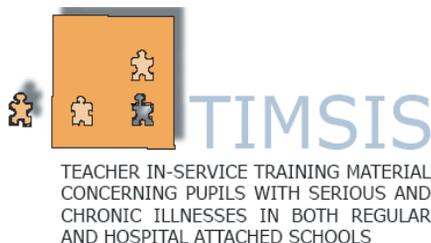


QUESTIONS ABOUT EDUCATION OF PUPILS SUFFERING FROM CHRONIC DISEASE OR ANOTHER GRAVE ILLNESS FROM THE PARENTS' POINT OF VIEW– INTERNATIONAL PROJECT TIMSIS

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Abstract: *A child suffering from grave illness or chronic disease presents not only a significant medical but also educational and pedagogical problem. International project TIMSIS maps parents' and teachers' opinions and needs in several European countries by means of a questionnaire survey. The results show that as far as parents are concerned, it is essential to be informed in a suitable and right way about the essence of their child's disease, about its complications, therapy, and resolving of critical stages. Parents should also communicate with the teacher; let him/her know about the nature of the disease, options of integration in the class, restrictions in the instruction. The parents have encountered the side effects of drugs, the impact on their child's psyche, and the influence on everyday life. From the parents' point of view, the most important person at school is the class-teacher, who should be provided with most information on the disease of the pupil, and should inform the other pupils to an adequate extent.*

Key words: *children, parents, teachers, school, hospital, disease, questionnaire, help, TIMSIS, project*

Introduction

Project TIMSIS (Teacher In-Service Training Material Concerning Pupils with Serious and Chronic Illnesses in Both Regular and Hospital-attached Schools)

The project is aimed at a creation of educational materials related to the issues of pupils with special educational needs, and especially at the group of children with chronic diseases. TIMSIS addresses teachers, who deal with the issues of re-integration of children and adolescents suffering from serious and/or chronic diseases (like tumours, epilepsy, diabetes, cystic fibrosis, ADHD, and food intake disorders) back to their regular schools.

Children with chronic or other serious illness have to face a number of difficulties – especially mental and physical strain. There are problems related to the oft-repeated absence of pupils from school, their hiving off from the normal school environment, difficulties related with their re-integration back to the regular school, problems in the family, and many others. This fact quite naturally means a substantial obstacle to their schooling.

Although many difficulties related to illness cannot be averted, the consequences of their impact on a child with a lingering disease can be mitigated. A number of negatives may be prevented, and it is possible to get prepared for the return of the pupil back to the educational process. After the completion of their therapy pupils return back to their regular schools; it is necessary to interface the components of pedagogical, psychological, and social working on the pupil. Last not least it is necessary to provide information on the issues of the chronic disease to all concerned.

The project is mainly focused on the following diseases:

- Tumoral diseases;
- Diabetes;
- Bronchial asthma;
- Cystic fibrosis;
- Food intake disorders;
- ADHD;
- Epilepsy.

Partners of the project

The TIMSIS project is implemented under the auspices of the EU, within the Socrates/Comenius programme. The partners include universities and hospital-attached schools of the participating countries:

- Czech Republic (MU, Faculty of Education, Department of Special Pedagogy, Basic School attached to the Faculty Hospital in Brno, 9 Černopolní Street);
- Finland (University of Helsinki, Department of Teacher Education);
- Norway (Oslo University College, Hospital School in Oslo);
- Germany (Ludwigsburg University of Education, Institute of Educational Science, Hospital school at the Olghospital);
- Hungary (Mosdós Hospital School);
- Russia (associate partner – State University of Education, Samara).

Main activities of the project

- Report on the situation in the participating countries, comparative analysis – contrasts and changes, exchange of experience;
- International survey of the needs of teachers and parents of children suffering from chronic diseases – what kind of information do they need, with what problems they struggle;
- Creation of supportive, counselling, and information materials in multimedia format (WWW, CD-ROM, DVD, video...);
- Testing, evaluation, and distribution of the developed materials.

The goal of the project

The main goal of the TIMSIS project is to develop information, educational, and other supportive materials for education and further education of teachers with an aim to support the re-integration process and the chronically ill children care. The created materials are primarily designed for the teachers of regular schools. Through their mediation advice as to how to help children/pupils to achieve the best possible falling in back to the collective of their peers is provided to other teachers.

Material and methodology

Target groups

The future materials and concepts are primarily designed for the teachers of regular schools. Another target group includes teachers at hospital-attached schools, especially because of improving the cooperation between their establishments and the regular schools. Subsidiary target groups are the ill children themselves and their parents.

Expected outputs

- Mapping out of the current situation in the sphere of education of chronically ill children;
- International research related to the needs of teachers and parents of the diseased children regarding the required information and advice;
- Development of modular courses in a multimedia form;
- Production of didactic materials and teaching materials (especially on CD-ROM and the Internet);
- Publication of the results.

The project is focused at a group of children/pupils suffering from chronic diseases. The care of this group necessitates cooperation of regular school teachers, hospital teachers, and last but not least also the parents. At present, however, there is a lack of materials and possibilities of a further education of the educational workers in this sphere.

re. The specificity of the project rests not only in enhancing of the competencies of the target groups, but also in upgrading of these issues by materials capable of a practical utilization. A part of the project also is an international research aimed at ascertaining of the real needs of the diseased children teachers and parents.

Questioning has been performed in all countries participating in the TIMSIS project (CR, Finland, Norway, Germany, Hungary, and Russia). This paper provides information on the results of questioning of parents with children suffering from chronic and/or grave illness.

Implementation of the questionnaire survey was carried out in several steps:

- Defining of goals;
- Creation of questionnaires (version for parents, version for teachers);
- A pilot study;
- Collection of data;
- Processing of the acquired details;
- Analysis of the outcomes and their completion;
- Publication of the ascertained information.

Implementation of the research survey has been divided into several stages; the first one was focused on the creation of the questionnaires. The main stumbling block was the lucidity of the questionnaires in all the original languages of the partners to the project. Consequently, after the creation of both versions, a pilot study has followed. After this the final versions of the questionnaire were created in English to be translated into national languages later on.

Creation of the questionnaires

Two different original questionnaires have been created, one designed for the parents of children suffering from chronic diseases, the other for the teachers of the diseased pupils. The goal has been to identify the real needs and problems both the teachers and the parents struggle with in the sphere of care, support, and education of pupils suffering from chronic or another grave illness, based on the implemented survey. Because of the scope of the research project and the problem, in this paper we have only presented the overview of the results acquired from questioning focused on ascertaining of the needs of the teachers of pupils suffering from chronic or another grave disease. The representative research survey itself was preceded by a pilot study. Table one provides an idea about the size of the questioned sample.

Each questionnaire has mapped out several specific fields. The parent questionnaire has observed the following:

- Who should be provided information on the disease of the child;
- From the point of view of the parent, which information is important for the class-teacher, and which for the classmates;
- Experience of the parents with the special needs of the diseased pupil.

The results of the research survey have played a key role in the implementation of the outputs of the project, especially in the creation of web materials for the teachers and parents of the diseased pupils/children.

Table 1: Numbers of the questioned teachers in the individual countries

Questionnaire for parents	All countries	Czech Republic	Finland	Germany	Hungary	Norway	Russia
N	243	50	56	30	51	32	24

Results of questioning of parents with children suffering from chronic or grave diseases

The results of international questioning of parents with children suffering from diseases are presented in tabular form with stated relative percent occurrences (%). The parents have reacted to each question by selecting a position ranging from 1 to 5, whilst 1 has represented the perception of the problem as the least substantial, 5 conversely as the most substantial.

Table 2: Answers to the question *From your point of view, how important it is to provide an information on the disease of your child to the class-teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	19.8	6.0	0.0	0.0	3.9	0.0	0.0
2	4.1	2.0	0.0	1.8	0.0	0.0	8.7
3	1.2	2.0	0.0	1.8	0.0	3.1	0.0
4	6.6	20.0	3.3	5.4	0.0	3.1	4.3
5 max	68.2	70.0	96.7	91.1	96.1	93.8	87.0

Table 3: Answers to the question *From your point of view, how important it is to provide an information on the disease of your child to the other teachers?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	18.6	15.2	0.0	1.8	23.5	0.0	13.0
2	12.2	10.9	6.7	0.0	0.0	3.1	13.0
3	12.7	26.1	23.3	7.3	0.0	18.8	4.3
4	16.5	19.6	43.3	10.9	0.0	21.9	17.4
5 max	40.1	28.3	26.7	80.0	76.2	56.3	52.2

Table 4: Answers to the question *From your point of view, how important it is to provide an information on the disease of your child to his/her classmates?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	22.5	16.3	3.3	5.5	27.5	3.1	47.8
2	17.1	20.4	3.3	7.3	0.0	0.0	21.7
3	16.7	30.6	23.3	16.4	0.0	9.4	26.1
4	11.7	18.4	16.7	12.7	0.0	21.9	0.0
5 max	32.1	14.3	53.3	58.2	72.5	65.6	4.3

Table 5: Answers to the question *From your point of view, how important it is to provide an information on the disease of your child to the other pupils at school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	20.9	30.4	23.3	5.6	76.5	10.0	60.9
2	34.6	32.6	50.0	5.6	0.0	6.7	13.0
3	17.1	26.1	23.3	22.2	0.0	26.7	4.3
4	11.1	8.7	3.3	18.5	0.0	26.7	13.0
5 max	16.2	2.2	0.0	48.1	23.5	30.0	8.7

According to the parents the information on the disease of their child should be provided both to the class-teacher and to the other teachers (Tab. 2-5). The classmates and the other friends of the pupil should be informed as well, although the relative frequency of this answer was lower with this question (especially according to the opinion of the parents from the Czech Republic, Finland, and Russia). It may be assumed that also the form and the extent of the communicated information should be different. It ensues from the results that the “best informed” person at school should be the class-teacher of the pupil. It is exactly the information communicated by the parents and important for the class-teacher at which the further part of the questionnaire has focused.

Table 6: Answers to the question *From the parents' point of view, how important are the basic information on the character of their child's disease for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	3.3	2.0	0.0	0.0	11.8	0.0	4.3
2	1.7	6.0	0.0	0.0	0.0	0.0	4.3
3	5.0	10.0	0.0	7.1	0.0	3.2	8.7
4	9.5	14.0	10.0	14.3	0.0	9.7	8.7
5 max	80.5	68.0	90.0	78.6	88.2	87.1	73.9

Table 7: Answers to the question *From the parents' point of view, how important are the basic information on the medicines and the drug regimen of the child suffering from a disease for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	13.7	24.0	3.3	1.8	33.3	0.0	8.7
2	6.2	12.0	10.0	7.1	0.0	3.2	4.3
3	15.4	28.0	13.3	23.2	0.0	6.5	17.4
4	17.4	18.0	20.0	25.0	0.0	19.4	30.4
5 max	47.3	18.0	53.3	42.9	66.7	71.0	39.1

Table 8: Answers to the question *From the parents' point of view, how important are the basic information on the possible side effects of the medicines for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	18.8	14.3	0.0	3.6	66.7	0.0	8.7
2	2.5	4.1	6.7	1.8	0.0	0.0	4.3
3	15.1	24.5	10.0	20.0	0.0	9.7	30.4
4	16.7	22.4	26.7	21.8	0.0	16.1	17.4
5 max	46.9	34.7	56.7	52.7	33.3	74.2	39.1

Table 9: Answers to the question *From the parents' point of view, how important are the basic information on the psychic reaction of their child to his/her disease for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	14.6	8.2	0.0	0.0	60.8	0.0	0.0
2	2.1	6.1	0.0	1.8	0.0	3.2	0.0
3	9.2	10.2	20.0	12.5	0.0	6.5	8.7
4	17.9	24.5	26.7	25.0	0.0	12.9	21.7
5 max	56.3	51.0	53.3	60.7	39.2	77.4	69.6

Table 10: Answers to the question *From the parents' point of view, how important are the basic information on the influence of their child's disease on the structure of the day for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	19.9	12.2	0.0	1.8	72.5	3.1	13.0
2	1.2	2.0	0.0	1.8	0.0	0.0	4.3
3	8.3	16.3	0.0	8.9	0.0	3.1	26.1
4	19.1	24.5	23.3	26.8	0.0	21.9	21.7
5 max	51.5	44.9	76.7	60.7	27.5	71.9	34.8

Table 11: Answers to the question *From the parents' point of view, how important are the basic information on when/how often does their child go to see the physician/to the hospital for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	15.5	8.2	3.3	7.4	49.0	0.0	13.0
2	6.3	8.2	3.3	13.0	0.0	3.1	8.7
3	15.9	22.4	16.7	22.2	0.0	21.9	13.0
4	15.1	10.2	26.7	20.4	0.0	12.5	34.8
5 max	47.3	51.0	50.0	37.0	51.0	62.5	30.4

Table 12: Answers to the question *From the parents' point of view, how important are the basic information on the adaptation of the instruction/timetable of the child for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	20.1	12.5	0.0	3.6	72.5	6.3	4.3
2	2.5	0.0	0.0	10.9	0.0	0.0	0.0
3	15.1	18.8	6.7	21.8	0.0	21.9	26.1
4	18.4	16.7	26.7	29.1	0.0	15.6	30.4
5 max	43.9	52.1	66.7	34.5	27.5	56.3	39.1

Table 13: Answers to the question *From the parents' point of view, how important are the basic information on the recognition of the symptoms of the disease and the right reaction to them for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	6.3	10.0	0.0	0.0	17.6	0.0	4.3
2	1.7	2.0	0.0	3.7	0.0	0.0	4.3
3	5.4	12.0	3.3	3.7	0.0	12.9	0.0
4	12.6	10.0	16.7	18.5	0.0	16.1	21.7
5 max	73.6	66.0	80.0	72.2	82.4	71.0	69.6

Table 14: Answers to the question *From the parents' point of view, how important are the basic information on a reaction in the case of their child's sudden health complications for the teacher?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	8.0	8.2	0.0	0.0	27.5	0.0	4.3
2	1.7	2.0	0.0	1.9	0.0	3.3	4.3
3	3.8	8.2	0.0	5.6	0.0	3.3	4.3
4	8.0	10.2	6.7	11.1	0.0	13.3	8.7
5 max	78.1	71.4	93.3	79.6	72.5	80.0	78.3

All the above mentioned information (Tab. 6–14) are important for the teacher from the viewpoint of the parent of the pupil suffering from a disease. It ensues from this that the teacher should be properly informed about the pupil’s disease itself, his/her therapeutic regimen, possible side effects of medicines (lower frequency of answers by the parents from Hungary). From the point of view of the parents it is very important to inform the teacher about the impact of the disease on the psyche of the child, distinguishing of the symptoms of the disease, and the ways to react on emergency situations (occurrence of sudden health complications). The disease and its treatment usually have an impact on the structure of the child’s day, and according to the parents’ opinion the teacher should be informed about this as well. The significance of the given items has been acknowledged by two thirds of the questioned parents.

Table 15: Answers to the question *From the parents’ point of view, how important are the basic information on their child’s disease for the classmates and the other pupils at school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	10.9	18.4	6.7	1.8	15.7	0.0	34.8
2	4.2	12.2	3.3	3.6	0.0	3.2	0.0
3	16.7	18.4	33.3	23.6	0.0	12.9	17.4
4	10.5	14.3	3.3	12.7	0.0	19.4	17.4
5 max	57.7	36.7	53.3	58.2	84.3	64.5	30.4

Table 16: Answers to the question *From the parents’ point of view, how important are the information on their child’s treatment in the hospital/at the physician for the classmates and the other pupils at school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	36.6	39.6	13.3	14.5	84.3	16.1	34.8
2	9.7	12.5	20.0	18.2	0.0	3.2	0.0
3	25.6	35.4	50.0	25.5	0.0	38.7	13.0
4	11.8	0.4	6.7	23.6	0.0	16.1	13.0
5 max	16.4	2.1	10.0	18.2	15.7	25.8	39.1

Table 17: Answers to the question *From the parents’ point of view, how important are the information on their child’s disease impact on everyday life and free time for the classmates and the other pupils at school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	13.8	20.0	3.3	3.6	35.3	3.2	4.3
2	10.4	18.0	16.7	16.4	0.0	0.0	8.7
3	22.1	34.0	30.0	32.7	0.0	19.4	13.0
4	16.3	14.0	30.0	18.2	0.0	25.8	21.7
5 max	37.5	14.0	20.0	29.1	64.7	51.6	52.2

Table 18: Answers to the question *From the parents' point of view, how important are the information on the right behaviour in case of an emergency situation for the classmates and the other pupils at school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	11.4	10.0	6.7	5.5	25.5	0.0	20.0
2	5.5	4.0	6.7	7.3	0.0	3.2	20.0
3	14.3	26.0	23.3	14.5	0.0	6.5	20.0
4	9.3	14.0	16.7	12.7	0.0	9.7	0.0
5 max	59.5	46.0	46.7	60.0	74.5	80.6	40.0

This section of the questionnaire (Tab. 15–18) was focused at ascertaining of the parent attitude to the information, which should be provided to the classmates and the other friends of the diseased child. It ensues from the outcomes that according to the respondent viewpoint the pupils should be informed about the basic characteristic of the illness. The parents in Russia think that classmates should know about what is happening at the physician; the parents in the Czech Republic are of an opposite opinion and consider this information unessential. Contrary to that, they have expressed consent to the information on the impact of the illness on the everyday life of the classmate. A high percentage of the parents agree to the necessity of informing the classmates about the first aid in case of an emergency situation.

Table 19: Answers to the question *Did/does your child have problems in the sphere of social relations in the class?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	50.2	37.5	33.3	56.4	65.9	68.8	27.3
2	12.1	12.5	20.0	7.3	18.2	9.4	4.5
3	19.0	29.2	23.3	10.9	11.4	15.6	31.8
4	9.5	12.5	10.0	16.4	2.3	0.0	13.6
5 max	9.1	8.3	13.3	9.1	2.3	6.3	22.7

Table 20: Answers to the question *Do you have your own experience that your child did/does not want to go to school?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	54.4	35.4	36.7	71.4	72.5	56.3	40.9
2	12.7	18.8	20.0	7.1	10.0	9.4	13.6
3	15.4	14.6	20.0	16.1	7.5	18.8	18.2
4	10.1	20.8	13.3	3.6	5.0	9.4	9.1
5 max	7.5%	10.4%	10.0%	1.8%	5.0%	6.3%	18.2%

Table 21: Answers to the question *Does your child lag behind in any subjects because of his/her illness?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	37.4	27.1	10.0	47.3	51.2	40.6	40.9
2	16.5	8.3	23.3	9.1	20.9	31.3	13.6
3	21.7	33.3	20.0	21.8	16.3	18.8	13.6
4	13.0	14.6	26.7	10.9	4.7	3.1	27.3
5 max	11.3	16.7	20.0	10.9	7.0	6.3	4.5

Table 22: Answers to the question *Does your child have a lower self-esteem because of his/her illness?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	37.4	29.2	23.3	37.7	45.2	53.1	36.4
2	16.7	25.0	13.3	7.5	19.0	21.9	13.6
3	22.0	16.7	43.3	28.3	21.4	3.1	18.2
4	16.3	20.8	13.3	18.9	9.5	18.8	13.6
5 max	7.5	8.3	6.7	7.5	4.8	3.1	18.2

Table 23: Answers to the question *Was/is your child emotionally imbalanced because of his/her illness?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	33.3	31.9	30.0	21.8	46.7	40.6	31.8
2	16.0	14.9	10.0	20.0	13.3	21.9	13.6
3	23.4	34.0	26.7	20.0	17.8	18.8	22.7
4	14.3	10.6	10.0	14.5	20.0	9.4	9.1
5 max	13.0	8.5	13.3	23.6	2.2	9.4	22.7

Table 24: Answers to the question *Did/does your child personally experience side effects of drugs?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	37.9	32.7	10.0	33.9	47.6	50.0	13.6
2	13.8	16.3	23.3	21.4	19.0	9.4	13.6
3	12.9	14.3	26.7	10.7	23.8	18.8	18.2
4	15.8	20.4	23.3	14.3	4.8	15.6	36.4
5 max	19.6	16.3	16.7	19.6	4.8	6.3	18.2

Table 25: Answers to the question *Did/does your child's illness necessitate an adaptation of his/her daily regime (physiotherapy, sleep, diet, school instruction ...)?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	30.2	20.9	23.3	32.7	39.5	43.8	13.6
2	9.3	14.0	16.7	7.3	14.0	0.0	0.0
3	14.2	23.3	16.7	18.2	9.3	3.1	9.1
4	14.7	11.6	13.3	10.9	14.0	18.8	27.3
5 max	31.6	30.2	30.0	30.9	23.3	34.4	50.0

Table 26: Answers to the question *Is your child in need of special hygienic measures?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	41.3	41.7	26.7	45.5	63.2	31.3	27.3
2	13.3	12.5	36.7	10.9	10.5	6.3	4.5
3	16.9	18.8	13.3	7.3	21.1	15.6	36.4
4	8.9	8.3	6.7	14.5	2.6	6.3	13.6
5 max	19.6	18.8	16.7	21.8	2.6	40.6	18.2

Table 27: Answers to the question *Is your diseased child provided with the same care as his/her peers?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	26.7	21.3	6.7	34.5	44.4	12.5	38.1
2	13.1	10.6	6.7	29.1	5.6	6.3	9.5
3	17.2	14.9	16.7	18.2	22.2	12.5	19.0
4	12.7	19.1	23.3	3.6	11.1	12.5	9.5
5 max	30.3	34.0	46.7	14.5	16.7	56.3	23.8

Table 28: Answers to the question *Were the teachers at school willing to cooperate?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	8.7	6.1	3.3	3.6	11.4	6.9	31.8
2	6.5	8.2	3.3	3.6	9.1	6.9	9.1
3	13.5	10.2	20.0	12.5	15.9	6.9	18.2
4	16.5	18.4	23.3	17.9	15.9	6.9	13.6
5 max	54.8	57.1	50.0	62.5	47.7	72.4	27.3

The above part of the questionnaire (Tab. 19–28) was focused at the specific needs of the defined group of pupils at school. Less than 20 % of parents have observed difficulties in the sphere of social integration of their diseased child. In Finland, Russia, and Germany the relative frequency was higher. There was no massive observation by the parents that their children would refuse to go to school (out of the mentioned countries this problem has been ascertained in the Czech Republic, Russia, and also in Finland more often). The parents have also stated that their children “lagged behind” at school because of their illness; this problem has been most often presented by the questioned parents in Finland and in the Czech Republic. The parents also have experience with lower self-esteem of their children together with problems in emotional sphere.

The issues of side effects of drugs were especially highlighted by the parents in Hungary. The parents in all countries have encountered the necessity to adapt the daily regime of their children and to take certain measures of hygienic character. The positive outcomes are the finding of the parents that their diseased children have received the same approach as their peers, and the fact that teachers were willing to cooperate with the families.

Table 29: Answers to the question *How intense is your experience with the cooperation between the hospital-attached school and the regular school of your child?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	36.6	20.0	34.5	39.3	32.7	45.2	65.2
2	7.1	16.0	13.8	1.8	0.0	6.5	8.7
3	15.1	22.0	20.7	21.4	0.0	12.9	13.0
4	10.5	16.0	20.7	12.5	0.0	9.7	4.3
5 max	29.8	26.0	10.3	25.0	67.3	19.4	8.7

Table 30: Answers to the question *From your point of view, how important is a further assistance of the hospital-attached school provided to the regular school of your child?*

Position on the scale	All countries (%)	Czech Republic (%)	Finland (%)	Germany (%)	Hungary (%)	Norway (%)	Russia (%)
1 min	7.2	6.0	3.4	5.6	4.0	12.9	17.4
2	2.1	4.0	0.0	3.7	0.0	0.0	4.3
3	15.6	30.0	13.8	11.1	0.0	12.9	34.8
4	15.2	28.0	27.6	14.8	0.0	12.9	8.7
5 max	59.9	32.0	55.2	64.8	96.0	61.3	34.8

The experience with the cooperation between the hospital-attached school and the regular school (Tab. 29) was acknowledged by more than 40 % of the questioned parents; the lowest frequency of positive answers has occurred among the parents in Russia. According to most of the parents the assistance of the hospital-attached school remains important even later on (Tab. 30). It follows from these answers that the necessary cooperation of the regular schools (teachers) and the hospital-attached schools has to be highlighted.

Conclusion

The outputs (materials for the target groups) of the TIMSIS project should correspond with the results of the questionnaire surveys among parents and teachers of the diseased pupils. As has been stated, it is important to provide information to the teachers, especially the class-teachers. A reasonable amount of information is based on a good cooperation of the parents and the teachers. It emerged from the survey that information is necessary also for the other teachers as well as the classmates of the child suffering from a disease. It is therefore necessary to focus the future projects also on the questions as to how and to what extent should information be provided.

By some teachers it is especially the information provided to the classmates that may be regarded as problematic. It is obviously important as well that the teacher receives all essential data related to the disease of the child from the parents. Many times this is a “new” situation for both the parents and the teachers themselves, who have not been trained for it. For this reason it is necessary to prepare for the conversation with the parents, to think over the possible questions. As parents have stated, they have faced the side effects of drugs/treatment, the impact of the disease on the child’s psyche; many times the disease influences the everyday life of the child.

The goal of the entire process is the possibility to respect individual needs of the child and the facilitation of his/her re-integration back to the regular school that may also be aided by the cooperation with the hospital-attached school.

From the point of view of the parents the most important person at school is the class-teacher who should also be the one to acquire most information on the pupil’s disease. The teacher should also inform the classmates.

The class-teacher should be provided with the following information:

- Basic information on the disease;
- Information on the medication/treatment and the possible side effects;
- Information on the impact of the disease on the child's psyche;
- Influence of the disease on the structure of the day;
- Frequency of appointments with the doctor;
- Information on the possible adaptation of the timetable to the needs of the pupil;
- Discerning of the symptoms and providing of help in emergency situations.

The classmates should be provided with the following information:

- Basic information on the disease;
- Influence of the disease on the everyday life of the child;
- The right reaction in case of a sudden deterioration of the health state.

The parents have experience with the following problematic situations:

- Side effects of drugs;
- The necessity of adaptation of the daily regime, acceptance of hygienic measures.

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OTÁZKY EDUKACE ŽÁKŮ S CHRONICKÝM ČI JINÝM ZÁVAŽNÝM ONEMOCNĚNÍM Z POHLEDU RODIČŮ - MEZINÁRODNÍ PROJEKT TIMSIS

Souhrn: Dítě trpící závažným či chronicky probíhajícím onemocněním představuje nejen významný medicínský, ale též výchovný a pedagogický problém. Mezinárodní projekt TIMSIS mapuje názory a potřeby rodičů a pedagogů v několika evropských

zemích pomocí dotazníkového šetření. Výsledky ukazují, že je velmi důležitá vhodná a správná informovanost rodičů o podstatě choroby dítěte, jejích komplikacích, terapii a řešení krizových stavů. Rodiče by měli též komunikovat s pedagogem, uvědomit ho o povaze onemocnění jejich dítěte, o možnostech integrace ve třídě, o omezeních při výuce. Rodiče se setkali s vedlejšími účinky léků, s dopadem nemoci na psychiku dítěte a s ovlivněním každodenního života dítěte. Z pohledu rodičů je nejdůležitější osobou ve škole třídní učitel, který by měl rovněž mít o nemoci žáka nejvíce informací a v přiměřené míře informovat spolužáky.

Klíčová slova: děti, rodiče, učitelé, škola, nemocnice, onemocnění, dotazník, pomoc, TIMSIS, projekt