

# Effect of Family Empowerment on the Quality of life of School-Aged Children with Asthma

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**Background:** Asthma is the most common, chronic, childhood disease. Its chronic nature and long-term treatment decrease the quality of life of children and significantly affect the family function. This study was conducted to assess the impact of family empowerment on the quality of life of school-aged children with asthma.

**Materials and Methods:** This was a quasi-experimental study. Forty-five asthmatic children (7-11 years) and their parents referred to the Pediatric Asthma Clinic in Masih Daneshvari Hospital were selected using convenience sampling and were randomly divided into case (n=14) and control (n=16) groups. Data collection tools included a demographic information questionnaire and Pediatric Asthma Quality of Life Questionnaire with standardized activities (PAQLQ). The validity and reliability of the questionnaire were tested. The family empowerment program for the intervention group included lectures, group discussions and demonstration of educational films. The questionnaires were filled out pre- and post-test.

**Results:** There were no significant differences before the intervention between the test and control groups in terms of demographic characteristics and PAQLQ scores. While, independent t-test showed significant differences between the two groups in PAQLQ total score and the subscale scores before and after the intervention (P<0.05). Paired t-test showed significant differences before and after the intervention in the case group in terms of PAQLQ total score and the subscale scores (P<0.001).

**Conclusion:** Considering the positive impact of family empowerment program on the quality of life of school-aged children with asthma, this program is recommended for proper control and management of disease and decreasing the complications in asthmatic patients of all age groups.

**Key words:** Family Empowerment, Quality of life, School-aged children, Asthma

## INTRODUCTION

Asthma is the most common chronic disease of the childhood, the first cause of absence from school and the third cause of hospitalization of children under 15 years of age (1). Asthma is a chronic, inflammatory disorder of the airways. This chronic inflammation is related to the hypersensitivity of the airways causing episodes of expiratory wheezing, dyspnea, chest tightness and cough

especially at night or early morning (2). The prevalence of asthma, its complications, and related morbidity and mortality are increasing worldwide. Such increase is attributed to air pollution, poor access to health care services, misdiagnosis and mistreatment (2). The World Health Organization (WHO) has estimated that the number of asthmatic patients will increase to 100 million

by the end of 2025. The results of a study by Entezari et al. revealed that about 8-12% of Iranian children and adolescents are suffering from asthma, and Kerman and Tehran cities have the lowest (2.7) and the highest (35.4) prevalence of asthma in Iran, respectively (3). The high prevalence of asthma poses a significant financial burden, for both direct and indirect treatment costs, on the health care system and the patients' families (4). Exposure to allergens or airway stimuli is the most common cause of development of asthma symptoms and asthma attack. Air pollution, weather changes, strong odors or perfumes, sport activities, stress, emotions, viral respiratory infections, some drugs like aspirin and esophageal reflux are among the most common stimuli for the initiation or exacerbation of asthma symptoms (5). Considering the wide variety of asthma stimuli, initiation of asthma symptoms/attacks cannot be predicted in child. This is a major challenge for children and imposes high stress on them. Moreover, the chronic nature of disease and its long duration negatively affect the quality of life of asthmatic children (6). Quality of life from the WHO's point of view, is an extensive concept affected by physical health, mental status, independence, social relations and communication with the environment (7). Physicians and researchers use the quality of life as a reliable index for assessment of treatment success in asthmatic children (8). The quality of life in school-aged children is influenced by the disease symptoms, subsequently limited activities, and asthma effects on the emotional and social functions of the child (9). The results of a study by Blackman showed that school-aged asthmatic children lose more school days than their peers and experience a high level of depression and other behavioral disorders (10). The high prevalence of asthma, its symptoms and complications and its effects on growth and development as well as other aspects of life of elementary school children, all emphasize the importance of research in this age group (10). During the school-age years, the children mimic their peers, become independent of the family and gain authority over their environment.

Lack of adequate physical strength may prevent the children's involvement in school activities and out of school programs and develops a sense of humility or insufficiency in them. Because, these activities result in acquiring social skills, sense of success and self-efficacy skills and learning effective stress coping strategies (1). Asthma in school-aged children particularly interferes with the communication of children with their peers. McGhan et al, in their study stated that school-aged asthmatic children were ashamed of using their medications in front of others. Also, due to activity limitations, these children are often made fun of, bullied or verbally abused by their peers. As the result, asthmatic children quit using their medications in order not to be different from others (11). As the asthmatic child grows, management of disease, which was used to be done entirely by the parents at home, is now done by the child under the supervision of parents. Thus, the child becomes more responsible about his/her condition. However, this self-management requires gaining knowledge and expertise regarding the nature and symptoms of disease, triggers and correct use of medications, and acquiring the necessary skills to adequately manage asthma attacks (1). Asthmatic children can gain the sense of control via education and support because school-aged children are capable of accepting the fact that they can very well manage their condition under the supervision of parents. Giving the responsibility of asthma management to asthmatic school-aged children is an important developmental process that promotes the sense of control and authority over the disease in the child. The National Heart, Lung and Blood Institute (NHLBI) and the National Asthma Education and Prevention Program (NAEPP) strictly emphasize on educating the asthmatic children, their parents and care takers. This education plays an important role in empowering the children and their families in asthma control, its better management and preventing its aggravation. It also improves the self-confidence of the children and their parents in control of disease symptoms. By appropriate management of

symptoms, the children can resume their normal activities and their quality of life is increased (12). Family as the main, most important pillar in the society, is responsible for providing adequate care for children (13). Evidence shows that family plays an important role in prevention and treatment of diseases. In the process of caring for a sick child, his/her family should have a correct perception of the disease. In addition to care for the sick child, nurses have the responsibility to help the family and increase their confidence and hope. This approach promotes family health and wellness (14). Chronic diseases of children adversely impact on the family function and involve the family with so many responsibilities and concerns regarding the child's health care needs, educational and medical services, disease costs, losing social opportunities, too many absences from work and physical and emotional problems. Thus, participation of the sick child in the process of care along side his/her parents is extremely important (1).

Empowerment is an intervention for better control of asthma and its management by the children and their parents. Empowerment is the cornerstone of the philosophy of family-based care. In this process, the patients no longer play a passive role in the course of their disease, instead, they become actively involved in the course of treatment and take responsibility of taking care of themselves by gaining adequate knowledge and skills in this regard. This participation in the treatment protocol further adds to patient satisfaction (15).

Studies on empowerment of children with chronic conditions emphasize on two important aspects of this intervention including its appropriate management, following a treatment regimen and establishing an effective interaction between the child and the health care team. The family-based care approach considers patients' family members as colleagues in the process of care in an effort to empower the family (16). Family empowerment aims to help families gain the required strength to change themselves. Family empowerment in asthmatic children

and their families aims to control asthma by enhancing knowledge, self-confidence and self-efficacy and coping with new behaviors. Nurses can also empower children suffering from chronic conditions via education, counseling and direct care. The process of empowerment can be facilitated by educating children regarding the method of disease prevention, control of symptoms, minimizing drug side effects, participation in physical activities and living a normal life (17). Patient education is a key intervention to promote the level of health and empower families with a child suffering from a chronic condition (18). This is among the most important responsibilities of nurses (19). In this process, instruction of empowerment emphasizes on educating the entire family and focuses on their strength points and capacities, educational needs, enhancing their knowledge and improving their participation in the process of care (17). Evidence shows that educating the sick children and their families enhances their authoritative knowledge and self-management skills (18). Asthma affects the quality of life of children as well as that of the other family members. Thus, this study aimed to assess the effect of family empowerment on the quality of life of asthmatic school-aged children. The hypothesis was that family empowerment would not affect the quality of life of asthmatic children.

## MATERIALS AND METHODS

This was a two-group semi-experimental study. The understudy population included all elementary school asthmatic children aged 7-11 years, presented to the Pediatric Asthma Clinic of Masih Daneshvari Hospital in Tehran from February 2012 to August 2013. Subjects were selected using convenience sampling and were then randomly divided into two groups of intervention and control. The inclusion criteria were children aged 7-11 years, presence of their parents, diagnosis of mild to severe asthma by the attending physician, no specific physical or mental disease, ability to fill out the questionnaires in Farsi

and willingness of the child and parents to participate in the empowerment educational program. The exclusion criteria were asthma recurrence (acute asthma attacks) and hospitalization that could affect the child's quality of life and was not controllable. Having another chronic condition (other than asthma) or a specific physical or mental disease were also among the exclusion criteria since they could adversely affect the quality of life of children. The limitations of the study were the psychological status of the child during the intervention period and their attention to details and accuracy when filling out the questionnaire; which could influence the results. The sample size was calculated to be a minimum of 17 subjects in each group using the sample size calculation formula and similar studies (20) taking into account the type I error ( $\alpha=0.05$  and possibility of type II error  $(1-\beta)=90\%$ ). A total of 45 subjects were selected and randomly divided into two groups of intervention ( $n=23$ ) and control ( $n=22$ ). Considering the drop out of 9 subjects in the intervention group and 6 in the control group (due to travelling, child or parents coming down with a disease, long commute, etc.), eventually data of 30 subjects including 14 in the intervention and 16 in the control groups were analyzed. Data collection tool was a questionnaire designed by the authors, which included 27 demographic questions (13 questions about the child's demographic information, 8 questions about the parents' demographic information, 6 questions regarding the family characteristics) and was filled out by the parents. The Pediatric Asthma Quality of Life Questionnaire with Standardized Activity (PAQLQ) designed by Juniper et al. that includes 23 questions in three domains of activity limitation (5 questions), symptoms (10 questions) and emotional function (8 questions) was filled out via interviewing the children (21).

The content validity of the tools was also assessed. Written permission was obtained from Professor Juniper to use his questionnaire in this study. Next, the tools were presented to 11 instructors and faculty members expert in the field and the tools were validated based on the

recommended modifications. The reliability of the questionnaires was assessed by calculating the Cronbach's alpha ( $\alpha=0.782$ ).

This study was performed in 3 steps:

*Step one (before the intervention):* After obtaining a written permission from the Research Deputy of the hospital, the researcher presented to the pediatric asthma clinic during work hours one day a week from February 2012 to August 2013 and considering the inclusion criteria, selected the patients for intervention and control groups. The patients and their families were also briefed about the objectives of the family empowerment program and received answers to their questions. The study protocol, the process of intervention and its safety were thoroughly explained to subjects and parents and written informed consent was obtained from parents. Verbal consent was obtained from children. Pre-test was then carried out.

*Step two (intervention):* Family empowerment program was used to improve the quality of life of asthmatic children, control of disease and self-management of asthma by the children and their family. The contents of the family empowerment program were designed by the researcher based on the requirements, concerns and weaknesses of asthmatic children and their families regarding the knowledge about asthma, its control and management according to accredited references in this regard. Based on the location of holding intervention sessions and better interaction and communication of children and their parents with one another and with the researcher, the intervention group was divided into two subgroups of 7 (parents and child) and two 2-h sessions per week and a total of 4 intervention sessions within 4 weeks were held for both intervention subgroups. In the first intervention session, subjects received information about asthma disease, its prevalence in children, pathophysiology of asthma, etiologic and aggravating factors and how to prevent them, control of asthma triggers both indoor and outdoor, most common asthma medications, their mechanism of action, correct use of

inhaler and respiratory supplements, instruction of pursed-lip breathing during asthma attacks, how to use a peak flow meter to manage asthma at home and how to use practical asthma guide. These topics were discussed by showing images and practical demonstration by the researcher. An educational film was also shown on how to use commonly administered inhaled drugs and respiratory supplements, washing and cleaning of these devices and use of a peak flow meter and how to read it. At the end of the first intervention session, a practical asthma guide card designed by the researcher under the supervision of an asthma specialist was given to the parents and it was emphasized that parents take the card with them to their physician and fill out all parts. Also, the children in the intervention group were provided with a colorful booklet of asthma management and control and an educational pamphlet containing a summary of all the information taught in the empowerment classes. Also, questions of the children and parents were fully answered during the sessions and after. In the 2<sup>nd</sup> intervention session, in the first hour, topics discussed in the previous session were briefly reviewed and all children were asked to show how they use their spray and inhaler one by one. Also, parents were requested to show the correct use of the spray, inhaler and their washing and cleaning. The researcher corrected them if they were wrong. In the second hour, the quality and quantity of nutrition of asthmatic children, nutritional problems of these children, foods that must be included in their regimen and important points in this respect were discussed by a nutritionist via showing slides and group discussion. During the 4-week intervention period, families were in touch with the researcher via phone and could discuss any problems with him. The control group underwent no intervention and received the conventional treatment as usual.

*Step 3 (post-intervention):* Post-test was carried out 2 weeks after the completion of interventions. Children and parents in the control group were also provided with a summary of all topics discussed in the empowerment

sessions in the form of a colorful booklet of asthma management and control and an educational pamphlet. To describe qualitative data, frequency and percentage and for quantitative data, mean and standard deviation values were calculated. In case of normal distribution of data, independent t-test or paired t-test was applied. For data with abnormal distribution, Mann Whitney test and Wilcoxon Signed Rank test were used for analysis.  $P < 0.05$  was considered significant and data were analyzed using SPSS version 16.

## RESULTS

The mean ( $\pm$ SD) age of children was  $9.57 \pm 1.38$  years in the intervention and  $7.86 \pm 1.75$  in the control group. The mean duration of disease was  $3.67 \pm 2.7$  years in the intervention and  $4.63 \pm 2.87$  years in the control group. The difference in this regard between the two groups was not significant ( $P > 0.05$ ). Table 1 shows that no significant difference existed between the intervention and control groups in terms of gender, participation in educational sessions, and use of spray ( $P > 0.05$ ). Table 2 shows the total and the subscale scores of the questionnaire before and after the intervention in both groups. The results demonstrated that in the intervention group, the total and subscale scores before and after the intervention were significantly different. The questionnaire scores in both groups before and after the intervention have been compared in Table 3. As seen in Table 3, no significant difference was noted between the two groups before the intervention but after the intervention, significant differences existed between the two groups in the total and all the subscale scores. Table 4 shows the mean subtraction before and after the intervention in both groups. In other words, difference in scores before and after the intervention was calculated separately for each group and the mean differences were compared between the two groups. The results revealed that significant differences existed in the mean subtraction before and after the intervention between the two groups in total and all subscale scores except for symptoms.

Table 1. The frequency and percentage of understudy qualitative variables in the intervention and control groups.

Group	Intervention			Control			P value
	No.	(%)		No.	(%)		
<b>Qualitative variables</b>							
<b>Gender</b>							
Male	16	(69.6)		12	(54.5)		0.299
Female	7	(30.4)		10	(45.5)		
<b>Participation in educational sessions</b>							
Yes	2	(9.1)		2	(9.5)		>0.999
No	20	(90.9)		19	(90.5)		
<b>Use of spray</b>							
Yes	23	(100)		20	(95.2)		0.477
No	0	(0)		1	(4.8)		

Table 2. Comparison of the mean and SD of the total score and subscale scores of the questionnaire in the two groups.

Group	Intervention group			Control group		
	Before the intervention	After the intervention	P value	Before the intervention	After the intervention	P value
<b>Subscale</b>						
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
<b>Total</b>	4.63 (0.73)	6.43 (0.28)	<0.001	4.81 (0.76)	5.77 (0.37)	<0.001
<b>Activity limitation</b>	4.92 (0.83)	6.52 (0.37)	<0.001	5.40 (1.01)	5.98 (0.57)	0.052
<b>Symptoms</b>	4.45(0.73)	6.56 (0.28)	<0.001	4.48(0.90)	6.10 (0.35)	<0.001
<b>Emotional function</b>	4.67 (1.02)	6.23 (0.31)	<0.001	4.85 (0.86)	5.23 (0.56)	0.091

Table 3. Comparison of the mean and SD of the total score and subscale scores of the questionnaire between the two groups of intervention and control before and after the intervention.

Group	Subscale	Before the intervention		P value	After the intervention		P value
		Intervention	Control		Intervention	Control	
		Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
<b>Total</b>		4.48 (0.73)	4.79 (0.73)	0.125	6.43 (1.27)	4.17 (1.36)	<0.001
<b>Activity limitation</b>		4.86 (0.87)	5.35 (1.10)	0.102	6.52(0.37)	5.98(0.57)	0.007
<b>Symptoms</b>		4.26 (0.77)	4.49 (0.87)	0.322	6.56(0.28)	6.10 (0.35)	0.001
<b>Emotional function</b>		4.52 (0.99)	4.82 (0.83)	0.277	6.23 (0.31)	5.23(0.56)	<0.001

Table 4. Comparison of the mean subtraction of total and subscale scores of the questionnaire before and after the intervention in the two groups of intervention and control.

Group	Intervention				P value	
	Variable	Mean	SD	Mean		SD
<b>Total</b>		1.80	0.75	0.96	0.75	0.006
<b>Activity limitation</b>		1.60	0.86	0.58	1.11	0.012
<b>Symptoms</b>		2.10	0.86	0.58	1.11	0.153
<b>Emotional function</b>		1.55	1.09	0.38	0.84	0.003

## DISCUSSION

The results of this study showed that the quality of life of school-aged asthmatic children was moderate to low. Dean et al. demonstrated that children with uncontrolled asthma gained low scores in all three aspects of quality of life namely physical, emotional and social aspects; which is due to uncontrolled asthma symptoms. Also, these children had more frequent emergency admissions and had more days absent from school due to frequent recurrences of asthma (22). The results of a study by Zandieh in Iran also showed that the quality of life, in the domain of activity limitation, in asthmatic boys was lower than symptoms and emotional function domains (23). Our results revealed that the mean total and subscale quality of life scores significantly increased after intervention in the intervention group compared to the control group. McGhan et al. indicated that group education for school-aged asthmatic children decreased patient admissions to the emergency room due to decreased frequency of asthma attacks (11). Alhani et al. also revealed that family empowerment intervention improved the quality of life of asthmatic children and increased their scores in emotional and functional domains, performance at school, and treatment of disease (20). In the current study, significant differences existed in the total and subscale scores before and after the intervention in the intervention group and all these scores significantly increased post intervention. Chatkin et al. demonstrated that 9.3% of school-aged asthmatic children in Brazil suffered from sleep disorders due to wheezing (24). Cano-Garcinuno et al, in their study on asthmatic children in Spain, Cuba and Uruguay showed that asthma management group instruction improved the overall quality of life of these children and its domains (activity imitation, disease symptoms, and emotional function) and also decreased asthmatic children's admissions to the emergency ward (25). McGhan et al. reported that instruction of asthma management and control improved the quality of life in the mentioned three domains and the intervention group children had less days

absent from school (11). Kelo et al. stated that instruction of patient empowerment intervention to diabetic school-aged children empowered the children and their families in blood sugar monitoring (19). Teach et al, also discussed that instruction of self-monitoring and self-management of asthma according to the principles of family-based care in asthmatics aged 12 months to 17 years, decreased occurrence of symptoms, patient admission to the emergency wards and consequently increased the quality of life of patients and their parents (26).

## CONCLUSION

The results showed that family empowerment program can help asthmatic children and their parents acquire the necessary knowledge and skills about their condition, its self-management and more efficient control. Larger scale programs are recommended to be performed on asthmatic patients in all age groups.

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