

COPING WITH FEELINGS: CHRONICALLY ILL CHILDREN AND THEIR FAMILIES

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Coping with a child's chronic illness presents many challenges for parents. To cope effectively, there are a number of adaptive tasks that all parents must complete, regardless of what type of chronic illness their child has (Hymovich, 1976, 1979; Mailick, 1979; Moos & Tsu, 1977). According to a number of authors, one of the most important of these tasks is being able to communicate with others in the family about the illness, including explaining the illness to the child and the siblings and encouraging the expression of feelings about the illness (Burton, 1975; Kaplan, Smith, Grobstein & Fischman, 1973; Kliman, 1978; McCollum, 1975; Steinhauer, 1972). Yet, little research has been done in this area.

If nurses are to be effective in their role of helping families with chronically ill children to cope, they must have an understanding of the adaptive tasks that parents face and of the coping strategies they employ in completing these tasks. Brailey (1984) emphasizes that, in order to study the effectiveness of coping, we must be able to obtain an accurate picture of how people actually do cope with the stressful events of their lives.

The present study was conducted to explore the ways in which parents cope with the adaptive task of communicating about their child's chronic illness within the family. This paper describes the study and reports on findings related to the communication of feelings within the family. The study questions were:

1. How do parents communicate about their child's chronic illness within the family?
2. What guidance have they received in communicating about the illness within the family?

Theoretical Framework and Literature Review

The theory of coping that provided the framework for this study was that of Lazarus and his colleagues (Lazarus & Launier, 1978; Folkman & Lazarus, 1980). This theory states that coping is the cognitive and behavioural efforts

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made by individuals to deal with the internal and/or external demands of a situation with which they are confronted. These efforts serve two main functions: to manage or alter the situation (problem-focused coping) and to control the emotional reaction arising from the situation (emotion-focused coping). These functions are also recognized by other theorists (Mechanic, 1974; Murphy & Moriarty, 1976; Pearlin & Schooler, 1978). Coping is effective to the extent that individuals have the skills and motivation to manage or alter their situations, and are able to regulate their emotional responses so that their energies can be directed towards meeting the demands of the situation (Mechanic, 1974).

Many of the interventions directed towards helping individuals cope focus on the person's emotional response (emotion-focused coping) rather than on the skills needed to meet the demands of the situation (problem-focused coping) (Hiebert, 1983). This author argues that we should concentrate more on helping individuals to develop problem-focused skills rather than focusing on reducing their emotional response. This premise is based on the assumption that acquiring the specific skills needed to cope with a situation will mitigate the emotional responses.

To determine if the individual has the skills necessary to deal with a situation being confronted, the demands or adaptive tasks inherent in that situation must first be specified. For parents coping with a chronically ill child, several tasks have been delineated in the literature, one of which is communicating about the illness within the family (Hymovich, 1976, 1979; Mailick, 1979; Moos & Tsu, 1977). The ways in which families carry out these tasks are known as their coping strategies or coping skills (Moos & Tsu, 1977). The coping strategies they choose will influence the effectiveness of their coping (Holaday, 1984).

While there have been a number of studies on how families cope with a child's chronic illness, few have focused on the adaptive task of communication about the illness within the family. Those who have examined family communication as part of larger studies report that the majority of parents give little or no information to the ill child or to the siblings about the illness and/or rarely discuss or encourage the expression of feelings about the illness (Burton, 1975; Canam, 1986; McCollum & Gibson, 1970; Tropauer, Franz & Dilgard, 1970). The most frequent reasons given by parents for not talking about the illness were their desire not to harm the child (Burton, 1975; Tropauer, Franz & Dilgard, 1970) or their perceived inability to answer questions about the child's prognosis (Burton, 1975; Canam, 1986; McCollum & Gibson, 1970). The major focus of most of these studies was family coping, of which family communication was one aspect, and therefore detailed descriptions on how parents communicate were not collected.

The study being reported here used an exploratory research design in order to provide a detailed description of how parents of children with a chronic illness communicate within the family about the child's illness.

Methods

Sampling procedures

A convenience sample of fifty-seven parents of chronically ill children was selected from two ambulatory clinics of a large urban hospital. The definition of chronic illness utilized in this study is from the work of Pless and Pinkerton: a physical, usually non-fatal, condition which lasts longer than three months in a given year or necessitates a period of continuous hospitalization of more than one month (1975, p. 90).

The criteria for eligibility were: the child with a chronic illness had been diagnosed for at least one year, was three years of age or older and had no major handicaps; there were siblings living at home who were three years of age or older; and the parents has a good command of the English language.

The first forty families to meet these criteria were approached by the investigator and the purpose of the study was explained to them. They were assured of confidentiality and their right to withdraw from the study at any time without jeopardizing their child's treatment. If they agreed to participate, arrangements were made to interview them and a letter of consent was signed before the interview began.

Description of subjects

Twenty-four families of children with epilepsy and 12 families of children with cystic fibrosis participated in the study. These included 23 mothers and 20 fathers of children with epilepsy, and 11 mothers and three fathers of children with cystic fibrosis; a total of 34 mothers and 23 fathers. Four of the families consisted of single parents; the remaining 32 were two-parent families.

The age range of the children with chronic illnesses was from four and a half years to sixteen years, the mean age being ten years. The average length of time since diagnosis was three years with a range of one to ten years. The number of siblings ranged from one to five and their ages ranged from three to twenty-one years.

Data collection

Data were collected by the guided interview technique. This technique is utilized when more information is required about a topic. It ensures that all the

information required will be obtained while allowing the informant freedom of responses and description (Field & Morse, 1985).

An interview schedule was developed by the researcher that was based on the literature review. The first section of the interview focused on communication of information; it included questions on the parents' knowledge of the illness and what information they gave their ill child and their well children. The second section focused on the communication of feelings; it included questions on the feelings that parents and their children experienced in relation to the illness and how these feelings were communicated. A third section of the interview schedule focused on the guidance parents received in communicating about the illness within the family.

The interview schedule was examined by a panel of three experts in the field of chronic childhood illness, revisions were made as suggested and the schedule was then pretested with three eligible families. Minor adjustments were made and the schedule was then used with each family.

In families where both parents volunteered to be interviewed, they were interviewed together, with either one or both parents responding to the questions asked. Each interview was taped, the tape recordings were transcribed verbatim and the transcriptions were used in the analysis. The interviews ranged from 60 to 90 minutes, with the majority taking approximately one hour. Sixteen of the interviews were conducted in a private office at the clinic and 20 were conducted at the homes of the families interviewed.

Data analysis

The transcribed data were analyzed by manifest and latent content analysis (Field & Morse, 1985). The interview schedule was set up to collect the data within three major sections (communication of information, communication of feelings and guidance received in communicating about the illness), and, as such, each section was analyzed separately. The data were examined, line by line, for similar comments, words or phrases used by the participants and a system of colour coding was developed to group like responses together. In interviews where both the father and mother participated, their comments were examined and coded separately.

Like responses were then organized into categories and the theme that dominated each category was defined by identifying the appropriate concept labels. The concepts were stated as simply as possible and often in terms the subjects had used themselves. Such terms as worry, upset and panic were grouped together and defined as fear. Once the categories were identified, responses were tabulated and descriptive statistics were applied.

Findings

The findings reported in this paper focus on the communication of feelings within the family. They include the feelings experienced by parents and their children in relation to living with a chronic illness, how those feelings are communicated within the family and the guidance parents received in helping them communicate about feelings.

Parents' feelings

All parents were able to identify feelings they experienced in relation to living with their child's chronic illness. The most frequent feeling expressed by parents was fear. Seventy-two percent of the participants mentioned the word fear, worry, upset, desperate, terror or panic when describing their feelings about their child's illness.

These feelings seemed to move along a continuum from worry to panic depending on the child's condition and the parents' perceptions of how much control they had over it. Parents admitted to constant worry even when the child was well: "Every time the phone rings at work I wonder if it's for me," but this worry escalated when the child became sick: "every time she gets sick I think, 'is this it?' and I can feel the panic rising in me." Parents also expressed worry and fear when they didn't have enough information or understanding of their child's illness:

Not knowing... we imagined all kinds of weird and wonderful things that were a lot more serious.... If we had the information, there would have been no problem.

Two other feelings commonly expressed by parents of children with epilepsy were frustration and confusion. Sixty-four percent of parents said they frequently felt frustrated and gave a number of reasons for this: waiting for long periods to see specialists; lack of seizure control in the child; the child experiencing side effect from the medications; and difficulty in trying to get their child to take the medications. One parent graphically described the frustration of trying to give her child his medication:

I was so frustrated with him. He'd gag and throw it up and we'd get mad and give him some more... it got into a real vicious circle. I basically, bodily had to hold this kid down and get it in and shut his mouth and say 'don't you dare throw it up' - and he would! I thought 'you little so and so, you're doing that on purpose'. I finally went to the doctor and said 'will you please get him off the liquid and give him capsules.'

Fifty-five percent of parents felt confused about the source of their child's behaviour change or declining school performance. They did not know how much of the behaviour was because of the seizures or the medication and how much was just the child trying to get away with something. This presented a real dilemma for these parents, and they were constantly weighing the best approach to use in dealing with their child's behaviour.

Parents' communication about their feelings

Over half of the parents in this study (56%) said they did not talk about their feelings with anyone; the most frequent reason given was that they felt that no one wanted to listen to their concerns.

There were people who didn't want to listen. I think some of our friends purposely stayed away because they didn't want to listen.

My husband's family won't talk about it. In fact part of their family don't even realize B. is sick.

The doctors seem fairly rushed... They don't spend enough time with you to find out if you do have any anxieties about things.

Forty-four percent of parents did communicate about their feelings and concerns by finding people whom they perceived as receptive and understanding of their situation. The following quotes illustrate the importance of these qualities to parents:

I think that the easy access when you have doubts or anything built up to the point where it really bothers you, you could phone and talk to her (the nurse) and get your fears and anxieties set aside. She's so calm about it all and so helpful. You don't really get that with the doctors. They are more into diagnosing and statistics and facts rather than emotions and how you feel and how things should be handled.

She [the psychiatrist] was really easy to talk to and she had time just for taking through what your concerns were - what you've been harbouring in your heart... because your doctor doesn't have time to listen to those concerns.

I talk to other parents when I come to the clinic.... It's nice to talk to someone else who is going through the same thing because among our friends, no one else is. Knowing that other mom's were also not sleeping at night helped me.

Parents identified the nurse in the ambulatory clinic and other parents of children with the same health condition as the most helpful sources of support for talking about their feelings and concerns.

Parents' perceptions of the ill child's feelings

Parents were asked if they thought their ill child had any feelings about having a chronic illness. Seventy-four percent of parents identified feelings they thought their ill child was experiencing. The feelings most commonly reported were worry, depression, frustration and embarrassment. Although the children rarely expressed these feelings verbally, parents identified them from their behaviour:

I really think her (13 years) subconscious resentment is coming up in that she's forgotten to take her pills a few times recently.

He (12 years) wouldn't carry his own pills because they rattle in his pocket. If we ate out I had to pass the pills under the table because he didn't want anyone to see him taking them.

She (10 years) didn't have too many friends... she wasn't inviting them over. She wanted to be on her own most of the time. But she doesn't talk about it. She keeps her worry inside.

Thirty-six percent of parents made the comment that their child keeps their worries to themselves.

Communication with the ill child about feelings

Although parents were readily able to identify their child's feelings, 81% said they did not talk to their children about their feelings. There appear to be two major reasons for this. One reason is that it did not seem to occur to parents to talk to their child about his or her feelings. Forty-four percent of the parents made comments that showed an awareness of the child's feelings, with no indication of a need to explore these:

I'm sure he's worried. He (7 years) often comes down two or three times after we've put him to bed but the subject of epilepsy has never come up in that discussion. It's always been monsters or people with guns or something scary.

When asked if she ever asked him if he is worried, the parent said, "No, we don't promote it." This same parent said the teacher had called them two or three times to come and get the child because he had locked himself in the bathroom at school and would not come out.

The following comments from other parents indicate their lack of awareness of the need to explore the child's feelings.

These questions you're asking we have, in a sense, already had inside ourselves but we don't know the answers. Like, is it bothering him or isn't it bothering him?

Parent: I think that he (10 years) is under a great deal of stress.

Nurse: How does he deal with it?

Parent: I don't really know.

Parent: I really think she (8 years) felt, at one point, a lot of despair. She scratched in a little notebook she had in great big bold letters, "*I hate epilepsy.*"

Nurse: Did you talk to her about it?

Parent: No, I didn't let on I saw it.

The other major reason for which parents did not talk to their children about their feelings was because they thought it would make the child feel worse. Thirty-eight percent of parents, when they recognized their children were upset, worried or frustrated tried to distract them or reassure them:

When she (12 years) looks down, I try to say or do something to shift her mind from it.

She (8 years) will say "I wish I didn't have this" and I'll say, "Well, really, you know, you don't have very big problems."

Some parents had actually tried to talk to their child but the child would not respond.

She (14 years) won't tell us anything. I don't know what's on her mind. We've never been able to figure it out.

Other parents felt they had made the situation worse by attempting to talk to the child.

She (11 years) is so quiet... every time we try to talk to her she gets her back up and goes into a negative mood.... Why get her upset?

Another parent who had never talked to her eleven-year-old son about his chronic illness (cystic fibrosis) reported that, one evening as they were sitting watching TV, he suddenly jumped up and said, "I hate you for giving me this disease and I'm going to die next year," and then he ran out of the room. She went after him and said, "Why are you saying that? Where did you get that idea? but he refused to talk about it any further. This mother was very upset about how she had handled the situation and admitted that she didn't know how to deal with her son's feelings.

I'll ask him sometimes if something is wrong and he'll say "no". I won't say anything more... maybe because I can't cope with it myself. I can understand the anger. Someone has to be there for him to take his anger out on. That doesn't bother me. What bothers me is how do I answer him? I'm very terrified to open my mouth in that I might just send him off on another frenzy. I'm not a psychiatrist, I haven't had any training in what to say to someone, especially someone you love so much.

Nineteen percent of parents reported that they did talk to their children about their feelings. These parents reported that the common times for feelings to come up for the child were at bedtime, during the night if they woke up, when they were being teased by their peers or during treatments. In most instances, parents thought that simply acknowledging the child's feelings helped the child to feel better.

I tell her (14 years) I don't blame her for feeling frustrated and mad at having to have treatments all the time. Then she usually goes out and jumps out her frustrations on the trampoline.

Parents' perceptions of siblings' feelings

Parents were asked if they thought their well children had any feelings about living with a chronically ill brother or sister. Forty-five percent of the parents did identify feelings that their well children had in relation to living with a chronically ill brother or sister. The most common feelings identified were fear and jealousy. The two main sources of fear for the siblings were that they would get the same illness or that their brother or sister would die.

He came home one day very upset because one of the kids at school had told him his sister was going to die. He was only seven and he thought it was going to happen right then; that he would come home one day and she'd be gone.

When we left M. (7 years) at the hospital, S. (5 years) became very upset and said, "Mommy, is she coming back?" and I said, "Yes." She says, "But she has a disease and she's never coming back. She's going to die!" The children had watched the movie *National Velvet* and the horse had a disease and died and M. had a disease, therefore she was going to die. She'd obviously been thinking about this for some time. (M. had epilepsy).

Twenty-seven percent of the parents mentioned that siblings were resentful of the ill child when the illness interfered with previously made plans. One mother said that they learned very quickly not to commit themselves to taking the children somewhere; sometimes their child with the chronic illness would not be well enough to go, and then the other child would be disappointed and resentful because the outing was spoiled.

The majority of parents said their well children, like their ill child, rarely expressed their feelings directly; the feelings came out in more subtle ways. For example, parents reported that the siblings who feared their brother or sister might die were overprotective of the ill child.

Communication with the siblings about feelings

None of the parents talked openly to their well children about their feelings. The reasons for this seem to be the same as those for not talking to the ill child — it didn't occur to them or they didn't want to dwell on it because it might make the child feel worse.

If the children did express feelings openly, parents reassured them or tried to distract them onto something else. A few parents mentioned that they tried to spend time with their well child if he or she seemed to be getting upset. One mother said that when her ill child was hospitalized, she took her well child to the hospital with her so she could spend time with both of them.

Guidance received from health professionals

Parents were asked what guidance they had received for talking about their children's feelings with them. Ninety-one percent of parents said they had received no guidance. Of the parents who did receive guidance, this came from health professionals and was often general in nature (e.g. "be honest with your child"). Only one parent said she had received specific guidance and this had been very helpful to her.

T (14 years) has very angry moods sometimes. I remember one day in particular. He was so angry at everything. Nothing came out but frustration and anger for two or three days. I had been trying to reach him saying "what is making you so mad? Why are you acting like this?" Finally, I was just about desperate and the Cystic Fibrosis Newsletter came and there was an article in it, written by a nurse, on anger - how it affects the child and how it affects the parents. It told me everything I needed to know - that he was angry at his disease and maybe at his parents for giving it to him. I talked to him about that and you know, the anger just faded away. It was gone with that little talk and yet it had been so hard to find the key.

Discussion

The majority of parents in this study did not talk about their own feelings, nor did they encourage their ill child or their well children to talk about their feelings. Communicating about the illness within the family is an important adaptive task in coping with a child's chronic illness, as such, it is imperative to examine the reasons why parents are not accomplishing this task.

The parents in this study did not talk about their feelings because they perceived that no one wanted to listen. The majority said they would have liked to talk to someone; this was borne out by the ways in which they readily shared their feelings during the interviews. Some parents mentioned that the interview itself was therapeutic for them. It seems that parents have a need to talk and, when they are provided with an opportunity, they are able to share their feelings and concerns openly.

Many authors emphasize the fact that parents need an opportunity to talk about their own feelings before they can allow their children to talk about their feelings (Grossman, 1973; Kliman, 1978; Leiken & Hassakis, 1973; Steinhäuser, 1972). Therefore, it was expected that parents who had opportunities to talk about their own feelings would encourage their children to talk about theirs; however, this did not occur. While opportunities for parents to talk about their own feelings may be a necessary condition for talking to children about their feelings, it was not a sufficient one, in this study.

Other factors must be operating and it appears that one such factor is parents' lack of awareness of the need for children to be able to share their feelings openly. This lack of awareness is interesting, in light of the fact that most parents stressed their own need to share their feelings with someone. The other factor that seems to be influencing parents' lack of communication with their children is their perceived lack of ability to deal with the child's feelings in a helpful way. They believe they will or, in some instances, did make the child feel worse by trying to talk to them about their feelings.

Based on what these parents are saying, they seem to lack the necessary knowledge and skills to communicate effectively with their children about feelings. This supports Hiebert's (1983) premise that we need to focus more on teaching individuals the skills they need to cope with situations and less on their emotional response to the situation.

While the findings of this study cannot be generalized beyond the sample due to the self selection of participants, they do have implications for nursing practice. There is clearly a role for nurses in assessing how parents are communicating about feelings within the family and in providing them with support when they are not accomplishing this task. Nurses can provide parents with opportunities to discuss their own feelings and concerns and ensure that they have the knowledge and skills they need to help their children express their concerns. This could include providing parents with information about children's emotional and cognitive development and helping them to realize that their children will have a greater probability of coping effectively if they can talk openly about their feelings. It could also include helping parents develop the skills they need to talk about feelings with their children.

In summary, parents of chronically ill children must complete a number of adaptive tasks if they are to cope effectively with their child's illness. One of these tasks is communicating within the family about feelings related to the illness experience. Findings from this study demonstrate that the majority of parents do not talk about their own feelings or encourage their ill child or their well children to talk about their feelings. The reason for this lack of communication appears to be that parents lack the necessary knowledge and skills to communicate effectively with their children about their feelings. These findings point to the important role that nurses play in supporting parents of chronically ill children to manage their own feelings and in teaching them to help their children manage their feelings.

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RÉSUMÉ

Savoir faire face à ses émotions: les enfants atteints de maladie chronique et leurs familles.

Les services infirmiers ont un rôle important à jouer à l'appui des familles qui doivent faire face à la maladie chronique de leur enfant. Pour remplir efficacement leur rôle, les infirmiers doivent non seulement comprendre les tâches d'adaptation des familles mais également les mécanismes d'adaptation qu'elles emploient pour mener à bien ces tâches. Cette étude exploratrice visait à étudier les stratégies d'adaptation qu'utilisent les parents pour accomplir une de ces tâches, la communication au sujet de la maladie au sein de la famille. Faisant appel à une technique d'entrevue dirigée, 57 parents d'enfants atteints d'épilepsie ou de fibrose kystique ont été interviewés et on a utilisé l'analyse de contenu pour étudier les données. La présente communication décrit l'étude et les rapports sur les observations liées à la communication des sentiments au sein de la famille. Les observations démontrent que la majorité des parents ne parlent pas de leurs propres sentiments ni encouragent leurs enfants à parler des leurs. Cette étude fournit une orientation très nette aux infirmiers, leur indiquant comment ils peuvent favoriser une adaptation plus efficace des parents d'enfants atteints de maladie chronique.