

## Introduction

This is an investigation into the lack of legislation and appropriate educational support for syncope. On a personal note, this study is being carried out because I have got Reflex Syncope and know the trials and hardships that are part of the condition. It is the aim of the study to highlight the recognition for syncope and to ascertain what is in place for sufferers. Research was gathered from the United Kingdom and the United States of America, through the use of STARS the charity.

Since the mid 1900's, education has taken into consideration medical conditions, disabilities and other health matters which ultimately aim to provide equal education for every child. (Gordon & Williams, 2002). These have covered conditions such as epilepsy, autism, asthma and many others. Protocols, laws and regulations have been put into place to deal with the process of these. In 1944, an Education Act was created which made universal secondary education; this was according to age, aptitude and ability. In section 34 of the Education act (1944) it sets out a requirement for Local Education Authority's to ascertain the needs of children in their area and decide whether they need special educational treatment. Once this was established they recommended that these children be educated in mainstream schools wherever this was possible. (Mackinnon, Statham & Hales, 1996).

More specifically acts like the Chronically Sick and Disabled Persons Act of 1970 allowed people to access facilities including universities and school buildings. Although it was not until the early 1980's that it became common practice for children with special educational needs and disabilities to be educated alongside their peers in mainstream schools, with the introduction of the Education Act 1981 and also later the Education Act 1996. After The Education Act (1993) '*The education of sick children*' made arrangements for suitable education to be provided for those who had illnesses that did not allow them to receive suitable education. Following on from these acts, the Education Act 1996, under Section 19, states that each Local Education Authority has to make suitable arrangements for children of compulsory school age who cannot for reasons of illness receive suitable education. Further to this, the Local Education Authority has the power to put in place suitable educational provisions other than at school for pupils over the age of 16yrs but under 19yrs old. (DfES, 2001)

More recently, guidance like the Access to Education for children and young people with medical needs have been put out across the country. (DCSF, 1995). This particular information highlights the role of the Local Education Authority and the part they play in making sure children with medical

needs have adequate access to education. Ultimately it is the responsibility of the Local Education Authority to put in place the arrangements; these are only for children of compulsory school age.

After compulsory school age the law that relates to students are covered in the Disability Discrimination Act 2005. The act makes it unlawful for education providers to discriminate against adult learners. (Direct.gov, 2009). In higher education institutes aim to provide support for everyone who needs it. Support is available for students who are not necessarily registered as disabled but may still require the support and help. Although they may have to provide medical evidence of their condition, the term 'disability' includes things like asthma, diabetes, sensory impairment, autism spectrum disorders, chronic pain and any other condition that has a long term effect on study. Manchester University (2009). Part 4 of the Disability Discrimination Act 2005 states in relation to education that it is unlawful for education and training providers to discriminate against disabled people. The act itself is divided into two sections, one that encompasses pre sixteen pupils and the other for post sixteen pupils. For post sixteen pupils the main requirements of the Act are that the educational providers must not discriminate against the disabled person when providing education to them.

Another key policy that requires schools to support pupils with medical needs is the Health and Safety at Work Act 1974. This states that schools must have a health and safety policy in place and the measures to implement it. It can cover things like first aid, making sure pupils with medical needs are supported and dealing with health and safety procedures and emergencies that arise.

In the United States of America, legislation has also been passed to try to accommodate for children with medical conditions. Some of the major acts have included the Rehabilitation Act (1973) which covers the rights of individuals with a disability and requires a school to provide free appropriate education to someone who has a disability.

Two years later, the Education Act for all Handicapped Children Act (1975) stated that all children who were then termed 'handicapped' were entitled to a free appropriate education in the least restrictive environment possible. (Heinich, 2001). The Education for all Handicapped Children Act was later replaced in 2004 with the Individuals with Disabilities Act (IDEA). This Act ensured services for children with disabilities throughout the nation. The Americans with Disabilities Act (1990) also covers

people who are deemed as having a disability and prevents discrimination in employment, public services and education. (EEOC, 2009).

Although multiple acts have been passed to aid specific conditions, syncope is one condition that has not received due consideration. Syncope displays a wide and diffuse impact on sufferer's abilities to receive education. (STARS, 2008).

Benditt, Blanc, Brignole & Sutton (2006, p.3) suggest that

*'Syncope' is the medical term used to describe fainting/blackouts. The word syncope comes from an old Greek meaning of to cut short or interrupt. Today its modern usage refers to the oxygenated blood supply that travels to the brain being temporarily cut off.*

Further to this Natole & Wazni, (2007, p.147) also suggest that clinically it is described as a *'relatively rapid, brief loss of consciousness, loss of postural tone and voluntary muscle tone'*. The lack of blood supply to the brain, then results in the loss of consciousness. The blood does not reach the head because of either a drop in blood pressure or a change in the heart rhythm, this changes the amount of blood the heart pumps or a drop in the amount of oxygen that is being carried in the blood. It is estimated that 120,000 people experience unexplained loss of consciousness each year in the UK, (Arrhythmia Alliance, 2009).

Syncope can differ greatly from person to person, one person may faint a couple of time a month where as another person may faint a number of times a day. In addition to fainting frequency, the type of syncope can vary, with at least six types identified. Vasovagal syncope is caused when the blood pressure suddenly drops which in turn reduces blood flow to the brain resulting in a loss of consciousness. (Hope, Longmore, McManus & Wood-Allum, 1998). The heart rhythm society estimates that twenty five to forty percent of fainting disorders are vasovagal syncope. (Heart Rhythm Society, 2009). Situational syncope a type of vasovagal syncope but it only occurs when in particular situations that cause unusual patterns of stimulation to certain nerves. These stimuli can include things like intense emotional stress, vigorously coughing, pain, shock and anxiety. (Clegg, 1987). Postural syncope which is also known as Postural Hypotension occurs when the blood pressure drops suddenly because of a quick change in position, such as getting up from lying down. Finally, Cardiac syncope a

loss of consciousness caused by a heart or blood vessel condition, this interferes with the blood flow to the brain and can include conditions like blood clots, heart rhythms and valve diseases. (Simpkins & Williams, 1989). Although there are many names for the types of syncope, most are caused because of a lack of communication between the brain and the heart.

RAS is a closely related condition and occurs mainly in young children but equally to syncope it can occur at any age. Unexpected stimuli like pain, shock or fright cause the breathing and heart to stop. (Stephenson, 1990).

Syncope and RAS can significantly affect a person's life and a person's ability to carry out daily activities. The first primary effects can include fatigue, injury, shock, reduced concentration and attention and these generally occur after an episode of syncope. Although in some sufferers they may get symptoms like headaches and nausea before an episode of syncope (NHS, 2009). The secondary effects can disturb a person's education, attendance, social interaction and their peer groups. All these effects can contribute to a person's life being severely affected by syncope. *'The more frequent the fainting episode, the greater impact on quality of life'*. Grubb & McMann 2001, p.3). A recent study researched reflex syncope in children and adolescents and found that the condition itself has an excellent prognosis but it may in turn have significant social repercussions and a dramatic impact on quality of life. (Wieling, Ganzeboom & Saul, 2004).

Further to the initial impact that syncope has on a person education, the drugs that are used in the treatment of syncope can also cause their own problems. Three of the main drugs used to help alleviate syncope are Fludrocortisone, Midodrine and Beta Blockers, see appendix 1. Both these drugs have their own side effect which range from chest pain, problems with vision, swelling, shortness of breath, irregular heartbeats to less serious problems like feeling of pressure or fullness in the head, sleep problems, headaches and increased urination, (Stewart. Thornton & Wilson, 2009).

Currently the only place that information is readily available on either two of the conditions is from STARS (Syncope Trust and Reflex Anoxic Seizures) a trust charity that is based in the United States and the United Kingdom. The charity *'works tirelessly with individuals, families and medical professionals to offer support and information on syncope and RAS'*, (STARS, 2007). The STARS website contains a section designated *'shining a light on education'* that has information specifically

for young people in education and also people in further education. It also contains links to the current legislation, for example it has links to children being included in the curriculum and the national curriculum inclusion statement. Other useful links like the disability rights commission and information on special educational needs. Despite the prevalence of syncope among young people, the condition itself goes fairly unknown among the general public, this includes members of staff in educational settings and also extracurricular activity groups. (STARS, 2007).

Currently with no legislation in place for syncope sufferers, this study aims to ascertain whether or not they require support to assist them through education. The legislation and guidance which is available for schools supporting children with medical needs, does not contain any information specifically on syncope. This is the same in both the UK and the USA.

## **Literature Review**

Syncope is a term that is widely used by medical professionals to refer to fainting. It is used to help to distinguish fainting from other such causes of a temporary loss of consciousness. (NHS, 2009). It is also defined as a brief loss of consciousness that is caused by a momentary reduction of the blood supply to the brain. (Readers Digest, 1987, p.1535). This reduction of blood supply to the brain can cause interruption of awareness of oneself and of the surroundings they are in. (Web Aid, 2003).

### **Cause**

Most investigators will try to divide the causes of syncope into two groups; these are the cardiovascular causes and the non cardiovascular causes. The first group consists of any condition that obstructs the blood flow through the heart, or a condition that alters the normal electrical conduction so much that the normal sequence of pumping is disturbed, this may result in syncope. (Forgos, 2006).

Cardiovascular causes of syncope are quite often very serious problems. (Grubb, 2008).

The second group of causes of syncope is the non-cardiovascular, this group of syncope's may occur due the body not being able to maintain an adequate blood pressure. When a normal person stands, gravity tries to move roughly 25 % of the body's blood volume to the legs, abdomen and lower arms. (Camm. Luscher. Serruys, 2006, p.933). When the movement of blood is not corrected immediately, then the fall in blood to the brain will result in syncope. The Autonomic Nervous system (ANS) would normally correct this, by sending a message to constrict the blood vessels in the lower parts of the body, which would in turn return the blood to the brain. (Appenzeller & Oribe, 1997).

### **Diagnosis**

There is no specific test for syncope. Instead, a series of differential diagnostic tests are performed to eliminate other possible causes and/or conditions. These tests include:

- ECG (Electro Cardio Gram): A test that measure the heart rhythm and the electrical activity of the heart. (British Heart Foundation, 2009).
- MRI (Magnetic Resonance Imaging): A safe and painless scan that shows detailed pictures of structures and other organs that are inside the body. (Bupa Health, 2008).
- Blood pressure monitor:
- Tilt Testing: The test is designed so that it triggers a syncopal episode. The heart rate and blood pressure are monitored throughout. (Zaret, Jatlow & Katz, 1997, pg 117). The person lies on a table to which they are strapped, the table can tilt up to 60-70 degrees (See figure 1). When the

table is tilted, changes in the patients blood pressure is induced which results in a syncopal episode. (Edwards, Maurer & Wellner, 2003, pg 239). (Deska-Pagana & Pagana, 2003, pg367).

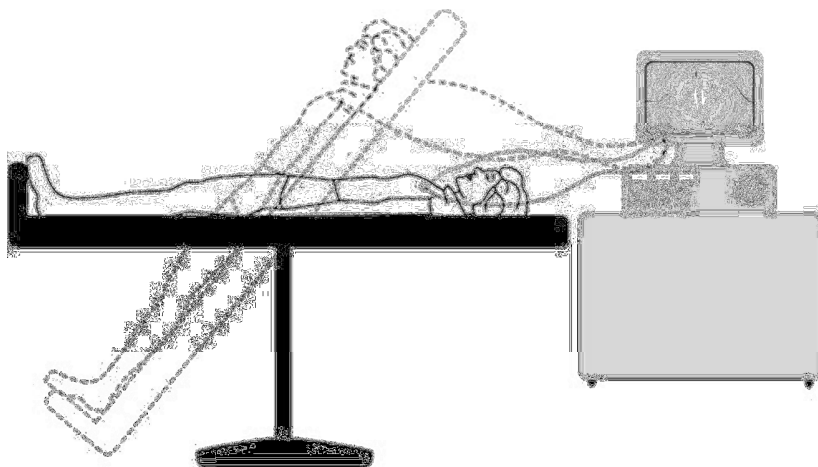


Figure 1. (Children' Heart Specialists, 2008)

If the patient does not experience any symptoms a nitroglycerin pill or spray is administered to help induce syncope. A complete test generally lasts from 2-4 hours. Despite these diagnosis, often the best form of a diagnosis of syncope is an eye witness account of what happened. (Irwin & Rippe, 2006, p.184)

### **Effects**

Syncope can show a wide and diffuse impact on sufferer's education and also their daily lives, including social repercussions. Although the prognosis for these conditions is excellent, the social repercussions can have a dramatic impact on quality of life. (Wouter. Ganzeboom. Saul, 2004). The effects may depend on how severe the condition is and the incidence of syncope episodes. (Krediet, 2007, p.13). The primary effects occur initially after a syncopal episode and these include fatigue, shock, injury, reduced concentration and attention. The secondary effects include interruption to education/attendance, social and peer interaction and these are usually as a result of the syncope episode. Further to the primary and secondary effects of syncope, the drugs used to treat the different syncopal episodes can cause a wide range of side effects. Non pharmacological treatments are preferred as appose to pharmacological therapy because no medication is completely free of side effects. (Walsh, Saul and Tiredman, 2001, p.466)

### **Treatment**

Literature from healthcare professionals has informed sufferers of the side effects of the drugs used to

help alleviate the symptoms of syncope. The three main drugs used are Midodrine, Fludrocortisone and Beta Blockers. Sometimes it is not only the condition itself that has an effect on education but the added side effects of the drugs taken to help alleviate the episodes. A common drug Midodrine can produce severe reactions in some people, which include decreased pulse rate, shortness of breath, fluttering feeling in the chest, nervousness/anxiety, closing of the throat and many more. (Robertson, 2004, p.413). The latter can also produce its own side effects, Fludrocortisone is a class of steroid and it helps to expand blood volume. Its side effects include problems with vision, swelling, dangerously high blood pressure, confusion and usual thoughts or behaviour, among others. (Hochadel, 2006, p.396). Finally, Beta Blockers, which can cause side effects like tiredness, depression, impotence, vivid dreams, the heart rate being too slow and some people develop cool hands and feet. (Rosenthal, 2009, p.55).

### **Impacts on education**

Syncope can have varying effects on a person's education depending upon the frequency of their episodes and the specifics of the condition. STARS a charity that leads a campaign into 'Shine a light on Education' has highlighted the educational support that is needed for people with syncope. *'It aims to increase general knowledge and understanding of syncope, RAS and Pots so that better support can be provided'* (STARS, 2007). Each individual is different and no two cases of syncope are identical. Not every child who has syncope will experience a syncope episode in their educational setting but it is imperative that the teachers, staff and carers are well informed. This is so that maximum support is available for the individual concerned. (STARS, 2007). There is little doubt that the frequency of recurrent syncope has a significant impact on quality of life and also a major effect on education, impaired social life and curtailed career opportunities. (Rose. Koshman. Ritchie. Sheldon, 2009). These effects on education also include injuries suffered as a result of a blackout, there is always a risk of injury and fractures after a fall, this could happen anytime whilst a student is at school, college or university. (Gammage, 2009).

### **Support Strategies in the United Kingdom**

In the United Kingdom, there are a number of key legislations that have taken into account children with medical conditions; these have aimed for these children to have access to education. They intend to provide support for children who are in compulsory education or to provide other support for children not able to attend school.

Past acts that have briefly contained information on medical conditions and education include the Education Act (1944), which suggested the eleven plus examination for all children to take to decipher what type of school they would attend. It aimed to create a universal system of education for all children according to their ability, aptitude and age and was called the tripartite system. After this act the Education Act (1996) section 19, was passed and stated that a local authority has to make arrangements for the provisions of suitable full or part time education other than compulsory school, for young people who may have illnesses, exclusions from school, or for young people who for any period of time not receive suitable education. In the act 'suitable education' in relation to a child, means an efficient education according to his/her age, aptitude, ability and to any special need he/she may have.

More recently and more specifically aimed at children with medical needs, the Access to Education for Children and Young People with Medical Needs (2001). It sets out a minimum standard of education for children that are unable to attend a school because of their medical need. The guidance highlights the role of the Local Education Authority and states that they should have access to as much education as their condition allows. It suggests ways in which education can be provided to a child and has clear policies, procedures, responsibilities and standards.

At university level, support for medical conditions is the responsibility of each individual establishment. Generally they have the same approach to aiding students in their studies. At the University of Worcester, the Disability and Dyslexia service provide support and help for students. In order to receive support from them, a student must provide evidence of their disability or condition to the co-ordinator. This help may be a detailed description of a person's condition which is given to the lecturers at the start of each semester or it may just be extra time allowance in examinations.

### **Support Strategies in the United States**

The support strategies in the United State include important legislation that covers children with disabilities in education, employment and other social aspects. Acts like the Rehabilitation act (1973) in which section 504 protects the rights of individuals with disabilities and specifically states all qualified persons that have a disability and are within the authority of a school district are entitled to a free

appropriate education. This cover primary and secondary schools, a qualified person with a disability is a person who is:

- (a) Of an age during which it is mandatory under the state's law to provide such services to a person with a disability.
- (b) Of an age that even though they don't have a disability they are still provided with a free appropriate education under the Individuals with Disabilities Act (2004).

An appropriate education is designed to meet the needs of the individual learner. The U.S Department of Education define a person as having a disability is they have a physical or mental impairment that may substantially effect one or more major life activities, has a recorded impairment or is regarded as having such an impairment. More recently the Individuals with Disabilities Education Act (2004) ensures the services to children with disabilities. Specifically it governs the states and public agencies on early intervention, related services for children with disabilities and special education. (Smith, 2005). It addresses the educational needs of children with disabilities right from birth up to 26 years. The Individual with disabilities act (2004) states that special education and the related service should be designed to meet the unique needs of children designated as having a disability. The act also requires that public schools provide a free appropriate education for these children. (Wright, 2005)

## **Methodology**

This section of the study will describe and justify how the research question will be answered. Different methodological approaches will be examined so that the combination of different techniques will allow the opportunity to compensate for limitations of one with the aid of another (Hurt and Bond, 1996), thus increasing validity. A rationale will be supplied for the adoption of the methods used.

### **Aims of the study**

It is the main aim of this study to ascertain whether all children with syncope should be given support to assist their education. I will fulfil this aim by firstly completing a literature review into the types of syncope, second I will look at the educational provisions for students and finally I will compare and contrast student responses to the questionnaire.

### **Design**

The study was designed to be aimed at students of all ages in different educational establishments. A questionnaire was used for participants to give their perspective on having syncope in education. This questionnaire was handed out at a Heart Arrhythmia conference, posted onto a moderated online youth board by STARS and thirdly paper copies were made available to be sent out to people who contacted STARS and requested a copy. The questionnaire used both qualitative and quantitative data, which gave a broad spectrum with a wide range of answers. (Mason, 1996). Using both these techniques gave me a better result outcome and I was able to evaluate these accordingly and get a conclusive conclusion. (Patton, 1987).

The questionnaire mainly received responses from online, using the programme Zoomerang, using this particular programme I was able to have a free range choice on the types of questions and the number of questions was not capped. It was used as appose to other programmes because it gave the best options. Having the most available questions and different ranges of questions, it was also easy to access and use. It has been suggested that using questionnaires are a good way of collecting certain types of information quickly and relatively cheaply. (Bell, 1993). The intention was to gain an equal number of responses from the UK and the USA, with the use of STARS, this was roughly achieved with 10 from the USA and 15 from the UK. The responses only came from these two countries because STARS is based in the UK and the USA and it was with their help that this was achieved.

**Participants**

Participants of the questionnaire were from the UK and the USA and ranged in ages from 8 years and below, up to 25 years and older. The responses ranged in educational settings, from primary and high schools to colleges and universities, some people who had left education had also completed one. The participants also ranged in where they came from and their experiences of education.

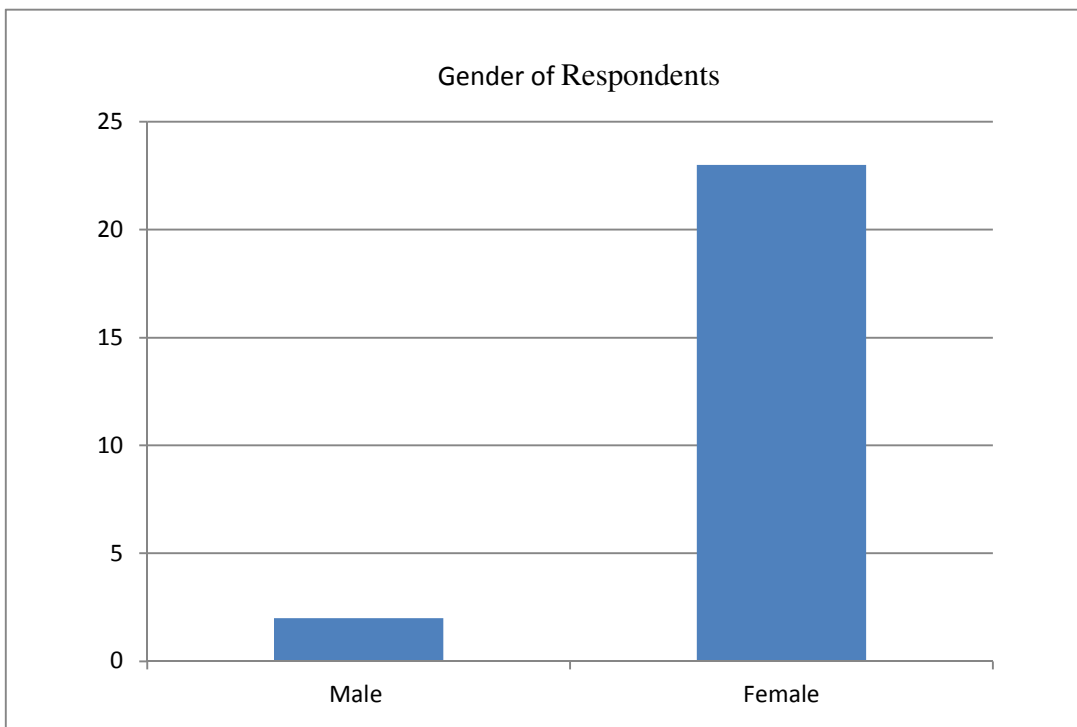
## Results

This section of the study will present and introduce the results which are split in to quantitative and qualitative data.

### Quantitative data

A total of 25 people answered a questionnaire, out of these 10 were from the United States of America and 15 were from the United Kingdom. The age of these participants ranged from four up to twenty five plus years old. The highest number of people recorded in an age category was seven people who were aged twenty five years plus. The second highest number was five people who were aged nineteen years old. Also in response to the questionnaire participants were asked what gender they were. Figure 2, refers to the gender distribution.

Figure 2: Gender Distribution

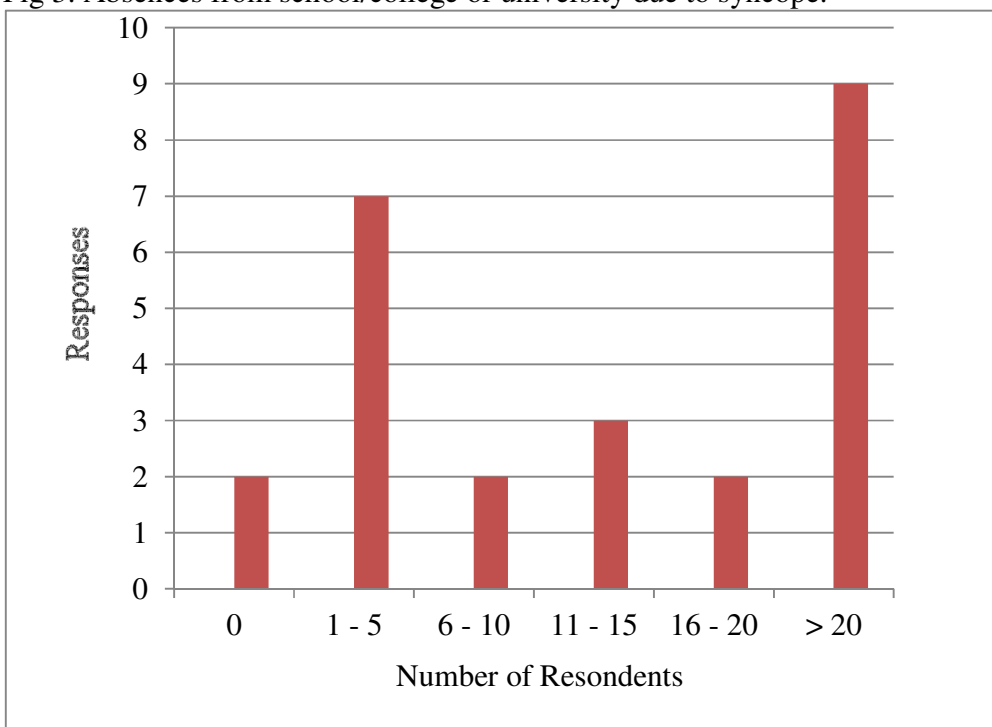


A total of 80 % of people who responded said that they attend either school, college or university, the other 20 % of people said that they had did not attend any of the above educational establishments. They were also asked if they were aware of any help for their education which may be available to them for syncope, 24% said that they were aware of help, whilst the other 76% said that they were not aware of any help available to them for syncope and education. In relation the latter question 32% of

participants said that they had or had received additional educational help for syncope, 68% said that they had never received any additional help. Further to this 57% said that the additional educational support that they had received was appropriate and beneficial, whilst the other 43% said that it was not beneficial or appropriate.

Fig 3. Below, Absences from school/ college or university, show the number of days of each respondent had due to syncope, since September 2007.

Fig 3. Absences from school/college or university due to syncope.

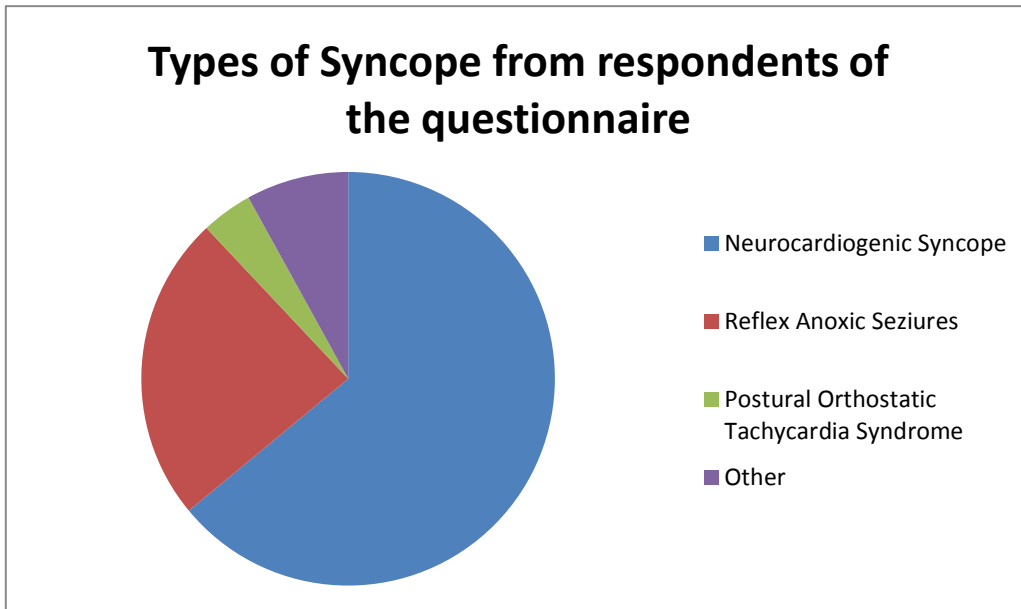


**Qualitative data**

The county/states that the respondents were from, were as follows,

<b>United Kingdom</b>		<b>United States of America</b>
Lancashire	Essex	Pennsylvania
Somerset	Hampshire	Washington D.C
Warwickshire	Nottinghamshire	Illinois
Essex	Staffordshire	Texas
North Lanarkshire	Middlesex	North Dakota
Wiltshire	Sussex	Ohio
Bedfordshire		Arizona

Fig 4. Types of Syncope shown below, shows the different forms of syncope that the participants of the questionnaire had.



Question 7 refers to ‘does your school/college or university provide you with any help for your syncope’. There were a total of twenty three responses to this question, with 47% saying that they did receive a form of help for their syncope and the other 52% stating that they did not receive any help. Figure 6. Table of themes, represents the result of the responses to Question twelve, thirteen and fourteen. The three questions referred to were included in a questionnaire into whether all children with syncope should be given support to assist their education, see figure 5 table of themes. The table of themes figure 5; recognised eleven themes Question twelve in figure 5, identified three key themes, whilst questions thirteen and fourteen identified 4 themes. Column one of figure 5 one presents the question numbers. The key themes shown in column two under the heading ‘terms used’ came from the responses to the questionnaires. The final third column is the number of responses to each question and the total number of respondents to each question.

Figure 5, table of themes

Question number	Terms Used	Responses
Q12. How does your condition affect your everyday education?	P1, P2, P4-8, P11, P13, P16, P23: Missed Lessons	8
	P1,P2, P6, P12, P21, P23: Tired	6
	P1, P3, P9, P16: Low Concentration	4
		Total = 18
Q13. What do you feel would help you with your syncope in school etc?	P2, P4, P5, P13, P21: Access to missed lessons	5
	P1, P3, P5, P13, P15, P17-19: Understanding	8
	P7, P10, P13: More information	3
	P10, P11, P18, P21, P22: Awareness	5
		Total = 21
Q14. Is there anything that could be done that would benefit your education?	P5, P6, P17 - 19: Educating People	5
	P4, P10, P13, P14: Understanding	4
	P8, P15, P16: Awareness	3
	P14: Support	1
		Total = 13

## Discussion

This section will discuss the findings of the research in relation to the literature looked at, review the objectives set out at the start of the study, evaluate the research and make recommendations for what should follow and finally a conclusion with an overview of the research.

This study gathered student's perspectives on if they wanted support in education for their syncope. In England, the CYPUP has developed a set of core principles of participation with supporting guidance; these are designed to give children involvement in policy and decision making. One of the main aims of the CYPUP is to give children empowerment. (Cohen, Moss, Petrie & Wallace, 2004). Currently there seems to be no support in place for students suffering with syncope conditions, it is not covered in the various acts or legislation discussed in the literature review. The results from this study suggest that students want understanding and greater awareness of syncope in their educational settings. Currently there is only one sentence in one article that mentions the need for greater understanding of syncope, this was discussed in Reflex syncope in children (Wouter & Ganzeboom, 2004). This only covered reflex syncope. The question which arises from this is whether students with different syncope conditions feel the same way. From the result of this research it would appear that students with different syncope conditions do fundamentally want support.

This study found that of the twenty five respondents to the questionnaire, 8% were male and 92% of people were female, there were 15 responses from the United Kingdom and 10 responses from the United States of America. Figure 6 shows the county/states that the participants were from.

Figure 6, county/states

<b>United Kingdom</b>	<b>United States of America</b>
Lancashire	Pennsylvania
Somerset	Washington
Essex	Illinois
Middlesex	Texas
Lanarkshire	North Dakota
Sussex	Ohio

Wiltshire  
Bedfordshire  
Hampshire  
Staffordshire  
Nottinghamshire  
Warwickshire

Arizona

The age of the respondents ranged from 8 years and below up to 25 years and over. The highest number of people in one age group was aged 25 years and over.

The types of syncope were identified as 64% neurocardiogenic, 24% reflex anoxic seizures, 4% postural orthostatic tachycardia syndrome and 8% other. When asked if they attend school/college or university 80% of people said yes and 20% said no, further to this they were also asked if the school/college or university provide help for syncope, 13 people said yes and 10 said no, one said not applicable.

The respondents were asked how many days off due to syncope, which they have had since September 2007, the highest category was 9 people who said they had 20 or more days off from school/college or university. The lowest number in two categories was 2 who said they had 6-10 days off and 16-20 days off. When asked if they were aware of any help that may be available to them, 24% said they were aware of help and 76% said they were not aware of any help.

### **Impacts of findings**

The findings of the study has an impact on the participants, STARS and personally. Firstly the participants, whom the study will have most impact on, the results of the study have hopefully helped them to realise that they are not alone in struggling in education. This study was all about getting the perspectives of students with syncope in education, so the study will help to provide some form of support for these students and has highlighted the significant need for this. Participants were given a great opportunity to express their own opinions on syncope and how it affects their education. Personally the study has helped me to realise issues relating to syncope and the significant impact that it has and continues to have on my life and everyone surrounding me. On my career, this study has helped me to realise my ambition on one day becoming a teacher and continuing my work on syncope

to be more extensive. The impact on STARS, a copy of this study will be given to them for them to use as they please. This should be used to help their campaign in 'shine a light on education' and for the sufferers of syncope to read. A copy may be used by STARS for future reference to highlight the need for support in education. This study has had a huge impact on my personal life and my academic career.

Currently syncope is not covered by any legislation covering medical conditions and education. It is clear that policy cannot be changed but guidance on syncope may be provided in the future to develop peoples understanding. STARS the charity is also very useful in helping to highlight the issues and impacts that syncope have on a student's education and on their daily lives.

## **STARS**

STARS is currently the only place where information on both syncope and RAS are available, at present STARS run a campaign to highlight the need for recognition of syncope in education and the need for understanding and a greater knowledge of the different syncope conditions. The campaign 'shine a light on education' contains information for teachers, staff, students and parents/guardians, there are different areas of the site that explain the relevant information. The teachers and staff page lists information on managing an episode, special lesson plans, care plans, essential information on what to do and what not to do during an episode and any triggers or warnings. A brief paragraph is contained in the parents/guardians page to explain the possible worries which they may have and to let them know there is help available to them. Both the young people's page and the post 16 students page have valuable information on who to tell, what to do, ways of helping and links to the youth board and adult board so students can talk post messages and chat to others about their condition.

Their main web page contains patient information, including, condition, diagnosis, treatment and travel information. It also contains sub sections of medical professionals, kids and teens, projects and campaigns and media centre. STARS has four main aims, these are:

- (1) To ensure that patients who have unexplained loss of consciousness receive a correct diagnosis, informed support, the appropriate treatment given to them and that they are sent to the right medical professional.
- (2) To help alleviate the effects of syncope and RAS and to provide support to those people who are affected directly or indirectly by a seizure or syncopal attack.

- (3) To continue to move forward the education of medical professional and the public in the knowledge of syncope and RAS and its implications for the patient and their family.
- (4) To promote the research into management of RAS and syncope and publish the relevant information. To also support the organisation whom are researching the conditions themselves.

The charity offers information, literature, leaflets on syncope and RAS which are endorsed by the Department of Health. (STARS, 2007). They provide a 24 hour helpline, an adult and youth messaging board and a UK and international syncope specialist database. In the future STARS are hoping to bring out a DVD that can be given to schools to inform them of syncope and RAS. It was this studies aim to ascertain whether or not students with syncope needs support in education, the work of STARS clearly proves this work is necessary. The objectives set out at the start have all been met and have highlighted that some form of support is needed. The following information shows the objectives set out; from here I will attempt to discuss each of the objectives in depth.

#### Objective 1

- To conduct a literature review into the various types of syncope.
  - A literature review was carried out and found that there are six types of syncope identified in medical literature. These have varying cause numerous forms of treatments for each. The literature helped two identify the two main groups that they are split up into; these were cardiac causes and non-cardiac causes.

#### Objective 2

- To critically analyse educational provisions for pupils in education between the United Kingdom and the United States of America.
  - This objective was met by gathering literature on the legislation in the UK and the USA and investigating to see if syncope was included in any of the acts. From the literature reviewed there is no reference made to the specific or general support of pupils with syncope in education in the UK or the USA. Although there is no official legislation, syncope sufferers in education may be provided with support on individual circumstances may be provided, particularly in higher education where it is down to the college or university establishment to provide support. In both the USA and the UK the

legislation did cover disabilities; however it was clear that syncope has not been classified as a disability.

### Objective 3

- To compare and contrast responses of pupils with syncope through the use of an online questionnaire.
  - This objective was met by gathering student's perspectives on whether they wanted support in education for their syncope via the use of a questionnaire. It found that most of all students wanted understanding and a greater awareness of syncope.

Following the objective this study has shown that students with syncope need understanding and a greater awareness of their syncope conditions, the responses to the questionnaires helped to highlight this. The respondents were clear in filling in the questionnaire and had a massive impact on the way in which the study was directed. From the onset it seemed clear that students would suggest they required some form of help in education for their syncope and when the responses came back this was confirmed. The range of respondents was also a great surprise, with a wide array of ages and a wide range of county's and states covered. The study on a personal note helped to highlight issues that having syncope may bring about, such as the effects that syncope can have on family, friends and partners.

If the study was to be repeated some of the wording on the questions would be changed, in particular the question about support and if this was beneficial. This is because to some it may have seemed confusing and slightly misleading as the questions followed on. Some of the questions were similar in the responses the questions generated. Particularly question nine 'are you aware of any help which may be available to you for syncope and your education', in which seventy-six percent said no, but this could mean that they may not have read the information. Next time a pilot questionnaire would be sent out first to test the questions; this was not originally done because of time restraints. Although the original questionnaire was checked by STARS, a support tutor in education and my tutor it was not understood by all the participants. Doing a pilot study would help to ensure the generation of a more specific line of questioning. Whilst also ensuring that the questions used in the questionnaire would be easily understood.

## **Recommendations**

After reviewing the research from this study and analysing the results, the following would be my recommendations.

- Syncope to be included in legislation for supporting students with medical needs.
- Guidance to be available for issue to schools/colleges and universities, when a student with syncope is enrolled at the educational establishment.
- STARS to release an educational DVD that may be issued to schools/colleges/universities when requested by a sufferer.
- STARS to continue their crucial support and help with sufferers of syncope and to carry on their dedicated work in highlighting the 'shine a light on education' campaign.
- My research into syncope and education to be extended and to be more extensive and to continue to include STARS.
- STARS to be made more publicly available, for example newly diagnosed sufferers should be given their contact details.

## **Conclusion**

In conclusion, this study has clearly emphasized the need for syncope to be included in some form of government legislation/guidance. This could just be guidance on syncope that could be issued as when it is needed. Medical professionals could also pass on the details of STARS, to ensure sufferers are fully supported and helped through their education.

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