

Epilepsy in Children in the National Capital District: a prospective longitudinal follow-up study

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Background

- Epilepsy is the most common neurological disorder in children worldwide (*WHO 2017*)
- 80% of affected children live in countries with limited resources where 90% of epilepsy is not consistently treated (*Banu SH 2007*)
- Study of 40 children with epilepsy in Port Moresby in 1991 showed that 80% had grand mal epilepsy, 90% were on a single AED and 55% had disturbed behaviour (*Danaya RT 1994*)
- Other neurodevelopmental or physical disabilities or outcomes were not reported, and there have been no other studies of epilepsy in children in PNG for nearly 25 years

AIM

Identify children with epilepsy seen at the Port Moresby General Hospital and document the extent of their condition, treatment, quality of life and difficulties faced by children with epilepsy and their families.

OBJECTIVES

- Identify the type of epilepsy the children have
- Assess :
 - neurodevelopmental comorbidities
 - effectiveness of anti-epileptic drug (AED) therapy
 - parents' understanding of their child's condition
 - the child's understanding of his/her condition if old enough
- Gauge parents' (and child if old enough) perceptions of community and peer stigma
- Determine effect of epilepsy on school attendance

METHODS

- Prospective longitudinal follow-up study
- Site: PMGH Paediatric Department
- Duration: July 2016 – June 2018 (23 months)
- Inclusion criteria
 - Children age >12 months -18 years who have epilepsy
 - Parental consent
- Structured questionnaire for parents and children

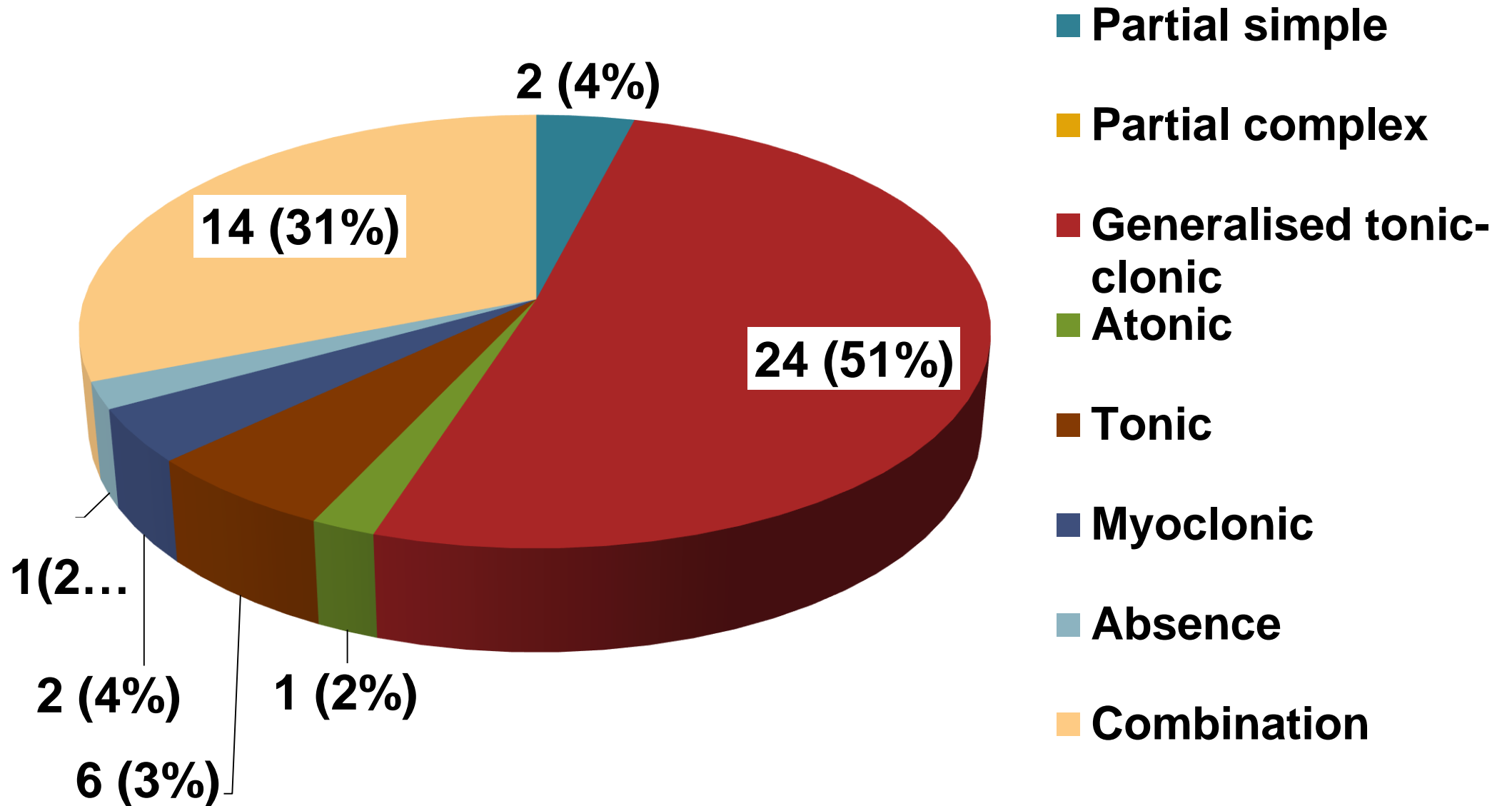
METHODS

- Neurodevelopmental assessment
- Parent diary
- Follow-up monthly or every 2nd month
 - Seizure control
 - Developmental assessment
 - AEDs use
 - School attendance
- Approval for research from SMHS Research Committee
- Data Entry and analysis: MS Excel and thematically

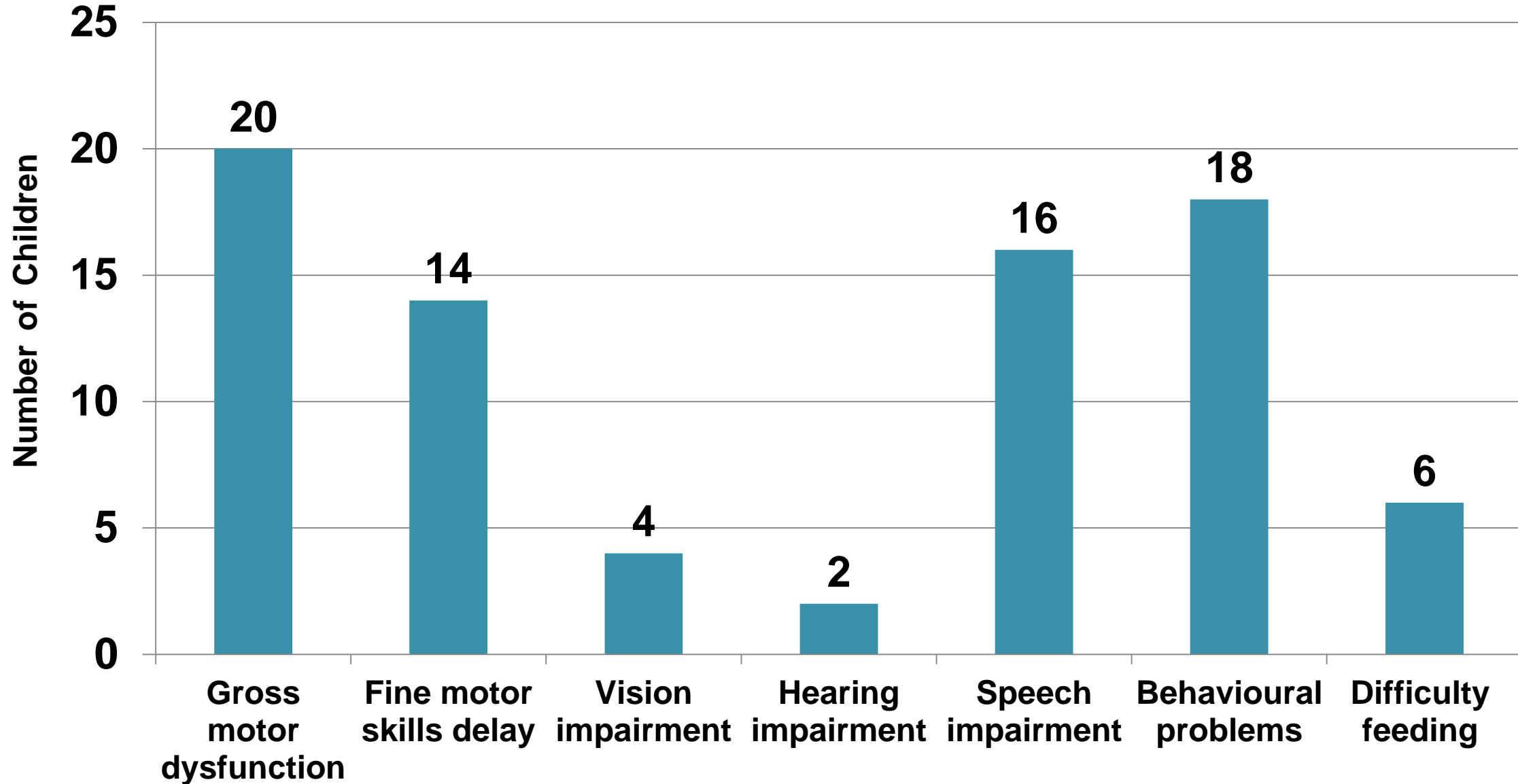
RESULTS

- Total 47 children
- 25 female (53%)
- Median age 6.5 years (IQR 5.5 – 12 years)
- 21 normal development (45%)
- 26 some developmental delay (55%)
- Phenobarbitone - 33 (70%) but recurrent stock-out
- Phenytoin, Diazepam, Sodium valproate - 1 each
- >1AED -11 (23 %) (Carbamazepine/Phenobarbitone)

Seizure classification of children



Neurodevelopmental Complications



Adequacy of seizure control at baseline and follow-up

Seizures / month	Baseline	5 months	10 months	15 months	20 months
	No. (%) (n=47)	No. (%) (n=47)	No. (%) (n=42)	No. (%) (n=43)	No. (%) (n=23)
Good <1-4	35 (74)	36 (77)	35 (83)	36 (84)	21 (92)
Moderate 5-10	5 (11)	5 (11)	3 (7)	4 (9)	1 (4)
Poor 11-30	2 (4)	4 (8)	4 (10)	3 (7)	1 (4)
Very poor >30	5 (11)	2 (4)	0	0	0

Challenges for parents and children

Challenges faced by parents

- Financial
- Behaviour of child
- Continuous care
- Stigma in the community

Challenges faced by children

- Restrictions
- Stigma from siblings and friends “sik muruk”, “gurua gurua meri” (imitate seizures)

Use of a parent diary

- 28 diaries were given to parents to record
 - seizures, possible triggers, missed medication, absence from school due to seizures or questions
- 2 had kept seizure diaries for several years already
 - Both with good control of seizures but had poor control at onset
- 3 out of 28 (11%) parents found diary useful
 - Details in diary used to change AEDs for them

Children's Perception of their Seizures

- headache or dizziness or blurred vision at onset of seizures
>40%
- “teeth locked”, “legs stiff”, “lewa shock”
- “..hard lo lukluk, brain stap lo narapela hap, mi sa harim ol man toktok but sik controlim brain blo mi na mi hard lo toktok” (it’s hard to see, my brain is somewhere else, I can hear people talking but the sickness has controlled my brain so I cannot talk) (16 year old)
- “Mi sa guria guria, tupla ear drum hot na brain sa move inside lo het” (I shake, my two ear drums are hot and my brain moves inside my head) (11 year old)

DISCUSSION

- First study of childhood epilepsy in PNG for 25 years
- Much scope for improving seizure control (1/4 have moderate or poor control)
- How to provide comprehensive care for children with epilepsy:
 1. Always have AEDs in stock
 2. Manage complications/ refer appropriately
 3. Use of parent diary
 4. Support and encouragement from health staff

DISCUSSION

- With close follow-up and attention, there was a trend towards improved seizure control (73% vs 92% good control at 20 months) $p=0.12$
- Frequent stock-out of phenobarbitone – children's seizure control affected
- Challenges faced by parents especially financially determines seizure control and thus quality of life

DISCUSSION

- Majority of children felt they had too many restrictions placed on them
- Children and adolescents with epilepsy who experience stigma have been shown to have lower self-esteem and increased anxiety and depression (*Jacoby, 2007*)
- Children's experience of seizures can be very frightening for them

CONCLUSIONS

- Comprehensive care for children with epilepsy requires a good knowledge of the individual patient - including their condition and comorbidities, their family, and their strengths and vulnerabilities
- It requires following patients over a long time, and being there to assist

RECOMMENDATIONS

- Regular supply of current AEDs phenobarbitone and introduction of other AEDs
- Adjustment of AEDs until better control achieved
- Value of parental diary
- Support for parents and children (social/educational)
- Need training in epilepsy and neurodevelopment

REFERENCES

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- Danaya RT, Johnson FA, Ambihaipahar U. (1994). Childhood epilepsy in Papua New Guinea. *PNG Medical Journal*
- Jacoby A and Austin JK. (2007) Social stigma for adults and children with epilepsy. *Epilepsia*; 48: 6-9
- WHO (2017) Factsheet on Epilepsy

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