The Turkish Journal of Pediatrics 28.47 - 53, 1986

THE PROBLEMS IMPOSED ON THE FAMILY BY THE NEPHROTIC CHILD*

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Key words : chronic disease, family education, idiopathic nephrotic syndrome, intra-familial problems

It is well known that chronic diseases lead to various changes in patients' personalities and interpersonal relations. While adults demonstrate adaptational problems which may even amount to depression, children with chronic diseases are observed to develop a variety of behavioral disturbances[1].

Moreover a sick child who requires long term treatment may well cause a disturbance of the equilibrium of parent-child interactions. The parents' reactions toward illness and the changes which take place in their attitude toward the healthy siblings, constitute the main effects of the illness at the emotional level. On the other hand the familial interactions and relations with the social environment may undergo drastic changes after the onset of illness. This especially holds true for the child who is taken out of his natural environment of work and play, while the parents may well sacrifice their relationship with one another, with the other children or with their social group, for the sake of the sick child on whom their attention is concentrated. On the economic level, the treatment expenses may exhaust the family's income and cause an alteration in its living conditions[2,3].

The parents knowledge and understanding of the disease, may well affect the way they handle their problems. Insufficient information may lead to both unnecessary feelings of guilt or self reproach and to faulty treatment procedures. The family with a chronically ill child has three main expectancies with regard to the physician[4]:

a) Diagnosis
b) Effective therapeutic devices
c) A meaningful explanation of possible outcomes.

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The physician who can meet these demands has a good chance of establishing the grounds for trust and understanding between himself and the patient's family. Such a positive relationship is far more likely to enable him to handle certain problems of the family which are only indirectly related to the illness.

The following are some of these problems and needs:

— The shock of acquiring knowledge about the disease,

— Demands for knowledge, even for promises about the effectiveness of the treatment,

— The difficulty of explaining the events of remission and relapse,

— The parents' adverse behavior related to the emotional and practical restraints put upon them (e.g handling the child badly or making treatment difficult).

Vance et al[5] observed 79 families where there was a child with a steroid-respondent nephrotic syndrome who suffered a relapse, and control families where there was no such illness. They started out with the hypothesis that the former would have significantly greater psycho-social problems than the latter, but the study did not establish any striking differences between the two groups; the conclusion, however, was that families with a nephrotic child had in certain respects a greater vulnerability. It was noted that the families did not talk about their problems openly, but the results of the psychological tests used in the study gave hints as to these problems. In our clinic also a study was conducted on the parents of children with the nephrotic syndrome which was steroid-respondent. Alone, the absence of a sick child in the family does not outrole other possible problems, hence a control group was not considered necessary in this instance. Rather, the aim of the study was to document the problems peculiar to this particular group of patients.

This study was carried out with two purposes in mind, one was the re-education of the parents about the disease and the other was to establish the effects of the disease and the steroid treatment on the family's emotional, interactional and economic structure.

Material and Methods

The instrument of the study was an interview form that consisted of 26 open ended questions. These questions were mainly concerned with the history of the illness and the parents' knowledge about its nature and its origins, the impact of the illness upon the economic, emotional and interactional status of the family and its effects on the behavior of the sick and the healthy siblings. The total number of subjects was 56. Of these 40 had had one or more relapse and were considered the "first group". The remaining 16 had been under treatment for less than 6

months and had so far experienced no relapse. They constituted the "second group".

The respondents of the interview were mainly the mothers. Although the aim of the project had been to direct the same questions to both parents separately, only 30 per cent of the fathers were willing to respond.

The mothers' ages ranged from 21 to 48 years, the mean being 29 and the mode being 30. The fathers' ages ranged from 23 to 49, the mean being 33 and the mode being 31.

As to the parents' educational and occupational status, they were generally lower-middle class as the data in Tables I-III show.

TABLE I

Educational Status of the Parents

	Mothers (%)	Fathers (%)
No education	32	9
Primary education	45	52
Secondary education	20	20
Higher education	3	19

TABLE II

Occupational Status of the Mothers

	(%)
Housewives	82
Teachers / State employees	12
Others (farm workers, workers)	6

TABLE III

Occupational Status of the Fathers

	(%)
Workers	29
Teachers / State employees	24
Officers	3
Tradesmen	18
Arts and crafts	23
Unemployed	3

All interviews were conducted by the same interviewer and no alteration was made in the sequence of the questions; but, so that an air of free interaction could be maintained and the parents feel free to relate whatever they had in mind, no questionnaire was used.

After the completion of an interview, the parents were given advice on the practical problems of the treatment procedure, but the medical details were not elaboratked on and the answers given to the parents' questions about the nature of the disease were kept standard. The responses were taken down word for word and the contents of each interview were analysed by the interviewer herself. The categorization of the responses depended upon the formulation of the questions. Some were categorized simply as "yes" or "no" (e.g. questions 15, 25, 26). Some were analyzed with respect to the frequency of the expressions of emotion (e.g. questions 7, 8, 13), whereas others were analyzed with respect to the frequency of certain behavioral and/or situational changes related by the respondents (e.g. questions 9 and 10, and questions 16 to 24).

Interview Questions :

1. Would you briefly tell me the history of your child's illness? Do you remember when and how the illness first manifested itself? Which persons and/or institutions did you consult before applying to our unit?
2. How would you evaluate your child's present state of health?
3. What are your impressions about your residence in our unit?
4. To what extent did you adapt to hospital residence?
5. Would you tell me whatever you know about your child's illness? Whom did you get this information from?
6. Do you have any idea about why your child has acquired this disease?
7. Have you ever held yourself responsible for your child's illness?
8. Did you ever wonder whether your husband/wife might be responsible for your child's illness?
9. Would you briefly tell me in what manner your child's illness has affected your family life?
10. What was the impact of the illness on your family budget? Did you need extra resources?
11. Who is the one to take the major responsibilty for the treatment of your child, your husband/wife or you?

12. Has your relationship with your other children been altered by the illness of this one? Would you say they were neglected in any sense?
13. Have you ever had any apprehension that your child's illness might be fatal?
14. Would you evaluate your marital relationship after your child's illness as strengthened, unaffected or more problematic?
15. Is the ill child a source of quarrels between your husband/wife and yourself?
16. Has the illness altered the behavioral characteristics of your child? If so in what manner?
17. Has this child's illness altered the behavioral characteristics of the siblings? If so in what manner?
18. Do you feel that the siblings are jealous of the ill child because he/she is receiving special attention?
19. Do you feel that the ill child is jealous of the healthy siblings?
20. Have you felt that your healthy children are trying to attract your attention?
21. Do your healthy children ever manifest spontaneous fever, vomiting, abdominal pain or headache?
22. Do you observe fears, negative attitudes or behavioral disturbances in your healthy children?
23. Do you observe in the siblings any instances of withdrawal from, or extreme attachment to, the ill child?
24. Do you ever have an impression that your ill child might be attempting to exploit his situation?
25. Have you ever sought the help or advice of someone in religion over this illness? Have you ever had your child prayed for? Have you ever bought "muska"* or "nazarlık"* for your child?
26. Is your child allowed to take salt in his meals? Does your child receive the same freedom to engage in sports and play as his siblings and friends do?

Results

Our findings mainly relate to the parents' knowledge of, emotions about, and reactions to, the illness, and to the effects of the illness on their lives and the behavioral of the sick children and their healthy siblings. It was observed that only 12% of the parents had adequate information about the disease and its treatment.

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* Charms to protect one from evil or misfortune.

The conclusion was that most parents had not comprehended the explanations that had been given to them after the diagnosis had been made. It was learned that 20% of parents considered themselves responsible for the child's disease, while 7% reproached their husbands/wives and 8% put the blame on close relatives, on the evil eye, "black magic" or previous illnesses. These faulty interpretations demonstrate the importance of family education.

When asked if the illness had had a profound effect on their lives, 78% of the parents said that it had. The most dramatic effects seemed to have been experienced at the emotional level: the parents told about the constant fear and sorrow they had to put up with and the limitations that the illness imposed on their lives. Moreover, 66% of the parents disclosed that they were expecting their children to die at any moment.

The findings indicate that about 50% of the first group of parents and 25% of the second group experienced changes in their private relationships with their husbands/wives. These changes were totally related to the illness which caused quarrels, mutual accusations and in some cases an almost complete break of intimacy.

The seemingly most dramatic problems within the framework of feelings and interactions, however, were those of the children; 50% of the parents explained that their healthy children had also developed problems following the onset of the illness of their sibling.

These problems may be grouped as deficiencies in care-taking and general health as well as behavioral disturbances. Among the behavioral disturbances, jealousy, somatic complaints for which no causes could be found and school problems were prevalent. In the first group 80% and in the second group 60% of the children were described by their parents as aggressive, nervous, irritable and stubborn; and, in contrast to our expectations, these behavioral disturbances persisted even long after the treatment had been terminated. This persistence may be related to the parent's exaggerated tolerance toward the ill child, who readily exploits the anxiety of his family. But to a certain extent, it also seems to be a product of the ill child's resentment of the limitations of his life. About 25% of our subjects disclosed mistaken approaches to the treatment. These were mainly consultations with religious figures and unnecessary or inadequate dietary or behavioral limitations imposed on the child. A final point worth mentioning is that 55% of the parents had various complaints about their child's stay in hospital. The main cause of concern seemed to be the deaths they had seen occur on the ward.

Discussion

All the findings outlined above may be discussed with reference to the importance of family enducation and social work especially in cases where there

is relapse and when long-term treatment is required. The families' education about the disease and its treatment, and their guidance so that they can face their emotional and practical problems, constitute a task to demanding to be incorporated into the routine work of the physician. A well-organized social service could undertake to assist the families to overcome problems of adaptation both in the hospital and at home. This could be important in correcting a mistaken approach to the illness and its treatment and in preventing unnecessary emotional distress on the part of the parents. The pediatrician's contribution to the family welfare (especially in the absense of a social service) may be as follows:

— The family of the chronically ill child should be offered a little more of the physician's time than is usual, to ensure that the information given about the illness is properly understood and accepted;

— The physician should be sensitive to the emotional problems of the parents because these may well disturb the effective application of therapeutic measures;

— As soon as the diagnosis is established the physician should prepare the parents for the probable effects on the behavior of the child.

Summary

The conduct of interviews with the parents of 56 children with a steroid-respondent nephrotic syndrome are described and the outcome discussed. Certain recommendations are made; the need to give more education to the families concerned is stressed as are the benefits to be gained from the help of a well-organized social-service program.

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