

**A Parents Perspective: Educational Problems Associated with Children who have Cystic  
Fibrosis.**

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Submitted in partial fulfilment of the requirements of the BA (Honours)  
Degree in Social Science at Dublin Business School of Arts, Dublin.

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April 2013

<b>Contents</b>	<b>Page</b>
<b>Acknowledgements</b>	4
<b>Abstract</b>	5
<b>Introduction and Literature Review</b>	6 - 13
Cystic Fibrosis insight	7
What is Cystic Fibrosis?	7 - 8
The rights of a child with Cystic Fibrosis in school	8 - 9
Students with Cystic Fibrosis and problems with attendance	9
Length of time absent	9 - 10
Problems with missed school work	10 - 11
How the treatment of Cystic Fibrosis negatively effects education	11 - 12
Negative social problems and lack of communication	12 - 13
Problems with homebound tuition	13
<b>Research Design and Methodology</b>	
Aims and Objectives	14
Introduction	14
Design	14 - 15
Participants	15
Materials	15
Qualitative Interview Process	16
Limitations	16 - 17
Method of Analysis	17
Procedure	17 - 18
Ethical considerations	18 - 19

<b>Results</b>	
Absence	20 - 12
Student's and Teacher's understanding	21 - 22
Catching up with schoolwork	22 - 23
Exams	24 - 25
Homebound/Hospital Tutoring Problems	25 - 26
Summary	26 - 27
<b>Discussion</b>	28 - 32
<b>Strengths Limitations Recommendations and Conclusion</b>	
Strengths and Limitations	33
Recommendations	33
Conclusion	33 - 34
<b>References</b>	35 - 36
<b>Appendix 1</b>	37 - 38
<b>Appendix 2</b>	39 - 40

## **Acknowledgements**

I would like to first thank the participants who took part in this study. Their openness and honesty about their experiences has helped create this research.

I would also like to thank my supervisor Dr. Niall Hanlon for his support and his dedication towards helping me with my research.

Also I would like to thank my mam, dad, brothers, sister and Ally for their support right throughout the year.

## **Abstract**

This research aims to identify what parents think of the educational services put in place for their children who have Cystic Fibrosis. The research that has been done previously in this area shows that there is a lack of adequate services in school for children who have Cystic Fibrosis and parents feel that their child has a disadvantage in education because of this.

Research in the past also shows that there is a significant lack of attention being paid towards children who are in school and have a life long illness and the services that are in place for Cystic Fibrosis sufferers are not suitable to attend to their needs in education.

This research aims to show how parents feel that the educational services in place in Ireland today are not good enough and how the students are suffering in education because of this. The research also aims to look for themes through each of the participant's experiences and opinions, to create a detailed account on why parents think the services for their children are unacceptable and how the services could change to help them in the future.

## **Introduction and Literature Review**

Cystic Fibrosis is a disorder that has affected children in education in many ways. Education is a very important part in any child's life while they are developing and is one of the main factors in maximising a person's chances in life. A child has the right to education and everything should be done in society to make sure that all children have the same opportunities when it comes to school.

The overall purpose of this research is to discover issues related to education and students who have Cystic Fibrosis. Cystic Fibrosis sufferers encounter a lot of challenges internally and externally in relation to school life. These obstacles can inhibit their chances of educational progress and can also affect their overall achievements in later life. It is important to research this problem as there is not a lot of attention being paid towards it and it is the responsibility of the schools and other services to make sure that children, who have Cystic Fibrosis, have the same chances in education.

Students who have Cystic Fibrosis are constantly dealing with a sickness they cannot get rid of. Even with this daily battle, they must go to school and try live a life that is as normal as possible and as similar as possible to their fellow students. This can be emotionally and physically tiring. The services available for Cystic Fibrosis students must be focused on to ensure that the best services are available to them and to make sure that their sickness has little effect on their education.

This literature review will examine the literature related to the research question "Parent's perspectives: Educational problems associated with Children who have Cystic Fibrosis". Cystic Fibrosis is one of many illnesses that can inhibit the educational advances of a person who suffers from the disorder. Sufferers of Cystic Fibrosis are commonly absent from school and in some cases for long periods of time. This can have negative outcomes when it comes to their overall education. In this literature review the problems children with Cystic Fibrosis face when they are in education and how the levels of attention paid towards them being involved in education when they are absent is being overlooked.

## Cystic Fibrosis insight

Cystic Fibrosis is something that the researcher has had experience with first-hand. The researcher has a family member who has the genetic disorder. Cystic Fibrosis is a disorder that affects sufferers when they are going to school as it causes them to miss out on days and some exams frequently. Cystic Fibrosis sufferers therefore fall behind on teachings while other students excel. This problem has existed for a long time and has not been acted upon to ensure that Cystic Fibrosis sufferers get the same chance in education. The researcher has seen the affects that a lack of school time and not properly bonding with classmates has affected the family member and the problems that he faces with school every day. The problems connected with chronic diseases and education needs to be examined and action must be taken on the problems that exist in the education system.

## What is Cystic Fibrosis?

Cystic Fibrosis is a genetic disorder that affects a person's pancreas, liver and intestines but affects the lungs the most. Cystic Fibrosis causes the lungs to become filled with mucus which is hard to eradicate and leaves the sufferer with difficulties in breathing and affects other various bodily functions. Other problems caused by Cystic Fibrosis is the stunt in growth, both in height and muscle mass (What is Cystic Fibrosis? n.d.). Infertility is also a problem which exists among Cystic Fibrosis sufferers. Ireland is said to have the highest incidence of Cystic Fibrosis in the world. It is said that around 1 in 19 people carry the gene which causes Cystic Fibrosis (Cystic Fibrosis Ireland).

Because Cystic Fibrosis is a genetic disorder that affects the organs, many people who have it do not show any signs of having the disease. Differences that Cystic Fibrosis sufferers have to other healthy people are all related to their breathing, intake of food and their digestive systems. Breathing problems that are caused by Cystic Fibrosis can easily lead to the sufferers getting infections which can cause them to begin to cough up blood or cause infections such as Pseudomonas, which is an infection caused by the build-up of bacteria in the lungs . In relation to the intake of food, Cystic Fibrosis sufferers need enzymes to help break down fatty foods that the pancreas cannot do because of the disorder. The enzyme, called Kreon, has not always been around for people with Cystic Fibrosis so their diets were not very broad and malnutrition was

common. The interaction between two people with Cystic Fibrosis can be dangerous when it comes to picking up infections. Because sufferer's immune systems are lower than healthier peoples, they can easily contract an infection from another person with Cystic Fibrosis, who has an infection that is dangerous to him/her. To try preventing the spread of infections between people with Cystic Fibrosis, they are usually isolated from each other when they are in hospitals or other healthcare related areas. Isolation is very important when it comes to the level of health Cystic Fibrosis sufferers have.

### The rights of a child with Cystic Fibrosis in school

Education is a very important part of a child's development. In Ireland today, the educational needs of a child are more accurately met than they were in the past. Students who have Cystic Fibrosis are just as able as classmates to do well in school but one of the problems they have with keeping up with others is that they have to prioritise their daily routine to fit in treatments they must undertake daily (The Cystic Fibrosis Association of Ireland). Since the 1990's there has been an increase of focus on how to help students with disabilities. These have been brought forward by the Education act in 1998 and the NCCA in 1999. The Education Act provided a basis for legislation and policy for educational needs and the NCCA (National Council for Curriculum and Assessment) provided policy on children with special needs, but it did not address systematic issues (Kenny & Shevlin, 2001). The right's for a child's education who has a disability has also been brought to the attention in today's society. The Education for Persons with Special Educational Needs (EPSEN) Act was introduced in Ireland in 2004, where one of the main aims was to introduce legislation for individual education plans for people who had special educational needs (McCausland, 2005). One of the services which could be accessed by Cystic Fibrosis sufferers is home tuition. Even if students with Cystic Fibrosis are healthy they need to attend regular check-ups and annual assessments, which can add to the amount of days that they are out absent. These home tutors are assigned to students whose medical condition causes disruption to their attendance at school (The Cystic Fibrosis Association of Ireland). Even though there has been more attention paid towards giving students with special needs suitable access to facilities, educational needs has yet to have a big involvement in services that are requested by Cystic Fibrosis Ireland. In a statement to the Joint Oireachtas committee by Cystic Fibrosis Ireland, there are requests for certain services to be provided for

Cystic Fibrosis sufferers, but none to do with the aid of their education. There were requests for very important things to improve a sufferer's life, such as isolation units and the need for funding to find a cure, but the lack of attention paid towards the educational problems they face is evident (Watt, 2013).

### Students with Cystic Fibrosis and problems with attendance

Cystic Fibrosis sufferers have, like other sufferers of other variable disorders, come to the realisation that they are more likely to be absent from school than others who do not suffer from life altering disorders. One of the main reasons for this is the lack of appropriately resourced policies, personnel and services which are vital to inclusive education (Walmsley, & Mannan, 2009). There has not been a lot of attention focused on children with Cystic Fibrosis of how they adapt with their disorder and education and how they develop compared to healthier classmates. The health care of people with Cystic Fibrosis has vastly improved over the years and new light has been shed on how to care for people with Cystic Fibrosis easily has also been introduced. One of the main problems with Cystic Fibrosis is that sufferers are sometimes out of education for long periods of time but there is not much attention paid towards their education when they are absent. The attention that is been paid towards the educational needs of chronic illness sufferers is little to none (Bowen et al. 2010). When a person with Cystic Fibrosis is forced to stop going to school because of an illness, they are usually absent for a substantially longer time than someone who is not suffering from a life-long illness. If a sufferer is overly sick it is more common than not for them to enter hospital for an assessment to make sure that they are relatively well and are not required a stay in for a lengthy period (a few days) in hospital.

### Length of time absent

Being absent from school is a common experience for students who have Cystic Fibrosis. Children who have a chronic illness miss an average of 17 days a year compared to healthy peers. Cystic Fibrosis sufferers commonly miss more days than this. The average number of days missed for Cystic Fibrosis sufferers is around 20 days (Shaw & McCabe, 2008). A huge problem of being absent when the person has Cystic Fibrosis is the extended periods of time they take to

rehabilitate compared to healthier peers. Something like a cold or the flu on top of the already existing problems related to Cystic Fibrosis can cause the student to be out of school for twice or three times the length another healthier student might be out for. When it comes to chronic illness, 58% of students who have chronic conditions regularly miss school and 10% of these miss over one quarter of the year. If a student misses this amount of days they are more likely to do worse than other students or fail (Thies, 1999). Even though Cystic Fibrosis sufferers do miss prolonged amount of days in school, there are also problems related to short termed absence. With Cystic Fibrosis, students commonly miss a few days of school or they get half days. The problem with this is the frequency that it occurs. If a healthy child misses 2-3 days it is acceptable because that is a rare occurrence, but a chronic illness sufferer is frequently out these amount of days which adds up to a lot of days spent absent which contributes to the decrease of educational progress. This recurrent absence because of their chronicity leads to students becoming physically and mentally tired, making the participation in education even harder (Thies, 1999).

Because teachers sometimes have a lack of knowledge about the chronic condition, they expect less from the student which can be harmful to them academically. If a student does not do well in a certain subject or area, the teacher sometimes does not confront the student about the problem in fear that they are putting a strain on the child instead of trying to improve the area they struggle upon. Their attitudes towards how well a student can do after being absent frequently or how well they can do because of their chronic illness, can be easily distorted (Thies, 1999).

### Problems with missed school work

The problem with people who are in education with chronic illnesses such as Cystic Fibrosis is the awareness and information around the disorder. Because people in a class with Cystic Fibrosis or other chronic illnesses are in the minority, they sometimes get left out or treated unfairly without a teacher truly understanding how the illness affects their educational progress. If a student with Cystic Fibrosis does not understand a certain lesson because of their

absence it might be seen that they can easily catch up and it is their own fault that they were not there for the lesson. The reason they were not there could be attributed to their illness (Lightfoot, Wright, & Sloper, 1999).

When a child with Cystic Fibrosis is out of school for long periods of time or they are absent frequently it is very difficult for them to get back into fully understanding what they are studying as they have missed what was being covered during their absence. When a child with Cystic Fibrosis is absent frequently or for lengthy periods there is not a lot of attention being paid towards the child being able to cover at home what is being taught in school at that time. In some cases they are too sick to cover the work being done but in most cases the reason they are absent from school for prolonged amount of times is because it takes a longer time for them to recover while at home or in hospital.

#### How the treatment of Cystic Fibrosis negatively effects education

Another main part of Cystic Fibrosis and education which is being overlooked is the educational consequences while dealing with their debilitating disease, compared with students who are well and healthy. Because they miss out on a lot more school-time than other students because of being vulnerable to illness and time spent looking after their sickness (hospital visits and other processes vital to their health) they subsequently fall behind in the work that the class is doing and having no certain way of obtaining the missed work. In education, 45% of students who have chronic illness say that they fall behind in their work which leads to having little interest in school. Another 35% at secondary school level report that they are failing in some classes (Thies, 1999). Because of the lack of services for Cystic Fibrosis sufferers, their problems are related to the results. In Cystic Fibrosis, a sickness that a healthy person can get that is seen as minor can be more serious for people suffering with the disorder. Even though this is a common occurrence, there are other reasons why Cystic Fibrosis sufferers tend to fall behind in school and have their education progress limited compared to healthier class mates. The vast amount of medication that a sufferer takes can also have negative results as well as tackling and controlling the autosomal recessive disorder. The medication which they take can take up a lot of time as they have to ingest several tablets or antibiotics and then take oral-steroids which help

their lungs. This can take up a lot of time depending on whether the person has to take this medication at specific times and how long the oral steroids take to finish (e.g. Nebulizers and other breathing apparatus). From the medication they take, the side-effects can cause them to have difficulty with memory, being very tired and not able to fully concentrate because of the medication they need (Thies, 1999). These different prescriptions can cause completely different and conflicting side effects and can influence a student's ability to function and learn properly. A problem with a student taking the medication is that the medical practitioners that prescribe the student the medications to help his/her chronic illness do not see how they are affecting the student when it comes to learning and their improvement in subjects. This could be solved by the school and by the medical team if they communicated in relation to the student's advancement. The impacts of this could see the student reaching their maximum academic performance (Shaw & McCabe, 2008).

#### Negative social problems and lack of communication

In school, there is a problem that schools face when there are students who suffer from chronic diseases, such as Cystic Fibrosis. The problems are that because they are absent more than healthier students, they sometimes encounter behavioural problems such as depression and social withdrawal. This is sometimes due to a student with a chronic illness coming back into school at certain times in the year and feeling left out because of certain things that have went on in the school during their absence e.g. school exams and changes of teachers, principals, which are big topics of conversation in the school. Social isolation is a problem mostly because of the lack of knowledge on behalf of other students about the chronic illness (Kaffenberger, 2006).

School re-entry is a problem for students with chronic illnesses as the work they have missed while other students have done, is usually not given to the chronic illness sufferer to catch up easily or without any help. This is because of factors such as lack of communication between parents and schools, schools and hospitals and the lack policies in the school to help out the student (Kaffenberger, 2006). A problem associated with this is the lack of communication when the child is out for a long period of time over whatever health related reason has stopped them from going to school. Kaffenberger said that when parents find out about their son/daughter

and how long they stay in hospital for, they prioritize in different ways and sometimes school is not seen as an important factor to the child. Schools then do not know what to do in relation to the child's education so commonly no action is taken and the child is left in hospital to recover, with little or no school work to do. This then leads to the child falling behind in work. When they are back in school make it very hard to keep up with work and the problem is regular when their health problems reoccur (Kaffenberger, 2006).

### Problems with homebound tuition

Even though there are homebound regulations for children who have chronic illnesses, they are not flexible enough for students who have Cystic Fibrosis. In order for a student to get homebound services they must be absent for more than thirty days. After this they have qualified for the homebound instruction but they are not allowed to attend school and must stay at home for their education (Kaffenberger, 2006). For Cystic Fibrosis, there needs to be an implementation of more flexible homebound services as even though they are rarely out for 30 or more days, they are frequently out each week and are absent from a lot of lessons. This can cause a problem as there are no implications on when a sufferer will be absent or for how long, but with schemes throughout schools put in place, the work which they might miss can be easily given to them to ensure that they do not fall behind.

Students with Cystic Fibrosis need both homebound instruction and to be able to go to school as their health status is not easy to forecast. They can go from school one week to be put in hospital the next. If there was a flexible policy on homebound services, this would help the Cystic Fibrosis sufferers to improve their education once they are healthy enough to attend school. Problems with this are also communication factors. If a school personnel does not see the student as falling behind because of their illness, but because of bad attitude towards their education or other reasons, the child may suffer because homebound services will not likely be mentioned to help the child while they are recovering from problems relating to their chronic illness (Kaffenberger, 2006).

## **Research Design and Methodology**

### Aims and Objectives

- The aim of this research is to discover what problems students with Cystic Fibrosis face in education.
- The research aims to identify how students are vulnerable in education in relation to work and absence.
- The research also aims to show how parents think their children could have more service support in education and how they can have the same opportunities in education as other students.

### Introduction

In this section the design of the research, the participants who were involved in the research, the materials used and the overall procedure of the research project will be discussed throughout. This section will also explain how the data was collected and how the data was analysed to find the results that were needed. Through this section, the limitations and the ethics that needed to be considered are also taken into account.

### Design

The design that was used throughout the research project was qualitative research. Qualitative research is based around in-depth answers to certain questions and finding out why there is such an opinion on something and also why someone thinks in such a way. This is different to quantitative, which looks at which way a person's views lean, instead of why they lean that way and how such an opinion has been found upon them. Qualitative research covers a vast range of approaches but the aims of it are mostly to find in-depth and interpreted understandings of the social world. This is done, mentioned before, by a person who has certain experiences and perspectives (Ritchie and Lewis, 2003, p.22). For this research, qualitative was the most suitable because the information needed for the research had to be in-depth to get the suitable information. The topic which was focused on was parent's perspectives on the educational services for their children who have Cystic Fibrosis. For this research, interviews

will be conducted with parents who have children who have been or still are in school as they will have experienced their child being absent from school for long periods of time and the difficulties associated with their children and education. Qualitative is a good research method for this because it gives the person being interviewed the time to discuss their true perspectives on a certain subject which would not be possible with quantitative. The person who is being interviewed can also feel comfortable in an environment where it is one-on-one. This gives them the time they need to answer certain questions they might not want to answer in groups and also give the interviewer the freedom to alter the question if the person does not feel fully comfortable with commenting on a certain question asked to him/her.

### Participants

Participants in this research, who were parents of Cystic Fibrosis sufferers, were needed to answer some questions in order to attain the information which was required for the research. The people that were chosen for the interviews all had experience with Cystic Fibrosis as all the participants had children who had the disorder and had experience in relation to their child and education. This was very important as experienced individuals were needed to create the best results. The researcher let all the participants know everything about the research which was being conducted and were given consent forms to sign to declare that they knew what was being researched, the questions that were being asked in relation to the research and the rights they had through the research process. These included the right not to answer a question they did not feel comfortable doing so and how their identity would not be revealed.

### Materials

The interviews which took place were in the interviewee's own environment. This is important because this helps them relax and become comfortable with answering questions fully. During the interview, there was a recorder placed on the table so that the researcher could later transcribe what had been said in the interview, so it would be easier to access what information was given which would in turn help with the results. A pen and paper, a consent form which the interviewee had to sign, a USB and a laptop was also present with the researcher so notes could

be taken down during the interview process and afterwards the recordings could be secured onto the laptop to make sure that it was protected to make sure it remained confidential.

### Qualitative Interview Process

The interviews that took place for this research were personal and there was a chance that some of the questions asked could bring up difficult experiences for the participant. Because of this the participants were interviewed in their own environment. The researcher chose the method of semi-structured interviews throughout the process. Semi-structured interviews were chosen because the interviewer could explain some of the questions to the sample if they did not fully understand it. This made it less likely that the answers the interviewee gave lacked the required information. Another important part of the interviewing process was that the researcher makes the question clear. This will lead to the sample understanding the question and honestly answering using their opinion. A slight change in wording could lead to the participant answering “yes” instead of “no” (Babbie, 2010, pg. 276)

During the interviews, the researcher was aware that some of the questions asked could be sensitive so they made it clear that they could answer at their own discretion. This kind of interviewing technique helped the participants ease into the interview and eventually open up fully about their experiences. If the answer that the participant gave was not elaborate enough the interviewer probed for more information. Sometimes if the participant does not give elaborate answers, the interviewer would sit there in silence, which would cause the participant to fill the silence with more information and additional comments about the question (Babbie, 2010, pg. 277). As the interviewee's opened up more throughout the interview, their inclusion of personal opinions and experiences around education and their child started to appear more in each answer.

### Limitations

The limitations that existed in this research were that the number of parents who were available to answer questions was lower than expected. Out of the 16 requests sent by the researcher, only 7 responded with intent to do the interviews. Another limitation was that some

of the participants were not up to date with some of the legislations on educational rights for students who have a disability and were not aware of some services that are available in schools. Because of this, they were not able to give honest opinions on the services their child has.

### Method of Analysis

Qualitative analysis allowed the researcher to create themes which were arising in each interview. Thematic analysis through NVivo is used as a way to analyse the reoccurring issues and the patterns which were raised during each of the interviews. This allowed the researcher to come up with themes where similar information came up in each interview. Quantitative is another research that could be used to gather similar data but by doing interviews with participants, they give insight into how education for their child has affected them differently and through quantitative research, the different insights into these areas is not possible.

### Procedure

“Parent’s perspectives: Educational problems associated with Children who have Cystic Fibrosis” is something that the researcher found very interesting as it had a strong connection in relation to their life. The research that was put into the subject proved that there was a need to research this certain area because it was a common problem associated with sufferers. After some research was completed, there were some things which needed to focus on in relation to the title.

Even though there were some articles related to the topic of choice, these articles were very limited and there was not a lot of focus on the subject in Irish society. For this reason, this topic was important as further research into Irish society's views on these problems would benefit any further questions which could be asked about the title's meaning. After many discovered articles and after the supervisor helped narrow down and pinpoint the relevant material, the literature review was created to further strengthen the research. This also helped the researcher come up with ideas for questions that could be asked for the best results.

The questions which needed to be asked to the participants were completed after looking at relevant material in the literature review and after some guidance from the researcher's supervisor. The questions that were going to be asked to the participants needed to be asked in a certain way to make sure the best results possible could be attained. The questions needed to be clear and concise. This helped the participants understand the question and go into detail that was relevant to the question. If the question was unclear or asked too much, the answer given might not be good enough information could be lost because of lack of understanding. The interviews which took place consisted of 16 questions. These were semi-structured interviews. This qualitative data collection method was chosen to gain the best answers possible during the interview.

### Ethical considerations

In research, ethics is something that is very important when it comes to the researcher and the participants. Ethical considerations that must be undertaken, help the researcher with the participants to make sure that anything that is said is said by the researcher is taken into consideration. When you are interviewing willing participants, the responsibility the researcher has over the people that they are interviewing and the values of the researcher has to be faced (Silverman, 2005, p.257) Because this is so important, ethical considerations must be undertaken every time an interview is taking place.

While carrying out the interviews, it was important that the participants knew that they were protected by the ethical considerations that were in place. To provide confidentiality, the interviews which took place were in private rooms and only the researcher and participant knew what information was being discussed. The anonymity of the participant must be upheld throughout the whole process including keeping their identity withheld throughout the findings of the research. The participants in the interview also had the knowledge that they were able to pull out of the research at any time if they were not comfortable with continuing on. This protects the participants and shows them that they have full control over the interview and are not under pressure to answer things they do not want to. The researcher must make it their responsibility that any questions that the participant does not want to answer are avoided. The

questions that might be asked to a participant could be something that they find to be sensitive or that the answer that they are giving might bring up sensitive areas that the participant does not feel fully comfortable talking about. The problem associated with this is that when sensitive subjects are brought up, the participant may not want to answer further questions because of the painful experiences that are brought up. If the participant does not want to answer this question, they have full control not to do it.

## **Results**

This research focused on the educational experiences of students who have Cystic Fibrosis, the disadvantage they have in education and the obstacles they must overcome every day. By using qualitative research analysis the researcher was able to find themes within the interviews. The following themes came up in all of the interviews in which the researcher conducted.

### Absence

Out of all the parents that the researcher interviewed, all of them said that absence for their child was a problem. Out of all the participants who were interviewed, every one of them said that absences from school had affected their child's progression throughout the school year and a few stated that the amount of days they were absent a year was a lot more than studies stated. "Well to be honest with you I think it is more than 20 days of absence. If they get a chest infection they could be hospitalized for up to two weeks, which is 10 days off school and they also need a week to recuperate and that would be 15 days. That could happen a few times a year". (Lori). Lori stated that her child, a 13 year old boy in first year is absent for over a month collectively every year. She felt that the amount of days children with Cystic Fibrosis spend absent from school does then lead on to them missing important things in school like lessons, making friends and getting to know teachers.

"When he was in hospital just before the Easter he missed 3 weeks and when he finally got back they were miles ahead with some of the work and he was left sitting there not knowing what to do". (Eileen). Eileen, a parent of a 16 year old with Cystic Fibrosis felt that with the amount of work her child was missing had very negative affects when it came to his knowledge about certain subjects. She expressed her concern about how badly it would affect him in further exams like the Leaving Cert.

Chris, a parent of a fourteen year old with Cystic Fibrosis, said that "The work she misses really puts her behind the rest of the class and because of this she gets frustrated". (Chris). Chris said that because his daughter misses so much school and therefore schoolwork, that she is constantly frustrated with attending and not understanding the work that the class are doing. He said that his daughter is losing some interest in school because she was not in for some of the

work and now she is being left behind while the class progresses with the lessons. All parents felt that things needed to be done to help children and insert a backup programme in both school and hospital because they miss so much due to their illness.

### Student's and Teacher's understanding

Because little is known about Cystic Fibrosis, there are problems with how students and teachers view the sufferer in school. One parent felt that her son did not want to let the other students know he had Cystic Fibrosis because they might have thought it was contagious or they would keep asking him questions about his illness. Other parents felt that because teachers did not know a lot about Cystic Fibrosis and they would not be lenient on them for the homework or projects because they are unaware of the regime they must go through at home in relation to medication and staying well.

One parent also said that when it came to things in school like sports, teachers would overlook her son because they did not know the implications about him playing football. “If they were picking for a team he would not be picked because they did not think he would be able for it whereas it would have been great for him to be picked because exercise is paramount in Cystic Fibrosis”. (Lori). Lori felt that because the teachers did not know enough about Cystic Fibrosis, they made a decision not to pick her son to play. She raised the issue that this does not help him have a normal school experience because the teachers perspective of his sickness stopped him from doing something in the school that others can.

Chris also expressed his concern about teachers and how they see his child when it comes to school work and tests. He said he has experienced his daughter getting very average results and when he was at teacher meetings they said the scores his child was getting were good. “If my daughter is feeling healthy and she gets a very average score in an exam, the teacher might say that it is very good. I don’t think it’s the right encouragement because therefore my daughter won't try harder because she'll see that as a good score”. (Chris) Others also felt that teacher’s views changed when they found out about their student's condition.

Another comment which was made by Mary about her child and classmates was that she felt her son did not want to tell them about him having Cystic Fibrosis. “When he first started last September and he was making new friends in the class he didn’t want them to know he had

CF” (Mary, Parent) Mary felt that her child did not want other students knowing about his Cystic Fibrosis because of the attention he would get in his first year of secondary school. She explained to the researcher how he had a peg inserted into his stomach for feeding and did not want students talking about it and asking him questions because he would feel different to all of them.

### Catching up with schoolwork

When the researcher asked each parent about the school work that their child had missed, the majority of them expressed their concern about how much work they were missing when they were absent. They also had different ideas on how their child could catch up with the work and how schools could provide for the student. All parents felt that services could be implemented even though there was not much being done for students with Cystic Fibrosis when they were out absent.

Chris said that there was a huge amount of school work his child was missing and that there was not much being done to help his child when she was absent. Chris said that there were some services which could be brought in to make things easier on children with Cystic Fibrosis in school. He thought that there could be some kind of system set up in the school which would be dormant in the school until the child with Cystic Fibrosis is absent and will be for the next few weeks. “Children with Cystic Fibrosis could be healthier than you and me one day, and the next day they are forced to stay in hospital for 3 to 4 weeks”. (Chris). For this to work Chris said that when the child is in hospital, the school or the teacher could send them the homework or the lessons that they are doing via e-mail with explanations along with it every few days. This would keep the student up to date with the curriculum.

Lori also thought that this kind of method would work and help keep her child's progress going while they are out of hospital. “I think that everyone with Cystic Fibrosis should be allowed use a laptop”. (Lori). Lori explained that she thought that if a student had a laptop and had all the work there, it would be easier for them to access the work while they were in hospital. She said that because most teachers now have laptops, it would easy for them to send work to

them from the school to the hospital. Lori also said that her son had the option to drop some “unimportant” classes that he did in first year to catch up on work but that it was not a long term solution. “When I inquired about the work he missed out on they suggested that he drops the non-important subjects. That was in first year but when it comes to the Junior Cert you wouldn’t be able to do that”. (Lori).

Eileen said that because her child is in the hospital, schools think that her child is too sick to do work but that it is not always the case. While talking about the work being given to her child, Eileen felt that there was a lack of understanding between the schools and Cystic Fibrosis. “Obviously this doesn’t make sense if my child is sick but sometimes they can be entered into hospital for IV treatment, where he can do work because he’s not actually sick, just he needs to stay in hospital”. (Eileen, Parent)

“I just feel that the schools or the CFI aren’t doing enough for our kids in education and there needs to be more focus on what they need to do in schools to make sure my child doesn’t miss as much work as everybody else”. (Claire). Claire who has a child doing the Leaving Cert this year, expressed her anger at the CFI (Cystic Fibrosis Ireland) not paying enough attention to the needs of children with Cystic Fibrosis while they are in school. She also believes that because of the lack of focus on this area, schools then do not realise that students with Cystic Fibrosis need educational aid.

Mary, who had a child in secondary school with Cystic Fibrosis said that there could be someone in classes when the student is not there, like a resource teacher, to take down notes and to get all the lessons for the student during their absence. “Well I think that someone could be in the class when the child is missing from school to take down notes”. (Mary). Mary said that she feels there would be positive affects in relation to her child catching and keeping up with work while they are out sick.

## Exams

When the researcher asked the parents of Cystic Fibrosis sufferers about exams, they all felt that there needed to be services for them to do exams even when they are sick and when it came to it, get a good result in the Leaving Certificate.

Frank talked about the added on points system that would work for his child when it comes to the Leaving Cert. He said that the introduction to this service was one of the very few things that are in favour of Cystic Fibrosis sufferers when it comes to exams. “Yeah well there is a point add-on system that works in favour of my daughter. When she does do the Leaving Cert, the educational board or the school will give her points towards her course or deduct the amount she needs, which will help her in that case”. (Frank).

Lori said that when her son was out for three weeks he missed all of his Christmas tests. She said that she did feel bad for not sending him in but she had to think about his health more than thinking about his education. She felt that this is something she always has dealt with. “He missed all his Christmas tests and I tried to ask the teachers to send him some of the work but when he finally did get it he was too sick”. (Lori, Parent) Lori also mentioned that there were no phone calls to her asking about her child even though he was out for that long and had not attended any of the exams.

Eileen said that she felt that there is a big impact on children with Cystic Fibrosis when they are not in for any exams and she expressed her concern about how this could affect them when it came to the Leaving Certificate. She said that because there is no such thing as repeats in the Leaving Cert, there could be other ways brought in for the student to do some work and earn a percentage before the exams begin. “I do think they should do more for students with long term illnesses as sometimes they can be out for months. There should be something like projects and other things like that to give them points towards the Leaving Cert, but I don’t know if that would be possible”. (Eileen, Parent). Eileen said that if there were projects introduced for children with long-term illnesses, she would worry less about keeping her child well for important exams that come up throughout the year.

Peter, who also has a son in secondary school with Cystic Fibrosis, said that because there was no option for his son to do any of the exams at home he felt he had to send him in. He wanted his son to do his mocks which would help him for the Junior Certificate. He chose to do this even when there was a chance his child could get sick. “Because having my son do his mock exams at home was not an option I kept him in school so he could do them while a virus was going around. He got the virus and ended up missing most of the exams being out of school for close to a month”. Peter said that he felt his son would have stayed healthy if he had of stayed away from school during the mocks, but he would have been at a severe disadvantage from missing the exams as the teachers would not know what progress he was making with his subjects and whether he should do honours or pass in the exams. Peter said that the decision he made putting education over health was wrong in some ways but because there were no exams that his son could do at home, he had to make a hard decision whether to send him in or not.

#### Homebound/Hospital Tutoring Problems

When the researcher asked the parents in the interviews about educational services for their children in hospitals and at home, many of them said that the services were completely inadequate for students who were not out of school indefinitely. They said that even though there are some services for children who are in hospital for months on end, there are not any services available for their child, even if they are out for a few weeks a number of times a year.

Peter said that the services for his child who has not been in hospital for very long periods does not give him the entitlement of having a teacher coming in to the hospital or teaching him at home. “Yes there are these services for children who are really sick and can't go back to school for the foreseeable future, but none for when they need to be in hospital for a month or so”. (Peter). He said he felt helpless as his child sits in hospital with nothing to do and no motivation to keep up with his school work. He said this then leads on to him having a disadvantage when he does go back.

Frank, whose daughter does have educational care complained that the frequency of visits by the teacher and the lack of flexibility gives his daughter a lack of opportunity in furthering her education. “Yes well my daughter is awaiting a lung transplant and has a teacher come in. The teacher only comes in for seven hours a week because that’s all that my daughter is well enough

for. But if she comes over when my daughter is sick she would not reschedule the teaching lesson and that could give my daughter even less than seven hours in one week. I think it has to change”. (Frank)

Lori said that there were not a lot of educational services available for her son when he had been in hospital multiple times. “I don’t think there is much to be honest because I found that there was not a lot when he was in the hospital. There is a school in the hospital but he wouldn't have been able to go because of cross infection with other patients”. (Lori). Because of cross-infection she said that her child would not be able to attend school in the hospital even if it was available, unless no one else was there. She felt that there was a lack of communication between the hospital and the school which led to her son having no work to do while he was absent. Lori also said that if they see Cystic Fibrosis as a disability in school there may be more done to help them out with the problems they face.

During the interview Mary said that one of the experiences she had with a teacher in the hospital showed her that there was not much attention paid to the needs of her child while they were hospitalized. “There was a teacher in the hospital that came down and gave him a newsletter and he had to answer questions on it and some maths. But the guy never came back to collect it so that wouldn’t encourage a child to do the work”. (Mary). Mary said that even though her son did do the work, he never found how he did. Because the teacher returned for the work, Mary felt that her son's educational needs were not being met in hospital, even though he was well enough in hospital at the time to do work. She also said that her son wanted to do some work because there was so much going on at school, but there was nothing being done because he did not know what lesson his class were doing or he needed someone to teach him how to do it.

### Summary

The themes which appeared in this showed that Cystic Fibrosis sufferer's needs are not being met when it comes to them being absent. There are no services there to aid them through school as they deal with regular absence and the difficulty with catching up in school work when they return to class. The problems brought up by the parents and the opinions on how the

problem can be fixed shows that the obstacles that children with Cystic Fibrosis encounter in education can be fixed by implementing different services throughout the school and hospital.

## **Discussion**

Students with Cystic Fibrosis have many obstacles to overcome. One of the problems that they have to live with is the amount of time they spend out of school because of illness. The number of days they spend absent is significantly higher than healthier students and the problem will not decrease unless suitable services are introduced to help them.

Cystic Fibrosis sufferers who are out of school frequently need services to make sure they can catch up with the work. The more services that are implemented, the less Cystic Fibrosis will be seen as a debilitating disease in relation to education. This study focused on parent's perspectives of their child's education and how Cystic Fibrosis affected it. The parents had the insight into how their children's education was affected in school and had their own opinions on how the services in school could improve for the children. This qualitative research aimed to investigate the lack of services for students with Cystic Fibrosis and how new services could be brought in to meet their needs.

Certain themes showed up through all the interview data. Absence was one of the main themes that appeared. Absence is a part of a student with Cystic Fibrosis's life that they have to get used to. Absence comes through the many infections they pick up and the check-ups and assessments that they go to when they have to attend hospital. Parents reported in the interviews that when their child was back at school after a long absence, there was little done to help them catch up and they fell behind with the work that had to be done. This is the same report that came from the literature which showed that for a chronic illness sufferer, like Cystic Fibrosis, the attention being paid towards their educational needs in and out of school were of little to none (Bowen et al. 2010).

A difference with the literature and the data gathered from the interviews also appeared. In relation to the amount of days absent, the literature said that the number of days a student with Cystic Fibrosis spent absent a year was about 20 days (Shaw & McCabe, 2008). Through the interviews, many of the parents said that the amount of days that their child spent absent a year was a lot higher than 20 days. Some parents said that the number spent absent was sometimes double that.

Other parents said that their child's interest in school decreased because when they came back from absence, they did not know how to do the work. This parallels with the literature which showed that with the frequent absences, it made the child tired and made it harder for them to participate in education (Thies, 1999)

Another theme which was presented was student's and teacher's understanding of Cystic Fibrosis in school. Many people do not know about Cystic Fibrosis and the majority of the parents who were interviewed stated that before the birth of their child, they did not know what Cystic Fibrosis was. The lack of knowledge about the existence of the disease leads onto other problems when sufferers are attending school. One parent said that when her son started secondary school he did not want the other students to know that he had Cystic Fibrosis. He did not want them to know because they would not understand or realise how it affects him or whether or not they can catch it. This also shows in the previous literature as it outlines that social isolation is a problem in schools because of the lack of knowledge about the chronic illness (Kaffenberger, 2006).

Along with the work that a child misses, some of the parents said that they thought the teacher's expectations of their children changes once they are informed that they have Cystic Fibrosis. In some interviews, parents said that teachers would not properly motivate their student with Cystic Fibrosis because they did not know how the child would react, which shows that there is a complete lack of understanding the illness and how it affects the students. The literature proved that the communication between schools, hospitals and parents were not adequate and could affect the child's education (Kaffenberger, 2006).

Another topic which came up throughout the findings of the research was schoolwork and how the students caught up with school work once they were back from their absence. Many of the parents who the researcher interviewed said that once their child was absent from school for a long time, there was no work or help given to them while they were out ill to keep them in touch with the curriculum required. Some parents mentioned that they thought the school did not pay enough attention to the needs of their child when they were out. They said they seen any work they missed because of absence as their own problem. One parent said that once the child was not in the school, the work they missed was not the problem in the eyes of the school. This was also highlighted in the literature as the reasons they were absent is to do with sickness. In most

cases they are absent from school and unable to do work because of their illness and not because they did not want to go in (Lightfoot, Wright, & Sloper, 1999). The problems that are associated with missed work were proof to some parents that there was not enough attention being paid towards the needs of Cystic Fibrosis sufferers by schools.

Through the research findings, parents also expressed their anger at the lack of services that were available within in the school to help their children get back on track from a lengthy absence. Some of the parents said that their child would go back to school after their absence, and would instantly be thrown into the deep end of the work and would not know how to do it. Parents said that there were a lot of ways their child could receive the homework and keep up to date with the work that was being done while they were in hospital, but that the services are non-existent within the schools. This relates back to the literature where it states that the lack of appropriately resourced policies, personnel and services causes children to fall behind in their work and have no way of catching up with other classmates (Walmsley & Mannan, 2009).

One parent felt that her child's educational needs were not been met by the hospital or by the school. She said that the school would not ring her even if her son was out for a month and that when her child did receive educational sheets do in hospital, they were completely inadequate for their needs and the work was not followed up upon. She felt that the schools and the hospital needed to communicate together in order to understand what was required to keep their child up to date with the work. This was similar in relation to the literature which stated that if the hospital and the school did communicate with each other about the student, the impacts could see the child reaching their maximum performance academically (Shaw & McCabe, 2008).

One parent expressed her anger at the lack of attention being paid by the schools and by Cystic Fibrosis Ireland in relation to the educational aid of children with the condition. She said that if there was more information put into schools about Cystic Fibrosis, this would lead to schools noting that children with Cystic Fibrosis were in need of extra support. This would begin to close the gap on the problems associated with Cystic Fibrosis and education. The literature backs up this point in relation to the lack of focus on the student's needs. In a letter wrote to the Oireachtas by Cystic Fibrosis Ireland, they display a set list of needs that Cystic Fibrosis sufferers require. This list showed numerous services and facilities which needed to be introduced for people with Cystic Fibrosis, but none of these related to the educational problems

that students with the illness have (Watt, 2013). The introduction of these requests for educational services could lead on to children in education getting the attention they need to help them through school.

Another theme which appeared throughout the research findings was in relation to exams. Some of the parents who expressed their views for the research revealed that their children had missed some main exams throughout school or that they were afraid that their children would be too sick to attend some exams like the Junior and Leaving certificate because they were sick. They felt that their children did not have the same chances as other students when it came to exams as they tended to miss a lot of work through sickness.

Many parents expressed that their child would not do as well as other students because of the amount of school they miss and that there was no way for them to do something during the year while they are well, which would add to their overall grades in these important exams. Some parents said that schools do not pay attention towards the needs of children with Cystic Fibrosis and similar conditions, and do not acknowledge that students with Cystic Fibrosis want to do as well as other students, but their sickness sometimes holds them back. The literature also proved that the amount of school that students with chronic illnesses do suffer when it comes to education. With 58% of students missing school regularly and 10% missing over a quarter of the year and there being no suitable education plans, students with debilitating conditions like Cystic Fibrosis, are more likely to fail important exams even though it was not because of lack of study (Thies, 1999).

Other parents brought up the issue of their child struggling with some subjects more than others. One parent said that when it came to her son, he was failing in classes like Irish and Maths because the work that was done while he was absent had progressed and his lack of understanding was noticeable. She did say that there was some extra point allowance put into place for Leaving Cert students with Cystic Fibrosis, but more needed to be done.

Another parent felt that there needed to be ways for the child to do exams outside of the school if needed. He said that if the child was sick there should be ways of him sitting the exam anyway, so the teachers would know what his strong points and weak points were, so they could work on it. The literature reinforced the importance of these ideas as 45% of students with a

chronic illness say they are falling behind in work. Whereas another 35% of these students said that they were failing in some of the classes (Thies, 1999).

The problems of home and hospital tutoring also came across in the research data. This was a problem which most of the parents were very familiar with because they had experienced it with their child. One of the problems one of the parents brought up was the issue of his child being in hospital with no education even though his child was well enough to study. He said that because he was not in the hospital for that long a period, that he did not have the entitlement of a teacher to give him lessons during his absence. He felt that there needed to be more flexibility for students with Cystic Fibrosis because of the frequency they are out of school. This parallels with the literature which covered home and hospital care where it mentioned that to qualify for homebound services they have to be absent for more than thirty days. If the student does qualify for this and feels well and goes to school, they will lose that homebound education privilege (Kaffenberger, 2006). This brings up a problem if the student feels well and goes back to school, only to return again after a short period of time. They will lose that education at home and therefore suffer academically.

There is a noticeable lack of research done in the area of Cystic Fibrosis and education in Ireland. The chances children have in education is a very important concept in Ireland but the lack of adequate educational services for children who have chronic illnesses like Cystic Fibrosis needs to be addressed. There has not been a lot of research conducted towards the needs of chronic illness sufferers or people with disability in relation to how much work they are doing outside of school to catch up on work they have missed through involuntary absence. Some of the negative experiences in relation to school work and absence have not been tackled and the research into how children with Cystic Fibrosis can get help has not been brought to the attention of people.

## **Strengths Limitations Recommendations and Conclusion**

### Strengths and Limitations

This research aimed to find out what educational services were in place for students with Cystic Fibrosis and how much focus was being put on the needs of Cystic Fibrosis sufferers. Because the researcher used a qualitative method, they were able to meet with the Parents of children with Cystic Fibrosis so they could discuss their own personal experiences and opinions. Through these interviews the researcher was able to gather information about parent's concerns in relation to education and focus on the patterns which appeared throughout the interviews.

One of the limitations of this research was that the opinions which were presented cannot be taken on behalf of all parents who have children with Cystic Fibrosis. Because the researcher only interviewed seven parents, the views of everyone else could not be defined through such a limited number.

### Recommendations

From the following research, there is still a lot of information about Cystic Fibrosis and the problems with their educational needs. The researcher thinks that there could be a lot more information gathered around services for children with illnesses like Cystic Fibrosis and how much attention is being paid towards their needs. The researcher also thinks that by combining qualitative and quantitative research, there could be a better chance of finding out information. By using qualitative research there could be in-depth analysis on certain areas of education and by using quantitative, a broader opinion could be gathered because of the vast numbers of people taking part in the study

### Conclusion

The aim of this research was to discover parent's opinions of the quality of educational services put in place for their children who have Cystic Fibrosis. Because there were only seven participants in this research, only a bigger research project could represent the overall feelings about the educational services for these students.

Even though there were a limited amount of participants to give a limited amount of information, their opinions and experiences were all similar in relation to the support services available for their child. All the participants had negative views on the support services for their child and the research that was conducted throughout this study supported their views and opinions.

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## **Appendix 1**

### **A Parents perspective: Educational problems associated with Children who have Cystic Fibrosis.**

My name is Sean Downes and I am conducting research that explores: Parent's perspectives: Educational problems associated with Children who have Cystic Fibrosis.

You are invited to take part in this study and participation involves an interview that will take roughly 40 minutes.

Participation is completely voluntary and so you are not obliged to take part. If you do take part and any of the questions do raise difficult feelings, you do not have to answer that question, and/or continue with the interview.

Participation is confidential. If, after the interview has been completed, you wish to have your interview removed from the study this can be accommodated up until the research study is published.

The interview, and all associated documentation, will be securely stored and stored on a password protected computer.

**It is important that you understand that by completing and submitting the interview that you are consenting to participate in the study.**

Should you require any further information about the research, please contact  
Sean Downes (downsey.d@hotmail.com)

Thank you for participating in this study.

**Participant Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix 2

- 1 Hi, how are you?
2. Can you tell me a little about yourself?
3. When did Cystic Fibrosis first affect your life?
4. And how has it affected your life since?
5. What sort of medication is your child on?
6. How does your child juggle school and their medication?
7. Are schools sympathetic to your child's needs?
8. How does this impact on your child?
9. Do you think that teacher's opinions of your child's abilities change after they find out they have Cystic Fibrosis?
10. Children with disorders such as Cystic Fibrosis are absent, on average 20 more days than other healthier children. Have you noticed some negative outcomes because of this and if so could you explain some of them?
11. Can you tell me some of the services available to help Cystic Fibrosis sufferers in education?
12. To your knowledge, are there any of these services in the school your child goes to?

13. According to the Cystic Fibrosis Association of Ireland, there are home tuition services that are available through the school your child goes to, to help them out with even short term absences. Has the school mentioned this service to you? If not, why do you think they have not.

14. What is your opinion on the quality of these educational services and are there any problems with them?

15. Students with Cystic Fibrosis are frequently absent from school and sometimes for long periods of time. This adds up to a lot of days absent without any educational aid for catch up. How do you think schools could help students with catch up on days of absence?

16. Why do you think these types of services have not been implemented?

17. Are there any benefits that your child might get when important exams such as the Leaving Cert come up?

18. Is there anything that I have not covered, which you would like to mention in relation to students who have Cystic Fibrosis and their education?