

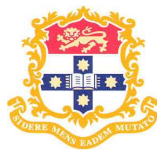
An exploration of the psychosocial effects that school-age children with Child  
Absence Epilepsy (CAE) experience when their condition is misdiagnosed as  
Attention-Deficit/Hyperactivity Disorder (ADHD)

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A thesis submitted in fulfilment of the requirements of the degree of  
Masters of Philosophy

Faculty of Education and Social Work  
The University of Sydney

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## **Author's Declaration**

This is to certify that:

1. This thesis comprises only my original work towards the Master of Philosophy degree
2. Due acknowledgement has been made in the text to all other material used
3. The thesis does not exceed the word length for the degree
4. No part of this work has been used for the award of another degree
5. This thesis meets the *University of Sydney's Human Research Ethics Committee (HREC) requirements for the conduct of research.*

Signature:

Name: Martin Raffaele

Date: May, 2009

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## Abstract

In today's society, the misdiagnosis of school-age children with the neurological condition Child Absence Epilepsy (CAE) as having Attention-Deficit/Hyperactivity Disorder (ADHD) has a low profile. This may be because of the lack of popular awareness of CAE. The increasing social salience towards the neuropsychological condition of ADHD places these children at risk of experiencing high psychosocial effects. Many symptoms of CAE are also associated with ADHD. However if the condition is misdiagnosed as ADHD, the child with CAE is often mistreated, both medically and socially until the correct diagnosis is made. There is little research available on the psychosocial effects of the misdiagnosis of epilepsy as ADHD, and none available relating to CAE.

This research study uses case study methodology to focus on how children with CAE are psychosocially affected at the time of the misdiagnosis of ADHD and subsequently. It also explores the experiences of their parents. An in-depth interview method was adopted to gather the personal recollections of these effects directly from the ten participants in this study. The participants were found with the assistance of Epilepsy Australia and constituted one adolescent from five different families who had experienced the sequence of events and effects under investigation, and a parent (guardian) who cared for these children during this period.

The findings of this research indicate that as a result of labelling, these children were misjudged in their communities, leaving strong psychosocial effects on each of the child participants who had previously been misdiagnosed with ADHD. These effects include low self-esteem, insecurity and fear experienced most often in the company of peers. As a result, when reaching adulthood, most of these participants chose to isolate themselves from social contact whenever possible. The findings offer a basis for further research in the area.

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# CHAPTER 1

## PURPOSE

The main motivation for conducting this research derives from my strong interest in the neurological condition, epilepsy. The need to study the psychosocial difficulties that children with Child Absence Epilepsy (CAE) experience when misdiagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD) became apparent when I began conducting the Epilepsy Action Inner-city Support Group in 1999. Members, both with epilepsy and those closest to them spoke of the difficulties that were experienced when symptoms of the condition were initially not correctly diagnosed. Some spoke of their child's initial behaviour patterns and of these being noted as symptoms of ADHD.

The emotional reactions of the parents of the children were quite strong when discussing this topic. Disappointment in the medical professionals, who initially failed to observe the CAE symptoms and the reaction of extended family members and the community towards their children, was evident. When discussing the topics of CAE or ADHD with members of the general public, I found that many people had heard of the neurological condition of epilepsy, but were unaware of Child Absence Seizures (CAS), which are those that a child with CAE experience. There was a stronger awareness of the neuropsychological condition of ADHD, many describing it as “a condition that bad children have.”

Another strong motivation arose from the choices made by the medical professionals I had spoken with. Some stated that ADHD is the same as the symptoms that a child with CAE experiences thus connecting the two conditions. Although there are similarities in some symptoms of CAE and ADHD, such as fidgeting and loss of concentration, the dangers of mistreatment when providing a stimulant medication rather than an anti-epileptic medication to a child with CAE were ignored. I followed this up by discussing this same topic with a medical specialist working at a children's hospital, who felt the misdiagnosis of ADHD to be unimportant. He disregarded the

need to correctly diagnose the condition as CAE and not ADHD. Astonishingly, he believed both conditions were so similar that his choice would be to give a child with CAE a drug that stimulates the brain rather than an anti epileptic medication that would exhaust the child; affecting neurological activity. The motivation for this research also arose as a result of my personal experience with epilepsy. Data collection methods for this section are described below.<sup>1</sup>

As with many children who develop CAE, I experienced my first period of febrile convulsions at seven months of age. At this time I was experiencing long periods of severe high temperatures. As little knowledge was available on what could possibly be causing these seizures to occur, actions including a spinal tap were performed to rule out meningitis. Following a good recovery and no signs of further illness, influenza B was noted as being the cause of these medical difficulties.

At the same time in the following year, as we were entering the colder months, the same symptoms surfaced. As the temperatures I was experiencing at this time were often unable to be reduced, I was placed in ice baths while in the hospital, yet my body temperature remained the same. After two weeks the high temperature finally reduced, and so did the convulsive seizure activity. The symptoms were once again felt to be nothing more than a result of the high temperature.

I began my schooling in 1976 at a public school in Dee Why. No problems were evident for some time. It was at the end of that year that my family moved to Tamworth and I attended a small school until the end of my third grade. However it was upon entering a private school in 1980, that difficulties in the classroom environment began to occur. My fourth grade teacher reported to my parents that I was experiencing difficulties with my memory and choosing not to pay attention while in the classroom. It was this teacher, who had gained her knowledge of

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<sup>1</sup> Data collected for this section has included informal interviews with my parents and other family members alongside other evidence as indicated.

teaching from other nuns, who caused further difficulties for me by often calling me ‘the dummy’ while in the classroom. This became the label that peers would also use when addressing me. This continued into the following year, 1981, when further complaints relating to a short attention span by a young teacher were made to my parents. Upon recommendation, I was referred to a child psychologist who undertook testing and reported that I was experiencing some sequencing problems. Because I registered a very high Intelligence Quotient (IQ), the diagnosis was left at that. Although this was the case, the fact that further medical examinations, including neurological scanning tests were not performed, a diagnosis of why these problems were occurring was not offered. The difficulties I experienced with both teachers and peers continued when I entered high school. How teachers assessed my academic knowledge throughout my secondary schooling, due to their failure to correctly recognise the symptoms of CAE that I was experiencing, are evident in the comments that were made in my end of year report cards. Examples of these from my year seven, year eight and year 12 report cards have been placed in Appendix B.

The evidence in Appendix B shows that both teachers and the school principal at two schools noted these symptoms as being a result of my choice to not fully apply myself to my studies. My year seven school report cards demonstrated that both teachers and the school principal noticed that I was having difficulty maintaining concentration, affecting my attention span. This was noted as being an action I was making out of choice. Following teacher comments such as “his attention span is quite short however and this is hindering his progress at times,” the school principal wrote that “it is obvious that Martin has incredible ability and if his concentration is maintained, he should do even better....If Martin can apply himself in year eight, he is capable of improving his marks.”

In the following year, comments written in relation to the difficulties I was experiencing with concentration by my teachers were very similar to the previous year. The reasons for these occurring were once again incorrectly noted as the result of self induced disruptive behaviour. One teacher commented that “Martin is a keen and interested student but seems to let his concentration wander.” These were once



again backed up by the school principal. The comment of the school principal was that “during all classes he lacks concentration needed to do the work. This must improve.” This indicates that all of my teachers and the principle of the school I was attending lacked awareness of CAE and the symptoms that are associated with the condition. Problems continued in the following year.

This resulted in social difficulties occurring when mixing with peers. I experienced a long period of bullying from this point, continuing throughout high school. This bullying was directly related to the staring I manifested as a result of absence seizures. In 1985, I became interested in singing, attained the principal role in the school musical and found my feet. My main interest became music. The same occurred in 1986. I was given the principal role in the school musical and I gained more stability through music. In this same year I won a vocal scholarship, which saw me attending singing lessons on a weekly basis until the completion of high school. My interest in opera began to develop.

Through the final two years of my time at high school (1987-1988), although I had changed the school I was attending, the same level of bullying occurred. The one thing I could never understand was why for so many years fellow students would aggressively say “what are you staring at?” or “stop looking at me like that.” I was unaware I was staring at others and therefore I just assumed it was a means for peers to reject and show disrespect toward me. Although the absence seizures seemed to increase, affecting my concentration, the reaction of my teachers at this new school, regarding how they observed and assessed the CAE symptoms did not change.

In the final year my mathematics teacher assessed the difficulties by writing that “Martin has been severely disadvantaged by his patchy grasp on the basics of mathematics and as a result has not applied himself as diligently as he could. This result is indicative of the quality of the work he has done.” My English teacher in this year also commented that “he has a good grasp on text, and if he could only concentrate on specific questions rather than ‘tell-me-all-you-know’ answers, he could go well.”

During the last four years in high school I also began to experience short periods, of around 15 seconds, where I would smell an unusual odour. I would ask others, “*what is that smell?*” and the reaction was always the same such as “*what smell?*” Following an appointment with a general practitioner, the diagnosis of a sinus infection was given and an antibiotic, with a number of repeat prescriptions were prescribed to control the symptoms. As this same pattern continued to occur, even though the antibiotic had been taken for several weeks at times, it was after a period of around a year that I chose to make no further comment about these short periods. I was informed by a neurologist several years later that I was experiencing ‘auras’ or Simple Partial Seizures (SPS) at that time. This was due to the scar tissue that had formed on my left temporal lobe as a result of the febrile convulsions I experienced as a child.

In 1989, I moved to Sydney, in the hope of one day commencing a career in the field of opera. It was within the following two years that I began to unknowingly experience Complex Partial Seizures (CPS). It was in December of 1990, following the opportunity to commence studies at the Queensland Conservatorium of Music in 1991 that the fact I was experiencing convulsive seizures were brought to my attention by my fiancé who witnessed the onset on several occasions. Although I had been experiencing a number of CPS, at least once a month for a period of around one year, the fear of how I would react saw her refusing to acknowledge them as being a problem. When informed, following a close car accident while I was driving, I was strongly affected both socially and psychologically. The ‘fear of the unknown’ saw me choose to turn down the offer from the conservatorium. I experienced many negative reactions, including fear and confusion as a result of the diagnosis and lack of education on the condition, leading to a severe reduction in my self-esteem.

With the frequency of my seizures increasing to as many as three a week over the next two years, and with high levels of medication unable to control them, I followed the recommendations of my neurologist at that time and was admitted into Royal Prince Alfred Hospital, Sydney for a full week of neurological examinations. In 1993, it was recommended that I should undergo a partial temporal lobectomy

operation to remove scar tissue that was causing frequent periods of irregular neurological activity. This would involve the removal of the hippocampus in the left hemisphere of my brain, which is a procedure that has an 85% success rate of a strong reduction, if not a full termination of seizure activity. Once again, the ‘fear of the unknown’ was mostly due to a lack of education on what effects may result from the operation, strongly influenced my choice not to undergo the procedure.

In 1997, I began my tertiary studies at the University of New England, Australia. Many years had passed with me taking different combinations of three medications at higher than recommended dosages, but these were unable to control my seizure activity. Eventually in 1998, following the experiencing of an increase of seizure activity of up to seven CPS on a weekly basis, I acknowledged the advice of a new neurologist and underwent a partial temporal lobectomy operation in the left hemisphere in August of that year.

After what was thought to have been a successful operation, having not experienced a seizure for five months, the following year I moved back to Sydney and commenced my studies in my Bachelor of Music degree at the University of Sydney. I began to conduct support group meetings I spoke of earlier on a monthly basis, in association with Epilepsy Action, Australia. The reason for doing this was to offer support and understanding for others from an angle that had not been made available prior to this point.

It was around 10 months after the operation (June, 1999) following the removal of one of the medications I had been taking that I began to experience CPS again, and the journey towards stardom was also once again put on hold. Following an increase in the regularity of seizures and a long period of neurological examinations, it was discovered the removal of the damaged tissue in the left temporal lobe had been inadequate and therefore a second operation was recommended and performed in October, 2000. As I had previously organised to audition for the Sydney Conservatorium of Music in September of that year I decided to do so and was offered a position as a student immediately following the audition. I felt obligated to inform them straight away of the necessary upcoming operation, and asked if the

starting of the degree could be suspended for one year, commencing in March, 2002. The offer was cancelled and I was advised that I must return in the following year to audition once again.

In mid 2001, following routine testing, it was discovered that small damage had also become evident on the hippocampus of the right temporal lobe. I was informed that an operation would not be possible. If they were to also remove the hippocampus within the right hemisphere I would not have the ability to retain memory past a period of 15 seconds in duration. It was following this diagnosis that the focus of my life changed from being one who would work as an opera singer and obtain greatness at a professional level, to one who would offer the better understanding of epilepsy and the difficulties of this condition to people in every environment. I chose to continue to pursue my goal of offering education on epilepsy from this angle, which led to my decision to write this thesis.

Following a long period of recovery, and my wish to offer what I felt was necessary education, I continued my studies on a part-time level, completing the Bachelor of Arts degree in June 2005. In the second semester of 2005 I commenced full-time studies for my Graduate Diploma of Psychology at the University of Sydney. Although I continued to face many difficulties, both medically and academically, it was my desire to attain this goal that saw me complete the degree in November 2006. Realising the lack of education of students at a tertiary level on the condition of epilepsy, the most common neurological condition experienced by human beings, the decision to begin research and education about this condition at a post graduate level was made.

My personal experience with epilepsy has enhanced the current research process. It allowed me to relate my experience to the child and parent participants during interviewing. Although I maintained a detached role when conducting interviews and interpreting the results, my personal knowledge has given me an opportunity to provide education and understanding of these results for professionals with the fields of education medicine and psychology from a viewpoint that up until now has not been available. The next chapter introduces my research and outlines this report.

## CHAPTER 2

# INTRODUCTION

The need for research on the misdiagnosis of Child Absence Epilepsy (CAE) as Attention-Deficit/Hyperactivity Disorder (ADHD) has been identified by a number of neuro-epileptic specialists, (e.g. Austin, personal communication, August 12, 2007 and Holmes, personal communication, September 2, 2007) and psychologists, (Halasz, personal communication, May 7, 2007; June 20, 2007). All advocate that research on the misdiagnosis of CAE as ADHD has been neglected for far too long. To date little research focuses on children with CAE and its misdiagnosis in relation to ADHD. Halasz (May, 2007) also felt that due to the lack of written documentation in relation to the epilepsy (especially CAE) and ADHD, a blurring has occurred that needs to be addressed.

As discussed in Chapter one, I am personally aware of the difficulties that can be experienced as a result of epilepsy, including the lack of education and social support available to those who are in need. I felt my experience and potential empathy for children with epilepsy and with their parents, gave me particular advantage in conducting this research. Some would see the bringing of knowledge based on my experiences with epilepsy into this research project as a scenario that might create bias, impeding me from maintaining an open mind when analysing relevant data. However, I feel that the choice to conduct research in this area, and offer what I feel to be an important analysis will allow for new knowledge to be provided from a perspective that until this point has not been accessible.

This exploratory study investigates the psychosocial effects that children with CAE experience when the condition is misdiagnosed as the neuropsychological condition of ADHD. In addition, how this can also affect their parents is investigated. It provides a foundation for further research in this area. Although my own condition was misdiagnosed as a child, it was never thought to be due to the neuropsychological disorder of Attention Deficit Disorder (ADD), which is

recognised as being a factor of ADHD in this generation. Understanding how children with CAE are psychosocially affected by its misdiagnosis as ADHD is therefore of strong interest to me. I wish to provide a rationale for more thorough education of pre-service teachers and health professionals so that stereotyping and bullying of these children can be avoided.

Following the initial diagnoses of ADHD, my interest was in how the individual, family, and community react to the misdiagnoses. The outcome of such diagnoses can lead to labelling. The condition of CAE in children will often remain undiagnosed until a form of seizures that displays more physical visible symptoms. This will include Juvenile Myoclonic Seizures (JMS), where due to irregular neurological activity in one hemisphere of the brain, for example the left, will see the opposite side of the juvenile's body, in this case the right, experience a short period of loss of muscular strength. This will see the body falling, yet the person experiencing the seizure remains conscious (Cavazos, Lum, & Spitz, 2007). A second form is Complex Partial Seizures (CPS), where irregular neurological activities commencing in a partial section of the brain, most often the temporal lobe, moves between both hemispheres of the brain. The patient loses consciousness and the body convulses due to the activity reaching the brain stem, linking it to the central nervous system (Murro, 2006). With the diagnosis of Juvenile Myoclonic Epilepsy (JME) or Temporal Lobe Epilepsy (TLE) in the child participants' teenage years, I was interested in the psychosocial effects that these children incur knowing that their condition of CAE was originally misdiagnosed.

### *Research Structure*

A qualitative case study methodology was chosen for the gathering and analysis of the data in this research. First-person in-depth interviews were conducted with five children and one of their parents. Figure 2.1 shows the main stages of the present study, and the relationship between the Investigation stage and the Anticipated Application stage. My study was divided into five stages as shown in Figure 2.1 below:



to the two conditions (epilepsy and ADHD), including the investigation of background information relating to the psychosocial effects that an action such as inaccurate labelling in general can impose on a child with all forms of epilepsy, the misdiagnosis of ADHD, the researching of JME, TLE and the related seizures that can be experienced as a result of these forms of epilepsy. Following the analysis of these data the following research questions were developed:

1. How is a child with Child Absence Epilepsy (CAE) affected once the negative labels associated with Attention-Deficit/Hyperactivity Disorder (ADHD) are placed upon them?
2. What are the reactions that school-age children with Child Absence Epilepsy (CAE) and their parents report when their condition is misdiagnosed as Attention-Deficit/Hyperactivity Disorder (ADHD)?
3. What educational changes do participants feel are necessary to reduce the frequency of misdiagnosis and its effects?
4. Do the psychosocial effects of misdiagnosis discontinue when an accurate diagnosis of epilepsy is provided?

Stage 3 employed the investigation technique of in-depth interviewing with the children with CAE and their parents. Although a set pattern of initial questions was constructed prior to meeting with all participants, this form of interviewing was chosen to ensure a freedom to further probe through the asking of additional questions if appropriate. The participants were also able to ask questions in relation to my own condition, which prompted the recall of additional incidents experienced by the child participants. I recorded each interview with the use of an MP3 player, and observation notes were also taken throughout each interview.

Stage 4 began with data analysis, creating sequential triangulation within this study: In-depth Interview, Observation, and Data Analysis. The participants' recommendations about how to counteract the cause of the misdiagnoses of CAE as ADHD were also addressed.



Stage 5 highlighted the implications and recommendations of the study for future research both in this area, and with other neurological conditions.

It is anticipated that the results of the investigation will be beneficial for others working with children experiencing these difficulties. Following the initial diagnosis of ADHD, the focus of this study is on how the individual, family, and community reacted to the misdiagnosis; the outcome often leading to labelling. With the diagnosis of JME or TLE in the participants' teen years it is important to increase awareness of the psychosocial effects these children incur knowing that their condition of CAE was originally misdiagnosed (Figure 2.2).

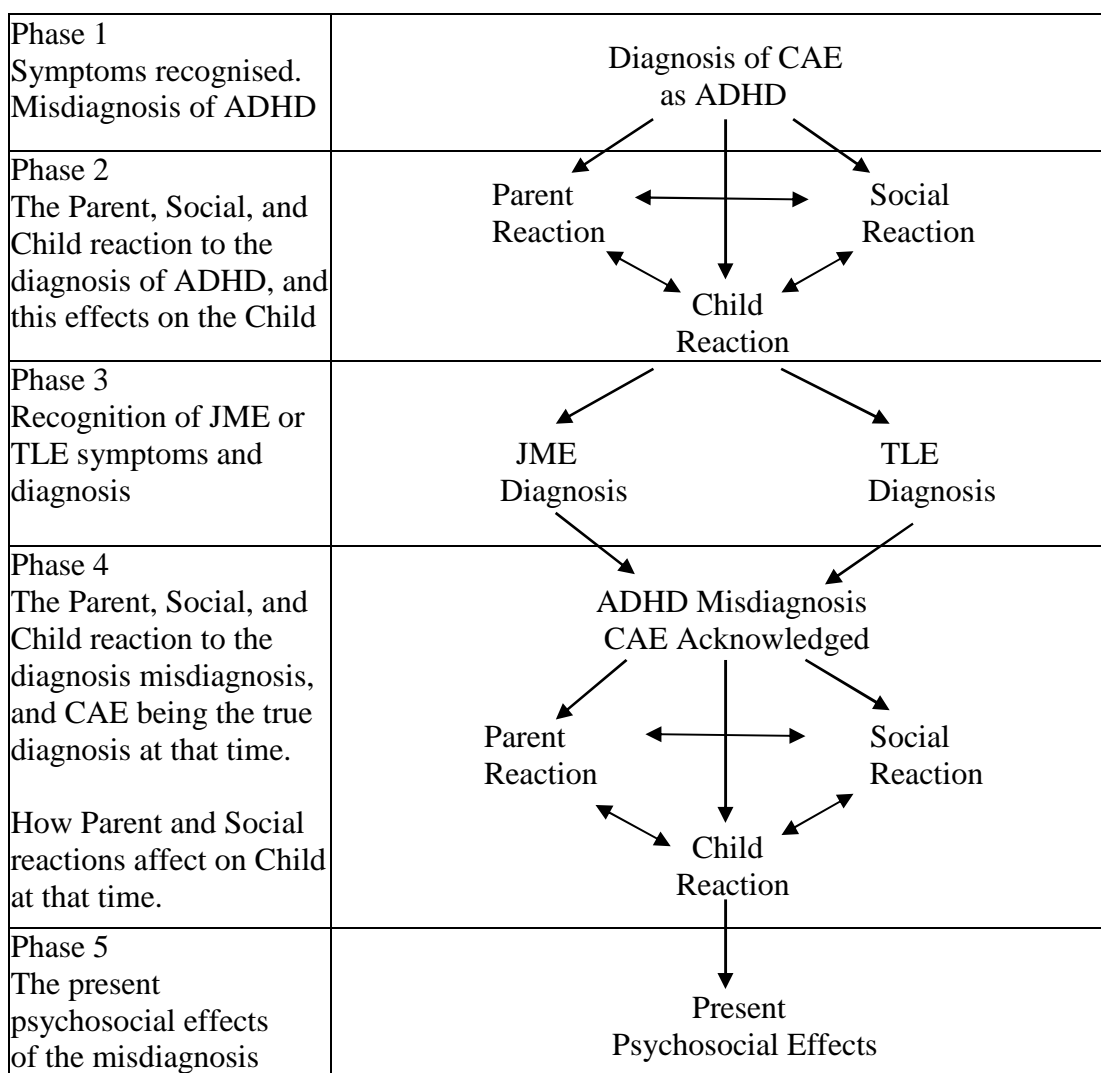


Figure 2.2 The relationship between the misdiagnosis of ADHD and its progressive psychosocial effects.

How the chosen research questions developed for this study is noted below.

### *Reflecting on Research Questions*

Difficulties can often arise in the classroom when incorrect neuropsychological labels are placed on a misdiagnosed child with CAE. A result of negative labelling and conflicting interactions with teachers may influence reactions with others in the classroom leading to stigmatisation (Partridge, 2006).

The early arrival of CAE caused absence behaviour, difficulty with concentration, and learning difficulties for most of the child participants in this study. The lack of education on the condition of CAE may result in these being interpreted as symptoms of ADHD by those within the classroom environment. One of the major causes of the increase in misdiagnosis could be a misinterpretation of the symptoms (Famularo, Fenton, Kinscherff, Barnum, Bolduc, & Bunschaft, 1992). Incorrect diagnosis could exacerbate an elevated level of reactions, such as withdrawal and low self-esteem. This can increase the risk of exhibiting aggressive behaviour if following a Child Absence Seizure (CAS) the children with CAE find themselves being confronted by either teachers or peers. For example, if a child is experiencing frequent CAS activity while in the classroom he will fail to understand all that is being taught. If asked to answer a question while experiencing a seizure, his delay in providing an answer as a result of this occurrence may cause a negative reaction on the part of the teacher. As he was in fact experiencing the seizure while the question was being asked, he would not have been aware of the question and therefore would be unable to provide an answer (see Appendix C. for a list of all CAS symptoms). The reactions of the teacher may confuse him and the criticism may cause aggressive behaviour. It is most likely due to the increase of public awareness of ADHD (Bishop, & Slevin, 2004) that the symptoms of CAE are being incorrectly labelled as those of this neuropsychological condition, resulting in these confrontations occurring.

There is little documentation that addresses the symptoms associated with CAE and the effects of misdiagnosis as ADHD on a child with a neurological condition such as epilepsy (Jacobs, 2002; Williams, Noël, Cordes, Ramirez, & Pignone, 2002). There are, however, many published documents that discuss ADHD and how

problems such as difficulties holding concentration and maintaining interest over long periods of time arise with the condition, and how an 'average child' is affected when incorrectly diagnosed with the condition (Brown, 2000; Sherman, McGue, & Iacono, 1997; Bhatia, Nigam, Bohra, & Malik, 1991). Many of these authors turn to the American Psychological Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) to establish diagnostic guidelines for their research.

In the current fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (Text Revision)* (DSM-IV-(TR)) diagnostic guidelines, published in 2000 by the American Psychology Association, the diagnosis of ADHD fluctuates as a result of the choice analysis structure. From the 18 possible behavioural symptoms (9 Inattention; 6 Hyperactivity and 3 Impulsivity), three subtypes of ADHD categories are identified by the American Psychology Association (2000):

- (1). ADHD, *Combined Type*: if 6 symptoms from both criteria are met for the past 6 months.
- (2). ADHD, *Predominantly Inattentive Type*: if 6 symptoms from the 1<sup>st</sup> criterion are met but 0 from the 2<sup>nd</sup> criterion for the past 6 months.
- (3). ADHD, *Predominantly Hyperactive-Impulsive Type*: if 0 symptoms from the 1<sup>st</sup> criterion are met but 6 from the 2<sup>nd</sup> criterion for the past 6 months. (p.87)

As there is an overlap of symptoms associated with ADHD and CAE, it is important to explore what are the individual symptoms that each child is experiencing, rather than labelling each child as being one who has ADHD based on its optional combination of 18 symptoms. More in-depth research is needed to develop consistent standards and tools to correctly assess ADHD and reduce the levels of misdiagnosis in children with CAE.

Data gathered in the study were derived from interviewing five adolescents/young adults who have experienced CAS and a parent of each. The participants were interviewed about the effect they felt the misdiagnosis and the later correct diagnosis of CAE played on the child participant at the time of diagnosis and sequentially within all social environments. All child participants spent 30 hours a week in schools during the first 4 phases of the investigation (Table 2.1). Therefore, it was important to explore the role that lack of social awareness in a classroom

environment played in mistreatment. This form of mistreatment is psychological or emotional characterised by a person subjecting or exposing another to behavior that is psychologically harmful, such as bullying, verbal harassment, or through manipulation (Stevenson, 2004). As this study was limited to the recall of the participants, further research in this area of investigation is needed.

To understand the psychosocial effects of the misdiagnosis of ADHD on the school-age child with CAE, a research framework based on a dual comparison construct was required. Coding in this research was based upon the personal reactions of the 10 participants over the study time frame (note the five phases listed below). It is based upon all participants' retrospective recalls of the relevant personal experiences of the child participants.

The task of the ten participants was to communicate their personal/child's experiences with the case study phenomenon: *the psychosocial effects experienced by a school-age child with CAE when the condition is misdiagnosed as ADHD*. Five child participants: Allan, 21 years of age, Betty, 19 years of age, Charles, 17 years of age, David, 20 years of age, and Elisabeth, 19 years of age. Allan's father, Betty's mother, Charles's father, David's mother, and Elisabeth's mother were the five parent participants who took part in this investigation.

The child and parent from each family were asked questions on how both they and the other family member reacted throughout each of the five phases. This allowed me to assess whether both participants were in unison on how each of them reacted, and if not, whether the dissimilar reactions caused the child to experience further psychological difficulties.

Table 2.1 Five phases of research

Phase 1: Precursor to diagnosis of ADHD
Phase 2: Diagnosis of ADHD and sequentially
Phase 3: Precursor to Diagnosis of JME or TLE
Phase 4: Diagnosis of Epilepsy and sequentially.
Phase 5: What are the psychosocial effects presently experienced by the adolescent participants as a result of the misdiagnosis?

*Delimitation*

Limited research in this specific area saw the need to examine sources of literature that discussed topics such as: the misdiagnosis of temporal lobe epilepsy as ADHD; the misdiagnosis of Autism as ADHD; and the misdiagnosis of many other neurological conditions as ADHD.

*Further overview of thesis*

Chapter three is divided into three parts. Part one investigates the diagnostic issues and controversies regarding ADHD. Part two investigates the diagnostic issues and controversies regarding CAE, and issues around the misdiagnosis of ADHD. Part three provides a review of current literature on CAE pertaining to research evidence, an outline of the medical symptoms of CAE, and the overlap with those of ADHD, which can lead to misdiagnosis. The incorrect identification of a medical condition or a disease by its signs, symptoms, and the results of various incorrect diagnostic procedures (Pugh, 2000). It explains absence seizures, the typical and atypical forms of the condition, and social reactions to CAE, sometimes caused by a lack in education. Issues that might arise pertaining to the misdiagnosis of ADHD and diagnosis of CAE are examined. Finally, documentation relating to JME, JMS, TLE, and SPS is discussed.

Chapter four discusses how the research was constructed, based on the following four sections. The first section involves the research questions, as outlined in Chapter three. The second section is the theoretical framework, underpinning the research method. The third section includes the methodology, data collection, and data analysis. The final section addresses issues of resonance and those of the constructivist interpretive paradigm theory used in the research; dependability, confirmability, transferability, reliability. Ethical concerns and limitations are also discussed. This chapter provides a detailed account of the specific qualitative research methods employed, sampling procedures, interview content and protocol, observations and data analysis techniques.

Chapter five provides reports on the findings of the analyses of interview data. This data concerns the psychosocial effects of the misdiagnosis on the child with CAE, from the individual and parental perspectives. This chapter provides an insight into the social reaction to both diagnoses, as perceived by the participants in this research, and offers the participants' views on the importance of education in relation to both conditions.

Chapter six provides a discussion of the themes and the issues that arise, and the application of findings. Chapter seven summarises the research findings, draws conclusions from those findings, and further explores some of the major implications of them. This chapter also documents the limitations of the study, and concludes with suggestions for further investigation in this field. Appendix A is a glossary that offers a full explanation of each medical and relevant term used throughout the thesis.

The following chapter offers a critical review of the research relating to epilepsy and ADHD and demonstrates the need for this current study.

## CHAPTER 3

# LITERATURE REVIEW & CRITICAL ANALYSIS

This chapter provides a framework for understanding the diagnoses of Attention-Deficit/Hyperactivity Disorder (ADHD) and Child Absence Seizures (CAE), misdiagnoses and psychosocial effects. In order to achieve this, a number of studies from a variety of environments leading to labelling are discussed along with the relationship between the diagnosis of ADHD and the psychosocial effects this may create. The literature concerning misdiagnosis and psychosocial effects is further categorised into matters involving social education at a national level, and matters of education at a tertiary level, providing an understanding of how both conditions are diagnostically structured and socially perceived.

This chapter is divided into three parts. Part one explores diagnostic issues and controversies regarding ADHD. Part two explores diagnostic issues and controversies regarding CAE, and issues around the misdiagnosis of ADHD. Part three provides a review of current literature on CAE pertaining to research evidence, an outline of the medical symptoms of CAE, and the overlap with those of ADHD, which can lead to misdiagnosis. It explains how the understanding of Child Absence Seizures (CAS), the typical and atypical forms of the condition, and social reactions to CAE, sometimes caused by a lack in education.

### *Theoretical framework*

The framework underpinning this study is based on Vygotsky's (1978) constructivist theory, being a psychological theory of knowledge that claims that knowledge and meaning is constructed by the experiences a human endures. Vygotsky's theory of social constructivist learning expressed a strong perspective on human psychology. Most psychologists hypothesize a psychological phenomenon of free will or theorise some interaction between the inner-being and social factors, whereas Vygotsky's constructivist theory asserts that human development is social. As a result, his theory has had a wide impact on many aspects of education, including teaching methods and

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learning theories (Dahms, Geonnotti, Passalacqua, Schilk, Wetzel, & Zulkowsky, 2007). The theory clarifies how learning takes place, when learners or researchers are using their experiences to understand new knowledge (Mace, 2005). However, constructivism is often associated with educational approaches that promote active learning or learning by experience. Vygotsky's (1978) argument was that, "learning is a necessary and universal aspect of the process of developing culturally organized specifically human psychological function" (p.90). As a result, he asserts that social learning tends to precede individual development (Mace, 2005).

Huitt (2003) supports this theory by pointing out that the foundation of social constructivism is based on the theory that an individual researcher must actively 'build' knowledge and skills. That information exists within these built constructs rather than in the external environment, emphasises the collaborative nature of much learning. Unlike the assumptions of cognitivists, such as Piaget (1985), who believed it was possible to separate learning from its social context, Vygotsky's theory (1978), based on the 'More Knowledgeable Other (MKO)' argues that all cognitive functions originate from social interaction and therefore must be clarified as products of these interactions. Vygotsky (1978) also emphasised the uniting of the practical and social basics in learning by pointing out that the important moment in the course of intellectual development takes place when speech and practical activity, two actions that had previously been considered as two completely detached paths of development, unite. The intrapersonal level of understanding is constructed through practical activity, while speech links this perception with the interpersonal world shared by the child and social community.

Applying Vygotsky's MKO theory to my research acknowledges the participants have more knowledge about the experience of the misdiagnosis of ADHD than I do. That learning is not merely the incorporation and adaptation of the new knowledge I have gained, but also the process by which I incorporated myself into this knowledgeable community. Vygotsky's (1978) theory on social constructivism evaluated child cultural development.



Every function in the child's cultural development appears twice: first, on the social level and, later on, on the individual level; first, between people and then inside the child. This applies equally to voluntary attention, to logical memory, and to the formation of concepts. All the higher functions originate as actual relationships between individuals. (p. 57)

In most cases, a child with CAE starts to experience absence seizures at an early age (Audenaert, Claes, Ceulemans, Löfgren, Van Broeckhoven, & De Jonghe, 2003). As there is little documentation that investigates the psychosocial effects of misdiagnosis and labelling, an aim of the study is to offer an understanding of these experiences from the point of view of the participants. Therefore the research findings are based on the knowledge that the child participants and their parents have personally gained as a result of their interaction with society. I also unknowingly experienced CAE as a child. My experience was shared with the participants and this helped develop trust during the investigation.

This investigation is researching the psychosocial effects that each child experiences as a result of the diagnosis and misdiagnosis of medical conditions. However, because this does not occur at a specific age or period in time for each participant, a set of five phases that relate to each change has been created to analyse this scenario (see Figure 3.1) and perceptions of psychosocial effects at each phase are explored. Constructivist theory acknowledges that the personal experiences of the participants can build our knowledge about epilepsy and ADHD. Do their experiences resonate with each other? Do they relate to my experiences?

### *Phases of Reaction*

Phase one represents the period of time precursor to the diagnosis of ADHD. Phase two represents the time when the diagnosis of ADHD is made and the sequential period leading into Phase three. Phase three focuses on the period precursor to the diagnosis of epilepsy. Phase four begins with the diagnosis of Juvenile Myoclonic Epilepsy (JME) or Temporal Lobe Epilepsy (TLE) and sequentially, at which point ADHD is recognised as being a misdiagnosis, and CAE is recognised as the true diagnosis. Finally, Phase five focuses on the childhood of each child participant and

how relevant participants feel each individual child is now psychosocially affected as a result of the misdiagnosis of ADHD in their earlier years. As members of the general public were not interviewed on this topic, the Social Reaction is based on the reflection of the participants.

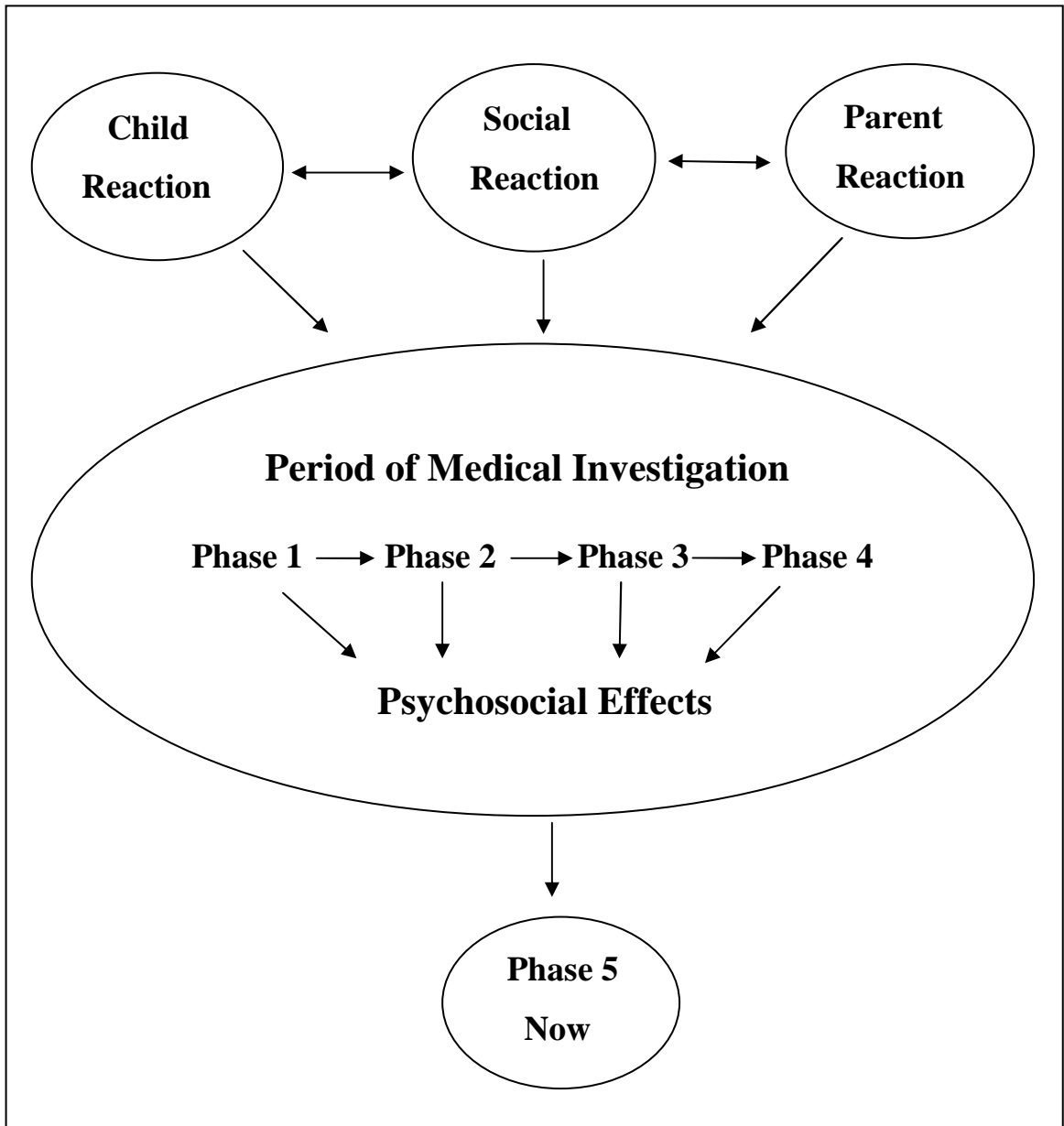


Figure 3.1 Phases of Reaction

## *Epilepsy*

Seizures are transient signs and/or symptoms due to abnormal, excessive or irregular neuronal activity in the brain (Cross, 2007), causing a change in a person's consciousness, movement and/or sensations (Austin, 2001; Ledingham & Warrell, 2000). The seizure disorder is characterised by recurrent unprovoked seizures and involves periodic disturbances of the brain's electrical activity, resulting in some degree of temporary-sequential relationship dysfunction (Epilepsy Action, U.K., 2007). Epilepsy is a neurological medical disorder that is the most common central nervous system (CNS) disorder affecting children. Approximately 5% to 10% of children experience a seizure during the first two years of life as a result of long periods (up to a week) of high temperatures, with 1% developing epilepsy (Cowling, Shaw, Hutton, & Marson, 2007). The scar tissue that can develop on the brain as a result of the influenza B virus, will most often result in children experiencing absence seizures in their childhood years, and may then lead to either Juvenile Myoclonic Epilepsy (JME) or Temporal Lobe Epilepsy (TLE) (Holmes & Ben-Ari, 2001).

### *Temporal lobe epilepsy (TLE)*

Before moving to temporal lobe epilepsy, more should be said about the temporal lobe and the neurological actions that these regions of the brain perform. It is in the temporal lobe that we find the nerve cells and interconnections that create the temporal-sequential relationship between the units of a sentence. It is in the left temporal lobe that the mental process of comprehension takes place. For children to perform actions such as reading this lobe must develop in early youth, prior to adolescence to ensure higher levels of learning are achievable (Holmes & Ben-Ari, 2001).

Selective attention to visual or auditory input is common with damage to the temporal lobes. Lesions pertaining to the left temporal lobe often affect recognition of visual content, e.g. recall of faces. Lesions pertaining to the left temporal lobe can also often result in decreased recall of verbal and visual content, including speech

perception. The temporal lobes are involved in the primary organization of sensory input (Corkin, Amaral, González, Johnson, & Hyman, 1997). Most individuals with temporal lobe lesions experience complications when placing words or pictures into categories; left temporal lesions disturb recognition of words, and the right temporal lesions cause a loss of self-consciousness when talking in community environments (Allan, Victor, Ropper, &, 2008).

The ability to retain and recall memory is highly associated with the temporal lobes. Lesions pertaining to the right temporal lobe often result in difficulties with the recall of non-verbal material, such as decreased recognition of tonal sequences, music and drawings (Svoboda, 2004). Temporal lobe seizures can have dramatic effects on an individual's personality. Temporal lobe epilepsy can cause preservative speech, paranoia and aggressive rages. Severe damage to the temporal lobes can also alter sexual behaviour, for example, an increase in activity (Blumer & Benson, 1975).

Psychologists and neuroscientists generally agree that the hippocampus has an important role in the formation of new memories and recall of experienced events and often refer to the hippocampus as a bridge allowing for the storage and recall of memories to occur (Kohrogi & Mitsudome, 1993; Levine, Carey & Crocker, 1999). Therefore the hippocampus, which is part of a larger medial temporal lobe memory system, is responsible for the general declarative memory or memories that can be explicitly verbalised including, e.g. memory for facts in addition to episodic memory (Svoboda, 2004).

### *Juvenile myoclonic epilepsy (JME)*

JME is often categorised as Generalised Epilepsy (GE) with the seizures resulting from abnormal activity in the whole brain simultaneously. In most cases, consciousness is not lost at the onset of the seizure, with a loss of muscle strength in the neck, shoulders, and upper arms occurring, resulting in an action similar to fainting. For many patients, Juvenile Myoclonic Seizures (JMS) most often occur soon after waking. They usually begin in adolescence or sometimes in early adulthood in people with a normal range of intelligence (Leach, Lauder, Nicolson, &

Smith, 2005). In most cases, these seizures can be well controlled with the continual taking of anti-epileptic medication. Sometimes a myoclonic seizure starts as a Simple Partial Seizure (SPS) (within the temporal lobe) and then becomes a generalised seizure. When this occurs the seizure is called secondary generalised (Holmes, 1993).

The following section offers a critical analysis of ADHD, including basic knowledge of the neuropsychological condition, the ages and frequency at which children are diagnosed, and the importance of ensuring accuracy in diagnosis. It also provides a critical analysis of CAE, the symptoms that are associated with absence seizures and the physical effects.

### *Part 1 Critical analysis of Attention-Deficit/Hyperactivity Disorder (ADHD)*

Attention-Deficit/Hyperactivity Disorder (ADHD) is a neuropsychological disorder that is often noted as being developmental in nature (LeFever & Arcona, 2003). The term 'developmental' means that certain attributes, such as impulse control, are significantly delayed in mental development in comparison to other children of similar age in the general community. ADHD has also been classified as a behavioural disorder and a neurological disorder and these amalgamated terms are now more frequently used in the fields of psychology and medicine to describe it. The behavioural classification for ADHD is not completely accurate in that those with Predominately Inattentive ADHD often display few or no explicate behaviours (Fadem, 2003).

#### *Research Evidence on ADHD*

##### *Increase in diagnosis*

In 2001 the National Institute of Mental Health (NIMH) estimated that 3% - 5% of Australian school-age children had ADHD. There have been many studies (Young, 2007; Tait, 2005; Pliszka, Carlson, & Swanson, 1999) that have indicated this

increase in the diagnosis of ADHD over the last 10 years. However, what accounts for the increase in diagnoses is not clear.

There has been an increase in the diagnosis of ADHD in the last fifteen years (Barbarese, Katusic, Colligan, Pankratz, Weaver, Weber et al., 2002). Following Fife-Yeomans' (2007) interview with Judge Paul Conlon, discussing the frequency of children taking Ritalin, she indicated that an increase of ADHD diagnosis has lifted dramatically since the early 1990's. She wrote that "last year (2006) there were more than 264,000 prescriptions for ritalin issued in Australia – compared to just 11,114 prescriptions written in 1992." She further commented that "with Australia's ADHD rates (being) among the highest in the world and 32,000 NSW school children now on medication for it, the judge's (Paul Conlon) comments will renew controversy about the use of Ritalin" (p.1).

ADHD is currently considered a persistent and chronic neuropsychological syndrome with a presupposed neurological basis for which no medical cure is available, although there is the belief that medication and behavioural interventions are accessible (Ledingham & Warrell, 2000). The diagnostic process is based on a specialist initially referring to the current Diagnostic and Statistical Manual of Mental Disorders IV, Text Revision (p.92) and making an assessment based on the related 18 optional symptoms of ADHD. Two of the three subsections of the condition require only six symptoms to make a diagnosis. Most often a parent will be asked several critical questions that include:

- (1) Are these behaviours excessive, long-term, and pervasive?
- (2) Do they occur more often than in other people the same age?
- (3) Are they a continuous problem and not just a response to a temporary situation?
- (4) Do the behaviours occur in several settings or only in one specific place like the playground or the classroom?

Based on the parent's recall of the behaviour patterns of their child, these are compared against the set of criteria and characteristics of the disorder found in the

DSM manual. The question is asked: Are these the behavioural actions of a ‘normal child’ at this age? If felt not to be a child with normal behavioural actions, the diagnosis of ADHD is given.

The DSM now characterises ADHD as a condition with continuous patterns of inattention and/or hyperactive impulsivity, being more severe than the norm for those of a comparable age and stage of development. However, now the condition indicates that a person with mostly the inattentive type may be diagnosed after the age of seven. Halasz (personal communication, May 9, 2007) commented that he had found that as several disorder subtypes and symptoms overlap, with many attributable to age, aetiology, and environmental context for child and adolescent diagnosis, conditions such as CAE can easily go unnoticed in this ‘one size fits all’ categorical approach. The DSM-IV-TR groups the syndrome into one multifaceted syndrome, defining high activity and low attention span as a feature of the disorder itself (Haber, 2003).

Despite, or perhaps in part as a result of the construction and continuous upgrading of the *DSM*, there exists a vast amount of critical literature on the diagnosis and treatment of ADHD (Fone & Nutt, 2005; Johnston, Murray, Hinshaw, Pelham Jr, & Hoza, 2002; Singh, 2002). Current research by the Department of Human Services (DHS), State Government of Victoria, Australia (2008) now indicates that ADHD may have multiple biological determinants, with symptoms being modified by family and social factors. Differences are said to be evident between children with ADHD and other children in brain neurochemistry, electroencephalographic (EEG) patterns, glucose metabolism, cerebral blood flow, and autonomic nervous system function. A strong genetic component to inattentive-hyperactive behaviour has also been established by the Department of Human Services (Australia). Despite the lack of a unifying biological theory to draw together the research findings described above, they believed that a possible diagnosis of ADHD can be analysed and diagnosed based on the consistency of symptoms.

In the last updated version of the *DMS*, ADHD was indicated that additional behavioural questionnaires were required to be completed by both parents and

teachers as part of the assessment and diagnosis. They distinguished that reports from parents and teachers are the best source of information to guide the diagnostic process. It is believed by the Department of Human Services that these observations can be quantified if standardised rating scales such as the Conners' Hyperactivity Scales or the Achenbach Child Behaviour Check Lists are used. Attaining scores that are above the 95% for age on parent and teacher checklists enables the identification of a group of children who fall statistically outside the normal range, as it is believed to improve the validity of clinical diagnosis. By relying on the personal reactions of classroom teachers and parents in this updated version of the Department of Human Services' diagnosis of ADHD programme, the Victorian government is allowing the ever increasing social salience, a result of a gap between an observer's expectations and observable attribute in social environments, to contribute to an increase in the diagnosis of ADHD (Corbett & Constantine, 2006). As most members of communities are not educated on the condition of CAE, their understanding of why a child with this is exhibiting symptoms relating to this condition is not clear. As a result, they are more likely to link these symptoms with the condition they are more familiar with; ADHD (McArthur & Ginsberg, 1981). This is impacting on the process of correctly assessing CAE in a child with this condition.

According to the Department of Health Services (2008), if the child is having difficulty with schoolwork then further developmental assessment (preferably cognitive testing by a psychologist) is indicated. It is believed that these results will be valuable for assisting the child when at school, irrespective of whether or not a final diagnosis of ADHD occurs. The problem with this analysis of the ADHD diagnosis programme is that it eliminates the opportunity for Electroencephalogram (EEG), Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) neurological assessment examinations to take place, making the correct diagnosis of CAE where pertinent, impossible.

### *Age and numbers of children on Ritalin in NSW*

Recent research by Fife-Yeomans (2008), found that children as young as two years of age are being prescribed Ritalin following a diagnosis of ADHD. She claimed that

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18,282 children between 6 to 18 years of age in NSW alone were taking Ritalin, a stimulant medication to control behavioural activity on a regular basis following a diagnosis of ADHD. Of the children taking these tablets, 37% of these children were aged between 6 to 10 years, 49% aged between 11 to 15 years of age, and 14% aged between 16 to 18 years. Her research also showed that a further 311 children aged between 3 to 5 years were also being prescribed Ritalin following the diagnosis of ADHD. In fact 4% of these children were three years of age, 19% were four years of age, and 77% of these children, five years of age. All were taking Ritalin on a daily basis. Her research has also indicated that strong conflict presently exists within the field of medicine in relation to the diagnosis of ADHD and the means of assessing the condition. The participants in this study may have been subject to dilemmas when their diagnoses were made.

### *ADHD defined as a neurological condition*

ADHD is defined by many professionals in the field of medicine as a neurological condition, caused by chemical imbalances in specific lobes of the brain, often the frontal (Tan & Appleton, 2005). It is believed that neurotransmitter chemicals such as noradrenalin and dopamine help with self-monitoring and controlling the sudden spontaneous actions associated with the diagnosis. The occurrence of ADHD is therefore characterised as an imbalance in these neurotransmitter chemicals.

Medical practitioners often express concerns about some of the specific language that the DSM-IV-TR uses to describe ADHD (Rafalovich, 2005). This is a more specific criticism of the manual, focusing on the words of the DSM-IV-TR and how they do not always translate into a unified interpretation of behaviour. This is especially relevant to whether or not that behaviour is perceived as abnormal. Rafalovich's (2005) research suggests that one cause of the increase in the misdiagnosis of ADHD may be a result of the misinterpretation of the symptoms. Research by Famularo, Fenton, Kinscherff, Barnum, Bolduc, & Bunschaft (1992), indicates that children who have been incorrectly medically treated are at a high risk of being diagnosed with ADHD, and therefore, early psychosocial trauma may result. Although the DSM-IV-TR provides some sub-categorical classifications, for the most part single

diagnostic categories are likely to identify a varied group of individuals exhibiting a collection of different symptoms to be diagnosed as having the same disorder (Doucette-Gates, Hodges, & Liao, 1999; Glod & Teicher, 1996).

### *Ensuring accuracy of diagnosis*

A diagnosis is the conclusion that is reached following the process of identifying a medical condition or disease by the signs, symptoms, and from the results of various procedures (Pugh, 2000). The findings assist with understanding the importance of ensuring accuracy in diagnosis (Taylor, 2000). An important way to do this is by increasing the knowledge of future medical professionals. It is essential for them to be able to communicate openly with one another on the types of cases they are treating or researching (Diller, 2002). To research the causes or best treatments for a disorder, the classification of the condition must firstly be categorised adequately (Davison, Neale, & Kring, 2004).

Following the reading of numerous journal articles, I found that in many cases a general medical definition recognises diagnosis as ‘identifying a disease by its signs or symptoms.’ In psychology the term has commonly been used in the same general sense as it has in medicine, making classification and categorisation the central concerns. Thus, a person displaying a particular form of abnormal behaviour may now be diagnosed as having ADHD, whereas in the past the presenting symptoms may have been associated with a neurological condition such as epilepsy (Ledingham & Warrell, 2000). Baughman and Hovey (2006) indicated that some studies in relation to ADHD have attempted to use neurological examination procedures, MRI or EEG scanning as the single criterion for the diagnosis of children with ADHD, but as ADHD is a neuropsychological condition, establishing its presence is not possible via these means. This is why it is important to firstly perform neurological examinations to assure that these symptoms are not the result of lesions on arterial brain tissue before choosing to diagnose the symptoms as resulting from the neuropsychological condition of ADHD.

CAE in most cases is caused due to lesions in brain tissue being the focal point from

which the irregular neurological activity stems. The use of MRI scanning will show imaging of tissue damage and irregular neural-activity will be visualised when noting the irregular activity in the specific region of the brain while the EEG scanning is in progress. With ADHD there are no neurological assessment processes. MRI or EEG scanning have never been validated as a means for the determination of ADHD (Diller, & Goldstein, 2006). There is no evidence that clearly confirms that there is a physical or chemical abnormality associated with the neuropsychological condition of ADHD. The claim that ADHD can be detected through neurological assessment, leads to many cases of CAE failing to be diagnosed (Neihart, 2002). The research literature on testing for ADHD in children lacks a single unifying concept for ADHD. This is most likely because the condition actually represents a collection of different problems that are grouped under the one label (Axelson, 2008).

Articles researching childhood behaviour establish that due to a lack of general knowledge on this neuropsychological condition, a substantial amount of ADHD diagnoses may be incorrect (Austin, Dunn, Johnson, & Perkins, 2004). It is possible that the behaviours believed to be common in children with ADHD (such as inattention) compare to those with CAE. It is possible that too often, a decision to label the child's symptoms as ADHD is based on the parent's or teacher's observation of the child's behaviour in comparison with that of a child demonstrating 'normal' or typical behaviour, (Austin et al., 2004). This increases the numbers of ADHD diagnoses as earlier shown (Fife-Yeomans, 2007). A question that must be asked is: What is average or typical behaviour for a normal child? It may be useful for researchers to draw on this question while conducting future studies similar to my own.

### *Reactions to the diagnosis of ADHD*

When a child with CAE experiences a Child Absence Seizure (CAS), he or she is likely to experience confusion when his/her behaviour is questioned after an episode. This may be accompanied by anger and fear, due to the way he/she is being treated by those within the school, and social community. It has been discovered that the parents of children diagnosed with ADHD experience greater stress than the parents

of children without ADHD, because of the additional parenting challenges they face (Rabiner, 2002). This may in turn result in further difficulties being experienced by a misdiagnosed child. Parental experiences of having a child diagnosed with ADHD can lead to firstly, mood and anxiety disorders, and secondly, a lower sense of parenting competence (Rabiner, 2002). Parents can be intimidated by the diagnosis and ignore what are thought to be symptoms of ADHD (Barkley, 2001), which as a result sees the diagnosis of CAE failing to be obvious. For some parents, if their child is experiencing difficulties in the classroom, including negative assumptions on the part of the classroom teacher, the diagnosis of ADHD is welcomed. Unnever and Cornell (2003) report that some psychologists consider the diagnosis of ADHD as having positive consequences for some children, even if the symptoms are questionable, as it allows for the acceptance of irregular activity by teachers. However, the taking of medication for ADHD can place children at increased risk of bullying and victimisation (Kochenderfer-Ladd & Wardrop, 2001).

Unnever and Cornell (2003) state that low self-control in an action correlates the ADHD status with bullying. This construction has been theorised to be the most important determinant of criminality. In contrast, Gottfredson and Hirschi (1990) believed that the correlation between ADHD status and bullying victimization are independent of self-control. Subsequently analyses found that self-control influenced bullying victimization through interactions with student gender and physical size and strength measures (Peace, 2001).

## *Part 2 Critical analysis of Child Absence Epilepsy (CAE)*

Child absence epilepsy (CAE) is a generalised epilepsy syndrome characterised by the onset of absence seizures in childhood, typically at the age of six or seven years (Svoboda, 2004). Research by Arzimanoglou, Guerrini and Aicardi (2003) shows that less than 1 in 1,000 children under 15 are diagnosed absence seizures. Michelucchi and Tassinari (2004) indicated girls are more likely to experience CAE than boys. This thesis is focused on children with CAE who are misdiagnosed with

ADHD. These seizures are symptoms and/or transient signs as a result of abnormal, excessive or synchronous neuronal activity in the brain (Cross, 2007).

### *Symptoms of Child Absence Epilepsy (CAE)*

For a child with CAE, a great amount of confusion often occurs following the seizure due to the lack of consciousness during the ictal period (when the seizure is being experienced). This can increase when the child is accused of acting in an impulsive and disrespectful manner (Austin, Carr, & Hermann, 2006; Austin, Harezlak, Dunn, Huster, Rose, & Ambrosius, 2001). The list of signs and symptoms mentioned in various sources for Absence Seizures (AS) includes the 12 symptoms noted in Appendix C. Note that the ‘symptoms of AS’ usually refer to various symptoms known to a patient, but the phrase ‘Absence seizure signs’ may refer to those signs only noticeable by a doctor (Corbett & Constantine, 2006; Ledingham & Warrell, 2000). As the typical duration of a non-convulsive seizure, such as an AS often varies from between 1 to 10 seconds in length, with an average of six seconds, the child can be in the middle of performing an action, such as talking or listening to another person speak, and lose full neurological awareness for this period (Austin, McNelis, Shore, Dunn, & Musick, 2002; Dunn & Austin, 2002).

The Concise Oxford Textbook of Medicine (2000) indicates that a common illness that most CAE children experience prior to this stage is febrile convulsions. The Influenza B virus is the usual cause for children experiencing febrile illness. Children will experience a combination of a sudden fever, chills, headache, myalgia, dry cough, sore throat and rhinitis or nasal stuffiness. In children, this often incurs regular abdominal pain and vomiting. The condition usually lasts two-three days, rarely up to one week. In around 1% of these cases, these children will develop epilepsy (Shinnar & Glauser, 2002). For those who go on to experience CAE, the physical effects of their CAS may be difficult for an observer unless one is educated about these symptoms.

### *Physical Effects of Child Absence Seizure (CAS)*

The posture of the body remains practically vertical while an absence seizure is in progress. In addition the head of the child remains in an upright position. However, rapid eye movement, blinking several times and the rolling back of the eyeballs into the orbit often occurs (Schachter, Holmes, & Kasteleijn-Nolst Trebite, 2008). Questions are unable to be asked of the child during the CAS, as they will not respond. Most commonly, these are the only external appearances of a seizure of this nature (Svoboda, 2004). The CAS has a tendency to become more frequent if they are not treated. Obtaining treatment is very important for the individual experiencing them. It is also very important that the treatment the child obtains is correct.

Epilepsy Action, U.K. (2006) indicates that CAS may be confused with 'daydreaming.' In nearly 70% of cases absence seizures stop by 18-years of age. Absence seizures often result in spells of decreased alertness and abnormal behaviours seen for brief intervals in some children several times daily (Austin et al., 2001). For the observer, these changes may be subtle and therefore difficult to detect. Not being conscious during the ictal period can result in a continuous loss of segments of information when learning. Alternatively, the child may misinterpret what is being taught, resulting in a lack of comprehension and disinterest occurring (Thomas, 2000).

Children with CAE may have experienced a history of staring spells, but infrequent CAS may not be diagnosed until Juvenile Myoclonic Seizures (JMS), Simple Partial Seizures (SPS) and/or Complex Partial Seizures (CPS) commence. A decline in school performance may be an indication of the onset of a SPS. Symptoms, such as behavioural problems, may be the presenting complaint. Although the brief seizures remain unrecognised, the loss of awareness interferes with the comprehension of what has occurred, resulting in frustration on the part of the child. As a result of an incorrect clinical examination, a child with typical absence seizures may be diagnosed as merely having brief spells of staring, and no further action is taken to address these symptoms (Leach et al., 2005).

Typical absence seizures may be the sole seizure type experienced by a child. If this is the case and the child is thought to be developing normally with no structural lesions present, the child is said to have CAE (Loiseau & Orgogozo, 1978). Alternatively, atypical absence seizures may occur as part of other epileptic syndromes, such as Juvenile Myoclonic Epilepsy (JME) or Temporal Lobe Epilepsy (TLE), in which other seizure types are also present at a later stage, including CPS. This differentiation into typical and atypical seizures is important, as the natural history and response to treatment varies in the two groups (Schwartzkroin, 1993; Loiseau & Orgogozo, 1978). Typical absence seizures have a strong genetic predisposition and girls are affected more often than boys (Cowan, Bodensteiner, Leviton, & Doherty, 1989). These seizures should not be confused with atypical absence seizures. Although both forms are detectable through neurological examination, the atypical absence seizure does differ markedly in EEG findings and ictal behaviour, and usually present with other seizure types in a child with a background of learning disability and severe epilepsy (Austin et al., 2002).

### *Part 3 Similarities and contrasts of CAE and ADHD*

#### *Recognising the difference in diagnoses*

The differential diagnosis between CAE, especially absence seizures, and ADHD (predominantly inattentive type), has been complicated by the overlapping symptoms associated with both conditions (Halasz, Personal communication, May 9, 2007). Of the primary overlapping behaviours, staring is strongly associated with CAS and is a hallmark of ADHD (Carmant, Kramer, Holmes, Mikati, Riviello, & Helmers, 1996). In one video telemetry study, Nagarajan and Bye (1992) claimed that staring was the most common non-epileptic phenomenon and occurred in more than 50% of the children with ADHD. Another common symptom, that of inattention, is claimed by Nagarajan and Bye (1992) as being seen in children with CAE who are often described as having problems with attention and concentration: also classic symptoms of ADHD. Further questions concerning staring episodes, such as whether there is preserved responsiveness to touch or a lack of interruption of activity have

been suggested by Rosenthal et al., (1998) as helpful in distinguishing non-epileptic events. These statements demonstrate why many interpret epilepsy as being an associated factor of ADHD (Ettinger & Kanner, 2007; Arzimanoglou, Aldenkamp, Cross, Lassonde, Moshe`, & Schmitz, 2005). It is this association that causes the symptoms of a CAS to be incorrectly recognised as a behavioural disorder, leading to the failure to correctly treat the condition for what it is; a neurological disorder.

For many of the children with CAE, whose condition continues to be active with the misdiagnosis of ADHD, it is often only once the condition has developed to the point that Juvenile Myoclonic Seizures (JMS), Simple Partial Seizures (SPS), or Complex Partial Seizures (CPS) are being experienced that the correct diagnosis of epilepsy is finally provided. According to Restak (1995, p.45), “since symptoms may occur in the absence of generalized grand mal seizures, physicians may often fail to recognize the epileptic origin of the disorder. Indeed, misdiagnosis and failures of diagnosis are common.” The knowledge of being misdiagnosed with ADHD and also having epilepsy that then develops to a point that JMS, SPS, or CPS is experienced often psychosocially affects many adolescents/young adults. “For this reason a physician should only undertake to make a diagnosis of this kind if he or she has sufficient training and experience in the overall management of epilepsy” (Restak, 1995, p.45).

A quantitative study by Williams, Sharp, DelosReyes, Bates, Phillips, Lange et al. (2002) research on symptom differences between CAS and inattention focused on the differentiation between the diagnoses of epilepsy and ADHD. The purpose of the study was to determine symptoms that would distinguish between the two disorders. Prior to a child being seen and diagnosed by a paediatric neurologist or developmental paediatrician, the parent was given the Attention Deficit Disorders Evaluation Scale (ADDES). Seventeen parents of children with CAE or ADHD (predominantly inattentive type) were administered the Attention Deficit Disorder Evaluation Scale-Home Version (ADDES-HV). A statistical model was then developed based on age, gender, race, and items from the Inattentive Scale of the ADDES-HV. The findings of Williams Jr., Hitchcock, Cordes and Pignone (2002) research, which questions clinical depression in children indicates that the Inattentive



Scale of the ADDES-HV assisted in distinguishing between the diagnoses. In contrast to hyperactive and impulsive behaviours, which were equivalent in the two groups in their research, inattentive behaviours were significantly more frequent in children thought to have ADHD (predominantly inattentive type) (Williams Jr. et al., 2002). Findings indicated that the ADHD (predominantly inattentive type) was frequently confounded by similarities in symptom presentation (see table 3.1). As a result, the study also established that absence staring occurred slightly more frequently in children with CAE. Further questions concerning staring episodes, such as whether there is preserved responsiveness to touch or a lack of interruption of activity, were suggested as helpful in distinguishing non-epileptic events (Paolicchi, 2002). While inattention is a symptom associated with CAS and ADHD (predominantly inattentive type), (see table 3.1) the indication by Williams et al., (2002) was that the intensity level of these behaviours was significantly greater in children with ADHD.

Following the completion and submission of the ADDES-HV, findings indicated that the two behaviours were effectively differentiated between the two diagnostic categories. Children with CAE were rated by their parents as having a low occurrence of not completing their homework and not remaining on task, while children with ADHD (predominantly inattentive type), were rated as having a high frequency of these behaviours. Williams et al., (2002) felt that although these variables suggested a lack of sustained attention in children with ADHD (predominantly inattentive type), compared to children with CAE, the findings needed to be validated based on further neurological research data. The observations of the authors in their study located two items, 'does not complete homework' and 'does not remain on task', that are felt to have correctly classified 40 of 43 children. It was found that children with ADHD understand what's expected of them but have trouble following through with the completion of tasks because they can't sit still, pay attention, or attend to details. For a child with CAE, the cause is the result of a short loss of consciousness as a result of an absence seizure. As this child is not aware that the loss of consciousness has occurred, he or she will continue to perform actions, such as homework studies from the same point that they were at prior to

experiencing the seizure. These results indicated that the use of a parent-completed questionnaire, which measures the intensity of inattentive symptoms, along with exploration of the child's sustained attention, may be helpful in the diagnostic process. The belief is that by asking questions during the clinical history concerning the child's task persistence and off-task behaviour could be a strong aid in establishing a correct diagnosis, especially when clinical evidence is not confirmatory or inconclusive. Yet without successful neurological examinations, such as EEG, MRI and PET scanning, the diagnosis of CAE cannot be confirmed.

### *Difficulties with diagnosis*

Little research has been undertaken about CAE and the symptoms of this condition, and very little educational material is available about it in most professional and social communities. Recognising these symptoms and understanding the condition can therefore be difficult for many people (Velazquez, Zhen, Garcia, Yevgen, & Snead III, 2007).

These children experience absence seizures that last from a period of one second (up to 300 a day) to 10 seconds (Epilepsy Action, U.K., 2008). Symptoms, such as loss of consciousness for one to two seconds, can be difficult to identify unless you are looking at the child experiencing a CAS at that moment. As a result, the high frequency of seizures causes great confusion and an inability to conceptually comprehend what another is saying, causing for example, a young child to misunderstand a story that is being read to him/her. For a child who is experiencing longer periods of unobserved absence, comprehension in relation to classroom learning will be strongly affected. For example, if one imagines a class of fifth grade children watching a video recording of the programme *Behind The News*, where the presenter says: *Barack Obama, the President of the United States of America, Kevin Rudd the Prime Minister of Australia and Gordon Brown the Prime Minister of England have made the decision to withdraw troops*. For a child who is experiencing absence seizures of around 10 seconds in duration, if he or she was to have a CAS of this length during the period of time this is being said, what may occur is that the child will hear: *Barack Obama*, and then start to experience the seizure. Following

the regaining of consciousness the child then hears; *the Prime Minister of England have made the decision to withdraw troops*. This may cause confusion to occur.

If this child is later asked by the teacher: “Tell the rest of the class what you heard the presenter on this television show say,” the reply will be: “*Barack Obama, the Prime Minister of England has made the decision to withdraw troops*,” as this is what he/she has heard. What may result from this is torment by fellow students. If this occurs frequently the reaction may be to question the child’s attention or concentration span. It is due to a lack of education about CAE that this can often lead to the belief that these are the symptoms that a child with ADHD experiences. As a result the child is mislabelled and may in fact be misdiagnosed with the neuropsychological condition.

### *The differences between CAE and ADHD symptoms*

The overlaps between medical factors and symptoms linked with disorders associated with ADHD (such as not giving close attention to details, making careless mistakes in schoolwork, etc.) mimic those of CAE, hinder the ability to accurately diagnose the condition (Locke, 2009). I spent a year carefully investigating both conditions through literature I found in libraries at the University of Sydney and from other academic institutions. I gained a strong understanding of how the lack of appropriate neurological testing is influencing the misdiagnosis of CAE as being ADHD. Following the combination of data on ADHD from the American Psychology Association and on CAE from Epilepsy Australia, I found that of the 16 symptoms that are associated with CAE, 11 of these overlap with those of ADHD (7 of 9 symptoms of Inattention and 4 of 9 symptoms of Hyperactivity and Impulsivity (see Table 3.1).

Table 3.1 Symptoms associated with Child Absence Epilepsy and ADHD.

Symptoms	Absence Seizures	ADHD
Medical Type	Neurological	Neuropsychological
Possible tests to determine focal point of condition?	8	0
Average age of onset of condition	5	5
Average age of termination of condition	15	18
Known cause of symptoms	Yes	No
Comparison of Absence Seizures to Inattention Hyperactive - Impulsive Symptoms	16	24
<b>Symptoms of Inattention</b>	<b>7</b>	<b>9</b>
Does not give close attention to details or makes careless mistakes in schoolwork, work, or other activities.	Yes	Yes
Can have trouble keeping attention on tasks or play activities.	Yes	Yes
Often does not listen when spoken to directly.	Yes	Yes
Often fails to follow instructions to finish schoolwork, chores, or duties (not due to oppositional behaviour or failure to understand instructions).	No	Yes
Often have trouble organizing activities.	Yes	Yes
Often avoids, dislikes long term activities that require high level of mental effort (schoolwork or homework).	No	Yes
Often loses objects needed for tasks and activities (e.g. toys, school assignments, pencils, books, or tools).	Yes	Yes
Is often easily distracted.	Yes	Yes
Is often forgetful in daily activities.	Yes	Yes

*An exploration of the psychosocial effects that school-age children with CAE experience when their condition is misdiagnosed as ADHD*

Symptoms	Absence Seizures	ADHD
<b>Symptoms of hyperactivity and Impulsivity</b>	4	9
Often fidgets with hands or feet or squirms in seat.	Yes	Yes
Often stands up when remaining in seat is expected.	Yes	Yes
Often runs about or climbs when and where it is not appropriate (adolescents or adults may feel very restless).	No	Yes
Has trouble playing or enjoying leisure activities quietly.	Yes	Yes
Often “on the go” or often acts as if “driven by a motor”.	No	Yes
Often talks excessively.	No	Yes
Often answers a questions before completed	Yes	Yes
Often has trouble waiting one’s turn.	No	Yes
Often interrupts or intrudes on others (e.g., butts into conversations or games)	No	Yes
Lip smacking and chewing.	Yes	No
<b>Executive Functioning Symptoms</b>	<b>4</b>	<b>6</b>
Poor sense of time and timing.	Yes	Yes
Carelessness.	Yes	Yes
Inconsistency.	Yes	Yes
Difficulty waiting for an outcome.	No	Yes
Low boiling point for frustration.	No	Yes
Poor judgment.	Yes	Yes

The common symptoms and reactions associated with both ADHD and CAE in school age children include: concentration problems, confusion and conflict, fidgeting and inattention, destructiveness, mood swings, outbursts of anger, anxiety, fear, depression, loss of self-esteem, loneliness, ignorance, and frustration.

While ADHD is over-diagnosed, the concern is that CAE is an under-diagnosed result of this (Haber, 2003). A child with CAE can be misdiagnosed with ADHD because both CAS and ADHD share characteristic symptoms such as inattention, emotional and behavioural problems, hyperactivity and impulsivity. Table 3.1 demonstrates that 11 of the 16 registered symptoms of CAS can be recognised as similar to those of the 18 primary symptoms of ADHD. When assessing the difference between CAE and ADHD, it is not as simple as observing the symptoms. One must investigate what is causing the symptoms to occur.

These symptom differences can be very subtle or patently apparent so both conditions must be correctly diagnosed and treated. Effective treatment depends on appropriate diagnosis of CAE in the school-age child. Stimulant medications used to treat ADHD in a child with CAE will not have any effect in controlling irregular neurological activity. This may make negative social reaction worse, and result in an escalation of psychosocial effects. The following data demonstrates the similarity in symptoms that those with CAS or ADHD can experience. Concentration problems are common in both the child with CAE and the ADHD child, but again, examination of the finer differences is needed. The ADHD child typically is aware of his trouble holding concentration (Stroink, Brouwer, Arts, Geerts, Boudewyn Peters, & van Donselaar, 1998).

Oppositional behaviour and disobedience towards authority figures may become habits that the CAE child develops as the result of the confusion experienced when accused of acting in a manner of which he/she is unaware. This can be inaccurately attributed to the reactions of a hyperactive child by parents and teachers. The misdiagnosis of ADHD can often follow this (Dunn, Austin, Harezlak, & Ambrosius, 2003).

Just as in a child with ADHD, CAE children may experience symptoms such as fidgeting and inattention (Lum, Connolly, Farrell, & Wong, 2005), but the cause that generates these activities differs. In the child with CAE the symptom of fidgeting is the result of irregular neurological activity reaching the brain stem while the seizure is in progress. As the brain stem leads to the central nervous system, these short

portions of irregular neurological activity results in muscular spasms; observed as fidgeting (Dunn et al., 2003). When analysing ‘the myth of ADHD’ one cause of the increase in ADHD diagnoses may be the misinterpretation of the symptoms of CAS (Haber & Baughman Jr., 2002). Children with CAE, who are accused of acting in an inattentive and disruptive manner, such as fidgeting, have an elevated risk of attaining the diagnosis of ADHD (Famularo et al., 1992). Destructiveness may be seen in both CAE and ADHD children but again this differs in origin. A child with ADHD will often break things through oblivious carelessness or frustration, whereas in a child with CAE the destructiveness is more often due to the clumsiness that occurs with the onset of the CAS (Stroink et al., 1998).

Table 3.1 illustrates that mood swings are common in both ADHD and CAE children. In the child with CAE these are generally a result of sudden awareness of changes in the reactions of figures of authority following the seizure (O’Leary, Lovell, Sackellares, Berent, Giordani, Seidenberg et al., 1983). An ADHD child is generally aware of his actions and the reasoning for the authority’s reaction, demonstrating that he is consciously aware of his choice to act in this manner (Glod & Teicher, 1996). For the child with CAE, these responses may lead to the experiencing of early trauma. Repeated event or events may completely overwhelm the individual’s ability to cope with or integrate the ideas and emotions involved with that experience (Reber & Reber, 2001). This may be reflected in those children who have been misdiagnosed.

Outbursts of anger are typically a reaction to conflict with authority figures, such as parents and teachers. These are not present while the child is being inattentive (staring unconsciously) for the duration of the absence seizure (Torta & Keller, 1999). The duration and intensity of symptoms and outbursts of anger differ greatly between the condition of ADHD and CAE. The school-age child with ADHD will usually take 20 to 30 minutes to calm down (Haber, 2003). The child with CAE will most often stop within a minute of the completion of the CAS, once full awareness is recovered (Epilepsy Action, U.K., 2006). The CAE child will demonstrate outbursts due to the shock of confrontation, while the anger of the ADHD child will more

likely develop into a temper tantrum that disperses a high level of physical energy (Haber, 2003). The Child with ADHD will actively seek conflict with authority whereas the misbehaviour of a child with CAE is often an accidental reaction as a result of the CAS (Tassinari, Rubboli, & Michelucci, 2006). The incidence of anxiety in children with CAE is harder to estimate than in children with ADHD as there have been fewer studies. Vazquez and Devinsky (2003) observed that between 15-25% of children with epilepsy are recognised as experiencing problems with anxiety. However, compared to the children with other forms of epilepsy, children with CAE would usually experience a lower level of anxiety. Social reaction towards the misdiagnosed condition may strongly influence the level of anxiety experienced by these children (Alwash, Hussein, & Matloub, 2000).

Anxiety is a symptom that can occur in both the pre-ictal (prior to) and post-ictal (following) periods of a seizure. In those whose epilepsy develops into a form that involves Simple Partial Seizures (SPS), the ictal fear is associated with complex partial seizures (CPS) of temporal lobe origin. Distinguishing the panic attack of a child with ADHD, which some believe mimic a CPS, is important for authority figures (e.g., teachers and social workers) once this stage has developed (Vazquez & Devinsky, 2003). Depression is a common difficulty experienced by children with CAE or ADHD (see Table 3.1), but is often an overlooked problem in a child with CAE (Kanner & Palac, 2000). As depression is a psychological symptom that can be present as a result of both conditions, diagnosing the cause of it in these patients can be especially challenging (Plioplys, 2003). According to Williams Jr. et al., (2002) if the symptoms of depression are due to a neurological illness such as epilepsy, but are attributed to ADHD (a neuropsychological condition), then patients may receive unnecessary medication. Loneliness often develops in children with CAE as a result of anxiety and depression (Ames, Ames, & Garrison, 1997).

Past studies have shown that loneliness is associated with shyness, poor social skills, and loss of self-esteem. Berguno, Leroux, McAinsh, and Shaikh (2004) indicated that teacher interventions were on the whole not effective in bringing an end to student experiencing victimization. Their findings indicated that both bullying and particular



kinds of teacher interventions contributed to a child's extended sense of loneliness at school. Many children experience isolation and loneliness as a result of ignorance about a medical condition (Woolfolk, Winne, & Perry, 2005). The way that society often judges an individual is influenced by a variety of characteristics of the person themselves, those of their community and the circumstance in which the interaction occurs (Aldenkamp, Renier, Dreifuss, & Suuremeijer, 1995).

For a child with CAE, ignorance about their medical condition may be an important additional characteristic that determines how they are treated in the home and community environments. This may be the 'starting point' that characterises the child as different (Gorter, 1981). Ignorance may often lead to misjudgement of both the personality and actions of the child with CAE. Social ignorance may see the child with CAE being misjudged as one who exhibits ADHD symptoms and this becoming the central characteristic by which the child's actions are evaluated (Aldenkamp, Renier, Dreifuss, & Suuremeijer, 1995). This often will see the usual behaviours and characteristics of the child with CAE being defined as deviant, leading to a negative treatment of the child by his peers (Safilios-Rathschild, 1970). This may lead to the child with CAE to feel isolated or even isolate himself from normal interaction to avoid negative treatment.

Ettinger, Weisbrot, Nolan, Gadow, Vitale, Andriola et al., (1998) found that inadequacy in the recognition and diagnosis of depression in children with epilepsy is common. In part, this may be the result of differences in symptoms of depression in children with ADHD versus those with CAE, and those which are also seen in adults with epilepsy. Children with CAE more often present symptoms of withdrawal, somatic complaints, irritability, and trouble sleeping. Difficulties with concentration may lead to problems when sitting examinations. Phioplys' (2003) findings indicate that adolescents may have similar complaints but also develop feelings of hopelessness, guilt, and suicidal ideation.

The school-age child with CAE and the ADHD child often differ greatly after arising from bed in the morning (Schachter, 2007). For a child with CAE, absence seizures are common and most often occur upon awakening in those children who later

develop JME (Cavazos, 2001). A child with CAE tends to be unsteady and drowsy in the morning, being affected by strong light. Children with ADHD more often wake up promptly and maintain alertness within minutes of this action (McAbee & Wark, 2000). The symptoms of CAE may or may not be the same as those of ADHD (see Table 3.1). ADHD as seen by the child psychiatrist is most commonly the combination of attention problems and hyperactivity, which includes inattention plus hyperactivity and impulsivity (Dunn & Austin, 2004). In contrast, children with CAE are more likely to present the inattentive symptoms of ADHD (Dunn et al., 2003). CAS may have a wider impact on multiple attentional networks within the central nervous system. Recent neuropsychological assessments in children with epilepsy show below-average verbal and visual attention skills, slowing of psychomotor speed, and impairment in sequential cognitive processing (Haverkamp, Hanisch, Mayer, & Noeker, 2001; Williams, Griebel, & Dykman, 1998).

#### *Part 4 Similarities and contrasts of CAE and ADHD*

##### *Labelling*

Originating in sociology and criminology, labelling theory focuses on the linguistic tendency of majorities to negatively label minorities or those seen as deviant from what is thought to be normal. Labelling is frequently associated with the concept of a self-fulfilling prophecy and with stereotyping (Reber & Reber, 2001; Katz, 2001). Therefore, sociologically, the social manifestation of a label is not restricted to institutional contexts (Jary & Jary, 2000). Behavioural issues in children with CAE suggest that children experiencing absence seizures are at risk of ADHD labelling. The behaviour patterns that the child experiences are more often associated with inattention rather than hyperactivity or impulsivity.

##### *Problems of stigma as a result of labelling*

The concept of stigma first gained popularity in social science research through the work of Goffman in 1963. Stigma is a word with a multitude of connotations and definitions. Stigma originally referred to the presence of bodily signs that exposed

something unusual or bad about the moral status of individuals (Priora, Wood, Lewis, & Pill, 2003). The mere existence of a diagnostic label, even in the absence of any covert sign of a mental illness, is often sufficient to draw out stigma (Link, Mirotznik, & Cullen, 1991; Link, Struening, Cullen, Shrout, & Dohrenwend, 1989; Link, Cullen, Frank, & Wozniak, 1987). We all hold certain assumptions about what the person we are observing or in contact with should be like. When a person fails to live up to expectations of 'what is normal' as Goffman (1963) indicates he or she "is thus reduced in our minds from a whole and usual person to a tainted, discounted one" (p.3). Scott (1969) indicates that this 'deviant labelling', that general society places on those with a disability does in fact lead to 'secondary deviance'. By this, Scott (1969) is suggesting that the powerless labelled school-age child with CAE may adopt the meaning of this deviancy and begin to exhibit symptoms and behaviours that will reconfirm the misdiagnosis of ADHD in the minds of others within the child's society. Self-awareness becomes fixed on the condition being ADHD and the deviant labelling rapidly increases (Goffman, 1963).

Before discussing this topic further, more needs to be understood about the influence Goffman's 1963 book, *Stigma* still plays on the understating of social stigma. Indeed, Goffman's analysis of social stigma continues to strongly influence medical sociology. Goffman's research was primarily interested in the way stigmatised and 'normal' individuals interact. How this is accomplished in relation to social roles when 'stigmatised' and 'normal' people are in the same "social situation." Being, in each another's immediate physical presence, whether it is a communication encounter or both just simply present at an unrelated gathering (Goffman, 1968, p.23).

Essentially in Goffman's view, stigma commonly results from a transformation of the body; labelling; a blemish of the individual character; or membership of a despised group. Building upon this definition by Goffman, Link (2001) defined stigma as existing when a person is identified by a label, which sets the person apart and links the person to undesirable stereotypes that result in unwarranted treatment and discrimination. Goffman highlighted how stigma upset social interaction, and

that it is managed by controlling the flow of information about real or imagined discreditable qualities in face-to-face encounters. Many deviant behaviours can be concealed from others if they are enacted while in isolation, but if CAS are not controlled due to misdiagnosis, it is grasped and identified, and the mechanism of labelling and stigmatisation is set into motion (Green & Sobo, 2000; Priest, Vize, Roberts, Roberts, & Tylee, 1996).

There are many published documents which address ADHD and the problems the 'average child' may experience when they are incorrectly diagnosed with the condition (Rafalovich, 2005, 2004; Armstrong, 1997; McCarney & Bauer, 1995). There is little documentation that covers the effects of the misdiagnosis of ADHD on those with epilepsy (Carmant, Holmes, & Lombroso, 1998), thereby allowing for problems in correct diagnosis occur. The changing definitions of ADHD within the series of DSM publications may relate to the increase in diagnosis. Children with CAE may exhibit depressive or aggressive and hyperactive symptoms in the post-ictal period that may also be interpreted as symptoms of ADHD (Glod & Teicher, 1996). As this results in false stigmatisation occurring for those with CAE, many of these children feel that they do not have any choice but to present themselves by means of information control: 'passing' (disguise and secrecy) and 'covering' (admitting to the stigmatised feature or attribute, but working hard to minimise its significance) (Thomas, 2007).

### *Stigma and its psychosocial effects*

In general, psychosocial effects describe the feelings and reactions experienced by children with CAE and adolescents experiencing absence seizures when they are affected by the misdiagnosis of ADHD. During childhood, getting less than appropriate social interaction, contact, and experience with peers, as a result of misdiagnosis often leads to psychosocial effects. These may include a poor sense of identity, frustration and stress. Such children may be particularly vulnerable to psychosocial problems because of the additional stresses they face as a result of labelling (Smith, 2003).

Research suggests that the difficulties that children with epilepsy tend to experience when misdiagnosed with ADHD are generally a result of psychosocial emotions, such as the fearful, powerless and traumatic states in which children with epilepsy often find themselves following a CAS (Epilepsy Action, U.K., 2006). When conducting this research, I felt that understanding the effects would be of great benefit for children with epilepsy and those closest to them. This understanding would also assist pre-service teacher education students who on the completion of their degree would be working with these children in schools. Similarly this knowledge would be extremely beneficial for medical, counselling and psychology students.

The investigation of the effects on these children is the important factor in this research. The history and makeup of influential factors, including diagnosis, misdiagnosis, labelling, and the effects of family and social reaction on the child are researched in relation to ADHD and CAE. Whether the reactions felt by participants vary in every case, or if they are duplicated in similar circumstances (e.g., Phase 1 and Phase 3), is also assessed, to determine the emotional influence of the reaction. The categories in association with both diagnostic points are compared to determine if the misdiagnosis of ADHD has caused additional problems to occur for the child participant, who has later been correctly diagnosed with epilepsy.

The child participant, who is labelled with ADHD, tends to elicit negative, harsh, and conflicting interactions from teachers, which influence negative reactions from peers (Haber, 2003). These children often encounter problems with social interactions and experience peer rejection and social isolation (McNelis, Beverly, Austin, Dunn, & Creasy, 1998). As a result, a noticeably negative flow of reactions and feedback from peers, who often tease, harass, and bully the child participant, may be recalled when questions regarding social reaction are asked of them (Ettinger & Kanner, 2007). Researchers have argued over whether the child with the condition does bring upon these difficulties due to lack of self-control (Mattison, Gadow, Sprafkin, & Nolan, 2002; Matthews, Barabas, & Ferrari, 1983).

*Introducing the knowledge or lack thereof of specialist and communities*

Holmes (personal communication, September 2, 2007) indicated that the education level of general communities about the condition of CAE is very limited. This is an issue that requires further research, as it affects not only those with the condition, but all of society. Many people show when faced with anyone who exhibits unusual physical or mental behaviours can make inaccurate judgements (Halasz, personal communication, May 7, 2007).

A study by Fernandes et al., (2005) measured children's perception of epilepsy. Twenty-nine children (15 girls and 14 boys; mean age 10 years, range 9–11 years) were interviewed. Only four children said they knew what epilepsy was. Their perceptions of epilepsy included it being: a disease that can kill; a disease of swallowing the tongue; a contagious disease; a serious illness; or a head injury. The research by Fernandes et al., (2005) offers important background knowledge. The present study reviews the knowledge that a child with CAE holds in relation to their condition and the effects of misdiagnosis, as well as the level of knowledge that those within their social environments hold.

Very little time has been dedicated to educating society on the condition of CAE. Understanding how the lack of knowledge about CAE can lead to misdiagnosis and the emotional consequences that a child with this condition can experience within their social environment is an important issue. The lack of acknowledgement of CAE often sees ADHD being employed as the label. When the child is diagnosed with ADHD, too often the neurological condition of CAE, which is the true cause of the symptoms, remains undetected (Haber, Austin, Lane, & Perkins, 2003). The misdiagnosis of ADHD leads to the prescription of incorrect medication such as Ritalin. The taking of incorrect medications can increase the likelihood of seizures (Edelman, 2002). These findings also assist in understanding how the misdiagnosis of ADHD can cause labelling of these children.

If the child with CAE starts to develop symptoms of JME or TLE, education should

be a standard part of the treatment for those at risk of behavioural problems. Parents need to be educated on exactly what may be expected to occur in the course of the child's epilepsy deteriorating to this level. Teaching parents how to manage these symptoms, explaining how to handle the medication, and identifying symptoms they should watch for during the pre-ictal period are all important (Lewis, Yeager, Swica, Pincus, & Lewis, 1997).

Relevant knowledge was gained from Halasz (personal communication, June 20, 2007), on the late 20<sup>th</sup> century changes in the categorisation of ADHD in the field of psychology, and how the perception of this condition has changed from being seen as a disease, to that of a brain generated form of medical illness. The recognition of ADHD as a mental disorder has blurred the understanding of differences between CAE and ADHD. The overlap of symptoms makes accurate diagnosis difficult unless appropriate neurological testing is performed. This misdiagnosis can have serious consequences for affected children.

### *Misdiagnosis*

When a general practitioner considers a patient's symptoms of illness or injury, reviews the evidence, but arrives at the wrong conclusion about the name or source of that illness or injury, a misdiagnosis results (Torrey, 2008). As people are different, and so are their emotions, beliefs, and behaviours, this is one of the problems that occur when a diagnosis of ADHD is based on the child's hyperactive or inattentive behaviours. However, at what point in the range of behaviours is a 'hyperactive' child actually suffering from clinical hyperactivity? Similarly, at what point do some children who are 'shy' or 'dreamy' have clinical inattention syndromes? Ritalin is often used to medicate hyperactive children, but its use is a controversial issue, as many believe that a large number of normal children are being over-diagnosed with ADHD and given unnecessary medication (LeFever, Arcona, & Antonuccio, 2003). The consequences of misdiagnosis can be profound. In the absence of effective treatment, in the case of CAE, patients may experience a greater number and recurrence of CAS.

### *Labelling and stigma as a result of awareness of misdiagnosis*

With some conditions, the misdiagnosis may lead to a number of negative social outcomes, depending upon the context in which the diagnosis is made (Kirk, 2005). Subsequently, the labelling and the stigma that misdiagnosed children experience in relation to ADHD may have continual psychosocial effects even after they have been correctly diagnosed with epilepsy. These include the child continuing to be thought of as one who chooses not to fulfil or complete necessary duties or actions; leading to mistrust on the part of others. Also fear that the child will purposely act in a disruptive manner in public environment, causing embarrassment to be experienced by those who accompany the child.

Too many people respond negatively when told their friends (or family members) have epilepsy, following the correct diagnosis of absence seizures. This may increase the negative stigma surrounding misdiagnosis (Brown, 2007). The reality is that many people do find a neurological illness more difficult to confront than a neuropsychological illness. Bjorklund (1998) wrote an autoethnographic paper, recalling how the psychosocial stigma that resulted from his misdiagnosis with schizophrenia had a devastating effect on him as an individual. He hoped to increase awareness of the serious psychosocial implications experienced by those who do not yet have an accurate diagnosis or diagnoses. Bjorklund (1998) proposed that the health professionals need to not immediately adopt a past diagnosis without at least questioning why past treatment plans have not worked for some individuals. For many CAE children, these are the problems that they face as a result of incurring the misdiagnosis of ADHD.

### *Discrimination*

There are not many human pathological disorders that extract more negative emotional reactions in social environments than epilepsy. Throughout history, in almost all cultures, people afflicted with this neurological disorder encountered severe discrimination, perhaps second only to that incurred by leprosy (Engel, Pedley, Aicardi, Dichter, & Moshé, 2007). Epilepsy remains a hidden disorder, even



among children, with ignorance, prejudice, superstition, stigma and discrimination (Gordon & Sillanpaa, 2008). A child with CAE may experience discrimination at school as a result of seizure activity. This will often influence the level of stigmatism and isolation shown towards the child, causing a lowering of self-esteem (Buelow Long, Rossi, & Gilbert, 2004). There is still room for changing people's attitudes towards children with epilepsy. The means that many people with epilepsy use to prevent discriminative treatment is through denial.

### *Denial*

One of the primitive defence mechanisms involving rejection of negative thoughts, feelings or behaviours is denial. It differs from lying in that the person, at least partially, believes his/her own distortion. It allows for the rejecting of the full reality and responsibility of an inappropriate diagnosis (Whitehead & Gosling, 2003). Children with CAE misdiagnosed with ADHD are over symbolised in most communities as disruptive in action. This may be a combination of factors including the inability to recognise the onset of a CAS, or acknowledge the awareness of their actions, which can place a child in high risk situations of peer judgement. The misdiagnosis of ADHD itself creates hyperactive symptoms in a traumatised child (Schachtar, Holmes, & Kasteleijn-Nolst Trebite, 2008).

### *Development of support groups*

The development of support groups for children with epilepsy and their parents at the time of the correct diagnosis of epilepsy and sequentially (Phase 4 and Phase 5) should be recognised as an important factor in the building of education for families. The Lewis et al., (1997) study on knowledge in relation to epilepsy, observed children in both individual and group educational sessions. Using a large-group educational format, both children with epilepsy and their parents were instructed about the condition, and provided with training in communication, coping techniques and decision making. Follow-up studies found improved knowledge, self perceived social competency, and behaviour.

Austin et al., (2001) developed what they called 'focused training', for small groups

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of usually two or three families. The authors asked the families to complete questionnaires assessing the concerns of both the children with epilepsy and their parents. Matching families by the age of child and the similarity of worries and concerns, they brought together these small groups of families for a conference call. Increased knowledge and decreased need for support and additional information were more likely to be a result of these small-group educational interventions. The authors propose that identifying the worries and concerns associated with the child's epilepsy at an early age would help prevent the behavioural problems observed in adolescents. Based on Austin et al., (2001) findings I believe that further research on this topic, also involving the misdiagnosis of ADHD will be beneficial in understanding the worries and concerns that arise when this action occurs.

### *Conclusion*

This chapter has discussed the nature of ADHD and CAE and presented the relationship between the two. It has provided a framework for understanding the diagnostic symptoms of ADHD and CAS, misdiagnoses and psychosocial effects. In addition, the research on ADHD and psychosocial effects suggested that more social education at a tertiary level is needed in relation to both conditions. The following specific research questions provide the focus for the current study.

1. How is a child with Child Absence Epilepsy (CAE) affected once the negative labels associated with Attention-Deficit/Hyperactivity Disorder (ADHD) are placed upon them?
2. What are the reactions that school-age children with Child Absence Epilepsy (CAE) and their parents report when their condition is misdiagnosed as Attention-Deficit/Hyperactivity Disorder (ADHD)?
3. What educational changes do participants feel are necessary to reduce the frequency of misdiagnosis and its effects?
4. Do the psychosocial effects of misdiagnosis discontinue when an accurate diagnosis of epilepsy is provided?

The following Chapter will focus on these specific research questions, discuss the research constructed and the methodology and methods chosen and outline the research process.

## CHAPTER 4

# METHODOLOGY

This chapter discusses how the research was conducted. It is divided into four sections. The first section provides a detailed account of the specific qualitative research methods employed. The second section documents the rationale for the use of case study and its relevance as a methodology for this research project. The next section discusses the data collection methods: the interview content and protocol, observations and data analysis techniques. The final section details issues associated with the choice of an interpretive paradigm; credibility, dependability, confirmability, and transferability. Ethical considerations are also discussed.

### *Qualitative research*

A qualitative research method allows the researcher to speak directly with participants on a one-on-one basis. By using the qualitative research methods, the researcher gains essential personal data more effectively than by using and analysis of statistical data. In this study I adopted a constructivist interpretive paradigm when observing and analysing data, which helped to gain an understanding of all participants' experiences.

An interpretive or constructivist paradigm assumes that there is no single social reality (Connelly & Clandinin, 1988). Instead, social reality is regarded as ambiguous because each individual understands his/her own social realities as a result of their personal experiences and their ways of reasoning (Miles & Huberman, 1994). This paradigm uses concepts including credibility, transferability, dependability, and confirmability, rather than the usual positivist criteria of internal and external validity, reliability, and objectivity (Denzin & Lincoln, 2000).

Rodwell (1998) analyses the categories of constructivism by paralleling these with those of positivism; credibility to internal validity, dependability to reliability, confirmability to objectivity, and transferability to external validity. This level of

comparison is helpful in that it allows for the making of decisions in regards to the applicability of results and interpretations of other fellow researchers studying similar topics in other contexts (Huberman & Miles, 2002). According to Green, Boissoles, and Boulet (1988), the combinations of these elements are proposed to assist in the assessment in the appropriateness of the methods, findings, and conclusions of a constructivist inquiry.

The methods of the constructivist interpretive paradigm guided my research in its design, and data collection. This was steered by Neuman's (2003) research, which utilised three qualitative techniques: interviews, observations, and document analysis. The analysis is based on the participants' perspectives of the subject under investigation.

Denzin and Lincoln (2000) define qualitative research as an approach that adopts sections of different areas, disciplines, and subject matter to study the various types of experience ranging from perception, through memory, imagination, and emotion to define such terms as randomised design, causal model, policy studies, and public science. It is important that qualitative researchers do not allow well established quantitative disciplines, to discredit the constructivist paradigm based on the assumption that bias occurs when the use of an assessment processes such as one-on-one in-depth interviews, observations, and previous personal experience in the area are used (Miles & Huberman, 1994).

In qualitative research, there are no predefined variables to be measured because access to individual encounters allows a more direct analysis of personal experience to occur (Douglass & Moustakas, 1985). The basic focus of my research was to identify how each participant in this study personally dealt with their perceptions and experiences relating to social reaction when diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD), and the psychosocial effects that they incurred. A case study methodology was also used because it was deemed most appropriate given my research questions. The case study method of investigation focuses on a particular bounded system or case, unit of study itself which is the case, or the research reports and outcomes that describe and analyse the case as a whole

(Merriam, 1998).

A combination of in-depth interviews, observations and audio recordings were the methods used for collecting data in this research investigation. In-depth interviews allowed me to observe and collect data about the individual difficulties that each of the child participants experienced as a result of misdiagnosis. In addition each parent participant provided their perspective on how the misdiagnosis affected their child. Thus, the focus was on the range of experiences of the study participants. These included what they observed as well as more extreme experiencing of bullying.

### *Case Study*

A case study is a research method used in many circumstances, contributing knowledge of a person, group, social community or phenomenon (Yin, 2009). Case study involves a choice of entity to be studied. By focusing on a solitary phenomenon or entity (the case) a case study seeks to discover the interaction of the significant characteristic of the phenomenon (Smith & Hope, 1992). Thus the case study method was appropriate for the investigation of the five phases in which the reactions to, and psychosocial effects of the misdiagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) on children with Child Absence Epilepsy (CAE) were explored.

As Yin (2009) proposed, the purpose for conducting case studies varies depending on:

1. The type of question posed;
2. The extent of control an investigator has over actual behavioural events;
3. The degree of focus on contemporary as opposed to historical events.

Yin (2009) acknowledges three individual categories of case study: exploratory, descriptive, and explanatory. The first, *exploratory case study* is based on the investigation of a number of cases of a condition or phenomena in order to develop propositions and pertinent hypotheses for further inquiry. It is a case study that is

chosen because it is believed that by understanding the condition or phenomena it will be possible to better understand a larger range of cases. The second, *descriptive case study* focuses on tracing a sequence of interpersonal events over time or topics that have rarely been researched to discover key phenomena. The third, *explanatory case study* is conducted to explain an issue, or to provide a refinement of a theory.

The current study has adopted the explanatory case study category, aiming to clarify the phenomenon of the psychosocial effects experienced by the child participants. The sequence of case studies provides evidence in chronological order, as the causal sequence occurs linearly over time. Ten participants, five adolescents with epilepsy and one of their parents were included in the study. Although diverse, these participants are united by their recall of the psychosocial effects experienced as a result of the child's CAE being misdiagnosed as ADHD. While there is further consideration of later psychosocial impacts on this group of children who are now adolescents or young adults, the study was not designed as a historical investigation.

### *Procedures: Research strategies and actions*

Structured interview questions were carefully worded and followed a precise agenda in the interview schedule, ensuring that each participant was asked the same questions and in the same order (see Appendix D and Appendix E). Observation notes were also taken over the period of each interview. This allowed for the possibility of comparisons in both aural and physical reactions to be made later, when analysing the data. Both participant groups (children and parents) were asked to give a descriptive account of the reaction of society towards the diagnosis of ADHD, the later diagnosis of JME or TLE. Social awareness in relation to the knowledge of the correct diagnosis of epilepsy also became prevalent.

In so many cases the social reaction towards any event is filtered by the individual perception. We all live within social groups that are constructed upon the make-up of each person; be that factors such as social class, gender, race, and religion that influences one's perception. This strongly disrupts the opportunity for any individual misdiagnosed with ADHD to give a full personal explanation of how an action has

completely touched them and the effects beyond the general accounts, or stories, on what they did and why (Denzin & Lincoln, 2000).

My research obtained data from a perspective that some researchers may interpret as more than one methodological source. The use of case study, adopting a constructivist interpretive paradigm allowed me to construct the thesis based on the personal experiences of 5 children and one of their parents through the conducting and analysis of in-depth interviews and observations. I also relied on knowledge I have gained through my experience with epilepsy to offer further understanding about the condition.

### *Illness Narratives*

Kleinman, (1988) proposes that illness narrative allows the story of the participant to be told. It also enables significant researchers to retell, giving understanding to the unique events and long-term circumstances of suffering. The path way, core descriptions, and rhetorical devices that structure the illness narratives are drawn from personal models for arranging experiences of participants is meaningful for effectively telling the reason for these experience. The personal narrative does not simply reflect the illness that is experienced, but instead plays a role in understanding the experience of symptoms and suffering (Williams, 1984). One thread when adopting illness narrative is that it may be recognised as merely the participant 'telling one's story' and integrating their symptoms into a new sense of self. (Thomas, 2007). This method was achieved through the process of providing knowledge about my own experiences, being the purpose of this study, and in-depth interviews with the participants in this research.

### *In-depth interviews*

Yin (2009) proposed that in-depth interviews allow the researcher to ask participants key questions about the facts of a matter as well as their opinions about events. This form of interview process also allows the researcher to ask the participant to suggest their insights into certain occurrences. Such propositions can provide the basis for



further inquiry.

In-depth interviews were conducted with participants recruited with the assistance of Epilepsy, Australia. To ensure that a natural flow of discussion occurred throughout the interview, I guided the participants from one topic to the next. My silence after the asking of each question gave each participant plenty of time to discuss their experiences, remaining comfortable while doing so. I maintained an open mind and did not anticipate responses. This enabled me to be open to unexpected information. I felt that it was important not to move too quickly from one topic to the next and allowed a short period of silence to elapse following the completion of each of the participants' answers.

The potential role of labelling these children in their social environments, or subsequent psychological difficulties that may have arisen from misdiagnosis of ADHD, and the emerging issues surrounding the misdiagnosis of ADHD were also investigated. This allowed for 'the bigger picture' of CAE, misdiagnosis of ADHD, and the psychosocial effects that resulted in these children to unfold. The value of incorporating child participants, who have experienced psychosocial difficulties due to the misdiagnosis of ADHD, is that they offer a first-person perspective. An understanding of the confusion experienced by these children through each of the five stages under investigation (see Table 4.1). Parent participants were included in the investigation because they were able to offer further information that a child participant would have difficulty doing, e.g., information about the child's behaviour precursor to the diagnosis of ADHD, or while experiencing a seizure. In the short period prior to the official start of the interview, I shared my experiences with epilepsy when speaking with each participant. This helped me to gain their respect and trust, and build a strong rapport.

### *Observations*

Patton (2002) defined the process of observation as a procedure that permits the researcher to evaluate and understand data to a level that is not entirely possible using the insight of the written findings of other researchers. Its purpose is to gain an

in-depth understanding of how participants may be affected by specific circumstances, providing the researcher with an understanding of physically related actions, such as body movement displayed when answering difficult questions (Atkinson & Hammersley, 1994). It was through observation that the emerging themes became familiar enough to be recognised and appreciated, or rejected as irrelevant for the purposes of my research inquiry.

Observational material focusing on emotional reaction when each participant answered a question was also gathered from each interview, and was compared to those of the other participants. The responses of the children and parents assisted with the understanding of how each participant felt retrospectively and whether an authentic balance between voice and physical reaction was present. The final section of the analysis consisted of the synthesis of the transformed meaning units into a general description of the situated structure of misdiagnosis. A great deal of what researchers in the field do is to pay attention, watching and listening carefully. Using these senses and noticing what was seen and heard in the variety of oral and physical changes, allowed for the maintaining of concentration, absorbing all sources of information.

I noted aspects of physical appearance such as tiredness, dress, and posture when the participants entered the interview room, thereby expressing messages that can affect social interaction. The manner in which the participants sat while being interviewed, the pace at which they spoke, and also their nonverbal communication, such as eye contact, facial expression, and gestures were noted by a combination of general words and my own shorthand symbol method (See an example in Appendix F). Following the completion of the interview, these brief notes were used as prompts to write more detailed accounts relating to the observations into a diary.

For the participants in this research with JME or TLE, whose previous experience with CAE was misdiagnosed as ADHD, the use of an in-depth interview method gave them an opportunity to articulate the everyday issues which incurred psychosocial effects. The opportunity for parents caring for a child with epilepsy to discuss the emotional difficulties they experienced with someone who understands

the condition beyond a basic academic level of investigation is also rarely available. Therefore having the opportunity to tell the stories of how they perceived their child felt at this time, and in some cases may still feel in relation to the psychosocial effects of misdiagnosis, may have been more difficult for the participants had I not personally experienced difficulties with this condition. An interview process that allowed the participants to openly express the difficulties they encountered to one who has experienced the same medical condition, encouraged them to tell their stories through a process, which in some cases may have been therapeutic for them (Gale, 1992).

### *The interpretative approach*

Interpretative research is qualitative in nature and focuses on construing sense from social interaction (Denzin & Lincoln, 2000). This constructivist interpretive approach allowed changes to be identified as they occurred in the perspective of the participant, rather than that of the observer. The focus was on the context of the child participants' and their parents' reactions to their treatment within the home and social environments, and how they interpreted their identity in relation to the psychosocial effects experienced during the five phases of investigation (see Table 4.1). The interviews were all recorded through the use of a MP3 player, and observation notes were taken, with prior agreement of all participants. The MP3 player sat on the table in between both me and the individual participant for the duration of the interview with all participants aware of it recording our verbal communication.

Each interview lasted between 50 and 70 minutes and took at least 20 hours to transcribe. The interviews and transcripts were listened to and read more than once to ensure that all was accurately recorded and the recognition of changes in voice patterns, including pitch and pace of speech was correctly noted. The observation notes taken during each interview, relating to actions such as body movement and voice variance were also compared with those noted following listening to the relevant interview recording. Further recognition of voice pattern changes was gained and noted following the additional listening to of each interview. Following

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the collection of necessary data, the use of a ‘periodic verses reaction’ process was adopted as a means for comparing participant data. This process of coding (see Table 4.1) was adopted so as to recognise those reactions experienced by the child participants within each of the phases under investigation and whether these reactions were replicated in a later/earlier phase.

### *Social resonance*

Social resonance represents the state of being that develops when individuals bond through face-to-face communication and feel strongly connected (Vrij, Edward, Roberts, & Bull, 2000). In choosing the term social resonance, I emphasize the participants in this research as being the focal point of analysis and theory. The social psychological notion of rapport, developed from anthropologist, Malinowski’s (1923) construct, ‘phatic communion,’ as well as recent-era reformulations bear a resemblance to the sense of social resonance used in this research. Constructing an environment that allowed participants to comfortably discuss the psychosocial effects the children in this project experienced as a result of misdiagnosis allowed me to incorporate the facet that many social and psychological methods of resonance phenomena fail to pursue. I closely analysed my observations of the participants speech and gestures, noted how they reacted both emotionally and physically throughout the interview (see excerpts in Appendix F).

### *‘Periodic verses Reaction’ process*

As each child experienced these diagnostic changes and difficulties at different ages, it was more beneficial to compare the changes during each of the five phase periods (see Table 4.1).

Table 4.1 Periodic versus reaction (Process of Phase)

Phase	Phase Description	Definition
1	Precursor to diagnosis of ADHD	The period of time leading up to the diagnosis of ADHD, when difference in irregular behavioural actions was recognised.
2	Diagnosis of ADHD and sequentially	The time when the symptoms experienced by the child were diagnosed as ADHD and sequentially until Phase 3.
3	Precursor to diagnosis of JME or TLE	The period of diagnosis with JME or TLE, when Simple Partial Seizures (SPS) and Myoclonic seizures began to be experienced.
4	Diagnosis of JME or TLE and sequentially	The time when the symptoms experienced by the child were diagnosed as TLE or JME and sequentially until the time of the interview.
5	Now: Interview	Discussion of the psychosocial effects experienced by the child participants as a result of misdiagnosis.

As children are not aware of the irregular activity occurring while a seizure is taking place, they are unable to explain the actions that occur while a seizure is experienced. Interviewing a parent from each family was essential in gathering data about the symptoms that each child was experiencing, especially in Phase 1 and Phase 3, and how both they and other members of the community reacted to the actions of the children's behaviour. Understanding the parent perspective also allows for comparison to be made about how both parties (children and parents) felt the others' reactions to particular circumstances and events later affected the child participants psychosocially. The observations on how the participants physically reacted to the asking and answering of questions were also noted as a means of determining their comfort in discussing the different issues that arose as the interview progressed. The content of the interview questions provided opportunities to explore with each participant issues arising in the literature review including ADHD and its diagnosis.

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Each interview was coded and analysed in relation to the phases.

## *Coding*

Generally, qualitative coding is the process that modifies or transforms raw data into conceptual categories. Instead of it being simply a clerical task, which is associated with a quantitative form of analysis, qualitative coding is an integral part of the data analysis process. The researcher hears or reads a sentence and codes the sequence of physical and acoustic events into a meaningful form (Neuman, 2003).

The coding process was achieved from the replay of auditory recordings and noting of observations taken during the period of the interview. Themes of reaction, which include: fear, denial, ignorance, embarrassment, isolation, withdrawal, anger and overprotection, were observed throughout Phase 4 and also identified when I later listened to the recording of interviews. Once transcribed, the reactions were identified through manual coding (see example in Table 4.2). Table 4.2 is an example that represents the reactions that Charles experienced during *Phase 4*.

Table 4.2 Example of coding.

<p><u>Core material</u></p> <p>Interviewer: “How did this diagnosis of epilepsy affect your everyday life?”</p> <p>Charles: “When I was told, I was like, you know scared. I then got really bored cause no one spoke to me. You know this likes lead to being, feeling lonely. I think that you should only tell people you really trust and who you've known for longer.</p> <p>It's real easy to start like blaming yourself for it, the way people treat you. You just feel weak. I also like think that if your mates are like treating you like this you shouldn't talk to them about it because there isn't anything that's different about you at all and there's no reason to be scared of you”.</p>
<p><u>Selected material for coding</u></p> <p>Charles: “When I was told, I was like, you know [<u>scared</u>]. I then got really [<u>bored</u>] cause [<u>no one</u>] spoke to me. You know this likes lead to being, feeling [<u>lonely</u>]. I think that you should [<u>only tell people you really trust</u>] and who you've known for longer.</p> <p>It's real easy to start like [<u>blaming yourself</u>] for it, the way people treat you. You just feel [<u>weak</u>]”. I also like think that if your mates are like [<u>treating you like this</u>] [<u>you shouldn't talk to them about it</u>] because there isn't anything that's different about you at all and there's no reason to be scared of you”.</p>

In Table 4.2 the manual coding process, data indicating reactions that expressed themes, shows that at this point Charles was experiencing fear, isolation, loneliness, self blame, withdrawal, and lack of self confidence. These were noted and compared with the reactions of other participants, which were then referred back to the findings of previous literature on similar topics; including ADHD to Autism, and ADHD to other forms of epilepsy. A full example of this process involving one of the participant's interviews can be accessed in Appendix H.

### *Credibility*

Credibility testifies to the methods and accuracy in comprehending the depth and range of the matters being researched. Credibility also acknowledges the accuracy of findings and analysis as viewed by participants in their perspective (Patton, 2002). The aim was to prevent confusion on the part of the participants and misinterpretation on my part, as the researcher. It is very important that my analysis and interpretations were realistic and comprehensible to those who read the thesis following its publication (Denzin & Lincoln, 2000).

Triangulation assisted my research in attaining a complete understanding of my findings. Triangulation utilises different approaches of data collection techniques offering more validity in data acquired (Jary & Jary, 2000). Lincoln and Guba (1985) recommended a combination of actions to increase the prospect of credible findings including triangulation. I attained this by comparing similarities and differences within observation documentation, and the transcripts of recorded interviews, and then performing a cross comparison of these findings (Miles & Huberman, 1994).

(Denzin & Lincoln, 2000) indicated that different perspectives, theories, or methods can be compared to ensure that the interpretation of previously published documentation from other sources and the understanding of the collaboration of my own data are comparable and correct.

### *Dependability*

Dependability testifies to the methods that all procedures employed when gathering, analysing and interpreting data within the expectations of constructivist research. Instability in the methodology and developing planned persuaded changes are accounted for and pursued through dependability (Rodwell, 1998). Triangulation was also an important factor when establishing dependability. The files of collected data are other 'raw' information also lies within this realm. This includes all observed and recorded documents, and other sources of information that can be broken down into units of data.

### *Confirmability*

Confirmability asserts the rationality and the logic of the evidence that evolved from collected data. The aim of confirmability is not to claim that the goal of the research was achieved because the results are demonstrated to be findings, but that the results as stated are linked to the data (Guba & Lincoln, 1988). In many cases, if another researcher uses the exact procedures of a previous one to undertake their own study, they will attain the same results and confirm the previous findings (Rodwell, 1998). It would be very unlikely that this would occur in the case of my research. Although another researcher may choose the same number of participants and ask the same list of questions, my own personal knowledge of epilepsy informs my analysis of the data.

Although this is the case, if another researcher was to use my findings as a foundation for their own study, more importantly, their findings could not yield authentic insider's perspectives of understanding the conditions as offered in the context of my investigation unless they too have experienced these conditions themselves. The voices or perspectives of all participants are present in the data and the analysis ensuring that the experiences of every participant play a part in the final discussion. The use of triangulation is a process that also supports confirmability (Rodwell, 1998).



### *Transferability*

Similar to confirmability, the fourth category of the constructivist interpretive paradigm, transferability offers researchers the opportunity to observe the results and procedures of previous ones in one context and make them valuable and significant in another (Rodwell, 1998). The question that must be asked is how the working theories of one constructivist study can be useful in another? As a result of my own circumstances, transferability is one which will be more beneficial to other researchers whose personal experiences are relevant to their research. The constructivist researcher must be careful to not confuse transferability with generalisability (Guba & Lincoln, 1988).

Although the context and previous experience of researchers in every study produce unique findings, and that there is no immutable truth. Researchers such as Geertz (1973) believe that through deconstruction and reconstruction, the unique findings in one research context may be applicable or purposeful in another study. Although this is not generalisability, the thought of how useful a hesitant application of findings might be in other environments can cause this to occur (Guba & Lincoln, 1988). Although the description provided on generalisability have been acknowledged by researchers as being a thick description (Brennan, 2001), the narrative must be abundantly descriptive to impart the explicit setting, difficulty, and findings of the new researcher's study (Rodwell, 1998).

### *Ethical consideration*

The object of ethical consideration is to consider participant concerns so that a sound ethical practice is built in to the study design. The researcher must ensure that dilemmas such as deception and loss of confidentiality are avoided.

Various ethical issues were addressed at all stages of the study. This study was approved by the Human Research Ethics Committee of the University of Sydney (See Appendix H). Consent forms including details of the project, myself, assurances of confidentiality, and the use of apparatus such as an MP3 player to record the

interviews were signed before commencement of the interviews and observations. During this study, all the participants realised that they could withdraw from the study at anytime (Appendix G presents examples of consent forms and other relevant material). For anonymity and confidentiality, each participant's identity was hidden by the use of a pseudonym. After the data was collected, the relevant documents and other material were kept in a locked cabinet and were not exposed, either intentionally or unintentionally.

### *Conclusion*

This chapter has discussed the research methodology and design for this study. It has also provided brief information about the participants who took part in the study and the context in which the study was carried out. The method of data collection and procedures of data analysis have also been discussed. A retrospective recall of experiences was the means by which the data was attained. The responses of the participants are presented in the following Chapter.

The next Chapter presents the participants' experiences. The five phases represent the period of time that the children experienced the particular circumstances and events that affected misdiagnosis: Phase 1, which is the Precursor to diagnosis of ADHD; Phase 2, which is the Diagnosis of ADHD and sequentially; Phase 3, which is the Precursor to diagnosis of JAE or TLE; Phase 4, which is the Diagnosis of JME or TLE and sequentially; and Phase 5, Now: the Interview.

## CHAPTER 5

### FINDINGS

This research paper has been written as a case study, which is prearranged on a progressive five phase structure. As all child participants have experienced the same diagnosis and misdiagnosis scenario through a period of phases, the themes were developed by reactions reported as experienced by the participants throughout five phases. This provides a basis for determining whether each of the participants experienced the similar effects, and whether the earlier reactions, such as when the diagnosis of Attention-Deficit/Hyperactivity Disorder (ADHD) is made in Phase 2, are mirrored when similar circumstances are encountered when epilepsy is diagnosed in Phase 4. Before discussing this topic further, more needs to be understood about the participants.

#### *Research participants*

The task of the ten participants was to communicate their personal/child's experiences with the case study phenomenon: *the psychosocial effects experienced by a school-age child with CAE when the condition is misdiagnosed as ADHD*. Five children participants: Allan, Betty, Charles, David and Elisabeth, and five parent participants: Allan's father, Betty's mother, Charles's father, David's mother, and Elisabeth's mother took part in this investigation.

Allan was 21 years of age when the interview was conducted. Allan is the older of two children and has a younger sister. Allan was studying at a university level and living away from home when the interview was conducted. Allan was three years of age when the initial symptoms of CAE began to be recognised. His parents felt that these symptoms were a sign of a playful child. At nine years of age he was diagnosed with ADHD. Allan was 14 years of age when symptoms of myoclonic seizures became evident and at fifteen was diagnosed with Juvenile Myoclonic Epilepsy (JME). Allan still experiences a myoclonic seizure on a monthly basis, but is able to obscure the symptoms as a result of tripping or clumsiness.

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Betty was 19 when her interview was conducted. Betty has three siblings; one brother and one sister who are older than Betty and a younger brother. Betty was studying at a tertiary level when the interview was conducted. Betty was nine years of age when the initial symptoms of CAE began to be recognised. It was at this age that a diagnosis of ADHD was given. At 12, the initial symptoms of Temporal Lobe Epilepsy (TLE) began to be recognised when experiencing Simple Partial Seizure (SPS), yet these symptoms were diagnosed as being due to a variety of other conditions, including schizophrenia and juvenile dementia. She was diagnosed as being a child with temporal lobe epilepsy at 17 years of age following the experiencing of a Complex Partial Seizure (CPS) while sitting a school examination. Betty still experiences CPS every two to three weeks. This frequency is most likely due to high levels of alcohol consumption when with friends. In my opinion, other symptoms that Betty spoke of occurring at an earlier age also indicated that Juvenile Myoclonic Seizures (JMS) may have been experienced in her early teenage years.

Charles was 17 years of age at the time of the interview. He has one older sister and a younger brother. Charles's parents are divorced and he is living with his father, while the other children are living with their mother. Charles is in his final year of high-school. The initial symptoms of CAE began to be recognised when he was six. At eight years, he was diagnosed with ADHD. Charles was 11 years when symptoms of SPS became evident. At the age of 12, he was diagnosed with TLE. Charles has recently started experiencing CPS, which is causing emotions of fear leading to a high level of overprotection on the part of his father, who made the point that he now wishes that it was ADHD that his child is suffering from.

David was 20 years of age when the interview was conducted. He is presently unemployed. He felt that his experiencing of AS and SPS often sees him being fired from part time and casual employment. David's mother was working as a secretary in an accounting firm when her interview was conducted. David comes from a family of five children of which he is the youngest; two older brothers and two older sisters. David was five years of age when the initial symptoms of child absence epilepsy (CAE) began to be recognised. At seven years of age he was diagnosed with ADHD.

David was 12 years when symptoms of TLE began to be recognised. His experience of SPS became evident, and he was diagnosed with TLE in that year. Every three months David presently experiences CPS.

Elisabeth was 19 years of age when the interview was conducted. She is presently unemployed. Elisabeth is an only child. She was five years when the initial symptoms of CAE began to be recognised. At seven years she was diagnosed with ADHD. As a result of the high frequency of CAS she was experiencing on a daily basis, difficulties developed between her parents and teachers through her primary school years. Elisabeth was sent to boarding school when she was 13 years to help this tension. As further difficulties were not reported, it was not until she returned home at 16 years, for her final two years of schooling, when the initial symptoms of simple partial seizures were recognised by her parents. Although SPS had been experienced for over one year, it was not until this point that the condition was diagnosed as TLE. She continues to experience complex partial seizures on a fortnightly basis.

Allan's father was working as a lecture at a tertiary institution when his interview was conducted. Betty's mother was working as a primary school teacher in a public school when her interview was conducted. Charles's father was working as a salesman for a real-estate firm when his interview was conducted. Elisabeth's mother was working as a full-time employee in a small gift store when her interview was conducted. Further details on the reactions of all participants are found in Chapter five.

### *Data Analysis of Phases*

The data obtained from the participants' oral responses to the in-depth interview questions, observational notes recorded during the interview, and an interpretive approach were regarded as a triangular source of knowledge. The analysis of data sought firstly, to understand how the child with Child Absence Epilepsy (CAE) depicted the psychosocial effects of misdiagnosis, and secondly, how their parent depicted the psychosocial effects of misdiagnosis on the child with CAE. Variations

emerging from similarities and differences in the reactions revealed by each pair of participants were registered throughout the process of data analysis. Questions regarding social response in relation to this sequence of events were asked of the participants to gain a third perspective of how the participants felt the knowledge and attitude of society could also add to the psychosocial effects of misdiagnosis.

In the task of analysis, I have approached the data in two ways. The qualitative methods used in this study encouraged and allowed the participants to personally reflect on how their lived experiences occur due to misdiagnosis. This Chapter documents findings from the research and the research procedures. Through the in-depth interview format, the open structured form of the investigation gave a child participant with CAE and a parent from the five family groups the opportunity to tell each child's individual story. The participants began to encounter the power of narrative and the healing nature that was the result of the discussing of their experiences for the first time. This continued to develop past the conducting of the interview as some participants later emailed me to talk of further experiences and express the gratitude for taking part in this study. Direct quotations are indicated by indenting the text.

The date and time that each interview was conducted with participants are listed in Table 5.1. Each participant was interviewed separately to ensure that they were not intimidated by the presence of other participants or family members.

Table 5.1 Dates and time that participant were interviews

<b>Interview</b>	<b>Participant</b>	<b>Date</b>	<b>Time</b>
1	Allan	March 01, 2008	11:00 AM
2	Allan's Father	March 03, 2008	01:00 PM
3	Betty	March 17, 2008	03:00 PM
4	Betty's Mother	March 28, 2008	03:45 PM
5	Charles	April 19, 2008	10:00 AM
6	Charles's Father	April 19, 2008	02:00 PM
7	David	April 17, 2008	04:30 PM
8	David's Mother	April 19, 2008	04:00 PM
9	Elisabeth	May 24, 2008	10:00 AM
10	Elisabeth's Mother	May 24, 2008	02:00 PM

References to each of these participants, both direct and indirect quotations gained during each interview will be found in the following chapters.

## ***Phase 1: Precursor to diagnosis of ADHD***

### *Child reaction*

During the first phase all child participants were unaware of 'what's the fuss all about.' They were uninformed of the fact that they were experiencing Absence Seizures (AS) and therefore were confused by the over-attention. A common reaction of the child participants during this phase was denial of the accusations regarding events that they were unaware of experiencing. This led to great frustration being experienced by the child participants.

It was from the reaction of a sibling in David's family that he became aware of the problems relating to irregular behavioural patterns that he was experiencing. David

explained:

Hang on, he (my brother) used to tell me to “*stop staring at me*” even before then (starting school). My parents would ask us “*why are you fighting*” and he would say, “*Because he keeps staring at me*”. I of course denied it (David).

### *Parent reaction*

Parents and, at times, siblings observed that CAE seizure symptoms, including staring and/or twitching, were being experienced by the child participants prior to the misdiagnosis of ADHD. Terms such as confusion, denial, frustration and fear were used by parents to explain what was experienced when their child demonstrated irregular behavioural patterns during this phase. One of the most common of these symptoms was staring. When questioning the parents on the reason why they felt the child was acting in this manner at the time, and why they were not questioning the reason why their child was experiencing these symptoms, Allan's father replied:

We just thought he was playing a game. You know, having some fun....there were these minor symptomatic signs of something, but we never thought of it as being (a problem), no one thought of it as being a problem.

Embarrassment, withdrawal and denial were the reactions that David's mother expressed when also questioned on the symptoms that her child was demonstrating at this time. She felt that due to the number of children she has (five within a 10 year period) she was unaware of any symptoms occurring until his teacher made a comment.

Admittedly he was forgetful and he was having some problems with reading, but he was also very bright and musical. As he was the youngest of five, I was used to the boys playing up and being silly and he did not seem any different (David's mother).

These reactions of David were similar to other child participants during phase 1. As they were unaware of the symptoms occurring, reactions of confusion, denial, frustration and unawareness were prevalent.



### *Social reaction*

Parent participants felt the reactions of the teachers of all child participants at this time were firstly, confusion, and secondly, frustration when noticing that the child was not always paying full attention when asked questions and given instructions. Parents felt that reactions of a disciplinary type were enacted due to the feeling of being unable to attain the child's full attention. Allegations by some of the participant's teachers was that ADHD was the reason for these actions of inattention and disrespect occurring. Most participants felt that peers were also thought to have been experiencing confusion at this time, due to a lack of knowledge of why a child with CAE was staring at them for short periods of time. This has been suggested as a reason why children with CAE were experiencing bullying by peers (LeFever et al., 2003). Table 5.2 is a review of the reactions stated in Phase 1.

*Table 5.2* Phase 1: Precursor to diagnosis of ADHD

<b>Participants</b>	<b>Themes (Reactions)</b>
Child	Confusion, denial, frustration, lack of awareness
Parent	Confusion, denial, frustration, fear
Social	Teachers: confusion, frustration Peers: confusion, aggression and bullying

## ***Phase 2: Reactions during Diagnosis of ADHD and sequentially***

### *Child reaction*

Withdrawal, anger and fear (due to a label such as 'a bad child') were some of the emotional reactions that many of the child participants spoke of experiencing when diagnosed with ADHD and subsequently. They demonstrated unawareness of the condition itself and what the diagnosis indicated.

At first I had no idea what they were talking about. I was taken off to this specialist psychologist who said it was due to ADHD. The only one who really said it was ADHD before that was my teacher. I felt quite angry (Allan).

Anger and fear were experienced by the first four children due to this ignorance; “I really didn’t understand what it was, so I guess I was scared” (Betty).

I got in trouble a lot of times, especially when I was around 10 years old. I had this one teacher who used to hit anyone who forgot their homework or even their P.E. (physical education) gear, so I’d end up with a swollen hand for doing so (David).

Loneliness was a reaction that Elisabeth spoke of experiencing. Her physical reactions suggested that this was not accompanied by anger or anguish. She explained:

I felt lonely sometimes, had few friends, but I had many dogs and that helped me to enjoy my everyday life.... I felt satisfaction with my life and enjoyed my time with my dogs. (I had) no problems and (would) smile to myself (Elisabeth).

### *Parent reaction*

David's mother and Elisabeth’s mother felt their children were experiencing difficulties in their behaviour patterns at times, not because their children had ADHD, but because of incorrect treatment in the classroom environment.

He was experiencing difficulties at school, but when it was assumed that it was because of a medical condition that was making him a bad child, this in fact was what upset him. He didn’t believe he was a bad child (David's mother).

She was angry and upset all the time. With teachers thinking there was something wrong with her before she even entered the class room (year after year), it was hard for her. I knew she would get upset with them because they believed she had ADHD and expected her to start yelling at them. So I think that’s why they just ignored her, hoping she wouldn’t start yelling (Elisabeth’s mother).

Over-protection, denial, offence and anguish were the reactions that most parents in this study experienced when the diagnosis of ADHD was given. When reflecting on the words of Elisabeth’s mother in the previous quotation, it is apparent that the recollections of Elisabeth and her mother on parent reaction during this phase were

very different from those of the first four families. Negativity, fear and aggression were some of the reactions that the child participants from the first four families spoke of their parents expressing during this phase. But for Elisabeth, due to a lack of communication with her parents in relation to the diagnosis of ADHD and little knowledge being provided on the condition, she felt the reverse occurred.

(My parents felt) Nothing! Maybe they didn't know much about ADHD or maybe I did not pay attention to them....Because, I have not heard anything from them or have felt that they are acting something different. I always stayed alone and played with my dogs more than stayed with my family members (Elisabeth).

Refusal to accept the diagnosis and fear were reactions that Allan's father and Betty's mother said that they had experienced at the beginning of this phase.

I found it difficult to believe that the diagnosis was correct, a psychological condition, as they're conditions that control your whole life. You can't escape conditions that cannot be correctly diagnosed and treated....everybody feared the consequences (Allan's father).

Our family as a whole didn't accept it either. There are members of our family who experience psychological conditions....so the diagnosis was refused to be accepted (Betty's mother).

Aggression and denial were reactions that David's mother, Charles's father and Elisabeth's mother spoke of experiencing throughout this phase.

I was rather surprised. I had seen some programmes on TV about kids with ADHD, and I did not believe that he had this condition (David's mother).

They (the paediatrician and psychologist) asked me a few questions about his attention span and how long it would take him to do homework, etc. They...proceeded to diagnose him with moderate ADHD. I fought the whole ADHD thing because I really felt there was something else going on. Dad's gut instinct I guess (Charles's father).

My husband felt the same way (as me). He was really pissed off....when we were told that our daughter was acting in a bad way, he would just yell at them, saying to them that: *"This is not my child. She doesn't act like this at home. You need to teach her properly"* (Elisabeth's mother).

### *Social reaction*

Difficulty maintaining peer relationships continued to be a problem for most child participants, resulting in withdrawal and denial. Due to the popularity of the diagnosis of ADHD at this time, Charles felt his peers treated him with respect and at times were jealous during this phase because of the amount of extra attention he was receiving in the classroom environment. Acceptance and a rise in self-confidence and self-esteem were reactions that only Charles experienced. “They (my fellow students) seemed to wish they had it too. Apparently a couple of them tried to convince their parents that they had it too.”

Elisabeth starting at a new school (a boarding school) during this phase felt that her fellow three roommates showed acceptance. However she felt of her school teachers demonstrated ignorance and denial towards her condition.

I have only three friends and all of my friends understand me and never act in anyway different to me. I don't have other friends and I don't mind that I don't have many friends. Teachers did not show anything that different from what they had done to other children. I never thought that teachers had any problem with me. They didn't tell my parents when I was younger because my father would yell at them and say “*that's not my child*” (Elisabeth).

David's mother explained that her child had little social contact outside of the school environment. The impact of the extended family was also thought to be quite minimal as “we lived a long way from our relatives so we really did not have much input from them.” She was unaware of whether this was a negative or positive factor. Acceptance was the reaction that Betty's mother felt society demonstrated during this phase.

Most others (fellow teachers) just believed that this was the reason why she got distracted and frustrated at times. It is easy to deal with any behaviour if you believe you know the reason for it (Betty's mother).

Betty's mother also seemed quite relaxed when discussing the reaction of school teachers, as she is a teacher herself. In contrast; aggression was a reaction that Charles's father expressed both orally and physically when commenting on social

reactions during this phase.

People in my neighbourhood all thought my son had ADHD....when your child comes down with something like this, you definitely find out who your true friends are (Charles's father).

Elisabeth's mother felt that due to a lack of education that most teachers hold on the neurological condition of CAE and the ever increasing social salience towards the neuropsychological condition of ADHD, teachers are "overstepping" their boundaries by labelling a child as experiencing ADHD symptoms. She believed that the result of communication between Elisabeth's second year school teacher, who believed that she was a disruptive student suffering from ADHD, and her future teachers at this school influenced how they, up until grade six (11 years of age) also judged her.

Her second-class teacher was this, just this new kid out of university with no practical experience who just blamed her for doing everything wrong, when it was the teacher who just had no idea on how to look after a class. She just told all the other teachers about her (condition) and she got a hard time by them all the way through primary school (Elisabeth's mother).

In contrast, Elisabeth's mother, during the time her child was attending boarding school (year 7 to year 10) felt that teachers demonstrated acceptance and support. As Elisabeth's mother had not heard of problems occurring during this period, her assumption was that she was correct when assuming that her child was not being disruptive in any way. Therefore, she felt that the problems that Elisabeth was experiencing were the result of the actions of her teachers who labelled her as having ADHD. Following the completion of primary school, complaints in relation to Elisabeth's classroom actions were no longer being made to Elisabeth's mother. Table 5.3 is a review of these reactions.

We never heard anything from the teachers there, so it definitely had to be the school she was going to before then. She enjoyed it so much that she didn't want to come home during the breaks (Elisabeth's mother).

Table 5.3 is a review of the reactions stated in Phase 2.

Table 5.3 Phase 2: Reactions during Diagnosis of ADHD and sequentially

Groups	Themes (Reactions)
Child	Withdrawal, loneliness, anger, fear, negativity
Parent	Over protection, denial, offence, anguish
Social	Teachers: disrespect, impatient Peers: confusion, aggression and bullying, jealousy

### ***Phase 3: Reactions during the Precursor to the Diagnosis of JME or TLE***

#### *Child reaction*

Most of the child participants were still unaware of the actions that occurred during the period of the absence seizure. Therefore, difficulty occurred with the acceptance of accusations.

We now know that she was experiencing Absence Seizures; but as she wasn't aware of this, she didn't believe that they were occurring (Betty's mother).

Both Charles and Betty began to experience Juvenile Myoclonic Seizures (JMS) at this point. The JMS that Betty experienced was not recognised by those closest to her until a much stronger twitching started to occur, with one side of her body being involved. Betty became quite upset when discussing this experience, with muscle tension increasing in both her face and upper body as she explained:

All my medical files, from cardiologists, neurologists and all manner of people, said that I was just dizzy. They said that as you broke your back at 14, falling down a block of stairs, they said you must have knocked your head (Betty).

Betty began to become aware of a signal that Charles and David were also experiencing at this time, which is a symptom of a SPS, also called an 'aura.' Betty said that "I would say to people: 'What's that smell?' And they would say: 'What smell? You must have schizophrenia.'" David explained that:

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I remember starting to get these smells....like a gas. It was as if someone had turned a stove on in the kitchen but had forgotten to light it. It would last for about 10 seconds and then stop. I'd ask, "What's that smell" and people would say "What smell?"

The form of SPS that Elisabeth had begun to experience was pertaining to lesions on the right temporal lobe. Similar to postings on the Epilepsy United Kingdom website (2007), Elisabeth explained her feeling of déjà vu, "as if I've lived through this moment and I even know what's going to be said next. Everything seems brighter and more alive." It was a sensation that she felt people judged her as having either due to insanity or having obtained a sixth sense. Allan's father spoke of the point at which Allan began to experience JMS.

Then when he was around 13 or 14, when he started puberty he started to become clumsy. Particularly early in the morning, when he was tired or oddly enough when he had a bright light in his eyes. And apparently this is symptomatic of the myoclonic seizures he began to experience later on in his teenage years.

### *Parent reaction*

All parent participants felt that due to the popularity of ADHD, those within the school environment were more likely to label their child with this neuropsychological condition before even considering the neurological condition of CAE. Anguish, over-protection, and denial are some of the reactions that the parents said they had experienced prior to the recognition of JMS or SPS, which led to them questioning whether it was another medical condition that their child was experiencing. Thus, the symptoms that were felt to be those of ADHD were not being controlled with the taking of stimulant medication, and new symptoms had developed.

He was doing well in some subjects and we perceived that he had a great understanding of literature, although he was still having problems actually putting his answers in writing....and he was still staring (David's mother).

Anguish was an emotion that the parent participants experienced when the symptoms that they were aware of their child experiencing prior to the diagnosis with ADHD,

such as losing concentration (staring), being easily distracted, and difficulties in co-ordination, continued following the taking of Ritalin. As a result, they began to question the diagnosis of ADHD. Parents also spoke of their surprise that other unusual symptoms, which they later became aware of their child experiencing while in the class room, were not being recognised by teachers. Elisabeth's mother spoke of symptoms relating to CAE, which Elisabeth was experiencing during her time at boarding school, that were only later recognised as important following the experiencing of a Complex Partial Seizure (CPS).

I don't know why her teachers didn't recognise it (the rolling back of her eyeballs into the orbit) when she was in their classroom. Maybe they thought she was bored and was showing this by doing this? (Elisabeth's mother)

Charles's father expressed fear about the fact that the condition could be something else, and the question of whether or not finding out what the true condition was would be to the advantage of his child. What it was that prompted many of the participants to become worried about the true diagnosis was that the child participants were now experiencing either JMS, or SPS and in some cases CPS.

Allan's father confirmed that, as is the case with a lot of JMS activity, the left side of Allan's body would lose muscular strength, the body falling to the ground, seemingly as if he was fainting, but failing to lose consciousness. Allan's father noted that it was this unusual behaviour that he felt could not be a result of ADHD, which prompted the family to seek neurological assessment.

He'd drop plates and occasionally he fell down, and it looked like he had tripped over and fallen, and it was just a momentary black out kind of thing, and it was embarrassing for him. I don't know if anyone got the idea he was being purposely disruptive?

Embarrassment, anger, and offence were reactions that parents physically demonstrated during the interview when questioning their own decision to accept the diagnosis of ADHD and not immediately obtain further assessment from a neurological specialist. Parent participants spoke of experiencing frustration and aggression, due to the discriminatory behaviour shown towards their child in the



classroom environment.

There was this particular class, in year three when (Allan) got into trouble with this particular teacher, who was a very traditional older primary school teacher. She just didn't handle him particularly well, and took grievous offence at him. There had to be a different reason for these symptoms (Allan's father).

### *Social reaction*

Confusion, aggression and bullying were common reactions of peers of the child participants during this phase. For several participants it was only following the comments of peers that participants were alert to the symptoms that they were experiencing while a CAS was occurring; encouraging withdrawal, isolation and loneliness to occur.

I would be staring in a particular direction without being aware of it and then suddenly I was being asked, "Why are you looking at me?" You then know you were looking in a certain direction, but you don't realise that someone is in the way (Betty).

Parent participants spoke of their children experiencing disrespect and impatience, on the part of teaching staff. The questioning of the child's intelligence was a regular inference that the parent participants experienced from their child's teachers. David's mother explained:

One teacher felt that his IQ was way below average and he needed to go to a special school. I was quite amazed at this, and said so. The child I knew was quite different to the one she was describing.

The parents spoke of being shown examples of examinations by teachers, such as a mathematics test or worksheet, where the child had failed to place an answer, or had placed incorrect answers on the examination paper. These actions were also now influencing the parents to question whether ADHD was the medical condition that their child was experiencing:

She will just stare and lose attention....and this caused troubles at exam times. We were told that she was not completing exams, and were shown test where the questions were too long and she would lose attention and end up putting an answer

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that was not correct (Betty's mother).

Table 5.4 is a review of the reactions stated in Phase 3.

Table 5.4 Phase 3: Reactions during the Precursor to Diagnosis of JME or TLE

Groups	Themes (Reactions)
Child	Withdrawal, loneliness, anger, isolation
Parent	Denial, questioning, fear, anguish, confusion, overprotection
Social	Teachers: Disrespect, impatient, questioning diagnosis Peers: Confusion, aggression and bullying, jealousy

### ***Phase 4: Reactions during the Diagnosis of JME or TLE and sequentially.***

#### *Child reaction*

Although a child with CAE does experience many symptoms that can be interpreted as those of ADHD, denial and fear of accepting the diagnosis, leading to further withdrawal and self-isolation, were reactions that several child participants spoke of experiencing during phase 4.

When I was thought to have ADHD, I was thought to be a bad child but when I was diagnosed with epilepsy it meant there was more to it.... (as) this now meant there was a problem with my brain... I became scared to participate in some sports, you know like football just in case I fell over and dropped the ball (Allan).

Most child participants were unaware of what the word 'epilepsy' was at the time of diagnosis, let alone the neurological condition itself. The only explanation given to the child from most families, relating to why they now needed to perform new activities, such as see a neurologist and start taking a new set of medication was: "because you have epilepsy" (Charles).

All child participants were now aware that they had been experiencing CAS during

the previous phases. As a full explanation of the condition had failed to be provided for them at that time, a lowering of self-confidence had developed. Charles and David recalled that they assumed that the reason for the seizures occurring at that time was because they were feeble and responsible for their condition. “It made me feel really weak. It was like it was my fault for being weak” (David). Due to peer rejection following their recognition of a CAS, the child participants from four families only then realised that some irregular behaviours were occurring. A further lowering of self-confidence and embarrassment were, and in some cases are, continuing to be reactions experienced by the child participants. This influenced their choice to inform only a limited number of people of their new diagnosis of epilepsy. When interviewing child participants about the action that took place during this phase, some demonstrated further reactions of frustration when discussing the way in which they were treated by others following the diagnosis of epilepsy and the recognition that CAE was the prior condition.

Everyone thinks I’m like this bad child who doesn’t like to know how to behave properly. You get told by everyone that you have the behaviour problems because you have ADHD, but they don’t like go away when you know its epilepsy (Charles).

Elisabeth spoke of beginning to experience withdrawal while at boarding school, following the treatment of her peers up to this point. Her denial of experiencing any problems was a reaction that was more evident in Elisabeth than in the child participants from the other four families. While Elisabeth was explaining these experiences, she spent more time looking downwards and shaking her head from side-to-side, which physically indicated her despair.

For many of the child participants, experiencing condemnation by their peers led them to believe that it was best to reject the new diagnosis of epilepsy. So at times, as far as they were concerned, the experiencing of these seizures was not occurring.

Was it better to tell others that I didn’t have ADHD, or would telling them that it is epilepsy cause even more pain and problems to occur? I was angry that I had been wrongly diagnosed, yet at the same time, I was now scared of what might happen when people found out that it was epilepsy (David).

I gained only short periods of eye contact with child participants when they spoke of these difficulties, which indicated that the child participants were feeling strong levels of anger towards the ignorance of others within their social environment. Although a child with CAE does experience many symptoms that can be interpreted as those of ADHD, their families were often initially happier to be aware of the diagnosis of epilepsy.

Elisabeth also spoke of not recognising differences in the behaviour of those within her social environment. This was most likely due to the fact that she chose to ignore them and withdraw from their presence:

People wanted to make fun of me but so what. I preferred to be alone, so I just went to the library and would read some books and stayed away from everyone. I have my normal life. Take my tablets and enjoy my life (Elisabeth).

The diagnosis of a neurological condition had however also caused other problems to occur in all five child participants. Disrespect and rejection were reactions that most child participants felt were being shown towards them by peers throughout the first three phases. Denial and withdrawal were the reactions that the child participants chose to demonstrate when questioned about their condition during the fourth phase. They felt that it would not make a difference to the way in which they were being treated by their peers if they were to inform them of the new diagnosis. "I didn't tell any of them. They weren't my friends anyway" (Allan).

### *Parent reaction*

As a result of the recognition that ADHD was a misdiagnosis, the themes of happiness and relief were reactions that Betty's mother and David's mother experienced when Phase 4 commenced.

We were so glad to finally have a correct diagnosis. One of the hardest things is waiting for a diagnosis....that the condition was epilepsy. Our children were all very understanding. They had no problems about the fact that she was experiencing seizures (Betty's mother).

Well, I was glad I finally had an answer for the problem, but was very worried about the consequences of the diagnosis... We really didn't believe the diagnosis (of ADHD) though. I always felt that my son did not have ADHD (David's mother).

Changes from aggression and disciplinary actions to overprotection were reactions that several child participants felt their parents showed during this phase, and the reaction of the child to this was withdrawal and offence. Betty explained that the actions of her parents are still overpowering, and therefore "I tell them on a need to know basis of what's happening." Betty explained how these actions affected her by saying:

My mother rings me up too often. (She asks) "Are you taking your medication?" I say to her; "of course I have to be taking it, have you taken yours?" She says, "I'm just checking," and I say "Of course I have woman" (Betty).

Reactions of fear and anxiety were the responses that many of the participants demonstrated following the discussion of Phase 3. It was at this point, when the parent participants realised that the conditions their child was experiencing, JME and TLE, were neurological ones that a division in diagnostic preference occurred. Most parent participants demonstrated a far more relaxed posture when discussing the correct diagnosis. It was at this point of the interview that eye contact increased, and the pace and variety in pitch patterns reduced in most participants, indicating the easing of tension. It was Charles's father whose reactions moved in the opposite direction.

Agitation and frustration were the reactions that Charles's father expressed when discussing the diagnosis of TLE. This mainly came from the fact that his child was now experiencing CPS. He told me that he regretted the diagnosis of epilepsy. He continued to focus on this point when I asked whether he felt that the misdiagnosis of ADHD had caused his son to experience psychological and social problems, inducing further psychosocial difficulties, following the recognition of the correct diagnosis. Although Charles's father was aware that his child had experienced difficulties due to this incident, he expressed a stronger focus on his own fears of how TLE may further physically harm his child.

I would (now) prefer ADHD because in general that isn't something that has to be medicated and in most cases it can't kill you. My son could die from a seizure or as a result of an accidental drowning or whatever. He could die in his sleep from a seizure, or could smother after having one (Charles's father).

Several limitations on the knowledge that Charles's father held in relation to TLE were also evident when discussing this topic. Although ADHD is a condition that demonstrates aggressive and disrespectful behaviour, as it is a neuropsychological condition, it is one that is felt to be controllable. When the condition is neurological, caused by damage to brain tissue, it is one that can be felt to be incurable. With the concern that his child's brain had deteriorated to a point where he was now experiencing convulsions, the fear that this will continue to deteriorate to the point "that my child will be mentally retarded" was a reaction that accompanied Charles's father's fear of his child experiencing death due to a CPS.

All participants showed agitation as they spoke of the possible future changes that need to be made in professions that care for children with CAE and all social environments, to ensure that these problems relating to misdiagnosis of CAE as ADHD cease. This need was most strongly felt in relation to changes in education.

During this period of the interview most child participants visually focused on a set point in the interview room, eyes moving only slightly in direction when speaking. This indicated that the topics of epilepsy and misdiagnosis of ADHD seemed to have caused further problems. The medical condition of all child participants' had now been correctly diagnosed as JME or TLE, and the recognition of CAE as being the cause of the previous difficulties had occurred. Yet adult participants recognised the emotional effects that the children experienced with the misdiagnosis of ADHD, which may have caused difficulties for their child when accepting this new diagnosis.

She was quite depressed when she was diagnosed with ADHD. She was pretty scared, which took some time to get better. She finally accepted the diagnosis of ADHD and began to pick herself up after that, but when she found out it was epilepsy she just fell again. As she had experienced problems from her teachers and class-mates when diagnosed with ADHD, accepting her epilepsy probably took a lot

longer than it would have if it was diagnosed first (Elisabeth's mother).

Several parent participants also reported that their child was experiencing denial as a reaction due to their refusal to accept the diagnosis. As the child participants had not heard of the condition prior to this point, their reactions were quite aggressive.

We saw symptoms occurring in high school, 12 years plus. She was experiencing Absence Seizures, but as she wasn't aware of this she didn't believe they were occurring (Betty's mother).

I couldn't now do things, like go swimming or ride a bike, which I had been doing up until this time. Suddenly because it was like epilepsy, the things I could do just reduced. I still used to like sneak into the pool and go for a swim (Charles).

### *Social reaction*

I observed that agitation was the most common reaction that participants expressed as this period of the interview continued. They spoke of experiencing frustration and anger due to finding problems relating to the lack of education on CAE in the school environment. Betty's mother, who as mentioned earlier is a school teacher, stated:

Most teachers don't really recognise the condition as epilepsy because it's too difficult. That's why ADHD is an easier diagnosis....if teachers stop taking it upon themselves to diagnose the symptoms as those of ADHD, and not be afraid of the fact that it could be epilepsy, the child would have a much stronger self-belief.

Some child participants felt the reaction of society in general was one of disrespect. They felt embarrassed by the fact they were still experiencing epilepsy and feared that the condition would develop to a point that seizures would be experienced regularly while in social environments.

So, I'm really hoping what I have, won't like end up to be full-scale epilepsy. I was like told that as I got older it might get better, but I see like no real sign of that this will at all. It may be a permanent thing for ever (Charles).

The parent participants of most of the family groups considered that the school teacher 'overstepped their boundaries' by making the assumption that they were aware of the reason for the child experiencing difficulties while in the classroom.

Parent participants considered that the ever increasing salience towards the condition of ADHD was affecting the judgments that others made about their children. Elisabeth's mother believes that:

Teachers and even GP's need to be taught how to recognise it (CAE) and how to treat the child. Stop thinking that a child who acts differently to others in the class has something like ADHD.

Charles's father also noted that as:

Teachers are not doctors. They can't diagnose a medical condition. I remember years ago they said that he was in class and the other kids got up and moved around the room. He kept working, or seemed to keep working and didn't notice that everyone else had gotten up and changed tables. I guess he could have just been focusing on his work, but he most likely was having a seizure.

Firstly denial, but then relief and happiness were reactions that David's mother experienced when it was a school teacher who recognised the symptoms her child was experiencing were those of CAE.

One of his teachers noticed that he was staring a great deal and she had some experience with children with absence epilepsy. He was doing well in some subjects and she perceived that he had a great understanding of literature, although he was having problems actually putting his answers in writing. She felt that he was having Absence Seizures, rather than ADHD.

Following David's teacher offering David's mother her observations on how he was acting and that these symptoms may be a result of CAE, David was taken to see a general practitioner and was then referred to see a neurologist. Following neurological assessments, including MRI and EEG scanning, it was established that scar tissue was located on the left temporal lobe, resulting in the occurring of irregular neurological activity. This was the cause of David experiencing SPS as well as CPS.

At the same time, David's mother also felt that too many people working with children use their position as a means to make decisions that are not valid. It was in fact the knowledge of CAE that this teacher held that was very beneficial. David's



mother believed that all classroom teachers do require further education in relation to understanding the condition of CAE.

I feel that education should be made available to teachers and doctors, especially within their training at university....how can they know what they're doing if they don't know what epilepsy is? (David's mother)

When discussing the present process of child education, frustration was the common reaction of most participants. These participants felt that problems have arisen due to a lack of education provided for professionals who work in the fields in which these children are present. It was also felt that due to this lack of education about CAE, the best option for many is to ignore the symptoms.

I think they (my teachers) were avoiding saying anything to me which was really good and I didn't want to hear anything from them too... I was not a good girl and I don't care about other people, so I don't know why they tried to avoid saying anything to me, it is not my problem at all. I feel good that nobody said anything to me (Elisabeth).

Charles, David and Elisabeth felt that large changes needed to occur in the education of those within professions that work with children with epilepsy and all social environments, about the condition of CAE. Mixed themes, including anger and frustration were physically expressed by the child participants when discussing the problems that arise due to this lack of education. These three participants felt that further education needs to be provided for all teachers, medical students and health professionals. David said, "how can they know what they're doing if they don't know what epilepsy is."

Everyone needs to like know what epilepsy is. Not just teachers, but doctors and everyone so they don't like keep getting it wrong by thinking its ADHD, and when they get it right they know what the hell it is (Charles).

If knowledge about epilepsy is made available for everyone to have access to learn and understand, that would be better. It is better than a lot of people not knowing anything about epilepsy at all (Elisabeth).

Table 5.5 is a review of the reactions stated in Phase 4.

Table 5.5 Phase 4: Reactions during the Diagnosis of JME or TLE and sequentially

Groups	Themes (Reactions)
Child	Ignorance, withdrawal, anger, embarrassment, isolation
Parent	Anger, embarrassment, fear, anguish, offence
Social	Teachers: disrespect, impatient, fear, anguish Peers: confusion, aggression and bullying

### *Phase 5: Now (time of interview)*

When discussing the psychosocial effects of the misdiagnosis on the child during the first three phases, similar reactions were expressed by all participants: frustration, anger, and disappointment. I had noted that participants at the time of the interview felt the early misdiagnosis of ADHD had created barriers for the child participants as a result of labelling. With teachers and peers categorising these children at an early age as bad, uncontrollable and unintelligent children, these categories continued to be associated with them following the correct diagnosis of CAE in Phase 4. When the children started to experience JMS or SPS and CPS, the initial assumption that CAE was ADHD was recognised as being the influential factor for these psychosocial effects occurring.

#### *Child reaction*

All child participants still experienced labelling due to their misdiagnosis of ADHD. A variety of labels, including being stubborn and difficult, annoying and unreliable, lazy and forgetful were words they felt were associated with them due to the ADHD diagnosis. Participants felt that by failing to diagnose CAE in Phase 1, which continued to be the situation for some time, the treatment that they received within the school environment had adverse psychosocial effects.

I was being accused of being a bad child and punished by teachers in the classroom, and then punished by fellow students when I went into the playground. I think that the way I was treated by everyone at that time made me prefer to be alone. This took my confidence away and the last thing I want to do is be around people who I knew would just do it again (David).

I think more time would have been taken to try to understand the condition. Instead of being so quick to judge him and treat him with so much disrespect, maybe teachers would have taken time to find out what it was. May be not? I think that the way he was treated by everyone up until the myoclonic seizures were diagnosed; including his classmates, have always affected his communication skills (Allan's father).

Although it was eventually recognised that the diagnosis of ADHD was in fact a misdiagnosis, with the later recognition of the correct diagnosis of epilepsy (Phase 4), most participants at this time felt that the misdiagnosis not only caused the child participants to be psychosocially affected at the time of occurrence (Phase 1 to Phase 4), but that it continues to affect them now (Phase 5). David explained that;

I don't have the confidence to ask any girl out. Girls, who know, just don't want to be near me alone just in case I have one (a seizure). So I mostly stay alone.

Elisabeth also spoke of the difficulties she now experiences.

I don't know if knowing it was epilepsy back then would have made any difference to me now, because I still have it. Maybe I wouldn't have had to be alone all the time and be treated like I was a bad child. May be my family would have been more prepared when the (SPS) seizures started. I guess if my parents knew what epilepsy was then, I wouldn't have gone to boarding school and so many things wouldn't have changed. I'd feel more comfortable being around people now-a-days I guess (Elisabeth).

In contrast, when talking about society and her place within it, Betty's comments were quite different. Betty had at an earlier point in the interview spoken of the difficulties that she experienced with peers in her later years in high school as a result of her epilepsy. Consequently, she now chooses to ignore the advice of neurological specialist and performs actions such as drinking alcohol.

If I go to a party and I drink, and then one out of 10 times I'll (have a complex partial) seizure, and then someone will just pick me up and put me in the back of the cab...and that is fine. I never drink to excess, but if I take my med at times, as I am a girl my hormones screw me up at different times of the month (Betty).

Betty felt that ignoring the advice of medical professionals allows her to live what

she feels is a normal life. Betty asked me if I drank alcohol. When I replied that I did not, she felt that this was due to weakness on my part. The difficulties that she experienced throughout childhood, due to social rejection and isolation, has led her to choose to ignore the consequences of drinking alcohol in the hope that she will not continue to experience feelings of rejection. Although her choice is to spend time with friends and drink alcohol, which is quite different from the other child participants, it is these actions that demonstrate how the difficulties with the misdiagnosis and the rejection and labelling she experienced through her school age years continue to affect her psychosocially. Betty's mother reflected on the psychosocial effects of the misdiagnosis in a much stronger manner. She explained:

It is the misdiagnosis (as being ADHD) and the attitude that comes from that diagnosis that causes a high level of the depression to occur. Betty has experienced depression throughout her life, but it was this diagnosis and the attitude of others that saw her being the most depressed.

### *Parent reaction*

Initially, most parent participants were confused by the claims that their child was experiencing medical difficulties, causing immediate reactions of fear and anger to surface. This initial reaction of the parents towards this incident was clearly remembered not only by themselves, but also by their child. When asked the question: "How did your family react to this allegation?" both Betty and her mother used similar wording to describe the effect:

My parents just freaked out. My father has a fear of schizophrenia. He is absolutely terrified of something that isn't normal in the brain (Betty).

We just freaked out. We found it difficult to believe that the diagnosis was correct, a psychological condition, as they're conditions of the brain that control your whole life (Betty's mother).

Comments by most child participants showed that the initial reaction of their parents was quite disturbing for them. The instability in the family environment caused the children to become quite emotionally volatile. This indicates the importance of maintaining a stable atmosphere within their family environment when problems

occur for these children.

The fact that they were getting stressed by it made me feel stressed also. I understand that if you are told that your child has a medical condition it would upset you but I think this upset can also affect you (Allan).

### *Continuing effects of labelling*

Participants from all family groups have noticed the difficulties that labels relating to the diagnosis of ADHD, which the child participants experienced with the misdiagnosis, still continue to psychosocially affect them. These consequences were felt to be due to feelings of weakness. These children were unable to tell others of their condition, which still affects their ability to make friends.

He isn't very communicative about what people say about it (a seizure). It's difficult to know to what extent. It was clear that he preferred that to not have them (JMS), and I think he did find it embarrassing (Allan's father).

All parent participants spoke of the effects of labelling on their child throughout the period of analysis. They felt that the negative labelling by those outside the family environment played a strong influence on the development of the personal identity of each of the child participants. The children went through a phase where their means of coping with the difficulties was by trying to pretend the condition did not exist. Allan's father explained that:

It was clear that he preferred that to not have them (seizures), and I think he did find it embarrassing. He didn't want to be known as someone who was clumsy, because he actually, is actually very well coordinated. So that was a little bit bruising to his self-esteem.

Of course these children spent some time experiencing absence seizures without being aware of their occurrence. Although, at the start of the interviews the theme for most of them was that they were happier to know that it was not ADHD, as the interviews progress further reactions were evident.

Charles's father explained that in relation to the stigma associated with both conditions:

The stigma (of epilepsy) is a lot worse than ADHD in my opinion. He may never drive. I worry for his future. Even though he is bright, I'm not sure if he'll be able to handle the inflexibility of university. These are just some of the reasons why I wished it were 'just' ADHD.

These children with CAE encountered rejection by society due to the consequence of experiencing CAS. Actions such as staring led to the boys being labelled with terms such as 'gay' by many of their male peers, thus causing a negative psychosocial effect to occur in these participants.

I started getting hit by other students. It was alright if it was one person, because I could hit them back, but most times it was more than one who'd push me around. With the fact you're always staring at people when you're having one (a CAS), I was told I was a gay and stuff like that (David).

For the children in the present study, these problems of discrimination that were experienced were, at times, more devastating than the knowledge of the condition itself.

### *Participants' suggestions for future change*

Many of the participants in this study felt that further education for students presently studying at university, who are to become classroom teachers is required. It was felt that education to assist with the recognition of CAS would not only be beneficial for the child with CAE, but also for other students in the classroom.

Maybe they should start sending the present teachers in schools to conferences to learn about it also. Also have specialists go into schools and teach all children about the condition. I think that would make a big difference (Elisabeth's mother).

Child participants felt that due to ignorance, fear and rejection, the only recognition that people in their social environments have of epilepsy is that: "a person will fall to the ground and start experiencing a convulsion" (Charles). This leads to incorrect labelling and negative stigma being experienced by children with CAE:

there is like very little knowledge about epilepsy, and if the only thing that they recognised as epilepsy is convulsive activity then the only way that you judge a child who is like blanking out, is as disruptive, disrespectful or an idiot (Charles).

The parent participants also felt that there was a strong level of ignorance in relation to CAE in social groups, and all medical fields in general, causing their children to experience strong difficulties in relation to labelling:

Several GP's I have spoken to throughout my son's young life had not seen a seizure. He was diagnosed with sinus infections when he was complaining about a smell (an aura). It was a petit mal seizure he was having. It is all too readily accepted as ADHD symptoms. My son suffered needlessly, I feel because of this lack of education. He was labelled as a problem child with a popular disease, when he had a condition that was correctly diagnosed and correctly treated after several years (David's mother).

Of course they needed to understand what the condition is. There is a lack of education. Many doctors don't recognise it as a major condition because as far as they are concerned it is a short term incident that doesn't truly affect the person for very long at all. Therefore the need to recognise the condition and educate others fails to occur (Betty's mother).

Charles's father felt that a strong level of knowledge needs to be available for people in society: "there needs to be pamphlets and stuff like that available for people in general society so they know what's going on." A general reaction of all participants in the research was that changes need to be made to ensure that the misdiagnosis of CAE as ADHD discontinues. In relation to general knowledge on the condition of epilepsy:

I feel that most people have no knowledge of epilepsy. Several health professionals have little knowledge of seizures, and what they can look like, as they come in many forms. I feel that education should be made available to teachers and doctors, especially within their training at university (David's mother).

Talk to his teachers and maybe that will help and the teacher can help the rest of the class to better understand epilepsy. It's sad, but kids are funny that when things are different they tend to pick at them. The only way, is through the school system, to push for more understanding of epilepsy. There is not enough (understanding) (Elisabeth's mother).

Most participants felt that the labels, such as being a bad child, uncontrollable, and disrespectful, remained with the child following the recognition of CAE. The

psychosocial effects that these labels and the negative stigma that developed from the misdiagnosis of ADHD were felt to be quite strong.

When it comes down to it, I don't think too many people change their mind on how to evaluate your child. He's thought to be a disrespectful and uncontrollable kid, because that's what ADHD children are supposed to be, but he is not. Just because he doesn't always listen to, or concentrate on, what his being told, which we now know is due to the seizure, he is still recognised as being this type of kid (Charles's father).

Table 5.6 is a review of the reactions stated in Phase 5.

*Table 5.6* Phase 5: Now (time of interview): How is the child psychosocially affected knowing that ADHD was a misdiagnosis?

<b>Groups</b>	<b>Themes (Reactions)</b>
Child	Frustration, anger, disappointment, isolation, withdrawal
Parent	Frustration, anger, disappointment

Overall, the findings demonstrated that psychosocial effects were evident in all child participants, relating to misdiagnosis and labelling. Reactions such as fear, rejection and discrimination led to withdrawal being experienced by all child participants. There was a common belief that the lack of information offered to the child with this condition, their family and social environment is causing a high level of frustration and fear to develop in the child. It is important to provide enough support to families that have a member with CAE, such as give them information and how to adjust themselves into the society. Chapter six will discuss on the results of this research and the benefits of these findings.



## CHAPTER 6

# DISCUSSION

The previous Chapter reported on the data analysis and presented the findings of the research questions. Participants' responses were categorised in five phases, and reactions were presented on the basis of the participants' descriptions of the phenomenon. This Chapter discusses the implications of the study and the findings including some issues relating to the research questions employed in the study. This Chapter investigates whether a repetition of reactions was found to be evident in different phases. When participants faced the same scenario, such as diagnosis of both conditions, were their reactions duplicated in both phases and if so, how did this later affect the child participants psychosocially?

The data did in fact show that there was a repetition of reactions within different phases. Reactions including confusion, denial, ignorance and frustration, were experienced by parent participants in both precursor periods (Phase 1 and Phase 3).

### *Denial and offence*

Denial and offence were reactions experienced by parent participants during both the diagnostic and sequential phases (Whitehead & Gosling, 2003). Denial was experienced in a similar context in both phases. When the children were diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD), Phase 2, several parents refused to accept the finding as it indicated that many of the problems their child was experiencing were due to a neuropsychological condition. As ADHD is the condition that was believed by many people to be the reason for the child participant's behaviour patterns, this justified others' actions in treating the child in a disrespectful manner (Haber, 2003).

When the diagnosis of epilepsy was given (Phase 4), although many of the participants were happy to hear that the original condition was Child Absence Epilepsy (CAE) and not ADHD, each child had now been diagnosed with a neurological condition which was not widely understood. Realising that the condition is due to damaged brain tissue, a reaction of fear was experienced by all in Phase 4.

There is like very little knowledge about epilepsy, and if the only thing that they recognised as epilepsy is convulsive activity then the only way that you judge a child who is blanking out is as disruptive, disrespectful or an idiot (Charles).

With the realisation of the symptoms, and the possible experiencing of further convulsive seizures, Charles' father now wished that the condition had been ADHD, as his belief was that it was a safer condition for his child to have. Although his reaction was by no means meant to cause negativity to occur in Charles, the denial and offence shown by his father was a strong memory that Charles recalled when discussing the family's reaction.

The integration of data, theoretical implications and recommendations of this study addressed the issue of the psychosocial effects on a child with CAE when the condition is misdiagnosed as ADHD. This included observations of the participants' recollection of problems experienced by the child during the 4 phase periods of medical assessment. Recognising the lack of knowledge about epilepsy provided for not only the participant with CAE, but also those closest to them, assisted my understanding of the difficulties that are experienced by the child participants (Schachtar, Holmes, & Kasteleijn-Nolst Trebite, 2008). In addition, I recognised how the low level of general education in community environments and also more specifically provided for teachers and doctors is a contributing factor to the misdiagnoses of ADHD. The effects of the inability to correctly analyse the reasons for changes taking place in behavioural actions on children and their parents was a focus of this study. Discrepancies in understanding and social status created between others within the school environment following the diagnosis with ADHD (Phase 2), as well as labelling, were considered as potential contributing factors to the negative and psychosocial effects that the child participants in this study were experiencing.

The data suggested these factors led to behaviours customarily associated with ADHD. Antisocial and withdrawn behaviours, associated with anxiety, depression, and other behavioural responses of all child participants, due to a lack of understanding of their condition (Phase 1), influenced the decision to diagnose ADHD, and all were treated accordingly (Phase 2). This was reflecting the immediate social assumptions rather than the disorder itself. I found in all five instances, community, educational resources, and the use of correct neurological assessment procedures were severely deficient and not attended to when the diagnosis of ADHD was made.

The recognition of continuing irregular neurological behavioural patterns and the addition of symptoms such as falling and auras led to the need for all parent participants to gain further understanding (Phase 3). When the children were later correctly diagnosed with epilepsy (Phase 4), following the experiencing of Juvenile Myoclonic Seizures (JMS) or Simple Partial Seizures (SPS), it was realised that CAE was the condition that the child had been experiencing at an earlier age. All children experienced reactions of anxiety, anger and depression following the correct diagnosis and knowledge of the misdiagnosis. Participants now felt that if it had been originally diagnosed as CAE then the new diagnosis of Juvenile Myoclonic Epilepsy (JME) or Temporal Lobe Epilepsy (TLE) would have been an easier situation to deal with (Phase 5). This demonstrated how the adolescent/young adult was psychosocially affected by the misdiagnosis of ADHD as a school-age child.

Further research is necessary about how those with JME and TLE, who live through the period of the misdiagnosis of ADHD, when it was CAE that they experienced, are still psychosocially affected by the circumstances today. This may be attained through further study with an increased the number of participants involved and combining interviews and observations with narrative inquiry. See further recommendations in Chapter seven.

### *Symptoms associated with CAE and ADHD*

There are many symptoms associated with both CAE that are mimicked by ADHD (Locke, 2009) that were reported as being experienced by child participants as the interviews took place. All of these 14 major symptoms (Figure 3.1) that were discussed with all participants occurred during the five phases of this study. Some participants felt more concerned about some symptoms, such as mood swings and fear, than the others, but all child participants were found to have experienced the 14 symptoms. These symptoms are reported as follows: Concentration problems, confusion and conflict, fidgeting and inattention, destructiveness, mood swings, embarrassment, outbursts of anger, anxiety, fear, depression, loss of self-esteem, loneliness, ignorance and frustration.

#### *Concentration problems*

One of the most common symptoms that all the child participants were initially observed as experiencing within both the home and social environments was a problem in maintaining concentration (Stroink, Brouwer, Arts, Geerts, Boudewyn

Peters, & van Donselaar, 1998). Most parent participants spoke of noticing this symptom being experienced by their child in Phase 1. The child participants' concentration problems or a short period of staring (1 to 10 seconds), being the result of a Child Absence Seizures (CAS), were at first thought by some parents to be nothing more than a game that their child was playing. As the rolling of their eyes up into the orbit is a action that most felt a child does when they are indicating they are bored with a conversation, the action was acknowledged as mere 'childish behavior.' This was also the reaction that many participants believed that teachers felt when observing the action. This reaction was a factor that caused difficulties to arise in the school environment.

Many participants argued that teachers felt the low level of concentration was thought to be a purposeful action. Therefore, any difficulties that the child participant might be having at an academic level were the consequences of their own actions. What participants indicated was that many teachers acknowledged the action as being a purposefully persistent choice to not pay attention or acting in a disrespectful manner towards them while the subject was being taught. Their inability to maintain the child's concentration and interest during this period offended the teacher. This resulted in frustration and disrespect arising within the classroom environment towards the child participants experiencing undiagnosed CAS; commencing in Phase 1. Initially, being unable to understand why the child was losing concentration and then deciding it was a purposeful action resulted in most teachers showing disrespect towards the child participants. Many participants acknowledged that lack of education about CAE contributed to classroom teachers making incorrect analyses, later influencing their decision to label these actions as a result of ADHD. The participants believed that as a consequence this confusion resulted in conflict.

### *Confusion and conflict*

All child participants lost consciousness while each CAS was occurring. Each child was unaware of these symptoms were a consequence of the CAE. The child participants became confused when people spoke of these symptoms and indicated that these occurred because each was a 'bad child.' As a result, frustration was a reaction that many child participants spoke of experiencing throughout the first four phases of the investigation, being the 'period of medical investigation' (see Figure 3.1, Phases of Reaction). Confusion was also experienced by most parent participants

in Phase 3 as a result of their questioning of the diagnosis of ADHD, which commenced in Phase 2. All parent participants experienced confusion based on the fact that their child was still experiencing symptoms that had been previously diagnosed as ADHD.

The symptoms each child participant continued to experience not only caused further frustration for many parent participants, but also fear that these symptoms may be due to another condition. This led to the need for parent participants to gain further knowledge about the condition their child was experiencing (phase 3). Most child participants were able to recall the emotional reactions that each parent was experiencing at this time.

The periods of staring, being a symptom of the CAS, resulted in problems developing in the relationships of child participants and peers. Being unaware of the reasons for this occurring saw conflict develop. All participants felt that the negative attitude adopted by society following the initial diagnosis of ADHD in phase 2, continued to be shown towards the child participants following the diagnosis of epilepsy (Phase 4). In most cases, this continued to be experienced by the child participants at the time of the interview (Phase 5).

The evidence suggests that the combination of the ever increasing salience towards the neuropsychological condition of ADHD and the low level of knowledge held by most people in relation to the neurological condition of CAE contributed to the many psychosocial effects experienced by the child participants. An increasing amount of research literature is now being published about the association of ADHD with autism (Gadow, DeVincent, & Schneider, 2009; Brereton, 2007; Reiersen, 2007; Corbett & Constantine, 2006; Mandell, Thompson, Weintraub, Destefano, & Black, 2005), and problems that arise in children with other forms of epilepsy when misdiagnosed with a neuropsychological condition (Becker, Sinzig, Holtmann, 2004; Dunn, Austin, Harezlak, & Ambrosius, 2003). Little research has been conducted that focuses of CAE and ADHD to date.

### *Fidgeting and inattention*

What caused the child participants to experience fidgeting was the result of small proportions of irregular neurological activity triggering muscular spasms via the connection of the brain stem to the central nervous system (Dunn, Austin, Harezlak,

& Ambrosius, 2003). It had been observed by the parent participants that their children with CAE would experience short periods of fidgeting. The short jerk of an arm or movement while sitting at the table during a meal often led to clumsiness and items accidentally knocked over or dropped. All of the parent participants were initially surprised by the action when first observed. This led to 'destructive actions' occurring. Some of the parent participants initially felt this to be the result of inattention, but with the sudden and unexpected occurrence of the action, they accepted it as being unintended.

Further evidence gained from the interviews, showed that participants were upset by the way teachers reacted to this action. Most participants spoke of a teacher having observed the child fidgeting while in the classroom. Both the child participants, following the action occurring, and parent participants, during a meeting with the teacher, such as at a 'parent and teacher night' were informed that they felt the action was intentional, disrupting overall class behaviour. In many cases, the teacher's misunderstanding of the reason for the fidgeting occurring resulted in them labelling the child as "one who demonstrates inattentive behaviour" (Famularo, Fenton, Kinscherff, Barnum, Bolduc, & Bunschaft, 1992). Following this, many child participants experienced further labelling, including being an inattentive child, causing a further psychosocial effects.

### *Destructiveness*

Unlike the claims of Stroink et al. (1998) who observed that the ADHD child's destructive behaviour is often purposely performed, this action is more likely to occur due to the periods of fidgeting a child with CAE experiences as a result of irregular neurological activity while the CAS is in progress (Dunn et al., 2003). The immediate reaction of disappointment towards their actions by those within the home and social environments was noted as causing the child to feel insecure. Many of the parents became aware that the action was not intentional and compensated by ensuring that glasses and extra plates were not placed close to the child. They tactfully tried to stop their child with CAE from carrying glasses or cups while walking around the house. The accusation of purposefully acting in a destructive manner was a label more often placed upon Allan as he entered high school than other child participants. Allan was regularly tripping or falling over items as a result of the development of JME. The loss of full body strength in combination with the fact that he did not lose consciousness, which occurs as a result of this form of

seizure, influenced further judgement on the part of those who observed these occurring. This was a factor that influenced the judgement of others, labelling him as a child with ADHD.

Overall, most child participants expressed disappointment that this involuntary action was misjudged as purposeful. The emotion influenced further social judgement. Many child participants believed that those within both their home and community environments interpreted the reaction as a factor of mood swing behaviour.

### *Mood swings*

Parent participants were aware of their child experiencing mood swings throughout the period of investigation, but due to the low level of knowledge on CAE, the reason for these were misunderstood by most people as being a result of ADHD. Some participants noted that the reactions that the parents experienced when contemplating the concept that their child may have ADHD initially led to themselves experiencing mood and anxiety problems, leading to a lower sense of parenting competence (Rabiner, 2002). Once the correct diagnosis of epilepsy was established in Phase 4, neurological specialists confirmed that the actions of the child participants were the result of pre-ictal and post-ictal activity (Lewis, Yeager, Swica, Pincus, & Lewis, 1997). Some parent participants spoke of their personal relief when realising that the actions of their child were not occurring as a result of parental incapability.

Staring is a symptom that is strongly associated with CAS and ADHD (Carmant, Kramer, Holmes, Mikati, Riviello, & Helmers, 1996). As a consequence of the frequent occurrence of short CAS, resulting in periods of unconscious staring, reactions of fear and aggression were demonstrated by most child participants when experiencing sudden conflicts following the completion of the CAS. This influenced reactions of peer bullying and isolation within the community environments. This caused the child participants to feel afraid and angry, leading to the further assumption that this was the consequence of ADHD.

Most parent participants in this research spoke of often noticing their child having difficulties making and maintaining friendships. It was assumed by these participants that this was initially a result of the child participants' incapability to control their emotional reactions. At a later stage these participants felt it to be due to a lack of self-esteem in their child. Most child participants expressed and demonstrated embarrassment and reduced self-confidence throughout the period of interviews.

They showed discomfort during the interview when discussing their difficulty retaining what would seem to be simple facts, such as a peer's name. Although this is an experience and reaction that the child participants were destined to experience as a result of the lesions in their brain tissue (Corkin, Amaral, González, Johnson, & Hyman, 1997), the lack of education offered on the reason for this occurring initiated a lowering of self-esteem in most child participants. Acts of disrespect from peers no doubt contributed to this.

### *Embarrassment*

Embarrassment was a reaction that most participants spoke of experiencing. Most parent participants spoke of experiencing embarrassment in both Phase 2 and Phase 4 as a consequence of their choice to both ignore symptoms, and accept the diagnosis of ADHD. In Phase 2, their embarrassment was the result of the fact that they noticed their child's symptoms in Phase 1, and realised they chose to ignore them as being the result of a medical condition (Barkley, 2001). Some parent participants, initially thought it easier for the symptoms to be 'swept under the carpet' than acknowledged, leading to social judgement shown towards both them and their child. These parent participants noted that at that time they justified doing so by observing these actions as being nothing more than a childhood game.

Once each parent acknowledged that their child participant was experiencing irregular medical symptoms they chose to take their child to a pediatrician for medical assessment. Their embarrassment in Phase 4 was a result of the fact that they chose to accept the diagnosis of ADHD in Phase 2. Although, most parent participants felt that the diagnosis was incorrect, they decided not to gain further medical assessment by a neurological specialist. This led to the parents experiencing self disrespect. One must note that without appropriate education about the condition of CAE, it cannot be assumed that the parent participants would have had the knowledge of who to approach to gain further assistance to ensure the diagnosis of their child's condition was in fact correct. Yet in hind sight these participants felt that as parents it was their responsibility to perform these actions.

Although the reactions of parent participants at that time were felt to be on behalf of their child, it was discovered the instability in parent reactions were recognised and remembered as negative by most child participants. Child participants remembered their parents' outbursts of anger during the first four phases as a result of



embarrassment and self disrespect. Instability in the reaction of a parent of a child with epilepsy can affect the child's own stability (Aldenkamp, Renier, Dreifuss, & Suuremeijer, 1995). This negative factor that arose when questioning the child participants on 'parent response to the diagnosis' indicated that these actions impacted on the lowering of self respect in each of the children. Some child participants indicated that instability within themselves influenced their own ability to comfortably deal with social reaction when outside of the family environment. Peer bullying often resulted from their occasional outbursts of anger.

### *Outbursts of anger*

Most child participants spoke of experiencing anger due to peer bullying. The CAS symptom of staring often caused problems throughout the period of investigation. As a result, reactions of withdrawal and a lowering of self-esteem were expressed. What seemed like uncontrolled outbursts of anger were wrongly associated as being a result of ADHD (Torta & Keller, 1999). Prior to Phase 4, the child participants were not aware of these actions. Following the period of lack of awareness, the CAE child found themselves being aggressively confronted for showing disrespect. The child's denial of the purposeful action of staring occurring led at times to a negative reaction by others, leading to their own anger.

This sequence of events continued to be experienced by most child participants throughout the first three phases of the 'period of medical investigation' (see figure 3.1), leading to them being labelled as a disruptive child. Although these outbursts of anger lasted for a maximum of one minute, unlike those of a child with ADHD, often being 20 to 30 minutes in duration (Tassinari, Rubboli, & Michelucci, 1999), the lack of education of CAS saw the CAE remain undiagnosed. The child participants who experienced fidgeting were often accused of purposeful disruptive behaviour. Most of the participants still experience slight fidgeting while performing basic actions, such as watching television. The stigma that developed as a result of this labelling continues to induce psychosocial effects in most of them, as they are aware and embarrassed by its occurrence. The anger experienced by parent participants was a reaction that commenced in Phase 2, due to society's assumption that their child had

ADHD. All parent participants later chose to question the original diagnosis of ADHD and sought further medical assessment (Phase 3).

The reaction of anger that was experienced by most parent participants as a result of social judgement of their child in Phase 2 was now turned upon themselves during Phase 4 as the result of their decision to accept the original ADHD diagnosis as correct. Most parent participants now felt their child had also been experiencing a high level of psychological difficulties due to their acceptance of this diagnosis, which was felt to be uncalled for, inducing further reactions of anger in these parent participants. As their child's condition was now realised to be a neurological one, their child had to continue to deal with the psychological experiences that had been incurred up until this point, as a result of the ADHD misdiagnosis. In addition the fear that the JME or TLE seizure activity would now increase was another problem. Although the true diagnosis had been made, the effects of the misdiagnosis of ADHD continue to affect the child beyond this point. The emotional reactions of parent participants during phase 4 added to the anxiety that each child participant experienced as a result of the knowledge of the misdiagnosis.

### *Anxiety*

Although feelings of anguish were noted as being experienced by all child participants, the anxiety that they had experienced in the first two phases of the research period was more likely due to mistreatment (Alwash, Hussein, & Matloub, 2000). The level of anxiety experienced by the child participants was strongly influenced by social reaction towards the symptoms of CAE. As these were observed and incorrectly analysed as being caused by ADHD, the disrespect and mistreatment on the part of communities also contributed to the anxiety experienced.

From a medical perspective, anxiety is a symptom that is recognised as being most often experienced by those with epilepsy in the pre-ictal period of a JMS or SPS and CPS (Vazquez & Devinski, 2003). Therefore anxiety in child participants experiencing CAS would not be expected to be present as a direct result of the medical condition until JME or TLE had developed. When all child participants entered Phase 4 medical specialists acknowledged the anxiety the child participants

had experienced was a result of CAE. Thus, the anxiety that child participants had experienced in the earlier phases was a result of incorrect treatment and the social assumptions that accompany ADHD.

The fear of what might arise the next time the child participants were in contact with others further influenced these feelings of anxiety, resulting in reactions such as withdrawal and low self-esteem developing. This was to progress to the point that most child participants now feared that further discriminatory actions would occur once peers became aware of the true diagnosis of epilepsy. This influenced many of these participants wishing not to inform others of the misdiagnosis of ADHD. Children and adolescents with new onset epilepsy often experience psychosocial emotions, such as embarrassment and fear of social contact when their condition is analysed and require counselling to assist with these effects (McNelis, Beverly, Austin, Dunn, & Creasy, 1998).

### *Fear*

The reaction of peers remained the same throughout the initial four phases of the period of assessment. As most child participants chose not to tell teachers and peers about taking medication as a result of their fear of further isolation, they contributed to their own isolation. In turn their self-confidence deteriorated as did their trust in others.

I didn't tell any of them. They weren't my friends anyway. Was it better to tell others that I didn't have ADHD, or would telling them that it is epilepsy cause even more pain and problems to occur? I was angry that I had been wrongly diagnosed, yet at the same time, I was now scared of what might happen when people found out that it was epilepsy (David).

I used to be teased about the times I was staring or dropping things, but I just choose to stay out of everyone's way. I just didn't tell anyone....well it obviously made me feel lonely, but it was better than being embarrassed (Allan).

Most parent participants were aware of the fear experienced by their children throughout the 'period of medical investigation.' A child at any age who is thought to be different is often isolated by peers (Haber, Austin, Lane, & Perkins, 2003). During Phase 1, the child participants began to experience fear in reaction to the ways in which others spoke of them and treated them. Following the diagnosis of

ADHD (Phase 2), the fear that the child participants were experiencing resulted in withdrawal, leading to depression.

For the parent participant in each of the family groups, fear of the unknown was found to be a regular emotional reaction that they felt their child experienced when they were diagnosed as having a medical condition. The parent from each family group initially found it quite difficult to manage questions asked by medical staff relating to their child's health, leading to a reaction of initial denial when the diagnosis of ADHD was given. This was felt to have been reflected onto the child and increased the level of fear of the unknown. The confusion that arises from not knowing why someone acts or looks different to the average child will often see this child treated in an aggressive manner, leading to bullying and isolation.

Due to the ever increasing salience towards the neuropsychological condition of ADHD, most participants believed that relevant social groups did not experience fear of the symptoms exhibited by the child participants during the first three phases of the period of medical investigation. They believed the social reaction was that of disrespect. It was only from Phase 4, when people became aware that the child participants were experiencing JMS, SPS or CPS, following the diagnosis of JME or TLE that fear began to arise in these environments. It was felt by most participants that it was only once JMS, SPS or CPS were known to be experienced by the child participants that the condition of epilepsy was accepted. Participants believed their school teachers were fearful in Phase 4. Some participants expressed that the teacher's fear of the child experiencing a convulsive seizure while in the classroom resulted in most teachers finding it difficult to communicate with the children.

### *Depression*

Depression was an emotional reaction that many children with CAE experience throughout the periods of analysis and diagnosis (Plioplys, 2003). The child participants in this study began to experience depression once they were made aware of their irregular activities, such as unknowingly staring at others. As small levels of depression are experienced by many throughout childhood, and the reasons seem very insignificant to adults, the cause of it occurring as the result of a medical condition, especially CAE is overlooked (Kanner & Palac, 2000). If thought to be the result of a medical condition, depression is more likely to be associated with the neuropsychological condition of ADHD.

When initially made aware of the actions they experienced during a CAS the child participants denied them occurring. This instigated isolation and withdrawal from peers, leading to depression. Participants reported that in some cases the anguish that arose as a result of child participants refusing to accept the accusation of performing actions that they were unaware of occurring resulted in stronger disciplinary action on the part of teachers. Labelled as being ‘a period of denial’, the confusion that the child participants were experiencing at this time resulted in an increase in depression (Ettinger, Weisbrot, Nolan, Gadow, Vitale, Andriola et al., 1998). They felt that this contributed to an increase in bullying, leading to further depression in the child participants. Once the child participants became aware of the fact they were now experiencing seizures and the reason for periods of staring at a younger age was in fact CAE, they reported further loss of self-esteem.

### *Loss of self-esteem*

All participants spoke of experiencing low self-esteem. Each child began to feel isolated, and separated from the rest of the class. This in turn greatly affected each child participant’s social skills and their ability to function in group-work activities, whether it is in the classroom or when playing some sports. Child participants experienced peer aggressive behaviour being directed towards them throughout the ‘period of medical assessment.’ The resulting loss of self-esteem led to withdrawal, which had an impact on the development of low self confidence in each child participant. Of all child participants, it was only Charles who indicated that during Phase 2 and Phase 3 his peers were jealous of him. Charles felt that this was due to the extra attention he was experiencing and their awareness of the condition, which also induced bullying. This was to cause him further isolation and loneliness.

Students who develop low self-esteem often believe that they are incompetent of changing their current situation as their effort will result in failure (Woolfolk, Winne, & Perry, 2005). The lack of control that the child participants felt caused many of them to give up, or in most cases not even try to fit in. Participants felt that teachers misinterpreted this behaviour as defiant while in the classroom.

If a teacher is not aware of what is causing the school-age child to experience added stress, it may simply appear that the child is unwilling to listen and participate in group studies. This is why it is important for teachers to be educated about the causes and symptoms of CAE and to ensure non-judgmental reactions are displayed.

### *Loneliness*

Loneliness is a reaction that developed in most of the child participants as a result of anxiety and low self-esteem. They first experienced loneliness in Phase 2. It continued throughout the rest of the period of medical investigation (Phase 3 and Phase 4). Loneliness developed in all child participants as a result of peer isolation. Most child participants often experienced victimization while in the playground (Kochenderfer-Ladd & Wardrop, 2001). In many cases, due to lack of teacher intervention and classroom student control, this same treatment occurred on entering the classroom (Berguno, Leroux, McAinsh, & Shaikh, 2004). Many of the child participants experienced isolation in both environments. Some spoke of the loneliness they experienced as a result of never being chosen by other students to participate in small group projects. As their teachers were not directing each child to a specific group, the child would often have to wait for the teacher to inform a group that he/she would also take part in their project. The ideas or suggestions of the child participants would often be rejected or ignored by fellow students, leading to further loneliness and isolation.

The fear of isolation and rejection are reactions that most of the child study participants continue to experience to this day. This has led to many of them experiencing long periods of loneliness. Social ignorance about absence seizures will continue to affect children with CAE until appropriate education is provided to all.

### *Ignorance*

For each of the child participants, ignorance about their medical condition was an important characteristic that determined how they were treated by peers. Social ignorance in most cases saw the child participants being misjudged as a result of symptoms such as staring becoming the central attribute by which the child's personality was assessed (Aldenkamp et al, 1995). Most participants indicated that this often saw the actions of the child participants being labelled as deviant by teachers, leading to further negative treatment of the child by their peers.

The reaction of ignorance in Phase 1 (Precursor to diagnosis of ADHD) was mostly due to a lack of knowledge in relation to CAE. This led to most parents choosing to ignore the symptoms that the child was experiencing at this time. The parents' confusion about why their child was acting in this way initially led to their denial that it could be a result of a medical illness. Most parent participants feared what problems their child may experience as a result of social judgement which led to frustration. This frustration was experienced in the final stage of the precursor period and led to the parent participants taking their child to a psychologist, and the diagnosis of ADHD being given (Phase 2). Most participants commented on the ignorance of those around them.

### *Frustration*

Frustration on the part of a child is often categorised as a behavioural problem (Leach, Lauder, Nicolson, & Smith, 2005). Although each absence seizure that the child participants in the study experienced when their condition was diagnosed as ADHD were short in duration, the frequency of them left a scrambled memory of what was taught while in the classroom. The loss of awareness interfered with the comprehension of what had been taught, resulting in this frustration. Details remained unrecognised and were often only realised following the completion of a class test. In all cases the child participants were assessed and treated incorrectly by those within the class environment, leading to the choice to have the child psychologically assessed by a paediatrician. As a result of an incorrect clinical examination report, each of the children failed to be diagnosed as experiencing absence seizures, leading to the misdiagnosis of ADHD.

All participants spoke of experiencing further frustration as a result of the lack of time taken by professionals to offer a full explanation of the condition that the child was diagnosed with at that time. The lack of general written information relating to ADHD and especially CAE was also a cause of great frustration for the parent participants during both periods of diagnosis (Phase 2 and Phase 4). All parent participants felt that the answer given to the request for further understanding of epilepsy was unacceptable. Information provided, including on how to live with epilepsy was thought to be very basic. The child participants were frustrated by their lack of awareness of why the seizures were occurring and therefore why they were experiencing discrimination and treated in any way differently to their peers.

Discrimination against those with epilepsy and the effect of lack of education is a topic that also requires further investigation (Gordon & Sillanpaa, 2008).

### *Epilepsy and discrimination*

Epilepsy is a neurological condition that has caused children throughout history to experience discrimination. The major factor that has contributed to this is a lack of education about the condition (Engel, Pedley, Aicardi, Dichter, & Moshé, 2007). A high level of discriminatory behaviour was experienced by most child participants when others became aware of the diagnosis of epilepsy (Peace, 2001). The participants felt this was worse than those which accompanied the original diagnosis of ADHD (Phase 2). Child participants thus chose not to disclose the diagnosis of JME or TLE (Phase 4) to most peers, due to the fear that a higher level of negative reaction and bullying would develop. Most child participants also experienced further withdrawal and denial when told of the symptoms that are associated with JME or TLE. The choice to not disclose these details as a result of their fear of discrimination led to a further lowering of self-esteem and inferiority (Buelow Long, Rossi, & Gilbert, 2004).

### *The effects of a lack in education*

As I pointed to earlier, most parent participants observed the symptoms of CAE occurring when their child was very young. As many of the seizure symptoms were not recognised or ignored due to a lack of education on epilepsy, this led to misdiagnosis occurring. As a result, all child participants in this study experienced difficulties that may have been reduced if appropriate education was provided (Ettinger & Kanner, 2007). All participants questioned the knowledge that general practitioners (GPs) have in relation to epilepsy, let alone CAE. Serious questions in relation to Australian doctors' knowledge on children with CAE must be asked. David's mother asked:

What is the capacity of GPs to correctly diagnose and treat Absence Seizures in children? What happens then if the absence seizures then stop? Will they stop taking the medication for ADHD? (David's mother)

All of the participants were surprised and upset when they realised that correct neurological assessments (such as EEG, MRI, and PET scanning) could have assisted with the correct diagnosis of CAE if they were performed when their children were experiencing CAS symptoms.



Many indicated that knowing that the symptoms were not due to a neuropsychological condition (ADHD), rather a neurological one (CAE) would have assisted not only with correct medical treatment, but also ensuring more respect for their children's difficulties. Participants felt that a more extensive investigation into the child's personal and medical history should have been completed and evaluated. More time should be spent with both the child and their parents. Further educational material needs to be available to ensure that all are aware of the true condition and how to correctly treat it.

All participants found it difficult to find written material in GP's surgeries to educate themselves and their families on epilepsy in general, let alone CAE. During the investigation I visited local medical practitioners' surgeries and found that none of these surgeries had available material for patients on the topic of epilepsy.

The social reactions that these children had already experienced as a result of the misdiagnosis of ADHD included rejection and denial. This led to the experiencing of negative stereotyping and stigmatisation, confusion and worthlessness. Without a strong level of regular family communication, this can cause further difficulties for a child with epilepsy (Austin, Risinger, & Beckett, 1992).

#### *Maintaining regular family communication*

Each parent believed they influenced the occurrence of behavioural problems. The measure most consistently predictive of behavioural problems is the level of control or overprotection that parents show towards their child (Corkin et al, 1997). This study shows that instructive overprotection manifested by some parent participants has also inhibited their child's development of self confidence. Three of the four child participants who have completed high school still live with their parents and express fear about leaving this environment. They express reluctance to take care of themselves and make their own decisions.

Fear and embarrassment were reactions that parents in Phase 2 of this study felt their child experienced when the stimulant medication was administered. David's mother and Charles's father faced difficulties having their children take the medication regularly. The difficulties arose due to the fact that both Allan and Charles asked why they needed to take tablets. Their questions were not directly answered. These parent participants at this time felt that each child was too young to understand their condition, and therefore tried to protect them by censoring what they told them.

These children felt that as clear reasons for taking the stimulant medication was not provided they did not understand the importance of regular medication.

Lack of family communication can also influence the incidence of behavioural problems (Austin, McNelis, Shore, Dunn, & Musick 1992). It is important that the parents of children with any medical condition requiring regular medication gather correct knowledge and answer all the questions asked by their child in relation to the condition. The families who were able to accept the child's epilepsy when diagnosed and were confident in handling the problems associated with the condition, were able to convey this confidence to their children, resulting in a stronger acceptance of the condition (Dunn & Austin, 2004). Such communication can strongly assist in reducing the fear of the unknown, and maintaining a strong relationship between both generations.

### *Conclusion*

This chapter demonstrates that the effects of the ADHD misdiagnosis had a lasting impact on both children and parent participants. The final Chapter reflects on the research questions. It offers an explanation of the behaviours of a child who has this condition and discusses this study's limitations. Moreover, it offers further recommendations to assist in the development of future research to increase knowledge of CAE and lead to a reduction in misdiagnosis.

## CHAPTER 7

# CONCLUSION

This study focused on five school-age children with Child Absence Epilepsy (CAE) and the psychosocial effects that each of them experienced when their condition was misdiagnosed as Attention-Deficit/Hyperactivity Disorder (ADHD). One parent of each of these children was also interviewed and asked how they felt their child was psychosocially affected. I explored the nature of the reactions that were experienced throughout the period of medical investigation as associated with five progressive phases, and the psychosocial effects evident in CAE children misdiagnosed or inappropriately labelled with the condition of ADHD. This chapter reflects upon the research process, discusses the limitations of this research, and offers recommendations on further research and education needed to develop stronger knowledge on the condition of CAE.

### *Reflection*

This study is unique, as it has explored the experiences of a group of adolescents or young adults and those of one of their parents. Until this point, these personal experiences have been largely ignored despite the pain and suffering incurred as a result of the misdiagnosis of CAE as ADHD. It is not just these experiences but the context in which they occurred that has been investigated in this study. In this research, children with CAE were identified as experiencing psychosocial effects when their condition was misdiagnosed as ADHD. Supporting parents were interviewed and confirmed that these children had experienced difficulties as a result of this misdiagnosis.

The research interview process gave all participants the opportunity to reflect upon, and explain examples of critical incidents that they had experienced in the school environment, and for some within their home environment. The case study methodology used in this study encouraged the participants to be reflective, relating their lived experiences, and communicating the meanings of these experiences from *An exploration of the psychosocial effects that school-age children with CAE* 118 *experience when their condition is misdiagnosed as ADHD*

their perspectives. When I asked all the participants about their feelings during each of the five phases, it was important that they trusted and were willing to speak to me. It is possible to ask those questions about what happened and how the experience had affected them, but I gained better responses by simply allowing them to tell me what they wanted to say. I found participants benefited from me informing them that my own condition of epilepsy had also been misdiagnosed by a general practitioner when I was a child. Although my own condition was not deemed to a neuropsychological condition at the time, the child participants trusted me and knew that I understood.

The first irregular behaviour patterns that all of the parent participants identified were the eye movements of their child. These ranged from one second Absent Seizures in Allan, where his eyes would roll up into the orbit, to those that David would experience, where he would stare in an unconscious manner for up to 10 seconds. Although these were recognised by other family members, all parent participants at first chose to ignore them, believing that these were the actions of a typical child having some fun.

When the children started school, it was not the Child Absence Seizures (CAS) that teachers recognised, but the results of these periods of absence, such as failing to pay attention and complete tasks. Participants felt that frustration was experienced by teachers. Due to the ever increasing social salience of the neuropsychological condition of ADHD, it was suggested by teachers that this behaviour was caused by ADHD. All parent participants at this point questioned this as being the reason for their child experiencing these difficulties. Although their initial reaction was correct, parent participants chose to follow the recommendation of these teachers and took their child to see a child psychologist or paediatrician. I found that most of the parent participants did so just to prove to their child's teachers that they were incorrect.

In most cases in this study, the diagnosis of ADHD was initially made by a general practitioner; and the child was referred to a specialist for confirmation. The reactions of parent participants were mostly connected to denial. I was very surprised to discover that none of these specialists chose to have neurological tests immediately

performed upon each of the child participants to ensure that CAE was not the cause of their symptoms. Following the need to now relieve the child of these stresses, the choice to have each child placed on a stimulant medication was accepted by the parent participants. As ADHD is recognised as being due to a neuropsychological behaviour disorder, many of the participants felt this influenced how society labelled and treated the child participants.

The parent participants started to recognise additional symptoms occurring in their children as they entered their teenage years. In Allan's and Betty's cases this included the dropping of items such as a plate or a cup, and also what seemed to be short periods of falling. Both symptoms are associated with the epileptic condition, Juvenile Myoclonic Epilepsy (JME). Both Charles' father and David's mother started to find their child asking the question; "What is that smell?" This is neurologically recognised as an 'aura' or a Simple Partial Seizure (SPS), which is most often experienced by people with Temporal Lobe Epilepsy (TLE) when scar tissue or lesions are located in the left hemisphere. Elisabeth began experiencing a symptom that is mostly experienced by people with TLE in the right hemisphere, which is the sensation of *déjà vu*; or more simply, the sensation of a feeling "that I have been here before." It was based on the recognition of these symptoms that the parent participants chose to take their child to a neurologist and allow EEG and MRI scanning to be performed. Following these neurological examinations, scar tissue or lesions were located on the brain of each child participant. This had caused irregular neurological activity to occur; resulting in the experiencing of CAS. It was only at this time that it was acknowledged that the child participants had previously been misdiagnosed with ADHD.

Many of the participants felt that teachers had been failing to recognise these symptoms as a result of their lack of education about CAE. Only one of David's teachers, who had previous knowledge of the condition of CAE suggested that CAS may be the cause of these disturbances. Four out of the five parent participants were happy to be made aware of the correct diagnosis of epilepsy. Each parent had become aware of the changes in their child's behaviours, such as the experiencing of

fainting, auras or déjà vu, and wished to understand the reason for these happening. The reaction of Charles's father was a negative one when the diagnosis of epilepsy was made. Fear of his child dying while swimming, or suffocating by placing his face in a pillow while sleeping in bed, due to the experiencing of CPS, meant that he now wished that ADHD was the reason for his child's irregular behaviour.

As all child participants up until this point had experienced difficulties in interacting with others, both in and out of the classroom, due to disciplinary action, bullying and isolation, most of child participants' preferred not to inform others of their new diagnosis. They questioned whether it would make a difference if people knew it was not ADHD, but epilepsy that was causing the symptoms to occur. As most child participants had become withdrawn and had a few friends, the reaction was, "Why bother? They're not my friends anyway" (Charles). The question was now: how did the misdiagnosis of ADHD psychosocially affect these children with CAE?

During the interview period, all participants commented that the misdiagnosis of ADHD had profoundly affected them during the first three phase periods of this investigation. Because the children were not correctly diagnosed with CAE, the treatment they received both medically and socially had a strong psychosocial effect. The stimulant medication did not assist in controlling the short periods of irregular neurological activity that were causing the CAS to occur. The treatment these children experienced as a result of the lack of social education about CAE, saw the child participants being labelled as disruptive and disrespectful; causing feelings of abnormality in these participants. Some of these children felt that the reason they were experiencing seizures was due to weakness on their part. All participants reported that the misdiagnosis continues to have a psychosocial effect on their lives. Most child participants now live very withdrawn lives, preferring to be with a small number of people who they can trust when socialising. I found that each of them demonstrated a low level of self-confidence and self-respect when discussing this topic throughout the duration of the interview.

Both participant groups reported that there is a lack of knowledge both in the professionals who work with these children, and in all social environments in relation

to CAE. The feeling of most participants was that education needs to be offered to those who currently work with children with this condition, and those who are pre-service. Participants also suggested that education needs to be provided for children who share a classroom with a child with epilepsy, to ensure that bullying and social isolation is reduced.

The emotional distress that participants experienced during the ‘period of medical analysis’ (Phase 1 to Phase 4), may at times have affected both their oral and physical reactions when asked a question. This may have lessened their perceptive responses of incidences and the reporting of effects. A larger study would help determine this. There were very complex and open responses from the participants during the interview period. However, the sensitive nature of the issue might also have meant that some participants may have been reluctant to fully disclose the extent of their experiences and difficulties when confronted with misdiagnosis.

The results gathered from this study principally contribute to understanding the effects that children experience through the five phases that are defined, and what reactions are re-experienced during these different phases. The results of interview analyses on the themes of reaction relating to psychosocial effect of the misdiagnosis on the child with CAE indicated that similar reactions were experienced by the participants in the two precursor periods (Phase 1 and Phase 3). This indicated how a situation that involves being unaware of medical reasoning can cause anxiety, fear and agitation in people with a medical condition. These findings indicate that further investigation needs to be undertaken, involving more participants to determine the effect that the repetition of reactions has on the child with CAE. These may include investigations using qualitative and quantitative methodologies, with additional instruments such as questionnaires to assist in the gathering of data. These questionnaire would be directed towards members of all communities; evaluating the strength of social knowledge about CAE.

This research study provides an understanding from the perspective of a researcher who has experienced Childhood Absence Seizures (CAS), Simple Partial Seizures (SPS) and Complex Partial Seizures (CPS). Importantly, the knowledge gained

relating to the diagnosis of ADHD, (which the researcher has not experienced) was solely gained from each participant and the review of literature. The place at which the child with CAE experiences most difficulty is within the school environment. This is an environment where children and young people with medical difficulties experience suffering, unhappiness and a loss in self-confidence through the acts of discriminative peers and poor teacher education about CAE. It is within this specific environment, where the child with CAE is highly vulnerable to bullying and isolation by peers in school communities, that the lack of education in relation to CAE is evident.

The research also found that difficulties were experienced by all participants as a result of the lack of an appropriate neurological investigation when the initial neuropsychological diagnosis of ADHD was given. Once again, only a limited number of participants were a part of this research, so a broader study is recommended.

Most child participants had a consistent ongoing presence of CAS throughout their school age years, which they were unaware of experiencing. They were confused and often self questioned why many peers treated them in such a negative manner. Counselling must be provided for those with CAE, and education must also be provided for all who are in contact with these children, including those within the classroom environment.

The value of reflection on the experiences was observed as being effective for increasing the wellbeing of the participants. Many of the participants in this study recognised how the reflective nature of the interview process gave them an opportunity for the first time to verbally express the reactions they had experienced, enhancing the process of investigation. Although Phase 4 of the period of investigation had a positive outcome for most participants in this study, that being the correct diagnosis of epilepsy, a lack of counselling following the outcome had caused some negative effects. It cannot be assumed that this is what all children with CAE, who are misdiagnosed with ADHD experience will need, but it is evident that counselling needs to be offered to their children and their families. Investigation of



the level of counselling offered to those who are misdiagnosed with ADHD, where it is CAE or other forms of epilepsy that are the true cause of the difficulties that these children experience is also required.

What all professionals who work with these children urgently need is to be provided with appropriate training in the recognition and correct treatment of this condition. The children need to be provided with ongoing clinical and professional supervision and non-judgmental support from their teachers and health professionals. As well as contributing to wider thinking, some findings of this research are appropriate to children with other neurological conditions, and to other educational settings. Children who may be 'outside' the school but have strong on-going links with this environment, such as local care-centres, may be experiencing many of the impacts identified in this research. Other educational investigations will also benefit from the finding of the need for further education and support for children with disabilities.

### *Limitations of the study*

Although the exploration of psychosocial effects was viewed from an individual as well as a parental perspective, the research did not explore the direct reaction of teachers and peers, and how child participants interacted with others in the school environments. Social reactions were only seen through the eyes of the study participants, which limited the information being obtained to that of a third-person perspective. The process could not include initial interviews as the events were experienced. This limitation could be addressed by future research, employing a case study approach combined with a narrative inquiry with members of society who initially are, and secondarily were part of these children's lives during the period of investigation. By incorporating this recommendation into further studies, researchers may also have the opportunity to observe child participants' individual reactions and symptoms while in the classroom. Observing how these children interact, how the classroom environment fits within their overall context, and the levels of stress created may provide a stronger understanding of the best means to educate the community about CAE.

## *Recommendations*

Following the recommendations made in this study, which may be helpful in preventing further misdiagnosis of ADHD occurring, the benefit of addressing the true causes of the child's behaviour is evident. This may help to alleviate emotional scarring, caused by psychosocial effects and give the child an increased chance of thriving in all social atmospheres, including the home and school/social environments.

Medical professionals must perform an extensive investigation into the child's personal and medical history (which may have included the experiencing of long periods of high temperatures within the first two years of life, possibly leading to febrile convulsions), and neurological assessments should be completed and evaluated. In-depth interviews with the persons involved in the child's life, such as parents, siblings, along with observations on the child during formal assessment and/or therapy should be included to rule out CAE.

School-age children spend 30 hours of their week, or six hours a day (Monday to Friday) in the school environment. The classroom has a strong influence on how the child learns academically and the development of self-identity. When the teachers who guide these children have little knowledge on the condition of CAE, the child is too often negatively affected. I recommend that professional learning should be undertaken to educate teachers presently working in the classroom environment about epilepsy and CAE.

As teachers have a strong influence on how children in their classroom view one another, uniformed attitudes can often be replicated in the school playground. These children are often bullied and isolated by peers. Education about epilepsy for children who share a classroom with a child who has this condition, including explanations about absences and other seizures is necessary.

Epilepsy Australia is presently voluntarily entering the classrooms of some children with epilepsy and offering basic education to teachers and other students about the condition. But limited finances and the high levels of misdiagnosis are restricting

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these initiatives. I recommend that Government funding be allocated to social support groups, such as the Epilepsy Australia Foundation to ensure that this necessary education continues.

A child that is experiencing difficulties in the school environment, mostly when studying at a secondary level is often referred to see a school counsellor. Unless the professional is knowledgeable on all forms of epilepsy, problems may occur for a child with CAE if reported as experiencing behavioural problems while in the classroom. The same level of education that I spoke earlier of providing for classroom teachers about CAE should also be provided for school counsellors. The problems that are being experienced by classroom teachers and school counsellors could be more adequately addressed if education on epilepsy was provided to relevant students while studying at a tertiary level.

Fundamentally, further knowledge needs to be provided to the professionals who work in the field of psychology regarding the condition of CAE to ensure that the frequent misdiagnoses of ADHD do not occur. Until it can be established that scar tissue or lesions on the brain are not present, one should not diagnose a child as suffering from ADHD.

Additional knowledge needs to be provided to those working in medicine on the condition of CAE. When seeing medical practitioners, to have a prescription written for one of my medications, I have had these practitioners ask me questions on epilepsy and my opinion on other patients that they are presently caring for, in relation to their symptoms. It was explained by one of these practitioners that the education offered at a tertiary level on all forms of epilepsy and how to recognise the symptoms related to CAE can be very limited. I recommend that further education on all forms of epilepsy be offered at a higher level by the universities. This will help reduce misdiagnosis relating to all forms of epilepsy.

Education needs to be offered to all people with epilepsy and those who are closest to them. Following the diagnosis of epilepsy, a high number of people neither receive information on the condition nor are supported through counselling. I recommend

that support groups for these people be created to offer this needed education. Unless adequate information is offered, people can experience difficulties accepting and understanding the condition.

The findings from this study have created a foundation for further research relating to the misdiagnosis of all forms of epilepsy as well as other misdiagnosed neurological conditions. Further studies, including exploring psychosocial effects on all age groups experiencing different forms of epilepsy, the effects on all family members, and people experiencing other neurological conditions is required. The assistance that support groups offer in terms of education on epilepsy in the classroom could also be investigated. Moreover, research through a case study approach combined with a narrative inquiry could focus on how addressing these issues could help in overall education about epilepsy.

It is necessary that non-judgmental support from the parents, teachers and health professionals be provided for children with CAE. Children with other forms of epilepsy and other neurological condition found within these and other educational settings may also benefit from the findings of this research.

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## APPENDIX A

### *Glossary:*

#### *Modifiers:*

*Cause:* An impaired or lost function may be “acquired,” i.e. the result of an insult or damage to the brain, or perhaps “congenital” or “developmental,” i.e. an impairment of the ability to develop the function (Pugh, Werner, & Filardo, 2000, p. 303).

*Degree:* The prefix “a” (as in aphasia) usually implies a loss of function, but in the developing child it may also mean a lack of the ability to develop the skill.

*Timing:* A disturbed function may be episodic, as with an episodic aphasia. If such an episode is due to a seizure, then it is a paroxysmal aphasia (Pugh et al., 2000, p. 468).

#### *Terms:*

*Absence seizure (AS):* may arise in several forms of epilepsy. Absence epilepsy refers to epilepsy in which the seizure is recorded as a loss in consciousness. Absence epilepsy is characterised by the age of onset, e.g., childhood absence epilepsy beginning in children between the ages of 3 and 12-years of age (Pugh et al., 2000, p. 1614).

*Acquired loss:* A loss of a physical function as a result of brain tissue damage, contrasting with a congenital or developmental loss (Pugh et al., 2000, p. 16).

*Anomia:* Memory problems for proper names, names of items, etc. *Anosognosia:* Unknowing or denial of a neurologic dysfunction (Pugh et al., 2000, p. 91).

*Aphasia, acquired:* Loss of meanings, or understanding of what has been spoken, or difficulty in articulating one’s thoughts through written language or speech, due to scarring, lesion damage, leading to dysfunction of vital language-processing centre (Pugh et al., 2000, pp. 110, 1758).



*Aphasia, expressive*: Loss of understanding of meanings of speech or of what is said, or difficulty in expressing one's thoughts through spoken or written language due to damage or destruction of Broca's area in the posterior inferior frontal lobe involving the dominant hemisphere (Pugh et al., 2000, pp. 110, 1133).

*Aphasic dyslexia*: Impairment in connecting meanings into written or spoken words when reading often associated with a more generalized aphasia (Pugh et al., 2000, pp. 110, 1133).

*Apraxia/dyspraxia*: Loss of the capability to translate a response concept into a motor act, such as speech, writing, or gesturing (Pugh et al., 2000, p. 117).

*Attention-Deficit/Hyperactivity Disorder (ADHD)*: Attention Deficit-Hyperactivity Disorder (ADHD) is a developmental disorder that is often noted as being neuropsychological in nature (LeFever & Arcona, 2003). The term "developmental" means that certain traits such as impulse control significantly lag in development when compared to the general population. ADHD has also been classified as a behaviour disorder and a neurological disorder; these compounded terms are now more frequently used in the fields of psychology and medicine to describe the disorder (Götz-Erik, 2006). The behavioural classification for ADHD is not completely accurate in that those with Predominately Inattentive ADHD often display few or no overt behaviours (MedlinePlus, 2008).

*Auditory agnosia*: The state of being confused and unable to recognize speech sounds or other familiar sounds (Pugh et al., 2000, p. 169).

*Choreoathetoid*: Shuffling, turning, and twisting, movements (Pugh et al., 2000, p. 343).

*Child absence epilepsy (CAE)*: A generalised epilepsy syndrome characterised by the onset of absence seizures in childhood. The seizures appear between ages 3 – 12-years of age, and can occur up to 300 times a day. The children are otherwise normal with no neurological or physical deficiencies (Pugh et al., 2000, p. 605). These seizures are temporary signs and/or symptoms due to abnormal, excessive or

synchronous neuronal activity in the brain (Cross, 2007, pp. 42-43).

*Child Onset Epilepsy (COE)*: including Childhood Onset Absence Epilepsy (CAE), Juvenile Myoclonic Epilepsy (JME), Idiopathic Generalized Epilepsy (IGE), and Complex Partial Epilepsy (CPE), Childhood seizures represent paroxysmal clinical events characterized by abnormal, excessive discharges originating from populations of cortical neurons and resulting in some clinically evident alteration of function or behaviour. Therefore, the clinical manifestations of childhood seizures need not include recognizable motor activity such as tonic-clonic movement; possible clinical manifestations may include staring, drop attacks, behavioural changes, or even autonomic disturbances (Pugh et al., 2000, pp. 605, 606, 737, 1614).

*Complex Partial Seizures (CPS)*: are seizures that impair consciousness to some extent. As a result the person's ability to interact with others is altered. The seizures usually begin with a simple partial seizure, but then the seizure activity leaves the focus point and spreads to a large portion of the temporal lobe, impairing consciousness. Symptoms may include motionless staring, automatic convulsive movements, with an inability to respond to others, unusual speech, or unusual behaviours (Pugh et al., 2000, p. 1614).

*Computed tomography (CT)*: originally known as computed axial tomography (CAT) scan and body section roentgenography (SSR), is a medical imaging method employing tomography where digital geometry processing is used to generate a three-dimensional image of the internals of an object from a large series of two-dimensional X-ray images taken around a single axis of rotation (Pugh et al., 2000, p. 1243).

*Congenital neurologic problem*: Incomplete development of a neurologic function due to a prenatal (around the time of conception through neonatal period) brain insult, usually bilateral. The term is often transitionally used with developmental neurological problem (Pugh et al., 2000, p. 398).

*Developmental neurologic problem:* A deficient development of a neurologic function due to a prenatal (around the time of conception through neonatal period) brain insult or deficiency, usually bilateral. The term is often transitionally used with congenital neurologic problem (Pugh et al., 2000, pp. 486, 525).

*Dextral:* Right-handed (Pugh et al., 2000, p. 488).

*Diagnosis:* The process of identifying a medical condition or disease by its signs, symptoms, and from the results of various diagnostic procedures. The conclusion reached through this process is called *a diagnosis* (Pugh et al., 2000, p. 501).

*Disfunction:* The partial loss or distortion of a cognitive function or language as opposed to a complete loss, as with dysphasia/aphasia, dyslexia/alexia (Pugh et al., 2000, p. 522).

*Dysfluency:* A neurologic impairment resulting in the break-up of the normal flow of speech, such as with stammering or stuttering (MedlinePlus, 2008).

*Dysgraphia/agraphia:* Deficient or distorted ability to write (Pugh et al., 2000, p. 552).

*Dyslalia:* Impairment of utterances, with abnormality of the external speech organs (Pugh et al., 2000, p. 553).

*Dysphasia:* A partial loss or distortion of understanding or expression of language (Pugh et al., 2000, p. 554).

*Electroencephalogram (EEG):* is a neurophysiologic measurement of the neurological activity of the brain, from a large number of neurons. The EEG is a brain function examination. When performing, it is not electrical currents are not measured, but rather voltage differences between different parts of the brain (Pugh et al., 2000, p. 575).

*Episodic dysfunction:* A brief episode of dysfunction, as with an episodic aphasia, dyslexia, etc. due to some insult the brain that temporarily impairs function of the related brain area (Pugh et al., 2000, p. 608).

*Frontal lobe epilepsy (FLE):* Epileptic seizures arising from the frontal lobe characterised by SP, complex partial (CP), secondary generalised seizures (SGS), or combinations of these. The seizures, which are short, may occur several times a day, mostly during sleep. Affected individuals usually have prominent motor manifestations which are tonic or postural, complex gestational automatisms at the onset, and fall to the ground when the discharge is bilateral. Status epilepticus is a frequent complication (Pugh et al., 2000, p. 606).

*Functional magnetic resonance imaging (fMRI):* a neurological examination that evaluates cerebral blood flow, studying the difference between venous oxyhemoglobin and deoxyhemoglobin; the blood oxygen level–dependent (BOLD) contrast technique. This measure the hemodynamic response associated to neural activity in the brain or spinal cord of humans or other animals. It is one of the most recently developed forms of neuroimaging (Passaro 2006).

*Generalised seizures (GS):* Epileptic seizures in which the first clinical changes indicate initial involvement of both hemispheres of the brain, as opposed to epileptic seizures involving a particular focal point of the brain (partial). Generalised seizures can be convulsive or non-convulsive. Consciousness may be impaired and this impairment may be the initial manifestation of the seizure. Motor manifestations, if present, are also bilateral (Pugh et al., 2000, p. 1614).

*Infantile myoclonic spasms:* A seizure syndrome of infancy marked by the onset of repetitive brief flexing or stiffening movements, at which time intelligence declines and the EEG shows a hypsarrhythmic pattern (high-amplitude, disorganized appearance, with multifocal spikes and occasional brief generalized suppression of activities) (Pugh et al., 2000, pp. 894, 1662).

*Ictal period (IP):* refers to a physiologic state or event such as a seizure, stroke or headache. In electroencephalography, or EEG, the recording during an actual seizure is said to be “ictal”. During this period, sudden abrupt; ictal emotions are transitory, fleeting emotions can be experienced. The conditions include loss of consciousness; body jerking; loss of bladder content (Pugh et al., 2000, p. 871).

*Juvenile myoclonic epilepsy (JME):* Also known as *Janz syndrome* is a common form of idiopathic generalized epilepsy affecting up to 10% of the population. This disorder typically first is apparent between 12 and 18-years of age, with myoclonus occurring early in the morning. Most patients also have tonic-clonic seizures and many have absence seizures. Linkage studies have demonstrated at least 60% loci for JME, 40% with known causative genes. Most of these genes are ion channels with the one non-ion channel gene having been shown to affect ion channel currents (Pugh et al., 2000, p. 606).

*Learning disability:* A specific learning disability is a disability of one or more of the basic learning processes engaged in the comprehension or using of spoken or written language, evidenced by an inadequate ability to speak, listen, think, spell, read, write, or do mathematical calculations. This includes disorders such as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. This does not include children who have learning problems that are principally the result of visual impairment, hearing difficulties, mental retardation, emotional disturbances, environmental disadvantages, or motor handicaps. Such children exhibit an inconsistency between expected and actual achievement expected for their overall mental age, commonly interpreted as meaning two standard deviations below normal (Adopted from Public Law 91-230, Section 602-15, Federal Department of Health, Education & Welfare, USA). A rarely applied concept that shows that the child who has a specific learning disability is handicapped in efforts to perform the task impaired by the learning disability, such as speaking, listening, thinking, spelling, reading, writing, or mathematics (Pugh et al., 2000, p. 979).

*Learning problem:* A non-specific term applied to any child who has difficulty in performing in school (Pugh et al., 2000, p. 980).

*Magnetic resonance imaging (MRI):* formerly referred to as magnetic resonance tomography (MRT); a non-invasive method used to render images of the inside of an object. It is primarily used in medical imaging to demonstrate pathological or other physiological alterations of living tissues (Pugh et al., 2000, p. 1135).

*Misdiagnosis*: The term misdiagnosis is the process of incorrectly identifying a medical condition or disease by its signs, symptoms, and from the results of various incorrect diagnostic procedures (Pugh et al., 2000, p. 1120).

*Myoclonic seizures (MS)*: A progressive encephalopathy characterised by myoclonic jerks (single or repetitive muscle contractions involving one body part or the entire body), mental retardation, and ataxia. The disorder, an autosomal recessive form of epilepsy, occurs usually in the teen-age years. The most important pathological findings are Lafora's inclusion bodies, which contain mucopolysaccharides (Pugh et al., 2000, p. 606).

*Neuropsychology (NP)*: a branch of neurology and psychology that aims to understand how the structure and function of the brain relate to specific psychological processes and overt behaviours (Pugh et al., 2000, p. 1212).

*Nonconvulsive status epilepticus (NSE)*: refers to simple partial (aura continua), psychomotor (complex partial), and absence status epilepticus. Psychomotor status epilepticus and absence status epilepticus exhibit an epileptic twilight state of altered contact with the environment. In simple partial status epilepticus, there is no impairment of consciousness, and the behaviour changes reflect focal ictal discharges confined to one area of the cortex (Pugh et al., 2000, pp. 605, 1693).

*Paraphasia*: A form of aphasia in which the patient uses wrong words or uses words in wrong and senseless combinations (Pugh et al., 2000, p. 1313).

*Paroxysm*: A sudden occurrence of a symptom, such as with a spasm (Pugh et al., 2000, p. 1318).

*Partial Seizures (PS), also called Focal seizures*: arising in the temporal lobe are often accompanied by stereotyped motor behaviour involving the lower part of the face; characterised by conserved consciousness in *simple* focal seizure, the child in this case displays impaired consciousness (dream-like) in *complex* focal seizures. Unusual feelings or sensations, sudden and unexplainable feelings of sadness joy, anger, or nausea are often experienced. Also an altered sense of hearing, smelling,

tasting, seeing, or feeling things that are not real, having a change or loss of consciousness (may appear dream-like). Strange repetitious behaviours such as twitches, blinks, and mouth movements are often observed. If these are in the motor cortex, the initial manifestation will be a contraction of the muscles in the opposite side of the body. Partial motor seizures are most likely to begin at the angle of the mouth, the index finger and thumb, or the big toe. If the seizure discharge then spreads through contiguous layers of cortex, the clinical manifestations march into the homologous parts of the body causing seizure activity to commence (Pugh et al., 2000, pp. 606, 1615).

*Perceptual dyslexia*: Confusion of similar letters and words, impairing the reading process (Pugh et al., 2000, p. 553).

*Petit Mal/Absence (aura continua) (PMS)*: Epileptic seizures that consist of a sudden cessation of ongoing conscious activity without convulsive muscular activity or loss of postural control. These seizures may be so brief as to be unapparent, lasting seconds and occasionally several minutes. Petit Mal usually begins in otherwise neurologically normal children and rarely appears for the first time in adults. The seizures may occur hundreds of times per day and go on for weeks or months before it is recognised that a child is having seizures (Pugh et al., 2000, p. 1614).

*Positron emission tomography (PET) scan*: An isotopic brain scan that measures positrons emitted by a variety of radioisotopes injected into the bloodstream to measure the chemistry and metabolism of areas of the brain (Pugh et al., 2000, pp. 1356, 1842).

*Post Ictal*: Loss of the ability to form new memories beyond a certain point in time. This condition may be organic or psychogenic in origin. Organically induced anterograde amnesia may follow Craniocerebral trauma; Cerebrovascular accidents; Seizures; Anoxia; and other conditions which adversely affect neural structures associated with memory formation (e.g., the Hippocampus; Fornix (brain); Mammillary bodies; and Anterior Thalamic Nuclei) (Pugh et al., 2000, p. 1431).

*Pre-Ictal (Amnesias)*: Loss of the ability to recall information that had been

previously encoded in memory prior to a specified or approximate point in time. This process may be organic or psychogenic in origin. Organic forms may be associated with Craniocerebral trauma; Cerebrovascular accidents; Seizures; Dementia; and a wide variety of other conditions that impair cerebral function (Pugh et al., 2000, pp. 60, 1439).

*Regression:* The loss of a previously attained skill, such as a speech or language regression (MedlinePlus, 2008).

*Retardation, mental:* Overall intelligence of at least three standard deviations (borderline) below the average. Retardation may be borderline (overall intelligence at least two standard deviations below average but less than three standard deviations below normal), mild (overall intelligence roughly one-half to two-thirds normal), moderate (overall intelligence roughly one-quarter to one-half normal), or severe (overall intelligence below one-quarter normal). Simple partial seizures: Seizures beginning in a part of the brain with intact consciousness at the onset, usually presenting with a movement, sensation, emotion, or memory. These may be auras progressing on to another seizure type (Pugh et al., 2000, p. 1557).

*School-age Children:* Children in Australia enter primary school at five years of age. Firstly commencing primary school, a child remains in this environment until eleven years of age (Grade 6). The child will then enter secondary school at twelve years of age and remain there for a further six years, completing their basic education at the age of seventeen (Grade 12).

*Seizures:* Neurological functioning found that although seizures do occur spontaneously, seizures can be provoked. Particular influences include factors such as metabolic factors (hypoglycaemia, hyperventilation), nyctohemeral factors (evening or awakening), fear, surprise, embarrassment, anger, sorrow, release of attention, meal-time for some children, and school-time for others. Of all these, the main influencing factor is hyperventilation (J. K. Austin, 2001; Corbett, 2006) Examples include: CAE, JME, IGE and CPE (Pugh et al., 2000, pp. 1614-1615).

*Sinistral:* Left-handed (Pugh et al., 2000, p. 1614).



*Simple partial seizure (SPS) (aura continua)*: the consciousness of the sufferer remains altered. Such seizures involves any of a variety of auras: déjà vu, an unusual smell, a sudden intense emotional feeling, a sensory illusion such as micropsia (objects growing smaller) or macropsia (objects growing larger), or other sensory hallucination. This seizure may progress to a CPS or to a generalized tonic-clonic seizure (TCS) in some sufferers (Pugh et al., 2000, p. 1615).

*Single photon emission computed tomography (SPECT)*: is a nuclear medicine tomographic imaging technique using gamma rays. It is very similar to conventional nuclear medicine planar imaging using a gamma camera. However, it is able to provide true 3D information. This information is typically presented as cross-sectional slices through the patient, but can be freely reformatted or manipulated as required (Pugh et al., 2000, p. 1663).

*Status epilepticus (SE)*: refers to a life threatening condition in which the brain is in a state of persistent seizure. Definitions vary, but traditionally it is defined as one continuous seizure or recurrent seizures without regaining consciousness between seizures for greater than 30 minutes. Many doctors, however, believe that 5 minutes is sufficient to damage neurons and that seizures are unlikely to self-terminate by that time (Pugh et al., 2000, p. 1693).

*Temporal lobe epilepsy (TLE)*: Epileptic seizures characterised by SPS, CPS, and secondary generalised seizures (SGS), or combinations of these. Seizures may present with autonomic and/or psychic symptoms and certain sensory phenomena such as olfactory and auditory. Most common is an epigastric rising sensation. Some seizures may begin with motor arrest and continue with oro-alimentary automatisms (with other automatisms following). Attacks are followed by amnesia and recovery is gradual. Usually, there is a history of febrile seizures in the individual or a history of seizures in the family. Seizures occur in clusters, randomly, or at intervals (Pugh et al., 2000, p. 1793).

*Tonic-Clonic seizure (TCS)*: The hallmark of a grand mal seizure is disordered muscular contraction. The first phase is known as the tonic phase. The body becomes

rigid, and, as it is incapable of maintaining a normal co-ordinated posture, the sufferer will, if standing, fall to the ground. The chest muscles also contract, forcing the air out through the larynx in an involuntary grunt or cry. The jaw muscles also contract, and the tongue may be bitten. The absence of ventilatory movements and the high oxygen consumption of the vigorously contracting muscles result in the rapid onset of cyanosis. The face becomes suffused by desaturated blood, which is prevented from draining into the thorax by the raised intrathoracic pressure.

The normal movements of swallowing are lost, so that saliva may dribble from the mouth. The disordered contraction of abdominal and sphincter muscles may result in incontinence of urine and, occasionally, faeces.

After a brief time in the tonic phase, which may vary from a few seconds to a minute, the seizure passes into a clonic or convulsive phase, with rhythmic contractions of limbs and trunk muscles. The amplitude of these contractions is variable. They continue for a few seconds to a few minutes, after which the individual lies in a deep stupor, which gradually lightens through a stage of confusion into full consciousness. Upon recovery, there is a gradual return to consciousness, disorientation, amnesia from the seizure, sometimes retrograde amnesia as well, headache, and drowsiness. The individual may not return to baseline functioning for days (Pugh et al., 2000, p. 1614).

*Typical absences (petit mal seizures):* This description should only be given to absence attacks associated with classical, 3-Hz spike-and-wave activity in the EEC. Petit mal is a disorder with onset in childhood, and attacks continuing into adult life are rare. A typical absence attack is very brief, lasting only a few seconds. The onset and termination are abrupt. The child ceases what he or she is doing, stares, looks a little pale, and may flutter the eyelids. Sometimes more extensive bodily movements occur, such as dropping the head forwards, and there may be a few clonic movements of the arms. Attacks are very commonly provoked by hyperventilation for 3 min or so, and this is well worth testing in the outpatient clinic or during electroencephalography. About one-third of all children with petit mal will have one or more tonic-clonic convulsions (Pugh et al., 2000, p. 1615).

## APPENDIX B

Year 7

REPORT ON Martin Raffaele  
 FOR Dec 1983

**GENERAL REPORT** (conduct, punctuality, uniform, attendance, reliability, etc.):

*A very good report. The Math and Science results are most pleasing. It is obvious Martin has considerable ability and if his concentration is maintained, he should do even better.*

M. James CLASS SUPERVISOR

Andrew O'P PRINCIPAL

REPORT ON Martin Raffaele  
 FOR December, 1983

**SUBJECT:** *Mathematics*

**MARK:** *80*

**GRADE:** *2*

**REMARKS:** *Martin is a very capable young man. His attention span is quite short however and this hinders his progress at times. If Martin can apply himself in Year 8, he is capable of improving his marks*

M. Callaghan Class Teacher

Year 8

REPORT ON Martin Raffaele  
 FOR June 1984

**GENERAL REPORT** (conduct, punctuality, uniform, attendance, reliability, etc.): Generally, Martin has made a good effort to achieve his results. During all classes he lacks concentration needed to do the work. This must improve.

He regularly attends school and is punctual to class.

Aue Howe CLASS SUPERVISOR

MK Moss PRINCIPAL

REPORT ON Martin Raffaele C2  
 FOR June, 1984

SUBJECT: English

MARK: 55½ Form Average - 65  
 Class Average - 59

GRADE: 4

REMARKS: Martin is a keen and interested student but seems to let his concentration wander. With greater care and attention to writing, his marks could improve.

J. Fagan Class Teacher



Year 12 cont.



SUBJECT: .....

English

CLASS: 2/3 UNIT R

Half Yearly	Yearly
-------------	--------

	CLASS	LEVEL
Mark		59
Position		35 / 45

Effort	G
--------	---

Martin has tried very hard all year. His writing continues to improve. His Trial result looks disappointing but scaling cost him 6 marks, so despair is not called for. He has a good grasp of his texts and if he can concentrate on specific questions rather than writing "tell me all you know" answers, he could go well.		
Parent Interview Requested	Yes	No
EXAM MARK	49	Teacher: <i>Abate</i>
LEVEL AVERAGE	60	



SUBJECT: .....

Ancient History - 3U

CLASS: 12AH

<del>Half Yearly</del>	Yearly
------------------------	--------

	CLASS	LEVEL
Mark		33
Position		5 / 5

Effort	G
--------	---

Martin has worked very hard throughout the year and has achieved pleasing results. He should now organise his time, his work, and preparation for the examinations, so as to achieve his best essays.		
Parent Interview Requested	Yes	No
EXAM MARK	32	Teacher: <i>R. A. Hedding</i>
LEVEL AVERAGE	37	

## APPENDIX C

### Symptoms of Absence Seizures

<i>Symptoms</i>	
<b>Muscle activity changes</b>	
<b><i>1. No movement</i></b>	
a.	Hand fumbling
b.	Fluttering eyelids
c.	Lip smacking
d.	Chewing
<b><i>2. Consciousness changes</i></b>	
a.	Staring episodes (unintentional)
b.	Lack of awareness of surroundings
c.	Sudden halt in conscious activity (movement, talking, etc.)
d.	May be provoked by hyperventilation or flashing lights, in some cases
e.	Abrupt beginning of seizure
f.	Each seizure lasts no more than a few seconds
g.	Full recovery of consciousness, no confusion (resume previous activity without impairment)
<b><i>3. Memory</i></b>	
a.	No memory of seizure

## APPENDIX D

### IN-DEPTH INTERVIEW

#### *Adolescent/Young Adult In-depth Interview*

**Name of Interviewer** \_\_\_\_\_

**Date** \_\_\_\_\_

**Name of Interviewee** \_\_\_\_\_

“Good morning, my name is Martin Raffaele. How are you going today.....?”

This interview is being conducted so that I can gain knowledge of your personal experiences with epilepsy. I am also interested to know what you experienced when you were first diagnosed with Attention Deficit-Hyperactivity Disorder, ADHD, and what you experienced when you were later diagnosed with Child Onset Absence Epilepsy. I am also interested in how people around you have reacted when these diagnoses occurred. If at any time you wish to rest or stop your participation in this interview please let me know and we can do so.”

“I have epilepsy myself. I developed the condition due to febrile convulsions, caused by high temperatures when I was around two years of age. While I was a teenager I experienced absence seizures, as I also had Child Onset Absence Epilepsy. At that time my epilepsy was not diagnosed”.

“If it is okay with you, I will start tape recording our conversation. The reason for doing this is to gain all the details and at the same time be able to hold an attentive conversation with you. I assure you that all your comments will remain confidential. I will write a research report which will contain all the participants’ comments without any reference to individuals’ names.”

“I’m now going to ask you some questions that I would like you to answer to the best of your ability. If you do not understand a question, please say so.”

**“I’d like to start by asking you to briefly tell me about your family.”** (*Note: I may need to probe- “Do you live with both your parents”, “Do you have any brothers or sisters?”, “(If so) is he/she or are they older or younger than you?”*).



**Can you also tell me what you are doing now in your life?** (Probes Re. school, study, job)

**“When were you first diagnosed with ADHD?”**

*(Note: I may need to probe – “How old were you when the diagnosis of ADHD was made?”, “What was explained?”, “What was explained as the reasons for these symptoms occurring?”, “What were the suggestions on how to minimize these symptoms?”).*

**“How did you feel when you were diagnosed with ADHD and how did this affect your everyday life?** (Note: If emotions such as confused, angry, or scared or relieved to have a label are mentioned, I may need to ask; “what do you mean by .....”, “How was this different from before the diagnosis?”). “Can you describe an actual incident or event you remember that occurred at this time connected with your diagnosis with ADHD?”

**“How did your family react when you were diagnosed with ADHD?** *(Note: I may need to probe-(for information on the individual reactions of family members) “What did your family members say to you?”, “Why do you think they felt this way?”, “How did you feel then?”).* “Can you describe an actual incident or event you remember that occurred at this time connected with their reaction to your diagnosis with ADHD?”

**“How did the people outside your family react when they were told you were diagnosed with ADHD?** (Note: I may need to probe information on the individual reactions of extended family members, peers, teachers and etc.) (“What did they say to you?”, “Why do you think they felt this way?”, “How did this make you feel then?”). “Can you describe an actual incident or event you remember that occurred at this time connected with their reaction to your diagnosis with ADHD?”

**“When were you originally diagnosed with Child Onset Absence Epilepsy?”**

*(Note: I may need to probe – “How old were you when this diagnosis was made?”, “What was explained as being the symptoms?”, “What was explained as the reasons for these symptoms occurring?”, “What were the suggestions on how to minimize these symptoms?”)*

**“How did you feel when you were diagnosed with child onset absence epilepsy?”**

**(Note: I may need to probe – “(If emotions such as confused, angry, or feared are relieved when diagnoses are mentioned, I may need to ask; “what do you mean by ..... ”), “How was your self-confidence affected?”, “How was this different from before the diagnosis?”).**

**How did this diagnosis of epilepsy affect your everyday life?**

“Can you describe an actual incident or event you remember that occurred at this time connected with your diagnosis with epilepsy?”

**“How did your family react when you were diagnosed with epilepsy?”** *(Note: I may need to probe-(for information on the individual reactions of family members)*

*“What did your family members say to you?”, “Why do you think they felt this way?”, “How did you feel then?”).* “Can you describe an actual incident or event you remember that occurred at this time connected with their reaction to your diagnosis with epilepsy?”

**“How did the people outside your family react when they were told you were diagnosed with Child Onset Absence Epilepsy? I’d be consistent with either epilepsy or CAE?** *(Note: I may need to probe information on the individual reactions of extended family members, peers, teachers and etc.)*

*(“What did they say to you?”, “Why do you think they felt this way?”, “How did this make you feel then?”).* “Can you describe an actual incident or event you remember that occurred at this time connected with their reaction to your diagnosis with epilepsy?”

**“What happened when you had a seizure?”**

*(Note: I may need to probe- “How long did your seizures last?”, “What did you do when a seizure was occurring?”, “Did other people notice the seizures occurring?”*

*(Note: if aware, I need to probe- who it is that recognised the seizures and their individual reactions as far as he/she is aware).*

**Do you still experience seizures?** (Probe re. frequency, type, ongoing medication, impact on life choices e.g. driving etc.)

**“What do you feel could be the reason why most people know so little about**

**Child Onset Absence Epilepsy?”** *(Note: I may need to probe- How much knowledge do you think people have about epilepsy?”, “What do you think people need to be told?”*

**“What do you suggest needs to be done to change the issues, such as a lack of knowledge in relation to epilepsy from continuing to occur?”** *(Note: May need to Probe - I may also need to probe to gather information on their opinion in relation to doctors, family members, peers, teachers, and etc.).*

“I wish to thank you for your time, your knowledge and suggestions in relation to these questions. Do you have any questions at all that you would like to ask me? Please take my card and if you have any further information you feel would be appropriate to this study, feel free to contact me at any time.” If you would like another opportunity to be interviewed I am happy to arrange this with you.

## APPENDIX E

### *Appendix E*

Name of Interviewer \_\_\_\_\_

Date \_\_\_\_\_

Name of Interviewee \_\_\_\_\_

#### **PARENTAL (OR GUARDIAN)**

##### **In-depth Interview**

“Good morning, I am Martin Raffaele.

This interview is being conducted so that I can gain knowledge of your personal experiences when your child’s/the child under your care’s condition was diagnosed as being ADHD and later with epilepsy. I am interested in how your child, you, and the people around you and your child reacted to these diagnoses. If at any time you wish to rest or stop your participation in this interview please let me know and we can do so.”

“I have epilepsy myself. I developed the condition due to febrile convulsions, caused by high temperatures when I was around two years of age. While I was a teenager, I also experienced Child Onset Absence Seizures. At that time my epilepsy was not diagnosed”.

“If it is okay with you, I will start tape recording our conversation. The purpose of this is because it will allow me to get all the details and at the same time be able to carry on an attentive conversation with you. I assure you that all your comments will remain confidential. I will compile a report which will contain all the participants’ comments without any reference to individuals’ names.”

**“I’d like to start by asking you to briefly explain your family structure and where your child is placed within it.”**

*(Note: I may need to probe to gather the information in relation to age/s and gender of other children, and age differences).*

“I’m now going to ask you some questions that I would like you to answer to the best of your ability. If you do not understand a question, please say so.”

**“When were you first aware that your child was experiencing symptoms that were later diagnosed as ADHD?”**

*(Note: If needed, probe – “How old was your child when this diagnosis was made?”, “What were the symptoms that you were told your child was experiencing?”, “What was explained as the reasons of the occurring symptoms?”, and “What were the suggestions on how to minimize these symptoms?”)*

“How did you feel/react when this diagnosis of Attention Deficit-Hyperactivity (ADHD) was made and how did this affect your everyday life?” *(Note: I may need to probe- “Why did you feel this way?”, “How did these reactions make your child feel then?)* “Can you describe an actual incident or event you remember that occurred at this time?”

**“What was the initial reaction of your closest family when this diagnosis of ADHD was made?** *(Note: I may need to probe to gather information on the individual reactions of family members)* (“Why did they feel this way?”, “How did these reactions make your child feel then?”). “Can you describe an actual incident or event you remember that occurred at this time?”

**“What was the initial reaction of your extended family and others when this diagnosis of ADHD was made?** *(Note: I may need to gather information on the individual reactions of grand parents, neighbours, school councillor/teachers)* (“Why did they feel this way?”, “How did these reactions make your child feel then?”). “Can you describe an actual incident or event you remember that occurred at this time?”

**“What was the initial reaction of your child’s friends and others outside your family when this diagnosis of ADHD was made?** *(Note: I may need to probe to gather information on the individual reactions of peers, teachers and etc.)* (“Why did they feel this way?”, “How did these reactions make your child feel then?”). “Can you describe an actual incident or event you remember that occurred at this time?”

**“When were you first aware that your child was experiencing symptoms that were later diagnosed as Child Onset Epilepsy?”**

*(Note: If needed, probe – “How old was your child when this diagnosis was made?”, “What were the symptoms that you were told your child was experiencing?”, “What*

*was explained as the reasons of the occurring symptoms?”, and “What were the suggestions on how to minimize these symptoms?”, “What medications was your child placed on?).*

“How did you feel/react when this diagnosis of Child Onset Absence Epilepsy (CAE) was made and how did this affect your everyday life?” (Probe- “Why did you feel this way?”, “How did these reactions make your child feel then?) “Can you describe an actual incident or event you remember that occurred at this time?”

**“What was the initial reaction of your closest family when this diagnosis of Child Onset Absence Epilepsy (CAE) was made?** (Note: I may need to probe to gather information on the individual reactions of family members) (“Why did they feel this way?”, “How did these reactions make your child feel then?”). “Can you describe an actual incident or event you remember that occurred at this time?”

“What was the initial reaction of your extended family and others when this diagnosis of Child Onset Absence Epilepsy (CAE) was made? (Note: I may need to gather information on the individual reactions of grand parents, neighbours, school councillor/teachers) (“Why did they feel this way?”, “How did these reactions make your child feel then?”). “Can you describe an actual incident or event you remember that occurred at this time?”

**“What was the initial reaction of your child’s friends and others outside your family when this diagnosis of Child Onset Absence Epilepsy (CAE) was made?** (Note: I may need to probe to gather information on the individual reactions of peers, teachers and etc.) (“Why did they feel this way?”, “How did these reactions make your child feel then?”).

**“What happened when your child had a seizure?**

(If needed, Probe- “How long did the seizure last?”, “What did you do while the seizure is occurring?”, “Did other people notice the seizures occurring?” (Note: if so I may need to probe to gather who it is that recognises the seizures and their individual reactions as far as he/she is aware). Does your child still experience seizures?

**“What do you feel could be the reason why most people know so little about Child Onset Absence Epilepsy?”**, **“What would you recommend needs to be done to change this?”** (*Note: May need to probe to gather information on their opinion in relation to doctors, family, peers, teachers, and etc.*) – (*“How much knowledge do you think people have about epilepsy?”*, *“What do you think people need to be told?”*).

**“What are your suggestions on how to go about changing the issues, such as lack of knowledge in relation to epilepsy, and its misdiagnosis in some cases, from continuing to occur?”**

“I wish to thank you for your time, your knowledge and suggestions in relation to these questions. Please take my card and if you have any further information you feel would be appropriate to this study, feel free to contact me at any time.”

## APPENDIX F

Short-hand system to assist with interviews

child A

Entry

in sit quick, is my boy + i

Phase 1

= ↑ mps m = ↑

→ ? ← m

→ = ← ↓, E m -

Ph 2.

↑ m m ↑ cause older. B m E m.

in dad "they didn't want to believe"

E ↑ in ADHD E ↑

Ph 3.

E ↓ B m - P ↑

✓ JMS ADHD / talk.

Ph 4

fear Soc

i CAE ✓ ADHD X P →

E ↑ giggle. = ↓ P ↓

Ph 5: i ↑ E ↑ B →. P → confident.

Footnote

E - eye contact

→ O ← - Focus

= Answer + and

P - pitch of voice.

↑ increasing

? question

B - body.

→ decreasing.

↑ quick lift

i happy i sad

↓ quick lowering

✓ correct X wrong.

m changing/moving

→ even

i felt uneasy.

x agitated.



## Child A

showed signs of nervousness when entering the room. Was quick to sit down and seemed he wanted to get on with it straight away. Spoke about our present academic studies. Was happy with the

Phase 1. Answered the question with short answers. Seemed a little nervous that he was being tape recorded. The answers were straight to the point. When asking the interviewer question the interviewee held focus. but when answering question this focus was wobbled.

Phase 2 He was more aware of the incidents as he was a little older. He would start by looking at the interviewer but then quickly looking away. He seemed to be having trouble remembering and remained focused on one specific area in the room when talking. Became agitated when speaking of family reaction as "they didn't want to believe it". When talking of social reaction the interviewee gained eye contact for a short time. started to look in the air and shake his head around when speaking of the label of being a Bad Child.

## APPENDIX G



The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee  
[www.usyd.edu.au/ethics/human](http://www.usyd.edu.au/ethics/human)

Senior Ethics Officer:

Gail Briody

Telephone: (02) 9351 4811

Facsimile: (02) 9351 6706

Email: [gabriody@usyd.edu.au](mailto:gabriody@usyd.edu.au)

Room 313A, Level 3, Old Teachers College – A22

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Human Secretariat

Telephone: (02) 9036 9309

(02) 9036 9308

Facsimile: (02) 9036 9310

28 February 2008

Dr S Colmar  
Faculty of Education and Social Work  
Room 8, Education Building – A35  
The University of Sydney

Dear Dr Colmar

I am pleased to inform you that the Human Research Ethics Committee (HREC) at its meeting on 18 February 2008 approved your protocol entitled “An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD)”.

Details of the approval are as follows:

<b>Ref No.:</b>	<b>02-2008/10616</b>
<b>Approval Period:</b>	<b>February 2008 to February 2009</b>
<b>Authorised Personnel:</b>	<b>Dr S Colmar</b> <b>Professor T Parmenter</b> <b>Mr M Raffaele</b>

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans-March 2007* under Section 5.1.29

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

### Special Condition/s of Approval

Please provide a copy of the letter of permission from Epilepsy Action, Australia, when received. Also, please provide Professor Trevor Parmenter's signature in Section 11 of the ethics application as soon as available.

### Chief Investigator / Supervisor's responsibilities to ensure that:

- (1) All serious and unexpected adverse events should be reported to the HREC as soon as possible.

- (2) All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- (3) The HREC must be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-
  - If any of the investigators change or leave the University.
  - Any changes to the Participant Information Statement and/or Consent Form.
- (4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. *Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or [gbriody@usyd.edu.au](mailto:gbriody@usyd.edu.au) (Email).*
- (5) Copies of all signed Consent Forms must be retained and made available to the HREC on request.
- (6) It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.
- (7) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.
- (8) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



Professor D I Cook  
**Chairman**  
**Human Research Ethics Committee**

cc: Mr Martin Raffaele, Room 518, Faculty of Education and Social Work, Education Building – A35, The University of Sydney

Encl. Copy of Approved Parental (or Guardian) Consent Form, Copy of Approved Parental (Guardian) Information Statement, Copy of Approved Participant Information Statement, Copy of Approved Participant Consent Form, Copy of Approved Participants Sought for Research Study, Copy of Approved Safety Protocol/ Child Onset Absence Epilepsy Research, Copy of Approved Child Onset Absence Epilepsy Research/ Off-campus Information and Record Form



The University of Sydney

Faculty of Education & Social Work A35

NSW 2006 AUSTRALIA

Dr. Susan Colmar  
Program Director School Counselling and School Psychology

Telephone +61 2 9351 6265  
Facsimile +61 2 9351 2606  
Email: s.colmar@edfac.usyd.edu.au

### PARENTAL (OR GUARDIAN) CONSENT FORM

I, ..... agree to participate, and permit my adolescent child (Name, please print)....., who is aged ..... years, to participate in the research project:

Title: An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that both I and my adolescent child can withdraw from the study at any time, without affecting my relationship with the researcher(s) now or in the future.
4. I understand that my adolescent child's involvement is strictly confidential and no information about me or my child will be used in any way that reveals our identity.

If further time is required to gather the full information, a second interview will take place.

.....  
Signature of Parent/Carer

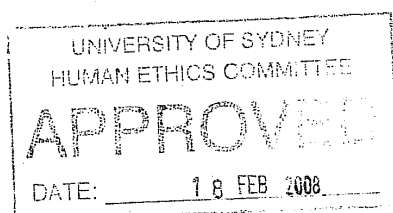
.....  
Signature of Participant

.....  
Please PRINT name

.....  
Please PRINT name

.....  
Date

.....  
Date



Mr. Martin Raffaele  
Telephone (02) 9351 6371  
E-mail: [m.raffaele@edfac.usyd.edu.au](mailto:m.raffaele@edfac.usyd.edu.au)



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NSW 2006 AUSTRALIA

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Email: s.colmar@edfac.usyd.edu.au

### Parental (Guardian) Information Statement

**Title:** An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).

This study will investigate the perceived psychosocial effects that a School-age Child with Epilepsy experiences when their condition is misdiagnosed and labelled as Attention Deficit/Hyperactivity Disorder (ADHD). The findings are potentially important for researchers and practitioners in medicine, psychology, education, and counselling.

The study is being conducted by Mr Martin Raffaele, and will form the basis for the degree of Masters of Philosophy in Education at The University of Sydney under the supervision of Dr Susan Colmar, Program Director of School Counselling, the Faculty of Education and Social Work and Professor Trevor Parmenter, Foundation Professor of Developmental Disability Studies Discipline of Medicine.

The study will involve five adolescents/young adults with Child Onset Epilepsy, whose condition was once diagnosed as ADHD and their care-givers at this time. Note: the parent (guardian) may no longer be required to care for the adolescent/young adult to obtain their perspective on the effects of that misdiagnosis might have on a child experiencing (CAE). Interviews will be conducted to collect data. The name of each participant has been provided by Epilepsy Action Australia.

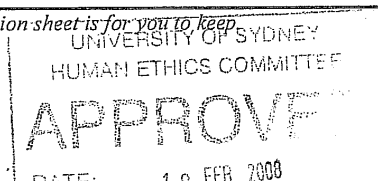
Interviews will be tape-recorded with participants' consent and will be of approximately one hour duration. The interview will be conducted in the home of the participant. A second interview will be made available if further time is needed to discuss the experiences and answer further questions once the initial one hour interview has come to an end.

Participating in this study is completely voluntary and you are not under any obligation to consent. You are free to withdraw your consent and to discontinue your participation in this study at any time without prejudice. All aspects of the study, including results, will be strictly confidential and only the researcher will have access to information on participants. The results of this study will be submitted to the University of Sydney for a Masters of Philosophy thesis being written in the Faculty of Education and Social Work.

When you have read this information, Mr. Martin Raffaele will be available to further discuss it with you and answer any questions you may have. If you would like to know more information at any stage, please feel free to contact Mr. Martin Raffaele [m.raffaele@edfac.usyd.edu.au](mailto:m.raffaele@edfac.usyd.edu.au), (02) 9351 6371.

**Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or [gbriodv@usyd.edu.au](mailto:gbriodv@usyd.edu.au) (Email).**

*This information sheet is for you to keep*





The University of Sydney

Faculty of Education & Social Work A35

NSW 2006 AUSTRALIA

Dr. Susan Colmar  
Program Director School Counselling and School Psychology

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Email: s.colmar@edfac.usyd.edu.au

## Participant Information Statement

**Title:** An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).

This study will investigate the perceived psychosocial effects that a School-age Child with Epilepsy experiences when their condition is misdiagnosed and labelled as Attention Deficit/Hyperactivity Disorder (ADHD). The findings are potentially important for researchers and practitioners in medicine, psychology, education, and counselling.

The study is being conducted by Mr Martin Raffaele, and will form the basis for the degree of Masters of Philosophy in Education at The University of Sydney under the supervision of Dr Susan Colmar, Program Director of School Counselling, the Faculty of Education and Social Work and Professor Trevor Parmenter, Foundation Professor of Developmental Disability Studies Discipline of Medicine.

The study will involve five adolescents/young adults with Child Onset Epilepsy, whose condition was once diagnosed as ADHD and their care-givers at this time. Note: the parent (guardian) may no longer be required to care for the adolescent/young adult to obtain their perspective on the effects of that misdiagnosis might have on a child experiencing (CAE). Interviews will be conducted to collect data. The name of each participant has been provided by Epilepsy Action Australia.

Interviews will be tape-recorded with participants' consent and will be of approximately one hour duration. The interview will be conducted in the home of the participant. A second interview will be made available if further time is needed to discuss the experiences and answer further questions once the initial one hour interview has come to an end.

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UNIVERSITY OF SYDNEY  
HUMAN ETHICS COMMITTEE  
**APPROVED**



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Faculty of Education & Social Work A35

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**PARTICIPANT CONSENT FORM**

I, ..... give consent for my participation in the research project.  
Name (please print)

TITLE: An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).

In giving my consent I acknowledge that:

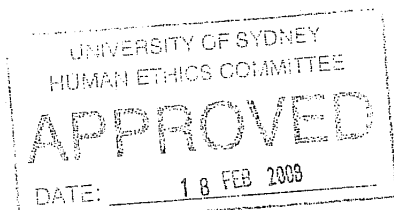
1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.
4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

If further time is required to gather the full information, a second interview will take place, and this interview will be audio-taped.

Signed: .....

Name: .....

Date: .....



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## Participants Sought for Research Study

**Title: An exploration of the psychosocial effects that school-age children with Child Onset Absence Epilepsy (CAE) experience when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD).**

Participants are sought to take part in the named research study.

This study will investigate the perceived psychosocial effects that a School-age Child with Epilepsy experiences when their condition is misdiagnosed as Attention Deficit-Hyperactivity Disorder (ADHD). The findings are potentially important for researchers and practitioners in medicine, psychology, education, and counselling.

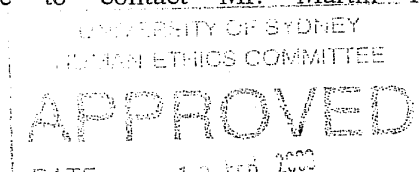
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### Safety Protocol Child Onset Absence Epilepsy Research

The following guidelines have been prepared to ensure ethical and safe outcomes when working with adolescents and their caregivers in the family home. At all times the welfare of the adolescent, their family and yourself must best be considered. The following guidelines have been prepared to ensure ethical and safe outcomes when working with adolescents and their caregivers in the family home. At all times the welfare of the adolescents/young adults, the family and yourself must best be considered.

#### Prior to attending the home:

- Phone the parent/carer to set up a time for the appointment, at least 7 days in advance of the proposed appointment. Outline the details of what will be addressed during the visit, who is to be there during the visit, and how long it will take.
- Provide the office phone number of the Research officer (Student) in case family needs to cancel the appointment.
- Following this through by sending via mail a written outline of the details discussed by phone.

#### Attending the home:

- Arrive on time, with mobile phone. (If you do not have one, collect one from the Chief Investigator.)
- Introduce yourself, showing a picture identification of yourself (e.g., University library card; not drivers license)

#### When interviewing an adolescent:

- Ask if the parent wishes to stay in the room. If not, please ensure they remain in the house during the assessment.
- Settle the adolescent, and make them comfortable
- Undertake only the interview that was outlined prior to the meeting
- Be aware of any difficulties the adolescent may experience, or tiredness that may be evident. Discuss with parent if required.

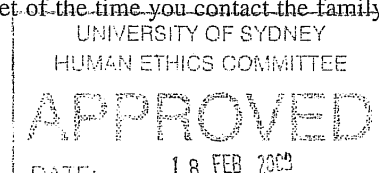
#### If conducting an interview with the caregiver:

- Make the caregiver comfortable. Answer any questions they may have about the
- Outline the process, including a request to tape the interview
- Conduct the interview with family. Provide a copy of the questions for them to read, and keep.

#### When tasks have been completed, thank the family and leave.

- Phone the Chief investigator to notify him that you have left the premises (e.g., leave a message on voice mail noting time and date).
- Follow the visit up with a thank you letter, and notice that the family can access a copy of the study findings at the end of the study.

At all times, a record must be kept on the accompanying sheet of the time you contact the family, when you visit and follow-up communication you have with the family.



## APPENDIX H

<b><i>Parental In-depth Interview: Parent [B]</i></b>	<b><i>Themes</i></b>
Name of Interviewer: <u>Martin Raffaele</u>	Reactions
Date: 28/03/08	
Conscious emotions [-]                      Unconscious emotions {-}	
Interviewer: "I'd like to start by asking you to briefly explain	Back ground family
your family structure and where your child is placed within	information.
it."	
How many children do you have, and what are their age	Family structure
differences to your child with child onset absence epilepsy?	
Parent Participant [B]: She has two brothers and one sister.	
Claire is our oldest child; she is twenty four, five years older	
than (Child [B]). Tom is twenty two, three years older, and	
Nathan is eleven, eight years younger.	
Interviewer: "I'm now going to ask you some questions that I	<u>Phase 1</u>
would like you to answer to the best of your ability. If you do	
not understand a question, please say so."	
"When were you first aware that your child was	
experiencing symptoms that were later diagnosed as	
ADHD?"	
Parent Participant [B]: She was 9 years old. [ <u>She was felt to</u>	Confusion,
<u>be becoming agitated and bored. (She) is a very intelligent</u>	
<u>child.] [She has a history of good speaking skills and</u>	Ignorance,
<u>sentence structuring.] It's only with the onset of the</u>	
complex partial seizures that this deteriorated.	
She was <u>experiencing depression at the time</u> ; sometimes	Frustration,
<u>[she would stand up and yell or speak to herself after short</u>	
<u>periods of staring,]</u> which brought on the diagnosis of	
schizophrenia. She was prescribed to start taking Zoloft.	

<p><u>[We were told that she needed to see someone because they (teacher and general practitioner)] [felt she had ADHD, so we did it just to keep them quiet, which was silly but we did it.]</u></p> <p>Interviewer: How did you react when this diagnosis of Attention Deficit-Hyperactivity (ADHD) was made and how did this affect your everyday life?</p> <p>Parent [B]: <u>[I found it difficult to believe that the diagnosis was correct, a psychological condition, as they're conditions that control your whole life.] [You can't escape conditions that cannot be correctly diagnosed and treated.]</u> She was happy that we were supporting her on the fact that it could not be psychological. <u>[She was quite worried of how this condition would affect her through life. As she was getting older, the misplacement of diagnoses saw her becoming very depressed.]</u> She wanted to have a 'normal' life, but <u>[although illness is a part of your life not what defines you if it is psychiatric or psychological it lives with you and affects you all day].</u></p> <p>Interviewer: Can you describe an actual incident or event you remember that occurred at this time?</p> <p>Parent [B]: One of her main focuses when she was young was at 20 she would get married and have children. <u>{With the misdiagnosis and limitations being described as possibly affecting her from that point on, the dream of this occurring was lost}</u>.</p>	<p>Ignorance of society and medicine Self embarrassed</p> <p><u>Phase 2</u></p> <p>Denial, Anger</p> <p>Anguish</p> <p>Confusion and Offence</p> <p>Effects of misdiagnosis <i>(relates to Phase 5)</i></p>
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<p>Interviewer: What was the initial reaction of your closest family when this diagnosis of ADHD was made?</p>	
<p>Parent [B]: {<u>Our family as a whole didn't except it either. There are members of our family who experience psychological conditions, her older brother having ADHD, so the diagnosis was refused to be accepted.</u>}</p>	Family denial
<p>Interviewer: What was the initial reaction of your extended family and others when this diagnosis of ADHD was made?</p>	
<p>Parent [B]: [<u>Her grand mother was also very worried.</u>]</p>	Family Anguish
<p>Interviewer: What was the initial reaction of your child's friends and others outside your family when this diagnosis of ADHD was made?</p>	
<p>Parent [B]: {<u>Most others (teachers) just believed that this was the reason why she got distracted and frustrated at times. It is easy to deal with any behaviour if you believe you know the reason for it.</u>}</p>	Frustration with teacher disrespect and impatience, and denial
<p>Interviewer: Can you describe an actual incident or event you remember that occurred at this time?</p>	
<p>Parent [B]: {<u>You can see her just stare, having absence seizures but they weren't recognised by everyone</u>}. Sitting her trial exams of the HSC, she experienced a high number of seizures. At this stage we were asked if she was taking drugs, because she had fallen from performing at a high level academically to now being unable to construct</p>	Frustration with Social ignorance

<p>correctly structure sentences. This [<u>“lose in attention” and the aggravation being experienced by her, due to these accusations of her taking drugs and failing to perform</u>], {<u>and this caused troubles at exam times. We were told that she was not completing exams, and were shown test where the questions were to long and she would loose attention and end up putting an answer that was not correct</u>} [<u>She saw a number of psychotic or psychological conditions being diagnosed. These included bi-polar disorder, schizophrenia, ADHD and depression.</u>]</p>	<p>Effects of AS on child academically. Anger and Frustration with Teacher and Government ignorance ( <i>relates to Phase 5</i>) Anger with medical ignorance</p>
<p>Interviewer: When were you first aware that your child was experiencing symptoms that were later diagnosed as Child Onset Epilepsy?</p>	<p><u>Phase 3</u></p>
<p>Parent [B]: {<u>We saw symptoms occurring in high school (12 years+).</u>} {<u>We now know that she was experiencing absence seizures, but as she wasn’t aware of this she didn’t believe they were occurring.</u>}</p>	<p>Child and parent confusion and frustration.</p>
<p><u>She will just stare and lose attention. Her hand drops, which assists her, as she is a modern artist it adds to the painting.</u> She would experience times when she just had these day dreams where she imagined what the out come of a situation would be, such as how a show ended.</p>	<p>Parent Fear and Questioning diagnosis</p>
<p>Interviewer: How did you feel/react when this diagnosis of Child Onset Absence Epilepsy (CAE) was recognised as being the correct diagnosis and how did this affect your child’s everyday life?</p>	<p><u>Phase 4</u></p>

<p>Parent [B]: We were relieved. {<u>We were so glad to finally have a correct diagnosis. One of the hardest things is waiting for a diagnosis.</u>} She was referred to 4 neurologists who the first three refused to recognise it as epilepsy. [I don't think that all epilepsy is the same]. [It was once she saw her present neurologist, who saw her experiencing convulsive activity in her right shoulder while talking to her that the condition was epilepsy]. {Her absences were not being recognised as seizures when she was younger by GP's.} {As she was experiencing fainting episodes, but not losing consciousness (myoclonic seizure activity) it was at that time diagnosed as being due to iron deficiency.} {Our children were all very understanding. They had no problems about the fact that she was experiencing seizures.}</p>	<p>Parent Relief and Happiness</p> <p>Parent Anguish</p> <p>Parent relief due to correct diagnosis</p> <p>Anger with GP's lack of education</p> <p>Accepted by siblings</p>
<p>Interviewer: What was the initial reaction of your closest family when this diagnosis of epilepsy?</p>	
<p>Parent [B]: <u>The kids would often talk about it with us.</u></p>	<p>Family Anguish</p>
<p>Interviewer: Can you describe an actual incident or event you remember that occurred at this time?</p>	
<p>Parent [B]: <u>As she had most of the seizures while asleep, her older brother would often go in to her room to check on her.</u></p>	<p>Family fear and protect</p>
<p>Interviewer: What was the initial reaction of your extended family and others when this diagnosis of Child Onset Absence Epilepsy (CAE) was made?</p>	

<p>Parent [B]: Once they knew it was epilepsy they were very supportive. <u>{Of course they needed to understand what the condition is. There is a lack of education. Many doctors don't recognise it as a major condition because as far as they are concerned it is a short term incident that doesn't truly affect the person for very long at all. Therefore the need to recognise the condition and educate others fails to occur}</u>.</p>	<p>Lack of education on social environments and fields of medicine. Further education (<i>relates to phase 5</i>)</p>
<p>Interviewer: Can you describe an actual incident or event you remember that occurred at this time?</p>	
<p>Parent [B]: <u>{A lecture at the university was holding this tutorial, which discussed light and the importance shading places on art. He started to quickly flicker the light switch, which caused her to have a seizure. It was not until this was experienced at the Arts School that the curriculum was changed and the structure of the course was adjusted and this part was removed. It is lucky this is a small faculty (the school of arts) as they were able to do this, unlike larger ones where the chances are it will not occur.}</u></p>	<p>Frustration with lack of education at a tertiary level.  Happiness due to recognition of seizures</p>
<p>Interviewer: What was the initial reaction of your child's friends and others outside your family when this diagnosis of Child Onset Absence Epilepsy (CAE) was made?</p>	
<p>Parent [B]: Her friends were quit understanding. [She feels that epilepsy is only a small part of her, so she doesn't tell anyone until they see a seizure occurring]. <u>{Most teachers don't really recognise the condition as epilepsy because it's too difficult. That's why ADHD is an easier diagnosis.}</u> <u>{As her convulsive seizures were not</u></p>	<p>Parent does not recognise child's embarrassment  Offence at lack of teacher education.</p>



<p><u>recognised as occurring until she was sitting her HSC</u>}, the trial marks were requested as the marks that represented her knowledge. {<u>Although they decided not to recognise the HSC exams as an indication, as she was then having convulsive seizures, the decided to use those trial marks, which saw her failing the HSC</u>}.</p>	<p>Anger due to social ignorance</p>
<p>Interviewer: What happened when your child had a seizure?</p>	
<p>Parent [B]: <u>She experiences both absence and complex seizures. The complex seizures are more recognizable. Her absence seizures last only a short time. She's not aware of their occurrence, so she doesn't believe they occur.</u> She will stare straight ahead. Her hands will just fall, so if she is painting it adds to it, being the style of painting she performs.</p>	<p>Aware of symptoms. Fear of child's refusal to except condition</p>
<p>{<u>When she was younger she experienced periods of daydreaming where she would imagine how the TV show ended.</u>} {<u>So she would have two versions; what did happen and what she imagined happened.</u>}</p>	<p>Confusion and Fear (relates to Phase 3) Symptoms of AS (starring) and SPS, (déjà vu).</p>
<p>Interviewer: What do you feel could be the reason why most people know so little about Child Onset Absence Epilepsy?</p>	
<p>Parent [B]: {<u>Very little is taught about the condition at all levels, especially in schools, when it most commonly occurs. Teachers aren't taught to recognise the condition, and in fact it's much easier for them to diagnose it as ADHD</u>}. {<u>The symptoms of the condition (CAE) are recognised as due to behavioural disorder and therefore if you take this tablet all will be well. This takes away the</u>}</p>	<p>Anguish with lack of education in schools  Anguish over the misdiagnosis and effects of incorrect</p>

<p><u>need to deal with the true condition.</u> }</p> <p>Interviewer: What are your suggestions on how to go about changing the issues, such as lack of knowledge in relation to epilepsy, and its misdiagnosis in some cases, from continuing to occur?"</p> <p>Parent [B]: Further education of the condition (CAE) needs to be taught too all, especially those in the classroom and other environments where the child is a participant. { <u>If teachers stop taking it upon themselves to diagnose the symptoms as those of ADHD, and not be afraid of the fact that it could be epilepsy, the child would have a much stronger self belief.</u> } { <u>It is the misdiagnosis (as being ADHD) and the attitude that comes from that diagnosis that causes a high level of the depression to occur. (Child [B]) has experienced depression throughout her life, but it was this diagnosis and the attitude of others that saw her being the most depressed.</u> }</p> <p>Interviewer: I wish to thank you for your time, your knowledge and suggestions in relation to these questions. Please take my card and if you have any further information you feel would be appropriate to this study, feel free to contact me at any time.</p>	<p>drug</p> <p>Phase 5 (Now) (refers to further education on CAE)</p> <p>Anger with teachers (Relates to Phase 4). Fear of psychosocial effects. Childs higher levels of depression.</p>
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