Met and unmet needs of children with epilepsy in a paediatric tertiary care setting

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Abstract

Objective To investigate the extent to which the health needs were met or unmet in children with epilepsy attending a tertiary care outpatient setting.

Patients and method A semi-structured interview was used to collect relevant information from the parents. It focused on ascertaining the quality of health care received by the children, including the extent to which attention was given to epilepsy related physical, behavioural, social and educational impairments that were identified by the parents.

Results There was satisfactory seizure control in the majority. Most children received only one anticonvulsant and side-effects were reported to be minimal. A large majority had behavioural problems, and social and educational difficulties to a lesser extent. Parents were concerned about the implications of these problems, but there was little communication about them in the doctor-patient contact. Even where the problems were communicated, parent satisfaction about the interventions was low. Parents identified the availability of more consultation time and provision of more information on epilepsy as their expectations from doctors.

Conclusions This study shows that awareness and communication about the multiple health problems of children with epilepsy are necessary to improve the quality of health care given to them.

Introduction

Children with epilepsy commonly suffer from multiple impairments and disabilities, including emotional, behavioural, social, cognitive and educational difficulties [1–3]. In addition, the impact of social stigma are negative experiences for them [4, 5]. When compared to other chronic illnesses, prevalence of such problems is higher with epilepsy [6]. However, management of epilepsy traditionally focuses on seizure control, whereas other related health problems receive minimal attention. In investigations into the quality of care in epilepsy using patient feedback, the medical profession is criticised for being unhelpful, and not adequately meeting their health needs [7]. By definition, health needs are considered unmet if relevant interventions are not made or are unavailable [8]. Similarly, met health needs minimise impairments and disability through recognition, and optimum treatment and care. Comprehensive care that effectively manages education and restrictions to life improves outcome in children with epilepsy [9–11]. In providing such care, it is important to take into account the needs expressed by the patient and family and their satisfaction with outcome of treatment [18, 12].

The broad objective of this study was to investigate the extent to which the health needs were met or unmet in children with epilepsy receiving outpatient care. The specific objectives were to explore (i) positive aspects of care, (ii) impairments and disabilities identified by the parents, and (iii) the extent to which communication occurred about them in the doctor-patient contact.

Method

The sample was chosen from children attending specialist paediatric outpatient clinics at the Lady Ridgeway Hospital for children in Colombo. At a given clinic, all the children who were taking treatment for epilepsy for 12 months or more were included in the study. Nine such clinics conducted by three specialist units were used for the study. Children who were on treatment for other concurrent long term illnesses were excluded.

The parent accompanying the child was interviewed for 15 to 20 minutes. This was a semi-structured interview which focused on (i) demographic data of the child, (ii) distance from residence to the hospital, (iv) educational attainment of the parent, and (v) different aspects of care under the following topics.

Information on drug treatment of epilepsy

This aspect of enquiry concentrated on (i) medication and its adverse effects, and (ii) level of seizure control. A

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checklist of common side-effects of anticonvulsants was offered to the parent to identify those affecting the child.

Parents' knowledge about epilepsy

The aim was to ascertain whether the parent had accurate knowledge about the cause of epilepsy, action of the drugs and first aid in the event of a seizure at home. If the source of this knowledge was the doctor, the parents were asked whether the information had to be requested or was volunteered.

Behaviour, social or educational problems in the child

The parents were asked (i) whether the child had problems in each of these aspects of functioning and to identify the type of problem from the checklist, (ii) whether the presence of the problems was communicated to the doctor, and if so, (iii) the intervention offered and its effectiveness. The checklists on behavioural, social and educational problems were constructed from published data on children with epilepsy and other chronic illnesses [2, 13].

Other expectations

The parents were asked to state whether they were satisfied with the (i) amount of information received on the child's illness, (ii) consultation time with the doctor, and (iii) the attitude of the doctor. They were also asked whether financial assistance was expected from the hospital.

Statistical analysis

The data was analysed using EPI version 6 (WHO) to calculate the frequency of occurrence of the variables studied and the association between them.

Results

The sample included 77 children aged from 2 to 13 years (mean 6.2, SD 3.5). Males were 57.1%. The duration of epilepsy in the sample was 1 to 11 years (mean 3.3, SD 2.66). The mean duration of treatment was 3.1 years. Information regarding the educational attainment of parent and the distance travelled to attend the clinic are given in Table 1.

Table 2 gives information on seizure frequency and medication. Parents were satisfied with the level of seizure control in 48.1% cases, moderately satisfied in 29.9% cases and dissatisfied in 22.1%.

All the children were taking anticonvulsant medication. Table 2 gives the frequency of side-effects of medication. Drowsiness was the commonest (32.5%). Restlessness was reported by 18.2%, but in some, the cause may be behavioural rather than medication.

In 64.9% sufficient and accurate knowledge was displayed by parents on the cause of epilepsy, and in 26% on the action of anticonvulsant drugs. In 62.3%, parents could not name even one drug given to the child. In 63.6%, parents showed sufficient knowledge of first aid in the event of a seizure at home. In 81.8%, doctors were the main source of information about epilepsy, but 65.2% of this group felt that information was provided only on request.

Table 1. **Information related to parent who responded to the interview**

	n	%
Educational attainment		
Primary school	32	41.6
Secondary school	41	53.7
Tertiary education	1	1.3
Never attended school	3	3.9
Distance travelled to attend clinic		
Less than 10 km	33	42.9
10 to 30 km	20	26
Over 30 km	24	31.2

Table 2. **Epilepsy related information about the child**

	n	%
Seizure frequency		
One episode per week	22	28.6
One episode per month	14	18.2
None in 3 months	9	11.7
None in 6 months	12	15.6
None in one year or more	20	26
Anticonvulsants		
Taking drugs	77	100
Taking one drug	57	74
Taking two drugs	14	18.2
Taking >2 drugs	6	7.8
Side-effects of medication		
Side-effects experienced	35	45.5
Mild	11	14.3
Moderate to severe	24	31.2

In 87.9% of children, parents identified one or more behavioural problems (mean 1.8, SD 1.34, SE 0.15). Lack of co-operation (24.7%), temper tantrums (22.1%) and aggressive behaviour (19.5%) were common; 10.4% of children were recognised as overactive.

Social problems were identified by parents in 61% of children (mean 1.3, SD 1.4, SE 0.15). Shyness (26%), low confidence (16.9%), reluctance to mix with other children (10.4%) were common. 46.8% of children were identified to have school related problems (mean 0.98, SD 1.25, SE 0.14), 18.2% had low achievement and 14.3% were reluctant to go to school. A further 9.1% were thought to be poorly motivated to learn.

Parents admitted that they did not complain to the doctor about the child's behavioural problems in 41.4% of cases, social problems in 66.1% and educational problems in 36.1%. However they were concerned and wanted help for these problems. Parents perceived the interventions offered by the doctor for behavioural problems as very useful in 5.9% of children, and somewhat useful in 19.2% of children. The figures for social problems were 4.2% and 10.6% respectively and for school related problems, 8.3% and 19.4% respectively.

In 71.4%, parents expected more epilepsy related information directly from the medical staff. In 13% assistance was expected in obtaining financial help in meeting the costs of the child's illness. In 19.5%, parents expressed dissatisfaction with the amount of medical consultation time of clinic visits and 6.5% thought the doctors were insensitive to their problems.

Discussion

Some published practice guidelines for epilepsy recommend focusing on biological, psychological and social needs of the patient [14]. Taking such guidelines and known impairments and disabilities into account, this study identifies several health needs that were met and unmet in epileptic children. On the positive side, over half the children (53.3%) had a reasonably good control of seizures, though parent satisfaction is marginally lower at 48%. In nearly 75% of the children, only one anticonvulsant was prescribed to control the seizures. The prevalence of side-effects was also low with over 85% either not reporting any or only mildly affected by them. In addition, a majority of the parents (64.9%) displayed sufficient knowledge about the cause of epilepsy and a similar number had accurate knowledge about management of a seizure at home. This level of knowledge matched the education of parents; a majority (55%) had received secondary school education. Another positive aspect was that doctors had played a major role in providing information and education about epilepsy, though the majority of parents felt that they had to ask for it.

The aspects where the health needs of these children were largely unmet were with regard to behavioural, social and educational difficulties. It is a known fact that patients and parents are reluctant to voice psychosocial needs to doctors but this may lead to dissatisfaction about care and poor compliance [15, 16]. In our study too, these burdensome difficulties were not reported by a majority of parents. At the same time, in the presence of a large number of unmet needs, the demand for better delivery of illness related information by patients and families is known to be high [5,17,18]. In our study the request for more information by parents of nearly 75% children, and dissatisfaction about consultation time with the doctor by nearly 20%, point to a high level of unmet needs.

A relatively small number (13%) expected financial assistance towards supporting the child's management. Over 30% of the patients travelled over 30 km to get treatment.

The small sample and the setting do not allow the results to be generalised. Absence of data on family background is a shortcoming and limits analysis and interpretation of parent responses to the interview. However, the study highlights shortcomings in the services for children with epilepsy. Such shortcomings even in a tertiary care paediatric setting where resources are better than elsewhere in the country is unfortunate in terms of quality of care offered to children with epilepsy.

References

1. Ott D, Caplan R, Guthrie D, Siddarth P, Komo S, et al. Measures of psychopathology in children with complex partial seizures and primary generalized epilepsy with absence. *Journal of the American Academy of Child and Adolescent Psychiatry* 2001; **40**: 907–14.
2. Faewell J, Batzel L. Neuropsychological abilities in children with epilepsy. *Epilepsia* 1985; **26**: 395–400.
3. Stanicolo M, Galleti F. Idiopathic epilepsy and school achievement. *Archives of Diseases of Childhood* 1994; **70**: 424–8.
4. Carlton-Ford S, Miller R, Nealeigh N, Sanchez N. The effects of perceived stigma and psychological over-control on the behavioural problems of children with epilepsy. *Seizure* 1997; **6**: 383–91.
5. Wiebe S, Bellhouse DR, Fallahay C, Eliasziw M. Burden of epilepsy: the Ontario Health Survey. *Canadian Journal of Neurological Sciences* 1999; **26**: 263–70.
6. Houston EC, Cunningham CC, Metcalfe E, Newton R. The information needs and understanding of 5-10 year old children with epilepsy, asthma or diabetes. *Seizure* 2000; **9**: 340–3.
7. Robinson RO, Edwards M, Madigan C, Ledgar S, Boutros A. Audit of a children's epilepsy clinic. *Developmental Medicine and Child Neurology* 2000; **42**: 387–91.
8. World Health Organisation. International Classification of Impairments, Disabilities and Handicaps. Geneva: WHO, 1980.
9. Tettenborn B, Kramer G. Total patient care in epilepsy. *Epilepsia* 1992; (Suppl. 1) **33**: S 28–32.
10. Garwick AW, Kohrman C, Wolman C, Blum RW. Families' recommendation for improving services for children with chronic conditions. *Archives of Pediatrics and Adolescent Medicine* 1998; 152: 440–8.

11. Jessop DJ, Stein RE. Providing comprehensive healthcare to children with chronic illness. *Pediatrics* 1994; **93**: 602–7.
12. Zeigler RG, Erba G, Holden I, Dennison H. The coordinated psychosocial and neurologic care of children with seizures and their families. *Epilepsia* 2000; **41**: 732–43.
13. Stawski M, Auerbach JG, Barasch M, Lerner Y, Zimin R. Behavioural problems of children with chronic physical illness and their siblings. *European Child Adolescent Psychiatry* 1997; **6**: 20–5.
14. Brown S, Betts T, Crawford P, Hall B, Shorvon S, Wallace S. Epilepsy needs revisited: a revised epilepsy needs document for the UK. *Seizure* 1998: **7**: 435–46.
15. Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. *British Medical Journal* 2000; 320: 1246–50.
16. Cassidy LJ, Jellinek MS. Approaches to recognition and management of childhood psychiatric disorders in pediatric primary care. *Pediatric Clinics of North America* 1998; **45**: 1037–52.
17. Laine C, Davidoff F, Lewis CE, Nelson EC, Nelson E, et al. Important elements of outpatient care: a comparison of patients' and physicians' opinions. *Annals of Internal Medicine* 1996; **125**: 640–5.
18. Kwong KI, Wong SN, So KT. Parental perception, worries and needs in children with epilepsy. *Acta Paediatrica* 2000; **89**: 593–6.