Kinderen met epilepsie
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SUMMARY.

Children with epilepsy. An investigation of the influence of an illness on the child and its family.

The chief aim of this study has been to acquire a better insight into the functioning of a child aged 10-12 suffering from epilepsy and of the functioning of its family. To investigate this problem, a matched sample design (individual matching) has been used. Mothers as well as fathers (both of the epileptic and matched control children) have been interviewed separately and intensively.

The research project has been supported by The National Committee on Epilepsy of the Organization for Health Research TNO (CLEO).

The problem area has been defined in Chapter 1: what is the relationship between epilepsy and the way a child suffering from epilepsy and its family, function.

In Chapter 2 epilepsy has been described from a social and medical point of view. For the social point of view use has been made of the theory of deviant behaviour applied to illness as formulated by Freidson (1965, 1973). The medical point of view involved a description of epilepsy in terms of definition, the etiology, classification and epidemiological aspects of the epilepsies as well as a short description of the fight against epilepsy in The Netherlands.

The problem area defined above has been elaborated in Chapter 3. On the basis of an extensive study of literature on the subject of 'illness and the family' and 'epilepsy and child functioning', the conclusion was drawn that neurological variables are likely to be less significant for the way epileptic children function than other, social variables. An attempt has been made to demonstrate that reactions from others, both within and outside the home, affect the way of functioning of children with a chronic illness, in this case epilepsy, and vice versa.

In Chapter 4 the problem and the main hypotheses have been formulated against the background of this literature. This chapter also includes a description of the design and procedures of the research project, as well as the response of persons and organizations who cooperated with this project (general practitioners, specialists, out-patient clinics, teachers and parents of the epileptic and control children).

* I would like to express my gratitude to Henk Werner for this translation.
Samples consisting of patients with epilepsy (as well as other disabilities) are often atypical: they are composed either of hospitalized patients or out-patients or both and often these patients have multiple handicaps. The children with epilepsy aged 10-12 whose mothers and fathers participated in my research project, had at least to meet the following criteria: (a) they should not have any other chronic illness than epilepsy; (b) apart from the epilepsy, they should not manifest other signs of brain damage; (c) they should have had at least one seizure and/or epilepsy should have been definitely diagnosed; (d) they should (have) use(d) anti-epileptic drugs; (e) they should attend normal schools (no special classes or schools). The family of the child with epilepsy (epilepsy family) as well as the matched control family had to meet the following additional criteria: (a) families had to be complete (neither divorced nor widowed); (b) fathers had to be employed full-time; (c) apart from epilepsy, none of the members of the epilepsy or control families should have any (other) chronic illnesses. Next, the epilepsy and control families have been matched on sex and ordinal position of the child, family size, socio-economic status and degree of urbanization of the place of residence. Interviews were held separately with 109 epilepsy and control mothers and 106 epilepsy and control fathers.

In Chapter 5 the group studied has been described with respect to several social and medical variables. It became evident that the group gave a reasonably good reflection of the structure of the Dutch population on the social variables considered. The composition of the group of epileptic children on some medical aspects may be summed up as follows: the mean age of onset, the mean duration of epilepsy (i.e. the period during which seizures occurred) as well as the mean seizure-free-period was four years; on average the children had used anti-epileptic drugs for six years; about 45% of the children had at least one seizure a month in the non-seizure-free period; 51% of the children (have) had tonic-clonic seizures (possibly combined with other seizures). The primary generalized epilepsies occurred in 42% of all cases and the partial epilepsies in 41%. Most of the remaining children had secondary or undetermined generalized epilepsies or unclassifiable epilepsies.

In Chapter 6 the aspects and dimensions of family and child functioning have been described. The following areas in the way the family functions have been distinguished:
- the recreational and social function; the disturbance of this function has been further elaborated as 'disturbance of spare time' en 'general psychological stress' (internal relations and family atmosphere);
- socialization function; three aspects have been distinguished here: (a) the daily socio-emotional parent-child relationship ('frustration' and 'annoyance'); (b) the daily pedagogic parent-child relationship ('pedagogic uncertainty', 'overprotection', 'indulgence', 'strictness' and 'number of behavioural restrictions imposed on the child'); (c) mobility attitudes ('mastery',

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'passivity', 'school orientation' and 'parental worries'). The following distinctions have been made regarding the child's functioning:
- aggressiveness and withdrawal; friendships; daily contacts with brothers, sisters and peers; membership of clubs; negative peer reactions; progress at school (marks for arithmetic, grammar and reading; failure to be removed to the next grade; remaining below the age-appropriate grade level; educational expectations). Various items have been drawn up for most dimensions distinguished; an orthogonal factor analysis and varimax rotation has been carried out on these items.

In addition to these dimensions describing the way the families and the children function, three criteria have been developed to indicate the psychological reactions of the epilepsy parents on their children's epilepsy, namely feelings of guilt, shame and fear.

Finally, to describe the epilepsy of the child in addition to epilepsy variables such as onset, duration, freedom of seizures and magnitude of the seizures, a frequency and a visibility index of the children's seizures have been made.

In Chapters 7, 8 and 9 the differences in the way the epilepsy and control mothers, fathers and their children respectively function have been investigated, as well as the way these differences in functioning are interrelated. The results may be summed up as follows.

In Chapter 7 the differences in the way the epilepsy and control mothers and fathers respectively function have been tested. It appeared from this that:
a. the epilepsy mothers showed significantly more general psychological stress, frustration, annoyance, overprotection, passivity, parental worries and a lower school orientation than the control mothers;
b. the epilepsy fathers showed more frustration, overprotection, passivity, parental worries and less indulgence than the control fathers.

Also, the epilepsy parents imposed more behavioural restrictions on their children than the control parents. It was clear that epilepsy mothers were most strongly affected. The effect of the socio-structural variables (sex and the ordinal position of the child; socio-economic status; degree of urbanization), of the psychological variables (fear; shame; guilt) and of the epilepsy variables (such as onset, duration, frequency and visibility index) on the differences found was generally rather moderate. In so far as these variables had an effect (in the sense of making the differences found between the epilepsy and control mothers/fathers increase or decrease) it may be concluded that the way the epilepsy mothers function is affected by their psychological reactions (fear; guilt) to their children's epilepsy rather than by the epilepsy variables themselves. Such a distinction in the effects of these variables could less clearly be made in the case of the epilepsy fathers.
Not only were the epilepsy and control mothers/fathers different from one another, but so were their children (as reported by their parents). The test results from Chapter 8 indicated that epilepsy children were considered to be both more aggressive and more withdrawn by their parents than was the case with control children. Moreover, epilepsy children joined clubs to a lesser degree, were inclined to have fewer friends, were treated more negatively by their peers and showed less progress at school than control children. It was remarkably that the socio-structural, psychological and epilepsy variables distinguished above had an (even) smaller effect on the differences in functioning between the children than on those between the parents.

From the correlations, calculated in Chapter 9, between the significant differences in functioning between the epileptic and control children and their mothers/fathers it turned out that these differences were often interrelated, sometimes quite strongly and in different ways. An attempt has been made to give a causal interpretation of these interrelations. Except for the fact that other interpretations were possible and plausible, a note has been made to the effect that it was often considered more meaningful to speak of an interaction than of a one-sided cause-to-effect relationship.

The interrelations with the differences in functioning between the epileptic and control children were somewhat different for the fathers than for the mothers. The differences between the epilepsy and control mothers, in particular in a socio-emotional respect (general psychological stress; frustration; annoyance) were connected with the differences in functioning between the children (especially in the areas of aggressiveness and progress at school). In the case of the fathers it were the differences in the non-socio-emotional area which were connected with the differences between the children (especially in the area of withdrawal and progress at school).

The differences in the degree of negative treatment which the epileptic and control children received from their peers were a sort of link between what happened within the family and outside. Epileptic children were treated more negatively than other children. On the one hand these differences partly stemmed from the fact that more behavioural restrictions were imposed on the epileptic children than on other children. On the other hand, the interpretation suggested that these restrictions led epileptic children to a more withdrawn pattern of behaviour than other children. This extra negative treatment, whether or not by way of the greater degree of withdrawal, also led the epilepsy mothers to react more negatively and strongly, in particular in a socio-emotional way. It especially led the epilepsy fathers to adopt a more pessimistic view of their children's prospects (in comparison with the control mothers and fathers respectively). And, as indicated above, these differences may in their turn lead to differences in other areas of the children's functioning.
The main results of the investigation have been summarized in Chapter 10. The general conclusion was drawn that not only the epileptic child, but also its family are the 'patient'. On that basis the suggestion has been made that, in addition to providing the child suffering from epilepsy with adequate medical treatment, it may also be desirable to give mental and social support to both the child and its mother and father. General practitioners and/or specialists ought to be alert to such problems and should attempt to create a situation where they may freely be discussed. In case no solution of the problems identified may be found, referral to more specialized establishments for medical and/or social aid should be considered.

The advice was given to parents and doctors to make sure that the child was raised in as normal a way as possible, to reduce the number of behavioural restrictions imposed upon the child and to encourage membership of clubs in order to prevent social isolation and/or lower school results of the child with epilepsy. In this respect it is also desirable for parents and teachers to have frequent contacts.

It is considered important that the Federatie en Vereniging voor Epilepsiebestrijding (Federation and/or Association against Epilepsy) pursue an active policy of providing information on this problem, not only in the media, but also in the classroom, by having the school doctor provide information sheets and explain the information to the pupils and teachers.