

# **Epilepsy Knowledge, Attitudes and Practices Among Primary Health Care Providers in an Indian District.**

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Word count (Abstract): 183

Word count (Text): 1659

Number of tables: 2

Number of illustrations: 1

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## ABSTRACT

*Introduction:* Scaling up the involvement of primary care providers in epilepsy management in low and middle income countries requires an understanding of their epilepsy knowledge, attitudes and practices (KAP). *Aim:* To document levels of knowledge about, attitudes towards and practices regarding epilepsy among different ranks of primary health care providers in a North-Western Indian district. *Methods:* The survey included government medical officers, auxiliary nurse midwives and accredited social health activists. They were administered a specially designed KAP questionnaire. Responses were analysed according to rank. *Results:* The survey showed that nearly ten percent of auxiliary nurse midwives and almost a fifth of accredited social health activists had never heard about epilepsy. A quarter of medical officers and over two thirds of auxiliary nurse midwife and accredited social health activists had never provided care to someone with epilepsy. There were significant differences in the levels of knowledge between the three groups of workers. *Conclusions:* Closing the huge gaps in KAP by educating primary care and community health workers about epilepsy should be a priority before engaging them in the epilepsy care delivery.

**Key Words:** Epilepsy; Accredited Social Health Activists; Auxiliary Nurse Midwives; Medical Education.

## Introduction

Epilepsy affects almost 50 million people worldwide.<sup>1,2</sup> Nearly 80% of people with epilepsy are based in low- and middle-income countries (LMICs) which lack the capacity to provide treatment to the majority of them.<sup>3</sup> There are no organized programs to deal with epilepsy at a national level in most LMICs.<sup>4</sup> Capacity building should therefore be a priority in these countries.

Scaling up epilepsy management at a national level requires several measures on the supply side. Ensuring the continuous supply of affordable antiseizure medications (ASMs) and availability of trained health care professionals are two critical supply-side issues requiring attention. There are few specialists available to manage epilepsy in LMICs.<sup>5</sup> The World Health Organization (WHO) survey estimates up to 0.3 neurologists/100,000 people in the African and Southeast Asian regions in comparison to 9 /100,000 in Europe.<sup>5</sup> Whereas nearly all countries report the availability of neurologists in capital cities, access to neurological care in non-capital cities and even more so in rural areas is trifling.

Epilepsy can be mostly managed by using simplified regimens of ASMs on the WHO essential list.<sup>6</sup> To cope with the lack of specialists, WHO encourages the involvement of primary healthcare providers in LMICs. Primary level physicians provide care for epilepsy in 91%, and primary care nurses are involved in neurological care in 86% of African and SEARO countries.<sup>3,5</sup> Efforts to train primary care workers in epilepsy would be rewarding in terms of community level outcomes. It is essential, however, to assess baseline levels of knowledge of, attitudes towards and practices regarding (KAP) epilepsy among various ranks off the primary healthcare workforce before commencement of training.<sup>7-10</sup> We report our assessment of KAP in different ranks of the primary healthcare providers and of educating

them in recognising and managing epilepsy. Our aim was to determine gaps in knowledge to guide future educational interventions.

## **Material and Methods**

Responses to a self-administered KAP questionnaire were gathered from primary healthcare providers working in Ludhiana in Northwest India. The area has a population of 3.2 million served by 97 government medical officers (MOs), 270 auxiliary nurse midwives (ANMs) and 575 accredited social health activists (ASHA) workers. The District Health Appropriate Authority has segregated the district in to: (1) urban and peri-urban areas and (2) rural areas. The former is further divided in to nine zones based on immunization practices (Fig. 1). Only personnel serving urban (n=203 ASHAs) and peri-urban rural areas (n=73 ASHAs) were recruited for the survey. Those from villages outside the urban limits were not recruited for logistic reasons.

### Respondents

Medical officers are medically qualified government employees. The ANMs secure a community-oriented, 3 years nursing diploma, and each caters to about 5000 people in relation to maternal and child health but also few other primary care issues. The ASHAs are secondary school qualified, live in the community where they are active and each caters for the primary healthcare needs of about 1000 people. Respondents were stratified in three groups according to rank: MOs, ANMs and ASHAs.

### Instrument Development

Items for the questionnaire were initially scripted by three experts, who then excluded duplicates and formulated the final, 34 item questionnaire by consensus. Responses to all items were set up as “Yes”, “No” and “Not sure”. The questionnaire was translated to

Punjabi and then back-translated to English for correspondence assessment. It comprised five sections that sought demographic details, knowledge about (15 questions), awareness of (5 questions), practices regarding (5 questions) and attitudes towards (10 questions) epilepsy. Five different sets of the questionnaire were assembled by shuffling the order of questions and were distributed to respondents. Before administration to respondents, it was also piloted in 20 Asha's mainly for assessing linguistic comprehensibility, cultural acceptability, test-retest reliability and internal consistency using Cronbach's' alpha.

### Recruitment

Respondents were contacted through the District Chief Medical Officer. The ANMs and ASHAs were reimbursed for travel. The questionnaire was administered shortly before half-day continuing epilepsy education programs for each of the three groups. The educational programs were based on the WHO mental health GAP curriculum and their content varied according to competency of the three groups.<sup>11,12</sup>

### Data collection and analysis

Responses were double-entered in to Microsoft Excel (ver. 2013) and transferred to Stata (Ver. 12, STACORP, Texas, USA) for analysis. Descriptive analysis of responses to each of the items in the questionnaire was first undertaken followed by comparison of the three groups (medical officers, ANMs and ASHAs using the Chi Square test. Continuous variables among the three groups were compared using ANOVA.  $P < 0.05$  was considered significant.

## Results

A total of 421 workers (ASHAs: 276, all females; ANMs: 120, all females; medical officers: 25, 14 females) completed the questionnaire. The computed test-retest reliability was 0.85 and Cronbach's alpha based on standardised items was 0.85.

Eleven (9.2%) ANMs and 65 (23.6%) ASHAs had never heard about epilepsy (Table 2). Four MOs (16%), 38 (31.7%) ANMs and 96 (34.8%) ASHAs had never witnessed a seizure. Six (24%) MOs, 89 (74.2%) ANMs and 225 (81.5%) ASHAs had never provided professional care to someone with epilepsy.

### Risk factors for epilepsy

More ASHAs than ANMs and more ANMs than MOs were unaware that brain injury, tumours and genetic factors were causally associated with epilepsy ( $P=0.001$ ), which was believed to be a form of mental illness by 4 (16%) MOs, 24 (20%) ANMs and 113 (40.9%) ASHAs ( $P=0.001$ ) (Table 2).

### Recognition of epileptic seizures and epilepsy

The ASHAs ( $n=185$ ; 67%) most of all, but also ANMs ( $n=74$ ; 61.7%) and MOs ( $n=10$ ; 40%) believed that purely focal seizures were invariably associated with loss of consciousness (Table 1) ( $P=0.001$ ). Likewise, 198 (71.7%) ASHAs, 90 (75%) ANMs and 10 (40%) MOs were unaware or unsure whether an aura was the equivalent of a focal seizure.

### Management of epilepsy

The implication of proper medication adherence was not understood by 49 (17.8%) ASHAs, 24 (20%) ANMs and two (8%) MOs. Conversely, 132 (47.85%) ASHAs, 33 (27.5%) MO supported the use of indigenous (Ayurvedic) medications in epilepsy treatment.

### Seizure first-aid

More ASHAs and ANMs than MOs lacked knowledge of appropriate seizure first-aid measures (Table 2). For example, 158 (57.2%) ASHAs, 31 (25.8%) ANMs and one (4%) MO endorsed the tradition of making people to smell shoes to abort their seizures.

### Social attitudes and practices

A proportion of ASHAs (8% and 11% respectively) and ANMs (8% and 2% respectively) believed that people with epilepsy should not go to school or be employed. Many respondents (n=36; 8.6%) also believed that people with epilepsy should not get married and 114 (including 85 ASHAs [30.8%], 20 ANMs [16.7%] and 9MOs [36%]) would object to their family members getting married to someone with epilepsy.

## **Discussion**

KAP assessments in primary healthcare workers are rare and only a few have been reported from LMICs.<sup>8-10</sup> We evaluated epilepsy KAP across a range of primary health carers in a resource-poor setting. Training primary care workers in epilepsy management is of overriding importance in such settings and this has to be practical and customized to the level of professional competence and roles of different personnel. Formalized programs for such trainings are unavailable. The WHO's mental health GAP (mhGAP) is an universally applicable framework for this purpose. It needs, however, to be adapted to local needs as well as levels of understanding of, and familiarity with epilepsy among the community and primary care workforce.<sup>11-16</sup> An analysis of findings of our survey and of similar surveys might suitably guide the adaptation exercise. Our results suggest that the majority of the primary healthcare providers including a quarter of physicians had never provided any form

of epilepsy care. A quarter of the paramedics had never witnessed a seizure. These observations bear out the low levels of epilepsy sensitization among the respondents. Clearly, training programs for primary care health workers need to cover a large ground to impart core competency in epilepsy.

Despite the limitation of various biases associated with KAP responses<sup>17,18</sup>, we see differences in the levels of knowledge and understanding of the ASHAs, ANMs and MOs. These differences are unsurprising in view of their disparate levels of training and education as well the scope of their roles in health care provision. While ASHAs work in the community towards improving health awareness, facilitating access to health care, and in some cases, maintaining and supplying medications in the community<sup>19,20</sup>, the ANMs are primary health centre-based and oriented towards maternal and child care.<sup>21</sup> The scope and roles and responsibilities of community health workers, however, varies across LMICs.

Epilepsy is well placed within the framework of the roles of ASHAs who are suited to create awareness in the community about epilepsy and the social issues that come with the condition.<sup>19,20</sup> They can encourage unwilling and non-adherent individuals in the community to seek care and could also act as providers/depot-holders of certain essential ASMs. They act as links between the community and health care facilities. Epilepsy with its health and social ramifications is a likely to benefit from their involvement. Conversely, ANMs oriented towards maternal and child healthcare could be involved in epilepsy management during and after pregnancy.

Perusal of the course curricula of the ASHAs and ANMs, however, found only a fleeting mention of epilepsy in the non-communicable disorders module for the ASHAs and none for the ANMs.<sup>22</sup> This underscores the need to incorporate elements of epilepsy management, especially seizure first-aid, adherence reinforcement and social edification in the ASHA

training program. Given the orientation of ANM training towards maternal and child healthcare, elements of epilepsy management, particularly, women's issues should be added to their curricula.

Our analysis is constrained by the limited socio-demographic information regarding the research participants, analysis of which might have provided useful insights. Future initiatives will involve analyses of the impacts of the educational intervention both immediately and in the long-term as these data would likely provide an understanding of the feasibility of involvement of various cadres of primary care in epilepsy management.

How do our findings compare with, and how do these add to our previous understanding based on other epilepsy KAP surveys on healthcare workers in LMICs?<sup>7-10,23</sup> Differences in make-up of the study populations, items in the questionnaires and methods employed preclude comparison between previous studies and ours. The findings, nevertheless, alongside those from other studies represent the breadth and depth of shortcomings that will need to be addressed if the primary care workforce is to be involved in epilepsy care to bridge treatment gap at a global level.

**Acknowledgements:** This study was supported by an *Ad-hoc* grant from the Indian Council of Medical Research (ICMR). The authors are grateful to Dr. Kurupath Radhakrishnan, Advisor, Neurology to the ICMR, Dr. Meenakshi Sharma, Scientist E, Non-communicable Diseases Division, ICMR, New Delhi and Dr. Geetha Menon, National Institute of Medical Statistics, ICMR, New Delhi for helpful suggestions in planning and implementing the study; and the Department of Health, Government of Punjab State, India and the Office of the Civil Surgeon, Ludhiana District for logistic support. A number of ASHA workers from the Health Department helped in the study. JWS is based at UCLH/UCL Comprehensive Biomedical Research Centre, which receives a proportion of funding from the UK Department of Health's NIHR Biomedical Research Centers funding scheme. He receives support from the Dr. Marvin Weil Epilepsy Research Fund, the Christelijke Vereniging voor de Verpleging van Lijdersaan Epilepsie, Netherlands, and UK Epilepsy Society.

**Authors' 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.

### **Conflict of Interest**

The authors declare no conflict of interest in relation to this work.

### **Financial support**

The study was funded by an *Ad hoc* grant no. No:5/4-5/127/Neuro/2013-NCD-I of the Indian Council of Medical Research.

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FIGURE LEGEND

Fig. 1. Geographic map of district showing the distribution of the primary health centers at which the ASHAs and ANMs were located.

**Table 1.** Demographic characteristics of the respondent groups.

	<b>ASHA (n=276)</b>	<b>ANM (n=120)</b>	<b>MO (n=25)</b>	<b>Statistical significance (P)</b>
<b>Age (Years)</b>				
Mean ± SD	35± 6	41±11	46±11	0.0001
Range	22-55	22-58	24-60	
<b>Gender (females)</b>	276 (100%)	120 (100%)	14 (54.9%)	0.0001
<b>Education</b>				
Illiterate	8 (2.9%)	0 (0%)	0 (0%)	0.0001
Primary school	153 (55.4%)	56 (46.7%)	0 (0%)	
Secondary school	84 (30.4%)	50 (41.7%)	0 (0%)	
Graduate and above	31 (11.2%)	14 (11.7%)	25 (100%)	

**Table 2. Responses to items in the questionnaire according to cadre in primary healthcare.**

		Group			p-value
		ASHA	ANM	MO	
A1. Have you ever provided professional care to someone with epilepsy?	Not attempted	7 (2.5%)	4 (3.3%)	0 (0%)	0.000
	Yes	43 (15.6%)	27 (22.5%)	19 (76%)	
	No	225 (81.5%)	89 (74.2%)	6 (24%)	
	Not sure	1 (0.4%)	0 (0.0%)	0 (0.0%)	
A2. Have you ever witnessed an epileptic seizure?	Not attempted	6 (2.2%)	0 (0%)	1 (4%)	0.137
	Yes	174 (63%)	82 (68.3%)	20 (80%)	
	No	96 (34.8%)	38 (31.7%)	4 (16%)	
A3. Do you know someone with epilepsy?	Not attempted	6 (2.2%)	2 (1.7%)	1 (4%)	0.004
	Yes	174 (40.6%)	40 (33.3%)	18 (72%)	
	No	158 (57.2%)	76 (63.3%)	6 (24%)	
	Not sure	0 (0.0%)	2 (1.7%)	0 (0.0%)	
A4. Have you ever heard or read about epilepsy?	Not attempted	5 (1.8%)	2 (1.7%)	2 (8%)	0.001
	Yes	205 (74.3%)	107 (89.2%)	23 (92%)	
	No	65 (23.6%)	11 (9.2%)	0 (0%)	
	Not sure	1 (0.4%)	0 (0.0%)	0 (0.0%)	
B1. Are road accidents a cause for epilepsy?	Not attempted	9 (3.3%)	5 (4.2%)	0 (0.0%)	0.000
	Yes	81 (29.3%)	25 (20.8%)	17 (68%)	
	No	124 (44.9%)	72 (60%)	5 (20%)	
	Not sure	62 (22.5%)	18 (15%)	3 (12%)	
B2. Is epilepsy an inherited disease?	Not attempted	6 (2.2%)	0 (0.0%)	1 (4%)	0.000
	Yes	33 (12%)	18 (15%)	13 (52%)	
	No	200 (72.5%)	92 (76.7%)	8 (32%)	
	Not sure	37 (13.4%)	10 (8.3%)	3 (12%)	
B3. Do you think epileptic seizures may be associated with high fever?	Not attempted	6 (2.2%)	3 (2.5%)	1 (4%)	0.001
	Yes	93 (33.7%)	42 (35%)	19 (76%)	
	No	88 (31.9%)	44 (36.7%)	5 (20%)	
	Not sure	89 (32.2%)	31 (25.8%)	0 (0.0%)	
B4. Do brain tumors cause epilepsy?	Not attempted	5 (1.8%)	1 (0.8%)	0 (0.0%)	0.000
	Yes	42 (15.2%)	22 (18.3%)	21 (84%)	
	No	152 (55.1%)	76 (63.3%)	3 (12%)	
	Not sure	77 (27.9%)	21 (17.5%)	1 (4%)	
B5. Do you believe that epilepsy is a form of mental illness or insanity?	Not attempted	6 (2.2%)	3 (2.5%)	1 (4.0%)	0.000
	Yes	113 (40.9%)	24 (20%)	4 (16%)	
	No	95 (34.4%)	76 (63.3%)	20 (80%)	
	Not sure	62 (22.5%)	17 (14.2%)	0 (0.0%)	

C1. Is it true that epilepsy occurs in one in 100 people approximately?	Not attempted	10 (3.6%)	2 (1.7%)	0 (0.0%)	0.171
	Yes	170 (61.6%)	72 (60%)	13 (52%)	
	No	34 (12.3%)	18 (15%)	8 (32%)	
	Not sure	62 (22.5%)	28 (23.3%)	4 (16%)	
C2. Is it true that someone having a generalized seizure will remember all events that occur during the seizure?	Not attempted	11 (4%)	0 (0.0%)	0 (0.0%)	0.00
	Yes	32 (11.6%)	21 (17.5%)	4 (16%)	
	No	154 (55.8%)	80 (66.7%)	21 (84%)	
	Not sure	79 (28.6%)	19 (15.8%)	0 (0%)	
C3. Is it true that a person having a focal seizure always loses consciousness?	Not attempted	11 (0.4%)	1 (0.8%)	0 (0.0%)	0.000
	Yes	185 (67%)	74 (61.7%)	10 (40%)	
	No	25 (9.1%)	23 (19.2%)	13 (52%)	
	Not sure	65 (23.6%)	22 (18.3%)	2 (8%)	
C4. Is it true that those people who have an aura before losing consciousness or awareness have focal seizures?	Not attempted	12 (4.3%)	6 (5%)	0 (0.0%)	0.000
	Yes	66 (23.9%)	24 (20%)	15 (60%)	
	No	42 (15.2%)	36 (30%)	8 (32%)	
	Not sure	156 (56.5%)	54 (45%)	2 (8%)	
D1. Would you take the person with epilepsy to a hospital emergency if the seizure lasts for more than two minutes?	Not attempted	3 (1.1%)	0 (0.0%)	0 (0.0%)	0.483
	Yes	252 (91.3%)	111 (92.5%)	23 (92%)	
	No	10 (3.6%)	7 (5.8%)	2 (8%)	
	Not sure	11 (4%)	2 (1.7%)	0 (0.0%)	
D2. During an epileptic attack, would you keep the person safe from harm?	Not attempted	4 (1.4%)	0 (0.0%)	0 (0.0%)	0.646
	Yes	237 (85.9%)	105 (87.5%)	24 (96%)	
	No	19 (6.9%)	9 (7.5%)	1 (4%)	
	Not sure	16 (5.8%)	6 (5%)	0 (0.0%)	
D3. Would you put something soft under his/her head to stop it from hitting the ground?	Not attempted	3 (1.1%)	3 (2.5%)	2 (8%)	0.000
	Yes	206 (74.6%)	89 (74.2%)	20 (80%)	
	No	24 (8.7%)	23 (19.2%)	2 (8%)	
	Not sure	43 (15.6%)	5 (4.2%)	1 (4%)	
D4. During a seizure would you make a person with epilepsy smell shoes?	Not attempted	6 (2.2%)	0 (0.0%)	0 (0.0%)	0.000
	Yes	158 (57.2%)	31 (25.8%)	1 (4%)	
	No	88 (31.9%)	78 (65%)	24 (96%)	
	Not sure	24 (8.7%)	11 (9.2%)	0 (0.0%)	
D5. Would you give the person with epilepsy water to drink during a seizure?	Not attempted	5 (1.8%)	0 (0.0%)	1 (4%)	0.000
	Yes	78 (28.3%)	15 (12.5%)	0 (0.0%)	
	No	158 (57.2%)	100 (83.3%)	24 (96%)	
	Not sure	35 (12.7%)	5 (4.2%)	0 (0.0%)	

E1. Is medication adherence mandatory in epilepsy?	Not attempted	3 (1.1%)	3 (2.5%)	0 (0.0%)	0.121
	Yes	185 (67%)	85 (70.8%)	22 (88%)	
	No	49 (17.8%)	24 (20%)	2 (8%)	
	Not sure	39 (14.1%)	8 (6.7%)	1 (4%)	
E2. Should a person with epilepsy be screened for depression?	Not attempted	11 (4%)	1 (0.8%)	1 (4%)	0.000
	Yes	120 (39.9%)	81 (67.5%)	19 (76%)	
	No	61 (22.1%)	15 (12.5%)	3 (12%)	
	Not sure	94 (34.1%)	23 (19.2%)	2 (8%)	
E3. Should people with epilepsy get their bone health evaluated regularly?	Not attempted	10 (3.6%)	6 (5%)	1 (4%)	0.000
	Yes	112 (40.6%)	78 (65%)	15 (60%)	
	No	69 (25%)	15 (12.5%)	1 (4%)	
	Not sure	85 (30.8%)	21 (17.5%)	8 (32%)	
E4. Do you think ayurvedic medicines are beneficial to the people with epilepsy?	Not attempted	7 (2.5%)	2 (1.7%)	0 (0.0%)	0.000
	Yes	132 (47.85%)	33 (27.5%)	1 (4%)	
	No	45 (16.3%)	23 (19.2%)	13 (52%)	
	Not sure	92 (33.3%)	62 (51.7%)	11 (44%)	
F1. Can women on anti-epileptic medications take oral contraceptives pills?	Not attempted	11 (4.0%)	2 (1.7%)	0 (0%)	0.124
	Yes	54 (19.6%)	37 (30%)	6 (24%)	
	No	92 (33.3%)	27 (22.5%)	9 (36%)	
	Not sure	119 (43.1%)	55 (45.8%)	10 (40%)	
F2. Is it correct that women with epilepsy on medications should be screened for birth defects with ultrasound at 12 weeks?	Not attempted	11 (4.0%)	1 (0.8%)	2 (8%)	0.001
	Yes	180 (65.2%)	88 (73.3%)	20 (80%)	
	No	14 (5.1%)	14 (11.7%)	3 (12%)	
	Not sure	71 (25.7%)	17 (14.2%)	0 (0.0%)	
F3. Can a woman with epilepsy breast feed her child?	Not attempted	11 (4%)	2 (1.7%)	0 (0.0%)	0.153
	Yes	136 (49.3%)	72 (60%)	18 (72%)	
	No	60 (21.7%)	19 (15.8%)	2 (8%)	
	Not sure	69 (25%)	27 (22.5%)	5 (20%)	
G1. Can someone with epilepsy lead a normal sexual life?	Not attempted	4 (1.4%)	0 (0%)	0 (0.0%)	0.004
	Yes	226 (81.9%)	114 (95%)	5 25 (100%)	
	No	25 (9.1%)	6 (5%)	0 (0%)	
	Not sure	21 (7.6%)	0 (0.0%)	0 (0.0%)	
G2. Can people with epilepsy drive?	Not attempted	5 (1.8%)	0 (0%)	0 (0.0%)	0.090
	Yes	62 (22.5%)	28 (23.3%)	11 (44%)	
	No	173 (62.7%)	81 (67.5%)	10 (40%)	
	Not sure	36 (13%)	11 (9.2%)	4 (16%)	
G3. Should children with	Yes	235 (85%)	105 (88%)	25 (132%)	026

epilepsy go to school?	No	22 (8%)	10 (8%)	0 (0%)	
	Not sure	19 (7%)	10 (4%)	0 (0.0%)	
G4. Do you think people with epilepsy can be employed?	Not attempted	1 (0.4%)	5 (0.0%)	0 (0.0%)	0.007
	Yes	221 (80.1%)	112 (93.3%)	25 (100.0%)	
	No	30 (10.9%)	2 (1.7%)	0 (0.0%)	
	Not sure	24 (8.7%)	6 (5%)	0 (0.0%)	
G5. Can people with epilepsy get married?	Not attempted	2 (0.7%)	0 (0.0%)	0 (0.0%)	0.000
	Yes	205 (74.3%)	110 (91.7%)	25 (100%)	
	No	28 (10.1%)	8 (6.7%)	0 (0%)	
	Not sure	41 (14.9%)	2 (1.7%)	0 (0.0%)	
G6. Would you object to a close relative of yours (brother/sister/child) to get married to someone with epilepsy?	Not attempted	5 (1.8%)	6 (5%)	0 (0.0%)	0.000
	Yes	85 (30.8%)	20 (16.7%)	9 (36%)	
	No	127 (46%)	87 (72.5%)	14 (56%)	
	Not sure	59 (21.4%)	7 (5.8%)	2 (8%)	
G7. Would you disclose about your son or daughter having epilepsy to his class teachers or at school?	Not attempted	1 (0.4%)	0 (0%)	1 (4%)	0.160
	Yes	249 (90.2%)	112 (93.3%)	23 (92%)	
	No	16 (5.8%)	4 (3.3%)	1 (4%)	
	Not sure	10 (3.6%)	4 (3.3%)	0 (0.0%)	
G8. Would you object to having any of your children associate with someone who sometimes had epileptic seizures?	Not attempted	5 (1.8%)	3 (2.5%)	0 (0.0%)	0.058
	Yes	65 (23.6%)	29 (24.2%)	1 (4%)	
	No	176 (63.8%)	84 (70%)	21 (84%)	
	Not sure	30 (10.9%)	4 (3.3%)	3 (12%)	
G9. Do you think the society discriminates with the people having epilepsy?	Not attempted	3 (1.1%)	2 (1.7%)	0 (0%)	0.000
	Yes	97 (35.1%)	22 (18.3%)	20 (80%)	
	No	143 (51.8%)	81 (67.5%)	5 (20%)	
	Not sure	33 (12%)	15 (12.5%)	0 (0.0%)	