

DOCUMENT RESUME

ED 407 638

CG 027 726

AUTHOR Perez, Lissette M.
 TITLE Children Coping with Chronic Illness.
 PUB DATE 23 Jan 97
 NOTE 24p.; Paper presented at the Annual Meeting of the Southwest Educational Research Association (Austin, TX, January 23-25, 1997).
 PUB TYPE Information Analyses (070) -- Speeches/Meeting Papers (150)
 EDRS PRICE MF01/PC01 Plus Postage.
 DESCRIPTORS Adolescents; *Childhood Attitudes; Children; *Chronic Illness; *Coping; Elementary Secondary Education; Family Environment; Literature Reviews; Mother Attitudes; *Parent Attitudes; Parent Child Relationship; Parent Influence
 IDENTIFIERS Childrens Responses

ABSTRACT

Children who live with chronic illness are confronted with challenges that frequently force them to cope in myriad ways. The ways in which children face chronic illness are summarized in this literature review. Also covered, are how the effects of family can influence coping strategies and how family members, especially parents, cope with their child's illness. Between 10 and 20 percent of children in the United States suffer from a chronic disease, such as asthma, congenital heart disease, and sickle cell disease. The literature indicates that children cope differentially at different developmental stages, with coping skills becoming more complex and more numerous as children age. The emphasis of coping strategies also changed with age. Older children tend to focus more on disease-related problems whereas younger children concentrate on pain-related problems. Family interactional patterns and mothers' health locus of control beliefs also influence the coping strategies of children, as do the child's gender, cognitive development, and stage of illness. Families benefit from outside support in which their needs are assessed and then addressed. Limitations of the studies are explored, and a summary of how a professional can enhance the coping skills of this population is given. Contains 22 references. (RJM)

 * Reproductions supplied by EDRS are the best that can be made *
 * from the original document. *

ED 407 638

Running head: CHILDREN COPING

Children Coping With Chronic Illness

Lisette M. Perez

Texas A&M University

Lisette M. Perez is a doctoral student in the Counseling Psychology program, Department of Educational Psychology, Texas A&M University, College Station, TX 77843-4225. Email: LMP8354@pop.tamu.edu.

Paper presented at the annual meeting of the Southwest Educational Research Association, Austin, TX, January 23, 1997.

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

L. Perez

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

2

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

- This document has been reproduced as received from the person or organization originating it.
- Minor changes have been made to improve reproduction quality.
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

BEST COPY AVAILABLE

027726



Abstract

The current literature review summarizes research regarding how children cope with chronic illness. Between 10% and 20% of children in the United States suffer from a chronic disease. The literature indicates that children cope differentially at different developmental stages with coping skills becoming more complex as children age. Family interactional patterns and mothers' health locus of control beliefs also impact the coping strategies of children. Counselors and teachers working with this population can provide parents and children knowledge about coping skills. Coping strategies and resources are summarized to further enhance knowledge about research in this area.

Children Coping With Chronic Illness

Children living with chronic illness are confronted with challenges that frequently force them to cope in myriad ways. According to Midence (1994), between 10% and 20% of all children in the United States suffer from a chronic illness. The most common chronic childhood diseases are asthma, congenital heart disease, chronic kidney disease and sickle cell disease. Children are particularly vulnerable individuals who lack knowledge and experience in coping, and especially in coping with such difficult life circumstances. Learning how children cope and where they derive their coping skills and knowledge may allow others to better comprehend how they handle the stress of living with a chronic disease.

Current literature describes coping as the way one adapts to stress and includes both the positive and negative responses to stressful situations. Coping can either be in the form of *direct action*, where one physically attempts to change the environment, or *cognitive modes*, where one manipulates thoughts or feeling to contend with a problem (Olson, Johansen, Powers, Pope & Klein, 1993). For the purpose of the present paper, the previous definition of coping will help the reader understand that children's coping strategies can occur in either of these two forms.

The process of coping in children with chronic illness has been extensively explored in several studies. Coping strategies used by children to deal with the stresses encountered by chronic illness, however, have not been as systematically studied. A vast majority of the investigations that examined the process of coping have been performed on children coping with only one illness, and few studies examined the common coping strategies shared by children with dissimilar diseases. Presently, a general understanding of coping methods has not been investigated or articulately delineated, and professionals or parents working with this population find little research or theory to help them better comprehend the difficulties these children often encounter.

The present literature review attempts to provide an overview of the empirical literature about how children cope, how the effects of family can influence coping strategies, and how family members, especially parents/or guardians, cope with their child's illness. Moreover, a summary of how a professional working with this population can effectively facilitate coping with the illness and stressors encountered daily will be examined.

Coping Skills

A cross-sectional study by Olson et al. (1993) investigated whether children with a chronic illness used cognitive coping strategies as frequently as healthy children. They also examined whether children living with chronic illness utilized cognitive responses different than those used by healthy children coping with other common stressful events in daily life. Olson et al. studied 175 children between the ages of 8-18 years who attended special summer camps for their chronic illness. They derived three different illness groups consisting of children with asthma, diabetes and juvenile rheumatoid arthritis (JRA). A control group consisted of 145 children from the public school population that were rated healthy children by the investigators.

Olson and his colleagues collected questionnaires evaluating cognitive strategies for trait anxiety and coping. Additionally, sociodemographic variables and information regarding disease control and severity were obtained only from the experimental chronic illness group. All participants were administered a cognitive questionnaire that asked them to respond to three types of common childhood stressors: the pain of a dental injection, delivering a talk in front of their class, and a recent personally stressful event. For each event, the participants were asked to describe their thoughts prior to the event and then thoughts that actually occurred during the event. In scoring the responses, the investigators determined which specific type of cognitive strategies were used and whether for each event the dominant cognition was coping or catastrophizing (responses that obstruct one

from adapting to a situation and focus on the negative aspects of the event). The questionnaires were also administered three months later to 10 randomly selected campers. The Revised Children's Manifest Anxiety Scale was subsequently given to assess whether trait anxiety was related to reported cognitive strategies.

The results of Olson's study suggested that children with chronic illness spontaneously utilize cognitive coping strategies as often as healthy children. Coping strategies tended to increase with age while catastrophizing often decreased. The most common coping strategy was positive self-talk with the most common decatastrophizing strategy being focusing on negative affect or fear. The results also suggested variations in coping for different events. For example, children with chronic illness demonstrated greater use of cognitive coping strategies than healthy children for one type of painful event but not for another. Older chronically ill children utilized more complex coping strategies than healthy children and were especially more advanced in the group with JRA. Overall, for all groups of chronically ill children, the presence of more severe illness did not indicate change in their main or overall cognitive coping strategy.

In a study by Spirito, Stark, Gil, and Tyc (1995), illness and non-illness related stressors reported by children and adolescents were examined across a wide range of chronic illnesses. The secondary objective of this study was to investigate whether utilized coping strategies were more consistent across personality traits or situations. The authors studied 93 male and 84 female subjects between the ages of 7 and 18 who had been diagnosed with a chronic illness such as sickle cell disease, migraine headache, congenital orthopedic problems, cystic fibrosis, ulcerative colitis, congenital heart disease or seizure disorders. Participants were assessed during outpatient visits or inpatient hospitalizations, and were asked two questions. The questions dealt with illness-related problems and other problems common to this group. Following questionnaire administration, the Kidscope instrument designed to assess 10 specific cognitive and behavioral coping strategies was

completed.

Several findings in the study provide a more comprehensive understanding of the everyday and illness related stressors encountered by chronically ill children. Multiple stressors, especially those related to everyday management of the disease, as well as those which are pain-related, were reported by the participants. Results also indicated that adolescents were more likely to select disease-related stressors while younger children chose pain-related stressors more frequently. These findings seem to suggest that older children have a better understanding of the implications of their illness and understand the reason for their pain. Thus older children seem more concerned with the stressors brought about by the illness and less concerned with the pain experienced by venipuncture. While the everyday concerns reported by chronically ill children were related to school, however, healthy children expressed more concern with boyfriend/girlfriend problems.

One of the main objectives of the study was to explore whether coping was based more extensively on situation or personality characteristics. The results indicate that in relation to age variations, coping was more situationally based. The only consistent effect of age across type of chronic illness and common problem was that adolescents reported using resignation as a coping strategy more often than younger children. Older children tended to use blaming others more often than younger children for chronic illness problems whereas younger children used blaming others more generally than older children.

Gender affected coping strategies in children with chronic illness but had little impact on children with common problems. Boys with chronic illness reported using cognitive restructuring and self-blame more often than girls whereas girls reported using more emotional regulation and social support. In dealing with common problems, both boys and girls used the strategies equally. The results seem to indicate that gender affects coping only with regard to illness-related problems. These findings suggest that coping is a process that differs between individuals and across situations but that also has some stable

components.

Developmental differences among youngsters in the preformal and formal operational stages have been studied to understand the variations in coping styles during these stages of development (Band & Weisz, 1990). The participants in Band and Weisz's study consisted of 64 children who were being treated for diabetes at three area hospitals. Two groups were included in the study: the preformal operational (13 girls, 19 boys averaging 8 years of age), and the formal operational group (18 girls, 14 boys averaging 14 years of age). The groups were chosen by asking each child to complete a Piagetian task which differentiated the formal operational from the preformal operational children.

Individual structured interviews were conducted to assess each child's diabetes-related coping approaches, perceptions of control, perceptions of coping efficacy and diabetes knowledge. Interviews addressed specific stressors of diabetes, and its treatment, and other broader concerns. Children rated their amount of perceived control, coping approaches they most utilized, and the efficacy of their coping efforts. Coping approach was coded using the dimensions of the primary-secondary control model proposed by Rothbaum, Weisz, and Snyder (1982). Additionally, each child's physician rated medical adjustment using the Medical Adjustment Rating Scale. Parents completed two measures of child adjustment, one which assessed the child social and behavioral adaptation to diabetes, and the other which assessed more global psychosocial adjustment.

The results of the investigation indicated the importance of looking at children's developmental levels when attempting to understand coping and adjustment to chronic illness. For children in the preformal stages of development, perceived control appeared to help them adjust better to their illnesses. The results indicated that perceived coping efficacy and diabetes knowledge was better for children in the formal operational stages, and that such children may then adjust better. Another finding indicated that children in the formal operational stages had more knowledge about their disease and subsequently used more

secondary coping strategies to help them deal with their illness. There was a positive correlation between the parents' ratings of sociobehavioral adjustment of perceived control and coping efficacy, but only among formal operational children. This result seems consistent with the notion that as children grow older and develop more formal stages of thinking, they also begin to emulate their parent's cognitive patterns.

Coping with Treatment and Procedures

Undergoing medical treatment and procedures is another major aspect of coping with a chronic illness. Some of these procedures range from minor surgery to more serious exploits that require days of hospitalization. During visits to the doctor or hospital, children often encounter invasive procedures that require the use of coping skills.

A study by Weisz, McCabe and Dennig (1994), looked at the primary-secondary models of coping. Individuals use primary control when they try to modify the environment, thereby, attempting to adjust events to be compatible with their desires. In secondary control, individuals make efforts to enhance rewards or reduce punishments by modifying themselves.

Weisz et al. (1994) examined the adjustment of children to relatively uncontrollable stressors associated with leukemia. The sample consisted of 33 children diagnosed with acute lymphocytic leukemia ranging in age between 5 and 12 years, and which consisted of 20 boys and 13 girls. Data were collected by interviewing children to assess their preferred coping approaches for specific stressors related to leukemia and its treatment. Parents completed a checklist of behavioral and emotional problems designed to indicate their child's general behavioral adjustment. Children completed a self-report distress measure to identify illness-specific adjustment. Additionally, an observational measure of distress completed by two trained observers was completed. Weisz's study along with others in this area indicate that stressors low in controllability are better handled if the children attempt to adjust themselves rather than trying to change the environment. In

this study, more positive adjustment was found among those children who used secondary coping methods rather than primary coping methods.

The coping strategies employed by acutely ill and chronically ill children to manage stressors encountered during hospitalization were examined by Spirito, Stark, and Tyc (1994). The relation between coping strategy and distress was also investigated. Two groups of participants were utilized, a chronically ill group (32 boys and 22 girls ranging between the ages of 7-17 years old) and an acutely ill/injured group (44 boys and 27 girls ranging in age from 7-17 years old). The majority of the participants were assessed within 1 and 2 days of hospital admission. Each child was presented with a question that would allow them to respond by explaining a situation that had disturbed them since their stay in the hospital. After describing the situation, each participant was asked to respond to three additional questions about anxiety as well as the Kidscope.

Results regarding coping strategies indicated differences in relation to developmental stage and illness type. In accordance with other studies, the investigation also suggested that adolescents more often selected illness-related problems, whereas children more frequently selected pain-related problems. The adolescents in the study utilized cognitive strategies (e.g., problem solving and resignation) more often than younger children, whereas the younger children typically used wishful thinking. Results also indicated that chronically ill children were less likely to use avoidance and negative coping strategies. Social withdrawal was used more by young acutely ill/injured children than acutely/ill injured adolescents, whereas self-blame was more often used by chronically ill adolescents and less frequently by acutely ill/injured adolescents. In addition, when the levels of anxiety were greater, the more frequently active coping strategies were employed. Additionally, anxious children were also found to use more avoidance coping. Overall, the more anxious children demonstrated greater use of coping skills.

Altshuler, Genevro, Ruble and Bornstein (1995) examined how age

relates to differences in children's coping knowledge and behaviors while they were hospitalized for surgery. They also explored how individual differences and development in problem-solving relate to children's coping capacities and how these factors affect relations between age and coping. Moreover, they investigated the degree to which coping knowledge and coping behaviors were related.

Altshuler et al. studied 44 patients between the ages of 5 and 11 years entering the hospital for elective pediatric surgery, 25 of whom were male. The Kaufman Assessment Battery for Children was used to collect data on children's performance in problem-solving with an interview conducted one week prior to hospitalization to assess coping knowledge. The Procedure Behavior Rating Scale was used to rate observations of coping behavior while the children were waiting to undergo surgery. Posthospitalization self-reports of coping behaviors were also collected after the children were hospitalized.

The results of this study indicate that age, problem-solving skills, and gender predicted children's knowledge of specific coping strategies (e.g., behavioral distraction, cognitive distraction, adaptive approach and escape). Behavioral and cognitive distraction were reported to be used more successively by older children with higher problems solving scores. Approach strategies, however, were used more often by older children with lower problem-solving scores. The results also suggested that girls asked more questions prior to surgical procedures. In general, specific coping knowledge related positively to aspects of children's coping behaviors while the children were hospitalized for elective surgery.

Ellerton, Ritchie and Caty (1994) examined factors that influenced 80 preschool children's coping during venipuncture. Using several measures such as the Children's Coping Strategies Checklist, the Palmar Sweat Index, the Stanford Preschool Internal-External Scale, the Behavioral Style Questionnaire, the Spielberger State-Trait Anxiety Inventory and the Faces Pain Scale, the authors examined data to understand how children cope with this procedure.

The researchers found that children used self-protective behaviors as coping methods. Visual examination of their surrounding, tense compliance, acceptance of help from the nurses and tension-reduction involving the self, helped these children manage through the procedure. Children who found the procedure most painful tended to use more coping strategies, especially self-protection. Overall, along with other studies, the research suggests that situation factors influence young children's coping.

Family Coping

Children with chronic illness do not encounter their illness solely; rather, it is beyond the child's capability to cope with and successfully handle the everyday stressors and hardships with which they are faced. Parents and family members are often the ones who have to cope and maintain the child's health, much as if it was their own illness. Strict diet and living regimens are far too complex for the child to manage alone. Often times, one parent must abandon a career to take full-time responsibility for the ill child. This in and of itself may cause various stressors in the family by cutting back the family's income or by even causing the family to depend on government benefits.

Family functioning and sibling relationships may also receive less attention, causing extensive tension within and between family members. Since the child's chronic disease becomes the family's illness, it is crucial to gain a complete understanding of the impact an illness poses on the family as a whole. Moreover, it is important to study the knowledge the family has about the illness, their coping abilities and the resources they have available.

A large amount of family coping research has concentrated on the mother's coping ability and on how her coping affects that of the child. Particular attention has been given to the emotional functioning of mothers. In a longitudinal study by Kovacs, Iyengar,

Goldston, Obrosky, Stewart and Marsh (1990), 95 children and their parents provided data over the course of seven years. Instruments such as the Beck Depression Inventory and the Issues in Coping with Insulin-Dependent Diabetes Mellitus were given to the parents of these children. The results indicated that the mother's overall psychological distress increased with the duration of the child's illness but failed to pose a risk for serious clinical depression. Another finding indicated that mothers who initially handled the diagnosis with a greater amount of symptomology also had more symptomology at any future point in time, whereas mothers who dealt with the diagnosis more smoothly from the beginning had less symptomology over the course of their child's illness. Overall, results indicated that most mothers found it easier to adjust to the illness over time.

Stability and change in the psychological adjustment of mothers with chronically ill children was also investigated by Thompson, Gil, Gustafson, George, Keith, Spock, and Kinney (1994). These researchers completed two longitudinal studies on mothers of children with Cystic Fibrosis and Sickle Cell Disease. Their sample consisted of 57 mothers in the Cystic Fibrosis group and 60 mothers in the Sickle Cell Disease group. Several assessments such as the Shwachman Clinical Evaluation System, the Hassles Scale, Ways of Coping Questionnaire, the Family Environment Scale, the Child Assessment Schedule and the Symptom Checklist 90-Revised were used in the study.

Results indicated that the majority of mothers adjusted better over time, but those who did not place more emphasis on daily stress, used more palliative methods of coping, and had lower levels of family support. Based on clinical findings, it was noted in the Cystic Fibrosis group that illness severity, child psychological adjustment, and family conflict contributed to maternal adjustment.

Hamlett, Pellegrini and Katz (1992) examined child stress events, family functioning and the adequacy of the resources available to the mother through extrafamilial social support to explore how a child's chronic illness impacts the familial

context. Interviews were completed with 30 mothers of children with asthma or diabetes as well as 30 mothers of healthy children. The Child Behavior Checklist, the Family Environment Scale, the Interview Schedule for Social Interactions and the Project Competence Life Events Questionnaire were administered to the mothers.

Similar to other findings, these results suggest that family functioning, maternal social support and chronic illness are related to a child's psychological adjustment. Additionally, family conflict and cohesion were related to the child's externalizing behavior. The findings also indicate that conflict and non-supportive family members exacerbate the child's temper leading them to act out with behavior problems. The authors of this article emphasized the importance of social support in the lives of these mothers.

The contribution of family interactions and resources, maternal self-esteem, social network and health locus of control beliefs was investigated to understand how these variables related to children's overall adjustment (Perrin, Ayoub & Willett, 1993). There were 187 children with a broad range of chronic physical illnesses who participated in this study. Various psychometric measures were used to assess family, maternal and child characteristics.

Consequently, family environment was found to have a significant impact on the child's adjustment. The important contributing factors in this finding were family interpersonal relations, maternal locus of control beliefs and the child's gender and age. Based on the reported results, one singular characteristic of the family alone does not make the difference; rather, it is the interaction of several family qualities that influence the subsequent adjustment of the child. Results also indicated that mothers who felt greater control over their own health also felt more control over their child's health.

Kliewer and Lewis (1995) looked at the effects of parental influences (e.g., parental coaching, parental modeling) and family context on the coping processes of 39 children and adolescents with sickle cell disease. Parental coping suggestions were

measured by the Parental Socialization of Coping Questionnaire. The coping strategies of the parents were assessed with the COPE instrument, and the Family Environment Scale was used to assess family context. The Children's Coping Strategies Checklist was employed to assess children's general coping preferences, and the Children's Hope Scale being was used to assess their level of hope.

The authors found that coaching variables predicted hope, modeling variables predicted avoidance coping, and family context predicted active coping. Demographic information such as children from one-parent homes versus two-parent residences indicated that children in one parent homes lived in less cohesive environments, received more avoidance coping suggestions, and observed more denial coping by their parents. Levels of hope also varied according to the type of sickle cell disease, as children with more severe forms had lower hope scores than children with milder forms of sickle cell disease. Overall, this study tended to support the notion that parental coaching and modeling as well as the family environment influences coping processes in children with sickle cell disease.

Parental coping is a major aspect of children coping with chronic diseases. The manner in which parent's cope can affect family functioning, the child's functioning, and most importantly, how successful the child's needs are being met. Birenbaum (1990) used the Coping Health Inventory to evaluate how parents cope with their child's illness. She posited in her review that parents try to encapsulate the disease by normalizing and controlling the meaning of the experience. By doing this, parents are better able to manage the everyday difficulties the illness may bring into the family. Furthermore, parents often engage in the "at risk" role where they take extreme precaution to comply with all treatments and to protect the child from more harm.

Treatment

To help families and children cope with a chronic illness, families need to be provided with outside support that can assess and provide what they lack to manage the

illness. Several studies examined the different aspects of family life where intervention can take place to increase the coping skills of the family and child. Gibson (1988) notes that parents reported coping effectively with stress by using available resources as well as action-oriented and emotional behaviors. The resources considered most helpful included: familial support, assistance from the multidisciplinary team at the clinic, contact with other parents undergoing similar stressful situations, ability to focus on the positive aspect of the situation, and deep beliefs about one's own ability to cope and help their children.

When working with this population, professionals need to assess and help families at various levels and stages. Cherry (1989) discussed the importance of using a model which examines the structure of family response to stressors and coping efforts to understand the complex processes involved. It is recommended that therapists examine four factors related to stress and coping: the illness and its hardships, the family views of the illness, the chronicity of the problem, and the family interactions and social network resources that effect the family's adaptation to the illness.

Professionals in the mental health field have a wide range of areas where they can provide valuable help and expertise to families of chronically ill children. Their assistance can help alleviate many stressful feelings that parents are not normally prepared to encounter. Sargent and Liebman (1985) discussed the importance of evaluating the emotional, cognitive and behavioral challenges with which families are often faced. Emotionally, parents need to accept the illness, grief and reactions that coincide with the illness. On the cognitive level, it is important for parents to understand the illness, and the potential complications, as well as intellectually recognize and appreciate the routines and reasons for treatment. Finally, on the behavioral level, families need to alter patterns in their daily living to integrate the treatment necessary for the care of their child.

The role of a psychotherapist can be further extended in helping provide interventions in situations where maladaptation, poor medical course or psychosocial

development occurs. Several characteristics such as poor compliance with treatment, repeated hospitalizations, decrease in physical function despite adequate treatment, social withdrawal and depression, emotional immaturity in the ill child, poor school performance, aggressiveness, and family conflict can suggest the need for family therapy. Sargent and Liebman (1985) suggested that the objective of therapy should be to help the family and child acknowledge and accept illness treatment and prognosis to help the family perform illness management with minimal disruption in family life, and finally to assist the family and the child as they resolve psychosocial problems, work collaboratively and achieve appropriate development and effective relationships.

Paluszny, DeBeukelaer and Rowane (1991) also point out the importance of a multidisciplinary team in helping families with chronic illness. They suggest interventions at five different stages through the course of an illness which can help strengthen the family and the child's own coping behavior. The five stages of intervention include: when diagnosis is first made, when a decrease in function or increase in physical symptoms occur, when life crises occur, when developmental maladjustment interferes with compliance, and finally, when the team and/or family recognize that little more can be done. The reasons that intervention is important at these stages is because it prevents disillusionment through unrealistic expectations and subsequently prevents overprotection. Further, intervention helps promote appropriate separation between parent and child as well as development for the children.

Coping strategies for children can also be in the area of social skills development. Many children when faced with an illness lack the education needed to learn how to deal with everyday stressors that are frequently encountered at school and with teachers and peers. Clark, Striefel, Bedlington and Naiman (1989) reported that working with children and families can help enhance and reduce problems in this area. It is suggested that children learn to be assertive with peers, how to respond to authority figures, anger control skills,

and problem solving techniques. These skills can be taught to parents, who in turn, can instruct their children, or children can be taught directly by teachers or counselors.

Teachers provide another resource to parents and children living with a chronic disease. Mescon and Honig (1995) reported that teachers need to be conscious of the child's interactions with the family as well as their own skills in promoting an inclusive environment in the classroom. Teachers can also provide support to parents by listening empathically to their concerns and by allowing parents an opportunity to express the frustrations of their experience.

Additionally, children can be assisted by learning ways to handle their coping skills such as denial and minimization. Children can also be helped by finding out more information about their illnesses, receiving more support from family and friends and by helping them increase motivation to manage any medical difficulties. Other ways of helping children consist of helping them normalize the illness, using fantasy to apply new hopeful meanings to their illnesses, reframing the situation, and learning open communication skills so that they feel comfortable in talking with adults. Play therapy can help children act out worries or fears, and other therapies such as art therapy or music therapy can soothe and distract a worried child or parent.

There are a large number of resources available to families and children. It is often difficult and time consuming for parents to find them, however, this can be facilitated with the help of a professional such as a teacher or counselor.

Conclusion

The available evidence suggests that there are many aspects of children's life that relate to how they cope with their illnesses. Studies indicate that a child's age, gender, cognitive development, stage of illness and family relations can have an integral impact on how he or she ultimately copes.

The literature suggests that the number of available cognitive coping strategies

increases with a child's age. A child's age also tends to predict the type of problem on which they will focus. Cognitive coping strategies were used more often by older children, while younger children used more wishful thinking. Older children typically utilized more cognitive restructuring and also tended to focus on more disease-related problems while younger children were more preoccupied with pain-related problems. Older children seem to have a better understanding of their illnesses, and subsequently are able to implement more complex understanding of their illnesses. They realize they cannot alter their situation, and most find other ways of coping with illness. Perhaps due to the greater length of time that they have had their illnesses, older children tend to use more problem solving skills.

Several studies also suggested that males tend to use more cognitive restructuring while females use more emotional regulation and social support. An individual's gender also plays a part in how an individual copes. Males tend to be raised with the notion that they can solve their own problems and that they do not need help from others. Conversely, females are often raised to be more aware of their emotional feelings and often seek support from others. Based on the literature, these findings are consistent with the manner in which children handle chronic illness.

Preformal and formal operational children differed in coping approaches, factual knowledge of the illness and their medical adjustment, at least as rated by medical personnel. For the preformal group, perceived control predicted adjustment to their illness, as children who perceived more control over their illness were better able to cope. For the formal group, the primary-secondary coping style, perceived coping efficacy and illness knowledge typically predicted their subsequent adjustment. A high degree of knowledge and a secondary control coping style was more prevalent in mature youngsters than in less mature children. Overall, children who are more mature have more knowledge and understanding, and their perceived control is greater than children who have less knowledge and understanding. Consequently, perceived control leads to better coping.

Chronically ill children demonstrated the use of more complex cognitive coping strategies. This may be due in part to the difficulty of their illness, and children may learn to use more elaborate skills to help them cope with their more complex illnesses. Adolescents and children with chronic illness tended to focus more on school-related problems, whereas healthier children focused more on boyfriend-girlfriend problems. Chronically ill children have to deal with missing school more often than other children and often become worried about falling behind their friends. Young acutely ill children use social withdrawal more often than acutely ill adolescents, whereas chronically ill children used self blame less than acutely ill children. This may result from the fact that the most acute problems children have are due to their own indiscretions while playing games. Thus, acutely ill children often realize that they could have prevented the problem from occurring.

Family was one very important aspect found to be influenced in children's coping. Family interactions predicted adjustment in children, as children with good family relations and interactions tended to cope and adjust better to their illnesses. The manner in which family, especially the mother, contended with the child's illness was related to how well the child was able to cope with his/her illness.

Study Limitations

Some limitations to consider when examining this literature review include the notion that many of the self-reports were filled out by children who may answer questions thinking of a hypothetical situation and not really a situation from their own experience. Children may also use coping strategies that they are not able to articulate during a study. Data collected from parents may be inaccurate because the manner in which parents perceive their children may not be consistent with the way their children actually cope. Some studies used only screening measures to assess coping. Most studies had small samples and were based on only one or two ethnic groups. Moreover, several studies examined one illness and generalizing to other illnesses may not be possible.

Future studies should use larger samples to gather more normative data which would also allow for more comparisons across different subgroups of chronically ill children. A cross-cultural study would afford researchers the opportunity to examine how diverse families influence their children's coping and whether different cultures have divergent coping styles. A stronger emphasis should be placed on studies which examine non-illness related stressors experienced by chronically ill children.

Counseling Recommendations

This review has implications for counselors and other professionals who plan to work with chronically ill children. First, it is important to assess the knowledge the children possess about their illnesses. It is important to help them understand what they know and to assist them in understanding that the illness is not their fault. Second, counselors should teach children cognitive coping strategies that will help them cope with illness. Third, counselors can help children join a support group where they can gain peer support. Finally, counselors can assist family members by helping them understand the child's illness and by assisting children in learning positive modeling coping skills that they can transmit to their children.

In conclusion, examining the use of coping strategies in childhood chronic illness is in its early stages, but holds the promise of furthering our understanding of adaptation to illness. The present review has provided a general overview of what is currently known about children coping with chronic illness. Further study on this topic needs to be thoughtfully considered when planning to work with this population.

References

- Altshuler, J. L., Genevro, J. L., Ruble, D. N., & Bornstein, M. H. (1995). Children's knowledge and use of coping strategies during hospitalization for elective surgery. Journal of Applied Developmental Psychology, *16*, 53-76.
- Birenbaum, L. K. (1990). Family coping with childhood cancer. The Hospice Journal, *6*(3), 17-33.
- Brotman, E., & Weisz, J. R. (1990). Developmental differences in primary and secondary control coping and adjustment to juvenile diabetes. Journal of Clinical Child Psychology, *19*, 150-158.
- Cherry, D. (1989). Stress and coping in families with ill or disabled children: Application of a model to pediatric therapy. Physical and Occupational Therapy in Pediatrics, *9*(2), 11-32.
- Clark, H. B., Striefel, S., Bedlington, M. M., & Naiman, D. E. (1989). A social skills development model: Coping strategies for children with chronic illness. Children's Health Care, *18*, 19-29.
- Ellerton, M. L., Ritchie, J. A., & Caty, S. (1994). Factors influencing young children's coping behaviors during stressful healthcare encounters. Maternal-Child Journal, *22*(3), 74-82.
- Gibson, C. (1988). Perspective in parental coping with a chronically ill child: The case of cystic fibrosis. Issues In Comprehensive Pediatric Nursing, *11*, 33-41.
- Hamlett, K.W., Pellegrini, D.S., & Katz, K. S. (1992). Childhood chronic illness as a family stressor. Journal of Pediatric Psychology, *17*, 33-47.
- King, N. J., Gullone, E., & Ollendick, T. H. (1990). Fears in children and adolescents with chronic medical conditions. Journal of Clinical Child Psychology, *19*, 173-177.
- Kliewer, W., & Lewis, H. (1995). Family influences on coping processes in

children and adolescents with sickle cell disease. Journal of Pediatric Psychology, 20, 511-525.

Kovacs, M., Iyengar, S., Goldston, D., Obrosky, D. S., Stewart, J., & Marsh, J. (1990). Psychological functioning among mothers of children with insulin-dependent diabetes mellitus: A longitudinal study. Journal of Consulting and Clinical Psychology, 58, 189-195.

Mescon, J. A. W. & Honig, A. S. (1995). Parents, teachers, and medical personnel: helping children with chronic illness. Early Child Development and Care, 111, 107-129.

Midence, K. (1994). The effects of chronic illness on children and their families: An overview. Genetic, Social and General Psychology Monographs, 120, 311-326.

Olson, A. L., Johansen, S. G., Powers, L. E., Pope, J. B., & Klein, R. B. (1993). Cognitive coping strategies of children with chronic illness. Journal of Developmental and Behavioral Pediatrics, 14, 217-223.

Paluszny, M. J., DeBeukelaer, M. M. & Rowane, W. A. (1991). Families coping with multiple crises of chronic illness. Loss, Grief, and Care, 5, 15-26.

Perrin, E. C., Ayoub, C. C., & Willett, J. B. (1993). In the eyes of the beholder: family and maternal influences on perceptions of adjustment of children with a chronic illness. Journal of Developmental and Behavioral Pediatrics, 14, 94-105.

Rothbaum, F., Weisz, J. R., & Snyder, S. S. (1982). Changing the world and changing the self: A two-process model of perceived control. Journal of Personality and Social Psychology, 42, 5-37.

Sargent, J. & Liebman, R. (1985). Childhood chronic illness: Issues for psychotherapists. Community Mental Health Journal, 21, 294-311.

Spirito, A., Stark, L. J., Gil, K. M., & Tyc, V. L. (1995). Coping with everyday and disease-related stressors by chronically ill children and adolescents. Journal of the

American Academy of Child and Adolescent Psychiatry, 34, 283-290.

Spirito, A., Stark, L. J., & Tyc, V. L. (1994). Stressors and coping strategies described during hospitalization by chronically ill children. Journal of Clinical Child Psychology, 23, 314-322.

Thompson, R. J., Gil, K. M., Gustafson, K. E., George, L. K., Keith, B. R., Spock, A., & Kinney, T. R. (1994). Stability and change in the psychological adjustment of mothers of children and adolescents with cystic fibrosis and sickle cell disease. Journal of Pediatric Psychology, 19, 171-188.

Weisz, J. R., McCabe, M. A., & Dennig, M. D. (1994). Primary and secondary control among children undergoing medical procedures: adjustment as a function of coping style. Journal of Consulting and Clinical Psychology, 62, 324-332.



U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement (OERI)
Educational Resources Information Center (ERIC)



REPRODUCTION RELEASE
(Specific Document)

I. DOCUMENT IDENTIFICATION:

Title: CHILDREN COPING WITH CHRONIC ILLNESS	
Author(s): LISSETTE M. PEREZ	
Corporate Source:	Publication Date: 1/23/97

II. REPRODUCTION RELEASE:

In order to disseminate as widely as possible timely and significant materials of interest to the educational community, documents announced in the monthly abstract journal of the ERIC system, *Resources in Education* (RIE), are usually made available to users in microfiche, reproduced paper copy, and electronic/optical media, and sold through the ERIC Document Reproduction Service (EDRS) or other ERIC vendors. Credit is given to the source of each document, and, if reproduction release is granted, one of the following notices is affixed to the document.

If permission is granted to reproduce the identified document, please CHECK ONE of the following options and sign the release below.



Sample sticker to be affixed to document

Sample sticker to be affixed to document



Check here

Permitting
microfiche
(4" x 6" film),
paper copy,
electronic,
and optical media
reproduction

"PERMISSION TO REPRODUCE THIS
MATERIAL HAS BEEN GRANTED BY

LISSETTE M. PEREZ

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

Level 1

"PERMISSION TO REPRODUCE THIS
MATERIAL IN OTHER THAN PAPER
COPY HAS BEEN GRANTED BY

Sample

TO THE EDUCATIONAL RESOURCES
INFORMATION CENTER (ERIC)."

Level 2

or here

Permitting
reproduction
in other than
paper copy.

Sign Here, Please

Documents will be processed as indicated provided reproduction quality permits. If permission to reproduce is granted, but neither box is checked, documents will be processed at Level 1.

"I hereby grant to the Educational Resources Information Center (ERIC) nonexclusive permission to reproduce this document as indicated above. Reproduction from the ERIC microfiche or electronic/optical media by persons other than ERIC employees and its system contractors requires permission from the copyright holder. Exception is made for non-profit reproduction by libraries and other service agencies to satisfy information needs of educators in response to discrete inquiries."

Signature: <i>Lisette Perez</i>	Position: RESEARCH ASSOC
Printed Name: LISSETTE M. PEREZ	Organization: TEXAS A&M UNIVERSITY
Address: TAMU DEPT EDUC PSYC COLLEGE STATION, TX 77843-4225	Telephone Number: (409) 845-1831
	Date: 1/29/97

III. DOCUMENT AVAILABILITY INFORMATION (FROM NON-ERIC SOURCE):

If permission to reproduce is not granted to ERIC, or if you wish ERIC to cite the availability of this document from another source, please provide the following information regarding the availability of the document. (ERIC will not announce a document unless it is publicly available, and a dependable source can be specified. Contributors should also be aware that ERIC selection criteria are significantly more stringent for documents which cannot be made available through EDRS).

Publisher/Distributor:	
Address:	
Price Per Copy:	Quantity Price:

IV. REFERRAL OF ERIC TO COPYRIGHT/REPRODUCTION RIGHTS HOLDER:

If the right to grant reproduction release is held by someone other than the addressee, please provide the appropriate name and address:

Name and address of current copyright/reproduction rights holder:
Name:
Address:

V. WHERE TO SEND THIS FORM:

Send this form to the following ERIC Clearinghouse:

If you are making an unsolicited contribution to ERIC, you may return this form (and the document being contributed) to:

ERIC Facility
1301 Piccard Drive, Suite 300
Rockville, Maryland 20850-4305
Telephone: (301) 258-6500