

Views of Parents and Teachers on Ways to Improve the Primary School's Response to Children with Chronic Diseases

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Many children with chronic diseases attend regular classes in public elementary schools, and their various needs are becoming a great challenge for the school and the educational system. Parents and teachers have the care giving responsibility for these children, but they do not always have the support or the means to meet those needs. Therefore, the school faces significant difficulties in responding to the challenge of attending to students with chronic diseases. This study's purpose is to assess, through an exploratory approach, the opinions of parents and teachers regarding what they consider to be the basic needs of the school to improve its response to the challenge of chronic diseases. Our methodology is qualitative, and we conducted interviews with 28 parents and teachers during the school year 2019-2020. We analyzed our data by applying the Thematic Content Analysis method. According to our findings, parents and teachers believe that if the teachers receive proper training on chronic diseases and specialists are integrated into schools, the response to the challenge will improve dramatically.

Keywords: Counseling, Chronic diseases, Education, Elementary school, Parents, Teachers

Introduction

Chronic diseases are defined broadly as conditions that last one year or more and require ongoing medical attention or are defined as such from the time of diagnosis (CDC, 2021), with cardiovascular diseases, cancer, chronic respiratory diseases, and diabetes being the deadliest among them (WHO, 2015; OECD, 2018; Harris, 2020). Today, chronic diseases are one of the biggest challenges worldwide and account for about 85% of deaths in Europe (Brennan, Perola, Van Ommen, & Riboli, 2017). Cardiovascular disease alone is responsible for more than 1.8 million deaths each year (EHN, 2017), while 3.7 million new cancer cases are diagnosed yearly (WHO, 2021). According to data from the European Academy of Allergy and Clinical Immunology (EAACI, 2018), about 150 million people suffer from allergies, and by 2025 it is estimated that half of Europe's population will be affected, while asthma rates are rising in most European countries (ERS, 2021).

Although chronic diseases are now considered the result of genetic predisposition, lifestyle, individual characteristics, adverse circumstances, and family and socioeconomic environment (Cattaneo, Tamburlini, Barcar, & Bruno, 2012; Tomljenovic, 2014; Agache et al., 2019), they also have common characteristics. These characteristics are chronicity, physical challenges, and the significant psychological impact on the individual

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and his environment. Their impact on quality of life is highly negative (Klein-Gitelman & Curran, 2015; Gillberg, 2016; Souza, Vasconcelos, Caumo, & Baptista, 2017; Barthel et al., 2018), and similar experiences often unite chronic diseases for the patient and caregivers (Dowrick, Dixon-Woods, Holman, & Weimann, 2005; Benkel, Arnby, & Malander, 2020).

Many children with chronic diseases attend regular schools, where in addition to their education, they also must manage their disease. In this context, the difficulties they face can cause them intense anxiety and confusion, uncertainty, and frustration (Bunford, Evans, & Wymbs, 2015; Vanclooster et al., 2019). In particular, the frequent absences of children with chronic diseases from school inevitably lead to significant academic difficulties (Gottfried, 2014; Hinton & Kirk, 2014; Bell et al., 2016) and undermine the healthy interaction in the school environment that is necessary for the normal development of the child (Maslow, Haydon, McRee, & Halpern, 2012; Klimstra, Beyers, & Besevegis, 2014; Emerson et al., 2016). In addition, they may have low school performance due to absenteeism, medication, or other special needs, but also due to the progress and management of their disease (Crump et al., 2013; Quach & Barnett, 2015; Vélez-Galarraga, Guillén-Grima, Crespo-Eguílaz, & Sánchez-Carpintero, 2016). Research findings suggest that these children are more likely to be bullied compared to their healthy peers (Sentenac et al., 2012; Crombez et al., 2012; Forgeron et al., 2013; Lucas et al., 2016).

School, however, is a vital part of the daily life of the children, and while it is a place that is already demanding, in the case where a child suffers from a chronic disease, the demands increase, especially when the education system is unable to respond effectively (Wambui, 2018; Boonen & Petry, 2019; Lum et al., 2019), with all the consequences for children, parents, and teachers.

In this context, our study's purpose was an exploratory approach to assess the views of parents and teachers of children with chronic diseases attending regular classes in regular public schools in Cyprus, as regards what they considered to be the basic needs of the school to improve its response to the challenge of pupils with chronic diseases.

Our research questions were: (a) What do parents consider to be the basic needs of the school to improve its response to the challenge of chronic diseases? (b) What do teachers consider to be the basic needs of the school to improve its response to the challenge of chronic diseases?

Methodology

Our methodology was qualitative, and we obtained our data by conducting semi-structured interviews with parents and primary school teachers in public schools in Cyprus. We chose this method because it reflects our belief that qualitative interviews allow an in-depth exploration of the participants' perception of how the school will improve its response to children with chronic diseases.

Sample

Twelve parents and 16 primary school teachers in Cyprus participated in the survey. The participation criterion for the parents was to have a child with a chronic disease attending a public primary school in Cyprus, and the participation criteria for the teachers were: (a) to serve in a primary public school in Cyprus and (b) to have come into contact with a child with chronic disease in a general classroom. Regarding the parents, the majority of the participants were mothers, and this is not surprising since relevant studies refer to the role of mothers of children with chronic diseases and indicate that in most cases, it is the mother who takes the central

role in the management of the disease (Macedo, Silva, Paiva, & Ramos, 2015; Skarstein, Bergen, & Helseth, 2020). Mothers are the ones who reconstitute their social and vocational status and dramatically reduce their free time for the care of their child (Nelson, 2002; Green, 2007; Smith et al., 2013; Hatzmann et al., 2013). Therefore, their more vital willingness to participate does make sense. To recruit our subjects, we used the avalanche method, and we present all parent and teacher data in Tables 1 and 2.

Table 1

Parent's Profile

Code	Sex	Child's disease
P1	F	Diabetes T1
P2	F	Idiopathic Thrombopenic Purpura
P3	F	Diabetes T1
P4	F	Congenital Heart Disease
P5	F	Diabetes T1
P6	F	Diabetes T1
P7	F	Food Allergy
P8	F	Juvenile Idiopathic Arthritis
P9	F	Cancer
P10	M	Diabetes T1
P11	F	ADHD
P12	F	Epilepsy

Table 2

Teachers' Profile

Code	Sex	Years of experience	Disease(s) they came to contact with
T1	M	35	Diabetes T1, Mental Illness, ASD
T2	F	32	Diabetes T1, Epilepsy, ADHD, Mental Illness
T3	F	27	ADHD, Epilepsy, Diabetes T1, Haemophilia, Cancer
T4	F	22	Diabetes T1, Cancer
T5	F	22	Diabetes T1, ADHD, Autoimmune Disease
T6	F	22	Epilepsy, Diabetes T1, ADHD
T7	F	21	ADHD, Diabetes T1, Asthma, Epilepsy
T8	M	21	Diabetes T1, ADHD
T9	F	21	Hearing Loss, ASD, ADHD
T10	F	20	Diabetes T1, ADHD, Asperger's Syndrome
T11	F	20	ADHD, Diabetes T1, Epilepsy
T12	F	18	Asthma, Epilepsy, ADHD
T13	F	17	Diabetes T1
T14	M	16	Diabetes T1
T15	F	13	Diabetes T1, Partial Blindness, Tetraplegia, Asthma
T16	M	11	Hemiplegia, Food Allergy, ADHD

Data Collection and Analysis

We collected our data through semi-structured interviews as this method provides an opportunity for the participant to express personal opinions in length. Data collection stopped when it became apparent that no new data would be added, and therefore saturation occurred (Latham, 2013). We recorded each interview and transcribed the data word by word to maintain each participant's style and tone. We carried out data analysis

by applying the Thematic Content Analysis, which according to Bengtsson (2016), is an ideal method for subjects where opinions and experiences are studied. We present the two phases of the thematic analysis in Table 3.

Table 3

Phases of Data Analysis

Phase one	Phase two
1. Transliteration	5. Grouping
2. Organization of data	6. Repetition
3. Coding	7. Transition
4. Repetition	

Following the processing of the data and the codification, two categories emerged: training the teachers on chronic diseases and the need to integrate specialists in schools. We present these categories in Table 4, along with their labels.

Table 4

Categories and Labels

Category	Label
Teacher training	The views of parents and teachers on whether there is a need for teacher training in chronic diseases
Integration of specialists in schools	The views of parents and teachers on whether there is a need for integrating specialists in schools, for the management of chronic diseases

Results

Category 1: Teachers' Training

According to all participants, the training of teachers on chronic diseases is not only necessary but must also be of high quality. As far as parents are concerned, all teachers should receive relevant training, as this will make them more aware and sensitive with children with chronic diseases:

Maybe the training made them more aware and sensitive, and they could... should I say act more voluntarily? If they have the knowledge, it will make them more sensitive, if they knew that there are these cases, there are these children who need help, and we must help them...Perhaps it further cultivated the sensitivity of the teachers. (P8—Juvenile Idiopathic Arthritis)

I believe they would be closer to the children and more sensitive. More aware. They would show more understanding. (P9—Cancer)

Teachers need to eliminate the fear and anxiety they feel when they have to manage a chronic condition in their class, and consequently, they will control their responsibility phobia. Training could help in this direction, and this is an obligation of teachers, as their profession is humanitarian:

Basically, they are anxious. Especially when they (teachers) must deal with a child with a health issue instead of behavior problems, especially when they must pay attention to something, I think this worries them. However, responsibility phobia is not a solution. Anyway, it is their profession since they are educators. Training is important. (P5—Diabetes T1)

A different opinion was expressed by one participant, who believed that although training is necessary, it cannot change those teachers who are not really interested in children with chronic conditions:

I believe that any professional in the field of education or the field of health or justice if he does not like what he is doing and he goes to work just for a salary, even if you train him nothing will change. However, ok, teachers need to know because there are children who either lost their parents, or children who are sick, or children whose father is an alcoholic... (P4—Congenital Heart Disease)

However, the only father who participated in our parents' sample explained how he experienced a significant change in his child's teachers when they began to be informed and gained knowledge about Diabetes:

The teachers' fear stemmed mainly from ignorance. They were terrified of this thing. That something can happen, and things might get out of hand. But I witnessed the change when they learned more about diabetes. Teachers must be trained, gain knowledge and through regulations, they must learn to follow protocols. (P10—Diabetes T1)

Teachers agree with parents that there is a need for training and that this can change things for the better. The teachers' opinions differed whether this training should be for all teachers or only for those who have a child with a chronic disease in their classroom during the current school year. Teachers understood that these are matters of life and death, and although chronic diseases are part of the school's everyday life, appropriate training is not provided:

Diseases are situations we encounter in life. Training is crucial, and maybe it is more important than any other training that we receive, which is valid only for a year. These are the most important issues, and we all had to deal with them. There are other pieces of training that we repeat every year, without anything substantial. In contrast, these matters of life and death are more important. (T4)

So far, we have seen only trivial and spasmodic moves by those in charge and only under the pressure of stakeholders' demands and any current circumstances:

Everything we do is trivial, spasmodic, under the pressure of demands from either parents or teachers, and then other problems occur. There is no strategy, no right approach, no policy to support knowledge and action. (T1)

A teacher criticized this situation with bitter humor and lurking anger:

The training must be specialized. Not this general first aid-thing, where we start with gauze and end up with acid and epilepsy. And you leave with 10-15 sheets of paper and you do not remember a word of what you heard, and you must start again from the beginning. Are we serious? (T8)

As one participant explained, if the teacher is held responsible for the child at school, then the Ministry of Education must also train and educate him regardless of the existence or not of a child with a chronic disease in the classroom, and in fact, this training should take place during the basic studies at the undergraduate level as well:

For such situations, there has to be something in basic education as well. With education, you become complete, and beyond that, since the teacher has part of the responsibility, you have to train him. There is a part of responsibility even when the instructions are to call the parents to give the medicine for any issue. There is part of the responsibility to the teacher, and in order to take it on, you must train him accordingly. (T10)

However, not all participants agreed with the general training either at basic studies or at postgraduate or in-service training. Five teachers believed that targeted training will have better results depending on the needs of the school unit. As one teacher explained, general training is vague, so the teachers should be trained according to the case they face each time:

Difficult situations occurred many times. Not because the teachers would not take the responsibility, or they do not feel the children and do not understand them. We are not an expert in all matters. I am neither a doctor nor a nurse. Based on the problem you have in front of you at any given moment, you should get the proper training. Properly, practically, and well organized. Not generally and vaguely, as we know that something like that will not work. (T5)

In any case, teachers need and require training for chronic diseases. The participating teacher with the most years of experience in schools expressed an opinion that stands out with its quality and simplicity, which seems to raise teacher training in its proper dimension. A message that should reach all levels of education and concern everyone involved with it:

If we, the teachers, spend more time with a student who is naughty, agitated, has problems with discipline, does not a child who is not to blame for his problem have the right to get more time and care? Since we do it with other children who cause problems not because of an illness but because of their parents or other situations, why not do it with sick children as well? (T1)

Category 2: Integration of Specialists in Schools

The participating teachers and parents agreed that training can significantly improve the situation, but it is not enough. In parallel with the training programs, they considered it necessary to include specialists in schools, people responsible for the children with chronic diseases, and supporters of the teacher in his work. This special staff could either be medical staff (nurse) or another specialist, such as a counselor or social worker.

As far as teachers were concerned, opinions on the required specialty differed. Seven teachers stated that there must be medical staff in schools, while nine argued that this was unnecessary. Instead, there could be some other specialty, as long as that specialist will bear the responsibility for the children with chronic diseases in the school unit. Those teachers who considered the integration of medical staff in schools to be an ideal solution focused more on the medical aspect of the diseases, taking into account other cases in school that might also need medical care: The participating teachers and parents agreed that training could significantly improve the situation, even though it is not enough. In parallel with the training programs, they considered it necessary to include specialists in schools, people responsible for the children with chronic diseases, and supporters of the teacher in his work. This special staff could either be medical staff (nurse) or another specialist, such as a counselor or social worker.

I think the training would be good but it would be much more essential to have a nurse. Because in cases where a crisis occurs or something very serious, I think even if you have the right information or even some support, it is not enough. A nurse would be great. A regular health visitor perhaps. Be there at school for any situation. For cases of accidents, where we wonder how serious they are, it would help a lot. (T3)

The above appeared to be the ideal solution for some teachers because the teacher, even if trained, will not be able to cover the full range of chronic diseases and their various medical aspects:

There should be a nurse at school anyway. I do not know, I am not the one to judge it, but it is good to have a specialist in the school, where you can turn; because we cannot cover the full range of the existing diseases. Things are hard for us. (T13)

Our findings indicate that the responsibility of medical issues in school was of great concern to teachers, which is why they believed that a specialist would be the most suitable person. As one participant explained, when referring to diseases and medical issues in general, one could not assign further responsibilities to someone whose role in the school is to teach:

It is good to receive training, but we cannot have the full responsibility. Okay? Training needs to take place; anything we learn is good. To have the knowledge, as for sure, we will have a child with a (chronic) condition in class, but we are not experts; we are teachers! (T12)

Teachers who did not focus on the medical aspect of the disease expressed the view that medical staff was not necessary. Instead, they believed that the teacher just needs support in his work and a responsible person who will act as a liaison between school and family:

I do not think that medical staff is necessary for schools. A social worker could also be valuable in a school to connect the school and the family. That would be very helpful. Moreover, primary school counselors could have a special role and would be very helpful. In other countries, they have this service, and it is also a connecting link between school and family. Nevertheless, he is a counselor—a psychologist. Think about it; this would be ideal. (T11)

This year, an experienced teacher who worked along with special education teachers at her school stated that this is the best and most important choice. Precisely because they are special education teachers, their work is very demanding but they have the required knowledge to be productive and effective. She expressed great faith in the new generation of special education teachers:

Experts generally push the system forward. I hope that when special education teachers, scientists-teachers come in, people with the expertise, the proper training, with the knowledge, we have a future. Because they will be demanding in terms of service, in other words, they will not accept discounts. Because the teachers of my generation, make their discounts. (T2)

On the other hand, most participating parents believed that only medical staff would be suitable for taking responsibility for children with chronic diseases in school. It is important to note that even participants who felt that a specialist, such as a nurse, may not have served their case, recognizing the needs of the children and the fact that teachers also need support, considered that this request was valid, and was not at all excessive to include medical staff in schools:

Having a nurse at school might not have been helpful in my case. Maybe for other diseases, yes. However, it must exist. I mean, a specialist is necessary, even if it would not help in my case. It can help the teachers, though. (P2—Idiopathic Thrombopenic Purpura)

In addition, the medical staff in the school might have sensitized the teachers and other school staff and set things in motion precisely because they can support, consult, and make use of their medical knowledge:

In our case, we would not need a nurse at school; she would not help us with something in the medical part. My daughter would not get sick at school to need medical attention on the spot, but knowing that there is a nurse on duty, someone who knows that this child has these problems might push things a little further to help her out. Educationally, I mean when she loses so many classes. (P8—Juvenile Idiopathic Arthritis)

As one mother explained with great concern, what will happen if a parent of a child with diabetes does not have time to go to school in case of emergency?

If a nurse is there, she could help. She could hold the medication. However, since there is no medical staff, I cannot keep the insulin at school, nobody would take it, I cannot give them to my child. In case of need, I have to go there personally. There must be a nurse in every school. It is not just my child. What will happen in case of an emergency? Will they wait for the mother? If she manages to get there on time? (P1—Diabetes T1)

Another participating parent explained how she set it as her immediate priority when the child went to

primary school, stating that for her, a nurse on duty would be a decisive factor in choosing a public or private school in order to feel safe for her child:

I would be very relieved to have someone (a nurse in school). It can help a lot, for many children, not just mine. Anything can happen. [...] It is important to feel confident. I may be close to the school, and so they may find me in an emergency, but... It is different to feel that someone gave him the medicine, that a specialist is with him. Do you understand? You feel safe that there is no time delay, there is someone who can handle it. (P7—Food Allergy)

Of course, parents realize that integrating medical staff in schools in Cyprus is not that easy: “It will surely help a lot but is it possible?” (P12—Epilepsy) The discussion on this matter is on-going, but still to no effect. As another participant explained, in case it were applied, it would be better than any other service:

They must get someone who knows, in—a nurse. There was a suggestion, I have heard it. I know it is challenging, but it is the right thing to do. It is better than having a school assistant. Nobody contacted me from the other services, nor anyone ever saw my child, nor can anyone else help. Only a nurse can. (P6—Diabetes T1)

Discussion

According to WHO and other health organizations, it is a fact that chronic diseases show an increasing trend (WHO, 2021; ECDA, 2021), and they are situations that profoundly affect both the patient and his environment and quality of life (Barthel et al., 2018). Our research focused on an exploratory approach of parents and teachers of children with chronic diseases in regular classrooms in primary school as to what the school needs to better respond to the challenge of pupils with chronic diseases. Regarding our research questions, both parents and teachers agreed that there is a need for teacher training in chronic diseases and specialists' support in the school unit. Teachers did not necessarily consider these specialists to be medical staff, but the vast majority of parents believed that medical staff is best suited for this role.

For the parents of children with chronic diseases, the school day should be a valuable break from the physical and psychological stress of caring for their child. They want their child to have positive school experiences and to enjoy an equal treatment at school. Instead, they often have to deal with problems such as the lack of support and ignorance (Brown, 2012; Jonsson, 2013; Kise, Hopkins, & Burke, 2017; Simon, 2017) so that the stress and pressure exerted on them increases. On the other hand, the teachers of children with chronic illnesses themselves do not remain unaffected, as they are called upon to face challenges outside the immediate field of their education, training, or experience, to reconstruct roles, and to take on responsibilities many times without the required knowledge and support (Lucas et al., 2012; Srivastava, De Boer, & Pijl, 2017; Getch, Neuharth-Pritchett, & Schilling, 2019). Therefore, both parents and teachers who participated in our study expressed the belief that training and support are required for better school responses to chronic diseases.

Our findings are in line with other researchers' findings worldwide. Numerous studies indicated that teachers very often are not able to adequately manage chronic diseases (Brabcová, Kohout, & Kršek, 2016; Snopek & Moravcikkova, 2017; Plisková & Snopek, 2017; Irwin et al., 2018), as they do not have the required knowledge (Kise, Hopkins, & Burke, 2017; Solé et al., 2017). For example, in Cyprus, a recent survey by Stavrou and Demetriou (2019), administering a questionnaire based on the Perception Scale for People with Epilepsy (ATPE), found a lack of knowledge about epilepsy and severe misconceptions about it in public school. Teachers' lack of knowledge is not limited to epilepsy, but the problem extends to the whole range of chronic diseases (Kise, Hopkins, & Burke, 2017; Berger, Valenzuela, Tsikis, & Fletcher, 2018; Irwin et al., 2018; Getch, Neuharth-Pritchett, & Schilling, 2019; Gómez et al., 2020).

This lack of knowledge from teachers raises strong concerns among parents about their children's safety and education and leads to discrimination against children with chronic diseases at school. Consequently, teacher training in chronic diseases is necessary (Murray, Hurley, & Ahmed, 2015; Kampra et al., 2016; Brabcová, Kohout, & Kršek, 2016; Berger et al., 2018). In addition, when qualified specialists do not support teachers, they feel that such a responsibility is a burden on them (Johnson & Melton, 2014; Horn, Mathis, Robinson, & Randle, 2015; Kime, 2014; Somech & Bogler, 2019; Wilt, 2020).

In terms of integrating medical staff in schools, this can be of great value for the children and teachers, and parents. It is considered crucial for the school when it comes to children's health issues (Peery, Engelke, & Seanson, 2012; Jones, Brener, & Bergren, 2015; Leroy, Wallin, & Lee, 2017), as specialists can improve attitudes, perceptions, and skills and fill significant gaps (Juliá-Benito et al., 2017; Ozberk & Altinay, 2019; Pour, 2019).

The absence of specialists or their loose engagement in the management of chronic diseases in schools is a severe problem when one would expect the various services and agencies to be more active. However, their absence from the forefront raises questions and concerns. In general, it seems that there is a significant gap in this matter, which complicates the work of the teacher and causes concerns to the parents and, therefore, the specialists should be more actively involved in the support and coordination of the school in the management of chronic diseases (Callan, 2013; Muntaner, Forteza, & Salom, 2014; Flanagan, 2015; Snieder et al., 2017; Berger et al., 2018; Ofsted, 2019). In this way, the needs of the children and the parents will be minimized, and teachers will, in turn, be able to support the children adequately and feel less isolated at work.

In conclusion, the presence of specialists in schools and the training of teachers are the key to the complete inclusion of all children in learning, regardless of their special needs inside and outside the classroom (Loreman, Sharma, & Forlin, 2013; Edwards et al., 2014; Williams, Russ, & Perdue, 2019; Charalambous & Papademetriou, 2019; Graciela Gómez et al., 2020). Teacher's training on chronic diseases must start early on (Salem, 2013; Plisková & Snopek, 2017; Irwin et al., 2018).

Conclusion

The purpose of this qualitative research was an exploratory approach of the opinion of parents of children with chronic diseases and their teachers as to what the public elementary school in Cyprus needs to respond more effectively to the challenge of chronic diseases. Our findings are in line with the findings of other researchers worldwide. They suggest that both the teachers' training for chronic diseases and the possibility of employing medical personnel and other experts in schools are matters that need much more attention from politicians and education stakeholders. Further investigation must be conducted, both by qualitative and quantitative methods, to support the gaining knowledge about the challenges the chronic diseases cause in schools, teachers, parents, and the children themselves.

Limitations

Although generalization is not a factor of concern in qualitative research, it is a fact that we conducted this study with a limited sample. Therefore, more research is needed in the specific area to assess the bigger picture and the possible benefits from what teachers and parents suggest. Irrespective of the limitations, the findings provide valuable data in an area still understudied in Cyprus and provide essential information for a population still invisible: the pupils with chronic diseases in mainstream schools in Cyprus.

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