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LISTENING TO THE VOICES OF LEARNERS WITH TOURETTE'S SYNDROME

By

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A research report submitted to the Wits School of Education, Faculty of Humanities and University of the Witwatersrand in partial fulfilment of the requirements for the degree Master of Education by combination of coursework and research

Johannesburg

2014

ABSTRACT

Tourette Syndrome (TS) is a genetic neurobiological disorder characterised by verbal sounds (phonic tics) and involuntary movements (motor tics) (Packer, 1995; Holts and Tessman; Prestia, 2003). Learners with TS have varying academic and socio-emotional difficulties, which are not well understood and accepted by teachers and peers in South African schools. Lack of understanding of TS increases these learners vulnerability to exclusion and marginalisation. There is much scope needed in the field of inclusive education to listen to the voices of learners with TS. The ultimate aim of this empirical phenomenographic research is to establish eight participants understanding, on a collective level, of how they perceive school. This study is set within a theoretical framework that includes Bandura's social cognitive theory and Bronfenbrenner's (bio) ecological theory of human development. The aim of this research is to gain knowledge and understanding of the learning and socialisation difficulties experienced by learners with TS. The study finds that learners with TS experience difficulties on an intrapersonal level (internal personal factors) and interpersonal level (external environmental factors).

Key Concepts

Inclusive education, exclusion, Tourette Syndrome, voices of marginalised learners, voice research, Bandura's social cognitive theory and Bronfenbrenner's (bio) ecological theory.

DECLARATION

I, Maureen Linda Dolowitz, declare that this research report is my own unaided work. It is submitted for the degree of Master of Education at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Maureen Linda Dolowitz
17th day of February in the year 2014
Student Number: 0314640R
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To all learners with Tourette Syndrome

ACKNOWLEDGEMENTS

I wish to thank:

- My supervisor Dr Elizabeth Walton for her guidance, patience and support.
- All the participants who took part in this study.

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LIST OF ABBREVIATIONS

DoE	Department of Education
EWP6	Education White Paper 6
UNESCO	United Nations Education Scientific and Cultural Organisation
SIAS	Strategy on Screening, Identification, Assessment and Support
RSA	Republic of South Africa
TS	Tourette Syndrome
AD(H)D	Attention Deficit (Hyperactivity) Disorder
OCD	Obsessive Compulsive Disorder
UNDP	United Nations Development Report
EFA	Education For All
UN	United Nations
NCSNET	National Commission on Special Needs In Education and Training
NCESS	National Committee on Education Support Services
SEN	Special Needs Education
DSM	Diagnostic Statistic Manual of Mental Disorders
APA	American Psychiatric Association
UNCRC	United Nations Convention on the Rights of the Child

CHAPTER 1

1.1 Introduction

"I have a spider inside me. It makes my lips smack….
I have a kangaroo inside me. It makes me jump up and down….
I have a wild horse inside me. It makes me feel like prancing….
I have a tiger inside me and it makes me growl….
I'm going to shoot those animals.
And then the puppy inside me will make me happy and play…
His name is Justin." (Bruun & Budman, 1992, p. 6)

Justin, the author of this poem, "The Animal inside me", has Tourette Syndrome (TS), expresses his feelings of despair. According to Bruun and Budman (1992, p. 6) Justin was home-schooled because he could not function in a mainstream school. In his poem Justin explains the involuntary nature of the tics through characterisation of the animals that "make him do unwanted things and experience negative emotions". The poem reflects his anger and rage and his need to hurt others to ease his pain. He is frustrated and filled with rage at his inability to stop the tics, and with the unfairness of not being accepted. He ends the poem showing that he craves acceptance and wants to emerge as a "joyful animal and thus represent his true self" (Bruun & Budman, 1992, p. 6). The full poem is in Appendix 1.

Justin and other learners with Tourette Syndrome (TS) present with many multifaceted characteristics that render them vulnerable to exclusion from, and marginalisation in school. 15 year old Nellie also shows how isolated and marginalised learners with TS feel and she asks people to look beyond her TS and see her for herself.

> "In the eyes of a child
> Everyone is the same
> And no-one needs to be ashamed – TS is just a name
> I wish I saw everything so black and white
> Then maybe happiness would not seem so out of sight…" (cited in

Chowdhury & Robertson, 2006, p. 56)

Justin and Nellie show the importance of listening to the voices of learners with TS so that they can be understood, acknowledged and accepted in school.

Learners with Tourette Syndrome (TS) present with many multifaceted characteristics that are not well understood and accepted by teachers and peers in South African schools. This renders these learners vulnerable to exclusion and marginalisation. In order to dismantle exclusion and marginalisation there is a need to listen to the voices of learners with TS in regard to inclusion.

1.2 Background to the Problem

TS is a neurobiological disorder according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association [APA], 2000). It is characterised by the presentation of uncontrollable involuntary motor movements and vocal tics, and is associated with additional co-morbidity with the onset being before 18 years. Diagnosing TS is challenging, not only because it is a clinical diagnosis, but is confounded by the variability of the tics and associated co-morbidity, which add to the confusing and potentially stigmatising disorder (Chowdhury & Christie, 2002; Hawley, 2012; Chaturvedi, Gartin & Murdick, 2011; Prestia, 2003). There are no blood tests or medical tests available to make the diagnosis and the cause remains unknown (Waltz, 2001), however it is thought to be genetic. The diagnosis of TS is through observations and evaluations of the tics and reliability of the medical practitioner diagnosing according to the DSM-5 (APA, 2013).

Co-morbid conditions commonly associated with TS not only reflects learners hardships of uncontrollable motor and vocal tics, but is associated with additional conditions such as Attention Deficit Hyperactivity Disorder (AD(H)D) and Obsessive Compulsive Disorder (OCD) (Packer, 1995; Robertson & Stern, 2000; Robertson, 2003). While AD(H)D and OCD are the most common associated disorders, other co-morbid disorders have also been noted, such as aggressiveness, anxiety disorders, self-injurious behaviour, explosive temper-tantrums as well as depression (Packer, 1995).

Learners with TS are misunderstood and stigmatised, as Justin and Nellie indicate above. These experiences are discriminatory and lead to the learners' marginalisation in, and exclusion from school. .The UNDP (1996, p. 1) defines discrimination and marginalisation as "the state of being considered unimportant and undesirable" (Messiou, 2006). Hence, the learners can possibly relate to the United Nations General Assembly statement, developed by the Children's Forum, entitled "A World Fit for us" (UN 2002). In this statement the children appeal for their voices to be heard and used to facilitate processes of inclusion (Messiou, 2006).Messiou (2006) says schools need to become inclusive by opposing discrimination and marginalisation, with the aim of developing communities that embrace and accommodate learners with problems.

By listening to the voices of learners with TS is an opportunity for the learners to verbalise their differences and share how they experience inclusion, exclusion and marginalisation. This can give insight into the complex and multifaceted social and academic environment of schooling for these learners.

1.3 Problem Statement

Learners identified with TS find it difficult to adapt and belong in a school environment. The exact prevalence of TS has been difficult to ascertain, and what was once thought of as a rare condition is now accepted as a much more common condition (Hawley, 2012; Scharf, Miller, Mathew & Ben-Shlomo, 2011; Prestia, 2003; Chowdlury & Christie, 2002). Although much research has been conducted on the neurobiological disorder of learners with TS (Koutsoklenis & Theodoridou, 2012), little is known about the learner's experiences of school. Lewin (2009, p. 157) proposes eight zones of exclusion, with the third zone posing particular interest in this study, as he talks about the "silently excluded" learners. Although some learners are attending ordinary schools, they may be excluded silently, as schools may not make every effort to include them. The result is that their educational experience may be unfair and unjust. As there does not appear to be any literature on this subject, there is a need for research to listen to the voices of learners with TS, and consider and explore their experiences in S.A., within an inclusive educational environment. We will not achieve inclusion without listening to the voices of learners with TS.

1.4 Purpose Statement

The purpose of this qualitative research study is to listen to the voices of learners identified as having TS within a school context. These learners need to be understood from a scholastic, social and emotional perspective. The intention in this study is to research and listen to the voices of these learners, to ascertain how exclusion and marginalisation can be reduced for many of them.

In order to hear and include children with TS, inclusion needs to be understood. Inclusion is the process by which learners, who might have been taught in a separate education system in the past because of their difficulties with learning, are now being taught in ordinary schools. Teachers and peers do not always understand the features and responses made by learners with TS, and as a result these learners may not be accepted or experience a sense of belonging within ordinary schools (Chowdhury & Christie, 2002; Zinner, Conelia, Glew, Woods & Budman, 2012).

At present there is insufficient awareness, as well as lack of education, of the huge range of pointers and symptoms of TS. Early and correct diagnosis and treatment is of the utmost importance in order to avoid psychological and emotional harm (Prestia, 2003; Koutsoklenis & Theodoriddou, 2012; Bruin & Budman, 1992). Due to the lack of research on the above topic, my own personal interest in learners with TS has motivated me to understand more about their experiences.

Relevance for Inclusive Education There is a need to listen to the voices of learners with TS as they speak about their differences and how they are being excluded and marginalized. Inclusive education is falling short as it is not meeting the needs of *all* in inclusive education (Slee, 2011). By “enabling voice” the findings, could be a powerful means for confronting marginalization and promoting inclusion (Nind, Boorman & Clark, 2012, p.651). This study therefore intends to listen to the voices of learners with TS as a first step towards promoting inclusion in schools. Article 12 of the 1989 United Nations Convention of the Rights of the Child (UNCRC, 1989) states that learners have the right to express their views and be heard in matters pertaining to their education.

1.5 Research Questions

The central question in this research study is: “How do learners with TS experience school?” In order to further explore the main research question the following sub-questions will frame the research:

1. In what way do learners with TS feel their condition affects their learning?

2. How do learners with TS perceive their social difficulties in the school context?

3. What do learners with TS expect their teachers and peers to understand about the condition?

1.6 Aims of the Research

- This research aims at gaining knowledge and understanding of how learners with TS feel that their condition affects their learning.
- This research aims at establishing how learners with TS perceive their social difficulties in the school context.
- It further aims at establishing how learners with TS perceive how their teachers and peers understand their condition.

1.7 Research Method

The underlying qualitative theoretical framework of this research is phenomenography (Martin, 1986, cited in Ornek, 2008). Phenomenography is interested in the collective meaning of a phenomenon, as opposed to phenomenology which is interested in the individual experience (Ornek, 2008). As phenomenography is empirical research, the researcher needs to approach the open-ended interview, which is the preferred method, and the data collection to be analysed open-mindedly, without any of his or her own perceptions (Ornek, 2008).

This research uses “homogenous” sampling that Cresswell (2008, p. 216) defines as sampling based on “membership in a subgroup that has defining characteristics”. It is based on listening to the voices of learners with TS with regard to their school experiences. This research will focus on the interview

technique, which consists of semi-structured questions. Eight participants diagnosed with TS were interviewed. The participants were selected from records obtained from paediatric psychiatrists; consent was then obtained from any parents and participants who expressed a desire to be part of this research. The interviews were three quarters of an hour long, and semi-structured in order to probe the learners' initial responses and allow them to 'voice' their experiences. The advantage of open-ended interviews (Cohen, Manion & Morrison, 2000) is to ensure comparability, reduce bias and facilitate organization and analysis of data. It also allows for a greater depth of information, as opposed to other methods of data collection.

1.8 Chapter division

Chapter 1 – provides the reader with an orientation to the research. It contains the introduction to the research and an understanding of what the reader can expect from this research. The background to the research problem is discussed and the research is placed within an inclusive, educational based context. The problem has been formulated in a clear statement from which the aims of the study have been derived. The concepts that are used in the study have been defined (included in Appendix 10). A brief outline of the research method has been provided and the scope of the study has been demarcated.

Chapter 2 – contains the literature review. The definitions of inclusive education, as well as the history and dilemmas of international inclusion have been discussed. These have led to the development of inclusive education in South Africa. Disability classification, the dilemma of difference and Bronfenbrenner's ecological systems theory have been discussed to show that learners encounter different environments throughout their lives, which will affect their physical and psychological growth and development. Bandura's (1989) triadic reciprocal determinism theory involves the continuous interaction between the person, their personal factors, their behavior and environmental influences. TS has been defined and classified according to the DSM-5 (APA, 2013), including diagnosis and co-morbidity. Listening to the voices of learners with TS, their experiences of school, and of marginalisation and exclusion, are also discussed.

Chapter 3 – Explains the qualitative research design that is used in the study. A detailed explanation of phenomenography is given, which explains how it links to the topic of the research. Phenomenography involves identifying and looking for underlying meaning within the concepts, as it is interested in the collective meaning of a phenomenon, namely the experiences in school of learners with TS. Data collection was undertaken by means of open-ended interviews and is described in detail in this chapter. Homogenous sampling was used and the limitations of educational research, namely legal and ethical considerations, as well as trustworthiness, were discussed.

Chapter 4 – contains the body of the report. It follows the research process of analysis and interprets the results from the open-ended questions. Two major categories of description were found. The **intrapersonal systems** (internal personal factors including internal and external behavioral factors) and the **interpersonal systems** (external environmental factors) based on Bandura's model of reciprocal causation, including Bronfenbrenner's bio-ecological systems theory of human development. The emerging categories show the variation in the way in which the participants collectively experience school.

Chapter 5 – contains a recap of the completed research process. It gives a brief analysis of the key facts found in the literature review as well as the main points from the phenomenographic qualitative research. Recommendations are made on the basis of the analysed and interpreted data, and the limitations of the study are pointed out.

1.9 Conclusion

Listening to the voices of learners with TS is important in addressing and understanding educational inclusion, exclusion and marginalisation. It therefore becomes essential that while inclusive education sometimes genuinely attempts to challenge the "injustices in education", it can also be used to "sustain these injustices" (Slee, 2011, p. 155). Therefore, in order to establish how schools can become more inclusive in accommodating learners with TS, it becomes important to look at the following literature review. The aim of the literature review is to gain insight into the dilemma of international inclusion, which has led to the

development of inclusion in South Africa. Furthermore, the purpose of the literature review is to identify relevant information on TS, and enlighten teachers and peers about this condition.

CHAPTER 2

Literature Review

2.1 Introduction

This literature review is by no means exhaustive. There is a large body of literature available on inclusive education. The relevance of the literature review is to help provide background and context for this study and to show how inclusiveness often falls short, as it is not reaching the needs of the *all* in inclusion (Slee, 2011). This is important to acknowledge, as a learner can be in an ordinary class, yet still be excluded due to the attitude of teachers or other children (Evans & Lunt, 2002). This shows that the need for acceptance and recognition of the basic rights of all learners to be accommodated in inclusive school communities remains a challenge (Grossman, 2008).

The literature review identifies and describes learners with TS, as well as the related co-morbid conditions associated with this disorder. Teachers need to understand that learners with TS can be marginalised academically, socially and emotionally (Prestia, 2003). This research cannot be based solely on the multifaceted characteristics of learners with TS; it needs to be placed within the context of inclusion to promote their inclusivity and belonging, by listening to these learners experiences of school. Hence the voices of learners with TS need to be heard as part of inclusive education.

2.2 Inclusive Education

Inclusion has become something of an “international and national buzzword” (Swart & Pettipher, 2005, p. 3), with numerous and confusing definitions of what inclusive education is, both internationally and in South Africa. There is therefore the need to define inclusion.

2.2.1 Definition of Inclusion

When attempting to define inclusive education, it is important to understand that there are numerous and contesting definitions of what inclusive education entails. Miles and Singal (2010) discuss an aporia, which provides some form of evidence

regarding the varying viewpoints into how inclusive education is, and should be, defined. On the one hand it argues in favour of Education For All (EFA), which can be viewed as the promotion of social justice. This maintains that learners should have equal access into educational institutions, however, in so doing the needs of learners experiencing barriers to learning may be denied. At the other end of the argument, it focuses on learners' disabilities and includes learners based on their disability, thereby categorising and labelling learners by accentuating their difference. The debate about categorisation and disability classification and the dilemma of difference is very fundamental to this research and will be discussed in more detail later (see 2.2.2.3 and 2.2.4.4 in Chapter 2).

What counts as inclusion both internationally and in South Africa, is largely determined by how inclusion is defined, as inclusion means different things to different people (Armstrong, Armstrong & Spandagou, 2011, p. 29). The reality is that in the end "inclusion may end up meaning everything and nothing at the same time" (Armstrong et al, 2011, p. 29), as there is no set definition of inclusion.

Ainscow, Booth and Dyson (2006, p. 15), in addressing the problem of defining inclusion, distinguish six ways in which one can consider inclusion. The first is concerned with "disabled students" as well as "categories of special needs". Traditionally inclusion was conceptualised from a disability standpoint, where the focus was placed on the integration of learners with disabilities or those categorised with labels. Although this view of inclusion is still very dominant, it poses questions around the value of categorisation, and challenges its narrow point of view. Ainscow et al (2006) maintains that categorisation acts as a barrier to the development of broader views of inclusion.

The second way Ainscow et al (2006, p. 15) considers inclusion is in the "response to disciplinary exclusion", which is connected to the third view whereby groups are seen as "vulnerable to exclusion". Similarly, Slee (2011) agrees with this view, as he maintains that inclusion can in fact create its own exclusion. By including different groups, a division is made between certain learners which can in turn highlight differences. Ainscow et al (2006, p. 15) define inclusion distinguishing two types of definitions, namely the "broad" and the "narrow" perspective. The "broad" definition recognises inclusion as responding to the

diversity of *all* learners (Ainscow et al, 2006, p. 15). The “narrow” definition promotes the inclusion of specific groups of learners, including learners with special educational needs, in ‘mainstream’ or ‘regular’ education, where a distinct divide is created between learners with special educational needs and those that don’t (Ainscow et al, 2006, p. 15) have those needs.

This relates to the fourth view of inclusion (Ainscow et al, 2006, p. 20) as “developing a school for all”. This is a view which eliminates barriers such as race, class, and disability (Ainscow, et al, 2006).This view embraces and values difference. Slee (2010, p.110) maintains that inclusive education is not about the formulation of ideas about special educational needs, “it is a theory of and tactic for education and social reform”. It is the process of making all individuals more socially aware; to teach us that injustice is not a feature of the law of nature (Slee, 2011, p. 110). In order to promote inclusion as social justice, we need to view special education as being included in inclusive education by providing equal access and opportunities for all learners, irrespective of whether or not they experience any educational barriers. If we “embrace inclusion as a model of social justice, we can create a world fit for us all” (Sapon- Shevin, 2003, p.26).

The fifth view of inclusion “education for all” (Ainscow et al, 2006, p.22) cannot be realised until the fourth view is addressed, and as Slee (2011, p. 172) maintains, “inclusion” is “everybody’s business”. EFA co-ordinated by the United Nations Education Scientific and Cultural Organisation (UNESCO) in the 1980’s with the emphasis on barriers which needed to be overcome, in order for *all* children to receive quality education (Ainscow et al, 2006). Particular attention focused on the education of girls, resulted in the question of what quality education is and how it can be defined.

Ainscow et al (2006, p. 23) sixth view of looking at inclusion is “principled approach to education and society”. This led to the suggestion that inclusion can be seen as an on-going process, and Messiou (2011, p.2) upholds that it “focuses on learners’ presence, participation and achievement in schools”. This means that schools need to be restructured and re-shaped, with policies and cultures addressing marginalisation and exclusion, striving to meet the diversity of all learners’ needs. The focus on meeting all learners’ diverse needs is a pivotal point

in this research. This reinforces Bernstein (1996 cited in Slee, 2011, p. 107), who maintains “inclusion is a fundamental right and requirement for a democratic education.”

Although Ainscow et al (2006) views of inclusive education have been dealt with briefly; this act is seen as a foundation for further deliberation and discussion on inclusion, marginalisation, categorisation and exclusion with placement in special schools. The focus of this research deals with listening to the voice of learners with TS, and whether they experience inclusion, exclusion and marginalisation, which is the central aim of this research. The voices of learners with TS need to be heard in order to establish in what way they may feel excluded and marginalised. Slee (2011, p. 155) maintains that “inclusive education has become a Trojan horse”, in that he challenges education systems and schools to change for all learners and not just for learners with disabilities. In order to understand the history of inclusion and the progress that has been made in inclusive education in South Africa, one needs to look at the history of inclusion from an international perspective.

2.2.2 History and Background of International Inclusion

The international movement towards inclusive education is firmly embedded within a human rights discourse aimed at including the previously excluded (Du Toit & Forlin, 2009; Farrel & Ainscow, 2002), with the focus on the transformation of educational systems based on the ideals of social justice (Artiles, Harris-Murri & Rostenberg, 2006). Hence the concept of inclusive education was developed (Farrell & Ainscow, 2002) and expanded across the world, to include those who are at risk of marginalisation or exclusion.

The development of inclusion has been unevenly staged internationally, and has involved a process of phases through which each government has experimented with various ways in which the needs of learners with barriers to learning can be addressed. Great Britain, America and various other developed countries have embraced inclusive education, and have been actively working towards creating an inclusive education system (Farrell & Ainscow, 2002). Developing countries especially have faced many challenges through this process of inclusion. There is

a commitment amongst governments in developed and developing countries, to build societies that are more democratic. The belief being that it is the responsibility of all schools to extend their services towards accommodating the needs of all learners, no matter how diverse those needs may be. The United Nations (UN) has been responsible for drawing international attention to disability rights, learners' rights and education through the United Nations Educational Scientific and Cultural Organisation (UNESCO) which has given force for inclusive education (Walton, 2006).

2.2.3 UNESCO's contribution to inclusion

The UN Convention on the Rights of Persons with Disabilities came into force in May 2008 (Croft, 2010, p. 1). It recognises that educational provisions vary around the world, and requires states to provide at least "an inclusive quality and free primary education". Inclusive education has been endorsed internationally by UNESCO's Salamanca Statement. This statement recognises and advocates "... the necessity and urgency of providing education for children, youth and adults with special education needs, within the regular education system" (UNESCO, 1994, p. viii). It also reflects the UN global strategy of EFA (Farrel & Anscow, 2002) which coincides with Ainscow et al (2006) fifth view of inclusion.

The Salamanca Statement moves away from the disability stance of inclusion to a broader definition of inclusion for all, where the provision of special schools are noted, yet not promoted. The Salamanca Statement aims at designing and implementing educational systems and programmes that facilitate and acknowledge the huge diversity of learners' unique abilities, learning needs and strengths, opposing discrimination and developing communities that accept and accommodate learners with disabilities (Messiou, 2006). According to Lindsay (2003), tension is inherent in the Salamanca Statement, as it advocates inclusion of the majority of learners into mainstream education; however it admits that a minority of learners might not be able to be included due to lack of structural and attitudinal barriers within schools and society. Slee (2011) points out further problems with the Salamanca Statement, maintaining that it stresses 'rights' of the individual to education but does not clarify provision of inclusive education (Slee, 2011, p. 118). Hence, as mentioned earlier, the acceptance and recognition of the

basic rights of all learners to be accommodated in inclusive school communities remains a challenge (Grossman, 2008).

Ainscow and Sandill (2010) maintain that in order to achieve inclusive schools, effective leadership practices in inclusive values are needed, which will help bring about change in education systems. The history and dilemma of international inclusion has led to the development of inclusive education in South Africa. South Africa adopted inclusive education in order to address the inequalities of apartheid.

2.2.4 Inclusion in South Africa

In 1994 South Africa had done away with the discriminatory apartheid system and has since been in the process of social, political, economic and educational transformation (Lomofsky & Lasarus, 2001). The terms “equity” and “education”, according to the Constitution of the Republic of South Africa, Act 108 of 1996, maintains that “everyone has the right to a basic education and equal access to educational institutions” (RSA, 1996, p. 4), and that “...no person may unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, age, disability” (RSA, 1996, p. 4). Despite the intentions of the South African Schools Act (1996), certain issues and rights of learners with special educational needs (SEN) and disabilities, have not been fully addressed. Due to these issues not being fully addressed in 1996, the National Commission on Special Needs in Education and Training (NCSNET) and the National Commission on Education Support Services (NCESS) investigated these needs, which led to the establishment of the (EWP6) Education White Paper 6 (DoE, 2001).

2.2.4.1 Education White Paper 6 (EWP6)

In agreement with international trends in education, South Africa adopted inclusive education, which has led to the understanding that inclusion is a process (Walton, 2006), with legislation and policy seen as an important ‘lever’ (Forlin, 2004, p.9), and that changes in educational policies and practices are needed to entrench inclusion. South Africa established the EWP6 on Special Needs

Education in July 2001 (DoE, 2001) based on the EFA (UNESCO, 1994), with the emphasis on inclusivity and combating discrimination.

The EWP6 (DoE, 2001, p, 17) perceives inclusive education as focusing on teaching and learning "with the emphasis on the development of good teaching strategies that will benefit all learners". A further aim of the EWP6 (DoE, 2001, p. 5) is to "provide the framework for establishing an inclusive education and training system and lists the key steps to be taken in establishing this system", with the EWP6 (DoE, 2001) stating that there is a need to recognise that all learners and youth can learn and need support. However, the implementation of inclusive education has been mixed. On the one hand there is evidence of ordinary schools in both state and independent schools that are committed to inclusive education and are including learners who would previously never have been admitted into ordinary schools (Engelbrecht, Oswald & Forlin, 2006). On the other hand, teachers' negative attitudes, lack of teacher training, large class sizes (Pather, 2011) and educational budgets have not always secured resources to realise infrastructure and other resource needs for inclusive education (Wildeman & Nomdo, 2007). In order for inclusive education to be achieved, South Africa needs to address barriers to learning such as poverty, language difficulties, inflexible curricula, inaccessible environments, inadequate support services and lack of parental involvement, in addition to impairment and illness (Engelbrecht et al, 2006).

According to Walton (2011, p. 241) even though the EWP6 focuses on educational access and support for learners with disability, it is "clear that inclusion in South Africa is conceived more broadly than this". The South African education system claims to be an inclusive one, whereby all learners are given the same opportunities and access to education. This is in direct contradiction to the existence of separate schools for learners, and the existence of separate schools for learners with moderate to high support needs. Although South African policies promote learners with low to moderate needs to be accommodated into ordinary schools, there are numerous factors such as insufficient funding, amongst other reasons, preventing this actualisation (Wilderman & Nomdo, 2007).

This presents a grim picture for inclusion in South Africa. However, Pather (2011) proposes that inclusion need not be dependent on resources, expertise and know how, as schools in rural areas are incorporating inclusive practices despite the lack of resources. People in these communities are making physical modifications to schools to enable access for learners with wheelchairs, and are including ways of inclusion as a natural part of schooling. Pather (2011, p. 8) maintains that if inclusion is to work and be successful, disability needs to be "seen as an accepted part of life in the community", whereby all learners can be placed together, not only in the classroom, but in the wider community as well. In order for the EWP6 (2001) to be implemented, The National Strategy on Screening Identification, Assessment and Support (SIAS) (2008) document was introduced as a means to address the most vulnerable and marginalised learners in school.

2.2.4.2 Screening, Identification, Assessment and Support (SIAS)(DoE,2008)

The SIAS (DoE, 2008) was compiled by the Department of Education as part of the implementation plan of the White Paper 6. The aim of introducing the SIAS (DoE, 2008) document is to provide clear guidelines for enrolling learners into special and state schools in order to screen, identify and assess their barriers to learning, thus facilitating assessment and diagnostic support which is needed. It also acknowledges the "central role played by parents and teachers" (SIAS, 2008, p.1). The SIAS (DoE, 2008) aims to respond to the needs of learners throughout South Africa, especially those learners who are vulnerable or disabled, and most likely to be marginalised and excluded (SIAS, DoE, 2008). The SIAS (DoE, 2008) does not insist on a specific diagnosis being made in order for the learner to benefit from intervention. The danger of misdiagnosis cannot be stressed enough, as there are far-reaching implications which could be detrimental to their academic and social process (Peake, 2013). Specific follow-up with regards to support and intervention is necessary. Recently South African education has brought out Guidelines for Inclusive Teaching and Learning (2010), which outline strategies and means of implementation that could contribute towards a more inclusive education system.

South Africa's SIAS (DoE, 2008) however, is very useful as it responds to the need for support based on a learner's behaviour, and not solely on the diagnosis

of the learner. Ultimately, whatever category or classification system is used, the aim will be to monitor the learner carefully with specific follow-up in regard to support and intervention.

2.2.4.3 Categorisation and Classification

Categorisation and classification of disabilities and difficulties, despite the controversy of discrimination and exclusion, is still deeply embedded in educational systems (Hollenwegar, 2008). Despite controversy, categorisation and classification still serve a valuable function in teaching, in terms of the interconnections between adapting the curriculum, pedagogy strategies and knowledge about teaching and learning (Norwich & Lewis, 2005). Categorisation and classification is needed to guide teachers in understanding the underlying causes of learner characteristics that operate independently of classroom processes (Florian & McLaughlin, 2008). When educating learners today, there is a need to take into account not only individual characteristics, but to also examine the interaction between the learner and his or her environment. Hence the challenge is not only on the correct categorisation and identification of the barriers to learning being experienced, but also the degree of support structures available, as well as planning and intervention strategies that are incorporated within the inclusive school. This becomes an essential feature in accommodating learners with TS.

In order to establish if classification in education will serve a function, one needs to classify disability and impairment (Croft, 2010). Disability, according to Croft (2010, p. 4), is an umbrella term used for problems such “as a deficit, a deviation from the norm, social oppression, exclusion, disadvantage, a collection of barriers, a challenge, an experience, an identity, a process, a predicament, difference, an aspect of diversity and at one end of a continuum with health.” Traditionally, disability has been known by the “medical model/individual model” of disability where the impairment /disability were noted within the individual (Croft, 2010 p.4).The individual is seen as the problem where the impairment is focused on rather than the needs of the person (Messiou, 2011; 2012). Many learners are not being included into mainstream education in South Africa due to intrinsic barriers (physical, mental, sensory or developmental) or extrinsic barriers (inflexible

curriculum or inaccessible environments) of schools and society (EWP6, DoE, 2001; Walton, 2012). South Africa focuses on the 'special needs' of learners rather than a disability classification, in order to meet and accommodate learners' needs in schooling (Department of Social Development, 2001).

To what extent might it be useful to identify learner difference, and if by identifying it, does it assist in the teaching and learning of learners with barriers to learning, or does it result in discrimination and labelling (Croft, 2010). In order to assist teachers, wanting to include learners into the general classroom, a general overview of various disabilities is given in Guidelines for Inclusive Teaching and Learning (DoE, 2010). The Guidelines give a brief definition as well as the characteristics, implications for learning and possible educational strategies for various disabilities. Medical conditions such as TS are included in Guidelines for Inclusive Teaching and Learning (DoE, 2010, p. 100), to ensure that learners with AD(H)D and TS are given the extra support needed. Learners do not always fall neatly into any group, so it is important for teachers to be aware of, and have an understanding of, "individual differences position", which allows for the unique individual needs as well as the common/general needs (Norwich, 2008, p.147). There is therefore the need for a classification that focuses on "individual functional difficulties" (Norwich, 2008, p. 147), which takes into account social, psychological, medical and biological factors, in order to design an effective pedagogy. Due to the recognition that many learning needs are associated with educational, social and economic factors, it appears that classification systems need to acknowledge both the social and educational context in which they occur (Rouse, Henderson & Danielson, 2008).

No classification system established in education to date has been able to adequately explain or represent what constitutes a disability or a special need (Hollenwegar, 2008). Dissatisfaction and disappointment in classifying disability has led to the need to find alternative ways of classifying. The problem arising is not on the classification system but on the form it should take, and how it can be improved and monitored (Rouse et al, 2008). Due to this controversy about classification today, the aim is not so much on classifying, but on the need to recognise that learners, including those learners with TS, have differences; to

accept their diverse needs, accommodate and support their individual needs and integrate them into ordinary schools promoting a more inclusive form of education.

2.2.4.4 Disability classification and the dilemma of difference

Measuring differences in learners, especially in relation to disability and special educational needs, are characterised on one hand by being the result of individual problems and deficits, and on the other hand by those that see the problems as originating from the inability of the schooling system to meet the needs and diversity of the learners (Terzi, 2008). Terzi (2008, p. 244) maintains that an essential aspect of this debate concerns the use of “classifications of disability and related forms of categorisations”. On the one hand, classification is necessary to ensure suitable educational conditions whereas other teachers may see it as discriminatory (Terzi, 2008). This creates a “dilemma of difference”, which is the choice between identifying their differences in order to accommodate learners, even at the risk of labelling and discrimination. Terzi (2008, p. 255) maintains that the “dilemma” can be resolved by means of the “capability approach” whereby the learner’s individual characteristics (special educational needs and disabilities) are taken into account within his/her schooling environment.

While classification can shape teachers expectations of the learner, as they may expect less from the learner, it can also give teachers and practitioners good direction with regards to intervention strategies, such as differentiated instruction, (Tomlinson, 2005) thereby teaching learners according to their readiness levels, interest and learning profiles. According to Walton and Lloyd (2011) learners with special needs need to be seen as included in the system. These learners should not be seen as burdens or guests where their stay is conditional, depending on the school’s continued ability to meet their support needs (Walton & Lloyd, 2011).

Most learners have been defined by the assessment, diagnosis and classification of their impairment (Croft, 2010). The challenge placed on a learner is not only the physical placement, but the correct classification and identification of the barriers to learning. Learners with special needs are not seen as individuals, but are often categorised or identified in a group (Walton & Lloyd, 2011). These terms, while significantly demeaning, create a standardising agent for describing a learner in

terms of what is ‘wrong’ with them, instead of trying to understand and support the needs of learners, for example those who suffer from TS.

Despite discrimination and labelling being caused by categorisation of learners, classification does have merit. One of the most persuasive arguments for the use of classification is that of planning, educational resources and provision, which in this instance would be to ensure that learners with AD(H)D and TS are given the extra support they need.

Croft (2012, p.2) maintains that the correct data on the amount of disabled children in schools can “demonstrate transparency and accountability in the distribution of resources and services” which can contribute to social justice. Diversity needs to be acknowledged in order to cater for individual learners to make inclusion obtainable. This can be achieved by focusing on Bandura’s social cognitive learning theory and Bronfenbrenner’s (bio) ecological theory of human development.

2.3 Theoretical Framework

This study is set within a theoretical framework that includes Bandura’s (1978; 1989) social cognitive learning theory and Bronfenbrenner’s (1979) (bio) ecological theory of human development, to show the complex interaction of human development and learning. There have been no studies used by Bandura or Bronfenbrenner in conjunction with TS, however both theories have been used in conjunction with Attention Deficit (Hyperactivity) Disorder (AD(H)D). This study has attempted to use both Bandura and Bronfenbrenner’s theory in relation to TS.

2.3.1 Bandura’s Social Cognitive Theory

Bandura (1978; 1989) provided an insightful concept concerning student learning by means of social cognitive theory. Social cognitive theory explains human behaviour in terms of Bandura’s (1989, p. 2) “triadic reciprocal determinism”. This model of reciprocal causation involves the continuous interaction between the person, their personal factors including cognition, their behaviour as well as environmental influences (Bandura, 1978; 1989). Hence human behaviour or

psychosocial phenomena can be analysed at the level of intrapersonal development, interpersonal transactions and interactive functioning of organisational and social systems (Bandura, 1978).

A person's physical structure, sensory and neural systems as well as their expectation and self-perceptions, affect and give shape to how they will behave (Bandura 1978; 1989). Learners' social status and observable characteristics can affect their social environment before they even say or do anything (Bandura 1978; 1989). Personal and environmental factors do not function independently, they determine each other. However their behaviour will evoke different reactions from their social environment (Bandura, 1978; 1989). This two-way influence between behaviour and the environment depends on how the learners behave (Bandura, 1978; 1989). Due to the bi-directionality of behaviour and environment, learners are both products and producers of their environment (Bandura, 1978; 1989). This means that learners will create, as well as draw environmental influences (Bandura, 1978; 1989). If a learner is aggressive, he/she will produce hostile environments wherever he/she goes. Those learners who act in a friendlier manner tend to generate a more amicable social milieu (Bandura, 1989). Thus environmental influences will ultimately play a huge part in which forms of behaviour are developed and activated.

Self-regulation (Bandura, 2001 cited in Thorlakson, 2010) is perceived as the intentional use of a learner's cognition and will to control their behaviour, and is an important form of learning. Bandura's (2001 cited in Thorlakson, 2010) triadic reciprocal causation is, as mentioned earlier, bi-directional. It constructs the learning experience, reminding one that it is not only inner conditions that affect learning, external factors also influence learning. Ultimately the interaction between the person, the environment, their abilities and the learner's behavioural responses result in the success or failure of scholastic and personal achievement (Bandura, 2001 cited in Thorlakson, 2010).

According to Martin (2004), Bandura did not pay enough attention to the developmental aspects of the learning process. Bronfenbrenner's (1979) ecological theory and his revised bio-ecological theory of human development (Bronfenbrenner, 2001) explains human development as being the interactions

between a learner (their biological being) and the ecology (interconnected systems around them).

2.3.2 Bronfenbrenner's (bio) ecological theory of human development

Bronfenbrenner's multi-dimensional model proposes that learners encounter different environments throughout their lives which affect their physical, biological, psychological and cultural growth and development (Bronfenbrenner, 1994; Sincero, 2012; Nel, Nel & Hugo, 2012). According to Bronfenbrenner (1979; 1994), every learner is largely affected by interactions amongst a number of overlapping ecosystems. The **'microsystem'** (Bronfenbrenner, 1994, p.39) is the direct environment and consists of the events closest to the developing learner including family, friends and peers. The **'mesosystem'** (Bronfenbrenner, 1994, p.40) is the next level and goes beyond the single learner setting, to the relationships and interactions between the learner and his family, school and peers. Problems at this level can impact on interactions with other systems, for example, interactional difficulties between learners with TS and their teachers and peers. The '**exosystem'** (Bronfenbrenner, 1994, p. 40) refers to environments where the learner does not have an active role, but which still influence the learner indirectly for example conflict between the parents can affect the learner's relationships with family, school and peer group. Since the early 1980's research has specifically focused on these families, school and peer groups which are particularly likely to affect the developing learner. The '**macrosystem'** (Bronfenbrenner, 1994, p. 40) refers to belief system, attitudes, values and ideologies within society and culture which could influence the learner's other systems. The last is the **'chronosystems'** (Bronfenbrenner, 1994, p. 40) which includes change or consistency over time in the characteristics of the individual as well as the environment in which the individual lives.

Bronfenbrenner's ecological systems theory and the more recently revised bio-ecological model is important in inclusive education, as it enables teachers to understand the complex interactions and inter-relationships that influence the learner's behaviour and academic environment (Nel et al, 2012). This gives the teacher insight into how to cope and deal with diversity in the classroom.

In the revised bio-ecological model of development (Bronfenbrenner, 2001 p. 6963) the four inter-related components “process, person, contexts and time” conceptualise the integrated developmental system during the course of human development. These proximal processes refer to the interaction between the personal characteristics of the organism and the environment that develops over time, with reciprocal interactions into human development (Bronfenbrenner, 2001). Every learner has their own genetic, physical, psychological and behavioural characteristics that influence development outcomes, for example impulsiveness, hyperactivity, TS etc. (Bronfenbrenner, 2001; Smith, 2011; Nel et al, 2012). It is these personal (internal) characteristics that can cause an imbalance or barriers to learning and development to arise. Any imbalance that occurs within an individual or in any system will affect the balance between the systems. This continuous causal process means that whatever happens in one system will affect or be affected by other systems, both internally and externally to the learner (Nel et al, 2012), influencing and impacting on learning and human development. According to Bronfenbrenner (2001), the bio-ecological theory can enhance learner’s interactions with the environment, hence its importance to development of interpersonal relationships which can influence a learner’s quest for knowledge. This can potentially be very important in enhancing interpersonal relationships, as well as improving academic performances in learners with TS.

2. 4 Tourette Syndrome (TS)

In order to promote inclusive education there is a need to provide equal access and opportunities for *all* learners including those with TS, irrespective of whether they are experiencing any educational barriers to learning.

2.4.1 Definition

TS is a genetic inherited neurobiological disorder characterised by verbal sounds (phonic tics) and involuntary movements (motor tics) that vary in severity, intensity and frequency, (Packer, 1995; Holtz & Tessman, 2007; Prestia, 2003; Koutsoklenis & Theodoridou, 2012)

2.4.2 Classification

Currently the DSM IV TR (Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2000) is used to determine diagnosis of TS. However, in the writing of this research the DSM-5 was released. I will highlight the changes made in the DSM-5. It has been recommended that the DSM-5 remove the description of a tic as "stereotyped" and rather define a tic as "a sudden, rapid, recurrent, non-rhythmic motor movement or vocalisation" making it easier not to misdiagnose TS (Walkup, Ferrao, Leckman, Stein & Singer, 2010, p. 600).

According to the DSM IV TR (APA, 2000) the tics are the defining features of this disorder and the following need to be present in order for a diagnosis of TS to be established. The following diagnostic criteria have been quoted verbatim from the DSM IV TR (APA, 2000)

- Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently. (A tic is a sudden, rapid, recurrent, non-rhythmic stereotyped motor movement or vocalisation).
- The tics occur many times a day (usually in bouts), nearly every day or intermittently throughout a period of more than 1 year, and during this period there was never a tic-free period of more than 3 consecutive months (the 3 months has been removed in DSM-5).
- The onset is before 18 years.
- The disturbance is not due to the direct physiological effects of a substance (e.g. stimulants) or a general medical condition (e.g. Huntington's disease or post viral encephalitis).

2.4.3 Diagnosis

According to Shapiro (2002) there is controversy about the above DSM IV TR criteria for TS as it changes significantly from the DSM III-R/DSM-4 and the TS Classification Study Group. Shapiro (2002, p. 244) maintains that the primary concern is that the DSM IV TR relies on the subjective criterion of "distress" for

diagnosis rather than a more objective measure of symptom severity of DSM III R/DSM-4. “Many researchers and clinicians continue as a result to use DSM III-R/DSM-4 criteria in order to maintain a more uniform definition of TS (Shapiro, 2002, p. 244). O’Donnell-Ames (2009, p. 96) found however that this “distress” diagnosis is helpful for learners with TS in understanding that it is not their fault that they have involuntary movements.

The DSM-5 in agreement with DSM IV TR has dropped the DSM III-R/DSM-4 requirements of tics causing clinically significant distress or impairment, because if it is absent no diagnosis of a tic disorder can be made (Roessner, Hoekstra & Rothenberger, 2011). The reason, according to recent studies, is often not the tics but the co-morbid condition such AD(H)D which results in social and academic impairment (Roessner et al, 2011). By leaving TS under the section “Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence” it retains the fact that TS is a neurological and not a psychiatric disorder (Roessner et al, 2011, p. 71). Lastly the DSM-5 (Roessner et al, 2011) has eliminated the maximum 3 month tic free interval which is not necessarily significant in diagnosis. Ultimately the DSM-5 is seen as an important step in diagnosis of TS as the changes help make the clinical diagnosis easier (Roessner et al, 2011).

Confounding diagnosis is that some learners are able to suppress their tics, and can even present as relatively “tic free” during school hours, however these tics must eventually be “released” (Shapiro, 2002, p. 244). Tics can be numerous and very debilitating for a few weeks, then can fade away almost completely before re-appearing and being replaced by new ones (Coffman, 2012). Another factor affecting the difficulty in diagnosis are that symptoms vary from day to day, resulting in these learners remaining undiagnosed and thus stigmatised and marginalised throughout their school career (Coffman, 2012). Diagnosis of TS remains difficult not only due to variability of the tics, but because it may be associated with (co-morbid) conditions, which add to the confusing and potentially stigmatising disorder (Chowdhury & Christie, 2002; Hawley, 2012;Chaturvedi, et al, 2011; Prestia, 2003). The most significant factor, despite this variability of tics, is that diagnosis relies solely on a clinical diagnosis as there are no blood tests or medical tests available to make the diagnosis (Waltz, 2001). Diagnosis is only

through observation and evaluation of tics, hence the importance and reliability of medical practitioners on the DSM.

2.4.3.1 Co-morbid conditions

TS therefore not only reflect learners' hardships of uncontrollable involuntary motor movements and vocal tics, but could be associated and worsened by co-morbid conditions. These conditions are characterised by additional problems such as AD(H)D, which is one of the most frequently associated disorders in school-age learners with TS, who appear inattentive, impulsive, distractible and sometimes hyperactive, resulting in difficulties in a regular classroom (Chowdhury & Christie, 2002; Hawley, 2012; Chaturvedi et al, 2011; Prestia, 2003; Packer, 1995). Obsessive-Compulsive Disorder (OCD) is also present in a significant percentage of learners with TS. OCD is characterised by an obsession which "is a recurrent, persistent idea, thought, image, or impulse that is experienced as senseless or repugnant. A compulsion is the ritualised or stereotypic behaviour in which the individual must engage to prevent some event from occurring" (Packer, 1995, p. 9), therefore a learner suffering from OCD may have an overwhelming need to repeat certain actions such as hand washing or checking that a door is locked. While AD(H)D and OCD are the most commonly associated co-morbid conditions, a significant percentage have presented with behavioural and affective disturbances such as aggression and conduct disorders (Packer, 1995). Some may present with anxiety disorders such as panic attacks and phobias, depression may occur in some, while others can present with self-injurious behaviours (Packer, 1995). A co-morbid condition which can present is explosive outburst of aggressive behaviour referred to as "rage attacks", which manifest for no apparent reason and often with minimal provocation (Packer, 1995, p. 10). If medication is required by learners, the impact of side-effects cannot be overlooked, namely drowsiness, weight gain and slow thinking that will further aggravate schooling and low self-esteem (Hazen, 2009).

Prestia (2003) ascertains that the tics are the most distressing and central feature of TS, whereas Shapiro (2002) maintains that the associated conditions such as OCD, AD(H)D or varying conduct disorders, social rejection and isolation are more central to the disorder, and can interfere more with school, peer and families

functioning than the tics themselves. A number of studies have also indicated that TS and autistic spectrum disorders may share a common denominator, however further research is needed concerning the educational implications of such co-morbidity (Koutsoklenis& Theodoridou, 2012).

2.4.4 Incidence

The precise prevalence of TS according to Hawley (2012), Prestia, (2003) and Chowdhury and Christie (2002) has been difficult to ascertain, and what was thought of as a rare condition is more widely recognised with boys being more frequently diagnosed than girls. Many researchers believe the prevalence is 0.7 – 4.2% based on school studies with male to female ratio varying from 2 – 10:1. However if OCD is included as a variant of TS the male to female ratio is 1:1 (Hawley, 2012).

2.4.5 Characteristics of TS

Tics can be simple or complicated varying from simple blinking, to shoulder shrugging to hopping and even bizarre body movements (Chowdhury & Roberson, 2006; Chaturvedi et al, 2011). Vocal tics can vary from grunting to making noises, repeating the words of other people, “echolalia”, and in severe cases swearing which is known as “coprolalia” (Chowdhury & Roberson, 2006, p. 12; Chaturvedi et al, 2011; Prestia, 2003). Tics come and go and the intensity can vary depending on numerous factors, they are thus referred to as “waxing and waning”, however in times of stress they are exacerbated (Chowdhury & Roberson, 2006, p. 12). Anxiety along with lack of sleep and fatigue exacerbates the tics (Coffman, 2012).

Learners with TS need to be aware of these characteristics and educated about their condition, rather than trying to hide it because they are ashamed. Parents and learners need to realise the falsehood of “ignorance is bliss”, but should rather adopt a better motto; “knowledge is power” (O’Donnell-Ames, 2009, p. 96). Tim Howard, Goalkeeper for Manchester United and USA has TS and maintains that understanding about the condition and about the tics helps with acceptance, “I have always said that TS is a speed bump, not a road block, on the road to

achieving what you want to achieve in life. A large part of that speed bump is understanding" (Chowdhury & Robertson, 2006, p. 7).

There is numerous data and research on the impact of medical and behavioural treatments on tics and associated co-morbid conditions of TS, however little data is available according to Koutsoklenis and Theodoridou (2012, p. 2) on the role of "school-based interventions". According to Packer (1995) in approximately 70% of learners with TS, the occurrence of tics will be reduced or they may experience a total remission of their symptoms by the age of 18. Ultimately the "long-term" prognosis as well as the "well-being" of TS is not necessarily dependant on tic severity. It is more reliant on factors such as the learner's and other people's attitude to the tics and how they deal with the co-morbidity, which will ultimately affect the learner's "self-worth" and adaptation into adulthood (Chowdhury & Christie 2002, p. 125). Schools therefore play an essential role in the development of self-esteem through the attainment of establishing peer relationships (Chowdhury & Christie, 2002) as TS is a lifelong disorder with an unpredictable course.

2.4.6 Schooling

Teachers and peers need to be informed about learners who have TS and how it affects them (Koutsoklenis & Theodoridou, 2012). Despite the increase in prevalence of TS, teachers and peers are not better informed about the condition. This could be related to a number of factors, namely families not informing the school due to the stigma attached to having TS (Coffman, 2012).Once teachers and peers understand that a learner's "barks" or "shouts" is not behavioural and intentional but involuntary, it makes them more accepted and understood (O'Donnell-Ames 2009, p. 96). The problem is that learners are able to control their tics at school at great expense to their concentration and will-power.

If one views the learner as "having a problem" rather than "being a problem" learners will then have a better chance of being accepted by their peers and teachers (Coffman 2012, p. 49). Recent literature according to Koutsoklenis and Theodoridou (2012) indicates that TS is not only a motor disorder but that the behavioural and cognitive features of the learner also need to be addressed.

Prestia (2003, p. 70) maintains that “our best academic efforts and interventions will not suffice unless we pay attention to the social-emotional wellbeing of students with TS who tend to have problems interacting with and being accepted by peers.” These learners’ difficulties are not only socio-emotional but also result in decreased academic performance.

2.4.6.1 How learners with TS experience school

Learners’ with TS can become very anxious and distressed if they realise that their symptoms are obvious to other learners and teachers (Koutsoklenis & Theodoriddou, 2012). Learners with TS worry about being accepted and being seen as different. If they feel different or are being teased, they may start to isolate themselves and withdraw from their peers, to protect themselves from teasing or bullying (Prestia, 2003), or they may react by becoming the bully due to their suppressed anger. Teacher and peer education of TS is important in order to accommodate learners with TS in the classroom.

2.4.6.2 Educational Intervention

Teacher education is important in enhancing teachers’ knowledge about TS, as well as any related special educational needs which are beneficial and that should be instituted on a regular basis (Chowdhury & Christie, 2012; Kotsoklenis & Theodoridou, 2012). Teachers should encourage and educate learners on the acceptance of their peers with TS. Books, videos and even giving the learner with TS the chance to explain the involuntary nature of their condition, may help eliminate some of the negative perceptions and attitudes related to this syndrome (O’Donnell-Ames, 2009; Koutsoklenis & Theodoridou, 2012, Chaturvedi et al, 2011). It was found that paring learners with TS with other learners in the class regarding assignments, projects and other social activities can encourage positive exchange and acceptance for these learners (Chaturvedi et al, 2011). Seating arrangements are very important for a learner with TS. Most teachers would put the learner in the front of the class, however according to Coffman (2012) the best seat is a spot where no one is behind them or on the side where there is more personal space.

An important, though not always an easy approach, for a teacher or a peer is to "purposefully ignore tics" (Coffman, 2012, p. 48). The only way for a teacher to try and ignore tics and not fall into that trap is to remember that tics are involuntary. The teacher needs to make arrangements to accommodate and incorporate these learners by adjusting time-tables where possible. Awareness in accommodation must include the knowledge that tics are exacerbated when learners are tired, fatigued, excited or stressed (Chaturvedi et al, 2011; Coffman, 2012).

Teachers also need to remain in close contact with parents to problem solve with both parents and learners when the learner's behaviour becomes "socially inappropriate and difficult to manage" (Coffman, 2012, p. 49). Various alternatives can also be discussed in accommodating these learners, such as extra time and separate venues, which will be beneficial to all learners as tics may be disruptive for all (Coffman, 2012.) Hawley (2012) advocates that by being compassionate and exercising tolerance with learners with TS, they will try their utmost to achieve their potential. If a separate venue for exams is not sufficient, oral exams or else a computer needs to be considered as tics can also interfere with writing (Hawley, 2012). Teacher flexibility and continuous assessment of learners with TS are crucial as the practical implications introduced for learners with TS may not be equally beneficial for all pupils (Kotsoklenis & Theodoridou, 2012).

In reviewed educational interventions for TS, as well as the management of behavioural and learning difficulties, it has been found that despite similarities amongst learners with TS, it is essential to acknowledge that each learner is an individual who has his/her own unique clinical and educational profile; hence their school intervention needs to be individually planned (Koutsoklenis &Theodoridou 2012). Intervention measures which are believed important to ensure appropriate academic support within a classroom would "include the social-emotional climate, physical arrangement, schedules and routines, instruction and assessment to determine how to support students with TS within the general classroom" (Chaturvedi et al, 2011, p. 58).

2.4.6.3 Lack of understanding learners with TS

Available literature suggests that learners with TS are constantly at risk of social rejection due to their social adjustment problems, which they may experience in the classroom, such as sudden rage attacks for the slightest provocation. It is these characteristics and responses of learners with TS that are perceived negatively by teachers and peers (Holtz & Tessman, 2007; Chaturvedi et al, 2011; Turton & Rayner, 2007; Prestia, 2003).

Due to these negative experiences, learners with TS feel embarrassed and anxious because of poor peer acceptance, victimisation, rejection and misunderstanding (Prestia, 2003; Holtz & Tessman, 2007; Zinner et al, 2011). Due to the confusing and potentially stigmatizing disorder of TS, whereby tics can be perceived by others as bizarre, hostile, or inappropriate, Holtz and Tessman (2007) undertook a study to examine the impact of a video-based intervention to determine peer knowledge about TS. Holtz and Tessman's (2007) findings as well as Van Rensburg (2001), who undertook a study in S.A. amongst Xhosa learners in schools in the Eastern Cape, found that the obvious physical symptoms of the disorder reduce opportunities for social interaction. The result is non-acceptance of these learners due to misinterpretation of their tics and behaviour.

Due to the difficulty in academic performance and social adjustments of learners with TS, more research is needed for the "improvement of school-based interventions, along with suggestions for further research" (Koutsoklenis & Theodoridou, 2012, p. 1). Studies to date have shown that teachers do not know how to manage these learners within a classroom situation (Chowdhury & Christie, 2002; Koutsoklenis &Theodoridou, 2012). Messiou (2012, p. 19) maintains that "valuing students perspectives" is very important especially as teachers might learn more about their own practices and how learners see issues in a different light. Bridging this gap between teachers and learners can go a long way towards making learners feel accepted and acknowledged. A future challenge is to find which approaches in relation to social adjustment and social skill training will be most beneficial, namely "instruction, modelling and role-playing" (Koutsoklenis & Theodoriddou, 2012, p. 8).

Research and interventions on TS in South Africa need to be explored, as these learners voices need to be heard in order for inclusion and the acceptance of diversity to be achieved in South Africa. At present there remains a lack of education and awareness of the huge range of indicators and symptoms of TS. Early diagnosis and treatment cannot be stressed enough, to avoid psychological and emotional harm (Prestia, 2003; Koutsoklenis & Theodoriddou, 2012; Bruun and Budman, 1992). Even though we acknowledge that teaching and learning is a major focus of schools, we also know that the social and peer group environment is important for meeting friends and socialising (Walton, 2012). Therefore, the need of listening to the voices of learners with TS as they speak about their differences, and how they experience inclusion and being excluded and marginalised, can give a degree of insight into the complex and multifaceted social environment of schooling. These insights can give some explanation as to why current policies and practices cause and sustain marginalisation and exclusion in schools. The way forward could be to listen to the voices of learners.

2.5 Voices of marginalised learners with TS

Although the main focus of inclusive education is placed on the accommodation of learners into ordinary schools as well as special schools, inclusiveness is falling short as it is not meeting the needs of the *all* in inclusion (Slee, 2011). Lewin (2009, p. 155) offers practical insight into educational exclusion, by putting forth a model of the “zones of exclusion from access” which limits learners physical and/or epistemological access to schooling. Messiou (2006, p. 306) explains exclusion by maintaining that “inclusion is concerned with any kind of marginalisation that might be experienced by any child”, irrespective if this is perceived as being “about notions of special educational needs or not”.

The UNDP (1996, p. 1) goes further and defines marginalisation within a broad context, maintaining that it is “undesirable” and results in “inequality, unfairness and deprivation”. According to this definition, if learners are seen by others or by themselves to be unimportant or undesirable, they are experiencing marginalisation. However, according to Messiou (2012), what counts as marginalisation and participation in a school setting is not clearly defined. Concerns regarding the attempts to dismantle educational exclusion and

marginalisation are complex, and despite some teachers' belief that they are including by merely tolerating specific learners, they are excluding rather than including. Slee (2011, p. 43) argues that these learners are "tolerated but never welcomed" and that "to tolerate is not to include" (Slee (2011, p. 118). This research study has been guided by an increasing need to listen to the voices of learners with TS in order to address and understand educational inclusion, exclusion and marginalisation.

According to Roaf (2002 cited in Messiou, 2006, p. 307), researching learners' voices in relation to inclusive education is a relatively new idea, and its potential resides in improving learners educational experiences as well as developing teachers' understanding of learners. This can be achieved by listening to the voices of learners with TS with regard to inclusion, in order to dismantle marginalisation.

2.5.1 Listening to the voices of marginalised learners

According to Messiou (2008, p. 27), listening to the voices of learners is a rather "neglected area", and marginalised learners have been "ignored and patronised", (Rose & Shevlin, 2004, p. 155) breeching the right of the child to be heard. As a result, on the eighth of May 2002, the United Nations General Assembly published a statement developed by the Learners Forum "a world fit for us" (Messiou, 2006, p. 306). Hence the listening to learners is now supported by international documents such as Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 1989), which states that learners have the right to express their views and be heard in matters pertaining to them (Kellet, 2010; Messiou, 2006; Walton, 2011).

The UN Committee (Rights of the Child, 2009, p. 6) is impeded when dealing with learners belonging to marginalised and disadvantaged groups. This breach also refers to South Africa in implementing Article 12. The UN Committee (Right of the Child, 2009, p. 24) urges States to listen to learners views in the planning of curricula and school programmes. The UN Committee (Right of the Child, 2009, p. 24) states that giving voice to learners is necessary for the elimination of discrimination and in the prevention of bullying.

According to Lewis (2010) and Lundy (2007, p. 930), Article 12 is widely cited, even though it is one of the most commonly misunderstood and controversial articles which is mentioned under the banner of 'voice of the child' or 'pupil voice'. Lundy (2007) goes further in establishing that Article 12 creates a gap between what is mentioned in the article as legally binding, and what is actually interpreted in practice. Lundy (2007) maintains that Article 12 is controversial as it is dependent on the co-operation of adults who do not always comply.

The learner, according to the empowerment rationale of the UNCRC (1989), was to be located in a position of "being" rather than "becoming" (Mannion, 2007 p. 407). If a learner is viewed as 'becoming' they are seen as a developing adult in need of support, whereas a learner viewed as 'being' is viewed as a person who has power and is capable of participating in matters pertaining to them. Thus listening to the learner's voice is becoming an ethical imperative (Messiou, 2012). Listening is defined as the "active process of communication involving hearing, interpreting and constructing meanings; not limited to the spoken word" (Clark & Moss, 2005, p. 491). Therefore, listening to learners is a multifaceted task which incorporates listening, consultation and participation (Clark, 2005). Listening to learners is an active process which involves interpreting and constructing meaning. Clark (2005) goes on to provide extensive definitions of listening as a process of communicating, which is not limited to hearing and speaking, but goes on to encompass all the senses such as facial expressions, gestures and actions. Participating is a dynamic process of listening which involves the adult and the learner constructing meaning through discussion, thereby sharing power and the responsibility of decision making (Miller, cited in Clark, 2005). The emphasis on listening in its broad sense cannot be underestimated, especially in inclusive education research.

According to Lewis (2010, p. 20) there is a danger in how one goes about hearing and listening to those voices, as listening must also include silence which is not 'neutral or empty'. There is a need to recognise that the learner has a choice to be silent. This silence gives a message of its own which can portray a very powerful statement, especially for authority figures who are expecting the learner's voice to be argumentative (Lewis & Porter, 2006). Thomson (2008) goes further, and

suggests that what is crucial to hearing learner voice in research and inclusive settings is a commitment on the part of the adult to listen to the voice of the learner. This is important so that adults do not edit the views and opinions of these learners (Thomson, 2008). Thomson (2008, p. 204) sees voice as "empowering people to be heard who might otherwise remain silent" or who are silenced by others. The learner's voice should be viewed as an essential component in educational contexts. Engagement with learners' voices is not only essential for understanding and dealing with marginalisation, but is a way of understanding the notion of inclusion itself (Messiou, 2012), and by listening to learners we empower them (Messiou, 2008).

The problem is that 'voice' is used so broadly in research, that according to Hadfield and How (2001, p. 486) "it is in danger of losing its specific meaning and becoming disconnected from different theoretical sources and critical praxis from which it originated." This results in the voices of the marginalised being ignored and in danger of becoming 'tokenistic', whereby their views are only given minimal attention. Research in relation to learners with TS needs to establish if they are being heard, or identified as troublesome because of their disruptions.

Nind et al (2012) maintain that learners who are given labels of behavioural, emotional and social difficulties are often 'voices' that are unheard in both education and in educational research. Listening to these learners voices is an aspect of inclusion and to "listen is to include" (Veck, 2009, p. 146). Messiou (2006) and Nind et al (2012, p. 651) echo the same thoughts, maintaining that "enabling voice can be a potential source of empowerment" which offers learners an opportunity to confront marginalisation. Learners must express their thoughts and ideas, casting new insights on the topic of inclusion and exclusion which have the potential to change current situations and existing structures; not only for themselves as learners suffering from TS but for others in education.

Inclusive education both internationally and in South Africa requires that learners be accommodated in schools. Despite well intended policy and written implementation, many learners are currently marginalised and excluded from the education system that is meant to be seen as a reform tool for ensuring equity (Engelbrecht, 2006). Slee (2011) maintains, as mentioned before, that

inclusiveness often falls short as it is not reaching the needs of *all* in inclusive education. Slee (2011, p. 107) goes on further to state that exclusion should be seen by those "who are devalued and rendered marginal or surplus by the dominant culture". This is reinforced by Veck (2009, p. 651) who maintains that one must challenge "hegemony of accounts that privilege certain voices over others".

The notion of "voice" is a complex concept and can mean different things in different contexts (Messiou, 2012). Thomson (2008, p.4) maintains that voice is "having a say as well as referring to language, emotional components as well as non-verbal means that are used to express opinion". Developing active listening and engaging with learners and young people is critical in order to gain rigorous and alternative perspectives of their experiences. Lewis (2005, p. 215) maintains that "...doing so in valid and reliable ways is often more problematic than is recognised", due to the fact that readers of research involving learners voices need to be aware that the participation of learners has been interpreted and written by adult researchers. In many school contexts, learners are not allowed to view their 'voice' as educational institutions are dominated by adult voice.

The study of learners' voices has become a contested and debatable issue. This growing awareness of the need to listen to the voice of learners remains a controversial issue in international research (Walton, 2011; Walton 2012), which concentrates on a variety of discourses, one of which focuses on learners' rights (Lundy, 2007), methodological innovations (Lewis, 2005) as well as philosophical and ethical issues (Haynes, 2009). Thus there has been a growing emphasis to include learners' views in relation to inclusive education (Lewis, 2005; Messiou, 2006), with recommendations that listening to these voices can be an incentive for change (Ainscow & Kaplan, 2004).

2.5.2 Challenges of Voice Research

Although voice research may reveal some promising insights into educational inclusion, exclusion and marginalisation it does not go without some critiques and contestations. Young (2000) maintains that the sociology of knowledge and epistemology is important educationally, and that there is a continual need to

discuss alternative approaches to policy, despite the inequality of education. It is therefore important to acknowledge the contested nature of voice research. Despite the challenges of voice research it would be potentially valuable to understand how inclusion and exclusion are perceived and experienced by learners in South African schools. The critical ethical issues which need to be considered when engaging in research with learners are informed consent, confidentiality and the safeguarding of research participants from harm and unequal power relations that operate between adult researchers and child participants (Kellet, 2010; Walton, 2011).

In addressing unequal power relations in research, Kellet (2010) upholds that this is when learners are seen as subservient to adults, both in homes and school. Kellet (2010) maintains that learners' voices have been twisted by adult voices of authority. Voice is an important element in the plan of researchers and practitioners who maintain that historically, social and cultural practices disregard learners' voice, which leads to marginalisation. Haynes (2009) found that in an educational context the learner is often seen as less competent, and as a result is unable to make decisions on their own, without adult domination of policy and practice in school contexts. If the adult voice is critical, it may challenge the way the learners' voice is heard and as a result attempt to influence the power relationship between the adult and the learner. Despite the shift in research 'on' learners, without them having any say or contribution to research 'with' learners, whereby the voice of learners could become a force for change and possibly enhance inclusive education and practices (Kellet, 2010 p. 16; Walton, 2011), children as a "powerless minority group struggle to have their voices heard" (Kellet, 2010, p. 16)

Although there are many advantages to using participatory research with learners, Fleming (2010, p. 2) points out that there is a "limit to how much research can rely from young people's participation". Fleming (2010) stresses the importance of finding out who benefits from the research, hence the issues of vulnerability of learners are crucial in research situations, and need to be considered a priority. Researchers need to reflect on who the recipients of research are, and if the information gained is to contribute to policy and practice of inclusive education

and not to merely support claims made by scholars for their own endeavour (Fleming, 2010).

Walton (2011, p. 86) maintains that the challenge of research in inclusive education is an “aporia” or a “dilemma”, which is confusing in establishing the truth of a position both for and against. Walton (2011) argues that researchers in the field, whilst attempting to promote inclusive practises, often unconsciously perpetuate exclusion. Actively listening to and exposing learners’ experience and ‘differences’, according to Walton (2011), assists the researcher in understanding exclusionary behaviour and attitudes. Despite it presenting numerous challenges by drawing attention to these individuals as ‘different’ and ‘excluded’, the ‘debate is valuable’ and on-going in listening to the ‘voices’ of these learners (Walton, 2011, p. 83). Slee (2011, p.50) goes further in drawing our attention in research to that of the “attitudes towards inclusive education”. Slee (2011, p. 50) maintains that firstly it focuses on people’s attitudes, as it “constructs the child with the disability as the problem” with a “defect”, and secondly this type of research, although it intends to change attitudes towards disability, the very act of pursuing research on these issues “obstructs social cohesion” (Slee, 2011, p.50). Slee (2011, p. 50) questions whether these researchers have the ‘correct tools’ to manage these multifaceted social issues. The ultimate dilemma in searching for answers is that researchers end up with more questions. In spite of the challenges and aporias that may occur in the process of research, the valuable research collected in and contributed towards inclusive education policies and practices cannot be denied. It is essential that the voices of learners illuminate the way. Slee (2011, p.164) maintains that this can only be achieved by reforming education through “reaching into the deep structure” of schooling in order to create “different policies, practices and cultures”. Until acceptance of difference is met and diversity accepted, marginalisation and inclusive education will not become a reality in South Africa.

The SIAS (DoE, 2008, p. 96) document encourages the voice of learners and states that their “own perceptions about themselves” and how they learn are “crucial when identifying the need for support”. Therefore, it is obvious that the learner’s voice is not only valuable but vital in terms of their development and

school placement, and these decisions cannot be undertaken “without consulting the learners themselves” (SIAS, DoE, 2008, p. 96). It is crucial that learners are consulted and not only given the opportunity for their voices to be heard, but also to be valued and taken seriously.

2.5.3. Conclusion

Being fully aware of the dilemmas and the debate raging about voice I have carried out research on learners suffering from TS, in order to hear their voice of how they experience schooling. In spite of the challenges and possible aporias that may occur in the process of this research, it is vital that the voices of learners with TS be heard and allowed to express their views and experiences and be understood. Hence there is the need for research ‘with’ rather than ‘on’ these learners which has become a dominant discourse (Kellet, 2010, p. 22; Walton, 2011 p.83). In Chapter 3 (Research methodology) I will explain the research design that is used in this study as well as the data collection instrument and the research process.

CHAPTER 3

Research Methodology

3.1 Introduction

The literature reviewed in the previous chapter shows the importance of collecting data directly from the participants in order to understand and listen to their 'voices' and their interpretations. In the sections that follow, I discuss how the research was devised and carried out. In order to do this I interviewed eight learners with TS.

3.1.1 Research objective

In order to be able to listen to the voices of learners with TS and their interpretations, the research needs to study the variations of the participants' perceptions of how they experience school (Marton, 1981 cited in Larsson & Holmstrom, 2007). In this regard the study incorporates a theoretical framework that includes Bandura's (1978; 1989) social cognitive learning theory and Bronfenbrenner's (1979; 2001) (bio) ecological theory of human development. Bandura's social cognitive theory and Bronfenbrenner's (bio) ecological theory of human development attempt to show the complex interaction of human development in learners.

This qualitative research uses a phenomenographic approach. Phenomenography is a qualitative research approach that explores variations in people's experiences of their worlds (Yates, Partridge & Bruce, 2012). This chapter gives an overview of phenomenographic research and includes the research design, data collection and data analysis, limitations of the research as well as the outcomes of phenomenographic research.

The ultimate aim of empirical phenomenographic research is to establish a descriptive level of the participants' understanding on a collective level (Barnard et al, 1999 cited in Ornek, 2008). Thus the empirical research objective is to understand collectively, the voices of TS learners as they experienced school.

3.1.2 Research design

To address the research problem this qualitative phenomenographic research used interviews to gain information from learners with TS. Eight participants were interviewed in order to understand how they experienced school. This qualitative research aimed at developing concepts to help understand social phenomena, within a natural (rather than in an experimental) setting, allowing the researcher to interview participants in order to gain an understanding of their views and experiences (Pope & Mays, 1995). This enabled the researcher to gather empirical data first hand, using open-ended interviews (McMillian & Schumacher, 2010) which are the main way of collecting phenomenographic research (Hasselgren & Beach, 2006).

The research is primarily concerned with describing, by means of words, the context of how the participants experience school, including their feelings, thoughts, actions and understandings (McMillian & Schumacher, 2010). The aim is not necessarily to generalise from the findings, but to uncover the different ways that the participants' perceived school.

The approach in this study used for research design and data collection, needed to be systematic and rigorous, in order to enable it to be used for further research. Rigour, according to De Wet and Erasmus (2005), is the verification of strategies and self-correction during the research process that ensures trustworthiness (reliability and validity) of qualitative data.

3.2 Phenomenography

The purpose of this qualitative research, as mentioned earlier, is to listen to the voices of learners identified with TS. The underlying qualitative theoretical framework, according to Martin (1986 cited in Ornek, 2008, p.1) is phenomenography, which "is the empirical study of the different ways in which people think of the world".

According to Ornek (2008); Larsson and Holmstrom (2007); Collier-Reed, Ingerman and Berglund (2009) phenomenography aims at discovering the

different ways in which people experience, conceptualise, interpret, perceive and understand the same phenomenon, or numerous features of a phenomenon in the world around them on a collective level. It is reinforced by the view that people collectively experience phenomena in a variety of qualitative different but interrelated ways (Yates et al, 2012). This includes the subject-object relations that phenomenography represents as experiences. This research explores the variation of meaning within a group of TS learners, rather than the individual learner's meaning in how they perceived school.

Phenomenographic research is more than simply reporting peoples different and multiple conceptions of a phenomenon (Orgill, 2012). It involves identifying and looking for underlying meaning within the concepts in order to further highlight the relationship between the different concepts (Ornek, 2008) as they are experienced by people.

Phenomenography as a research approach is not known as well as phenomenology, hence the need to explain their differences within educational settings (Larsson & Holmstrom, 2007; Akerlind, 2007). Phenomenography and phenomenology both have the term "phenomenon", which means "to make manifest" or "to bring to light" (Larsson & Holmstrom, 2007, p. 55). Phenomenography differs having the suffix "graph", which explains a research approach by describing the different ways a group of participants will understand a phenomenon. Phenomenology on the other hand has the suffix "logos" that seeks to explain the structure and meaning of a phenomenon (Larsson & Holmstrom, 2007, p. 55).

A key distinguishing feature of phenomenography is the use of "second-order" perspectives (Yates et al, 2012, p.99). Marton (1981 cited in Yates et al, 2012, p. 99) explains the difference between "first-order" and "second-order" perspectives, whereby the former "describes various aspects of the world", and the latter being concerned with "people's experiences of the various aspects of the world". This, according to Marton (1981 cited in Yates et al, 2012, p. 99), makes the second-order perspective of phenomenography an "insider perspective" demarcating the strength of phenomenography, as opposed to first order scientific research which is seen "from the outside". Insider perspectives can be related to voice research,

providing an insider view of the learner into the inequalities of schooling, and offering some promising insights into educational inclusion, exclusion and marginalisation. Despite Moore's and Muller's (1999) criticism of voice research lacking sustainable credibility because it is based on a relative perspective of learners' perspectives, it has merit. This second hand order perspective influences the formulation of research questions, and is the "what" difficulties are experienced, in order to maintain the emphasis on "how" expectations are formed, (Yates et al, 2012, p.99) instead of the first order perspective of "why".

As phenomenography is empirical research, the researcher needs to approach the open-ended interview and the analysis of the data collected open-mindedly without any of his/ her own perceptions (Ornek, 2008). In order to avoid "researcher subjective bias", the researcher must focus on understanding the participants and focus on the phenomenon under study (Larsson & Holmstrom, 2007, p. 59).

3. 3 Data Collection

The data collection provides an inside view of how the learner sees the inequalities of schooling.

3. 3.1 Sampling

In order to establish representation in this research, sampling of participants needed to be organised. Purposeful sampling, according to Cresswell (2008), is the research term used for qualitative sampling. Cresswell (2008, p. 214) maintains that in purposeful sampling researchers deliberately choose individuals or sites that are "information rich" to acquire information and knowledge about the phenomena being investigated. This "provides voice to individuals who may not be heard otherwise". In this research 'homogeneous' sampling was used, which Cresswell (2008, p. 216) maintains is sampling based on "membership in a subgroup that has defining characteristics". The learners I used in this study were diagnosed with TS by a paediatric psychiatrist according to the DSM. These learners needed to be diagnosed with TS in order to take part in this study. My research deals with listening to the experiences in school of learners with TS.

According to McMillan and Schumacher (2010), sample size is dependent on the availability of information-rich cases. The sample size in this study is related to the availability of informants, who are not easy to identify or locate as they have to meet the criteria of the DSM for TS. I obtained fourteen learners with TS from a few paediatric psychiatrists. I phoned the parents after the paediatric psychiatrists had gained permission from the parents for me to do so. Out of fourteen, eight parents and participants accepted and agreed to be part of the study. I chose this method and acknowledge that it is not ideal, however due to time constraints I deemed this the most appropriate method. Power relations between psychiatrist patients and parents were a concern however it was something that could not be avoided. In fact six out of the possible fourteen patients declined participation suggesting that the invitation to be contracted by me was phrased in such a way that made people comfortable to decline. The university student as well as the student who had finished school were also patients of the psychiatrists and obtained as participants in the same way as the other participants.

These eight participants of which there were seven boys and one girl, ranged in age from eleven years to twenty two years, from Grade 6 -12 (one student had just completed school and another is a university undergraduate).

The sampling size is also dependent on theoretical saturation or when "redundancy" (Merriam, 2009, p. 80) is achieved when no new data emerges and individuals do not provide any new insights. I felt that I had achieved data saturation when I obtained no new information; this led me to believe that recruiting further learners would not elicit any new information.

3.3.2 The Interview

The research was undertaken at each participant's home, where they were audio-taped and interviewed. This was done to avoid the dilemma of labelling these learners by interviewing them at school, thus marking them as 'different' (Walton, 2011). According to Cannell and Kahn (1968 cited in Cohen et al, p.269) a research interview is defined as "a two-person conversation initiated by the interviewer for the specific purpose of obtaining research-relevant information, and focused by him [sic] on content specified by research objectives of systematic

description, prediction or explanation". Cohen et al (2000) maintains that the characteristics of the standardised open-ended interview, is that questions are determined in advance, and participants are asked the same questions in the same order which does result in reduced flexibility.

3.3.2.1 Advantages of the interview as a research tool

The advantages of the interview as a research technique, according to Cohen et al (2000), is to ensure comparability, reducing bias and facilitating organisation and analysis of data. The interviewer has the opportunity to observe the subject (Cohen et al, 2000). The flexibility inherent in an interview allows the interviewer to probe and go into more depth, so that questions can be clarified and additional information given if requested (Cohen et al, 2000). This encourages a rapport and co-operation between the interviewer and the subject, with greater in-depth responses that would not be possible with a questionnaire or other methods of data collection (Cohen et al, 2000).

3.3.2.2 Type of questions

The interview schedule (Appendix 2) included a mix of combined structured questions with less structured and open-ended questions, in order to probe and achieve in-depth responses (Merriam, 2009; Yates et al, 2012). Semi-structured interviews of approximately forty five minutes were conducted, following a predetermined interview guide (McMillian & Schumacher, 2010). However, elements of the unstructured interview emerged at times during the discussions, allowing for spontaneous development of interaction and flexibility of the questions. Allowing for open-ended questions gave the participants freedom to answer questions according to their experiences. The processes of phenomenographic interviews are semi-structured, whereby the questions are open-ended in nature (Yates et al, 2012). Open structured questions enable the interviewer to pursue unanticipated lines of reasoning that may lead to new reflection (Yates et al, 2012).

The participants were encouraged to verbalise their everyday experiences openly, and encouraged to give concrete examples of how they perceived conditions or

events at school, in order to gain a better understanding of events (Larsson & Holmstrom, 2007). Further data was obtained when the participants explained how they coped if their 'tics' or 'concentration' was problematic. Finally they were presented with a genie granting them three wishes; one about their teacher, one about their peers and any other wish that they desired (genie wish list for participants to complete included in Appendix 3). Participants were informed of provision for a revisit, and given my telephone number if they wanted to contact me.

3.3.2.3 Disadvantages of the interview as a research tool

The disadvantages of the interview as a research tool is subjectivity and bias from the interviewer, as responses may be interpreted in terms of preconceived notions (Cohen et al, 2000), and participants' responses misinterpreted. To address this in part, data analysis should be carried out soon after the interview so that the interviewer does not forget details (Cohen et al, 2000). The subject could also be biased positively or negatively by the interview situation, which could also be affected by the participants wanting to be seen in a favourable light (Cohen et al, 2000).

There is also a need for careful formulation of questions in order to prevent ambiguity, which could affect the credibility (validity) of results. Questions must be made very explicit so misunderstanding can be avoided (Cohen et al, 2000), and if necessary questions may be clarified in the interview situation. Interview schedules are prepared in advance, to ensure that questions are not only explicit but structured to yield sufficient data (Merriam, 2009).

In order to overcome inaccurate representation of responses, audio recordings of data are made. Recording also ensures that the interviewer can focus on the interview without being slowed down by taking notes.

3.3.2.4 The interview process

The interview began with a brief description of the research aims and purposes, and a request that the interview be taped. The aim was to listen to the voices of

‘insiders’ (Walton, 2011, p. 83) to gain knowledge and understanding of the socialisation difficulties experienced by learners with TS in the school context. The interview provided the most direct data of listening to the voices of learners with TS. They were semi-structured which allowed me, the researcher, to probe their initial responses, and enabled them to ‘voice’ their experiences.

3.3 Data Analysis

Data analysis in phenomenography adapts a “second-order” perspective (Maybee, 2007, p. 454) that focuses on how participants experience or perceive phenomena. Data analysis in phenomenographic research aims (Yates et al, 2012) to uncover the variation in how the phenomenon that is being investigated is experienced, and the analysed transcripts are then interpreted collectively and not individually (Sin, 2010;Yates et al, 2012). It is this insider perspective that distinguishes the strength of phenomenographic research which, as mentioned earlier, is in contrast to the traditional first-order research, where the world is expressed as seen through the eyes of the researcher (Yates, et al, 2010). There is no single technique in analysing phenomenographic data, and this has led to a number of authors criticising phenomenographic research (Yates et al, 2012).

The data from transcribed interviews was analysed to determine the various ways in which participants experienced school. The researcher (Bruce, 1997 cited in Maybee, 2007, p. 454) focused on identifying referential elements which refer to the “significantly different meanings ascribed to”, in this case, the participants’ experiences of school. The second part of the analysis, according to Maybee (2007), is the structural elements. This includes the awareness and meaning structures, which are central to the ways participants experience a phenomenon, namely schooling. Awareness structures show what participants focus on when experiencing information, and meaning structures refer to the underlying meaning (Maybee, 2007), which once identified are compared to determine variations.

The referential and structural elements are then drawn together to form categories of description (Maybee, 2007), which are arranged into an outcome space showing how each category is referentially and structurally related. Therefore, according to Maybee (2007, p. 455), “The categories of description and the

outcome space represent the collective experience as analysed and described by the researcher". The categories provide a description of the ways schooling is experienced (Maybee, 2007), and the outcome space shows how all the categories are referentially and structurally related.

In analysing the data, I read and reread the transcripts from the audio tape recordings of the interviews with the eight interviewees, to familiarise myself with the data in order to determine the various ways that the participants experienced school. I identified and highlighted the different meanings evident in the participant's transcripts. Secondly, I looked at how the participants experienced school. I then took the information created and labelled it with codes. This was followed by reducing overlap and redundancy of codes, and lastly the codes were collapsed into themes and developing patterns (Cresswell, 2008; McMillian & Schumaker, 2010).

These patterns were then drawn together to form categories of description, describing the collective experiences of the participants' experiences of schools (Maybee, 2007). These were arranged into an outcome space, which shows clearly how all the categories representing the collective experiences of participants' experiences of school were related. This was achieved by coding, revision, recoding and ultimately developing a pattern which left me with two main categories. The first main category is the **intrapersonal systems** (internal personal factors which include psychological, physical and internal behavioural factors). The second category is the **interpersonal systems** (external environmental factors) namely teacher-learner interaction and peer interaction

This research was conducted within a theoretical framework that included Bandura's (1978; 1989) social cognitive learning theory, which explains human behaviour in terms of triadic reciprocal determinism. This model of reciprocal causation explains learning experiences and shows how the internal personal factors of the participants interacted with the external environmental factors.

Bronfenbrenner's (bio) ecological theory of human development was used to show how important each learner's internal (genetic, physical, psychological and behavioural) characteristics interacting with the external environmental factors

such as teachers or peers (Nel et al, 2012). According to Bronfenbrenner's (bio) ecological systems theory (Nel et al, 2012), personal (internal) characteristics or predispositions such as TS, AD(H)D, OCD and behavioural issues, cause an imbalance or barrier to arise towards learning and development. This will be discussed in detail in Chapter 4. Thus the outcome space showed both the similar and different ways in which learners with TS experienced school. In Chapter 4 I will explain and show the findings in detail.

3.4 Limitations of Educational Research

Educational research involves a number of constraints when conducting research (McMillan & Schumacher, 2010). The following constraints dealt with in this research are legal and ethical considerations and methodological difficulties (McMillan & Schumacher, 2010).

3.4.1 Legal and Ethical Considerations

McMillan and Schumacher (2010, p. 339) identify three main areas of ethical issues, namely 'informed consent', 'confidentiality and anonymity', and lastly 'caring and fairness'.

3.4.1.1 Informed Consent

Informed consent is when the participant knows exactly what they are consenting to (Kellet, 2010). Konza (2005) maintains that informed consent is one of the most critical issues in qualitative research. It is more than a signature on a piece of paper, and can be identified as the "protection of human rights, specifically self-determination, privacy, anonymity or confidentiality, fair treatment and the protection from discomfort and harm" (Konza, 2005, p. 17).

I gave information forms to participants (Appendix 4) and information sheets to parents (Appendix 5), explaining the purpose of the research and describing the procedure, including a description of confidentiality of records. Parents and participants were informed of the voluntary nature of the interview, that refusal to participate would involve no consequences, and that they may discontinue participation at any time. I gave parents, where applicable (some learners were

over 20 years), and participants, separate consent forms to sign (Appendix 6 - participants) and (Appendix 7 - parents). There were also consent forms asking for permission to audiotape the interview (Appendix 8 learners audio taping consent forms, and Appendix 9 parents audio consent forms).

3.4.1.2 Confidentiality and Anonymity

Confidentiality is something all researchers can guarantee except in disclosures about abuse or harm (Kellet, 2010). As participants with TS are vulnerable, particular care was taken to ensure anonymity and confidentiality.

Confidentiality - I ensured parents and participants of the confidentiality of their contributions. I ensured the confidentiality of all academic writing, publications or presentations arising from the research, by ensuring that research data would be kept safe by being locked up in a cabinet in my study and destroyed within 3 – 5 years.

Anonymity – was guaranteed by the use of pseudonyms instead of names being used in any research, reports or publications. Direct quotes from the data were used in the presentation of results in the research report, but would not include any identifying information. The direct quotes would be attributed to pseudonym identities.

Participants were reassured again about the voluntary nature of the interview, and that they were free to refuse to participate or withdraw at any time, with no negative consequences.

3.4.1.3 Caring and Fairness

Although physical harm to participants does not usually occur in qualitative research, occasionally a learner could experience humiliation and loss of trust (McMillan & Schumacher, 2010). Due to the vulnerability of participants with TS, I conducted the interviews with sensitivity, ensuring at all-times that no humiliation or loss of trust arose. Parents and participants were provided with 24 hour telephone contact details of the researcher, and daytime telephone contact details of my research supervisor. Some parents and participants expressed reservations

prior to the interview, but were reassured that if they felt any discomfort they did not have to answer the questions, or they could withdraw at any time without any negative consequences.

3.4.2 Trustworthiness of Qualitative Research

Due to the apparent lack of methodological rigour in qualitative research in 1970s to 1980s, Lincoln and Gaba (1985, cited in De Wet & Erasmus, 2005) introduced and developed new criteria to evaluate rigour of qualitative research findings. Hence trustworthiness was established to improve rigour, as well as to ensure that the findings of the research reflect, as clearly as possible, the meanings described by the participants (Lincoln & Gaba, 1985 cited in Shenton, 2004). Collier-Reed et al (2009) agree that trustworthiness has become an alternative construct to validity and reliability for measuring the value of research. Mouton (2012) maintains that the researcher in empirical research must take into account any factors which may confound variables and ultimately threaten the trustworthiness of the findings. Lincoln and Gaba (1985, cited in De Vos, 2005; Shenton, 2004) established four criteria for the trustworthiness of a qualitative research project, namely credibility, transferability, generalisability, dependability and lastly confirmability.

3.4.2.1 Credibility

According to Lincoln and Gaba (cited in De Vos, 2005, p. 346; Shenton, 2004 p. 64), ‘credibility’ must ensure that the research measures or tests what is actually intended to be tested, by ensuring appropriate research methods and demonstrating that a true picture of the phenomenon under scrutiny is being presented. Credibility is one of the most important factors (Lincoln & Gaba, 1985 cited in Shenton, 2004) in establishing trustworthiness.

Phenomenological researchers have been critiqued for the lack of clear relationship between representation and reality in interviews, which has led to theoretical and methodological problems in interpreting interview data (Sin, 2010). In order to address this danger of inaccurate interpretation of data, and consequently inaccurate drawing of conclusions, the interview questions I asked

were audio taped for accuracy. I ensured that the questions asked showed an in-depth description of all the complexities and interaction, and measured the concepts being studied (De Vos, 2005; Sheldon, 2004). I undertook to see my supervisor after the first interview, in order to establish the effectiveness of my questioning technique. I was in constant contact with my supervisor thereafter, especially if any problems arose.

Akerlind (2007, p. 331) maintains the phenomenographic approach can be problematic in that the participants' experience of a phenomenon can be "context sensitive" and they can change what they are saying at any time during the course of the interview; I needed to be aware that participants might change their interpretation during or after the interview. Lastly I gave participants the opportunity to refuse to participate, with no negative consequences to them, ensuring that only participants who were genuinely willing to participate were included. This, according to Shenton (2004), helps ensure credibility and honesty in informants.

3.4.2.2 Transferability or External Validity

In order to allow for transferability, sufficient detail of the context must be given so that a reader can decide whether the existing environment is similar to other familiar situations, and to what extent the findings in one study can be applied to other settings or situations (De Vos, 2005; Shenton, 2004; Merriam, 2009). Lincoln and Gaba (as cited in De Vos, 2005;Shenton, 2004; Merriam, 2009) suggest that the term transferability can be problematic, as it can be difficult, if not impossible, to show that the generalisability of findings and conclusions of a qualitative research are applicable to other situations and populations.

Some researchers (Merriam, 2009, p. 225) maintain that generalizations are too 'lofty' a goal for social science, and that researchers should rather consider a 'working hypothesis' that "reflects situation-specific conditions in a particular context", which is ultimately not a "conclusion". In this research, I attempted to show, as Shenton (2004) maintains, a "baseline understanding" of the 'voices' of learners with TS.

3.4.2.3 Dependability, Reliability or Consistency

Dependability addresses reliability, in which the researcher needs to show that if the research was repeated with the same participants, the same interview and in the same context, similar results would be obtained (Shenton, 2004). Dependability is difficult in qualitative work, although researchers should strive to ensure further investigators can repeat the study, since human behaviour is never static and replication does not yield the same results (Merriam, 2009). The importance, according to Merriam (2009, p. 221), is "whether the results are consistent with the data collected". Lincoln & Gaba (as cited in Merriam, 2009 p. 221) were the first to conceptualize reliability in qualitative research as "dependability" or "consistency", hence the question is not whether the results will be found again but that the results are consistent with the data collected.

According to Shenton (2004, p. 71), to ensure dependability, the researcher needs to report everything that is undertaken within the research 'in-depth' or 'audit trial' (Lincoln & Gaba, as cited in Merriam, 2009, p. 228), which describes in detail how each individual interview is undertaken. An 'audit trial' (Lincoln & Gaba, as cited in Merriam, 2009, p. 228) ensures how the data is collected, how categories are derived and gives a clear indication of how decisions are made throughout the enquiry, to ensure consistency and reliability. I must ensure that everything undertaken in this research is documented and reported. I must ensure that every step, from data collection to categories is described in detail.

3.4.2.4 Confirmability

This is objectivity which cannot be adequately ensured in qualitative research due to the researcher's biases (Shenton, 2004). I attempted to undertake this research with an open mind, without my own interpretations clouding it. I also identified and recognised my own preconceptions, which I will document fully and explicitly in each stage of the research process, so that the reader can judge for themselves. Sin (2010, p. 310) talks about 'reflexivity' in which a researcher's preconceived ideas are dealt with at the beginning of the research process. Critical self-reflection is essential for me as a researcher to uphold regarding assumption, biases, theoretical orientation as well as my relationship to this study which could

affect the investigation (Merriam, 2009). In this research I acknowledge my own preconceived ideas about TS due to my own personal interest.

3.5 Conclusion

In order to ascertain how eight learners with TS experience school, they were interviewed. The interviews were analysed to determine the various ways the participants experienced school. As explained in Chapter 3, the referential elements (different ways participants experienced school) and the structural elements (perceptions of participants' awareness and meaning) were joined together to form the various categories of description, and then represented in the outcome space (Maybee, 2007) constituting the results of the phenomenographic study showing the various ways in which the participants collectively experienced school (Larsson & Holmstrom, 2007).

CHAPTER 4

Findings and Discussion

4.1 Introduction

Phenomenographic research was chosen in order to understand the collective experiences, and listen to the voices of learners with TS as they experienced school. The aim of this study was to gain knowledge and understanding of the learning and socialisation difficulties experienced by learners with TS. The intention was to allow these eight participants with TS, the opportunity to share and voice the collective difficulties they encountered at school.

This study was set within a theoretical framework that included Bandura's (1978; 1989) social cognitive theory and Bronfenbrenner's (bio) ecological theory of human development (2001). The report findings reflect that learners with TS experienced difficulties on an intrapersonal level (internal personal factors) and interpersonal level (external environmental factors).

4.2 Analysis of Data from the Interview

Before the eight interviewees were asked open-ended questions which were transcribed in the interviews, they were asked for some background information. This information is only to give the reader an understanding of the participants; however it is the participants' collective experiences which this research is interested in. This information is summarised in Table 1 which included their age, sex, what grade they were currently in, if the participant attended an ordinary or special school which was either a public or independent school and what associated co-morbidity they suffered in addition to being diagnosed with TS by a paediatric psychiatrist. The participants' ages ranged from eleven to twenty two years. There was a dominance of males with a ratio of 7:1. This could be due to the fact that boys are more frequently diagnosed with TS than girls.

- Two participants attended special schools, one being a special independent school and the other a special public school. The participant attending the special independent school matriculated in 2012.

- Five participants are attending ordinary independent schools with the Grades ranging from 6 to 12.
- One participant matriculated from an ordinary independent school four years ago.
- All the participants have one or more associated co-morbidity conditions in addition to TS; namely AD(H)D, OCD and various behavioural problems (see 3.3.1 Chapter 2).

Table 1: Background summary information of Participants

Age	Sex	Grade in 2013	Type of school	Co-morbidity
20 years	Female	Matriculated 2012	Special Independent school	AD(H)D/OCD behavioural problems
17 years	Male	12	Ordinary Independent school	AD(H)D
11 years	Male	6	Special Public school	AD(H)D, behavioural problems
13 years	Male	8	Ordinary Independent school	AD(H)D
16 years	Male	10	Ordinary Independent school	AD(H)D
13 years	Male	8	Ordinary Independent school	AD(H)D/OCD
13 years	Male	8	Ordinary Independent school	AD(H)D
22 years	Male	B.Com (not completed) Matriculated 2009	Ordinary Independent school	AD(H)D, behavioural problems

The purpose of the interview was to establish what difficulties learners experienced in school, and the role teachers and peers played in their schooling. Sub questions were structured to allow participants the opportunity to clarify what they wanted teachers and peers to understand about TS.

4.3 Findings and Discussions

4.3.1 Categories of Description

The findings of the open-ended interviews resulted in two categories of description (Larson & Holmstrom, 2007). These categories of description are arranged in the outcome space which represents the collective experience of the participants (Larson & Holmstrom, 2007; Maybee, 2007). The two main categories that emerged are based on the collective similarities and differences experienced by the participants, obtained from the data in the interviews. The first main category is the **intrapersonal systems** (internal personal factors which include psychological, physical and internal behavioural factors). The second category is the **interpersonal systems** (external environmental factors). **Intrapersonal systems**, namely the internal personal factors, relate to the physical and psychological characteristics of the participant, which affects and determines their behaviour. The behavioural factors, which include the internalisation of the participant's condition, resulted in either internalised (internal personal factors) or externalised observable behaviour, such as rage and aggression in some of the participants. These behavioural manifestations influence how the participants interact with **interpersonal systems**, which include environmental factors such as teachers and peers, and how they in turn will react and relate to the participants.

These categories relate to Bandura's model of reciprocal causation, which determines human behaviour and learning, and include Bronfenbrenner's bio-ecological systems theory of development. Bandura (1978; 1989) believed that human behaviour is determined by a three-way relationship between personal factors, behaviour and environmental influences. Hence the categories of description are a modification of Bandura's (1978; 1989) triadic model of reciprocal determinism (see 2.2.4.4 in Chapter 2). Included is Bronfenbrenner's bio-ecological systems theory of development, which tries to show the complex

interactions and inter-relationships that also influence behaviour and academic environment (Nel et al, 2012). These emerging categories and outcome space show the variation in the way in which the participants collectively experience school. As this research aims to give voice to what learners with TS have to say, the findings presented draw strongly on the actual words of the participants.

4.3.1.1 Intrapersonal Systems

The first main category, **Intrapersonal systems,** consists of internal personal factors, including the physical and psychological characteristics and disposition of participants with TS, which affect learning and development by causing imbalances or barriers. **Intrapersonal systems** comprise three categories of description. The first category includes the *physical characteristics,* caused by the 'tics' that the participants felt affected them interacting normally. This resulted in activating psychological and environmental reactions, which in turn could affect their behaviour. Secondly, the *psychological characteristics,* which together with the physical factors, such as the tics, inhibit the participants socially, emotionally and scholastically. Third are the *internalised behavioural factors* resulting in participants overreacting at times and responding in a behaviourally inappropriate way, thereby affecting environmental interaction. Most of the participants however, felt that the tics played a defining role in how they coped at school.

4.3.1.1.1. Physical Effects of Controlling Tics

TS is a complex neurobiological disorder with a spectrum of involuntary motor and vocal tics (Hagin, 2003). The tics both motor and vocal are the defining features of TS and need to be present for a diagnosis of TS to be established.

Most of the participants stated that their tics affected them physically, psychologically and emotionally. The interviews showed a variation in how the participants dealt with their tics, which they tried to mask, at school. Most of the participants expressed the need to control and hide their tics at school so that they would be accepted, and seen as normal, and not different from other learners, as they did not wish to be singled out; as one participant said from the "other normal learners".

The energy expended controlling the tics left some participants complaining of feeling exhausted most of the time.

i) Exhaustion

The participants described varying degrees of exhaustion when trying to control the tics. When explaining how they controlled tics a participant described

> Trying to control the tics makes me use up all of my energy.

And as another participant explained

> If I do control my tics at school they are out of control at home and it makes me so exhausted… I get so tired fighting my tics …my whole body aches.

A third participant maintained that the “vocal tics were the hardest to control”.

Fighting the tics at school resulted in a number of participants complaining of fatigue, which caused an inability to sustain attention on tasks during the day. This resulted in a contradiction from participants as to whether they should partake in sport after school.

ii) Impact of sport

A contrast was noted here, as one participant explained that physical extramural activities makes

> my tics better because it helps me to relax

whereas another participant said that

> I do not like playing sport as I get so tired and it makes my tics worse … I can’t control them at school.

A third participant explained

> Sport makes no difference to my tics…I do not like playing sport…I am useless at sport…

Despite the contradictions in the partaking of sport, a number of participants complained of difficulty in falling asleep at night.

iii) Sleep

When learners had tics affecting them all day they used up considerable energy not only trying to control the tics, but to focus and pay attention. This resulted in some of the participants complaining of an inability to sleep at night. As a result participants woke up exhausted the next day. The reasons for their inability to sleep differed. One participant expressed that the sleep medication caused the feeling of exhaustion the next day. Another explanation was that the waxing and waning of tics when exacerbated resulted in…

> I can't sleep at night. I don't really have insomnia. I'm just active because I have no control over my tics so I am forced to stay awake.

A further explanation expressed by a participant was due to sustained tics all night; their body ached resulting in the inability to sleep.

The effects of lack of sleep left the participants feeling exhausted which lead to an exacerbation of the tics. The exacerbation of tics was never the same, leading to the participants experiencing different tics.

iv) Unique manifestations (sensations) of tics

Most of the participants talked about the variation of their tics, which due to the tics waxing and waning, changed at any time of the day, week or month. They could not establish when an old tic would disappear, and a new tic replaces an old tic, adding to existing tics.

The participants could also not establish when a vocal tic changed to a motor tic or vice versa, or even what caused both motor and vocal tics to occur at the same time, hence the manifestation of their own unique expression of their condition (see 2.4.5 Chapter 2). As one participant explained "I never know what new tic is going to appear".

Another problem that participants complained about was that tics could disappear, or even partially disappear, for a while, resulting in their condition not being recognised. As two participants explained, their tics were initially mistaken and associated with them playing up in class and seen as “naughty and acting out”.

Most of the participants’ associated reduced tics with “good days at school”. This shows an acute awareness of how their tics impacted on their everyday life; however participants were not really sure what reduced their tics. Continually trying to fit in with their peers, made the tics more noticeable, as according to them, they faced the uncertainty of how they would tic or react every day when they arrived at school. This caused them severe stress and anxiety manifesting in various psychological characteristics.

4.3.1.1.2 Psychological Characteristics

Participants found that in conjunction with the tics, concentration difficulties were a very worrying aspect which affected their performance at school on a daily basis. Some of the participants spoke about anxiety resulting in panic attacks, OCD, emotional disturbances such as social withdrawal, and depression as a result of the stress and unpredictability of their condition. These psychological characteristics had implications on a social, emotional and academic level (Bandura, 1978; 1989).

All the participants maintained that they could never totally relax. One participant explained how they could never come to terms with having TS, and elucidated that every day was a struggle

> I find it very difficult and very frustrating to accept and come to terms with my Tourettes, especially when no one understands … you feel all alone as you do not really know what is happening. No one knows what it involves … I suffer every day and it is so hard…

Another participant expressed volatility in daily interaction; “why do I always over-react… I wish I could take back what I said”. This uncertainty as well as anxiety about the unpredictability of their condition resulted in participants talking about

panic attacks. Some participants spoke about their anxiety, which was expressed in the form of OCD.

i) Anxiety

The physical manifestation of the tics and the psychological effects of TS are very closely related. As one participant maintained

> I feel anxious about going to school every day especially when my tics are bad… I try to control the tics and miss out on work in class… which makes me even more anxious…

According to the participants, anxiety goes hand in hand with TS. As one participant explained

> This feeling of anxiety is always there. I am always on guard…I never know what to expect, sometimes it just comes out and people want to know what was that! I just ignore them… So now I cannot slip, I must control my tics as well as the vocal noises at all times.

Another participant expressed that their anxiety resulted in self-injury, whereby the perception of anxiety manifested in an overpowering inability to cope. According to the participant the only way to relieve the stress was by cutting her/himself

> I found that the physical pain helped dull the mental pain.

The anxiety, according to three participants, has resulted in their suffering from panic attacks.

a) Panic Attacks

Three participants spoke about suffering from panic attacks. One participant maintained that suddenly in class…

> I can't breathe and I start to sweat, it just comes so suddenly for no reason.

A second participant explained the effects of a bad day at school

> I need to lie down and I try to breathe slowly in order to control my breathing and calm down.

A third participant complained of waking up at night feeling overwhelmed

> I get this intense wave of fear and feel scared… all I can do is concentrate on my breathing like my therapist taught me.

b) OCD

Two participants talked about having OCD, and one maintained how nothing could stop the progression of movement despite the teacher and peers staring

> When I study or am trying to concentrate I can't stop moving and touching. I have to touch in a symmetrical manner and I have the need to move all the time especially when I am learning. I tap all the time especially in class as I am not allowed to move.

Another participant could not explain what triggered OCD; once started, the need to touch became uncontrollable and it was almost impossible to stop the momentum once it had been triggered.

The uncertainty and anxiety of every day led to varying emotional disturbances, such as social withdrawal and depression.

c) Emotional Disturbances

Due to the anxiety, a number of participants maintained that they became socially withdrawn whereas others complained of depression.

- **Social Withdrawal**

Three participants talked about social withdrawal, where they felt the need to isolate themselves from the world around them in response to the anxiety and the frustration of having a bad day and being out of control. As one participant said "every day is a struggle and when the tics are bad I go to my room and lie down".

Another participant felt a need to withdraw as there weren't any good days at school "… I go to my room after school…I need to be alone…"

A further explanation of the need to withdraw went hand in hand with peoples' reactions to an outbreak of tics

> To be honest, on a bad day it has a negative effect on my mood and I don't want anyone around me…when it is bad I feel frustrated and feel that no one wants to help me, no one understands, they are just pretending to …I get angry and feel so embarrassed and rejected.

Two participants complained that owing to the feeling of being disempowered and helpless due to the difficulties of facing each day, they became depressed.

- **Depression**

Two participants talked about depression which impacted on every aspect of their lives, and that led to self-loathing and self-mutilation. The overwhelming effect of the tics, having no friends and concentration issues, resulted in their inability to cope at school. These participants felt they had nothing to live for and so they attempted suicide and spent some time in a psychiatric hospital. One participant explained that their attempted suicide was made due to feelings of "hopelessness and depression". The other participant added "I wish the world would have a better understanding of what I go through".

One of the participants went further and said that the depression had resulted in reckless behaviour which lead to promiscuity

> I don't know why I do it, but it like takes pressure off.

Two other participants spoke about their condition causing severe internalised frustration and anger which eroded their self-control, resulting in outbursts of rage and aggression affecting their behaviour. Participant's behaviour caused reciprocity of rage and aggression between self and the environment (see 4.3.1.1.3 under behavioural factors). Compounding all these problems was the inability to concentrate in class which often led them to fall behind in their work.

ii) Lack of concentration

All the participants complained of concentration issues however their reasons for lack of concentration differed. One participant maintained that “trying to control the tics” resulted in the inability to concentrate in class. A second participant complained

> I get so anxious in class… I don’t always understand the work or keep up as I lose concentration …

A third participant echoed

> I find it very difficult to follow in class… the teacher goes so fast…I can’t help it if I zone off…so I don’t always finish the work in class and I have to finish at home…it’s so unfair.

Another response was

> My medication makes me so tired and drowsy that I can’t always focus in class resulting in decreased concentration.

A further complaint was

> I have to work twice as hard as other learners due to my lack of concentration and because of my tics.

One participant admitted “I get so restless … I lose my place”. Another participant complained “I get distracted by the other learners in the classroom”.

Lack of concentration is linked to the previous sub-themes such as exhaustion and fatigue from controlling tics. Lack of sleep, as well as panic attacks, cause increased arousal which affects these learners’ concentration. All this leads to a build-up of tension which not only affects concentration, but leads to emotional outbursts.

4.3.1.1.3 Behavioural Factors

There is no set definition of human behaviour, however, according to Ucadia (2009, n.p.), behaviour is “the physical and or psychological effect” of “relationships” of “one human being(s) on other human being(s) and/or their environment”.

The participants explained the vicious cycle of having to control tics, trying to concentrate and keeping up with their peers in class, which caused tremendous stress and anxiety. As a participant explained “I can’t control my emotions and I lash out…” It is sometimes very difficult to separate the physical from the psychological aspects, as it is cause and effect for example anxiety causing tics and the exacerbation of tics causes anxiety creating a cyclical response. Ultimately with the exacerbation of tics and heightened anxiety, school work was affected, creating behavioural and social problems affecting the relationship with teachers and peers. This resulted in affecting environmental conditions that not only affected their behaviour but also how teachers and peers responded to them, creating a reciprocal process of behaviour, internal personal factors and environmental reactions (Bandura, 1978; 1989).

The participants talked about their on-going frustration and anxiety that at times resulted in them responding in a behaviourally inappropriate way. Some of the participants maintained that their behavioural issues were associated with their condition, whereby they lost control and reacted inappropriately which further aggravated their stress levels. The participants expressed that they often felt frustrated, and reacted by showing rage and aggression in response to the frustration of trying to cope with their disorder, as well as in defence to the way they perceived others saw them. Rage and aggression resulted in negative interactions as shown in the next subsection.

- **Rage and Aggression**

A few participants spoke about their condition affecting their self-regulation which interfered with their environmental and interpersonal relationships, especially with their peers, resulting in uncontrollable outbursts of frustration and anger.

> I have a big mouth…it just happens because I have no self-control or impulse control and I am sorry…

Two participants narrated about their temper tantrums at school which led to them being asked to leave the school, intensifying their feelings of anger

> My parents moved me because of all the fights…I was not allowed to make any decisions about moving schools or where I should go… they just moved me…it's so unfair

A number of participants felt vulnerable to bullying and rejection from their peers, due to their social and emotional problems, which inhibited their social skills and had a huge impact on their interpersonal (environmental) interactions.

As one participant maintained

> I get so angry … no one understands what it is like to have TS

This creates an imbalance, affecting interpersonal relationships, which is reflected by the above participant's inability to control his/her anger.

In the interaction of everyday life, behaviour alters environmental conditions (Bandura, 1989) and is altered by the very conditions it creates. Through participants' actions they create, as well as select, their environments (Bandura, 1978). If participants act aggressively they will create hostile environments; whereas if participants behave in a friendly manner, they will generate amicable social milieu (Bandura, 1978). In this research, behavioural factors are described as interaction between the individual interacting with the school environment, which includes interaction with teachers and peers. Any imbalance that occurs within an individual, or a system, will affect the balance between the systems. This continuous causal process that happens in one system will affect or be affected by the other systems (Bronfunbrenner, 1979; Nel et al, 2012).

4.3.1.2 Interpersonal Systems

Interpersonal systems are the second main category, and consist of the external environmental factors that comprise the two categories of description. The first category includes the interaction of the participant with the schooling system, including the *participant's perception of the teacher's interaction*. The second category includes the *interaction of participants with their peers* and how this impacts on their self-development and concept of 'self'. Included, is what participants want their teachers and peers to understand about their condition.

4.3.1.2.1 Teacher learner interaction

The attitude of teachers had a profound influence on how the participants adjusted to school. There was an overwhelming need for teacher acceptance and understanding of their condition, and of the difficulties they faced with their school work, which was aggravated by inconsistencies due to their condition.

i) Participant's perceptions of teacher awareness/knowledge of TS

- **Participant's desire for teachers acceptance**

Three participants expressed the need for acceptance, understanding and approval from their teachers. This is reflected in a statement from a participant

> I wish they [teachers] would recognise that I am not like everyone else…

Another participant reflected in the following statement

> I wish my teacher would listen to me…and I could be treated the same as others [learners]

A third participant stated

> I want teachers to know basically how to deal with it [TS] or what it [TS] is…I don't want them to think I am naughty

One participant reflected positively that “there was always a special teacher who helped me”. This reflected that the participant acknowledged the teacher’s extra support. This shows the importance of the teachers’ perceptions of participants, how much it meant to the participants to be helped and understood, and how they needed their teacher’s approval and acceptance. The need for teachers to know about their condition was not unanimous; as one participant maintained “it’s none of their business”.

- **Participant’s perceptions of teacher disapproval**

Three participants complained and felt that teachers did not understand their condition

> She [teacher] is always telling me to stop making a noise

This was echoed from another participant who expressed “my teacher hates me…she is always shouting at me to stop making noise and sounds”. Another said “why can’t my teacher realise that I can’t help moving or making noises and that I am not deliberately being the class clown or trying to disrupt the class”.

Participants not only expressed a need for teachers to have some knowledge about their condition, but also to understand how TS affected their scholastic ability. Participants reflected that school would be easier if teachers helped them emotionally and scholastically. Teacher attitude is vital for the school experience of learners with TS, according to research. Grace & Russell (2005 cited in Koutsoklenis &Theodoridou, 2012) found learners who were the happiest and managed the best at school, were those learners who felt that teachers understood and respected their feelings and offered them assistance.

ii) Participant’s perception of teacher’s awareness/knowledge of their scholastic difficulties

- **Participant’s desire for scholastic support from teachers**

The participants felt that due to all the problems associated with their condition, school was fraught with many problems and difficulties, and some participants

verbalised that if teachers gave them some assistance and support with their school work, life would be easier.

Participants need for teachers to help with their “scholastic difficulties” were reflected in the following statement

> I don’t mind if they focus on me during class as I realise they are trying to help me…it would be helpful if they repeated the work for me.

Another participant went on to say

> I wish my teacher could understand why I don’t understand the work, especially the mathematics … I want them [teacher] to be there for me and allow me to ask for help because I can’t help it if I can’t listen in class.

This reflects the participants need for “help on a deeper level” with regard to his/her scholastic progress. This was echoed by another participant, who also felt that school would be easier if teachers could give them personal help with their school work. The participant said

> I wish teachers would become good teachers and try their best to help people like me with extra support…I wish they would understand that learning can be hard sometimes.

Another participant stated

> I would like them [teachers] to give me more support than other people (I suppose that sounds selfish)

possibly showing low self-esteem. This particular participant felt insecure and constantly doubted himself/herself and complained of anxiety attacks.

One participant suggested that “photocopying” would be helpful. Others however, were not able to give specific examples of support needs, but reflected a very generic need for “more support than the others”. This appeal for personal support was not unanimous, as is indicated in the next section on participant’s perceptions of their teacher’s dissatisfaction with their scholastic difficulties.

- **Participant's perceptions of their teacher's dissatisfaction with their scholastic abilities**

A number of participants were conscious of their teacher's dissatisfaction, which is reflected by the following statements

> Teachers must not be so impatient to students who need extra help… I wish they would back off at times and realise that I am trying my best

Another participant stated

> I wish they would stop criticising me. I wish everyone would stop criticising me as I am trying my best (participant got very agitated and upset and did not wish to discuss the issue further).

Further displays of teacher unhelpfulness were

> they [teacher] never give me enough time to finish my work…and my teacher punishes me when I do not do my homework…I find work so hard…my teacher says I should know it…

whereas another participant explained that

> Teachers are so unhelpful and get irritated when asked to repeat.

All the participants maintained unanimously that teachers shouted or complained at them to concentrate and focus. As mentioned earlier in psychological characteristics, lack of concentration is due to the associated co-morbidity of TS, and is not something they do deliberately. The participants believed that their inability to concentrate at times exacerbated their anxiety levels, which resulted in increased tics and decreased concentration that ultimately impacted on their scholastic ability, showing the interrelationship between a learner and his/her environment.

One participant did not wish to discuss his teacher, implying withdrawal. Discussing his teacher invoked anger or hurt. Lewis (2010, p. 20) maintains that refusal is not "neutral or empty" and that silence portrays a message of its own.

This particular participant was asked to leave the school due to repeated altercations. I interpreted this silence as portraying hurt and rejection.

The participants not only complained about the hardships of school work, but found that their socialisation with peers, due to the unpredictability of the tics and involuntary responses, added to their problems. Even though we acknowledge that teaching and learning is a major focus in schools, we also know that peer interaction is very important for meeting friends, socialising and feeling accepted. Belonging to a group will help the development of a positive self-image. Unfortunately this does not come naturally to these participants as they have always felt that they sit on the periphery and have never been accepted. This will be shown in the findings below.

4.3.1.2.2 Peer Interaction

The attitudes of peers, and teachers, have a profound influence on how participants adjust to the school environment. Most of the participants felt the need for acceptance, understanding and support from their peers. Due to some of the participants' lack of control, outbursts of rage and aggression were common, leading to social rejection and bullying.

i) Need for acceptance and understanding from peers

Participants felt that because they often felt isolated, acceptance and understanding from peers had a profound influence on their adjustment to school, and how they coped with their condition. Acceptance and understanding from peers was reflected in the following statement

> When I am accepted I feel normal

Another went on to say

> I wish they [peers] would support me and understand what I am going through…I wish I had more friends and that people would like me.

Another expanded by saying

> I'm never the in-crowd…I wish they [peers] would be more comfortable with the TS issue.

This was further reflected by the following

> I want my friends to know that I am who I am because of my condition

A number of participants were aware of non-acceptance and ridicule from their peers

> They treat me as different…laugh and mock me because I twitch

Echoed by

> I get anxious and think that everyone is looking or laughing at me

This reflection of non-acceptance was not unanimous as one participant maintained "I am never teased or mocked".

Some participants however, due to their lack of confidence and poor self-esteem, exacerbated by the inconsistencies of having TS, felt that this influenced their social interactions and they were susceptible to rejection from peers.

ii) Social Interactions

The participants felt that the characteristic tics of the syndrome greatly affected their control over their social interactions with others (Markova, 2012). This leads to tension and maladjustment affecting environmental factors. Environmental influences determine which forms of behaviour are developed and activated (Bandura, 1989). As mentioned earlier, aggressive behaviour will produce a reciprocal hostile environment in response (Bandura, 1989). Therefore, due to the bi-directionality of behaviour and environmental situations, people are both producers and products of their environment (Bandura, 1989).

As one participant maintained

> I always react to the slightest provocation

Cognitive (personal) factors determine which, or how, external events are observed (Bandura, 1978; 1989), and as a result show how participants respond to the environment

One participant could not understand his reactions and responded

> …Why do they always start with me?

Participants poor social interaction not only made them “feel rejected” by their peers, but made them inappropriately attribute their social problems to causes outside themselves. As one participant said “they [peers] always get me into trouble…why is it always only me? They [peers] get into trouble very rarely”.

Social behaviour does not occur in isolation, but consists of the reciprocal interaction of an individual with his immediate environment. Participants activate different environmental reactions by means of their physical, psychological, genetic or behavioural characteristics (Bandura, 1989), which are reinforced by Bronfenbrenner (2001) bio-ecological theory of development. Due to the bi-directionality of influences between behaviour and environmental situations, learners, through their actions, will create and select their environment (Bandura, 1989). In other words, learners who are unable to control their impulsivity, over-reaction or aggressive behaviour, may cause an imbalance in peer relationships, leading to bullying and peer rejection.

a) Bullying and Peer Rejection

Poor social skills displayed by a number of participants led to negative social interactions with their peers, leading to bullying and peer rejection. Participants complained of being bullied most of which was verbal abuse. As one participant explained “they call me weird”, expanded by another “they make fun of me because I twitch…they imitate me and laugh”.

One participant complained of being bullied by his brother at home, and as a result became the bully at school and fought with other learners

> My brother hits and bullies me …my therapist says that is why I start with children at school …

This learner, due to an imbalance at home, has become the bully and aggressor at school, taking out his frustrations and anger on his peers.

Social interactions with peers were ultimately fraught with problems, leading to a number of participants becoming aware of their inability to interact with their peers appropriately at times and resulting in feelings of rejection. This was reflected by one participant explaining, “They [peers] rejected me” therefore the participant refused to go back to school and changed schools as a result.

Feelings were mixed amongst the participants as to what they wanted peers to know about their condition. As one participant commented

> I would hope they would support me a bit and understand …it’s not like I have cancer or I’m dying you know but it’s so hard…

Whereas another reflected

> I do not discuss such things with them [peers]

The underlying experiences of some of the participants regarding bullying and rejection were shrouded in misunderstanding. The participants felt that the stress, frustration, and pain that came with the misunderstanding of those around them created difficulties in terms of learning, emotions and physical well-being.

4.4 Conclusion

The participants verbalised some internal and external factors that inhibited them. They maintained that the sense of being different, coupled with the social consequences, hindered their learning and their personal growth and stunted social integration.

Bandura’s social learning theory (2001 cited in Thorlakson, 2010) recognises the interaction between self and society, as well as biological and affective factors; whereas Bronfenbrenner (2001) reinforced both the developmental as well as

developmental imbalances that may arise. The interaction between the person, their environment, their abilities and their behavioural responses will ultimately affect and influence their learning performance at school (Thoriakson, 2010), as also how others will interact in return.

The participants have acknowledged that their behavioural responses have played a role in their success or failure in scholastic and personal achievement, and their interpersonal relationships with teachers as peers. These participants have identified some further issues, which if acknowledged, would make life easier for them. The participants have shown how hard it must be to live with this disorder and must feel as if they are trapped within their own body, which is constantly letting them down. Even though there is no cure at this point, despite medication and interventions helping, knowing about their hardships can help educators and peers understand and make life a little easier for them.

The last Chapter links the findings of this research data with the research question and sub-questions. It also offers recommendations based on this research, draws final conclusions, and shows the limitations of this research.

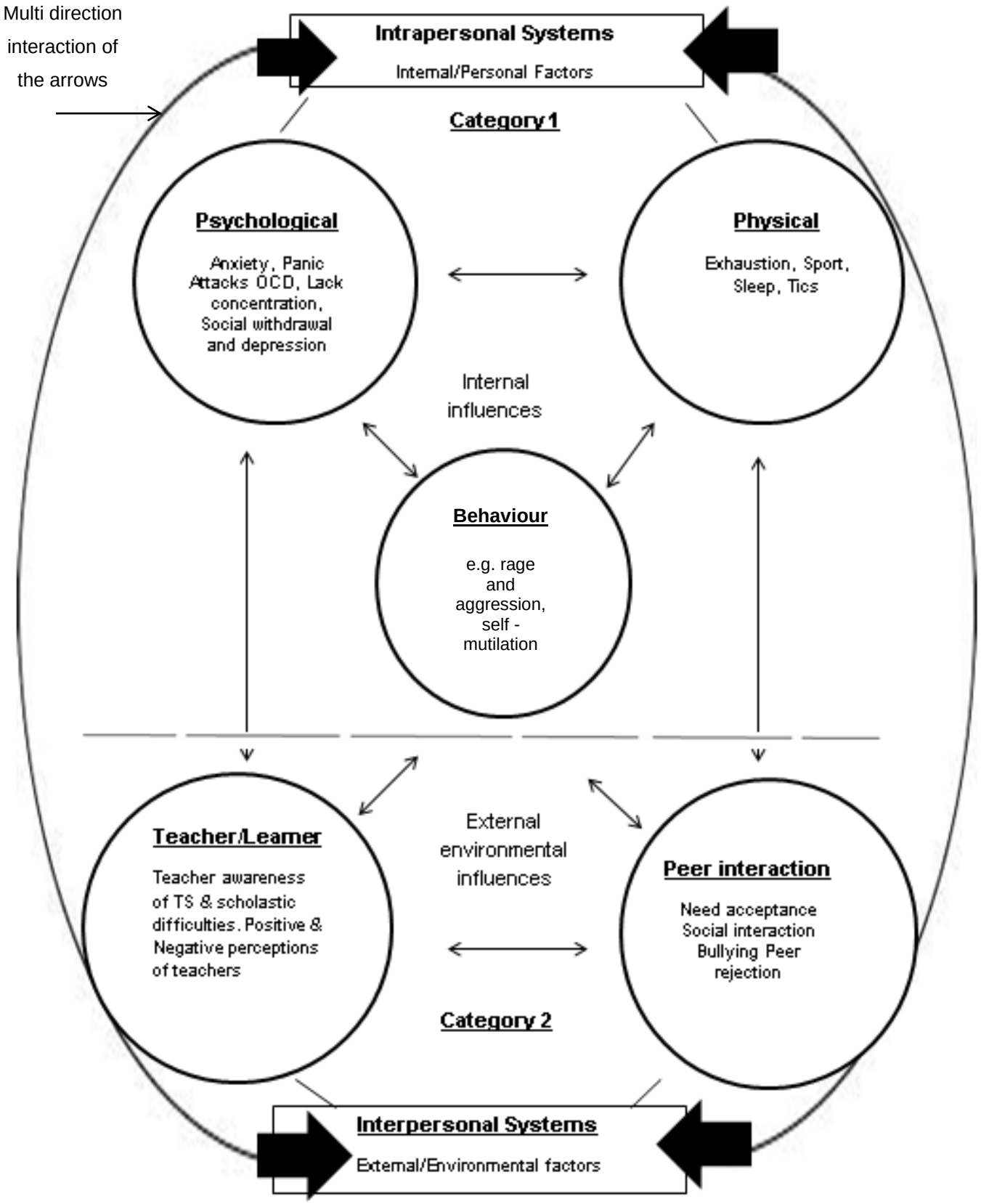
The two main categories of description can best be shown by Figure 1 (shown at the end of the chapter), which gives a visual representation of the categories of description in the outcome space, describing how the participants collectively experienced school. Included are the combined factors of Bandura's triadic reciprocal determinism model (1978; 1989) and Bronfenbrenner's (2001) bio-ecological theory of human development. The diagram shows the multi-directional interactions, represented by the arrows between the circles, which influence the participant's experiences of school.

- **The first main category is intrapersonal systems** (internal personal factors). This consists of three categories: the physical, psychological and behavioural characteristics of TS. *Physical characteristics* include feelings of exhaustion, impact of sport, lack of sleep and the effect of the tics. *Psychological characteristics* include internal factors such as anxiety, panic attacks, social withdrawal and depression, OCD and ADHD, which causes reciprocal two way reaction with behavioural factors. *Behavioural factors*

include either the internalisation or externalisation in observable behaviour, which manifests in some participants as rage and aggression.

- **The second main category is the interpersonal systems** (external environmental factors). This consists of two categories: teacher learner interaction and peer interaction. *Teacher learner interaction* included participant's perceptions of teacher awareness/knowledge of TS, and scholastic difficulties. Also included were participant's perceptions of teacher's positive and negative reactions. *Peer interaction* included the need for acceptance, and bullying and peer rejection.

Figure 1: Categories of Description in the Outcome Space



Chapter 5

Summary, reflections, recommendations and conclusion

5.1 Introduction

Learners with TS are not well understood or accepted by teachers or peers in South African schools, which makes these learners vulnerable to exclusion and marginalisation. This research study has been guided by a need to listen to the voices of learners with TS regarding inclusion, in order to dismantle exclusion and marginalisation. Phenomenographic research was used in order to understand the collective experience of learners with TS.

This chapter reflects upon and summarises the results of this study. Comments are made on the limitations of the research, and recommendations made for teachers and for further research.

5.2 Overview of the Study

The aim of this research was to gain knowledge and understanding of the difficulties with learning and socialisation experienced by learners with TS in a school context. It also tried to establish the participants' perceptions of how much teachers and peers understood about TS. Eight participants diagnosed with TS, were interviewed through open-ended questions. This allowed the participants to reflect and voice how they experienced school, including any difficulties they encountered socially, emotionally and scholastically. In this research voices of these participants were listened to, and the findings analysed in relation to other research. This suggests that listening to learners is a "neglected area" (Messiou, 2008, p. 27) and that marginalised learners have been "ignored and patronised" (Rose & Shevin, 2004, p. 155).

5.3 Findings from the Research question and sub-questions.

The central question to this study was, 'how do learners with TS experience school?' In order to further explore this main research question, the following sub-questions were addressed:

- In what way do learners with TS feel their condition affects their learning?
- How do learners with TS perceive their social difficulties in the school context?
- What do learners with TS expect their teachers and peers to understand about TS?

The results from the interviews found that these participants experienced difficulties on two levels or systems, namely intrapersonal and interpersonal. The **intrapersonal systems** (internal personal factors) consist of three categories: the physical, psychological and behavioural characteristics of TS. The **interpersonal systems** (external environmental factors) consist of two categories, namely teacher-learner interaction and peer interaction.

This research was conducted within a theoretical framework that included Bandura's (1978; 1989) social cognitive learning theory, which explains human behaviour in terms of triadic reciprocal determinism. This model of reciprocal causation explains learning experiences and shows how the internal personal factors of the participants interacted with the external environmental factors.

Bronfenbrenner's (bio) ecological theory of human development was used to show how important each learner's internal (genetic, physical, psychological and behavioural) characteristics interacting with the external environmental factors such as teachers or peers (Nel et al, 2012). According to Bronfenbrenner's (bio) ecological systems theory (Nel et al, 2012), personal (internal) characteristics or predispositions such as TS, AD(H)D, OCD and behavioural issues, cause an imbalance or barrier to arise towards learning and development. This imbalance affected the relationship between the participants and other interacting systems such as school and peer interaction. Any imbalance that occurs within an individual or within a system, will affect the balance between these systems. The causes of this imbalance are internal and external difficulties which affect the socio-emotional wellbeing and the academic efforts of learners with TS.

This was reinforced by Bandura (1978; 1989), who maintains that personal and environmental factors do not function independently, they determine each other. Therefore the participant's behaviour would evoke different reactions from others

in their social environment, depending on how they behaved. The participants are thus both products and producers of their environment (Bandura, 1978; 1989). If a participant behaves aggressively, they will produce a hostile environment. This was the result in a number of participants experiencing social difficulties at school. These social difficulties, which included teacher and peer interaction, influenced and impacted on the participants learning and self-esteem.

5.3.1 In what way do learners with TS feel their condition affects their learning

The greatest difficulty participants experienced in school was trying to deal with their tics as well as their concentration problems. Most of the participants felt that the debilitating and stigmatising effects of the tics drained them physically and emotionally, resulting in socio-emotional difficulties and decreased academic performance. Most of the participants expressed the need to control and hide their tics at school so that they would be accepted and seen as normal by other learners.

The participants spoke about the tremendous stress and anxiety they experienced in the vicious cycle of having to control tics, trying to concentrate and keeping up with their peers in class. The strain manifested in various ways, such as panic attacks, social withdrawal, depression and co-morbidity conditions such as OCD and AD(H)D. *Ultimately, participants complained that increased stress and anxiety exacerbated the tics, which affected their school work, leading to behavioural and social problems in their relationships with teachers and peers.*

These findings reflect the conclusions of Prestia (2003) and Shapiro (2003). According to Prestia (2003) the tics are the central and most distressing feature of TS. However, Shapiro (2003) finds that the co-morbidity, such as AD(H)D, OCD and behavioural manifestations, play a more central role in scholastic problems, social rejection and isolation. All the participants struggled with concentration resulting in scholastic problems of varying degrees.

5.3.2 How do learners with TS perceive their social difficulties in the school context?

The majority of the participants said they had experienced negative social interactions with teachers and peers. Many expressed that these interactions left them with a negative self-image and with feelings of marginalisation in school. They were anxious and feared rejection by their peers because of their tics. This heightened awareness of continually worrying about being accepted made them sensitive to any form of criticism or provocation from teachers and peers. Because of their need for acceptance, some of the participants were positioned differently from the norm, setting them up for teasing or bullying, or alternatively becoming the bully due to suppressed anger.

Low self-esteem and emotional volatility was evident in some of the findings, suggesting that participants were not empowered to confront marginalisation. This was echoed in the participants' recall of incidents where they commented on the importance of approval, acceptance and being understood. However, there were contrasting statements, and as one participant reflected, there was always a special teacher who helped him/her. Another contrasting statement concerning peers was that one participant maintained that he/she was never bullied by peers.

Teasing and bullying reflect the learners' marginalisation. The UNDP (1996, p.1) defines marginalisation as being "undesirable." This leads to "inequality, unfairness and deprivation" (UNDP, 1996, p.1), and problems such as being teased and mocked were voiced by some participants after they were labelled as having behavioural, socio-emotional and academic difficulties. It is usually these learners with socio-emotional and academic problems whose voices are unheard in education and in educational research. Therefore by "enabling voice" (Nind et al, 2012, p.651) the findings, could be a powerful means for confronting marginalisation and promoting inclusion.

5.3.3 What do learners with TS expect their teachers and peers to understand about TS

The participants' inability to self-regulate resulted in their being misunderstood and subsequently marginalised. They felt that neither teachers nor peers accepted them because of their behavioural problems. The fact that the school did not make changes to accommodate their needs was voiced as evidence of their marginalisation and the lack of understanding in the whole school community about TS. They did not want to be treated as different or as "freaks." Participants echoed a strong need for acceptance and understanding from their peers which was an essential aspect of their wellbeing. The **external environment**, which included teacher and peer interaction, influenced and impacted on the participants' learning and self-esteem.

The interviews demonstrated how the attitudes of teachers and peers and their understanding of TS had a profound influence on the participants adjusting to school life. Participants wanted teachers and peers to not only understand their condition, but also to be aware of the difficulties they faced with their school work. Participants wanted to make teachers and peers aware that their school work was compromised by inconsistencies in their performance due to their condition.

Teacher attitude was vital for the school experience of learners with TS, and according to research by Grace and Russel (2005 cited in Koutsoklenis & Theodoridou, 2012) learners who were the happiest, and managed the best, were those learners who felt that teachers understood and respected their feelings, and offered them assistance.

Getting assistance with school work was another problem mentioned, and a number of participants verbalised the feeling that if a teacher gave them some assistance and support e.g. photocopying work or repeating work, it would make their school life easier.

Messiou (2008) maintains that engaging with learners' voices provides valuable insight into their experiences, can help us understand inclusion in schools and can be a powerful lever for change (Ainscow & Kaplan, 2004). By listening to learners

we not only empower them, according to Messiou (2011), but we allow learners to identify aspects within a given context that can promote inclusion and help towards their acceptance within the school environment.

5.4 Limitations of the study

5.4.1 Sample size and location

This study is limited because the sample size is small (n=8). Participants were recruited from paediatric psychiatrists who were in a private practice. At Chris Hani hospital, the biggest government hospital in Gauteng, the department head of the paediatric psychiatric unit, Dr H. Clark, maintained that she has not treated any black learners with TS, although some of these learners do present with tics (however there could be personal reasons why they are not brought into the clinics. One can only surmise that they go to traditional healers or that these learners are not identified as having a problem serious enough to be taken for treatment). There is however no research, according to Dr H. Clark, to back up this statement. The study is therefore limited by the fact that only middle class white learners were investigated.

5.4.2 Limitations of execution

Fourteen learners and their parents were approached, however only eight learners agreed to do the interviews. Reasons cited were not only due to the stigmatising nature of the disorder, but to the fact that some parents did not want their children to know that they had TS.

5.5. Recommendations from the study

5.5.1 Teachers need to improve learning outcomes

According to Messiou (2012, p. 19), “valuing students perspectives” is very important, particularly for teachers who can learn more about their own practices and see learners issues in a different light. Bridging this gap between teachers and learners can go a long way towards making learners feel accepted and acknowledged. Inclusion is understood, as seen in the literature, to be an

approach that is based on the notion of acceptance, tolerance and understanding of diversity. Inclusion requires that a school or educational system makes changes to accommodate learners with TS, rather than expecting the learner with TS to change in order to fit in with the school.

The findings revealed that a number of participants expressed a need for acceptance, understanding and approval from their teachers, who play a crucial role in assisting learners with TS to improve *academically*.

A number of strategies which teachers could attempt to incorporate, in order to assist learners with TS, include the following;

- The participants expressed difficulties with concentration, as well as an inability to always keep up with other learners in the classroom. Teachers could assist learners with concentration issues by teaching at a slower pace and repeating if necessary.
- Teachers could explore differentiation strategies in order to cater for learners' diversity. This would help to alleviate some of the anxiety expressed by the participants about their school work, and indirectly help with the tics because learners are less anxious.
- Some participants complained that they worked slower than their peers. Teachers can accommodate them with concessions such as allowing them extra time, especially in exam situations.
- Some participants complained that teachers could not always decipher their handwriting, and that it was difficult to write when they had tics. Oral examinations could be considered in these cases.
- Teachers could shorten homework exercises to a few necessary items, especially if learners have AD(H)D. Some participants stated that they did not always complete their homework, with some citing fatigue as a problem.
- Teachers could experiment with seating arrangements, seating learners with TS where there is more personal space, so that they can get up and move when necessary. This would be beneficial, especially for those learners with OCD or AD(H)D, who find it difficult to sit for long periods.

5.5.2 Teacher and Peer Education

Overall findings from the interviews were that teachers and peers lack education regarding TS, particularly its identifying features. There is a need to educate teachers and peers in order to facilitate an acceptance of diversity. By listening to the voices of learners with TS, it shows learners that their opinion and their need to contribute to decisions made about them are valued. This pertains especially to their placement in schools. It is imperative that learners are consulted and are afforded the opportunity for their voices to be heard, valued and taken seriously, in order to promote inclusivity.

5.5.2.1 Teacher Education

Educating teachers about TS, and giving them an understanding of learners with TS is important. Teachers have an enormous impact on a learner's emotional growth. Those teachers, who have insight and knowledge about TS, can assist in the adjustment and development of learners with TS. This will help these learners to develop a *positive self-image*.

The acceptance at schools, of learners with TS could be enhanced if teachers shared their strategies of knowledge with colleagues. This study has shown that teachers need to act as role models for acceptance of diversity.

5.5.2.2 Peer Education

One of the findings from the study was poor social skills. A number of participants complained about negative social interactions, resulting in rejection, isolation and feeling different, which hindered learning, personal growth and social integration. In order to assist learners with TS:

- Teachers need to educate learners on how to accept their peers who have TS.
- This could be introduced by teachers using books, videos and role playing scenarios about coping with peer conflict and bullying.
- Peer education could also be introduced by affording learners with TS the opportunity to explain the involuntary nature of their condition. This might help

eliminate some of the negative perceptions and attitudes that people have about this syndrome.

5.5.3 Recommendations for further research

- It would be interesting and beneficial to hear the voices of teachers on what difficulties they encounter when teaching learners with TS, and how they deal with these difficulties as they arise.
- There is a need to ascertain the prevalence of TS among different South African communities.
- There is also a need to conduct similar research in all provinces and utilise a bigger sample size of the S.A. population

5.6 Reflections

My close and personal interest in learners with TS may have contributed limitations and strengths to my research study. I feel that my close connection to the study gave me a compassionate listening ear, which I believe put participants at ease. I also feel this may have contributed to the participants' opening up to me and divulging more than they intended to. The downside was the need to consciously remind myself to put my own personal opinions aside, in order not to bias any findings. I also needed to be open to seeing things I had not previously thought about.

5.7 Conclusion

Actively listening to and exploring learners' experience in school can assist researchers in understanding exclusionary attitudes and practices. By listening to the 'voices' of learners with TS, who are often marginalised, can be an effective way for teachers, peers and family members to change their negative attitudes towards this syndrome. There is a need to allow the voices of these learners to illuminate the way. This research has allowed the voices of learners with TS to be heard and their views and experiences understood.

These learners' lives have been drastically affected by this disorder. Today they are troubled learners; tomorrow will be the same, unless we do something to change this. By accepting difference, and acknowledging diversity, schools in South Africa can make inclusive education a reality.

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Appendix 1

Poem: The Animals inside Me

“The Animals Inside Me” (Bruun & Budman, 1992, p. 6)

“I have a spider inside me.

It makes my lips smack.

I have a spider inside me

and it makes me feel black.

His name is Tourette’s.

I have a kangaroo inside me.

It makes me jump up and down.

I have a kangaroo inside me

and it makes me feel brown.

His name is Tourette’s.

I have a frog inside me.

It makes me warty and mean.

I have a frog inside me

and it turns me green.

His name is Tourette’s.

I have an eel inside me

and it makes me slither.

I have an eel inside me

and it makes me shiver.

His name is Tourette’s.

I have a wild horse inside me.

It makes me feel like prancing.

I have a wild horse inside me

and it’s always dancing.

His name is Tourette’s.

I have a tiger inside me

and it makes me growl.

I have a tiger inside me”

and when I get mad, I go “r-o-w-l!”

His name is Tourette’s.

I’m going to shoot those animals.

I’m going to bring a banana.

I’m going to shoot those animals.

I’m going to wear a bandanna.

And then the puppy inside me

will make me happy and play.

And then the puppy inside me

won’t ever run away.

His name is Justin.”

Appendix 2

Interview Schedule

Interview Schedule

Schedule for forty five minute session which will be audio-taped (Cresswell , 2008, p. 234)

Introduce yourself

Describe the project, telling the participant about

a) Purpose of the study

b) What will be done with the data to ensure confidentiality?

c) How long the voluntary interview will take and that the session will be audio-taped.

Time of Interview:

Date:

Place:

Interviewer:

Interviewee:

Position of Interviewee:

Project: Listening to the 'voices' of children with TS

Questions:

1. What difficulties, if any, do you experience in school?

2. How do your "tics", "ADHD/ADD", "OCD" or "disruptive behaviour" affect your learning?

3. Could you explain a bad day at school to me?

4. Whom do you talk to when you have a bad day/or if tics are bad?

5. What ways do you cope with your day/tics if they are bad?

6. Could you explain a good day at school to me?

7. What would you like your teachers to know about your condition/tics?

8. What would you like your peers to know about your condition/tics?

9. A genie grants you three wishes for you have released him from a bottle.

Please will you make or write one wish about your “Peers” and one about your “Teachers” and anything that you desire.

Is there anything you would like to tell me?

“Thank the participant for their co-operation and participation in this interview. Assure them of the confidentiality of the interview and their responses.”(Cresswell, 2008, p. 234). If they have anything further to report they are welcome to contact me.

Appendix 3

Genie wish list



Sir Gandal

As luck would have it you have been granted three magical wishes for you have released Sir Gandal- the genie- from an ancient glass bottle.

You may make or write any wish about your:-

Peers_____

_____

_____

_____

_____

Teachers_____

_____

_____

_____

_____

Anything you

desire_____

_____

_____

_____

_____

Appendix 4

Learners information sheet - Interview

INFORMATION SHEET: LEARNERS - Interview

DATE

Dear _____

My name is Linda Dolowitz and I am a Masters student with the School of Education at the University of the Witwatersrand and I am doing research on: *An Investigation into how learners with Tourette Syndrome experience school*

I would like to invite you to be part of my research project in Term 1 of 2013 at a time convenient to you. Please understand that you can decide to be involved. The choice is yours alone (with your parent's permission). If you decide not to take part in this study, there will be no negative consequences. If you agree to be involved, you are free to stop participating at any time and again there will be no negative consequences.

I would like to interview you at your home, after the school day has ended. My investigation involves you answering between 8 to10 questions about being at school. Please note that these questions may be personal but will not violate your privacy. You are free to stop at any time and you do not have to answer a question if it makes you feel uncomfortable. There will be no negative effects for you if you choose to stop or not participate. I will be writing down and audio taping the information with your consent for accuracy purposes so that I do not make any mistakes about understanding what you say.

I will not be using your name when I write up this research however I will make up a name so no one can identify you. All information about you will be kept confidential in all my writing about the study. If you decide to be in this research study, you will be asked to sign a consent form. This will give me permission to use this information to complete my research. These findings will be used in my research report and possibly in other academic writing like books, journals or conference presentations.

I do not expect there will be any negative risks in participating in this research. There will also be no direct benefit to you or your parent/guardian. However, the

information you share with me may be of benefit in improving schooling for other Tourette Syndrome (TS) learners in the future. You can phone me if you would like to discuss anything further with me. I will also give you the opportunity of seeing what I have written with the option of adding or changing anything written.

All collected information will be stored safely in a locked cabinet and destroyed within 3-5 years after I have completed my research.

Your parents have also been given information and a consent form, but at the end of the day it is your decision to join me in my study.

I look forward to working with you!

Please feel free to contact me or my supervisor if you have any questions.

Thank you Linda Dolowitz

P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469 Cell: 084 7280851

E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton: Elizabeth.Walton@wits.ac.za

Appendix 5

Parents Information Sheet - Interview

PARENTS INFORMATION SHEET - Interview

DATE

Dear Parent

My name is Linda Dolowitz and I am a Masters student with the School of Education at the University of the Witwatersrand and I am doing research on*: An Investigation into how learners with Tourette Syndrome experience school*

I would like to invite your child to be part of my voluntary research project in term 1 of 2013 at a time convenient to you. Participation is entirely voluntary and there will be no negative consequences for choosing not to participate. If you agree I will interview you child at your home, after the school day has ended. My investigation involves your child answering between 8 to10 questions about his/her school experience. Some of the questions will be personal but will not violate privacy. I can e-mail or fax you the questions before hand if you prefer. I will be writing down and taping the information that he/she gives me so that I do not make any mistakes about interpreting what he/she says. Your child will not be advantaged or disadvantaged in any way if they choose not to participate. He/she will be reassured that he/she can withdraw his/her permission to participate at any time during this interview without any penalty.

The interview is anonymous with no identifying information in all reports and writings including books and that I will be using pseudonyms to ensure anonymity and confidentiality. Hence all information about your child will be kept confidential in all my writings, presentations or publications resulting from this study. If you decide to let your child be part of this research study, you will be asked to sign an interview consent form as well as a consent form for the audio taping of the interview so as to ensure accuracy. This will give me permission to use this information to complete my research project.

I do not expect there will be any negative risks in participating in this research. There will also be no direct benefit to you or your child. However, the information your child shares with me may be of benefit in improving schooling for other

Tourette Syndrome (TS) learners in the future. Your child with your permission can phone me if he/she would like to discuss anything further with me. You as a parent are also welcome to phone me at any time to discuss anything further.

All collected information will be stored safely in a locked cabinet and destroyed within 3-5 years after I have completed my research.

Please feel free to contact me or my supervisor if you have any questions. An electronic summary of the research report upon finalisation in February 2014 will also be made available should you wish to receive one.

Thank you very much for your help.

Yours sincerely,

Linda Dolowitz P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469 Cell: 084 7280851 E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton Supervisor: Elizabeth.Walton@wits.ac.za

Appendix 6

Learner's Consent Form - Interview

Learner's Consent Form - Interview

I am inviting you to participate in this voluntary interview and there will be no negative consequences for choosing not to participate. Please fill in the reply slip below if you agree to be voluntarily interviewed. I will use your answers to my questions for my study called: *An Investigation into how learners with Tourette Syndrome experience school*

Permission for this voluntary interview

My name is: _____

I have read and understand the information sheet.

YES/NO

I know that it is voluntary study and there will be no negative consequences if I choose not to participate

YES/NO

I would like to be interviewed for this voluntary study in Term 1 2013

YES/NO

I know that Linda Dolowitz will keep my information safe and

confidential.

YES/NO

I know that I can stop the interview at any time and don't have

to answer all the questions asked.

YES/NO

I understand that there will be no negative consequences if I decide to stop

YES/NO

I know that my real name will not be used in any writing, presentation

or publication YES/NO

I know that the electronic and written data will be locked away in a cabinet and destroyed within 3-5 years after completion of the research YES/NO

Sign_____ Date_____

Linda Dolowitz P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469 Cell: 084 7280851

E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton: Elizabeth.Walton@wits.ac.za

Appendix 7

Parent's Consent Form - Interview

Parent's Consent Form: Interview

I am inviting your child to participate in this voluntary interview and there will be no negative consequences for choosing not to participate. Please complete and I will collect the reply slip below indicating your willingness to allow your child to be voluntarily interviewed in my research project called*: An Investigation into how learners with Tourette Syndrome experience school*

Permission for the voluntary Interview

I, _____ the parent of _____

I hereby consent/do not consent for my child to be interviewed for 45 minutes after school at home in term 1 2013.

[ ] I am aware that participation is voluntary.

[ ] I am aware that there are no negative consequences for my child's refusal to participate.

[ ] I know that my child may withdraw from the voluntary interview at any time and that there are no negative consequences for terminating.

[ ] I know that my child will not be compelled to answer any questions that he/she does not want to answer.

[ ] I am aware that the researcher will keep all information safe and confidential through the use of pseudonyms in all academic writing, publications or presentations arising from the research.

[ ] I am aware that my child's interview will be kept locked in a cabinet and destroyed within 3—5 years after completion of the research.

Parent's Signature: _____

Date: _____

Contact person:

Linda Dolowitz

P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469 Cell: 084 7280851

E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton: Elizabeth.Walton@wits.ac.za

Appendix 8

Learner's Consent Form - Audio taping

Learner's Consent Form - Audio taping

I am inviting you to participate in this voluntary interview and to be audio taped and that there will be no negative consequences for choosing not to participate. Please fill in the reply slip below if you agree to have the voluntary interview audio taped. I will use these audio tapes for my study called: *An Investigation into how learners with Tourette Syndrome experience school.*

Permission for audio taping of my voluntary interview

My name is: _____

Participation is voluntary and I can withdraw at any time with no negative consequences

YES/NO

I agree to be audio taped during this voluntary interview in Term1 2013 for the purpose of accurate recording

YES/NO

I know that I can stop the audio taping of the interview at any time without any negative consequences.

YES/NO

I know that I can withdraw from the interview at any time and will not be advantaged or disadvantaged in any way.

YES/NO

I know that the audiotapes will be used for this project only.

YES/NO

I know that the audiotapes will be kept in a securely locked cabinet and will

be destroyed within 3-5 years after completion of this research.

YES/NO

Sign_____ Date_____

Contact Person:

Linda Dolowitz P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469

Cell: 084 7280851

E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton: Elizabeth.Walton@wits.ac.za

Appendix 9

Parent's Consent Form - Audio taping

Parent's Consent Form - Audio taping

I am inviting your child to participate in this voluntary interview and to be audio taped and that there will be no negative consequences for choosing not to participate. Please complete and I will collect the reply slip below which indicates your willingness to have your child's voluntary interview audio taped for my research project called: *An Investigation into how learners with Tourette Syndrome experience school*

Permission to have my child's voluntary interview audio taped

I, _____ the parent of _____

Participation is voluntary and my child may withdraw at any time with no negative consequences.

I hereby consent/do not consent to have my child's interview recorded after school at home in term 1 2013 for the purpose of accurate recording.

- I understand that my child may withdraw from the study at any time and that there will be no negative consequences for my child choosing not to participate.
- I understand that my child can stop the audio-taping of the interview at any time with no negative consequences.
- I understand that the audiotapes will be used for this project only.
- I understand that the tapes will be kept securely in a locked cabinet and destroyed within 3-5 years after completion of this research.

Parent's Signature: _____

Date: _____

Contact person:

Linda Dolowitz

P.O. Box 46189 Orange Grove 2119

(H) 011 883-4469

Cell: 084 7280851

E-mail – dolowitz@mweb.co.za

Supervisor: Elizabeth Walton: Elizabeth.Walton@wits.ac.za

Appendix 10

Definition and explanation of concepts

Definition and explanation of concepts

The following words and phrases are used in the study. They are briefly explained and defined to ensure clarity and aid understanding.

Attention Deficit (Hyperactivity) Disorder AD(H)D	AD(H)D is a neurobiological disorder causing distractibility, (hyperactivity/impulsivity) and a general inability to focus attention.
Behavioural Disorders	Behavioural disorders are an associated disorder of TS which may consist of aggressiveness and explosive temper tantrums (Packer, 1995).
Co-morbidity/co-morbid conditions	Medical term used when one condition or disorder occurs along with another. However, one condition does not directly cause the other.
Corprolalia	Corprolalia is involuntary utterances of obscene or inappropriate statements or words.
Echolalia	Echolalia is involuntary repetition of words or phrases just spoken by others.
Obsessive-Compulsive Disorder (OCD)	OCD is when a person has uncontrollable thoughts and compulsive behaviours to the extent that they impair functioning.
Tic	Tics are either involuntary movements (motor tic) or involuntary vocalisations (vocal tic) or both.
Tourette Syndrome (TS)	TS is defined as multiple motor and vocal tics, lasting for more than one year, with the onset before the age of eighteen.
Waxing and waning	A naturally occurring increase and decrease in severity and frequency of TS symptoms.
Inclusion	For the purpose of this research, 'inclusion' means that all learners have the right to access good quality education, despite any form of disability they may have. Equal education opportunities are provided for all learners.
UNDP (1996, p. 1) defines marginalisation	"State of being considered unimportant, undesirable, unworthy, insignificant and different resulting in inequality, unfairness, deprivation and enforced lack of access to mainstream power".

These terms are cited from the National Tourette Syndrome Association website http://tsa-usa.org/

Appendix 11

Ethics clearance approval

Wits School of Education

27 St Andrews Road, Parktown, Johannesburg, 2193 Private Bag 3, Wits 2050, South Africa
Tel: +27 11 717-3064 Fax: +27 11 717-3100 E-mail: enquiries@educ.wits.ac.za Website: www.wits.ac.za

Student Number: 0314640R
Protocol Number: 2012ECE184

Date: 21-Nov-2012

Dear Maureen Dolowitz

Application for Ethics Clearance: Master of Education by Coursework

Thank you very much for your ethics application. The Ethics Committee in Education of the Faculty of Humanities, acting on behalf of the Senate has considered your application for ethics clearance for your proposal entitled:

An investigation into how learners with Tourette Syndrome (TS) experience school

The committee recently met and I am pleased to inform you that clearance was granted.

Please use the above protocol number in all correspondence to the relevant research parties (schools, parents, learners etc.) and include it in your research report or project on the title page.

The Protocol Number above should be submitted to the Graduate Studies in Education Committee upon submission of your final research report.

All the best with your research project.

Yours sincerely

MMabeta

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