POSSIBILITIES OF EDUCATION OF CHILDREN WITH CYSTIC FIBROSIS

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Abstract

The present study deals with possibilities of education of children suffering from disease called cystic fibrosis. There is little research analysing how children with this disease feel, what their experience with school attendance is and what related problems there are from parent view. The study searches for answers to these questions. In order to answer research questions, the author chose qualitative research design. The data collection method used was interview with children suffering from the disease and their parents. Once the data were collected, interviews were transcribed and statements of parents and children suffering from the cystic fibrosis were coded. Coding generated these categories: teachers and child's disease, dealing with school duties, school absence, children's popularity within their peer group and children's school satisfaction. One of the findings of the research, among others, was the fact that the biggest problems of children were caused by cough and frequent time consuming inhaled therapy. Results also reveal that children also felt limited in education. They could not perform certain school activities. In her study, the author analyses these and other acquired categories. In spite of constantly improving treatment conditions, cystic fibrosis remains an incurable disease, which affects quality of education of young school-age children to a large extent. Especially teachers working with these children should take this fact into consideration.

Keywords: *child, parent, cystic fibosis, school attendance, teacher*

1. INTRODUCTION

Cystic fibrosis is a serious incurable disease which is often detected at an early age (neonatal or infant). Many children suffering from cystic fibrosis complains about dry mouth. Children are prone to infection (James, Nelson and Ashwill, 2013). Mucus which is on the surface of air passages is typically very dense, viscous and is a nutrient substance for bacteria. A dense mucus accumulates in air passages and is very hard to expectorate. For this reason there are different types of bacteria in air passages. Bacteria are transferred between ill people by a direct contact or by hands of medical staff (Austová, 2004). School attendance is compulsory for every child. A school together with treatment may place great demands on chronically ill children with cystic fibrosis, therefore it is possible to allow them a postponed school attendance or prepare them an individual study plan. Children with cystic fibrosis usually go to school regularly, a mild cough or treatment does not threaten them at school much. Teachers must know something about the disease and be acquainted with the information that cystic fibrosis is not an infectious disease. Children with cystic fibrosis cough more often or are more ill than normal healthy children. They need inhalation frequently during the day and take medicine before every meal. Meal during day is also important. A child has to eat regularly, he cannot skip a meal. It is important for a child to take part in a normal physical education like his classmates. With more demanding exercises a child does only what he can (Vávrová et al., 2000). Especially teachers working with these children should bear this in mind.

2. MATERIALS AND METHODS

2.1. Methodology

The aim of the study is to discover how cystic fibrosis affects life quality of a child of a younger school-age from the view of the child/his family in the field of education and school attendance.

The research population consisted of three mothers and their children. All the children were girls aged 10 to 11 suffering from cystic fibrosis. The mothers and the children themselves participated in the interview. The choice of respondents was intentional because they met these criteria: age, the same disease (CF), willingness to cooperate, consent with conducting the interviews. We obtained parents' consent with conducting anonymous interviews with them and with their minor children. In order to keep anonymity, every child and her mother were given a number and a fictitious name. Only mothers of ill children without their fathers were present at all the interviews. The age range of the mothers was 40 – 42 years. All three mothers responded willingly. One of the mothers is employed, other two do not work because they take care of their children at home and receive allowance for their ill child. The child No. 1 is Ema and she is 11 years old. The doctors diagnosed her with cystic fibrosis when she was 8 years old. She has been undergoing treatment only for 4 years. She is in the fifth grade of primary school. The child No.2. Eleven years old Sára was diagnosed with the disease when she was 8 months old. In fact she has been undergoing treatment since her birth. She also attends primary school and is in her fifth grade. The child No. 3 Klára is 10 years old and she has been fighting the disease since she was four. She is in the fourth grade of primary school.

We used the research method of structured non-standardized interviews with a child and her mother.

2.2. Research organization and data processing

The qualitative research was conducted in autumn 2017. The interviews were conducted with consent of the legal representatives of the children. Contacts of the respondents were obtained in consulting rooms of general practitioners for children and youth. After obtaining contact information of families and consents with conduction of the research from the parents, we arranged meetings with the parents and children. The interviews were always conducted with one mother and her child individually. They were given questions separately. The children responded in rather shorter sentences and inaccurately as well as one of the mothers. After agreement with the respondents, the interviews were conducted in a neutral place. The length of an interview with one mother and her child took approximately 35 minutes.

With consent from legal representatives, the interviews were recorded to voice recorder and then transcribed into electronic form. Obtained information was analyzed. We did content analysis of each case study. The results were processed and put into individual categories: teachers and child's disease, coping with school duties, school absence, popularity of children in a group, satisfaction of a child with school.

3. RESULTS

Teachers and child's disease – Information from parents: In all three cases teachers were informed about the disease of a child. Their disease was taken into consideration, especially in physical education classes. Children were limited to certain extent also in other school activities, e.g. outdoor school and swimming. *"Of course teachers know about the disease, when I registered her in aerobics I wanted them to know what it was about and that there were no one else. They always said that although they were two at school not to meet and miss each other. Therefore I checked that, the coach also knows. Because she is often ill. She, when she coughs, so they know it's normal. At school, her teacher also knows about it, I gave her a brochure, I think it's for teachers. When they were interested they read it. She was even at outdoor school in the second or third grade. She goes to these events, I always had to ask her teacher to help her. Because there is inhaler, medicine to take, because she takes medicine for livers twice a day and for digestion before meals. The teachers have always been very willing. They all praise her for being so good. They are willing to help so she can go to these events. And they help her when she needs"* (mother No. 1).

"The teachers know about the disease. My daughter said that her teacher seated her beside the sink, so I send a message that she could seat her in a different spot or she is big enough now, she says that herself, there is a sink here and the teacher knows. They went to the garden and she said she could not work with the soil because there are bacteria, we don't have plants nor stagnant water at home. And the teacher said you have flowers in the garden too, so stop talking and do it. So she got a note in the

record book for them to read and learn. For example the art teacher asked me if when we do something, the colors are a problem. It depends on each person, on the attitude. The class teacher told me that she had seen it on TV and then she searched for the information on the internet and she looked for them" (mother No. 2).

"Teachers know about the disease. I think that when it is necessary they take it into consideration" (mother No. 3).

Teachers and child's disease - Information from children: *"They see it like they want less from me in something, like in the physical education the teacher said I didn't have to run two rounds but only one but I told her it wouldn't influence anything and that I don't lose my breath"* (child No.1) *"No problem"* (child No. 3). *"I don't have problems with the teachers"* (child No. 2).

Coping with school duties – Information from parents: *"She handles the school just by herself. It's across the street from our house, so she comes home for lunch. She goes to primary school. She has nice grades, A's and B's. She had even an excellent midterm school record"* (mother No. 1). *"She copes with her school duties by herself, but because she is often ill we learn together at home"* (mother No. 2). The answer of Klára's mother was brief and rather harsh but in the view of what I learnt about Klára I was not surprised by it. *"She doesn't study at all, she has D's and she says nothing is worth it, she will die anyway"* (mother No. 3).

Coping with school duties – Information from children: Ema coped with school independently, she studied well and had nice grades. *"I handle the school by myself. I don't have much problems with anything"* (child No. 1). Sára was unfortunately frequently absent, which was reflected in her school results. *"I learn well but I have Cs"* (child No. 2). Klára went to school because of her friends, she is not interested in studying. *"I can handle school. I'm not often ill. Mostly when I don't feel like I'll die I don't want to stay home in bed"* (child No. 3).

Disease and school absence - All three girls were frequently absent from school. Apart from Sára, Ema's and Klára's absences were within rather normal limits. Sára tried to compensate her school absences by a more intense home preparation with help of her mother. If their acute condition allowed that, the girls went to school even when they were taking antibiotics. However, in these case they did not participate in physical education. Girls did not avoid more frequent appointments at doctor's consulting rooms which raised their absences as well.

Disease and school absence – Information from parents: *"she, although she is taking antibiotics, we don't let her stay at home, only on the most necessary days, when she is really ill. For example when she coughs and has a fever, but otherwise we send her to school, because it is really very close for her, she gets to school in two minutes. We discussed it also with her doctor, that unless she feels really very bad there's no reason to isolate her from her peers. In fact the antibiotics treatment of 14 days, the first five days are the worst but then she normally goes to school. She doesn't go only to physical education"* (mother No. 1). *"In our case, she is ill all the time. She goes to school and has to catch up with studies. Even at home I have to study with her. Her teacher gives remedial lessons, so we can go there anytime"* (mother No. 2). *"She is not often absent. But when she is, she doesn't catch up anything. She doesn't care at all"* (mother No. 3).

Disease and school absence – Information from children: *"Well I'm absent from school only when I go to the doctor or when I'm ill. I don't catch up on school work much, I don't study much"* (child No. 1). *"When I return after being ill, the girls ask me what's wrong with me. My teacher sends me pre-printed papers with tasks to fill them in"* (child No.2). *"I'm not absent much"* (child No. 3).

Popularity of children in a group – Information from parents: All the children were popular in the class group. *"Well, they have a good class, they are all friends. They are a group"* (mother No. 2). *"I think she is popular at school, she has many friends there"* (mother No. 1). *"I think she is popular in the group"* (mother No. 3).

Popularity of children in a group – Information from children: *"I like it at school, I have many friends. The teachers are nice too"* (child No. 2). *"Well, I have many friends in the class. I go out with them. There are my best friends"* (child No. 1). *"I think I'm popular, I talk to everyone"* (child No. 3).

Satisfaction of children at school - Information from parents: *"She is happy at school. She likes going there"* (mother No. 2). *"She is definitely happy at school, she looks forward to it, she has nice grades too. Nobody laughs at her because she is ill, they help her instead"* (mother No. 1). *"She is happy at school, she always looks forward to it"* (mother No. 3).

Satisfaction of children at school - Information from children: All the children liked it at school and were satisfied. *"I like school. I like art the most. I'd like to be a painter, guitar player or game manufacturer"* (child No. 2). *"Yeah, I'm happy at school, it's fine, I like it there. I like physical education and art the most. I'd like to be a teacher in a nursery school"* (child No. 1). *"I don't like it at primary school but I have fine friends there. I'm looking forward to secondary school"* (child No. 3).

4. DISCUSSION

Entering school is another level of socialization of a child and of his overall development. At a younger school-age, motivation to achieve something and for comparison of oneself with others is at the forefront. In the past, school attendance of children with cystic fibrosis was automatically postponed for health reasons due to their short stature and more fragile body constitution. Today in most children it is not necessary for these reasons. If they are also socially and emotionally mature, nothing impedes entering school in due course. We recommend the parents to inform in a written form the school management upon child's entering the school about their child's disease. We also recommend to inform the class teacher of their child about his or her disease in more detail, give the teacher printed materials or recommend web pages (Šmídová et al. 2009).

In all our three cases the teachers were informed about cystic fibrosis. One of the reasons why it is good to inform teachers about the disease is the fact that it is important that more children with cystic fibrosis do not meet at school – they could transmit bacteria on each other. During the teaching-learning process children were limited mainly in activities outside of school, but with teacher's understanding they could attend these events as well. Other disadvantages were frequent sickness rate and doctor's appointment. All three children were still attending primary school. In one case the child learnt well and coped with the school well. In the second case the child was often ill and studied at home a lot, the grades were worse. In the third case the child did not care what her grades were. All the children said they were satisfied at school. The parents also said the teachers were informed about the disease and took it into consideration, for example in more frequent absences or limitations given by cystic fibrosis. The parents also said that their children were happy at school. According to Kovácsová (2013, p. 39), "The educational process is complicated particularly due to frequent hospitalizations and long-term infects. These absences cause problems especially at primary and secondary school with a compulsory school attendance. However, it depends on and individual arrangement with teachers. Especially at primary and secondary school it seems to be indispensable to inform teachers about health condition and warn them that a person with cystic fibrosis is more frequently absent from school. We can say that the educational process is complicated by cystic fibrosis but the situation can be solved by an individual arrangement with teachers, hospital school or home education."

We consider very positive the fact that children with cystic fibrosis at a younger school-age are mostly open and communicative. They often talk about their disease free of constraint when they find a responsive environment. Some children want to show their classmates how they use their inhaler and breathing aid. They feel "special" in a positive way. It is good to support their communicativeness and lead the other healthy children towards thoughtfulness and help (Šmídová et al., 2009).

5. CONCLUSIONS

Children do not perceive their illness differently by their age but mostly they adapt to the disease and take it as a part of their life, of course with greater or smaller limitations. In conclusion we can summarize that the quality of life of the children was described differently in each ill child. To a large extent, both parents and children assessed the quality of life positively. Cystic fibrosis was well tolerated by all the children but they were limited in certain activities and they had to regularly adhere to therapy.

The educational sphere was considerably disrupted, since children could not participate in some school activities. In one of the cases the child was limited also in physical education. In another case the school attendance was disrupted by frequent sickness rate of the child and frequent appointments at the doctor. Teachers always tried to be responsive towards children and parents, but they were evidently insufficiently informed about cystic fibrosis. Raising teachers' awareness of chronic diseases might improve quality of educational process of children with a chronic disease in the future.

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