

HOW PARENTS COPE WITH A CHILD WITH CYSTIC FIBROSIS

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A major problem confronting the health-care system today is the effect of chronic illness on the family (MacVicar & Archibold, 1976). If the family member with the chronic illness is a child, the impact is enormous when superimposed on the complex dynamics of the family in general (Zamerowski, 1982). The most critical influences on the adaptation of the family to the illness as well as on the growth and development of all its members are the responses of the parents. Therefore, an understanding of the parents' responses to chronic illness in their child is vital.

The case of cystic fibrosis (CF) in a child was chosen to demonstrate the impact of chronic illness on the family. Although sound medical treatment is necessary for management of this disease, the successful care of a CF child depends upon the parents' willingness to modify family life in response to a complex, time-consuming regimen of daily therapy (McCubbin et al., 1983).

Review of the Literature

Previous research studies related to the psychological aspects of CF have generally focused on maladaptation and the dysfunctional aspects of family coping (Lawler, Nakielny, & Wright, 1966; Meyerowitz & Kaplan, 1967; Tropauer, Franz, & Dilgard, 1970; Turk, 1964). Gayton, Friedman, Tavormina, and Tucker (1977) note the dearth of literature on coping with CF and suggest that future research would benefit from a focus on the strengths and resilience of children with CF and their families. As well, Tavormina, Boll, Dunn, Luscomb, and Taylor (1981) point out that parental and family functioning with physically ill or handicapped children have rarely been evaluated.

Only one study was found that identified parental coping behaviours that facilitated family adaptation to CF in a child. Venters' (1981) study revealed two coping strategies that minimized the illness-related hardships: familial sharing of the burdens created by the disease, and endowing the illness with a

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personally significant meaning. Tavormina *et al.*'s (1981) study of coping strategies employed by parents of children with asthma, CF, diabetes, and a hearing impairment used a battery of measures to sample areas of personality functioning, parental attitudes, and parental reports of problems with the child's behaviour. Although findings suggested that the sample was essentially a normal group, coping strategies were not identified and one cannot assume that the normative scores on the study's instruments are synonymous with positive coping strategies. Lewis and Khaw (1982) found that healthy adjustment in the CF child was more dependent upon family functioning than on the presence of disease. However, the coping behaviours of mothers – and the perspectives of the fathers – in contributing to family functioning were not explored. Because of the dearth of literature on how parents cope to meet the demands on the family unit associated with having a child with CF, further study was indicated.

Research Questions

Adaptations of Lazarus and Launier's (1978) cognitive-phenomenological theory of stress and coping and Moos and Tsu's (1977) theory of the crisis of physical illness constituted the conceptual framework that guided the study. In this paper the following questions are addressed:

1. What is the parent's appraisal of coping with a child with CF?
2. What are the reported parental coping behaviours used and found most helpful in coping with a child with CF?
3. What is the relationship between selected family characteristics and parental coping behaviours?

Method

The sample

The convenience sample consisted of 56 parents whose children were diagnosed with CF and aged 10 years or under. The upper age limit of 10 years was selected to avoid the effects of confounding variables related to the developmental stage of adolescence on family relationships. A convenience sample was used because institution policies required that potential subjects be selected and approached by a clinic nurse. Consequently, 25 percent of the potential population was excluded from the study. Therefore, the findings are restricted to the study population.

Procedures and instruments

Parents were approached in the clinic waiting room of a metropolitan children's hospital at the time of their child's routinely scheduled clinic appointment. All of the parents who were approached were willing to

participate in the study. Following an explanation of the research protocol as well as subject rights, the parents provided written consent. Then, they completed a series of questionnaires, which included the following, in order of administration:

The Family Profile was a questionnaire designed to obtain demographic information on the parents, family situation, and child with CF.

The Parent's Perception of Coping (PPC) was a 100 mm. linear analogue that measured the parent's evaluation of his coping efforts. One end of the analogue represented "not coping" while the other end represented "coping very well." This instrument was adapted from Brailey's (personal communication, February 23, 1983) study of coping strategies used by mothers of preschool children. Not only was the wording of Brailey's question modified for this study, but also the format of the response was changed from a closed-ended Likert-scaled response to a linear analogue in order to achieve a higher level of measurement for data analysis. In Brailey's study, the test-retest reliability of the overall instrument was .78.

The Parent's Perception of the Most Difficult and Helpful Factors of Coping with a Child with CF (PPMDHF) questionnaire consisted of three open-ended questions: (a) what has been the most difficult thing for you in having a child with CF? (b) what has helped you most in managing the illness in your child?, and (c) what would be helpful to you in managing the illness in your child? To analyse the data elicited by these questions, the responses were coded at a nominal level of measurement. A categorization scheme was, then, formulated by the investigator so that the categories were mutually exclusive and collectively exhaustive (Polit & Hungler, 1978, p. 310). Two nurses who were experienced in the parent-child nursing field also independently categorized the data using the same coding scheme. The overall index of interrater reliability achieved was .95. Those items that did not attain consensus were discussed between the raters, individually, and categorized once agreement had been reached. Both the PPC and the PPMDHF operationalized the parent's appraisal of coping (Research Question #1)

The Coping-Health Inventory for Parents (CHIP) was a 45-item questionnaire developed by McCubbin, McCubbin, Nevin, and Cauble (1981) that rated as "extremely helpful" to "not helpful", using a four-point Likert scale, the parents' perceptions of their coping behaviours when they have a chronically ill child. The items were categorized into three coping patterns (CP): (a) CPI – maintaining family integration, cooperation, and an optimistic definition of the situation; (b) CPII – maintaining social support, self-esteem and psychological stability; and (c) CPIII – understanding the medical situation through communication with other parents and

consultation with medical staff. The internal consistency reliabilities for each coping pattern, respectively, using Cronbach's alpha were (a) .79, (b) .79, and (c) .71.

Results

The Statistical Analysis System (Freund & Littell, 1981) was used for descriptive and inferential statistics. Both parametric (Pearson r) and non-parametric (Kendall's Tau) tests were used depending on the level and distribution of the data. The Point Biserial Correlation Coefficient (r_{pbi}) was used to measure the degree of association between two variables when one variable was continuous and the other was dichotomous (Roscoe, 1975, p. 113).

A total of 56 parents (46 mothers and 10 fathers) participated in the study, representing 53 families with 56 children with CF. The mean age of the parents was 32 years ($SD=5.5$) while the ages of the children ranged from 11 months to 10.75 years with a mean of 5.75 years ($SD=3.2$ years). In less than one-third of the families, the affected child was the only child ($n=16$). Selected characteristics of the sample are noteworthy. The parents were well educated – 71 percent had at least a high school education. The level of family income was favourable – 71 percent reported an income greater than \$20,000. The marital status of the parents was remarkably stable – 91 percent were married or living in a couple relationship and only 14 percent had experienced a change in marital status. The majority of children (83.5 percent) had CF in a mild stage and the majority of children were diagnosed at a young age (56.5 percent were diagnosed before six months of age). Such characteristics may not be representative of all families with a CF child.

Parent's appraisal of coping

Parent's perception of coping. An analysis of the scores from the 100 mm. linear analogue suggested that the majority of parents perceived themselves as coping very well. Over 75 percent of the parents placed an "X" beyond the 75 mm. mark. The mean score was 84.6 ($SD=12.57$); the median was 90. The scores ranged from 45 to 100.

Parent's perceptions of the most difficult and helpful factors of coping with a child with CF. Factors ($N=64$) the parents perceived as being most helpful in managing the illness in their child fell into three discrete categories: (a) social support (59%) – which was broadly defined as the resources provided by other persons (Cohen & Syme, 1985); (b) an ability to focus on the positive aspects of the situation (25%) and (c) internal strengths (16%). (Some parents cited several factors; therefore the frequencies refer to the number of factors identified by the parent, and not the number of parents.)

Although the factors ($N=64$) the parents perceived as being most difficult in managing the illness in their child fell into only two categories, the coding was complex because several themes and sub-themes emerged that were frequently interrelated. Both categories clearly related to the disease – (a) difficulty accepting/adjusting to the changes caused by the disease (56%) and (b) problems with carrying out the prescribed regimens and the management of problems attendant on carrying out the regimens (44%).

For the 29 parents (52%) who responded to the question that asked them to identify what would be helpful to them in managing the illness in their child, the responses ($N=33$) fell into four categories. These included: (a) social support (37%) – continued support from the family, the clinic, or other parents of CF children; (b) relief (33%); (c) a cure (18%); and (d) modification or alterations in the treatment regimen (12%).

Parent's coping behaviours

Parental coping behaviours measured by CHIP were compared with data from a sample of 308 mothers and fathers of children with cystic fibrosis, myelomeningocele, or cerebral palsy (J. Patterson, personal communication, July 17, 1984). Results indicated that the means of the parents' scores for each coping pattern closely approximated the comparative means (see Table 1).

An item-by-item analysis of the coping behaviours in CHIP indicated that the majority of extremely helpful behaviours were represented in CPI, which focused on doing things as a family unit, strengthening family relationships, and maintaining a positive outlook on life (see Table 2). The behaviour identified as being most helpful was "Believing that my child is getting the best medical care possible." The second most frequently reported extremely helpful coping behaviour was "Being sure prescribed medical treatments for the child(ren) are carried out at home on a daily basis." This latter behaviour fell within Coping Pattern III which focused on understanding the medical aspects of care. The most frequently reported behaviour in Coping Pattern II, which focused on efforts directed toward self, was "Being able to get away from the home care tasks and responsibilities for some relief;" yet among coping behaviours reported as extremely helpful, it stood eleventh.

Significant relationships between the sex of the parent and Coping Patterns I and II were found that suggest that mothers directed more effort toward maintaining family integration ($r_{\text{pbi}} = -.27, p < .05$) and strengthening themselves $r_{\text{pbi}} = -.33, p < .01$) than fathers. As well, findings suggested that single parents made lesser efforts at maintaining family integration ($r_{\text{pbi}} = .28, p < .05$), that increased family size facilitated

mothers in making greater efforts toward strengthening themselves as individuals ($T = .28, p < .02$), and that mothers made greater efforts toward understanding the medical situation when the child was diagnosed at a younger age ($T = -.24, p < .03$).

Table 1

A Profile of Fathers' and Mothers' Coping Patterns in the Coping-Health Inventory for Parents (CHIP)

No. of Parents	Sample Mean (SD)	Comparative Mean	Sample Range	Comparative Range
Coping Pattern I Maintaining Family Integration, Cooperation, and an Optimistic Definition of the Situation				
Fathers 9	35.11(7.59)	36	24-46	16-56
Mothers 44	42.07(9.49)	40	15-55	25-55
Coping Pattern II Maintaining Social Support, Self-Esteem and Psychological Stability				
Fathers 9	21.33(11.60)	25	1-39	10-41
Mothers 44	30.34(09.21)	28	2-48	16-40
Coping Pattern III Understanding the Medical Situation Through Communication with Other Parents and Consultation with Medical Staff				
Fathers 9	13.67(05.85)	12	4-20	4-19
Mothers 44	16.34(04.93)	15	3-24	8-22

Note: $N=53$. One father and two mothers did not complete CHIP.

Table 2***Frequency of Coping Behaviours in CHIP Identified by Parents as Being Extremely Helpful***

Coping Behaviour	Coping Pattern	Frequency	%
Believing that my child is getting the best medical care possible.	I	41	76%
Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.	III	40	74%
Doing things with my child(ren)	I	38	70%
Having my child with the medical condition seen at the clinic/hospital on a regular basis.	I	36	67%
Doing things together as a family (involving all family members).	I	36	67%
Trusting my spouse (or former spouse) to help support me and my children	I	35	65%
Believing that the medical centre/hospital has my family's best interest in mind.	I	33	61%
Building a closer relationship with my spouse.	I	31	57%
Talking over personal feelings and concerns with my spouse.	I	31	57%
Talking with medical staff (nurses, social workers, etc.) when we visit the medical clinic.	III	30	56%
Being able to get away from the home care tasks and responsibilities for some relief.	II	28	52%

Note: $N=54$. Two parents (from the same family) did not complete this questionnaire.

Discussion

Parent's appraisal of coping

The parents in this study have provided insight into the challenges that a chronic illness, such as CF, in a child bring to them. As well, they have provided an indication of the resources that have enabled them to manage. Although the parents perceived themselves as coping very well, all the parents experienced a degree of illness-related stress. While they recognized that the treatment regimen was necessary for the child, many parents ($n=27$) acknowledged problems related to it. Parents reported feeling "tied down", not having enough time in the day to do all the things they would like to do, and feeling pressured to organize the child's treatment into the family routine. While the parents noted a need for respite from the child's care, they also were hesitant to leave their child. Two parents reported siblings did not understand the extra attention the CF child needed and, consequently, jealousy was another problem with which those parents had to contend. The daily treatment regimen – the medications, inhalation therapy, chest physiotherapy, and the dietary management – are constant reminders to the parents that their child has CF. The parents frankly acknowledged that aspects of the treatment regimen, acceptance of the diagnosis and the prognosis of CF, and living with the uncertainty of what the future may bring all imposed degrees of stress for them.

Nevertheless, the findings suggest that parents were able to maintain or develop functional thought and/or behavioural patterns to meet the illness-related hardships. An examination of the parents' external and internal resources provides insight into how parents cope with the demands of CF.

Social support. Social support was clearly the most frequently identified resource. Folkman, Schaeffer, and Lazarus (1979) have noted that social support serves as a source of emotional support and encouragement as well as information about a situation and how to deal with it. The bases of support for the parents were three-fold.

Parents ($n=22$) most frequently reported that the spouse or family was the source of support that was most helpful. The husband's support would appear to be an important factor in the mother's ability to cope with the many caregiving demands. This study would have been enriched if there had been more mother-father dyads to provide information on the coping behaviours of both parents and, perhaps, how they complement each other, and if the nature of the support given had been determined.

Another support system that 10 parents acknowledged was the services offered by the multidisciplinary CF clinic. Both mothers and fathers

benefited from communication with the clinic in terms of receiving, understanding, and mastering the medical information needed to care for the child. The role of the CF clinic as a source of support for the parents must be underscored since a healthy relationship between the health-care team and the parents promotes successful clinical and psychosocial management of CF. Furthermore, parents acknowledged that continued support from the clinic would be helpful. As others have pointed out, parents of chronically ill children need not only realistic professional support and assurance but also recognition of the extent of their responsibilities in caring for their child (Longo & Bond, 1984; Tavormina *et al.*, 1981).

A third source of support that a few parents ($n=6$) identified as being helpful was their association with the CF Foundation. Parents commented on the value of talking to people in the same situation "because they really understand what it is like". Shapiro (1983) summarizes the value of such support groups as (a) minimizing individual feelings of isolation and differences, (b) demonstrating universality of feelings, thereby diluting their intensity, (c) providing information, emotional expression, and support, and (d) encouraging the formation of friendships and participation in group activities. Gallagher, Beckman, and Cross (1983) have noted that the availability of adequate support for families of handicapped children appears to be an important mediator of stress. Although the majority of parents identified social support as being very helpful, the ability of the parents to accept the available support must not be overlooked. Pearlin and Schooler (1978) have indicated that the conditions under which help from others can be effective is not known.

Focusing on the positive aspects of the situation. Another factor which enabled the parents ($n=15$) to manage the illness in the child was their ability to focus on the positive aspects of the situation. Several categories of parents' responses revealed this ability as indicated by: a positive evaluation of the disease; the recognition of the treatment regimen as being most helpful; and the notation of positive attributes of both the family and the child. The parents appeared to recognize that the situation would be worse if the child was not diagnosed or if there was no treatment. Pearlin and Schooler (1978) would label this thought process "the making of positive comparisons" (p. 6). Furthermore, the notation of the positive attributes of the family and the child appears to enable the parents to draw on their own resources, to feel less overwhelmed, to have a higher morale, and to minimize the awareness of emotionally painful factors that otherwise could be overwhelming.

Strengths within the parent. To a lesser extent, the parents ($n=10$) recognized that their own deep-seated beliefs and attitudes facilitated their coping behaviours. Such personal strengths and other psychological

characteristics can be very helpful in sustaining people facing strains that arise from conditions over which they may have little direct control (Pearlin & Schooler, 1978). Moreover, Lazarus and Launier (1978) note that beliefs, attitudes, and personality characteristics contribute to or prevent certain kinds of stress from ever happening and therefore, influence the coping process. In addition, the parents' beliefs in a cure or miracle also provide hope and serve as encouragement to do one's best to deal with difficulties (Moos & Tsu, 1977; Venters, 1981).

Parent's coping behaviours

The greatest efforts of the parents would appear to be directed toward adhering to the treatment regimen and maintaining family stability. Parents' reported diligence in attending to the medical aspects of care reflects their efforts in controlling the progression of the illness. Such efforts in doing everything possible to contribute to the child's health are potent coping behaviours, since they serve to combat or counteract the threat of the child's condition worsening. These behaviours possibly also give parents a sense of control, in contrast with the feelings of helplessness that could be generated because of the fact that there is no cure for this disease. Parents may also perceive an acute awareness of their parenting role in contributing to the child's well-being which motivates them to adhere to the treatment regimen. Shapiro (1983) notes that a coping goal for parents, who have a chronically ill child, has been conceptualized as maintaining relationships with the child that afford some gratification and at the same time fulfill that child's physical and psychological needs. The parents in this study have clearly made great efforts toward caring for their child and have been rewarded for them.

Parents also made great efforts toward maintaining family stability. Joint family experiences and sharing thoughts and feelings with the spouse were behaviours that parents found particularly helpful in coping. Efforts directed toward the family unit, including the care of the CF child, would appear to surpass the parents' own individual needs. The positive feedback from efforts directed toward the family may have increased the parents' sense of well-being and reinforced their ability to manage the illness-related hardships, and hence, the ability to cope.

The relationship between sex of the parent and coping behaviours

Mothers put forth greater efforts than do fathers to maintain family togetherness and an optimistic outlook as well as to maintain social support, self-esteem, and psychological stability. Although the number of fathers in this study was small, the findings may suggest that either fathers' coping behaviours or their perceptions of coping are different from those of

the mothers. Three of the nine fathers that completed CHIP stated that the coping behaviours constituting CHIP were behaviours they used but not ones they used "to cope". Perhaps, mothers may view coping as daily ongoing efforts which have adaptive consequences whereas fathers may perceive coping as efforts to deal with stress when habitual responses fail. Thus, higher scores for mothers on CHIP may arise because CHIP measured the behaviours used on a day-to-day basis rather than behaviours mobilized in response to managing a particular stressor.

Nevertheless, it is possible that the findings reflect the fact that the mothers were, undoubtedly, the primary caretakers in most of these families and, hence, bore the responsibility for the child's care. Perhaps fathers do feel greater impact of the child's illness in terms of changes in their social lives and time spent with the spouse. Fathers may not experience the positive feedback associated with the caregiving role. Zamerowski (1982) has noted the difficulties fathers find in being fully involved in the child's care. Mothers may reach out and benefit from the support of their husbands while fathers, perhaps, may hesitate to seek emotional support from their wives. They may feel their wives are already overburdened with the responsibility of the child's care overriding other aspects of family life. Possibly, fathers do not care to talk about their feelings. Fathers may also have been experiencing other stressors besides CF, to which the questionnaires in this study were not sensitive. Cummings (1976) has reported that fathers of handicapped children feel intense stress, experience less gratifying relationships with their children, and feel inferior as parents. There is a dearth of literature on fathers' reactions to chronically ill children, and thus, further research in this area is indicated.

The relationship between number of children in the family and parent's coping behaviours

The presence of more than one child in the family tended to foster mothers' coping efforts toward gaining support, maintaining self-esteem, and developing psychological stability. Other researchers have noted that having more than one child has a positive effect on families with a handicapped child (Gallagher *et al.*, 1983; Steinhauer, Mushin, & Rae-Grant, 1974; Murphy, 1982). Healthy siblings may serve as a source of support and a balance for family life. Older siblings may help with the care of the CF child or other responsibilities in the home. In larger families, a healthy climate is likely because the hopes, dreams and burden of care are dispersed among several children (McKeever, 1983). The presence of healthy children may also reinforce the parents' perceptions of their abilities to have normal children which increases their self-esteem as parents.

Implications for Nursing

Findings from the study reinforce the importance of a family-centered approach to health care. Both mothers and fathers should be assessed in terms of how CF in their child has affected them. Parents of younger children, in particular, are in need of information and encouragement from the health care team. Parents should also be encouraged to plan for respite from the child's care. As well, they should be informed about the role of the CF Foundation and encouraged to become involved with the chapter in their community. Parents could also be helped by the acknowledgement of health care providers that the experience with CF is difficult and requires a great deal of their time and energy. They need some positive feedback for their coping efforts and the importance of their role in contributing to the overall health of the child.

Finally, each parent-child-family must be treated individually. Each family situation is unique and each family interprets and responds to the illness situation in its own way. Thus, nurses ought to assess not only the problems but also the parents' coping behaviours, and they should assist the parents to cope in ways that are functional for them. Successful coping should be evaluated in terms of the particular stressors and of the parents' abilities to use their internal and external resources.

Although specific areas for further research have been noted in the discussion, providing all subjects in the target population an equal opportunity to participate in a research study is imperative. The sample in this study was biased toward those parents who were perceived to be coping well and, consequently, would not be threatened by the questions in the questionnaires. In such a study of parental coping with any chronic illness in a child, the parent may not only contribute valuable information that could be useful in planning nursing interventions or in directing further research, but also may indirectly benefit from being given an opportunity to communicate his or her thoughts and feelings and, perhaps, gain further insight into the situation.

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RÉSUMÉ

Les modes d'adaptation des parents aux prises avec un enfant atteint de fibrose kystique

Le diagnostic d'une maladie chronique au long cours, telle que la fibrose kystique (FK), chez un enfant et le régime de soins accaparants dont il a besoin ont de nombreuses répercussions sur la famille. Parmi les influences critiques qui jouent sur l'adaptation de la famille à la maladie de même que sur la croissance et le développement de tous ses membres, mentionnons les réactions des parents. Cette étude avait pour principal objectif d'étudier comment les parents font face à la FK de leur enfant et à tous les problèmes qu'elle suscite. Un échantillon pratique de 56 parents dont les enfants étaient âgés de 10 ans ou moins, ont répondu à une série de questionnaires lors de la visite médicale de suivi de leur enfant.

Bien que les observations indiquent que les parents ressentent un certain stress, ces derniers ont fait preuve d'une capacité de maintenir ou de développer des schèmes de pensée et de comportement fonctionnels leur permettant de faire face aux difficultés suscitées par la maladie. Les parents ont identifié différentes ressources qui les ont aidés à s'adapter: a) l'appui de leur famille, de la clinique pour les enfants atteints de FK et de la Fondation de la FK; b) une aptitude à voir les aspects positifs de leur situation et c) leur force de caractère. La rétroaction positive des efforts dirigés vers la famille, et notamment les soins dispensés à l'enfant atteint de fibrose kystique, semblent influencer favorablement sur la situation et contribuer au caractère positif de l'ensemble des observations.