Psychosocial well-being in children with epilepsy

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Abstract

Objective: To examine the aptitude, school performance and parent satisfaction (psychosocial wellbeing) of epileptic children in comparison to a control group

Method: A prospective study was conducted from 30th May to 8th August 2005 at the Lady Ridgeway Hospital for Children, Colombo. Data was collected by a trained investigator. All children between the ages of 6 and 10 years, diagnosed with epilepsy for a period extending 2 years, and attending the hospital during the study period, were included as cases. Only children who were attending school (mainstream or special needs) were included. 102 questionnaires were administered and none were discarded. The controls were identified from 3 primary schools in the same district. Each epileptic child was matched by age and sex with a non-epileptic child. The social class profiles of the 2 groups did not differ significantly. Each participating parent completed a pre-tested questionnaire to assess the psychosocial well-being of the epileptic children and their parents. This was followed by a standardized aptitude test which was completed by both cases and controls. The data was entered into the Statistical Package for Social Sciences (SPSS) Version 12 for Windows to examine the differences between the groups via frequency distributions.

Results: When compared with the non-epilepsy sample, the epilepsy sample was characterised by low academic achievement, extra-curricular participation, self and life skills, dependency, lethargy, restricted independence and less equal opportunity towards success. On the other hand, on items relating to aggressive behaviour and family relationships no significant differences were found between the two groups. On the Aptitude test the average score by an epileptic child was 4.12/10 whereas it was 8.42/10 in the control group.

Conclusion: The psychosocial wellbeing of epileptic children is poor in comparison to the control group.

(Keywords: children; psychosocial well-being; parent satisfaction; aptitude)

Introduction

While much research on epilepsy focuses on the neurobiology of the disorder, perhaps an equally great handicap is placed by its psychosocial consequences on the wellbeing of the individual and his or her family[1]. Anecdotal evidence from Sri Lanka portrays the stigma and negative public perception of the disorder, exemplified by epileptic individuals traditionally being considered as a burden on families, ill suited for school and play and subsequently marriage, family life and employment.

Collins[2] delineates the literature on the aetiology of the psychosocial consequences of epilepsy as two-fold:

- The psychosocial consequences are directly caused by epilepsy, with the severity of the problem correlated to the severity of the medical condition.
- The psychosocial consequences are mediated by other individual and social characteristics, especially by the person's perceptions of him- or herself and of his or her condition.

Collins[2] suggests that the latter conceptualization is more holistic than the former and better suited for inclusion in management plans. This approach also sheds light on the individual differences in the psychosocial consequences of epilepsy, which may or may not be related to the severity of the disorder.

There has been literature to support this hypothesis. For instance, Ryan et al.[3] demonstrated how perceptions of stigma by people with epilepsy were more strongly influenced by self-perceptions than by the objective facts of their epilepsy. Similarly Stanley and Tillotson[4] noted how participation in social and employment activities related more closely to perceptions of disability than to seizure frequency and other more objective measures of epilepsy.

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Collins[2] himself showed general low well-being among the epileptic and found this to be associated with people's perceptions of themselves, employment status, seizure frequency, certainty of diagnosis, time since diagnosis and absence of seizures.

Much of this research has been in Western societies, and adapting their results to the collectivist culture of Sri Lanka can be ethnocentric. Further, the focus has been on the epileptic adult and not on the epileptic child and his/her family. Furthermore, with the advances in the treatment of epilepsy in recent years, it would be useful to explore if these negative associations still persist.

Objective

The objective of the study is to examine the aptitude, school performance and parent satisfaction (collectively defined as psychosocial well being for the purposes of this research) of epileptic children in comparison with a control group.

Method

The study was conducted from 30th May to 8th August 2005. Time and financial considerations prevented the selection of a sample that was strictly representative of the childhood epilepsy population of Sri Lanka. Instead, cases were identified via paediatric clinics at the Lady Ridgeway Hospital, the only hospital specializing solely in paediatric care in Sri Lanka. Hence, although this is largely an opportunity sample, the Lady Ridgeway Hospital caters for seriously ill children from all societies of Sri Lanka, and given the gravity with which recurrent seizures are viewed by Sri Lankan parents, it is fair to say that the sample is representative of a wide range of socio-economic backgrounds.

Data was collected by an investigator, who had been trained to introduce the project to potential respondents and to administer the research questionnaire in a standardised manner. All children between the ages of 6 and 10 years, diagnosed with epilepsy for a period exceeding 2 years, and attending the hospital during the study period, were included as cases. Only children attending school (mainstream or special needs) were included.

To 'control' for extraneous factors (e.g.: socio-economic status) affecting intra-individual variability, the controls were identified from three primary schools in the same district. Each epileptic child was matched by age and sex with a non-epileptic child. The social class profiles of the two groups did not differ significantly.

Each participating parent completed a questionnaire to assess the psychosocial well-being of the epileptic children and their parents. In brief, the questionnaire yielded information relating to the following:

- General physical and mental health
    - Achievement of milestones
    - Hospital admissions
    - Physical/mental disability
    - Accidents requiring medical attention
- Academics
    - Age appropriate – current and past
    - Performance
    - Aptitude
    - Absenteeism
- Extra-curricular activities
- Self care and life skills
- Social and behavioural difficulties
    - Decision making
    - Interpersonal relationships with family, peers and teachers
    - Participation in cultural and social events
    - Aggression
    - Lethargy
    - Dependency
    - Adopting a sick role
    - Over protection
    - Anxiety
- Impact of epilepsy on parents
    - Stigma
    - Freedom
    - Employment
    - Socialisation
    - Mood/Affect
    - Worries
- Parents' views on societies attitude towards child
    - Socialisation
    - Equal opportunities
    - Designations and responsibilities
    - Perceived future success

In addition, background information on age, sex, marital status, living situation, region of residence, and educational and employment histories was also obtained. The questionnaire was pre-tested with ten parents attending clinics at Lady Ridgeway Hospital, following which changes were made. The finalised questionnaire was then administered to parents in both the case and control group. This was followed by an aptitude test, standardized by the National Institute of Education, which was completed by both cases and controls. Informed consent was taken from both parents and child. Prior ethical approval was obtained by the Ethical Review Board of the University of Colombo.

The aim of the statistical analysis was to compare the well-being profiles of the epilepsy and non-epilepsy samples. The data was entered into the Statistical Package for Social Sciences (SPSS) Version 12 for Windows to examine the differences between the groups via frequency distributions. Further, using a combinational analysis on Microsoft Excel, the relationship between other extraneous variables was explored to identify any possible confounding factors influencing the results.

Results

102 questionnaires were administered and none were discarded as all had been completed in full.

The duration of epilepsy in the sample was 2-4 years in 60 children, 5-7 years in 24 children and more than 7 years in 18 children. Forty nine (48%) epileptic children had a family history of epilepsy. The age and sex distribution in the epilepsy sample is shown in figure 1.

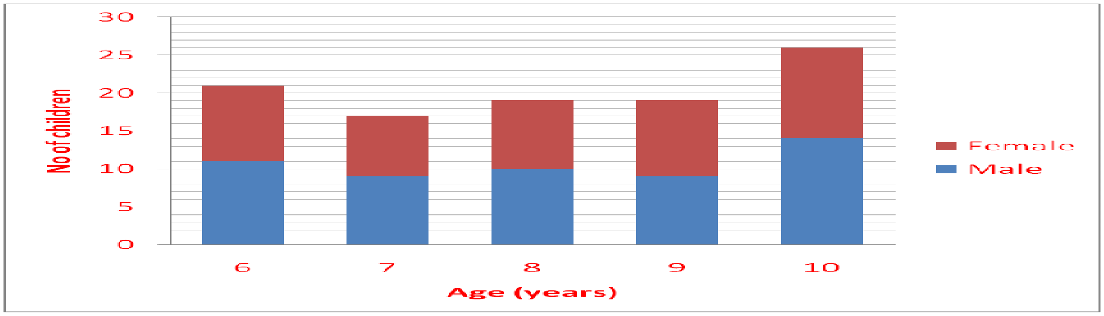

Figure 1: ***Age and sex distribution in epilepsy sample***

Table 1 compares the scores on each of the main well-being scales.

General physical and mental health

Physical and mental disabilities included speech, hearing, visual, gross motor and cognitive difficulties. Interestingly, the control group reported a significantly higher number of accidents at home or school compared to the epileptic group (Table 1).

Academics

On the aptitude test the average score by an epileptic child was 4.12/10 whereas it was 8.42/10 in the control group.

Extra-curricular involvement

Swimming and field sports were some of the activities that the epileptic children were believed to be unable to participate in.

Self care and life skills

A significant number of epileptic parents were dissatisfied with their child's ability to perform every day tasks in an age appropriate manner in comparison to parents of the control group (Table 1).

Social and behavioural difficulties

Significant numbers of parents of epileptic children were dissatisfied regarding their child's decision making ability, participation in social and cultural events and their interpersonal relationships with peers and teachers. There was no significant difference between aggressive behaviour reported in both groups (Table 1).

Impact

Significant numbers of parents of epileptic children felt that epileptic children did not receive equal opportunities at school as compared to the control group (Table 1).

Confounding factors

Combinational analysis indicated that there was no relationship between parental education level and school performance in the children.

Table 1: ***Wellbeing of cases and controls in percentage***

Well being item	**Epilepsy (%) (N = 102)**	**Control (%) (N = 102)**	**P value**
General physical and mental health			
Delayed milestones	44	2	<0.0001
Hospital admissions in past year	38	15	<0.0001
Disability	31	6	<0.0001
Accidents	27	45	<0.01
Academics			
Not age appropriate class	23	0	<0.001
Performance below average	58	2	<0.0001
Performance on aptitude test below average	48	0	<0.0001
Absenteeism over 4 days	85	4	<0.0001
Extra-curricular activities			
Not engaged	59	17	<0.0001
Self care and life skills			
Below age appropriate skills	39	4	<0.0001
Social and behavioural difficulties			
Below age decision making skills	47	4	<0.0001
Unsatisfactory social relationships: Peers	22	0	<0.001
Unsatisfactory social relationships: Family	9	0	>0.05
Unsatisfactory social relationships: Teachers	20	8	<0.01
Unsatisfactory social involvement	50	6	<0.0001
Aggression	39	33	>0.05
Dependency	59	24	<0.0001
Lethargy	43	10	<0.0001
Insecurity	50	12	<0.0001
Impact of epilepsy on parents			
Stigma	24	0	<0.0001
Independent play allowed	49	16	<0.0001
Problems at work for parents	20	5	<0.001
Limits on parents socialisation	50	0	<0.0001
Parents views on societies attitude towards the child			
Equal opportunities given at school	62	6	<0.0001
Below par parental expectations	38	0	<0.0001

Discussion

The focus of this research has been on an examination of the well-being of a sample of children with epilepsy. When compared with the non-epilepsy sample, the epilepsy sample is characterised by low academic achievement, extra-curricular participation, self and life skills, dependency, lethargy, restricted independence and less equal opportunity towards success. On the other hand, on items relating to aggressive behaviour and family relationships no significant differences were found between the two groups.

There is a viable argument that there may be a correlation between the educational level of parents and the performance of children[8]. This would confound the results if the level of parental education differed between the control and experimental group. However, a combinational analysis conducted on the data indicates that there was no such correlation between parental education level and child's school performance in the samples studied, which indicates that parental education level is not a confounder in this study.

The study does, however, have limitations, which although not invalidating the results does constrict a degree of caution in their interpretation and applicability. First, the sample was drawn from Lady Ridgeway Hospital, and it could be argued that this represents the more severe cases of epilepsy, mostly from the Colombo district and from those in socioeconomic backgrounds seeking free health care. However, the chosen control group largely matches the sample on age, sex, socio-economic status (i.e. receiving free education) and district. We should be cautious about the use of self-report methods as there is always the possibility of bias influencing responses. For instance parents may be influenced by the social desirability bias in reporting on the 'burden' of epilepsy on the family, and be circumspect of disclosing this 'burden' in candid terms.

The study findings are in keeping with the results of several previous investigations that have revealed that psychosocial problems are often associated with an epilepsy diagnosis[2,5,6]. Hence, the psychosocial concerns are not restricted to adults with epilepsy, but seem to arise at a young age and thus affect the entire family. Some of the variables investigated overlap those of previous studies. Dodrill et al[6] found considerable homogeneity in the psychosocial problems suggested despite substantially different patient characteristics and referral sources. Emotional, interpersonal, vocational, and financial concerns were most commonly found, as well as difficulties in dealing with seizures; these concerns were largely similar to those voiced by the parents in the current study, where parents of the epileptic sample showed statistically significant concerns with regard to vocational (employment) and interpersonal (social) experiences. These concerns with regard to employment and vocation were also identified in Collins's work[2]. It seems that there is homogeneity in concerns and stressors regardless of whether the individual has epilepsy or whether it is his/her child that is diagnosed.

Collins's[2] analysing specific aspects of lowered well-being found that the people with epilepsy experienced a good deal of difficulty in situations requiring intimate contacts with others but also in more superficial, everyday situations. These may overlap with our findings that children with epilepsy have difficulty in their social relationships with peers and teachers. Collin's sample displayed heightened self-consciousness while the children we studied displayed symptoms of insecurity. Collin's also studied life fulfilment in epileptic adults by measuring the extent to which people's actual life situation matched their desires. The particular areas of low life fulfilment revealed among the epilepsy group centred on employment, peace of mind, and social, but did not extent to satisfaction with leisure pursuits and finances. We found significant numbers of parents of epileptic children felt that epileptic children did not receive equal opportunities at school and also had social and behavioural difficulties as compared to their peers. There were also concerns with regard to children's participation in extra-curricular activities and as mentioned above with regard to the parent's employment and socialisation.

The measuring instruments employed in this study allowed an analysis of more specific aspects of lowered well-being that could usefully form the basis for various care and counselling initiatives[7]. The sources of low life fulfilment seem important ones for focusing on by counselling and advice services. Our findings indicate a need for initiatives in the area of academic, social and interpersonal skills with non-family members for children with epilepsy.

Conclusion

The psychosocial wellbeing of epileptic children is poor in comparison to the control group.

References

1. Livingston S. Psychosocial aspects of epilepsy. In: British Epilepsy Association, editors. Perspectives on epilepsy 80181, Berkshire: British Epilepsy Association; 1981. p. 17-27.

2. Collins JA; Psychosocial well-being and epilepsy: An empirical study. *Epilepsia* 1990; **31**(4):418-26. http://dx.doi.org/10.1111/j.15281157.1990.tb05497.x

3. Ryan R, Kempner K, Eden AC; The stigma of epilepsy as a self-concept. *Epilepsia* 1980; **21**:433-44. http://dx.doi.org/10.1111/j.15281157.1980.tb04091.x

4. Stanley PJ, Tillotson A. Epilepsy in the community. Leeds, England: School of Social Studies, Leeds Polytechnic; 1982.

5. Dowds N, McCluggage JR, Nelson J. A survey of the socio-medical aspects of epilepsy in a general practice population in Northern Ireland. Belfast: Department of General Practice, The Queen's University; 1983.

6. Dodrill CB, Breyer DN, Diamond MB, Dubinsky BL, Geary BB; Psychosocial problems among adults with epilepsy. *Epilepsia* 1984; **25**:168-75. http://dx.doi.org/10.1111/j.15281157.1984.tb04174.x

7. Collings, JA. The social, psychological and physical well-being of people with epilepsy in the community: A report of a research study. Leeds: Leeds Polytechnic; 1986.

8. Education Matters. First Results from the 2003 Programme for International Student Assessment. 2004; 5