtle face and hand movements may be more difficult to recognize than GTCS which involves more obvious motor movements. With good control of generalized events following the initiation of ASMs, the patients may be thought to have well-controlled epilepsy. Unreported FIAS will still put them at increased risk of injury or death.

Despite adequate knowledge and a positive attitude, the presence of knowledge-practice or knowing-doing gap, knowledge-faith gap and knowledge-recognition gap in the CG-A were the most obvious findings from our study. This can be explained by the "knowledge-gap hypothesis" which points to the faster acquisition of knowledge by people of higher compared to people of lower socio-economic status when information is given to any social system thereby increasing the knowledge gap between them [27]. Education is the most commonly used indicator of socio-economic status [27,28]. The major difference between our study groups has been the lack of formal education among CG-A compared to CG-C. All the three gaps mentioned above are essential offshoots of the education gap between the two groups.

Health care professionals have been the major source of information for both the groups. The CG-A group would have had more frequent interactions and counseling sessions with health care personnel than CG-C, considering the longer duration of their caring. Their good overall performance and knowledge and attitude scores on par with the scores of CG-C stand testimony to this. Duration of epilepsy of PWE was also shown to positively predict knowledge of CG-A. However, the closed-ended questions used for knowledge assessment test more of awareness knowledge than factual knowledge. It is well known that socio-economic status-based knowledge gaps become less with awareness-based knowledge measures compared to factual knowledge measures [29]. Though there was no difference in the awareness knowledge between the groups, difference in the factual or in-depth knowledge in relation to seizure recognition and response persisted. The recognition of seizures in general and FIAS in particular as mental disorder by a good number of caregivers is disturbing since myths, superstitious beliefs and ritual healing practices are commonly associated with mental disease in India [30]. Similarly, more myths about epilepsy persisted among CG-A suggesting the knowledge- belief gap. Despite reasonable knowledge, CG-A had convictions that were accepted as true without proof. In addition to poor education, religiosity and culture could be the other factors which make CG-A rely on non-scientific information to shape their views [31].

We need to adopt measures to bridge the various knowledge gaps identified specifically in the CG-A group. The proposed "knowledge translation" strategy to incorporate our research generated knowledge into healthcare practice for the benefit of caregivers of PWE is depicted in Figure-1. The main goal would be to impart more factual or in-depth knowledge with the aim of improving seizure recognition and response along with removal of prevailing unscientific beliefs. Caregivers without formal education on epilepsy in general and CG-A in particular should be targeted. Appropriate media for information transfer should be chosen. Though accessibility to mass media improves knowledge, it may not close the gap [32]. Print media may be more accessible to the higher socio-economic groups and cognitively demanding. Audio-visual media though accessible to the lower socio-economic groups may have more superficial content and would receive less repetition. The "digital divide" in internet use is visible in our study with CG-C using it more frequently than CG-A. This would leave the health-care professionals including doctors, nurses and other paramedical staff as the most suited for the information transfer. Many caregivers still prefer to receive health education one-on-one from neurologists or physicians which may not be practically feasible [33]. Nurses and other paramedical staff specifically trained in epilepsy may be employed for this purpose. Video animations have been shown to be successful in improving epilepsy knowledge among caregivers of children [34]. Interactive sessions with caregivers for 4–5 h using modules may be planned [35]. In addition to providing education to bridge the knowledge gap, certain tasks and skills must be introduced (Fig. 1) to ensure that the caregivers acquire and master self-management skills [36]. Educational anti-myth interventions present factual information about the belief with the goal of correcting misinformation. An example would be showing PWE occupying high ranks in the soci-

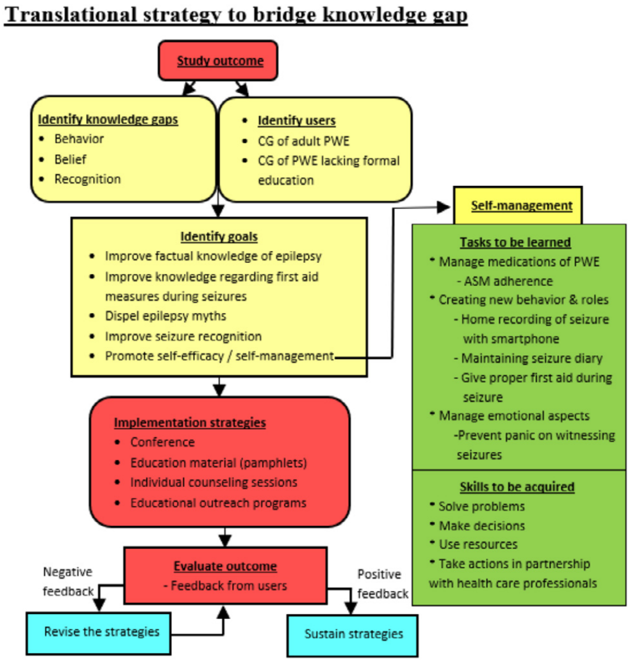

Fig. 1. Suggested translational strategy to bridge the knowledge gap observed in our study. CG-caregiver; PWE-people with epilepsy; ASM-anti-seizure medications.

ety to counter the idea that they are intellectually disabled and cannot hold high positions in the society. Myth renunciation is unlikely to be easy and can be expected to encounter resistance. Periodic post-intervention studies can help monitor outcome. Information campaigns should be periodically repeated to bring about changes in behavior. While designing new campaigns, change management models can be utilized as guides to make changes and navigate them so that they are accepted and put into practice.

Our study has few limitations. It is a small single center study. The findings could be different in a community-based study. Our sample of caregivers may be of a better socio-economic status compared to those in the community who could not reach us. Information bias is another limitation which includes misclassification and recall bias. Interviewer bias is another limitation since the interviews were conducted by members of our clinical team. We practiced a few dry runs within the team to ensure that we just play a role and remain neutral. Due to the cross-sectional design, causal interpretations cannot be defined. Using open-ended questions instead of closed-ended ones could have resulted in smaller knowledge gaps. Despite the limitations, our study is the first comparative analysis between CG-A and CG-C which helped us bring out the knowledge gaps existing in CG-A, thus calling for focused education strategies to bridge the gap.

5. Conclusion

We present novel observations from our study comparing the caregivers of adults and children with epilepsy. Though less educated than CG-C, our cohort of CG-A had good awareness and positive attitude towards epilepsy. However, the education gap led to inadequate factual knowledge which resulted in poor seizure recognition, improper first-aid response during a seizure and persistence of epilepsy myths. More focused counseling strategies are required to help bridge the knowledge gaps among our CG-A. This will help enable them to dispel epilepsy myths and recognize and respond more effectively to people withseizures.

Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Declarations of interest

None.

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Conflict of interest

None of the authors has any conflict of interest to disclose.

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