

PARENTS' COPING WITH THEIR CHILD'S ASTHMA

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Abstract: The aim of this qualitative study was to understand and explore parents' experiences of coping with their child's asthma, contextually important mechanisms for coping and parents' ascribed meaning to their coping strategies. Twenty-six parents (11 fathers) were interviewed individually (6 subjects) or as a couple. The taped interviews were transcribed verbatim and analysed in line with the grounded theory tradition. Two core categories, describing contextual focus of parental coping with asthma, were identified in the data. These core concepts, "cognitive control" and "locus of confidence in caring", formed a typology of parental coping with asthma. Combinations of variations in these core concepts were related to six qualitatively different parental coping strategies: "problem-solving", "avoiding-assuring", "reducing", "relying on self", "complying" and "enduring". The core concept "chaos in caring" described the experienced stress in caring for the child's asthma. Six additional categories were related to this core concept: parents' experience of "lack of control", "incompetence in caring", "disease-focusing", "existential fear", "closeness" and "uncertainty due to a non-understanding environment". The result gives a deeper understanding of the experienced meaning and context related to parents' coping efforts and might be of importance in developing and evaluating family therapy/rehabilitation programs

Introduction

Asthma is the most common of the chronic diseases in childhood in the western world while the prevalence differs considerably between countries. A steady increase in the number of children suffering from the disease is seen (ISAAC, 1998. Sears, 1997). The importance of the role of the family in the management of the illness is well recognised (Weinstein, Chenkin &

Faust, 1997. Godding, Kruth & Jamart, 1997). The "psychosomatic family model", emphasising closeness and lack of flexibility as a contributing factor in the development of difficult-to-treat childhood asthma has been predominant (Minuchin, Rosman & Baker, 1978). Recent studies have shown that these phenomena do not precede the onset but seem to appear as a result of the disease (Gustafsson, Bjorkstén & Kjellman, 1994). Research even suggests

that cohesion of family members and rigid manners of function of caregivers may have positive rather than negative influence on the welfare of the asthmatic child (Meijer, Griffioen, van Nierop & Oppenheimer, 1995. Meijer & Oppenheimer, 1995). In any case the social, psychological, and economic burden of asthma upon the family is heavy with social isolation of the family, economic constraints, and influencing the psychological well being of the child (Lenney, Wells & O'Neill, 1994. Weiss & Sullivan, 1994).

A number of investigations have demonstrated a multiplicity of attitudes, role perceptions, conceptions of causative factors, and effective management behaviours among families with asthmatic children and a substantial difference between views held by parents and health personnel (Mesters, Pieterse & Meertens, 1991. Brook & Shemesh, 1991. Wilson, Mitchell, Rolnick & Fish, 1993. Peri, Molinari & Taverna, 1991. Spykerboer, Donnelly & Thong, 1986).

With the advent of family therapy in the treatment of childhood asthma, an interest in the ways parents attempt to master the consequences of asthma has emerged. A critical understanding of the wider contextual relations, in which modes of consultations, nursing care, psychotherapy and scientific knowledge develop, has stimulated investigation into the strategies used by parents in

adapting to the disease and fighting its consequences as well as attempts at overcoming the lack of knowledge of patient and parent perspective on coping with childhood asthma (Towns, 1994. Onnis, Tortolani & Cancrini, 1986. Onnis, 1993). In this sense context refers to the parents and the family's social situation, including life cycle, inter-familial relations and the specific tasks related to the child's' asthma.

Lazarus views coping as a process of cognitive and behavioural efforts to master psychological stress. The evaluation of good or bad coping must be viewed in a context and in a long-term perspective (Lazarus, 1993). Later, Folkman (1997) has proposed a modification of the cognitive theory of stress and coping to accommodate positive psychological states. Folkman states that positive psychological states are the results of meaning-based processes that individuals choose to cope with stress, the search and creation of positive psychological states as a response to distress and the renewal function of meaning-based coping processes. Family resources in coping with childhood disability have been summarised as a balanced and reciprocal relation between illness demands, balanced coping and meaning. The meaning can be a part of the family identity and promotes competence and mastery (Cohen, 1999). Using a qualitative method, Jerrett and Costello (1996) found that coming to grips with

the child's asthma, and integrating its management into family life, were the primary issues for the parents. Of the four broader categories explaining the activity of the parents: symptom control, management strategies, having information, and gaining control, the latter emerged as the core category. The meaning of gaining control and integrating asthma management into family life were constructed over time (Jerret & Costello, 1996).

The complexity of the models of coping presents methodological and conceptual challenges for research. There are also inherent complexities in studying coping and adaptation as a dynamic, interactional process in the family. Descriptive research is needed, maintaining the essential holistic, person centred ways of coping. Somerfield (1997) argues that applied coping research must focus the specific challenge to allow broader, more conceptually sophisticated analyses of adaptation. In this study we chose a holistic perspective, emphasising the parents' experiences of coping. The description includes experienced stress, related coping responses and broader, contextually important factors and relations. We chose a research approach having its major benefits in the logical and systematical procedure of discovering hypothesis and substantive theories (Glaser & Strauss, 1967. Strauss & Corbin, 1991).

The aim of this qualitative study was to understand and explore parents'

experiences of coping with their child's asthma, contextual important mechanisms for coping and parents' ascribed meaning to their coping strategies.

Method

Subjects

The study sample consisted of 26 parents to 27 children with moderate or severe asthma aged 2 to 18 years, median age 8.4 years. The sample was selected from a group of parents with children suffering from asthma/allergy who had participated (20 subjects) or shown interest (six subjects) in family therapy. The family therapy program offered families with children suffering from asthma/allergy 1-6 therapy sessions, with two family therapists, one of them a paediatric allergologist and the other a social worker. In order to form a heterogeneous study sample, the parents were selected strategically in co-operation with the family therapists. Selected parents for the study were asked by letter about participating and informed about the aim of the study 1-3 months after family therapy or when it was sure that they wouldn't participate in family therapy. One parent did not accept being interviewed. When the study began 29 families had participated in the program described.

Data collection

Information was collected by means of thematised in-depth interviews in the homes of the families. 20 parents were interviewed in pairs and 6 parents alone. The interviews were audio-taped and transcribed word by word. The first five interviews were made by a psychologist in an attempt to evaluate the program of family therapy and describe challenges in parenting when a child is suffering from asthma. The following 11 interviews were made by another researcher, the first author of this report. None of the researchers participated in the family therapy sessions. Data collection and analysis was a simultaneous process and proceeded until saturation of information was reached. The interviews started by asking parents to tell about their family and continued by probing questions within four areas: (1) certain difficulties in parenting a child with asthma, (2) adaptation and strategies to master experienced difficulties and to receive support needed to manage their child's asthma, (3) perceived parental role in asthma and (4) perceived meaning of coping strategies.

Analysis of data

The method for sampling and analysis of interview protocols is inspired by the constant comparative method for grounded theory (Glaser & Strauss, 1967. Strauss & Corbin, 1991). Analysis of data was carried out in two ways: overview analyses and line-by-line coding to analyse and verify findings in

detail. The coding procedure in grounded theory was used with (1) open coding where substantive codes were identified, labelled and grouped together in more abstract categories, (2) axial coding where connections between categories were sought and (3) selective coding, the process where the core categories, the central phenomenon in the studied area and the relationships between these main categories were systematically identified. Two focus-group discussions, with 6 and 8 parents, of parental strategies and family consequences in caring for a child with asthma were made with the purpose of overview analysis, to develop theoretical sensitivity (Glaser, 1978). One focus-group, with 4 parents interviewed three times, was used for ensure validity of categories, as a kind of respondent validation process, in a late step of analysis. Validity was also ensured by verifying findings in one coding step by comparing with all other interview protocols. A high correspondence between a theoretical concept and its indicators as reflected in quotations from the interviews was regarded as a strong evidence of validity.

Results

Three core concepts and 12 descriptive categories related to these higher order core concepts were generated in the analysis of the interview protocols.

The story line

The core-concept describing the parents' experienced stress in caring for their child's asthma was labelled "chaos in caring". This concept includes dimensions of parents' experiences of stress such as "lack of control", "incompetence in caring", "disease-focusing", "existential fear", "closeness" and "uncertainty due to a non-understanding environment".

Two core-concepts, "cognitive control" and "locus of confidence in caring", describe the main contextual factors influencing the parents' coping with the experienced stress. Combinations of variations in the two core concepts were related to six categories describing strategies of parental coping (figure 1). These qualitatively different parental strategies, used by the parents to manage their everyday life situation, were grounded in data (see analysis) and labelled "problem-solving", "avoiding-assuring", "reducing", "relying on self", "complying" and "enduring" coping. The parents expressed that they used different coping strategies depending on their "locus of confidence" in a specific situation. Parents who were "confident of self" in a specific situation coped by "relying on self" or "problem-solving" coping, parents who were confident to a significant other coped by "complying" or "avoiding-assuring" coping and parents who experienced non-confidence in a situation coped by "enduring" or "reducing" coping. Parents using a high degree of "cognitive

control" in caring expressed coping by "problem-solving", "avoiding-assuring" and "reducing". Parents having a lower degree of cognitive control in a specific situation coped by "relying on self", "complying" to a significant other or "enduring" the specific situation. The core concepts of coping and the related six descriptive categories were included in a descriptive typology (figure 1).

Chaos in caring

Parents' expressed their experienced stress as a "chaos in caring". The related categories are described in the following text.

Lack of control

The lack of control includes parents' experienced uncertainty of the process, consequences and severity of asthma. Due to their uncertainty the parents were frequently visiting the emergency unit. Parents experienced a lack of control when the maintenance treatment was not adequate and extra medication was not sufficient.

Incompetence in caring

The parents described stress due to lack of confidence in their own ability and uncertainty of the best care. One common stressor was the lack of knowledge about effects and side effects of medication. Parents also described difficulties in sustaining care and treatment and coping with child's feelings towards care.

Disease-focusing

The time-consuming care and the focus of details in caring were experienced stressors. Examples were the parents' daily conflicts of finding time for personal interests, work, and attention to other family members.

Existential fear in caring

Uncertainties about the child's acute attacks were identified as a specific challenge. Important questions were when the acute attack would happen, how bad the incident would be and how the parents managed during attacks. Parents described a more or less daily fear of the possibility of the child's death during an incident. Some parents expressed having unbearable feelings of protection of their child due to an existential fear.

Closeness

The closeness includes a close relationship to the child with asthma in the more or less constant observation in caring. Some parents also described a family closeness because the whole family was being isolated from relatives or friends because of the child's asthma. This could bring feelings of sadness and a sense of frustration.

Uncertainty due to a non-understanding environment

Parents experienced a stressor in the lack of understanding, support and confirmation from the environment. They expressed feelings of being misunderstood, hurt and not appreciated

in the parental role. The uncertainty includes difficulties in co-operating and communicating needs to the child's environment.

Cognitive control

Cognitive control is the level of cognitive order and structure in coping experienced by parents. The concept describes parents' attempts to master challenges in caring such as gain control, assure protection, being available and gain competence. Parents have described using a high or low degree of cognitive control for the purpose of mastering experienced chaos in caring. Cognitive control is described as either necessity or a use of high or low levels of cognition in coping. The belief and confidence in one's own ability to influence the child, confidence in the child's own competence, perception of the child's state of illness and the risks inherent in the situation are critical for degree of control, protection and availability. Parents have described that coping by using cognitive control supports their efforts to distance themselves to and gain perspective on their life-situation. With increasing experience, the planning for maintaining the control describes as becoming more automatic.

Locus of confidence in caring

This concept describes how parents attempt to gain confidence in coping including integrity or inferiority, value and trust. Parents described self-confidence, confidence in a significant

other or a lack of confidence in the actual situation. The significant others pertains to the spouse, the teacher of the child or a doctor/nurse. The locus of confidence can differ according to situation and context. The parents' sense of self-confidence and self-worth regarding their role and function in

parental caring, as well as the parent's feelings of integrity and inferiority in relation to authorities, play an important role in this concept. The locus of confidence in caring is of critical importance for mastering interaction situations and acts like a trigger for changing coping strategies.

		<i>Locus of confidence in caring</i>		
		Self-confidence	Confidence in a significant other	Lack of confidence
<i>Cognitive control</i>	High degree of cognitive control	Problem-solving	Avoiding -Assuring	Reducing -Conflicting
	Low degree of cognitive control	Relying on self	Complying	Enduring

Figure 1. Parental coping strategies in caring for the asthmatic child described in combination of the two core concepts: cognitive control and locus of confidence in caring.

Problem-solving

Parents appreciate their own responsibility for ensuring which possibilities are open for their child's and their family's well being. They identify the goal, calculate the risks and obstacles and have openness for controlled testing to let the child live as normal a life as possible. This strategy allows the parents a sense of independence for finding solutions and satisfaction in surmounting obstacles. Parents are actively using cognitive strategies to assure security, i. e. good enough control, protection and availability, for

the purpose of not letting the child's asthma take too much time away from and cause too much worry in their own and their child's daily life. Parents mainly using this strategy give priority to their child's and their own independence and possibilities for a normal life. They have frequently described the importance of teaching the child about asthma and supporting the child's development of responsibility, independence and competence in managing asthma. The parents actively inform the child's surroundings and make lists and contingency plans for acute situations.

Parents try to solve problems by seeking information and are questioning experts until they gain satisfaction. In contact with important experts, like doctors and teachers, parents try different ways to overcome difficulties in communication and co-operation. They try to avoid identification with the disease. *Gaining a normal life* was described as the meaning to this strategy.

Avoiding-Assuring

Parents are using a high degree of cognitive structure in caring by assuring a constant availability, physical protection and control for the purpose of avoiding risks, presumptive risks and allergens. Parents describe an experienced lack in their own competence about asthma and manage by relying concretely upon advice and instructions given by health professionals. They described taking precautions for a wide range of possible risks. The fear of serious attacks of asthma is described as a driving force in cognitively assuring their child's security. Protecting the child is a prioritised necessity and a time-consuming activity, which demands a lot of planning around the details and circumstances of their child's asthma. They can have closeness with the child and isolate themselves by being constantly available for the child's needs. -*"We have no social life outside the family. We have to avoid meeting friends"*. Parents teach the child to avoid risks and be careful of its own health. Routines play an important role in maintaining security in daily caring.

Parents express a stepwise introduction, for the child, into new surroundings. *Gaining security* was described as the meaning to this strategy.

Reducing

These parents describe a lack of confidence in their situation and by minimising their own and their child's needs, they focus on the child's disease and prioritise its health at the expense of other aspects contributing to their quality of life. The consequences can be few social relations, loneliness and isolation for child and parents. -*"The home and school are free from critical allergens...the children have complained about having no friends...but it's important they are not tired and affected by their asthma"*. Parents can also manage by reducing the perceived importance of the non-understanding surrounding. They achieve this by conflicting with and/or intellectually reducing the importance of the other person and/or the current threatening event. Parents express that they have often felt disappointed about the lack of support from the health care system and the people in their surroundings.

Relying to self

These parents describe a certainty in relying on their own competence in caring for their child with asthma and are not using a high degree of actively cognitive coping. They even dissociate themselves from ensuring control. -*"If you struggle for control, you will lose control...therefore it's better not to*

have control". They find personal solutions and are not necessarily compliant to authorities. -"*I want to manage this with those I love, with my own family and I know I can. I do not often go to the hospital*". "*My child and I have to learn to feel what's right for us. I can't protect her from her difficulties with her asthma in school... she has to manage by herself*". Parents express that they are coping by guarding their own and their family's integrity. Parents express they are honest about their own and their child's emotions and are open-minded while attending meetings for learning experience, but do not of necessity follow given advice. Confidence in one's own convictions plays a role as power of resistance against a non-understanding surrounding. Parents are encouraging the child's self-confidence in managing asthma. Parents cope by viewing their life situation with a sense of coherence and find satisfaction in learning by experience. *Gaining wisdom* was described as the meaning to this strategy.

Complying

Parents have confidence in and compliance towards significant others surrounding the child such as the spouse, health care providers and teachers but also towards the general needs of the child. Doctors' and nurses' advice is interpreted as definite and followed without questioning. -"*He (the doctor) has not suggested that we could try...so I do not dare to challenge*". The parents are compliant to the rules in

school and pre-school and express a satisfaction in being orderly and no burden to others. -"*I send food everyday to school...so they don't need to think about the extra cooking and shopping*". Some parents have described a sense of inferiority towards authorities and/or lack of knowledge about asthma. Parents also described that they had difficulty influencing authorities and difficulties in arguing. The child's disease, with medication, treatment and caring occupies a significant portion of the parents' time. Routines are important in daily care and parents express an uncertainty in their own independent problem-solving ability. Parents describe a great desire for and the importance of meeting a sympathetic attitude from authorities and significant others. *Being orderly* was described as the meaning to this strategy.

Enduring

Enduring is the strategy using a low degree of structure while having a lack of confidence in oneself or any other close significant other in the current situation. Parents coping with the help of this strategy express difficulties in communicating needs and receiving support and are managing by passively enduring, unobtrusively comparing themselves to others having a worse situation, and hoping that the situation will change. -"*It is so hard and meaningless to ask for help...we do not have the strength*". Parents describe tiredness and sometimes resignation in own reactions toward the non-under-

standing surrounding. *"Most people do not understand. How could you tell them...?"* Parents express *"It has to work"* but are not planning *how*, *"I have to undergo and bear this"*.

Discussion

The findings highlight the parents' perspectives regarding challenges of childhood asthma, contextual important factors in their experienced coping and, also, the variation in parents' ways of managing their situation. The results imply that the use of cognitive structuring of thoughts and actions in caring, and the role of locus of confidence in caring, play an important role for parental coping with childhood asthma. According to the data, parents are using one coping strategy more than others but they are changing strategies according to experienced stress and confidence in specific situations. Our results do not include interpretations that one strategy is superior to any other strategy nor that there is a clear desirable sequence in the process of acquiring new strategies.

Finding or creating meaning in suffering has been described in a variety of settings. The findings in this paper give support to the modified model of coping proposed by Folkman (1997). Ways of coping experienced as meaningful generate positive feelings and support parents' ability to find solutions. In the present study, having a

positive psychological state due to meaning-based coping processes was found when using the "problem solving", "relying to self", "avoiding-assuring" and "complying" coping strategies. In this data, we identified no category describing meaning related to the coping strategies "reducing" and "enduring" coping. However, there's a possibility that the meaning related to "enduring" can be described as some kind of suffering, to remain in the situation. The meaning related to "reducing" could possibly be described as gaining or holding onto a feeling of being normal.

Parents' experiences of caring for their asthmatic child included intensive emotional stress, such as feelings of a chaotic lack of control and daily uncertainty. Some parents described an almost daily awareness of the risk that their child could die during an acute attack of asthma. The experience of stress was related to the possibility of an acute asthma attack. The paradox was that they had to rely extensively on their own competence and, during parts of the day, the competence of others, e.g. teachers in their child's surrounding. Having a non-confidence in the child's surrounding is a described stressful experience, linked to the nature of childhood asthma. The core category of the experienced stress, "chaos in caring", have similarities to Jerret's description of parents' initial reaction of confusion and emotional turmoil (Jerret, 1994) and, also, with

Jerret's and Costello's category "being out of control" (Jerret & Costello 1996). Advancing in the process of the model described by Jerret, parents "taking charge" of the situation; control, routines and schedules framing the experiences and opening the door to new possibilities (Jerret, 1994), is similar to our category "cognitive control/high degree". Although, while all parents in Jerrett's study described "taking charge" by taking control, all parents in our study did not. Even though we did not study the learning process, we found that there are parents not using a high degree of "cognitive control" in caring, as they do with the strategy "reliance on self", but even dissociating themselves from having control. The purpose expressed by the parents was that there was no personal need of structure in life by cognitive control or by giving priority to other values such as developing a more emotional confidence in oneself and one's child, by learning from experience and reliance upon oneself. Parents who use "complying" as a coping strategy can be viewed as having external, rather than internal, locus of control, for example control exercised by the health care provider or by the partner.

The use of higher respectively lower degree of "cognitive control" in caring can also be viewed as using more or less active and passive coping, respectively. Active coping can be easier to estimate and recognise than

are dimensions of passive coping both in research and in practice. One of the self-confident strategies, "problem solving", have similarities to what has been considered as an "empowered person" (Starrin, 2000). Some parents describe meanings in becoming active advocates for other parents, for example through a parents' association. Being appreciated in the role as an advocate for other parents as well as the new bonds and relationships with others sharing the same experiences is described as meaningful and supporting the parents' meaning-based coping.

Theories of coping focus on the regulations of distress by problem-focusing or emotion-focusing (Lazarus, 1993). Problem-focused coping attempts to influence the environment like strategies in the present study utilising high degree of "cognitive control" in caring. Emotion-focused coping strategies attempt to change the relational meaning, like strategies in the present study when related to "locus of confidence" in caring. Information and advice that parents receive from the hospital is mostly concentrated around the contextual dimension of "cognitive control" in caring while the psychotherapeutic conversation often deals with parents desire to give emotional aspects of coping like the "locus of confidence in caring".

Chronic uncertainty has in earlier studies been found to be an important stress factor for parents of children with

a life-threatening disease. The perceived meaning of mothering a child with asthma was conceptualised as "mastering uncertainty" by MacDonald (1996). Having a naive trust or absolute trust in the health care provider decreases the parents feeling of uncertainty but if the parents recognise discrepancies or ambiguity from their health care professionals, their trust was destroyed. Establishing trust for health care providers became an urgent issue for these parents (Thorne & Robinson, 1988). This mechanism is similar to what we described as parents using the coping strategy "complying" but opposite to the mechanism of using "relying on self" as a coping strategy.

Miller and Wood in a review of childhood asthma in interaction with family, school and peer system also present a biopsychosocial model for the treatment of chronic illness. They discuss the role of parenting and describe critical situations with parental challenges and conditions (Miller & Wood, 1991), similar to the experienced specific challenges we found, without relating and further describing parental coping strategies. There are several levels at which the health care provider can become involved in this process; from simply providing educational information to conducting intensive individual or therapeutic intervention (Doherty & Baird, 1986).

The results should be considered as a substantive theory of parental coping in

caring for their child's' asthma or, as an inductively discovering of systematically derived hypothesis. Further studies, with interviews at different stages of the disease and family development, could describe the different strategies in a process and be used in the evaluation of family interventions in childhood asthma. Studies comparing children, and later adults, with varying degree of asthma in comparison to parental challenges could illustrate how context of challenge promotes certain coping strategies of child and parent.

The study-group consists of parents who have shown an interest in family therapy about childhood asthma and the results have relevance for coping strategies represented by parents in this context. A positive aspect of our selection, which may have made the data "richer", is that the parents in the sample have both experience of and are positive to describing thoughts, feelings and strategies. An additional advantage of our selection is that parents in families utilising family therapy wish to expand their strategies, being dissatisfied with their previous coping and wishing to discuss how additional strategies could fit in with current tasks and how the family looks upon itself.

Data were collected by interviewing caregivers in pairs or alone. Strategies used and created jointly by parents in order to master their situations were the object of interest in this study. Although individual points of view

could have been hindered while interviewing couples, individuals mastering strategies are illustrated when shown in contrast to those of partners.

The results can be of importance in developing and evaluating family therapy interventions. The model of parental coping in asthma can also have practical importance for health professionals' assessment of parental coping for the purpose of meeting families, assisting them with their needs and helping families to find ways to use the health care system.

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Acknowledgements:

1. To Certified Psychologist Marie Levan for interviewing the first five families.
2. To "The Göteborg Medical Society", "Foundation for Research on Asthma and Allergy", "Arne Nyström's Memorial Foundation" and Nordic School of Public Health for financial support.

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