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Chronic Childhood Illness: Family Stress in Cystic Fibrosis

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ABSTRACT

The presence of a chronic and life-threatening illness such as cystic fibrosis has a profound effect on the family. On the one hand the daily stress affects individual family members, the entire family unit, including their responses and coping patterns. On the other hand the coping variables are psychological factors which are decisive in determining how stressors are perceived and how they determine individual and family behavior.

The aim of this paper[1] is to investigate the psychological consequences of the child's illness on mothers in comparison to fathers. In order to achieve this goal, the following issues have been analyzed:

1. The responses to CF diagnosis and sense of burden which reflects the extent of parents stress.

2. Coping strategies according to McCubbin's approach with special focus on the social support system as the coping resource and on the value system as a set of goals important for decreasing the stress.

30 couples, parents of CF children have been examined. The results show that fathers had been much more burdened by the child's disease than the mothers and need much more professional assistance. It is important, since chronically ill children learn coping strategies from other family members, the quality of intrafamilial coping is a critical component of the child's ability to negotiate the stressful demands of disease-related consequences, his ability to socialize with healthy peers, and to function effectively later in life.

INTRODUCTION

Cystic fibrosis (CF) is the most common genetic disease in the white population, inherited from both sides of the family (autosomal-recessive). CF is a multiple-system chronic disease usually manifested in infancy or early childhood, with owerhelming clinical manifestation (recurrent respiratory infections, malnutrition). Progressive deterioration of lung functions is the most severe problem, and premature death is

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usually due to respiratory failure. Effective management on a daily basis consists of complex regimens (very demanding, time-consuming, and expensive) which impose a heavy burden on parents. Cystic fibrosis is at present incurable, with the child in constant danger of death.

There is a sufficient body of literature to suggest that presence of a chronic and life-threatening illness such as cystic fibrosis (CF) has a profound effect on the family members (Kornas-Biela, 1987–88, 1988b, 1989). This effect depends on the type of illness — research indicates that each clinical group exhibited different patterns of stressful response, consistent with the nature of the child's illnesses and the requirements for care imposed on the families (Holroyd & Guthrie, 1986; Bouma & Schweitzer, 1990; Goldberg, Morris, Simmons, Fowler & Levison, 1990). Families in which the child with CF was not the firstborn were found to be functioning more healthily than those in which the child was the firstborn (Hahnemann, 1985). Parents who have confronted the CF diagnosis go on to minimize the normal stresses of the developmental period (Cowen, Corey, Keenan, Simmons, Arndt & Levison, 1985), but the daily stress connected with the child's disease still affects individual family members (siblings: Jochmus & Stolz 1976; Cowen, Corey, Keenan, Simmons, Arndt & Levison, 1985; Cowen, Mok, Corey, MacMillan, Simmons & Levison, 1986; Thibodeau, 1988), the entire family unit (Kalnins, 1983) and also influences family responses and coping patterns (Venters, 1981; Phillips, Bohhanon, Gayton & Friedman, 1985; Möllering, 1986). On the other hand, the coping variables (cognitive, emotional, behavioral) are psychological factors which are decisive of how stressors are perceived and how they determine individual and family responses. Since chronically ill children learn coping strategies from their relationship with other family members, the quality of intra-familial communication and coping is a critical component of the child's ability to negotiate the stressful demands of the disease, his ability to socialize with healthy peers, and to function effectively in school and later at work (Drotar, Crawford & Bush, 1984; Goldberg & Simmons, 1988). The way in which the fam ily functions has also indirect effects on critical indices (height, weight, pulmonary functioning) of a CF child's health (Patterson, McCubbin & Warwick, 1990) and on compliance (Patterson, 1985).

THE AIM OF THE STUDY

The aim of this research is to investigate some of the psychological effects that the awareness of a high genetic risk and the illness of child have on mothers in comparison to the consequences which the same factors exert on fathers (cf. Cowen, Corey, Keenan, Simmons, Arndt & Levison, 1985; Goldberg, Morris, Simmons, Fowler & Levison, 1990).

In order to achieve this goal, the following issues have been analyzed:

1. The reactions of parents to CF diagnosis and sense of burden which reflects the extent of parents stress.

2. Coping strategies according to McCubbin's (1983) approach with special focus on social support as coping resource, and on value systems as a set of goals important for decreasing the stress.

SUBJECTS

Thirty parent couples have been examined: 30 mothers (Mo) and 30 fathers (Fa). The parents have formerly received genetic counseling in the Genetic Outpatient Department at the National Institute of the Mother and Child in Warszawa. The parents had at least one fibrocystic child. The parents were middle-aged (Mo = 36, Fa = 38.5 years), lived mostly in cities (large cities = 60%, small cities = 30%, villages = 10%). Almost half of the working women (43%) and one fifth of the men (23%) were professionals, the other half had various types of manual jobs (Mo = 43%, Fa = 46%) or were craftsmen (Mo = 14%, Fa = 31%). No significant differences existed with respect to their level of education (primary: Mo = 33%, Fa = 30%; secondary: Mo = 33%, Fa = 33%; and higher: Mo = 26%, Fa = 30%), income and housing (53% Mo and 60% Fa self assess of economical situation as average). Almost half of the families have only one child (46%), one third have 2 children (33%), and only 13% families have 3 children. Forty percent of the families had already experienced a death of the child, 12% of the women have had miscarriages, and 33% had abortion. Forty percent of the mothers and 23% of the fathers assessed themselves as believers who regularly went to church, while 53% of the parents were believers who went irregularly.

METHODS

The following methods have been employed in the research:

1. The Open-Ended Personal and Illness Orientation Questionnaire which measured some personal data and the responses of the parents to CF diagnosis and the sense of burden resulting from the illness of the child.
2. The Social Support Scale and The Scale of Values that were composed by the author of this report.
3. The Coping Health Inventory for Parents by McCubbin (1983).

RESULTS

The Responses to CF Diagnosis

It is generally traumatic when a parent is first confronted with the fact that his/her child has been diagnosed with cystic fibrosis. The first reaction is generally dysfunctional:

A. Dysfunctional responses — 100% of the parents in my survey verbalized different kinds of negative responses: shock — 33%, depression — 21% (cf. Möllering, 1986; Walker, Ford & Donald, 1987), anxiety — 19% (cf. Yarcheski, 1988), resignation — 12%, annoying — 12% (Möllering, 1986), and grief — 3%.

B. Functional responses — The first reaction to the diagnosis in 10% of the parents was also a stimulus to cope with the CF.

Psychosocial stress connected with the illness does not lead to specific psychopathological disturbances, but with additional intra- or extra-familial stress, patients and family members are more vulnerable to psychoreactive disorders (Frey, 1992).

It was also shown that certain periods in the child's life and perceived increases in illness severity were associated with increased

maternal distress. The mother's subjective rating of the child's illness severity is a better indicator of her reported stress than is the clinical rating (Walker, Ford & Donald, 1987). Parents psychological functioning is influenced by the patients' physical parameters (Cowen, Mok, Corey, MacMillan, Simmons & Levison, 1986). A decline in the child's pulmonary functioning is also associated with a pile-up of the family's life changes, especially in the areas of: family development and relationships, family management and decisions, and family finances (Patterson, McCubbin & Hamilton, 1983). The impact of hospitalization upon parents is the most prevalent "major problem" (Phillipe, Bohannon, Gayton & Friedman, 1985).

The Sense of Burden

Several studies have concentrated on the effect of CF children on the emotional life of families. Since disease adds pressure to parents and siblings, a serious communication breakdown is often experienced (Baum, 1975). Families with CF child are forced to adjust to a new set of psychological realities including a high level of uncertainty.

Our findings confirm the results of the earlier research that the sense of burden on the part of the mother is significantly greater compared to that of the fathers (Leonard, Chase & Childs, 1972; Evers-Kiebooms, 1987). The means are higher and manifested in the following statistically distinctive ways:
— less leisure time: Chi Kruskal-Wallis = 11.08, p = 0.001 (cf. Turk, 1967);
— less care about their own health: Chi = 11.08, p = 0.001 (cf. Allan, Townley & Phelan, 1974; Holroyd, 1974);
— less (few) opportunities for pursuing the professional careers: Chi = 9.15, p = 0.01 (Meyerowitz & Kaplan, 1967; Cowen, Corey, Keenan, Simmons, Arndt & Levison, 1985). Mothers of CF child have most often feel pressured to give up their education or their professional career (Michalsen, Folleras, Bentsen & Heiberg, 1988);
— decrease in their aspirations in life: Chi = 6.65, p = 0.01 (cf. Holroyd, 1974);
— changes in reproductive plans: Chi = 3.92, p = 0.05 (cf. Meyerowitz & Kaplan, 1967; Jochmus & Stolz, 1976; Evers-Kiebooms, Denayer, Cassiman & Van Den Berghe, 1988; Pritchard, 1988);
— lower satisfaction in sexual contacts with their married partner: Chi = 3.92, p = 0.05 (cf. Turk, 1964, Lawler, 1966; Phillipe, Bohannon, Gayton & Friedman, 1985).

How much time parents have available was also related to their attitudes towards aborting a genetically ill fetus. If the parents are more involved in their professional career, they are more accepting of the selective abortion solution (Mo: r = 0.38, p = 0.05; Fa: r = 0.34, p = 0.05). And in turn, women are more accepting of that solution when they have more leisure time activities and hobbies (r = −0.44, p = 0.05). Presumably the care of a chronically ill child would place more of a burden on the lives of these parents.

Jochmus and Stolz (1976) report follow-up of 15 families with cystic fibrosis child. Most families accepted the problem and tried to provide as much help as possible for the child, although they perceived the child's problem as an ever-present burden. Other families tried to live as before, hiding the condition and providing less care. The parents often experienced a decreased en-

joyment of life and a decrease of social contacts: their marriages often suffered.

The System of Values

In general, both men and women seem to share very much the same system of values. They aspire to have: healthy children, harmony in family life, and an acceptable standard of living. They are not particularly ready to help other people, although they welcome the help given to them. It would therefore be the task of social support groups to develop in the parents a better understanding of the need to help others who have found themselves in the same situation.

The statistically significant differences were found only for religious values which were more important for women than for men (especially "life according to religious–moral norms"). Men on the other hand, value friendship more and the possibility of pursuing their own interests as well as furthering their education.

The strong strivings for such goals in males as: "a pleasant and comfortable life" ($r = 0.50$, $p = 0.01$) and "a high standard of living" ($r = 0.50$, $p = 0.01$) were related to more positive attitude towards selective abortion. Striving towards religious values such as: "salvation" ($r = -0.41$, $p = 0.05$), and "a life, lived according to moral-religious norms" ($r = -0.46$, $p = 0.05$) were negatively related towards selective abortion attitudes. For women there was only the negative correlation concerning religious "salvation" ($r = 0.35$, $p = 0.05$). Moreover, there was a relation between the men's acceptance of selective abortion and their spouses' system of values. For instance — the women for whom the most important values were their self-realization and development of their knowledge and interests ($r = 0.37$, $p = 0.05$), who value higher than others harmony in family life ($r = 0.49$, $p = 0.01$) have partners who accept selective abortion with stronger convictions.

The Social Support

Generally, the mothers were more eager to seek social support than were the fathers. Mothers' need for social contacts drives them to seek such contacts in which they get emotional support. (cf. Schilling, Schinke & Kirkham, 1985). They are trustful, open, and sometimes even naively believe in the good will and uprightness of others (Kornas-Biela, 1988a). In the Social Support Scale the mothers listed a greater number of people who provide them with "coping assistance" and showed greater sense of social support than the fathers, especially:
— in daily life stressors ($Chi = 4.56$, $p = 0.05$);
— in expressing one's most intimate and personal feelings ($Chi = 3.33$, $p = 0.05$).

I found that, the greatest satisfaction is received from social support when more people are involved in giving such support and the closer they may be to the subject. Previous research data support the inclusion of social support variables in the stressor-illness model. Social support has significant effects on health (psychiatric symptoms) and well-being of parents (Frydman, 1981).

Coping Strategies

The findings of many research indicate that patients with CF and their families are subject

to major stresses, yet many manage to function without observable dysfunction (de Wet & Cywes, 1984). Many of them enhanced and developed coping mechanism in order to prevent possible dysfunction (Butler, 1984; Creed, 1985; Pinkerton, 1985; Gibson, 1986, 1988; Levison, Garner, MacMillan & Cowen, 1987; Stullenbarger, Norris, Edgil & Proser, 1987). It must be mentioned that family resources and family coping mechanism are important predictors of a child's health status (Patterson, McCubbin & Warwick, 1990) and compliance. Joint parental coping to maintain integration, cooperation, and optimism led to higher compliance (Patterson, 1985).

Generally, there are no differences between coping strategies used by mothers and fathers. The results show that the most important matters to both parents are: confidence in mutual assistance ("trusting my spouse to help support me and my children" — Means: Me = 3.83, Me = 3.91), optimistic outlook at the health prospects of the child ("believing that my child will get better" — Me = 3.77, Me = 3.70), and active participation in the development of the child's independence ("encouraging child with medical condition to be more independent" — Me = 3.53, Me = 3.57)

Some gender-dependent differences in coping strategies were observed. Mothers used more coping strategies than fathers. In 62% of the items the mothers average measurement were higher than fathers. The strategies which were particularly more helpful for mothers were the following (cf. Venters, 1981):

— imparting a meaning to the illness. With regard to the meaning strategy, the mothers report that it is helpful for them to:

a) focus on the most positive aspects of the situation (cf. Bentsen, Michalsen & Folleras, 1988 — indicated that the parents tend to judge their child's condition as less severe than the professionals. The difference of opinion was greatest in the group of seriously affected children). This optimism gives mothers more confidence in the present and hope for the future (Chi = 4.19; df = 1; p = 0.05);

b) belief in God — helps them to define the meaning of stressful events surrounding the child's illness, especially a better understanding for the suffering and the eventual death of the child. They draw on the Almighty for hope and security (Chi = 4.16; df = 1; p = 0.05). As research demonstrate praying is the most often coping strategies most often used by parents of chronically ill children (Hymovich & Baker, 1985).

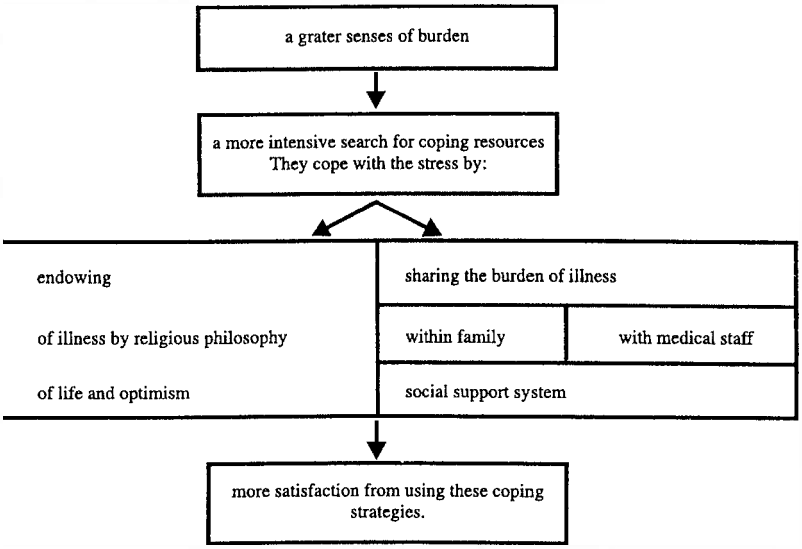
— sharing the burden of the illness, consists in applying the following two patterns of behaviour:

a) strengthening togetherness and maintaince of mutual help and empathy between family members. The commitment to a harmonious life of the family gives satisfaction to the mothers, who obtain in this way social support from their family (Chi = 4.19; df = 1, p = 0.05);

— sharing the burdens of the illness by expressing their anxieties to competent persons. The mothers have a personal sense of how much help can come from others and place a great deal of value on all contacts with the trained medical personnel (Chi = 4.82; df = 1; p = 0.05). They want opportunities to discuss the state of health and the emotional development of the child and dietary issues (Andersson-Segesten & Plos, 1989).

Figure 1. General conclusions

In comparison with fathers, mothers demonstrate:



CONCLUSIONS

Cystic fibrosis is a disease that has profound consequences on the family unit. It influences every aspect of family life, including time constraints, finances, and relationships among family members. Early intervention should be initiated before the family is in a crises. The family must live with CF on a daily basis for the remainder of the child's life; therefore, it must be able to function at its optimum level. It is the medical and psychological personnel's responsibility to be able to recognize and assist the family in need (Reed, 1990). The importance of counseling and the possibility of preventive work and distribution of information must be underscored, with awareness of the caregiver for gender-related, and age-independent and age-specific problems (Jedlicka-Kohler & Gotz, 1989). There should be organized individual counseling and social support group, concentrated on psychological and familial problems, and on communication between patient, parents, and personnel (cf. Bywater, 1984). Adequate family adjustment depends among others things on the physician's having the medical expertise to manage this complex multisystem illness and the ability to make the medical knowledge comprehensible to patient and family members (Levison, Garner, MacMillan & Cowen, 1987).

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