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Education and Social Exclusion of Children with Chronic Diseases: The School Reintegration

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Abstract
This research attempts to identify the conditions under which children with chronic diseases are reintegrated into formal education after they have been hospitalized for a long period. In addition, it attempts to probe the conditions under which the children are being taught during the home schooling period. Educational inequality is a thorny issue that concerns every education system. Many important social vulnerabilities affect the equal distribution of educational opportunities, but the education of children with chronic illnesses creates a double vulnerability, the results of which are most often truly tragic for the affected students and their families. The research data was collected after a series of interviews with parents whose children had been hospitalized with a serious illness and teachers who had worked in hospital schools and in formal education. The findings of the research show that the reintegration of hospitalized children who have been absent for a long time from school is difficult and often causes anxiety due to the abusive behaviors they receive from their classmates. It is also emphasizes that the teachers of the formal education have serious lack of training related to the reintegration of children with chronic diseases as well as a holistic cooperation plan that should prevent the stigmatization related to the disease is necessary.
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1. Introduction

Chronic childhood illnesses require systematic and long-term treatment, repeated visits to the hospital at regular basis, and a lead to an uncertain future (Katz & Madan-Swain, 2006, Eiser, 2004). Nowadays, treatment practices have evolved and the survival of children with neoplasm has increased dramatically (Eiser, 2004). The fact remains, however, that illness and education and, by extension,[1] social exclusion, are significantly related to each other.

Undoubtedly, the education of children with chronic health problems presents extremely high demands, both during their stay in the hospital [2] and when trying to reintegrate them into the everyday life of school after discharge. In the context of a wider discussion about hospital education internationally, alternative educational practices are considered which mainly concern the stage of children's recovery and their return to everyday life outside the hospital (Kontogianni et al., 2021). These are educational practices that take place, either at home with home education or during the formal reintegration of children into their classroom environment, and are more or less differentiated in various countries of the European Union.

In the Netherlands, for example, hospital schools and hospital teachers were replaced by a counselor for the education of sick pupils. This fact allows a better arrangement of the educational needs that arise during the long periods of stay of young patients at home or in the hospital (Capurso & Vecchini, 2010). In Greece, children with chronic diseases fall under a law that refers to people with disabilities and special educational needs. Among other things, the law provides for home schooling (Government Gazette A΄ 199/2-10-2008).

2. Theoretical Framework

2.1 School reintegration after hospitalization

Children suffering from a chronic illness cope with many different issues that determine their daily life. In addition to the doctors and daily examinations, their institutionalization in the hospital (Feldman, 2010) and the sudden disconnection from their ordinary life, they are also called to face the problem of reintegration into school, which is a major issue for their cognitive development and socialization. After the end of the treatment

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[1] The phenomenon of social exclusion has been a field of extensive analysis in the international literature (see for example Byrne, 1999; Hills et al. 2002). In this research we adopt the definition given by Tsiakalos, according to which, social exclusion is considered the situation and process in which there is prevention to the absorption of social and public goods -such as health care, participation in the political process, education- the lack of which usually leads to economic destitution. In the case where access to education is prevented, we have educational exclusion (Tsiakalos, 2008: 184).

[2] This is the so-called hospital education, which refers to the school and preschool education provided to children in the various pediatric and pediatric oncology hospitals of the country, during their hospitalization (Patsalis & Darladima, 2013).

and the period of stay at home, until they return to their new everyday life, the main request is for them to return to school. As we read in Bruskeli (2013), even immediately after the diagnosis, they wonder about when they will return to school.

It is known that students with chronic diseases face an increased risk of social isolation, which is directly linked to the lack of understanding of their condition by their classmates (Kaffenberger, 2006). Their inclusion in the classroom community is considered a catalyst for recovery from the illness. Too often, parents focus on their children's health, without considering the importance of their school reintegration. In research conducted on socially isolated children, high levels of cortisol were observed, which were directly related to correspondingly high levels of stress (Van der Meulen, et al., 2017).

Also, an extremely important parameter during school reintegration, is the concern of parents regarding the possibility of rejecting behaviors and discrimination towards their children, due to illness and long-term absences during hospitalization (Muntaner et al., 2014). In a study carried out at the Finnish University Hospital "Turku", it was found that a significant percentage of sick students were bullied when they returned to school, mainly because of their appearance, by classmates who had not received sufficient information about the adventure of their victims (see further discussion below).[1]

In general, we would say that upon returning to school, children survivors from a form of cancer cope with difficulties and limitations in almost all fields of their lives. Research has shown that time out of school have detrimental effects on children’s mental health, well-being and educational outcomes (Burns, et al., 2021). They are very likely to present with low energy, deficient motor skills and balance problems (Eiser, 2004), which limit participation in sports and other activities that require physical endurance, thus contributing to their social isolation.

The situation is even more difficult in the case of children who are ill and come from immigrant families. In particular, immigrant mothers with limited fluency in the official language of the host country have difficulty communicating and understanding complex medical procedures and treatments, resulting in the frequent misinterpretation and exaggeration of the problem (Sahler et al., 2006). In addition, they are unable to communicate directly with the school staff in order to request personalized support and a range of services to their sick children. Therefore, for some immigrant parents, it seems more practical to keep their sick child at home, than to pursue the return to school as soon as possible (Katz & Madan-Swain, 2006).

2.2 The role of the teacher in the formal school during reintegration

In the context of the reintegration into the classroom of a student who returns after hospitalization, the teacher undertakes a particularly demanding role, since the need to deal with medical problems that may occur during everyday school life is imperatively added (Muntaner et al., 2014). The formal education teacher is usually not trained to academically address or emotionally handle such a challenging role or to develop an academic plan for a child with cancer (Hay, at al., 2015). According to studies, teachers are concerned about their lack of knowledge on these issues and are not at all sure about the realistic limits of the expectations they have to meet for each case, while at the same time having to worry about more effectively addressing the needs of the other students (Worchel-Prevatt et al., 1998). In general, they consider it necessary to be informed about a wide range of medical issues, as well as appropriate ways of dealing with school bullying incidents against children who have experienced the painful adventure of a chronic illness, mainly due to their appearance after treatment (Kaffenberger 2006). A recent survey of teachers in the formal education system found that participants were unable to adequately respond to issues related to the reintegration of children with chronic diseases into their normal classrooms after a more or less long period of hospitalization (issues related to performance and attendance, homework completion, and managing behavioral problems and discipline) (Hay et al, 2015).

Finally, teachers often receive little information from parents or medical staff and are unaware of life expectancy, the severity of the disease, or possible medical complications that may occur at school. Therefore, in order to effectively address the issue of reintegration, various integration intervention programs have been designed, as a "bridge" for the exchange of information between teachers, students, parents, classmates and medical staff of hospitals. Relevant reintegration programs should give immediate priority to proper information to the teachers of the standard classes regarding the chronic diseases and their close cooperation with their hospital teachers/colleagues who take care of the children during their hospitalization. Examples include Sachs's "Return-To-School Plan" in 1980 (Worchel-Prevatt, et al., 1998). Likewise, there is a pilot program with an intent to examine the experiences of children with brain tumors, their parents, and the collaborating educators (Bruce et al., 2012).

In Greece there is no official program for the reintegration of children with chronic diseases in formal education. Teachers are not provided with any educational material to inform and deal with such situations, and

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[1] Children with cancer are at increased risk of developing psychological problems if their peers do not understand the disease and its side effects (McCarthy et al., 1998).

as a result, the child and parents become deeply concerned about what the future holds. Reintegration programs may provide the opportunity for children who suffer from chronic illness and long academic exclusion to explore their fears, concerns and anxieties on their return to school and help them to deal with issues such as self- and body-image, classmates' reactions, teachers' attitudes, and schoolwork (Georgiadi & Kourkoutas, 2010). Thus, these school reintegration programs and their development in an official state level has been identified as an important need (Paré-Blagoev, et al., 2019).

2.3 Technology in the service of school reintegration of children with chronic diseases

Research shows that children with cancer and other chronic diseases, although they received instruction during their hospitalization, there was a decrease in their school performance upon their return and had difficulty reintegrating into regular school (Michalopoulou, 2013). This fact led to the examination of the possibility of offering new educational models and very specific therapeutic protocols to be followed, both during hospitalization and after discharge from the hospital (Trentin, 2013). Online education, for example, is an important solution in this particular case and, perhaps, one of the rare cases that is considered, in our opinion, necessary.[1]

In Europe, therefore, efforts have been made to develop specific software to provide the possibility of the participation of sick children in the everyday life of their classroom, throughout their hospitalization. We mention, for example, the project *"Bambi"* (Bambini Insieme) of the hemato-oncological pediatric department of the hospital "Silvestrini" of Perugia, a system of recreational and educational applications from a distance, during the therapeutic quarantine (Benigno & Trentin, 1998).

Another interesting project is the "Monkey in My Chair"[2] program, created by The Cure Starts Now foundation in Australia and now established in America and Canada. This is a program originally developed for preschool children diagnosed with cancer. Through the program, each child is provided with a "monkey kit", which includes a stuffed monkey that takes their place at school when they cannot be there. In addition, a book is included to help teachers explain to their students the situation faced by their classmate who is ill. Finally, electronic exchange of images and documents is planned, in order to ensure live communication between the sick child and the rest of the class.

3. Method of research

The aim of this study is to investigate the various dimensions of the reintegration of children with chronic illness during their return to formal education after a short or long-term treatment in the hospital. The ultimate purpose is the detection of cases of social and educational exclusion of children in this certain category and the repercussions of the lives of all members of their families. Specific scientific questions constitute whether or not the institution of home education is effective, the importance of cooperation of the enmeshed entities (teachers of the regular classes, hospital teachers and home schooling teachers, parents and the medical and nursing crew), the effectiveness of new technologies and the existence -or not- of the versatility of the present institutional framework while, in addition, a summarized valuation of their further school career of these children was attempted.

It's a qualitative research conducted on semi-structured interviews to fifteen parents and eight teachers, of which five serve or have previously served as hospital teachers at the two pedo-oncology clinics in Thessaloniki located at "Hippocratio" and "AHEPA". The other three are practicing teachers who have had experience with children with chronic diseases not only during their return to the regular classes but also in the context of home schooling. In the selection of subjects, the contribution of parents' association with children with neoplastic diseases of N. Greece called "LAMPSI" was decisive. The people in charge offered to bring us into contact with parents whose children were patients in the past and survived -or not- the illness, as well as with teachers who served both within the hospital schools and in the typical schools. The research procedure was followed by a convenient sampling with an avalanche of characteristics. The context of the interviews after their recording and digitization, were analyzed through the method of qualitative content analysis, with the "subject" as a unit of recording. As a result of the analysis, three basic axes emerged which are composed in a number of thematic categories and subcategories (Table 1).

A semi-structured interview questionnaire was used as a means of data collection, the main axes of which emerged from the overview of the existing literature and from conducting informal interviews, in the form of discussion, with selected persons/informants during the pilot research.[3] The interviews took place, either in a

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[1] It should not be overlooked that what the machine captures is but a form of learning cut off from its real and cultural references, stripped of its human meanings and critical potential. It is limited, essentially, to the skillful training of an animal, a behaviorist logic that ignites the imagination of bourgeois politicians through the stimuli of modernism and computer science, while at the same time increasing the super profits of the barons of capital (see Philippe Val, in: Michea, 2002: 40).

[2] See http://www.monkeyinmychair.org/program

[3] It refers to interviews with two parents who had children with neoplastic disease in the past and a nurse from the nursing staff of AHEPA

pre-arranged meeting place (in the subjects' home, in outdoor places or in the office facilities of "LAMPSI") or through tele-conferences. Last but not least, the interviews with the hospital teachers, who continue to work in this working place, were conducted within the hospitals, in order to ensure the possibility of life observation of the school premises and the daily life of children and their teachers.

Table 1

Axes – Thematic Categories of analysis

Axe	Thematic Categories	Sub Categories
A_1 **Home Schooling**	$A_{1.1}$ General operating framework	
	$A_{1.2}$ Advantages of home schooling	$A_{1.2.1}$ Alternative way of education, as a response to the medical limitations
		$A_{1.2.2}$ Alternative way of education, as a response to post-surgical appearance issues
		$A_{1.2.3}$ Filling cognitive gaps from long-term absence from classes
	$A_{1.3}$ Disadvantages of home schooling	$A_{1.3.1}$ Problematic teacher selection process
		$A_{1.3.2}$ Inadequate teaching of knowledge subjects
A_2 **Re-entry to the formal education**	$A_{2.1}$ Interpersonal relationships	$A_{2.1.1}$ Positive experiences
		$A_{2.1.2}$ Negative experiences
	$A_{2.2}$ Valuation of scholastic progress	
	$A_{2.3}$ Proposals regarding reintegration	

4. Discussion

From the qualitative content analysis of the interviews conducted with parents and teachers, two thematic axes emerged for each of the two categories of research subjects:

1. Home Schooling
2. Re-entry to the formal education

Below is a summary table with the main thematic axes and the relevant thematic categories and subcategories that emerged from the qualitative content analysis of the interviews conducted with parents and teachers.

The in-hospital study of children with chronic diseases is generally regarded as a vestibule for their following school course by parents and teachers; it is decisive and supportive in terms of their school reintegration and career in standard classes after hospitalization. Home education, we could say, is a necessary intermediate stage in the transition of children from healthcare to formal school. Regarding the reasons why a child should be homeschooled after hospitalization, parents focused on the child's safety, as children's viruses can significantly worsen their health condition. Several times, doctors advise parents to keep children at home for a while, until their immune systems can cope. Also, the changes in the children's appearance, as a result of the chemotherapy they receive also play an important role, which causes intense narcissistic trauma and makes it difficult for them to return to the school classroom.[1]

> *"(...) (child's name) needed to be protected from viruses. While he was an athlete before his surgery, after the surgery we ended up in a wheelchair and had trouble getting around. His appearance, which had changed terribly, as well as his psychological state, he was not prepared to face it completely and go to school. We had some facial deformities, but the main reason were the viruses*

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hospital. The specific formal discussions were conducted in the context of our pilot implementation of the draft questionnaire which was further developed and constituted the main data collection tool.

[1] Worchel-Prevatt et al. (1998) report that children with chronic illnesses find it difficult to return to school after prolonged absences due to hospitalization·, this is compounded by low self-confidence regarding school achievement and narcissistic trauma caused by changes in their appearance.

> *that were circulating and shouldn't have, because we continued the chemotherapy at home. For us, the chemotherapy was in the form of pills, it was not intravenous and the child had to be protected a lot (...)" (Interview 7).*

According to the literature, home education is rarely mentioned as an alternative method of educational intervention in official texts concerning educational policies. Schools do not have a specific plan, but instead decide to cover emerging needs based on the situation they are called upon to handle (Shaw et al., 2014). The following are the parents' statements about the current framework:

> *"It was summer when we entered the hospital. So, in September, I was informed that home teaching can be done, which of course we never had, because, while I had done all the necessary paperwork for Primary Education, because then the child would have to attend 5th Primary, (...) teacher never came! We were told it was approved, but there were no credits" (Interview 10).*

The teachers' comments are similar:

> *"Home education, I'll tell you! It's a huge chapter too. Those who are extras at schools... For someone [an educator] to do home education, they have 10 hours left over or they have time left over here and there. They are the ones who really run out. With what all that means…" (Interview 18).*

Parents' views on home education were shaped by the teachers their children had. Since Language and Mathematics monopolized the teaching provided, any individual variations or deviations were left to the individual teacher.

> *["(...) in the 10 hours a week you can't get [teaching content] completely done... For example, in the first year, at the end, when there were five days left empty, they also did a bit of History (...) In Geography we had taken an Atlas, but it was not official , [the child] was not attending normally (…) Now, if it was in the program... I don't think it was. I think it's just the basics'"] (Interview 8).*

Despite the positive assessment of some parents regarding the effectiveness of home education, the vast majority of people who participated in our survey stated that the child in home education does not manage to cover, neither the learning gaps nor the percentage of the content corresponding to his study class. This is confirmed by the research of Shaw et al. (2014), in which it is argued that a major pedagogical barrier to homeschooling is the fact that one hour of instruction at home cannot in any way reflect the educational experience of seven hours of instruction in the typical, traditional classroom. Brown (2006) informs us in his research that many families were dissatisfied with the quality and quantity of home teaching their child received before returning to school. The following statement from a parent who participated in the research is typical:

> *"(...) However, he didn't lose from the home education, by any means! In the 5th grade, he managed to get a literary prize, writing a story that was somehow autobiographical. That is, in the lessons he was taught, he did not fall behind. He was left behind in the rest that the school offers (…)He does not have the general education that the school can give you. He misses the ideas, the opinions that are heard in the classroom (…) Managing the time he has in a classroom is completely different" (Interview 8).*

Similar statements were made by teachers who welcomed their students back to their classes after their illness and hospitalization:

> *"[the teachers] go to home education two hours a day, if I'm not mistaken. They weren't enough! Although the…. [child's name] was very good (...) came with a lot of cognitive gaps. And the biggest problem was that he had many gaps in organizing things. I mean, he had forgotten to attend! He had forgotten what happens at school (...) I tried to keep him with a remedial teaching. He never accepted! (…) Still, he got left behind. I was wondering at that time, what would happen to a child who left school anyway with many gaps. A child who, let's say, did not do well in the 1st grade, what would happen when he returned to the 4th grade? (…) However, something must definitely change in the structures and in hospital education and at home (…)" (Interview 23).*

In addition to the cognitive field that is not served as it should be, homeschooling, by its very nature, fails to provide the child with the right to participate in the classroom and interact with his classmates. These are basic psycho-pedagogical functions which, however, are not performed with this specific type of education. As a teacher and a mother tells us:

> *"Look, homeschooling is something that only helps with the learning part. In nothing else! If a child can be found in the school place, then no home teaching offers him the slightest" (Interview 19).*

According to Brown (2006), for home teaching to be considered effective and to facilitate the smooth reintegration of the child into the standard school, his academic performance should be maintained at levels comparable to those of their male and female classmates. Therefore, according to Boles et al. (2017), it is important that home education aims at a fruitful interaction, both cognitively and socially, always based on the learning needs of the sick child.

As for the transition to the main phase of the child's reintegration into the typical school, a series of issues arise that are obviously a continuation of the previous education process he experienced, both during hospitalization and later, during home education. We focus below on the choice of repeating a class, a particularly anti-pedagogical practice, as a mother said:

> *"However, when home education stopped and we went to school, we had a problem. We couldn't read, we couldn't stay in class, we couldn't do anything! So he had to repeat the class, but also to be able to cover the learning gap that existed from kindergarten and pre-kindergarten [sic], because other children knew how to write!"(Interview 13).*[1]

It is, also, interesting how the teachers cope with the problem of the hospitalized child's communication with the class and his classmates. The introduction and use of new technologies and IT systems in schools is seen as particularly useful:

> *"I was lucky, because in 2007, suddenly, [the school] got technological equipment. We had internet in the school, we had a computer in the classroom, a projector and we could make a connection (...) This, of course, we did only in the first month, because it didn't take longer. Then (child's name) entered the classroom for good, as if he had never been absent!" (Interview 23).*

Nevertheless, the use of technology also requires specific skills from hospital and typical education teachers. The need for information on the new technological data is another issue that must be addressed immediately by the competent bodies. Benigno et al. (2018), after a systematic review of the existing literature, point out the great importance of technologies in terms of connecting students with their school during their hospitalization and a possible extension at home. The relation between the original school and the hospital one can be supported by an electronic register and through the creation of a personal portfolio with recorded activities of the student (Caggiano et al., 2021). However, the integration of the technology tool into the teaching of this particular population of students proves to be quite complex for several reasons, including the skills required by teachers for their effective use. From this research it was also found that the communication of the hospitalized child with his previous school environment is often undermined by the contributors involved. Thus, upsetting practices of confrontation and competition occur between hospital teachers and their typical education colleagues. There are also obstacles put up by the medical staff of the hospital. The statements of a hospital teacher are indicative:

> *"This [online communication with the regular class] is a very important part and it was the first thing I asked when I entered the clinic, but everyone - and when I say everyone, I mean my colleagues and the nurses and the parents of the children – they advised me not to have any contact with the school! That is, there should be no cooperation! (...) one reason is that no one is involved with anyone (...) They are another school and we are another school. The second reason is that we help the children more in the psychological part and do not focus so much on the lessons, so there is no need for a direct connection with the school" (Interview 21).*

Even parents undermined the whole process, in an attempt to completely hide the fact of their children's illness and hospitalization:

> *["There were parents who did not accept the situation and said: "You will not say that I am a parent at "LAMPSI", you will say that I am a volunteer" and I told her: "Well, is this possible, the child is seen going to and from the hospital". "No!", she says, "We leave and cover him with caps and scarves. It is winter, it is night, they will not see him" (...)"] (Interview 5).*

Hiding the child and his problem under the pretext of protecting him from teasing or bullying are practices that increase the risk of the sufferer slipping into conditions of social exclusion. Valamoutopoulou & Valamoutopoulou (2014) state that the information of the general public, as well as of teachers, about the issue of chronic disease, continues to be insufficient (see discussion below), as the main concern of some families is "acceptance from the others". Obviously, this attitude is a reaction to the social stigma that pervades the case of people with chronic diseases, however, it acts as a feedback loop in the formation of a vicious circle that contributes to the aggravation of their health recovery process. The quasi-intolerance of some children towards diversity, which of course reflects the general attitude of their families, often contributes to their adoption of bullying behaviors at school:

> *"Some children who were bothering him... Due to the illness he was going through, he was a little, let's say, "in a bubble". We were told to stay away from sports, not to participate in gymnastics, not to go out in the sun for a long time. He was a little guarded, because we were afraid about the surgery he had done. (...) At some point we noticed acts of violence on him, when he was beaten. In*

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[1] An extensive presentation of the anti-pedagogical nature of the measure of the compulsory repetition of a class (commonly known as stagnation), can be found in Tourtouras (2017). Quite interesting is the reason given by the mother in this particular passage, regarding the necessity of her child's repetition of class. With this specific testimony, the tragedy of the neoliberal educational model is outlined. In the context of the market logic that runs through it, an unprecedented over-intensification of the pace of learning and one-sided offer of knowledge objects is promoted, on the basis of which education in the arts and aesthetic development are defiantly ignored or substituted by other fields of knowledge that are evaluated as more important (Robinson, 1999) even at the pre-school level today (we recall the recent introduction in our country of the subjects of English and Information Technology in kindergarten, as well as the now traditional insistence of many kindergarten teachers to teach reading and mathematics to the toddlers they undertake to educate).

> *particular, there were two children (...) Finally, things normalized. They left, they went to another school and we obtained our peace!" (Interview 12).*

Possible marginalization or a condition of social exclusion has adverse consequences on the academic and psychosocial development of children with cancer in particular (Helms et al., 2014). Given the concerns that children with chronic illnesses face when returning to school (due to the change of their appearance, trying to maintain their cognitive level, anxiety about acceptance by their environment, etc.), coping with similar issues is a central topic of the general discussion within the school community. It is considered crucial that schools provide ongoing support to children and their families (Schilling & Getch, 2018).

However, in order to enable a similar support for the children during their reintegration into school, the cooperation of all involved bodies (hospital teachers, teachers of formal education and home teaching, parents and nursing staff) is considered necessary, within the framework of a holistic reintegration plan. Such programs have been proposed in foreign countries and, despite their different approaches, they are based on the cooperation of the various participants. It is impressive that the Hospital Educator and Academic Liaison Association (HEAL) and the Société Internationale d' Oncologie Pédiatrique (SIOP) recommend that school support for students with cancer should begin at the diagnostic stage. It is important, therefore, to offer school reintegration programs and to have uninterrupted and mandatory communication between school and hospital staff. However, despite the recommendations, no standard reintegration plan based on research results has yet been established (Thomson et al., 2015). Canter & Roberts (2012) propose a "multi-systemic" model of collaboration, underlining the importance of a unified approach when returning the child to school and focusing particularly on the need to utilize the institution of the consultant as a link between the agencies involved. The importance of a similar approach can also be seen from the testimony of a class teacher whose pedagogical instinct led her to seek cooperation with her colleague who provided the child's home education, while there is absolute convergence with the views of a mother.

> *["(...) the teacher who goes to the home school, who is an extra to us, goes with specific material, which I will send her. "Today you will do this, because in class we will also do [it] (...)"] (Interview 18).*

In summary, a school reintegration program should take into account a variety of factors, such as, for example, psychological-type inhibitions concerning general relationships with classmates and body image, accompanying elements of anxiety, melancholy or even depression, appearance of more general malfunctions. The developmental perspective of a reintegration program is an appropriate framework for defining both the content and the nature of interventions, consistently taking into account any information about the cognitive capabilities of reintegrated children (Worchel-Prevatt et al., 1998). To the question regarding the provision or not by the Ministry to implement a reintegration program, the responses of the teachers in the sample are typical:

> *"(...) What I want to say is that this is a part of education that, unfortunately, the Ministry and our country are dealing with as if we were in the previous century (...) since we have so many incidents, I think that the state , finally, it must bend down and see this problem seriously and not be afraid and not hide, as it always hides behind deficit structures, such as the integration departments, the "co-teaching" [meaning the model of parallel teaching support] or whatever else (...)" (Interview 23).*

This insufficiency is not only observed in Greece. In a survey conducted in America, the results showed similar deficiencies in the implementation of good practices, such as the establishment of interdisciplinary school reintegration teams under the guidance of authorized consultants, the development of school reintegration systems, and the exchange of information with the agencies involved (Schilling & Getch, 2018).

The result of the above shortcomings is the strengthening of a series of prejudices that prove to be particularly burdensome and decisive for the later school career of the children who were ill. We mention, for example, the following:

> *"Of course, I have also heard horrible stories (...) There was a child who wanted to return with a hat and [the teacher's] fear was about not to get infected. I mean, I can't believe in 2019 that there is a person who believes that cancer is contagious! (...)" (Interview 17).*

In the international literature we find serious misconceptions of healthy classmates about chronic diseases. Impressive among them is the view on the transmissibility of cancer (Worchel-Prevatt et al., 1998). Thus, school becomes particularly toxic, as the child recovering from the disease finds it difficult to manage, on the one hand, the various prohibitions related to his health and, on the other, the frequent negative reactions of his classmates (Pini et al., 2019).

> *[(...) I mean, just imagine, the gymnast still wanted to make her do gymnastics! But, she tells him: "I have an exemption" and he wanted her to bring him a notice! He didn't think she had a problem. "And what do you want me to do, to show you my leg?"] (Interview 15).* [1]

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[1] This particular child, after the treatment of osteosarcoma in the knee, was experiencing movement problems and therefore an additional limb was placed.

It is important to note at this point that a potential exclusion or marginalization in the context of the school process, contributes to the further burden of the cognitive function. Research supports this claim, providing clear evidence that brain regions associated with executive functions and higher-level cognitive processes, located in the frontal lobes, are affected by experiences of social exclusion. However, possible conditions of marginalization and social exclusion have serious implications in the behavioral domain as well. The literature finds rejection hypersensitivity to be associated with higher levels of aggressive behavior and more interpersonal difficulties (Tobia et al., 2017). The following extract is characteristic:

> *"The child had an adjustment problem. He was aggressive to a point, he cried easily, he didn't hang out with the other kids because he was aggressive. He felt marginalized, so his reaction was this" (Interview 13).*

The role of formal education teachers is undoubtedly crucial, since they are not only the ones who first welcome children after hospitalization and confinement at home, but also those who help them to obtain a desired academic level. However, the insecurity of teachers is evident when it comes to interacting with children who have undergone heavy forms of therapy (see related references above). This is observed, due to their insufficient training on specific issues,[1] as well as their unpreparedness regarding the mental domain, to respond to such a demanding role and to develop an effective academic plan for their students with cancer (Hay et al., 2015). Below there are extracts from the narratives of parents with completely different experiences with teachers when reintegrating their children:

> *"We had a lot of psychological support, from the school, from the teachers and all the educational staff and the principal and, even though our child had this teacher for the first time, they immediately developed a very special relationship. He came to the hospital, saw him, we had, if not daily communication, very regularly. He was being informed about his health (...)" (Intervview 9).*
>
> *"(...) Our first grade teacher, when the child returned to school, considered that... [child's name] was a burden (...) Because, she needed to take care of him and she didn't want a problem in the classroom (...) On the other hand, in the second year, another mistake was made. His teacher believed that with the arrival of "co-teaching" -another teacher, that is, inside the school- maybe the child will be targeted (...) Maybe the rest of his classmates considered him dumb, stupid, whatever, so the marginalization would intensify!" (Interview 13).*

It is worth highlighting, at this point, the convergences on the part of the teachers:

> *"So, I had to somehow raise awareness among my kids, make them a team, that's my goal anyway! That is, to create the community of my class, so that they can then welcome... [child's name] (...) Through activities aimed at raising children's awareness of diversity (...) to build social identities... that we are all equal in here and we all respect each other (...)" (Interview 18).*

Another important issue that emerged from the research was the effects on the mental balance and daily life of the rest of the family. From the international literature we know that caring for a child with complex needs at home requires multi-dimensional parental involvement, full acceptance of responsibility for problem solving, decision making, many times teaching, managing and coordinating various actions and interventions· and, of course, all of the above unfold in the wider context of family life (Hewitt-Taylor, 2005). Previous research has compared children with chronic diseases and their siblings in terms of their cognitive skills, quality of life and psychosocial development. It was found, indeed, that the children who got sick -and were eventually cured- had more cognitive and educational deficits than their siblings. In recent studies, it was the healthy siblings who presented higher rates of social isolation, more post-traumatic stress symptoms and significantly worse school performance than those who suffered from childhood cancer (Barrera & Atenafu, 2008). However, beyond the contradictory results of some studies, it has been observed that the siblings of cancer survivors show an increased frequency of school absences compared to the general population. Possibly, this occurs on the basis of a more general permissiveness or tolerance of parents regarding school absences, resulting from their awareness of the painful mental processes that their healthy children face during the hospitalization of their siblings (French et al., 2013). In general, we would say that burdening parents with additional obligations in terms of nursing and caring for sick children is a major issue that directly affects the schooling of the family's children. It is worth recording a phrase that was said many times during the interviews and by different parents each time: "When one member of the family gets sick, the whole family gets sick."

Very often, the home turns into a makeshift hospital and this has direct effects on sick children, their siblings and parents. As we read, during the home care of children with complex needs, parents often provide a type of care that corresponds to professionals (Kirk, 2001). Further aggravating, for the already mentally charged

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[1] Regarding the issue of lack of knowledge and information, this is a serious issue for teachers and schools. In a survey carried out in England in a pediatric oncology department, teachers emphasized their need for better information in relation to aspects of treatment, diagnostic tests and treatment, as well as the need for training in the preparation of the rest of the school students (Brouskeli, 2013).

parents, the factor of the voluntary or, more accurately, forced abandonment of work by one of the two parents, due to their inability to cope with the new increased demands entailed by the recovery of their children's health. Parents, very often, feel that they cannot control the course of the disease, which makes them feel helpless. Sometimes, again, they feel guilty as they poke their child with the needle and cause him pain. Other times, they are suffocated by the absolute dependence of their sick child. All these together, are stressful factors that further burden the already burdened everyday life (Valamoutopoulou & Valamoutopoulou, 2014). The multiple and daily obligations of parents, in terms of planning and organizing the child's life on the basis of strict hospital settings and complex home treatments, justify any concerns they have about the possibility of side effects during treatment (Eiser, 2004). A father's statement is indicative:

> *"(...) Our everyday life has also changed. We, suddenly, became nurses, we became doctors, without knowing anything!' (Interview 9).*

In the long period of continuous handling at exhausting rates, the school is reduced to a serious mechanism of support and optimism. There are many parents who will not look for psychological support anywhere else, except from the school staff (Salzberger-Wittenberg et al., 1996). Therefore, one realizes the importance of trained teachers in matters of school integration of children with chronic health problems. This is a necessity that was demonstrated in another part of this work and is highlighted in all the relevant reports of the parents who took part in the research.

Finally, it is necessary to say that feedback on the range of attendance and long-term results concerning the general school career of children who suffered from chronic diseases was not possible to obtain, due to the fact that most of the children, whose parents participated in the research, are still at school. The fact, however, of giving them the possibility of admission to Tertiary Education without the National University Entry Exams (Greek SATs), but using a prescribed percentage of the grade, if nothing else, justifies some optimism, obviously restrained, since no privilege policy can be a panacea in solving both complex and demanding issues, as was evident from all the above. The following contradictory passages are typical:

> *"They have some help in the future to enter the University more easily. Of course there should be special treatment! Because we are talking about children who have suffered for many years! Therefore, they can't have the same drive and vitality, in any case, because they miss too much of their school (...) Being in the oncology department, I tried to use a lot of this dynamism on some students who were older. (...)" (Interview 20).*

5. Conclusion

In summary, we would say that hospital education in Greece is still in its infancy. As far as the teachers are concerned, the absence during the circular studies of training related to teaching in hospitals, is a significant aggravating factor and is attributed to the general indifference of the state, while also making the curricula of the individual Pedagogical Departments hollow. Hospital schools are treated by legislation exactly like other formal education schools in terms of opening hours and the selection of teachers, although they are a very different type of educational structure with multiple requirements. The poor organization and the almost non-existent communication between the teachers, inside and outside the pediatric clinics, raises a more general concern, since the adoption of an interdisciplinary cooperation plan of the involved bodies is considered crucial. It is found, that the maintenance of dividing lines between formal and hospital education does not at all serve the learning and socialization process of children experiencing the case of a chronic disease. On the contrary, it prevents the correct information and management of the various issues that arise. Similarly, the possibility of online communication with the school - both during and after their hospitalization, during home education - is considered necessary for their more effective reintegration into school and society in general. Nevertheless, from discussions (informal interviews) with parents, our initial feeling was reinforced, about a completely unprepared and unscientific handling of the whole issue by the state. Thus, in a prolonged period of unsuccessful treatment of the pandemic by the Greek government, where adherence to neoliberal dogma prevented the exercise of a - if not radical, at least effective - social policy, the area of public health was underfunded and understaffed. The policy was similar in the area of education, where the only response to the risk of the spread of the coronavirus was the consecutive closing and opening of schools for a period of approximately 1.5 years, during which distance education (synchronous or asynchronous) alternated periodically with face-to-face teaching. Despite significant and fair objections to the anti-pedagogical and anti-social character, the established educational and socialization costs of this option (Bueno, 2020; Fitzpatrick et al., 2020), distance education was imposed on all schools in the country. They forgot, however, to use it in hospital schools and home education, in perhaps the only cases where its utility would hardly be disputed. We wonder, then, whether distance education is ultimately another means of "social distancing" of the population, serving the modern social contract recently signed with the neoliberal political instrumentalization of the pandemic, rather than being, as it should be, an alternative teaching practice to overcome situations of lack of communication between burdened groups of the country's student population.

Finally, some common practices of keeping the disease silent from those around children with chronic diseases are considered ineffective and pedagogically unproven, while they reinforce other possible adjustment problems when they are reintegrated into the standard school.

From all the preceding, it is certain that children with chronic diseases are hampered by their equal participation in educational processes, which negatively affects the general quality of their lives, addicting them to a constant flirtation with situations of social exclusion, which seem insurmountable. Any successes in the educational field are due to the efforts of the children themselves and their families and, of course, to the personal sensitivities and daily sacrifices of their teachers.

The field of our research is still open for future and more specific research approaches. For example, the educational trajectory of children recovering from chronic illnesses could be examined. In addition, a comparative study of the social characteristics of these children in relation to their school outcomes would be of particular interest. Finally, a comparative study of national policies and the corresponding educational practices followed could be undertaken.

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