

## Investigating the Relationship Between Schools and Families of Children with Chronic Diseases in the East of Turkey

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### Abstract

**Objective:** The purpose of this study is to investigate the relationship between schools and families of children with chronic diseases.

**Design:** The study conducted was designed as a descriptive and relational study.

**Methods:** The population of the study comprised of the teachers and parents of primary school children attending 28 primary schools in Central Ağrı, who also have a chronic disease. Two thirds (2/3) of these schools was selected using a simple random sampling method. The study was conducted with 98 parents and 100 teachers that accepted to participate in the study. Descriptive information of the parents and teachers, and two different subject-related questionnaires were used to gather data between 15 March and 30 April 2008 for this study. Data were evaluated by using percentages and chi-squares.

**Results:** Results of study concluded that 83.9% of mothers and 73.8% of fathers shared their child's disease with their teachers; 43.6% of mothers and 63.9% of fathers had never met their child's teacher prior to her/his illness; and 76.9% of mothers and 61.1% of fathers met with their child's teacher from parents' meeting to parents' meeting after their child became ill. In terms of illness and adaptation to school, half the mothers and 54.8% of fathers collaborated with their child's teacher; 61.9% of mothers and 66.7% of fathers collaborated with their child's teacher regarding diet, medication, and activity.

**Conclusions:** Results of study concluded that the parent-school relationship of children with chronic diseases was inadequate. It is recommended that parent-teacher and healthcare personnel collaboration is improved so that children with chronic diseases can continue their school life in the same way as their peers, they can cope with the difficulties they experience due to their disease, and succeed academically.

**Keywords:** Child; Chronic Disease; Parent-School Relationship

### Introduction

Today, the number of children and adults with chronic diseases is constantly increasing; chronic diseases are one of the major health issues seen throughout the world, and in all industrialized countries [1]. It is a known fact that 1%-2% of the entire child population has a chronic health issue that affects daily activity or requires daily treatment [2].

Subject-related studies in literature report that children with chronic diseases experience various difficulties in adapting to school and social life [3]. Teachers have one of the most important roles in helping children adapt to schools. More often than not, teachers cannot receive adequate information from the parents and healthcare personnel regarding the overall health state of the child. Parents avoid informing teachers of their child's illness because they cannot foresee the reaction of teachers towards their child's illness, they are worried their child's illness will become common knowledge, or that their child will be treated differently [1,4,5]. After taking into consideration the different situations, teachers should establish solid communications with the ill child and their family, lean towards activities that make staying at school for the child easy, and decrease their anxiety, and should have realistic expectations regarding the child in order for ill children to take part in school activities like normal children; however, they should not be over protective [6-10].

One of the health objectives, set by the World Health Organization, for everyone in the European Region for the 21<sup>st</sup> century was, "Adolescents should be healthier by the year 2020 and should be able to play their part in society in a healthy manner." This objective highlights the importance of school health services [11, 12]. The school health services throughout Turkey, in particular in the East of the country, are

not at the required level. The parent-school collaboration is extremely important in terms of school efficacy, and the social, emotional, academic development, and academic success of the student [13]. Bilgin [14] reported that teachers conducted successful studies in order to develop parent-school relations. Literature states that parents only come to school when requested to do so for parents' meetings, and that the collaboration between family and school, the two most important elements that play a first degree role in preparing children for life, is insufficient [15,16]. In his study, Aslan [17] identified that there was no regular communication between schools and family in Turkey, and that relationships were unplanned and random.

The purpose of this study is to investigate the relationship between schools and families of children with chronic diseases.

### Methods

#### Design

The study conducted was designed as a descriptive and relational study.

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## Study Population

The population of the study comprised of the teachers and parents of primary school children attending 28 primary schools in Central Ağrı, who also have a chronic disease. Two thirds (19) of these schools were selected using a simple random sampling method; the parents and teachers of 107 primary school students having a chronic disease and attending these schools were planned to be included in the study. However, the study was conducted with 98 parents and 100 teachers as 9 of the parents, and 7 of the teachers refused to participate in the study.

## Data collection

Two different questionnaires, one directed at parents and the other for teachers were used to gather data for this study. The questionnaires were prepared by researchers based on related examples in literature.

**The parent questionnaire:** A questionnaire comprised of questions that investigate the socio-demographic characteristics of parents and ill children, whether or not parents share their child's illness with their teacher, the frequencies of their visits before the child become ill and after they inform the teacher of their child's illness, and how much they collaborate with teachers in terms of illness and school adaptation, medication, diet, and activity.

**The teacher questionnaire:** A questionnaire comprised of questions about the descriptive properties of teachers, the level of knowledge they have regarding the child's illness, whether or not they talk about the child's illness, whether or not they make a special effort to get in contact with the parents, whether or not they help the ill child to catch up in their lessons and homework, the teachers' thoughts on how helpful they are in supporting the children to continue their education successfully and whether or not their level of support is adequate, and the level of information they gain during training regarding ill children and their school life.

## Completing Questionnaires

Headmasters of the relevant schools were visited to determine the teachers with chronically ill children in their class in order to complete the teacher questionnaire. Teachers were provided information regarding the study, and appointments were made according to their availability. The questionnaire was given to teachers that accepted to participate in the study. Researchers went back to the school the following day in order to collect the completed questionnaire. The contact numbers of parents with chronically ill children were obtained from the schools in order to complete the parent questionnaire. Parents were contacted and provided information regarding the study over the phone; those that accepted to participate in the study were asked to complete the questionnaire sent to them via their children. Researchers went back to the school the following day in order to collect the completed questionnaires.

Chronic diseases were defined as illnesses, disorders, and disabilities present three months, or more, before the interview, or since birth, in accordance with literature [18]. The chronic diseases of children were categorized in seven groups based on systems; respiratory system diseases (Group 1), neurological diseases (Group 2), cardiovascular system-related diseases (Group 3), urinary system diseases (Group 4), endocrine system diseases (Group 5), hematologic-oncologic diseases (Group 6), and musculoskeletal system diseases (Group 7).

49.0% of children participating in the study were classified under Group 1, 15.3% were classified under Group 2, 12.2% were classified

under Group 3, and 8.2% were classified under Group 6, while those classified under Group 4, Group 5, and Group 7 were 5.1%.

## Statistical analysis

A Statistical Package for the Social Sciences (SPSS) software, Version 11.5 for Windows, was used to conduct statistical analysis. Percentage distributions and the Chi Square Significance Test were used to assess data. P-values less than 0.05 were regarded as statistically significant.

## Ethical Considerations

Verbal and written approvals were obtained from the related organizations before initiating the study. An ethical approval was obtained from the Research Ethics Committee at Atatürk University. The parents and teachers were informed about the purpose of the research, and assured of their right to refuse to participate or to withdraw from the study at any stage. The parents and teachers were informed that participation in the study was voluntary.

## Results

69.6% of mothers included in the study were aged between 26 and 35, 63.5% were primary school graduates, and 94.6% were unemployed. 42.8% of fathers participating in the study were aged 46 and over, 52.4% were primary school graduates, and all of them were employed. 57% of participating families were nuclear families, 54% had four or more children, and 55% had outgoings exceeding their income. 56.1% of the chronically ill children were boys, 41.8% were aged between 9 and 11, 38.8% had been suffering from their illness between 1 and 4 years, and 38.8% had been suffering from their illness between 5 and 8 years (Table 1). 56% of teachers participating in the study were aged

Characteristics	Mothers (n=56)		Fathers (n=42)	
	Number	%	Number	%
<b>Age</b>				
26-35	39	69.6	12	28.6
36-45	12	21.4	12	28.6
46 and over	5	8.9	18	42.8
<b>Education Level</b>				
Not Primary school graduate	9	16.1	9	21.4
Primary level	35	63.5	22	52.4
High school	12	21.4	11	26.2
<b>Alive</b>				
Yes	55	98.2	41	97.6
No	1	1.8	1	2.4
<b>Employment Status</b>				
Employed	3	5.4	42	100.0
Unemployed	53	94.6	---	--
<b>Total</b>	56	100.0	42	100.0
<b>Characteristics of children</b>	<b>Number</b>			<b>%</b>
<b>Gender</b>				
Girl	43		43.9	
Boy	55		56.1	
<b>Age</b>				
6- 8	27		27.6	
9- 11	41		41.8	
12- 14	30		30.6	
<b>School Year</b>				
Level 1	76		77.6	
Level 2	22		22.4	
<b>Illness Period</b>				
Less than a year	4		4.0	
1-4 years	38		38.8	
5-8 years	38		38.8	
9 years and over	18		18.4	
<b>Total</b>	100		100.0	

Table 1: Socio-Demographic Characteristics of Parents and Children.

between 20 and 29, 56% were female, 78% were class teachers, and 48% had five, or less, years of experience (Table 2). 83.9% of mothers and 73.8% of fathers share their child's illness with their teacher. 43.6% of mothers and 63.9% of fathers never met their child's teacher prior to his/her illness. 76.9% of mothers and 61.1% of fathers only met up with their child's teacher at parents' meetings after their child's illness. In terms of illness and adaptation to school, half the mothers and 45.2% of fathers collaborated with their child's teacher; 61.9% of mothers and 66.7% of fathers did not collaborate with their child's teacher regarding diet, medication, and activity (Table 3). 31% of teachers had not spoken to the child about their illness; 48.4% of teachers expressed that they did not feel the need to talk to the child regarding their illness, and 35.5% thought that talking to the child about their illness would upset them. 54% of teachers made no special effort to communicate with parents of ill children. The branch of the teacher had an effect on the level of communication established with parents ( $p < 0.05$ ). 68% of teachers believed that they were helping ill children to catch up with their school work and homework; however, 66% of teachers believed that the support they offer ill children at school was insufficient. 79% of teachers expressed that they received no information about ill children and their school lives during their training sessions. The majority of teachers (84%) believed that ill children would successfully continue with their education (Table 4).

## Discussion

School children experience more difficulties when coping with chronic diseases [5]. It is important that teachers know about the child's illness in order for the child to receive the necessary support from family at home, and from teachers at school. More than half of the parents participating in this study expressed that their child's teacher was aware of their child's illness. In his study, Alçı [4] reported that 23.5% of parents had not informed teachers of their child's illness; however, nearly half of them (43.3%) did not provide the teacher with the sufficient level of information regarding their child's illness. In their study, Coulter and Koester [19] discovered that parents had concerns about telling teachers about their child's illness. In his study, Andrews [20] identified that parents believed that the teacher should be notified of the child's disease; however, they preferred that the necessary information about the illness and treatment was provided by healthcare personnel.

Descriptive Characteristics	Number	%
<b>Age</b>		
20-29	56	56.0
30-39	37	37.0
40 and over	7	7.0
<b>Gender</b>		
Female	56	56.0
Male	44	44.0
<b>Department</b>		
Class Teacher	78	78.0
Branch Teacher	22	22.0
<b>Years of Experience</b>		
5 years and below	48	48.0
6-10 years	35	35.0
11 years and over	17	17.0
<b>Class Taught</b>		
Level 1 (first five years)	78	78.0
Level 2	22	22.0
<b>Class Size</b>		
20- 29	22	22.0
30- 39	48	48.0
40 and over	30	30.0
<b>Total</b>	100	100.0

Table 2: Socio-Demographic Characteristics of Teachers (N=100).

43.6% of mothers and 63.9% of fathers never met their child's teacher prior to his/her illness. 76.9% of mothers and 61.1% of fathers met with their child's teacher only at parents' meetings after their child's illness. The overall meeting frequency of parents and teachers for this study was insufficient. Literature also states similar findings to those of our study; parents only attend parents' meeting [15]. In his study, Demirbulak [21] identified that mothers had better communication with school in comparison to fathers, and that the level of communication deteriorated together with the increase in education level of parents. Leitch, Lauri & Sandra, and Tangri [22] determined that the level of communication with the school decreased together with the decrease in the education level of parents.

In terms of illness and adaptation to school, half the mothers and 45.2% of fathers collaborated with their child's teacher. Numerous subject-related studies in literature report that ill children cannot adapt to school and social life and they experience various difficulties [3]. Even though the attitude and behaviour of teachers is extremely important in ill children adapting to school, parents included in the study failed to establish the desired level of collaboration with teachers.

More than half of the parents participating in this study collaborated with teachers regarding the subject medication, diet, and activity. Literature states that a set of medication children need to take during school hours should be put in their school bags, and a spare set should be kept in a cupboard at school under the supervision of the teacher in order to make sure that there are no disruptions in the treatment of children with chronic diseases. Literature also states that family, teachers, and school management should work together in order to keep the child away from factors that may trigger their illness such as cigarette smoke, excessive effort, eating foods that disrupt their dietary needs, and excessive stress [23]. Parents participating in this study were identified to have no collaboration with their child's teacher in an effort to support the school life of their ill child.

Literature talks about the benefits of allowing ill children, regardless of their age group, to express their problems and need for help, to ask questions, and to talk about the causes and results of their illness [24]. It is a satisfactory finding that 69% of teachers participating in this study talked to ill children about their illness and shared their worries; however, near to half of the teachers expressed that they did not talk to ill children about their illness because they did not feel the need to do so, which proves the teachers lack of knowledge on the subject.

54% of the teacher participating in this study made no special effort to get in touch with the parents of ill children. The branch of the teacher had an effect on the level of communication established with parents ( $p < 0.05$ ). This result only proves that branch teacher must increase the level of sensitivity of other teachers towards ill children. Literature states that teachers place great importance on teacher-parent interaction, in particular [15]. In his study, Bilgin [14] reported that teachers carried out successful studies to improve teacher-parent relationships.

More than half the teachers participating in this study help ill children to catch up on their schoolwork and homework. Literature states that teachers need to help ill children to catch up on their schoolwork and homework in order for them to be successful in school [25, 26]. 66% of teachers participating in this study expressed that they felt the support they were providing ill children was inadequate. This result proves that teachers do not have the adequate knowledge to provide ill children with the professional support, as well as illustrating that factors such as the excessive number of children in a class, and the physical conditions of the schools also affect the support provided by teachers.

Parent's level of collaboration	Mother* Number	%	Father* Number	%
<b>Sharing the illness with the teacher</b>				
Yes	47	83.9	31	73.8
No	9	16.1	11	26.2
<b>Frequency of visits with the teacher prior to the child's illness **</b>				
Frequently	--	--	2	5.5
Parents' meetings only	22	56.4	11	30.6
Never	17	43.6	23	63.9
<b>Frequency of visits with the teacher after the child's illness**</b>				
Frequently	5	12.8	4	11.1
Parents' meetings only	30	76.9	22	61.1
Never	4	10.3	10	27.8
<b>The level of collaboration regarding illness and school adaptation</b>				
Collaborating	28	50.0	19	45.2
Not collaborating	28	50.0	23	54.8
<b>The level of collaboration regarding medication, diet, and activity ***</b>				
Collaborating	16	38.1	12	33.3
Not collaborating	26	61.9	24	66.7
<b>Total</b>	<b>56</b>	<b>100.0</b>	<b>42</b>	<b>100.0</b>

\*Column percentage

\*\*The number of mothers and fathers with children diagnosed ill after school started

\*\*\*The number of mothers and fathers with children that take medication, and have diet and activity restrictions

**Table 3:** The Level of Collaboration Between Parents and Teachers Regarding The Child's Illness.

Teacher's level of collaboration	Number	%
<b>Do they talk to the child about their illness</b>		
Yes	69	69.0
No	31	31.0
<b>Do they communicate with the ill child's parents</b>		
Yes	46	46.0
No	54	54.0
<b>Do they help the ill child with their lessons and homework</b>		
Yes	68	68.0
No	32	32.0
<b>Do they find the level of support they provide adequate</b>		
Yes	34	34.0
No	66	66.0
<b>Do teachers gain information about ill children during their education</b>		
Yes	21	21.0
No	79	79.0
<b>Do teachers believe that ill children can continue their education</b>		
Yes	84	84.0
No	16	16.0
<b>Total</b>	<b>100</b>	<b>100.0</b>

**Table 4:** The Level of Collaboration Between Parents and Teachers Regarding The Child's Illness

The majority of teachers participating in this study believed that ill children would successfully continue with their education. Johnson [27] reported that numerous teachers believed that health issues experience by children would restrict their education process.

79% of teachers participating in this study expressed that they were not informed about ill children and their school lives during their education. This result supports the assumption that teachers included in this study do not have adequate knowledge about ill children and their school lives. In their study, Gültekin and Baran [28] concluded that teachers need to attend regular in-house training courses in order to portray the correct approach towards ill children.

## Conclusion

Results of this study conclude that meetings between parents and teachers are not healthy and functional. It was recommended

that parents and teachers should be informed about chronically ill children, the collaboration better parents and teachers should be better established, and school health services should be activated in order to make sure that ill children can constantly continue with their school lives, and for them to have academic success and better life quality.

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