

Intervention models on psycho-social health in families with an asthmatic child

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Despite an increase in the prevalence of asthma during the last few decades, the need for hospital treatment of children with asthma has become less. One reason for this is that children and their parents are now more involved in the treatment of the disease, and responsibility has been shifted from the medical care system to the family. This new responsibility may cause increased psycho-social tension within the family. We conducted a pilot study on three limited methods of intervention to find the best way to help families in this respect. All three methods (individual family meetings, family group meetings, and evaluation of the child's environment in school) reduced the psycho-social burden of having a child with asthma. This indicates that families should be supported by being given the opportunity to participate in meetings to discuss the disease or to have the environment in the child's school evaluated, in addition to receiving regular medical care.

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Despite a doubling in the prevalence of asthma in children in recent decades, a markedly reduced need for hospital treatment has been observed (1,2). The morbidity of out-patients with asthma has probably also decreased, but this has not been clearly shown. Possible explanations are improved medical treatment and better understanding of the mechanisms involved in the disease. The child and parents have been taught when to give medication and when to stop it. They have also learned how to avoid situations that trigger the development of asthma. Thus, responsibility for treating the disease has been shifted from the medical services to the parents and children themselves (3–5).

The psycho-social consequences for the family as a result of this responsibility might create new problems. Therefore, this pilot study aimed to evaluate whether a limited intervention in the family can reduce the negative psycho-social effects caused by asthma in the child.

Subjects and methods

Study population

All children attending the pediatric out-patient clinic in a Swedish medium-sized community,

Örebro (Örebro Medical Center Hospital), during 1996, in the 4–13-year age-group (mean age 9.8 years) and with a diagnosis of asthma, were included (n=351). Children with moderate-to-severe asthma are referred to this out-patient clinic from an area with 30 000 children in this age-group. The group of families investigated comprised every other child admitted (n=170, three had moved and two were missed). This cohort was chosen to fulfil the following criteria: to ensure that the sample was representative; to include children with asthma of varying severity; and to include families who were coping in a variety of ways.

Study method

The study was designed to investigate and work with the family as a unit, in order to simplify the methods of intervention. 'Family' is defined as the unit of parent/s managing the child's daily care and possible siblings. A questionnaire entitled 'Impact of Childhood Asthma on the Family scale' (ICAF) was developed. It consisted of 68 questions from which 30 were chosen for evaluation. The questions were divided into eight broad domains: economy, work, contacts, free time, health, knowledge, environment, and

family. The economy and work domains were not used in the analysis because measurable changes in these domain values were not expected to be caused by the intervention. The parent was asked to rate each question on two dimensions: frequency and perceived weight of the problem. The former refers to how often a particular problem or situation arises, and the latter to the extent of the perceived problem it produces. The two dimensions in each question were scored as 1, 2 or 3 on an scale of increasing severity. Adding the figures for these two parameters created a 'severity index' for each question. A 'mean severity index' was calculated for each domain. The aim of the ICAF was to estimate the consequences for the family caused by the child's asthma, to identify problem areas, and to categorize families perceiving severe problems caused by this disease (stage 1).

The ICAF also included a questionnaire on the medical history to compare medical status with the perceived problems. One hundred and thirty-nine of the 170 families (95 boys and 44 girls) responded to the questionnaires. The male/female distribution of the non-responders was 21/10.

The families were divided into two groups: a high-score group, which comprised those reporting a 'mean severity index' higher than the mean for the whole cohort in at least one domain ($n=70$, mean age 9.2 years); and a low-score group ($n=71$, mean age 10.4 years). The high-score group took part in the intervention, but the low-score group did not.

Beta-2 agonists were used by 92% in the high-score group and by 82% in the low-score group. In the high-score group, 45% used this medication more than three times a week compared with 34% in the low-score group. Inhaled steroids were used for longer than 3 months in the last year, by 47% in the high-score group and by 39% in the low-score group. Seventy-one per cent in the high-score group and 52% in the low-score group had hay fever.

The 70 families in the high-score group were randomized to four groups (stage 2), three of which were intervention groups and one a control group (17 families). Group 1 (18 families) was offered one meeting (duration 1 h) alone with the pediatric allergologist and a social worker for information-sharing and also an evaluation of the environment in the home, day care center or school (15 of the 18 families participated). For nine children, both parents were present at the information meeting.

The second group was given the opportunity to participate in group discussions with other families and with the paediatric allergologist

and the social worker. These discussions involved information-sharing as well as an evaluation of environment. The second group was provided with the opportunity to attend two meetings, each lasting 1 h (six out of 17 families participated). Of three children, both parents attended each meeting. During both the family and the group meetings, the discussion followed a prearranged protocol. This protocol included questions with a high degree of similarity to those of the previously used questionnaire.

The third experimental group were only offered an investigation of the environment (17 out of 18 families participated). In all three intervention groups an allergology staff member from the Department of Paediatrics carried out the investigation. The environmental evaluation also included a telephone interview with parents and teachers. This interview followed a semi-structured design to evaluate the parent's perception of the school or day-care environment. When visiting the school or day-care centres, the staff member interviewed the child's physical education, handicraft, and chief class teachers. The environment investigation included evaluation of the child's classroom, the gymnasium, and the handicrafts workshop, as well as discussions about these environments and their effects on the child's asthma. Data from this evaluation was not fed back to the parents.

Stage three of the study consisted of an evaluation of the various interventions. All families received a new questionnaire that was constructed similarly to the ICAF. The families completed the first questionnaire in March 1997 and the second in March 1998. The second questionnaire was answered by 54 of the 70 families. All families who had taken part in any of the interventions, except for one from group one, answered the second questionnaire.

Ethics

Approval for this study was obtained from the ethics committee of Örebro Medical Center Hospital.

Results

Table 1 summarizes the questions and results obtained from each group, before and after intervention. Families who took part in the family sessions (group 1) showed a decrease in the severity score for most questions after this intervention. The differences were significant in the contact and free-time domains compared with the control group. As only six families took part

Table 1. Impact of childhood asthma on the family scale (ICAF) instrument questions, severity index for intervention groups, and control group means and significance

	Control (n=17)		Group 1 (n=14)		Group 2 (n=6)		Group 3 (n=17)	
	1997	1998	1997	1998	1997	1998	1997	1998
<i>Contacts</i>								
The family does not meet relatives and friends so often because of the illness	2.2	2.4	3.3	3.2**	3.2	3.7	3.2	3.1
When visiting friends or relatives, we can stay for only a short while	3.0	2.4	3.4	3.4	3.5	3.2	3.5	3.0
If there are siblings, we cannot let the friends of the sibling visit our house	2.0	2.0	2.5	2.8	2.0	2.0	2.4	2.4
We often decide that the child should not meet certain friends	2.0	2.0	3.2	3.0**	4.0	2.8	2.6	2.3
Sometimes it's difficult to use public transport	2.0	2.2	2.3	2.8	2.8	2.0	2.8	2.9
We often have to make last-minute changes	2.2	2.2	3.0	2.5	2.7	2.3	3.0	2.4
<i>Free time activities</i>								
The things we do together have been limited by the illness	2.0	2.6	2.7	2.6	2.0	3.2	3.4	2.7*
It is more difficult to find a baby-sitter	2.0	2.6	3.0	2.4*	2.0	2.0	3.0	2.2**
We have to restrict the child's activities considerably	2.2	2.2	2.5	2.6	3.0	4.0	2.8	3.2
Our planning of activities with the family has become more complicated	2.0	2.4	2.7	2.8	2.7	2.7	3.2	2.9
<i>Health</i>								
Because of the illness, we are sometimes psychologically or physically exhausted	2.0	2.4	3.6	2.7	3.0	2.3	3.4	2.7
We often feel that we are standing before an acute crisis	2.2	2.2	2.7	2.5	2.0	2.0	3.1	2.5
We often feel helpless, when handling medication in an emergency situation	2.8	2.6	3.1	2.8	3.3	2.0	3.1	3.0
We are afraid that acute medical situations may suddenly arise	2.8	2.4	3.8	3.2	2.0	3.3	2.7	3.0
We do not get enough sleep because of the illness	2.8	2.4	3.6	2.6	2.7	2.0	3.4	2.7
<i>Knowledge</i>								
We do not know enough about asthma.	2.6	2.2	2.8	2.6	2.3	2.0	2.3	2.7
We do not get enough information about asthma	3.0	2.2	2.5	2.4	2.0	2.3	2.4	3.0
The medical instructions are often so complicated that we misunderstand them	2.4	2.0	2.5	2.2	2.0	2.0	2.6	2.1
<i>Environment</i>								
There are factors in the home environment that negatively affect our child's asthma	3.4	2.5	3.2	2.4	3.2	2.3	3.2	3.0
Factors in the school/day-care environment affect our child's asthma negatively	2.9	2.8	3.4	4.2	2.6	3.5	3.4	2.8
In the home of the relatives, friends or in public areas the child can get asthmatic symptoms	3.3	3.8	3.8	3.9	2.9	4.0	3.3	3.5
<i>Family</i>								
One of the parents takes more responsibility for the child's disease, which results in discord	2.4	2.6	3.3	2.6	3.4	5.0	3.3	3.0
Siblings get less attention because the asthmatic child needs a lot of the attention	2.0	2.2	3.0	2.8	2.0	3.3	3.5	3.2
Discord within the family sometimes happens because of the child's illness	2.0	2.0	3.0	2.5	3.4	3.3	3.0	2.6
It is difficult explaining to siblings about their brother's/sister's illness	2.0	2.0	2.6	2.6	2.3	3.3	2.8	2.2
It is difficult explaining to the child about the illness	2.4	2.2	2.3	2.1	3.0	3.3	2.8	2.5
We have to suppress strong feelings within the family because we do not want to upset the child	2.0	2.0	2.2	2.0	2.0	2.8	2.5	2.6
We get problems because we have difficulty handling emotions within the family	2.0	2.0	2.2	2.0	2.6	2.0	2.5	2.4
It takes a lot of time because of the importance to always protect the asthmatic child	2.0	2.2	2.9	2.7	3.0	2.0	3.2	3.0
Because of the extra considerations we have to take, flexibility within the family has decreased	2.2	2.2	3.0	2.8	3.0	2.5	3.4	3.0**

*p<0.05; **p<0.01.

in the group meetings (group 2), the results were not analyzed statistically. In group 3, consisting only of evaluation of the environment, most questions showed decreases in the severity index, although they were only significant in the free-time and family domains. In the control group, no significant differences were detected between the two questionnaires.

Prior to evaluation of the environment, 23 of the 37 families (groups 1, 2, and 3) were of the opinion that such an evaluation is essential for understanding and treating asthma. After the evaluation, this figure had increased to 31 families. Five of the six families who took part in group meetings stated afterwards that group meetings increased their knowledge about asthma and its effects on the family. Before these meetings no family in this group believed in this method. Likewise, after the intervention, 12 of the 14 families who attended individual meetings approved of this method.

Statistics

To assess the quality of the measurement, a questionnaire reliability coefficient was calculated for each domain. The alpha value ranged from 0.79 (knowledge domain) to 0.87 (family domain). The reliability coefficient alpha tells how well scores obtained by testing represent universal scores. The accuracy or dependability of measurement and the reliability of measurement, is important if the researcher is interested in interpretable statements about differences. A score of ≥ 0.80 is considered good (6). A correlation analysis was carried out to test the relationship between the frequency of a problem and the perceived weight of problem for all questions. The correlation was ≥ 0.80 for all questions. A paired *t*-test was performed for all questions to evaluate the effect of intervention between 1997 and 1998 (for means and significance values see Table 1).

Discussion

Several authors have devised questionnaires to assess the impact of chronic illness on the family and their quality of life in groups similar to the one investigated in this study (7–11). We focused on the family as a unit and planned to evaluate both the frequency and weight of the problem. Currently available instruments did not fulfil these requirements, as they focused only on individuals in the family and problems were estimated only for one variable. The questionnaire used in this type of study should be easily completed by the

parent(s), fairly brief but wide in range so that the problems perceived can be assessed in several domains. The choice of gathering information through questionnaires and not interviews is a question of priority. If the measurement properties of the questionnaire are maximized, a questionnaire is both the most practical and objectively the most precise instrument in a population-based study (12). A high reliability factor for all domains used strengthened the view that the ICAF questions that were developed are relevant. A high correlation coefficient between the frequency and severity of problems indicated that the 'severity index' used here was appropriate. The population studied consisted of a random sample of children with asthma attending an ordinary pediatric out-patient clinic. Therefore the results of this study are probably applicable to children with this disease in other out-patient clinics.

The mean severity index, in each domain, was rather low despite the fact that families often reported problems. An explanation for this is that problems in single questions are high, but low-problem values are reported for other questions in the same domain. A severity index higher than the mean in at least one domain resulted in inclusion of the family in the active group. A severity index of 2 implied that the parents have denied psycho-social problems and an improvement can therefore not be studied. Selection of families with more pronounced problems would probably show more clear-cut results. Unfortunately, families in the control group had fewer psycho-social problems than the intervention groups at the start of the study.

The conclusions drawn from group two with group meetings as intervention are limited because few families participated. Parents had problems in finding time for a prearranged group meeting. The group session should therefore in our opinion not be used as a standard solution because of these practical problems. However, the families who did participate reported positive benefits.

For the other two intervention groups a positive effect was evident. Families were able to meet more easily with relatives and friends after the intervention, probably as a result of increased self-confidence. Therefore, the families could also, for example, use baby-sitters and have more time together. The psychological tension and fear of acute situations was decreased. In the family domain it was reported that the relationship between the family members was improved, and the possibility of openly discussing the

situation was increased. Effects concerning knowledge of the asthma disease and the medical situation were not influenced by the intervention because it focused on psycho-social and not medical questions.

As group one was intervened by both a family meeting and environmental analysis and group three by only environmental analysis, it was believed that the effect of the intervention would be more pronounced in group one than in group three. This was true for the contact domain, but differences for other domains were small. Evaluation of the child's school environment by a representative of the medical health service seems to be an efficient and easy way to create understanding of the child's asthma. This helps the family to improve treatment and also facilitates collaboration between parents and the medical service. Other studies have suggested that interventions like this could be used in children with other illnesses (13–15).

From the results of this study, it can be concluded that a limited intervention in families of a child with asthma and reporting psycho-social problems can result in measurable, positive, psycho-social effects. Families involved in the study reacted very positively to the intervention. Those families should be offered extra support beyond the traditional medical consultations.

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