

TOURETTE SYNDROME: THE EFFECTS OF PSYCHOEDUCATIONAL
INTERVENTIONS IN SCHOOLS

BY
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75

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 Atomic 0759
 Electronics and Electricity 0609
 Elementary Particles and High Energy 0752
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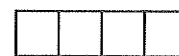
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Travail social	0452

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Pathologie végétale	0480
Physiologie végétale	0817
Sylviculture et taune	0478
Technologie du bois	0746
Biologie	
Généralités	0306
Anatomie	0287
Biologie (Statistiques)	0308
Biologie moléculaire	0307
Botanique	0309
Cellule	0379
Écologie	0329
Entomologie	0353
Génétique	0369
Limnologie	0793
Microbiologie	0410
Neurologie	0317
Océanographie	0416
Physiologie	0433
Radiation	0821
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Paléontologie	0418
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Palynologie	0427

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Administration des hôpitaux	0769
Alimentation et nutrition	0570
Audiologie	0300
Chimiothérapie	0992
Dentisterie	0567
Développement humain	0758
Enseignement	0350
Immunologie	0982
Loisirs	0575
Médecine du travail et thérapie	0354
Médecine et chirurgie	0564
Obstétrique et gynécologie	0380
Ophtalmologie	0381
Orthophonie	0460
Pathologie	0571
Pharmacie	0572
Pharmacologie	0419
Physiothérapie	0382
Radiologie	0574
Santé mentale	0347
Santé publique	0573
Soins infirmiers	0569
Toxicologie	0383

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Généralités	0485
Biochimie	0487
Chimie agricole	0749
Chimie analytique	0486
Chimie minérale	0488
Chimie nucléaire	0738
Chimie organique	0490
Chimie pharmaceutique	0491
Physique	0494
Polymères	0495
Radiation	0754
Mathématiques	0405
Physique	
Généralités	0605
Acoustique	0986
Astronomie et astrophysique	0606
Électronique et électricité	0607
Fluides et plasma	0759
Météorologie	0608
Optique	0752
Particules (Physique nucléaire)	0798
Physique atomique	0748
Physique de l'état solide	0611
Physique moléculaire	0609
Physique nucléaire	0610
Radiation	0756
Statistiques	0463

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Génie industriel	0546
Génie mécanique	0548
Génie nucléaire	0552
Ingénierie des systèmes	0790
Mécanique navale	0547
Métallurgie	0743
Science des matériaux	0794
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Technologie hydraulique	0545
Mécanique appliquée	0346
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Généralités	0621
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Psychobiologie	0349
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Psychologie du comportement	0384
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**A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial
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Abstract

The purpose of this study was to determine the effectiveness psychoeducational interventions may have on 1) the teacher's treatment of a child with Tourette Syndrome; and 2) the Tourette Syndrome child's behaviour and academic performance. Seven children, ages 8 to 12, and their teachers, were given pre and post measures. Results from the Piers-Harris Children's Self-Concept Scale, the Behavioral Academic Self-Esteem Rating Scale, the Child Behaviour Checklist, the Tourette Syndrome Global Scale, the Behavioural Observation Form, the Tourette Syndrome Knowledge Survey, the Structural Parent Interview, and the Structured Teacher Interview indicate that the psychoeducational interventions had a positive effect on the 2 major variables.

Table of Contents

ACKNOWLEDGEMENTS.....	ii.
ABSTRACT.....	iv.
CHAPTER	
I. INTRODUCTION.....	1.
A. Background to the Study.....	1.
B. Diagnostic Criteria.....	4.
C. Symptomatology.....	5.
D. Characteristics.....	6.
E. Associated Features and Disorders.....	8.
F. Statement of the Problem.....	10.
G. Purpose of the Study.....	10.
H. Limitations of the Study.....	11.
I. Hypotheses.....	12.
II. REVIEW OF RELATED LITERATURE.....	14.
III. METHODOLOGY.....	19.
A. Subjects.....	19.
B. Instruments and Measures.....	19.
Structured Parent Interview.....	20.
Structured Teacher Interview.....	20.
Tourette Syndrome Knowledge Survey.....	20.
The Piers-Harris Children's Self-Concept Scale.....	20.
Behavioral Academic Self-Esteem.....	23.
Child Behavior Checklist.....	24.
Behavioral Observation Form.....	26.
Tourette Syndrome Global Scale.....	26.
C. Procedure.....	27.
D. Variables.....	29.
E. Experimental Design.....	30.
IV. RESULTS.....	31.
V. SUMMARY AND CONCLUSIONS.....	49.
A. Suggestions for Further Research.....	53.

REFERENCES.....	54.
APPENDICES.....	62.
A. STRUCTURED PARENT INTERVIEW.....	62.
B. STRUCTURED TEACHER INTERVIEW.....	65.
C. TOURETTE SYNDROME KNOWLEDGE SURVEY.....	68.
D. PIERS-HARRIS CHILDREN'S SELF-CONCEPT SCALE.....	72.
E. BEHAVIORAL ACADEMIC SELF-ESTEEM.....	74.
F. CHILD BEHAVIOR CHECKLIST.....	76.
G. TOURETTE SYNDROME GLOBAL SCALE.....	78.
H. BEHAVIORAL OBSERVATION FORM.....	80.
I. SUBJECT SCORES--TEST BY TEST.....	82.
J. CONSENT FORMS.....	90.
K. PRESENTATION PROTOCOL.....	95.
L. ETHICAL APPROVAL.....	98.

List of Tables

Table-1: Core and Associated features of Tourette Syndrome Disorder.....	9.
--	----

List of Graphs

Figure-1: Subject 1: Results of 5 personal attribute tests from 6 administrations	32.
Figure-2: Subject 2: Results of 5 personal attribute tests from 4 administrations	33.
Figure-3: Subject 3: Results of 5 personal attribute tests from 8 administrations	34.
Figure-4: Subject 4: Results of 5 personal attribute tests from 6 administrations	35.
Figure-5: Subject 5: Results of 5 personal attribute tests from 6 administrations	36.
Figure-6: Subject 6: Results of 5 personal attribute tests from 8 administrations	37.
Figure-7: Subject 7: Results of 5 personal attribute tests from 7 administrations	38.
Figure-8: Subject 1: Results of 3 teacher administered tests..... over 6 administrations	41.
Figure-9: Subject 2: Results of 3 teacher administered tests over 4 administrations	41.
Figure-10: Subject 3: Results of 3 teacher administered tests over 7 administrations	42.
Figure-11: Subject 4: Results of 3 teacher administered tests over 6 administrations	42.
Figure-12: Subject 5: Results of 3 teacher administered tests over 4 administrations	43.
Figure-13: Subject 6: Results of 3 teacher administered tests over 7 administrations	43.
Figure-14: Subject 7: Results of 3 teacher administered tests over 7 administrations	44.

CHAPTER I

INTRODUCTION

A major challenge confronting teachers is the growing number of children who engage in inappropriate behaviours. For some teachers, one group of students' behaviours have become all too familiar. These children disturb, disrupt and distract their classmates and the teachers. They do this by making unusual sounds and strange movements. They often are unable to stay on task for any length of time. Many of these children are aggressive towards both the teachers and classmates. Often this occurs with no seeming explanation. At times, these children can behave appropriately, but in many cases they suddenly begin to manifest the behaviours that cause interference in the classroom's activities. Some of these children displaying these intrusive behaviours may be afflicted with a disorder known as Tourette Syndrome (TS), a relatively little known neurological disorder characterized by involuntary muscular movements and noises coming from the nose or throat.

A. Background to the Study

Current research indicates that many children and adolescents with Tourette Syndrome experience a wide range of academic, interpersonal, and behavioural difficulties. These difficulties are frequently manifested in school, causing disruptions in the classroom (Harcherik, Carbonari, Shaywitz, & Cohen, 1982; Shady, Fulton, & Champion, 1988; Stefl & Rubin, 1985; Teitelbaum, 1979; Wertheim, 1982).

A factor complicating an already sensitive situation is that these behaviours do not remain fixed but "wax and wane" that is, come and go; grow and disappear. This gives the appearance of wilful misbehaviour on the part of the children when they indeed, may have very little if any, control over the exhibition of their behaviours.

It therefore becomes critical to the overall academic success of children with Tourette Syndrome that information concerning the "waxing and waning" as well as the involuntary nature of the symptoms be provided to the teachers and classmates of the Tourette Syndrome children. This is so in light of the fact that Tourette Syndrome children who have teachers who are knowledgeable about the disorder get on much better in the classroom than do those students whose teachers have not received information about the disorder and implications arising out of the disorder. There is however, a lack of resources to address the special needs of students with Tourette Syndrome in the Canadian educational system (Shady, Fulton, & Champion, 1988).

There are however, many strategies that may be employed to assist teachers and their TS students in overcoming the many learning problems TS may bring. However, before teachers can implement these techniques, they need to know that they exist. Unfortunately, the majority of teachers (70.4%) in a Canadian survey were described by students with TS and their parents as not at all knowledgeable about TS (Shady et al, 1988), and the educational recommendation made most often in the TS literature is education of the educators (Cohen, Ort, Leckman, Riddle, & Hardin, 1988; Comings & Comings, 1987; Hagin, Beecher, & Pagano, 1982; Hagin & Kugler, 1983; Lagiewka-Cook, Goulet, Shady, & Broder, 1989; Lerer, 1987; Shady et al., 1988, Shapiro & Shapiro, 1982, Stefl, 1983; Teitelbaum, 1979; Wertheim, 1979).

In the face of teachers' lack of knowledge and awareness, the strange movements, sounds and inappropriate language uttered by TS children may result in inappropriate punishment or in these students becoming labelled as "trouble makers." Development of an adequate classroom climate for such students depends strongly on the attitude and teaching style of the teacher and the school officials in charge (Shady et al., 1988).

It would be an ideal situation if all teachers could be made aware of the symptomatology and the educational and behavioural techniques required to deal with this very complex disorder. Teachers, and the peers of the Tourette Syndrome child need to be

informed fully about the disorder. This is best accomplished by a psychoeducational intervention whereby the Tourette Syndrome children could be better understood and with understanding receive a better education. The psychoeducational intervention consists of a multimedia presentation (video, slides, lecture, and discussion) concerning the history, background, causes, symptomatology, and educational implications of the disorder.

When the educational team from the Tourette Syndrome Clinic at St. Boniface Hospital began psychoeducational presentations some eight years ago, assistance was requested by, families of, teachers of, and children with Tourette Syndrome, in dealing with these difficult tics. The team makes repeat visits to schools as children move on to new classes or, even to new schools. About seven years ago the team began to notice that requests for assistance for the Tourette Syndrome children focused on other features than the tics. These "other" features were more problematic than the tics, in most cases. At the time, there was next to nothing in the literature documenting the existence of these features. The clinic team compiled a list of associated features which has since been confirmed by researchers in the United States (Comings, 1990;DSM IV, 1994).

The clinic team has made presentations to over 400 schools and community groups in the last seven years. Psychoeducational presentations have been given to over 1500 teachers, and 4000 students involving about 300 patients and their families. Anecdotal reports repeatedly referred to the interrelationships of the associated features.

Teachers and administrators, parents, school, and the TS children themselves frequently made reference to what, to the Clinic Team was an interesting phenomenon. When the TS tics were relatively mild, possibly due to a "waning" period, the associated features, at least some of them, became more problematic.

In many instances this exacerbation of the associated features added new problems for the TS child because the associated features then become the focus for attention, treatment, and intervention by teachers as well as other professionals. It would appear that treating the associated features, or at least the most problematic of these features would

have less than a desirable result because the underlying TS symptoms would not be adequately addressed.

To address these difficulties, TS Clinic staff began incorporating these two strategies (i.e. provision of written educational material to teachers and classmates of students with TS, and use of TS video tapes) as part of a 60 to 90 minute multi-media presentation. This included descriptions of historical, psychosocial, symptomatological, educational, and treatment aspects of the syndrome as well as discussion and recommendations targeted to the specific TS child. Anecdotal reports from teachers, parents and TS students following these presentations suggested sometimes dramatic improvements in academic, interpersonal, and behavioral functioning. These presentations appeared to be useful because they helped the child to feel less isolated and stigmatized. They also seemed to help teachers and classmates to become more accepting of the child's behaviour, and to provide teachers with concrete ways of dealing with the behaviours and learning problems associated with TS.

B. Diagnostic Criteria

Tourette Syndrome is a neurobiochemical, familial, chronic movement disorder and neuropsychiatric syndrome. It is characterized by motor and phonic tics that vary in degree of intensity, frequency, and complexity (Champion, Fulton & Shady, 1988; Stokes, Bawden, Camfield, Backman and Dooley, 1991). The diagnostic criteria for Tourette Syndrome, according to the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM IV) 1994, which uses the term Tourette Disorder, are:

A. 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, nonrhythmic, stereotyped movement or vocalization).

- B. The tics occur many times a day (usually in bouts) nearly every day or intermittently throughout a period of more than one year, and during this period there was never a tic-free period of more than 3 consecutive months.
- C. The disturbance causes marked distress or significant impairment in social, occupational, or other important areas of functioning .
- D. The onset is before age 18 years.
- E. 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 postviral encephalitis).

According to the DSM IV (1994), the median age of onset is seven years; the great majority have an onset before age 14. The symptoms may appear as early as one year of age. The estimated lifetime prevalence of TS is at least 0.5 per thousand. Tourette Syndrome is at least three times more common in males than in females. Tourette Syndrome is usually a lifelong disorder, though periods of remission lasting from weeks to years may occur.

C. Symptomatology

In order to have Tourette Syndrome a person must have two core features: motor tics, and vocal tics. The tics are further divided into simple and complex motor and vocal tics. Simple motor tics, which are rapid, darting and meaningless, consist of the following movements: eye blinking, facial grimacing, neck-jerking, shoulder shrugging, hand jerking and kicking movements. These can involve any part of the body. According to Bruun (1994) they are the most characteristic type of tics.

Complex motor tics may consist of any of the following movements: jumping, hand gestures, touching self or others, squatting, hopping, and tumbling. More serious types of complex motor tics are self-abusive behaviours which include headbanging, and self-mutilation such as lip or cheek biting, and hitting oneself.

Simple vocal tics can be any noise that emanates from the nose or throat. Usually these sounds are fast and meaningless. The most common simple vocal tics are: throat clearing, sniffing, grunting, snorting, yelling, screaming, spitting, humming, and animal noises.

Complex vocal tics are the most baffling feature to most people. These tics can consist of words, phrases, or complete statements. The three most common types of complex voice tics are echolalia, the tendency to mirror the speech of others--much like a parrot.; palalalia, being the tendency to repeat one's own words sounding much like a broken record repeating itself; and coprolalia which is the involuntary uttering of obscenities. These obscenities may be racial, sexual, or other inappropriate comments. According to Comings (1990) between 8 and 30% of Tourette Syndrome sufferers are afflicted with this complex vocal tic.

D. Characteristics

Tourette Syndrome is a spectrum disorder. That is to say it is a disorder whose severity and frequency of symptoms can range from mild to severe. The symptoms also wax and wane over time. Symptoms can increase in severity and frequency for short periods of time and then either disappear or become rather mild, and then increase again. The etiology for this occurrence is unknown at present.

Tourette Syndrome symptoms are increased with stress or excitement. Consequently, situations that produce stress such as test time, or class presentations often result in acute performance anxiety with an increase in tics. Other situations that can

increase tics are birthdays, school holidays or festivities such as Easter, Valentine's Day, school concerts and school social activities.

Indicators to date are that intelligence is unaffected. The vast majority of TS students would fall within the normal curve of the distribution of grades. This information has proved to be very important to the children upon being diagnosed. Many were under the misapprehension that their learning would be severely disrupted and that they would become mentally ill.

The medical director of the Tourette Syndrome Clinic, Dr. R. Wand describes Tourette Syndrome as having a "symptom pattern." He contends that, generally, the disorder begins in the first ten years of life, becomes more severe in the second ten years of life (the time of natural growth spurt and hormone changes in the body), and may disappear, become very mild or remain about the same in the last ten years of life.

One troubling aspect of Tourette Syndrome is that many children have a measure of suppressibility of tics. This ability to contain tic symptoms can change from seconds to hours. Suppressibility varies from child to child. Not all children are capable of doing this. The troublesome aspect is that this ability to suppress or not suppress tics can appear to be wilful on the part of the child.

Anecdotal reports from children, their parents, and teachers indicate that concentration can reduce symptoms. This may occur when a child with TS is engaged in an activity such as playing a musical instrument, playing a video game, watching interesting television programs, reading a book, or working on some type of project that involves whole-hearted participation. Once again, not all children will be capable of focusing their attention in such a way as not to display symptoms.

Some children with TS are able to "mask" their symptoms. They are able to camouflage their tics. A child whose tic involves a body movement may indicate that he or she is cold and shivering. A child who has a vocal tic may cough as if to clear the throat due to a cold.

In addition to the fluctuating motor and vocal tics that define this neurobiochemical disorder, there are many associated features of TS such as mental coprolalia. i.e. obscene words swirling around in one's head as obsessive thoughts (Comings, 1990.)

E. Associated Features and Disorders

The DSM IV describes the associated features in this way:

The most common associated features of Tourette Syndrome are obsessions and compulsions. Hyperactivity, distractibility, and impulsivity are also relatively common. Social discomfort, shame, self-consciousness and depressed mood frequently occur. Social, academic and occupational functioning may be impaired because of rejection by others or anxiety about having tics in social situations. In severe cases of Tourette Syndrome, the tics may directly interfere with daily activities (e.g. reading or writing). Rare complications of Tourette Syndrome include physical injury, such as blindness due to retinal detachment (from head banging or striking oneself) orthopedic problems (from knee bending, neck jerking, or head turning), and skin problems (from picking). The severity of the tics may be exacerbated by administration of central nervous system stimulants which may be a dose-related phenomenon. Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, and Learning Disabilities may be associated with Tourette's Syndrome.

The following is a graphic representation of the core and associated features of Tourette Syndrome. The author is indebted to Dr. Rox Wand M.D. F.R.C.P. for his permission to use this graph.

CORE AND ASSOCIATED FEATURES OF TOURETTE'S DISORDER

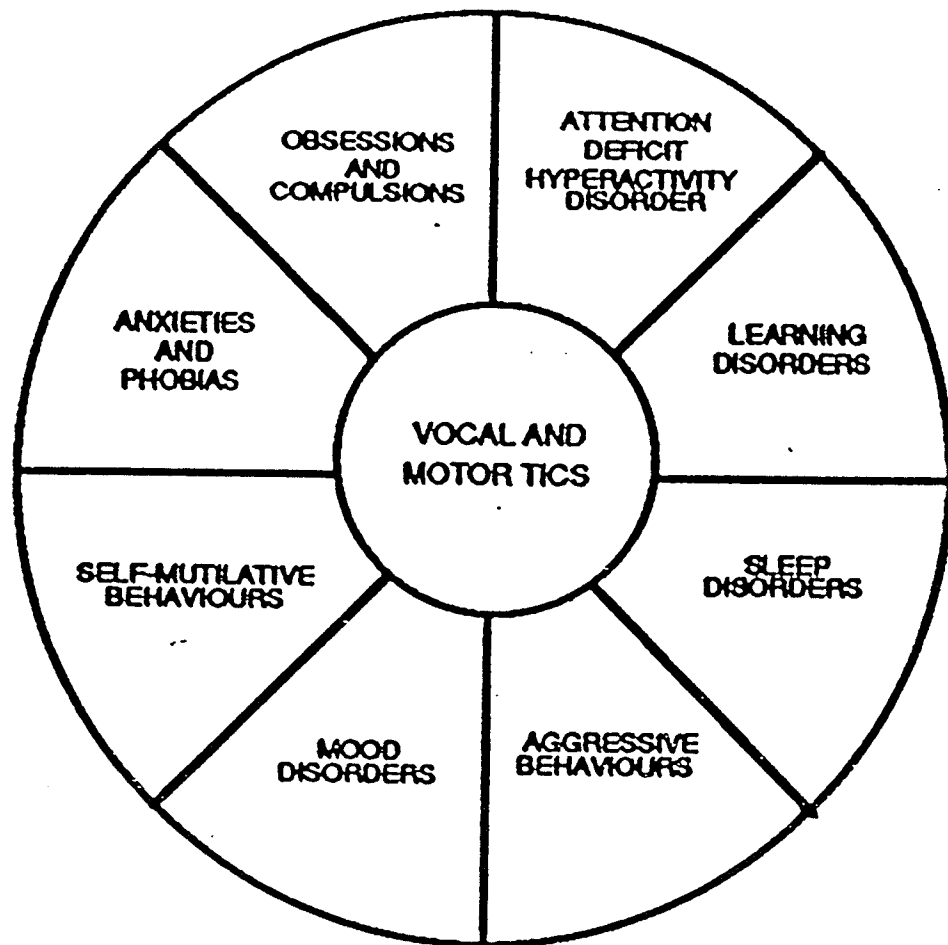


Table-1

F. Statement of the Problem

Current research indicates that many children and adolescents with Tourette Syndrome experience a wide range of academic, interpersonal and behavioral difficulties (Harcherik et al. 1982; Shady, et al. 1988; Stefl & Rubin, 1985; Teitelbaum, 1979; Wertheim, 1982). However, TS children who have teachers knowledgeable about the syndrome fare much better in these areas than do students whose teachers have not received information about TS and its effects on learning. There is, however a lack of resources to address the special needs of students with TS in the Canadian educational system (Shady et al.).

To bridge the gap between the special needs of students with TS and the lack of resources to address these needs, staff from the Tourette Syndrome Clinic (TS Clinic) at St. Boniface General Hospital in Winnipeg Manitoba, Canada, began to try various means of presenting information about TS to teachers and classmates of TS students. Dissemination of written material to teachers proved ineffective on its own because it left them with unanswered questions about which strategies they should use to address a given TS child's unique difficulties, how to identify tics and other TS-related symptoms. Supplying teachers with commercially produced video tapes about TS, with or without supplementary written material, proved ineffective for comparable reasons. In addition, problems were encountered when classmates were educated about TS either by teachers or through watching video tapes supplied by the Clinic. Most teachers, for example, did not know enough about TS to answer many students' questions, nor did the teachers or the video tapes alone provide students with concrete ways of coping with their TS classmate's behaviour (Shady et al., 1988).

G. Purpose of the Study

The purpose of the study is to investigate the effect that psychoeducational interventions may have on a) the teacher's treatment of a child with Tourette Syndrome;

and b) the Tourette Syndrome child's behaviour and academic performance. A psychoeducational intervention consists of a sixty to ninety minute multi-media presentation (see Appendix J). The presentation was given by staff of the Tourette Syndrome Clinic at St. Boniface General Hospital, Winnipeg, Manitoba, Canada, to the teachers and/or classmates of the Tourette Syndrome child .

H. Limitations of the Study

The conclusions of the study must be viewed within the following limitations:

1. The study has a small number of subjects. This makes it difficult to generalize the results to the whole TS population.
2. The reliability and validity of the standardized tests is acceptable. Those of the interviews, surveys, and non-standardized tests is not established.
3. It is difficult to quantify information obtained by interviews.
4. A section on social interaction was lacking in the psychoeducational interviews.
5. The size of the changes obtained from the test results is small. This may not reflect the magnitude of the changes in the subjects' behaviour.
6. There is a possibility that a natural variability or instability of what was measured accounted for some of the changes.

I. Hypotheses

There is no available data on the effects of psychoeducational interventions on a) the teacher's treatment of a child with Tourette Syndrome, and b) the Tourette Syndrome child's behaviour and academic performance. Therefore, data from the proposed study will be used to evaluate seven main hypotheses.

These hypotheses are grouped on teacher ratings and the child's responses to self-rating scales. It is hypothesized that as a result of the interventions:

1. The child's overall self-esteem, as measured by the Piers-Harris Children's Self-Concept Scale (Piers-Harris, Piers, 1984,) would show an increase from the pre-test to the post-test
2. The child's self-esteem as rated by the teacher on the Behavioural Academic Self-Esteem Scale (BASE, Coopersmith & Gilberts, 1982,) would show an increase from the pre-test to the post-test.
3. The child's social acceptance as measured by the Social Attraction subscale of the BASE, would show an increase from the pre-test to the post-test.
4. The severity of the child's tics as measured by the teacher's reports on the Tourette Syndrome Global Scale (TSGS, Harcherik, Leckman, Detlor, & Cohen, 1984), would show a decrease from the pre-test to the post-test.
5. The child's level of behavioural problems as measured by the teacher's form of the Child Behaviour Checklist (CBCL, Achenbach & Edelbrock, 1983), would show a decrease from the pre-test to the post-test.

6. The child's classroom disruptiveness, and negative social consequences of the child's behaviour as measured by the Behavioural Observation Form (BOF), would show a decrease from the pre-test to the post-test.

7. Teachers' own knowledge about, and classroom accommodation to the child's Tourette Syndrome following the intervention as measured by the Tourette Syndrome Knowledge Survey and the Structured Teacher Interview would show an increase from pre-test to post-test.

CHAPTER II

REVIEW OF RELATED LITERATURE

A comprehensive review of the related literature has been done using the following data bases: Educational Resources Information Center (ERIC) consisting of 2 major publications; Resources in Education (RIE) and Current Index to Journals in Education (CIJE); and Review of Educational Research (RER) and PsychLIT. In addition to these electronic databases, the extensive collection of the journal reports, articles, and books held by the Tourette Syndrome Clinic at St. Boniface General Hospital have also been included in this review.

The few studies that currently exist concerning the difficulties experienced by Tourette Syndrome school aged children tend to focus on 3 areas: (1) the difficulties that Tourette Syndrome presents in a classroom setting; (2) the problems that the Associated Features that accompany the Syndrome cause; and (3) suggestions for remediating these problems as they relate to a classroom setting. Many of the studies report on the more vivid features of the Tourette Syndrome tics: gross motor movements and unusual noises. These reports then may offer suggestions for dealing with the interference that these tics may cause in the classroom.

Other studies report on the characteristics and difficulties caused by the associated features which often accompany Tourette Syndrome. These features frequently can be more problematic than the Tourette Syndrome Disorder itself.

Individuals with TS report a much higher frequency of academic difficulties (Shady et al., 1988) than would be expected in light of consistent evidence that the overall range of intellectual ability in this group parallels that of the general population (Shapiro & Shapiro, 1982). Approximately sixty-five percent of school-age children with TS fail to progress academically in spite of normal intellectual abilities (Cohen, Detlor, Shaywitz, & Leckman, 1982; Lerer, 1987). The findings of several recent clinical and epidemiological

studies, suggest that this gap between intellectual ability and academic achievement may be attributable to attentional, learning, and behavioural difficulties (Harcherik et al., 1982; Hagin and Kugler, 1983; Stefl and Rubin, 1985; Meyers, 1988). Self-report data from two large surveys, one Canadian (Shady et al., 1988) and one American (Stefl, 1983) support this conclusion. The vast majority of respondents listed concentration (82%), paying attention (78% to 80%), and performing on timed tests and assignments (71% to 74%) as major concerns. Over fifty percent of these individuals also reported difficulty with mathematics and/or reading. Other research showing that children with TS are generally better at mental calculation than written mathematical computation suggests a specific learning disability in the area of written computation (Incagnoli & Kane, 1983).

Tourette Syndrome symptoms themselves may also interfere with academic functioning. Motor tics may, for example, impede reading and writing. Eye-blinking, and head jerking tics may hamper the child's ability to focus on his or her work.

As well, motor tics may decrease the legibility of hand writing (Lagiewka-Cook et al. 1989), and spending large chunks of time enacting compulsive behaviours such as repeating words, counting the number of words in a sentence, or rearranging objects may prevent optimal academic functioning (Hagin et al, 1982; Hagin & Kugler, 1983; Bauer & Shea, 1984; Comings & Comings, 1987).

Comings and Comings (1984), in a study involving 250 cases of Tourette Syndrome patients over 3 years of age, 201 of whom were male and 49 were female, found that the sex ratio was 4 to 1 males. The study also found that over 95% were self-referred, referred by school districts, and by the Tourette Syndrome Association in the United States.

Further, they found that 62% of male and 42% of female TS patients between the ages of 6 and 21 could be concurrently diagnosed as having Attention Deficit Disorder (ADD), using criteria from the Diagnostic & Statistical Manual of Mental Disorders, Third Edition (DSM-III, 1980). Bruun (1984) similarly found a high prevalence of TS children

with ADD, and suggested that the attentional and other difficulties associated with ADD may impair the ability of TS children to learn, socialize, and work effectively (Bruun, 1984). This conclusion is supported by the finding that a high percentage of children with TS do poorly on measures of attention and concentration (Hagin & Kugler, 1983; Incagnoli & Kane, 1983, 1982, 1981; Shapiro, Shapiro, Bruun, & Sweet, 1978; Stefl, 1983; Comings & Comings, 1987).

Comings and Comings (1984) also found that TS patients with ADD (DSM-III, 1980) tended to have more severe TS symptoms (e.g., greater frequency and earlier onset of coprolalia, lower age of onset, and more frequent and severe tic symptoms) than TS patients who did not meet the DSM-III (1980) criteria for ADD with hyperactivity (ADD-H.) Moreover, the descriptions of TS and ADD patients in the literature are strikingly similar. These groups are all frequently described as impulsive, disruptive, aggressive and intolerant of changes in routine (Comings & Comings, 1984; Pincus & Glaser, 1966), as well as being quick to anger, having low frustration tolerance, short attention span, low self-esteem, learning problems, and as being difficult to discipline (Comings & Comings, 1984; Sandburg, Rutter & Taylor, 1978). These features cannot help but affect a child's interpersonal and academic functioning at school.

Lowe, Cohen, Detlor, Kremnitzer, & Shaywitz (1982), Golden (1984), Borcharding, Keysor, Rapaport, Elia, and Amass (1990), Braun (1994), and Yeates, and Bornstein (1994) note that early TS symptoms may be difficult to distinguish from ADD. Barkley, McMurray, Edelbrock, & Robbins (1989) found that in 13% of ADHD children treated with psychostimulant medications, the drugs may exacerbate preexisting tics. The data, of Comings and Comings (1984), and Shapiro and Shapiro (1988) indicate that TS symptoms would develop with or without the use of stimulant medications. These researchers contend that stimulant medications do not cause, provoke, or precipitate TS symptoms. Other researchers such as Sverd, Gadow, Poalicelli (1989), and Gadow, Nolan, Sprafkin, and Sverd (1995) indicate that use of stimulant drugs appears to be safe

and effective in treating children with Tourette Syndrome. In the absence of a clear resolution of this controversy, it seems reasonable that caution should be exercised in prescribing stimulant drugs for the treatment of ADHD if there is a family history of TS or chronic tics, or if mild tics are present.

This causes a new difficulty, as the associated features then become the centre of attention to the detriment of appropriate treatment for the child. In other words, for example, an Attention Deficit Disorder that becomes a problem for a TS child may become the focus of intervention to the neglect of the TS tics. An example of the difficulty this could cause is medication. The treatment of choice for Attention Deficit Disorder is stimulant medication. According to Champion (1989) It is important to recognize the relationships that often exist between these two disorders because researchers such as, Lowe et al. (1982), Golden (1984), Cohen, Riddle, and Leckman (1992), and Lipkin, Goldstein, and Adelman (1994) suggest that stimulant medication can precipitate TS symptoms.

In addition, several researchers have found that students with TS show patterns of perceptual-motor functioning that have potential to interfere with academic progress (Bornstein, King & Carrol, 1982; Ferrari, Matthews, & Barabas, 1984; Golden, 1984; Hagin et al. 1982; Incagnoli & Kane, 1981, 1982, 1983; Shady et al., 1988; Sutherland, Kolb, School, Wishaw & Davies, 1982). These and other studies (Shapiro et al., 1978; Shapiro, Shapiro & Clarkin, 1974) indicate that children with TS tend to show deficits in visual processing, primarily in visuographic skills. However, this body of research has also been interpreted also as suggesting that TS children show impaired visual perceptual skills, independently of motor operations (Ferrari et al., 1984). A non-constructural visuographic deficit (regardless of the source or cause of the visuographic deficit-i.e. motor or non-motor driven) would be likely to interfere with written work while the majority of schoolwork requires writing. More global-visual-perceptual impairment would likely have an even broader detrimental impact on school performance.

Youngsters with TS also show evidence of higher than normal rates of behavioural problems (Ferrari et al., 1984; Grossman, Moldofsky & Harrison, 1986; Matthews, Eusta, Grad, Pelcovitz & Olson, 1985; Newman, Barth, & Zilner, 1986; Wilson, Garron, Tanner & Klawans, 1982). For example, both Stefl (1984) and Champion et al. (1988) found that people with TS report high rates of obsessive-compulsive behaviours, hyperactivity, extreme anxiety, temper tantrums, and extreme mood swings. They also have reported that well over one-third of respondents perceived problems in coping, and feelings of inadequacy.

These TS-related behavioural problems may create difficulties for the TS child in the school setting. Obsessive-compulsive behaviour, for example, may hamper the child's ability to complete school work. Extreme uncontrollable mood swings and outbursts of anger can be devastating to interpersonal relationships, especially if these affective changes are not identified appropriately as involuntary TS-related difficulties.

A number of authors have suggested techniques teachers can use to facilitate the positive social and academic adaptation by TS children in the classroom (Hagin, et al., 1982; Harcherik et al, 1982; Parker, 1985; Shady et al., 1988; Teitelbaum, 1979; Wertheim, 1982). For instance, (Hagin et al. 1982; Hagin & Kugler, 1983) and others (Stefl & Rubin, 1985) found that children with TS learn best in a moderately structured classroom in which accommodations for TS symptoms can be made.

Improved performance on cognitive tasks has been demonstrated when the situation is highly structured, with minimal distraction (Harcherik et al., 1982). Tourette Syndrome children also need opportunities for physical movement, and access to a "refuge" for times when symptoms are intense so they may release their tics unobtrusively (Comings & Comings, 1987; Hagin et al., 1982; Hagin & Kugler, 1983; Teitelbaum, 1979; Wertheim, 1979).

CHAPTER III

METHODOLOGY

A. Subjects

Seven voluntary participants, their parent(s) and consenting teacher for the proposed study were recruited through the Tourette Syndrome Clinic at the St. Boniface General Hospital. They were contacted by the investigator regarding their participation in the study and fully informed regarding the nature of the research. All subjects were required to meet the following inclusion criteria:

1. They must be diagnosed as having TS.
2. They must have IQ's that do not fall below the Low Average Range as measured by the Wechsler Intelligence Scale for Children (Revised). This is due to the likely difficulty that children with Low Average Range scores would have providing the required self-report information.
3. They must be in grades three to six.
4. They must sign, or have their parent or guardian sign a consent form for research purposes (see Appendix I).

B. Instruments and Measures

The instruments to be used in the proposed study were chosen to measure severity of TS symptoms, degree of behavioural problems in the school setting, level of classroom social acceptance, self-esteem, level of academic performance, and disruptiveness and negative social consequences of the child's behaviour. Where possible, the instruments were chosen based on a prior clinical and research use in measuring these variables.

On each of the measurement occasions, the following instruments and items were administered:

Structured Parent Interview

This brief questionnaire (Appendix A) is to be completed by one of the parents of the TS subject. This questionnaire includes questions on medication usage, and recent family changes and stressors.

Structured Teacher Interview

This brief questionnaire (Appendix B) is to be completed by the teacher of the TS subject. This questionnaire includes questions on the child's grades and/or interventions that may have been used to deal with the child's behavioural and/or academic difficulties.

Tourette Syndrome Knowledge Survey (TSKS)

The TSKS (Appendix C) is a 30 item questionnaire for teachers. Its purpose is to establish a baseline of the level of knowledge teachers may or may not have about TS. The results of this questionnaire are charted in the graphs by the number of questions that were answered by the phrase "I don't know." Thus, as with the Tourette Syndrome Global Scale and the Behavior Observation Form, a decreasing score on the Tourette Syndrome Knowledge Survey indicates a positive trend.

The Piers-Harris Children's Self-Concept Scale

The Piers-Harris Children's Self-Concept Scale (Piers-Harris, 1984) (see Appendix D) is an 80 item scale designed to measure self-concept in children and adolescents. The items are read aloud to younger children (up to age 12), while older children (12 to 18) may complete the scale independently. Each item was answered "yes" or "no." Raw scores may be converted to percentiles, stanines and/or T-scores. The scale was normed on children aged 8 to 18.

The test takes about 10 to 20 minutes to administer. Higher scores are associated with higher self-concept (Piers, 1984). Scores are summarized into a Total Scale Score. Six Cluster Scale Scores may also be obtained. These are Behaviour; Intellectual and School Status; Physical Appearance and Attributes; Anxiety; Popularity; Happiness and Satisfaction.

Test-retest reliability on the Piers-Harris ranges from .42 (testing interval of 8 months) to .96 (testing interval of 3 to 4 weeks), with a median test-retest reliability of .73 (Piers, 1984). Correlations with other measures of children's self-concept range from .32 to .85; correlations between children's self-report on the Piers-Harris and peer and teacher rating of behaviour or self-concept range from .03 to .55.

Piers-Harris Children's Self Concept Scale.

1. Behavior;

This 16 item cluster reflects the extent to which the child admits or denies problematic behaviors. Item content ranges from specific behaviors (e.g. Item 56; "I get into a lot of fights.") to more general statements concerning problem situations in the home or at school. Item responses may provide important clues about how the child views his or her problems, where they occur, and whether or not the child assumes responsibility for these or externalizes blame for them on to others. A low or moderately low score on the Behavior scale...suggests acknowledged behavioral difficulties. High scores... are more difficult to interpret. They may reflect either a lack of behavioral problems or an attempt to deny such problems (Piers-Harris, 1984, p.38).

2. Intellectual and School Status:

This cluster of 17 items reflects the child's self-assessment of his or her abilities with respect to intellectual and academic tasks, including general satisfaction with school and future expectations. This scale may be useful in identifying particular areas of learning difficulty and in suggesting possible remediations. A low score on this scale suggests specific difficulties with school-related tasks. In children with a record of high academic achievement, this pattern may indicate unrealistically high expectations from themselves or their parents. The attitudes of such children frequently convey a sense that whatever they do is never good enough. In children with a record of low academic achievement or a history of learning or behavioral problems in school, this negative self-evaluation may reflect an internalization of the low appraisal of others or a lack of investment in doing well academically. This lower self-concept on academic tasks may or may not be compensated for by more positive self-concepts in other areas (Piers-Harris, 1984, p.39).

3. Physical Appearance and Attributes:

This third cluster, consisting of 13 items, reflects the child's attitudes concerning his or her physical characteristics, as well as attributes such as leadership and the ability to express ideas. This scale is more sensitive than the other scales to sex differences. For example, 78% of girls in the normative sample responded positively to Item 29: "I have pretty eyes" compared to 53% of the boys. Conversely, 70% of the boys responded positively to Item 15: "I am strong" compared to 51% of the girls. Thus, in interpreting this scale, it is important to take into account the extent to which the score reflects low self-esteem in relation to body image and related attributes or simply reflect adherence to traditional sex role stereotypes. Although noteworthy, the latter is not necessarily problematic. (Piers-Harris, 1984, p.39).

4. Anxiety:

This cluster of 14 items reflects general emotional disturbances and dysphoric mood. Individual items tap a variety of specific emotions including worry, nervousness, shyness, sadness, fear, and a general feeling of being left out of things. More than the other cluster scales, this scale contains items which may suggest the need for further psychological evaluation or referral (Piers-Harris, 1984, p.39).

5. Popularity:

The 12 items in this cluster reflect the child's evaluation of his or her popularity with classmates, being chosen for games, and ability to make friends. Low scores on this scale may reflect shyness, lack of interpersonal skills, or personality traits which tend to isolate the child from others. In addition, some children with learning or physical handicaps may feel picked on or made fun of, or may simply feel left out of things (Piers-Harris, 1984, p.39).

6. Happiness and Satisfaction:

This cluster of ten items taps a general feeling of being a happy person and easy to get along with, and feeling generally satisfied with life. Low scores on this scale are associated with general dissatisfaction, feelings of negative self-worth and a longing for things to be different (Piers-Harris, 1984, p.39).

Behavioral Academic Self-Esteem: (BASE)

The BASE (Coopersmith & Gilberts, 1982) consists of 16 items which assess children's academic self-esteem on five factors: self-initiative, social attention, success/failure, social attraction, and self-confidence. Each of the BASE factors is

measured with 2-3 items. Children are rated on 5 point scales ranging from 1 (never) to 5 (always). In general, higher factor scores and total scores indicate higher academic self-esteem.

Internal consistency coefficients are based on correlations of individual items with the total score and range from .37 to .76 with a mean z transformation correlation of .61. Intercorrelations of factor scores with the total score range from .71 to .94 with means of .83 for boys and .84 for girls. Interrater reliability was computed on 216 students and reported as .71. The authors contend that construct validity of BASE derives from Coopersmith's self-esteem theory and that the five factors reflect those personality traits most germane to academic self-esteem. Teachers completed a series of BASE tests. The first completion of the instruments preceded the intervention. The subsequent test completions are considered post intervention results.

Child Behavior Checklist: (CBCL)

The CBCL Teachers Report Form (TRF) (Achenbach & Edelbrock, 1983) (Appendix F) has been designed for both clinical and research purposes. No special qualifications are needed to administer this test. It is designed to be filled out by teachers and can usually be completed in less than an hour. If this instrument is used in an applied research setting, the time interval between testings can be adjusted to serve the purposes of the research. In the current study the CBCL TRF was to be completed on a monthly basis throughout the scheduled test month period.

The CBCL provides the researchers with a Child Behavior Profile. Behaviour problems are identified and arranged into clinical scales which are based on extensive factor analysis of checklist items. There are 9 behaviour problem scales. These are arranged under three headings; Internalizing Syndromes, Mixed Syndromes, and Externalizing Syndromes. The exact position of each of the 9 scales vis-a vis the three

headings varies with the age and sex of the child. For example, the behavior problem scales are arranged in the following way for boys age 6-11:

Internalizing Syndromes

- Schizoid or Anxious
- Depressed
- Uncommunicative
- Obsessive-Compulsive
- Somatic Complaints

Mixed Syndromes

- Social Withdrawal

Externalizing Syndromes

- Delinquent
- Aggressive
- Hyperactive

The (CBCL) was "designed to record in a standardized format the behavioural problems and competencies of children aged 4 through 16, as reported by their teachers" (Achenbach & Edelbrock, 1983, p.7). The CBCL consists of 113 behaviour problem items, scored on a 3-step response scale, plus 20 social competence items. The raw scores then can be converted to T-scores. Coefficients of reliability are above .90. Several tests of criterion related validity support validity of the instrument.

The CBCL has been found to be a highly reliable instrument. Test-retest reliability, interrater reliability, and longer term stability were assessed and found to be .74, .96, and .60 (6 month period) respectively (Achenbach & Edelbrock, 1983).

The teachers completed a series of CBCL's. For purposes of this study, the completion of the first instrument preceded the intervention. This test completion is considered the pre-test. As with, the Piers-Harris, the subsequent test completions are considered post intervention results.

The authors describe these two syndromes as "broad-band groupings of behavior problems." They go on to add that, "they reflect a distinction between fearful, inhibited, overcontrolled behavior, and aggressive, antisocial, undercontrolled behavior."

Internalizing and externalizing are described further by the authors as a "dichotomy." The authors also refer to these groupings as having other names such as Personality Problem versus Conduct Problem, Inhibition versus Aggression, and Overcontrolled versus Undercontrolled (Achenbach & Edelbrock, 1983, p.31).

Behavioral Observation Form: (BOF)

The BOF (Appendix H) is an instrument designed to provide a measure of the disruptiveness and negative social consequences observed by the teacher for the child's behaviour in the classroom, on the playground, or at lunch. The teacher unobtrusively records the frequency with which 15 peer and teacher reactions and behavioural consequences occur in six random five-minute intervals during one day, three in the classroom, and three at recess or lunch time. The recorded frequencies can be summed up to provide two indices, one for classroom and one for school yard negative consequence. A decreasing score on the BOF indicates a positive trend. It means that the number of disruptive behaviours as recorded by the teacher has decreased.

Tourette Syndrome Global Scale: (TSGS)

The Tourette Syndrome Global Scale (TSGS) consists of two major parts. The first part rates the frequency and severity of simple and complex motor tics, as well as

simple and complex vocal tics. Part two rates the child's severity in three elements: Behaviour, Motor Restlessness, and School and Learning Problems.

The TSGS (Appendix G) is a multidimensional scale "specifically designed to permit reliable and valid cross-subject comparisons on several dimensions of TS symptomatology including behavioural symptoms, motor restlessness, and school or occupational performance, as well as simple and complex motor and phonic tics" (Harcharik, Leckman, Detlor, & Cohen, 1984, p. 356).

Harcharik et al. (1984) describe the scale as being composed of eight individually rated dimensions summed into an overall global score. Interrater reliabilities vary from 0.65 to 0.89. Validity is measured in two ways: (a) rank order comparison to consensus global scale (0.46 to 0.99), and (b) interrater reliability-parents and clinicians. A decreasing score on the TSGS indicates a positive trend. It means that the frequency of the tics has decreased.

C. Procedure

Surveys (Appendices A to H) assessing the impact of the presentations were delivered to the school and family according to the following schedule: approximately one month prior to, approximately one week after, and approximately three months following the presentations, surveys (Appendices A to H) were delivered to the school and family to assess the impact of the presentations. These were completed by the teacher, parent, and child. Resulting data was obtained by mail and returned to the author of this study.

As part of their initial contact with the TS Clinic, all families were informed that clinic staff make semi-structured audiovisual presentations taking 60 to 90 minutes, to teachers and/ or classmates of TS children when requested by either teachers, parents, or TS children, given consent of all parties involved.

When a school presentation is initially requested, the nature of the proposed study is explained to all parties. Written consent forms (Appendix J) are mailed to both the

teacher, and family along with a stamped return envelope, if verbal consent is given during the arrangements. Participants were seven consecutive cases for which written consent had been obtained, although requested presentations were done regardless of agreement to be involved in this investigation.

Data was collected from the parent(s), TS child, and teacher on three to eight occasions at three-week intervals over a seven month period. This included a 9 to 12 week baseline observation period prior to the school presentation, and a subsequent 9 to 12 week follow up assessment period. Due to the length of baseline and follow up periods viable cases can be initiated into the study from September to December.

The same overall procedures were used to collect data. The questionnaire to be completed by the TS child (Appendix D) was personally delivered to the home and administered by Clinic staff. During the same visit, information was obtained from the parent regarding any changes in the TS child's medication, and recent family changes or stressors (Appendix A).

Information was collected from the child's teacher in two ways. Questionnaires to be used for: rating (a) the severity of the child's TS symptoms (Appendix G), (b) the disruptiveness and social consequences of the child's school behaviour (Appendix H), (c) behaviour problems shown by the child (Appendix F), and (d) the child's behavioural academic self-esteem (Appendix E) were personally delivered to the teacher with a stamped return envelope.

A survey assessing the teacher's knowledge of TS (Appendix C) was included in the monitoring occasions just before and after the school presentation. When the surveys were delivered, an appointment for a thirty minute telephone interview was made for that week during which data on the child's recent grades, classroom behaviour, and any interventions the teacher has tried (Appendix B) was collected.

For cases outside of Winnipeg, data was collected for the parent and the child by telephone rather than in person. The four questionnaires completed by the teacher were

delivered by mail along with a stamped return envelope. Information on the child's recent grades, and any means used to deal with the child's academic or behavioural problems were collected from the teacher by telephone.

Confidentiality was ensured in all cases. No presentations were made nor instruments administered without consent of all parties. Information from the study concerning the child will not be divulged to the school without informed, written consent from the child and parent(s). Individual measures completed during participation will be accessible only to the investigators. A general summary of the study's results was given to all participants on its completion.

D. Variables

The variables in the study will be measured in the following way: there is one independent variable, the intervention, while there are seven dependent variables:

1. School grades, as measured by tests, exams, and assignments.
2. Self-esteem, as measured by self-esteem items on the Child Behaviour Checklist (CBCL)-Teacher's Report Form and the Investigator designed instruments.
3. Social competence, as measured by the CBCL.
4. The number of, the type of, and the severity of tics perceived by parent and teacher, as measured by the Tourette Syndrome Global Scale (TSGS).
5. Attitudes towards TS of teachers as measured by items on the TS knowledge survey.
6. The levels of behavioural problems as measured by the teacher's form of the Child Behavioral Checklist (CBCL).
7. Degree of classroom disruptiveness, and negative social consequences of the child's behaviour as measured by the Behavioural Observation Form (BOF).

E. Experimental Design

The proposed study uses a quasi-experimental simple interrupted time design (cf. Cook & Campbell, 1979), and single case methods (cf. Kazdin, 1984; Kratchowill, Mott & Dodson, 1984).

The proposed design is appropriate for evaluation of a clinical treatment and enables elimination of many potential threats to the internal validity of such research (Cook & Campbell, 1979; Kadzin, 1982; Kratchowill et al, 1984). The use of group-based designs incorporating random treatment assignment was ruled out due to potentially insurmountable threats to internal validity.

The vast majority of Clinic cases indicated they would opt out of the study if assignment to a non-treatment group were a possibility. The compatibility of such treatment and control groups would be questionable at best. Moreover, because the symptoms of TS change, and teacher attitudes differ across schools and classrooms, the most appropriate standard against which to measure change is the given child's and teacher's previous behaviour. Multiple pre-and-post-testing provides such measures of change in the behaviour of the TS student and teacher.

The effectiveness of the audiovisual presentation will be analyzed for each subject through visual inspection of changes in each of the dependent variables over time (Kazdin, 1982; Martin & Pear, 1988).

CHAPTER IV

RESULTS

The purpose of the study was to determine the effectiveness psychoeducational interventions may have on a) the teachers' treatment of a child with Tourette Syndrome; and b) the Tourette Syndrome child's behaviour and academic performance.

Data obtained by the seven major instruments used in the study support the hypotheses that psychoeducational interventions would bring about an increase in the child's overall self-esteem and social acceptance while generating a decrease in the severity of the child's tics, behavioural problems, classroom disruptiveness, and negative social consequences. Also the results support the hypothesis that teachers would show an increased knowledge about and, classroom accommodation to, the child's Tourette Syndrome.

The results of the instruments administered to the seven subjects were obtained and the subsequent data has been arranged in graphs. Figures 1 to 7 illustrate the results obtained on 5 test instruments: the internalizing and externalizing syndromes of the Child Behavior Checklist (CBCL), the Piers-Harris Children's Self-Concept Scale (Piers-Harris), the total score of the Behavioral Academic Self-Esteem Rating Scale (BASE) and the score on the social attraction subscale of the BASE. In figures 1 to 7, raw scores obtained on the 5 instruments graphically illustrate the results. In all cases, the intervention occurred after the first package of tests were administered, (Test Package 1). The subsequent packages of tests i.e. packages two to seven represent post tests. In the case of the Piers-Harris Children's Self-Concept Scale, and the Behavioral Academic Self-Esteem Rating Scale, a higher score indicates a positive trend i.e. an increase in self-esteem, overall self-esteem, and social acceptance. A lower score on the internal and external subscales of the CBCL indicate a positive trend. When the score drops on the graph, this indicates a decrease in undesirable behaviours in the two subscales.

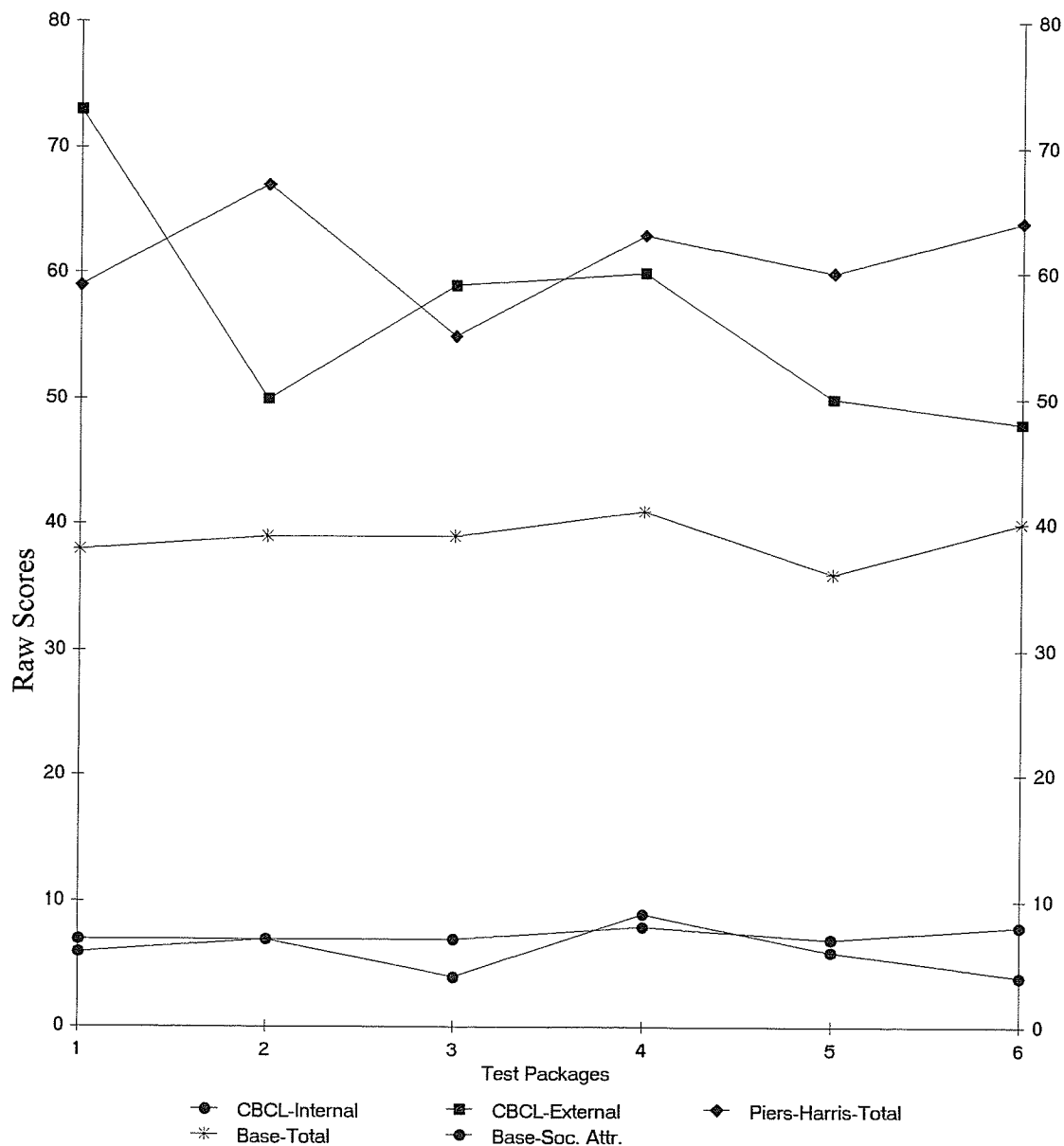


Figure-1. Subject 1: Results of 5 personal attribute tests from 6 administrations: represents the raw scores that subject 1 obtained on five test instruments. The subject was administered the five test instruments on six separate occasions. A positive trend was noted on all five tests.

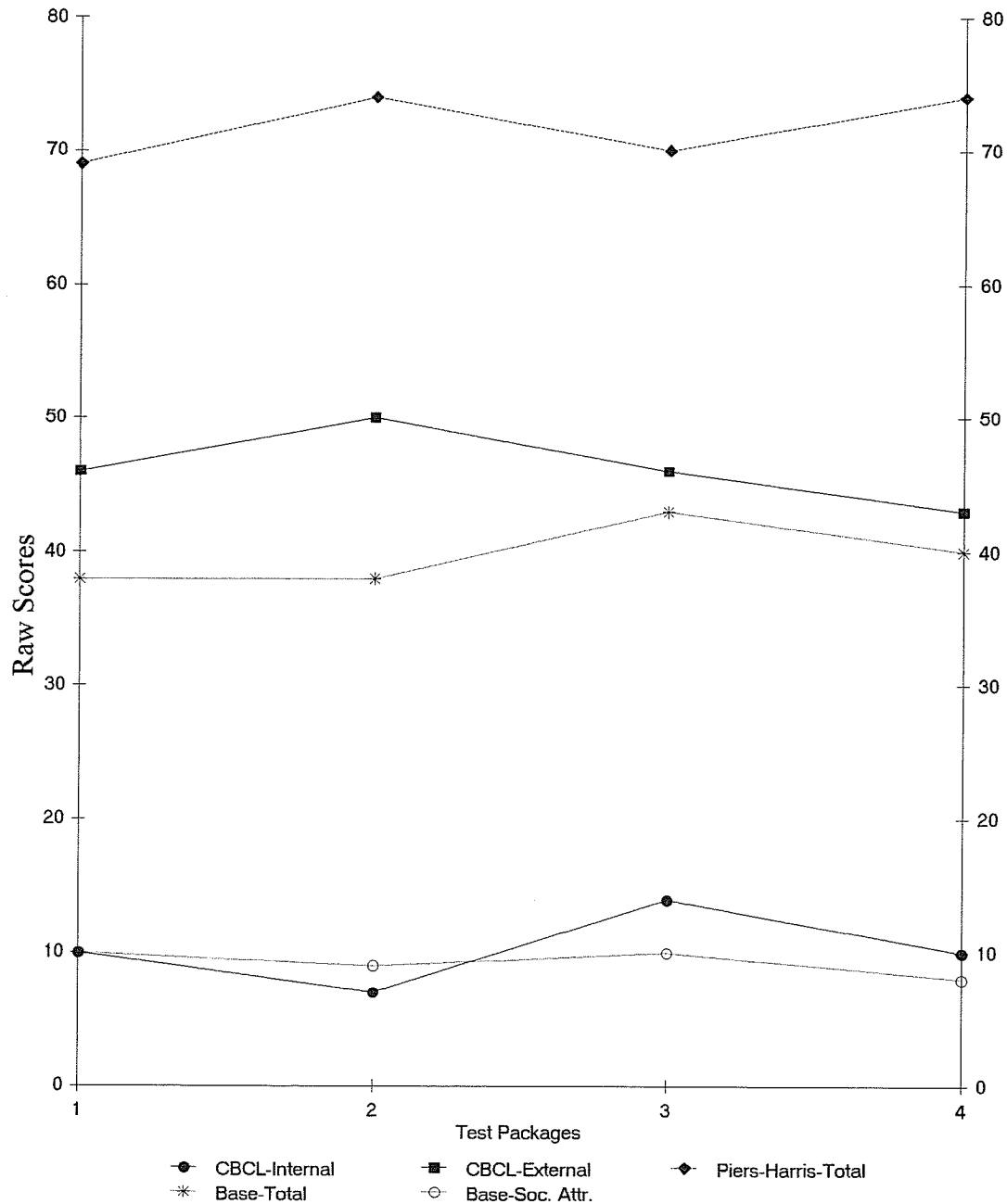


Figure-2. Results of 5 personal attribute tests from 4 administrations: represents the raw scores that subject 2 obtained on five test instruments. The subject was administered the five test instruments on four separate occasions. A positive trend was noted on three tests- there was no change noted on the CBCL-Internalizing scores, while a negative trend was noted on the Social Attraction Subscale of the base.

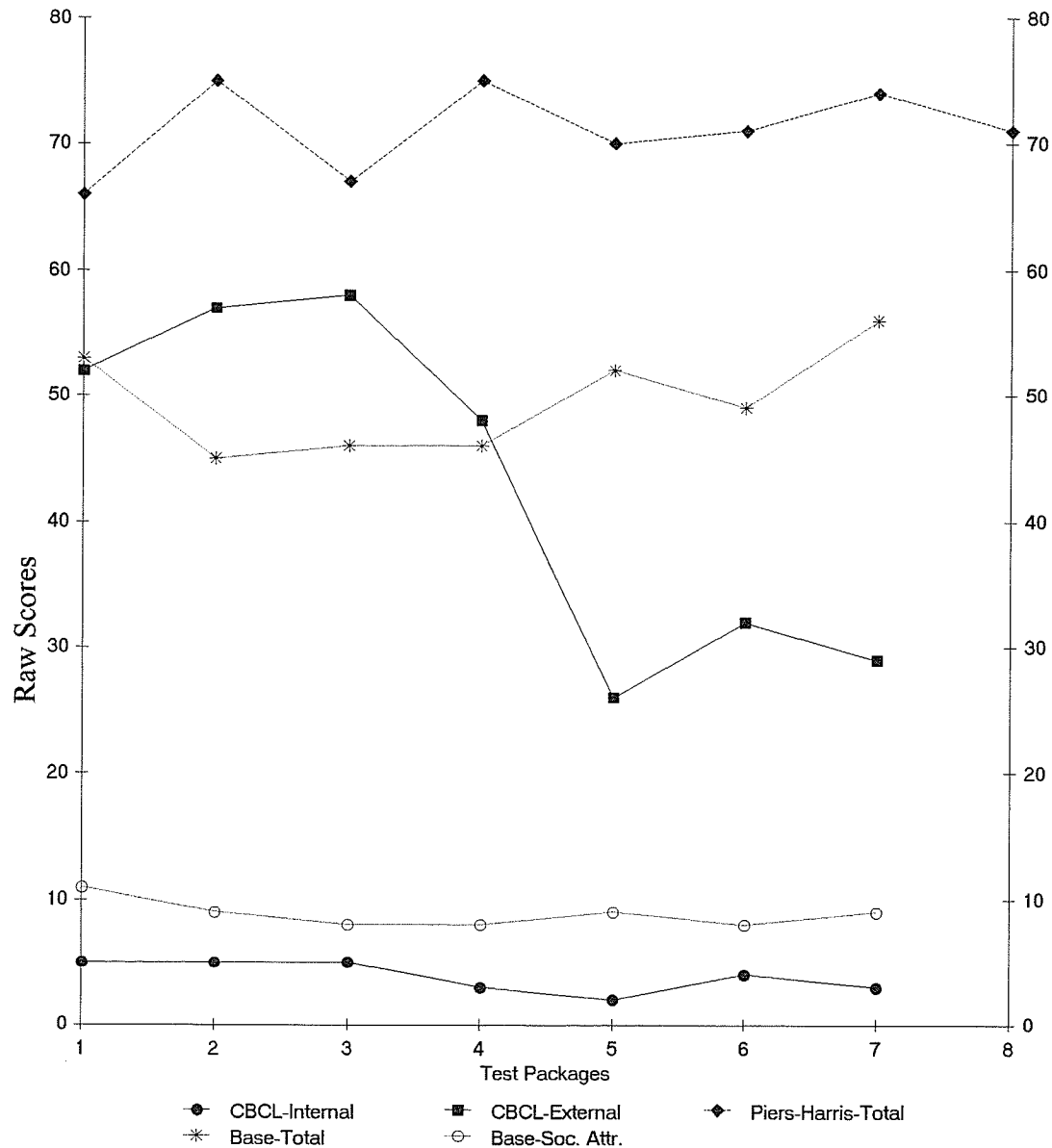


Figure-3. Subject 3: Results of 5 personal attribute tests from 8 administrations: represents the raw scores that subject 3 obtained on five test instruments. The subject was administered four test instruments on seven different occasions and the Piers-Harris was administered on an eighth occasion as well. A positive trend was noted on four tests, while a negative trend was noted on the Social Attraction Subscale of the BASE.

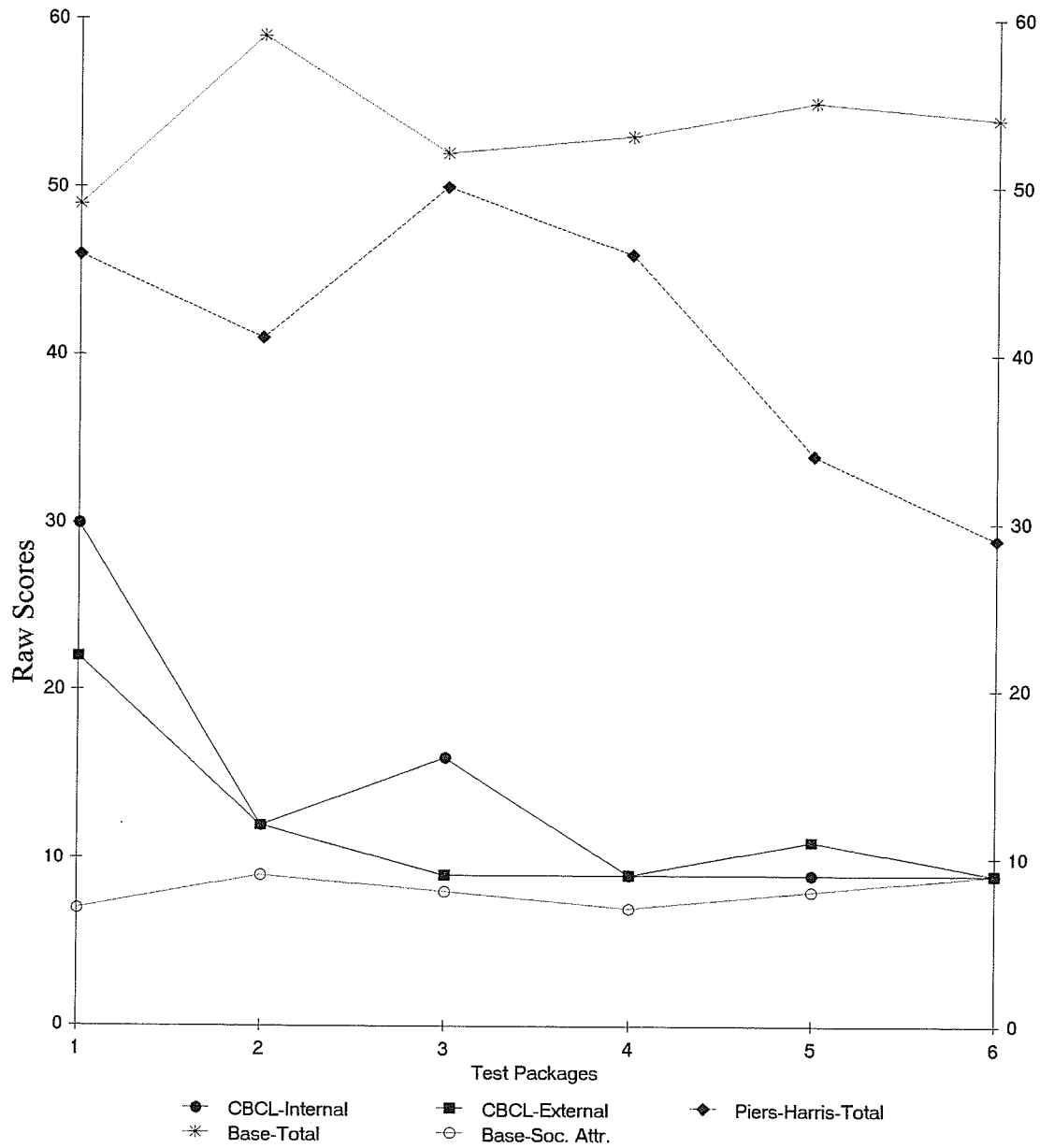


Figure-4. Subject 4: Results of 5 personal attribute tests from 6 administrations: represents the raw scores that subject 4 obtained on five test instruments. The subject was administered the five test instruments on six separate occasions. A positive trend was noted on four tests, while a negative trend was noted on the Piers-Harris.

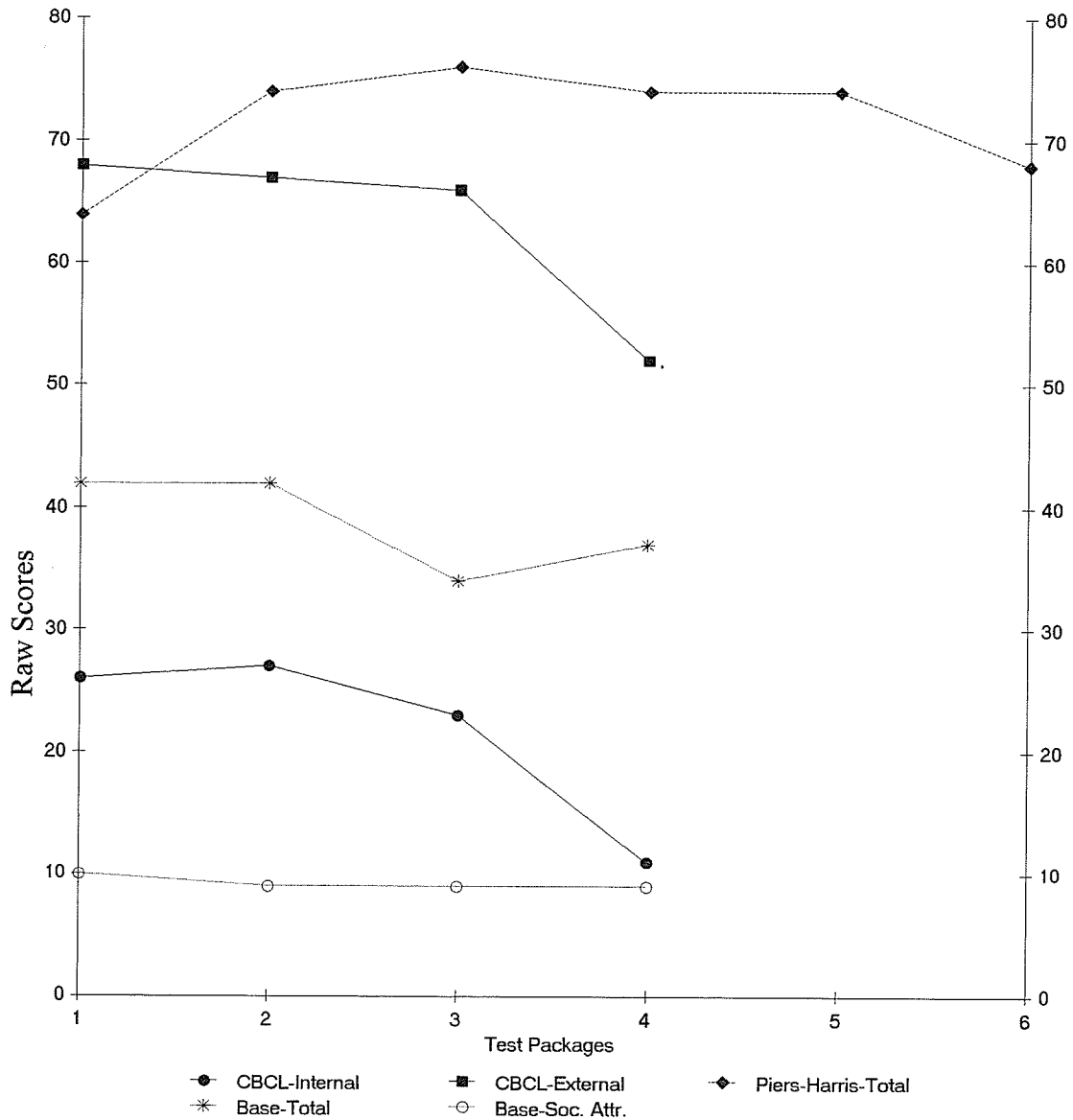


Figure-5. Subject 5: Results of 5 personal attribute tests from 6 administrations: represents the raw scores that subject 5 obtained on five test instruments. The subject was administered four of the test instruments on four separate occasions-- the Piers-Harris was also administered on a fifth and sixth occasion. A positive trend was noted in three of the tests and a negative trend was noted in the total BASE scores and the BASE Social Attraction Subscale score.

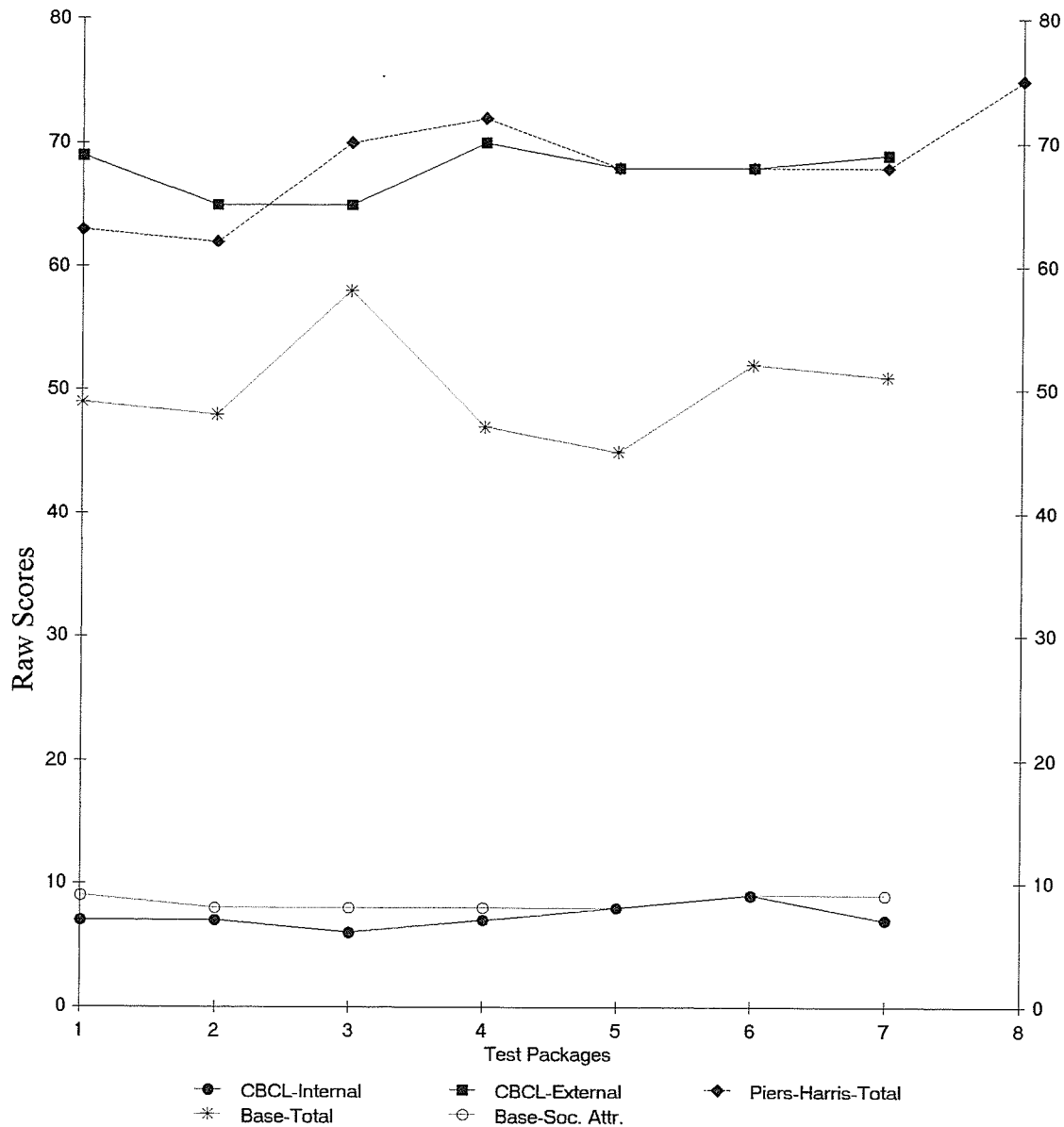


Figure-6. Subject 6: Results of 5 personal attribute tests from 8 administrations: represents the raw scores that subject 6 obtained on five test instruments. The subject was administered four of the test instruments on seven separate occasions--the Piers-Harris was administered on an eighth occasion. A positive trend was noted on the Piers-Harris and total BASE, while no change was noted in the two CBCL scores and the Base Social Attraction Subscale score.

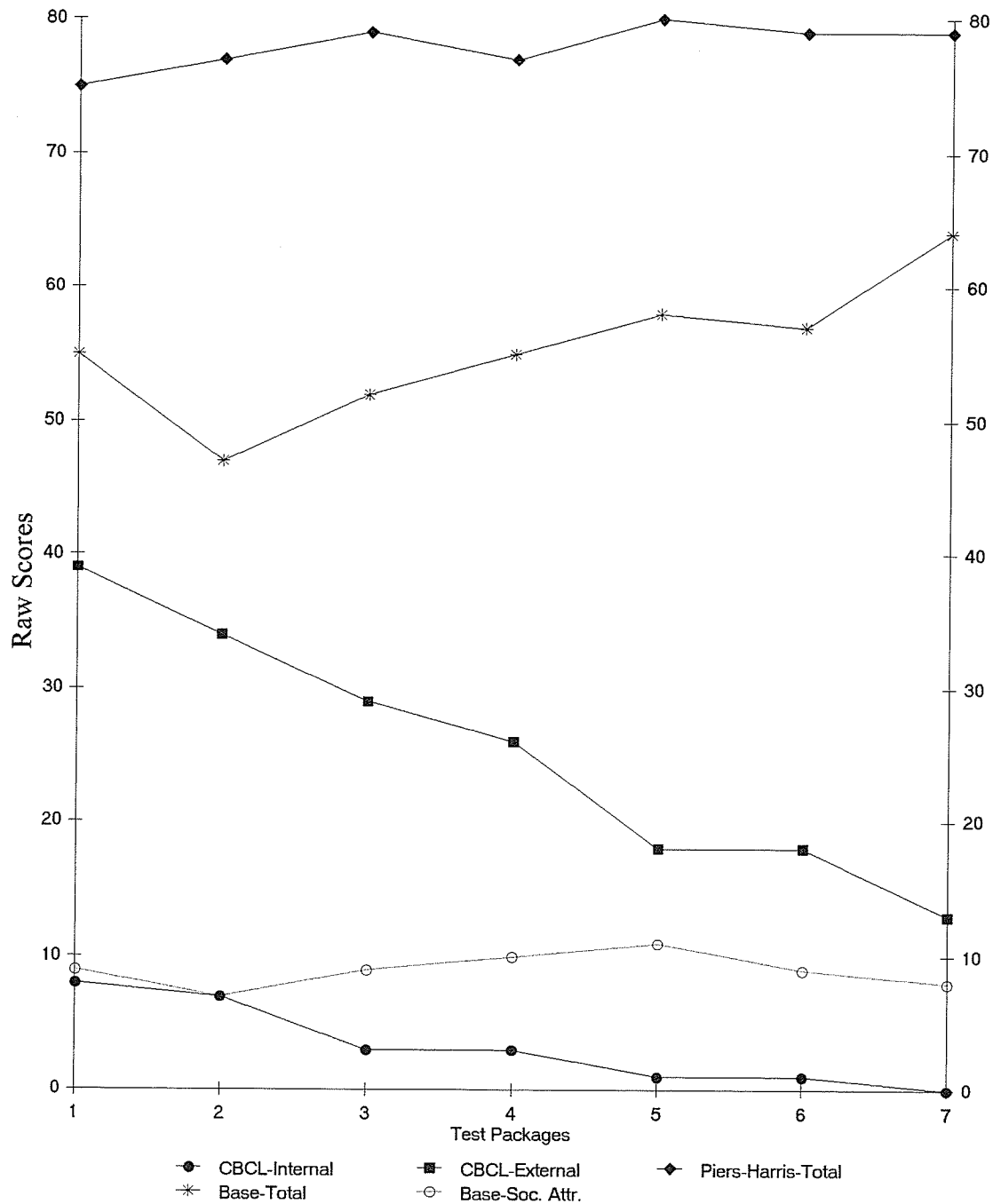


Figure-7. Subject 7: Results of 5 personal attribute tests from 7 administrations: represents the raw scores that subject 7 obtained on five test instruments. The subject was administered the five test instruments on seven different occasions. A positive trend was noted on four tests while there was a negative trend on the BASE Social Attraction Subscale score.

Figures 1 to 7 present the raw scores obtained by the seven subjects on 5 tests: the Piers-Harris Children's Self Concept Scale (Piers-Harris, 1984), the total score of the Behavioral Academic Self-Esteem Rating Scale, and the score of the Social Attraction Subscale (BASE, Coopersmith & Gilberts, 1982), and the Internal and External Syndromes as rated by the teacher's form of the Child Behavior Checklist (CBCL-TRF, Achenbach & Edelbrock, 1983).

Examining the data indicates that a positive trend was noted on the 4 tests. The results show that for hypothesis 1, that an increase in the child's overall self-esteem as measured by the child using the Piers-Harris Children's Self Concept Scale (Piers-Harris, 1986) is supported: when, with the exception of subject 4, the raw score of Test 1 (the pre-test) was compared to the raw score of the last test administered (the post-test) the overall self-esteem increased.

The results show that for hypothesis 2, that an increase in the child's self-esteem as rated by the teacher on the Behavioral Academic Self-Esteem Scale is supported. With one exception, subject 5, when the raw score of Test 1 (the pre-test) is compared to the raw score of the last test administered (the post-test), the children' self-esteem increased.

The results show that for hypothesis 3 that an increase in the child's social acceptance as measured by the teacher using the Social Attraction Subscale of the Behavioral Academic Self-Esteem Scale is inconclusive. When the raw score of Test 1 (the pre-test) is compared to the raw score of the last test (the post-test) 3 children showed an increase in social acceptance, 3 showed a decrease while the 7th subject had no change.

The results show that for hypothesis 5, that a decrease in the child's level of behaviour problems as measured by the Child Behavior Checklist Teacher's Report Form (CBCL, Edelbrock & Achenbach, 1983) is supported. With one exception (Subject 6), when the raw score of Test 1 (the pre-test) is compared to the raw score of the last test

(the post-test) of the Internalizing syndrome, the children's level of behavioural problems is decreased.

The hypotheses that the child's severity of tics as measured by the Tourette Syndrome Global Scale (TSGS, Harchherik et al. 1984), the child's classroom disruptiveness, and negative social consequences of the child's behaviour as measured by the Behavioral Observation Form (BOF) would show a decrease are supported. Also, the hypothesis that teachers are predicted to show increased knowledge about classroom accommodation to the child's Tourette Syndrome as measured by the Tourette Syndrome Knowledge Survey (TSKS) and the Structured Teacher Interview (STI) also is supported.

Figures 8 to 14 present the results obtained on 3 test instruments: the Tourette Syndrome Global Scale (TSGS), the Behavioral Observation Form (BOF), and the Tourette Syndrome Knowledge Scale (TSKS). In the case of the Tourette Syndrome Global Scale (TSGS), Behavioral Observation Form (BOF) and the Tourette Syndrome Knowledge Survey (TSKS) lower scores indicate a positive trend.

In figures 8 to 14 raw scores obtained in the three instruments illustrate an overall positive trend. In all cases the intervention occurred after the first package of instruments were administered (Test Package 1). The remaining packages of tests, i.e. packages 2 to 7, represent post tests. In the case of the Tourette Syndrome Global Scale, the Behavioral Observation Form, and the Tourette Syndrome Knowledge Scale, lower scores indicate a positive trend.

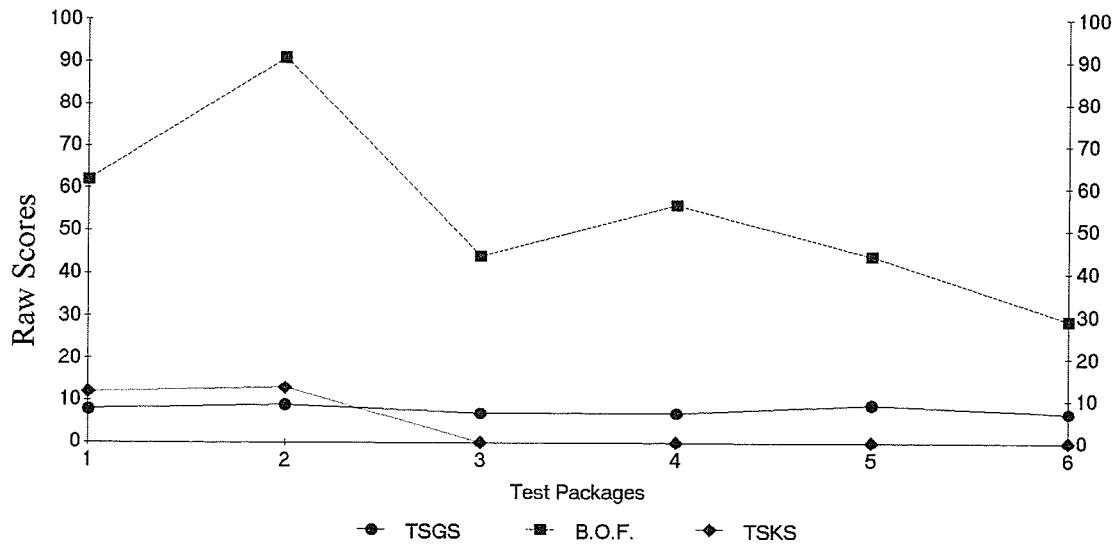


Figure-8. Subject 1: Results of 3 teacher administered tests over 6 administrations: represents the raw scores that subject 1 obtained on 3 instruments. The teacher completed all 3 test instruments on 6 separate occasions. A positive trend was noted on all 3 instruments.

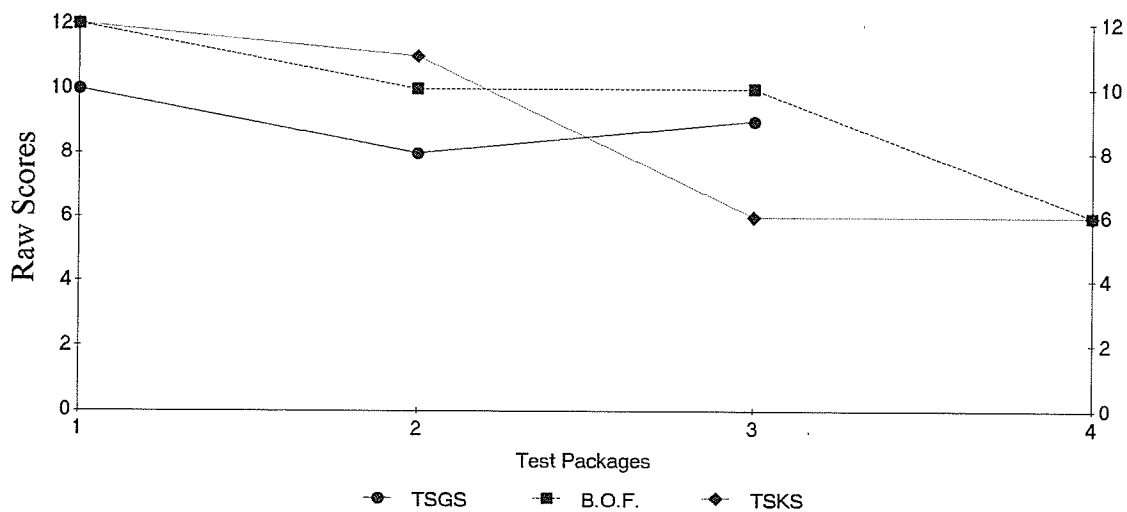


Figure-9. Subject 2: Results of 3 teacher administered tests over 4 administrations: represents the raw scores that subject 2 obtained on 3 instruments. The teacher completed 2 of the test instruments on 4 separate occasions (the BOF. and the TSKS). The TSGS was completed on 3 separate occasions. A positive trend was noted on all 3 instruments.

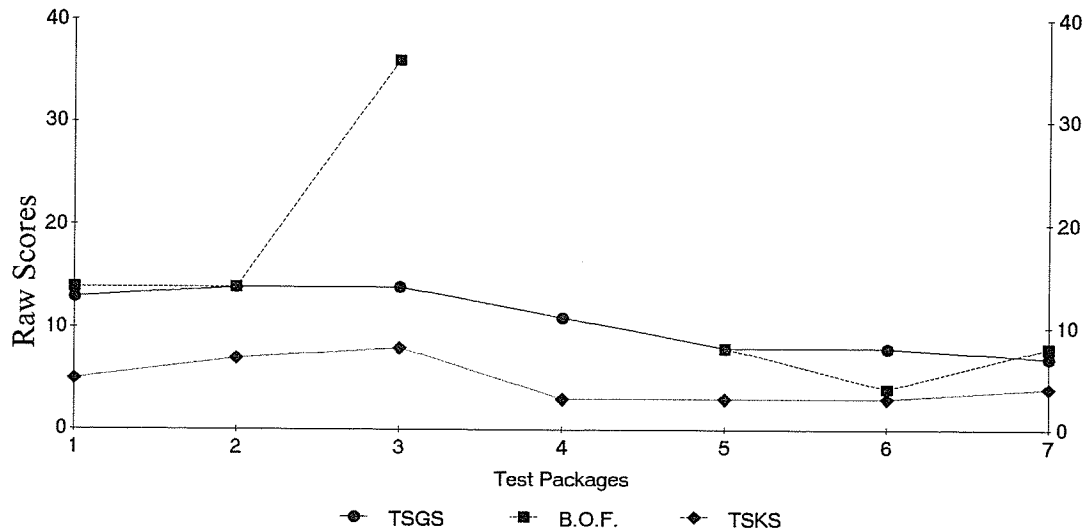


Figure-10. Subject 3: Results of 3 teacher administered tests over 7 administrations: represents the raw scores that subject 3 obtained on 3 instruments. The teacher completed 2 of the test instruments on 7 separate occasions (the TSGS and the TSKS). A positive trend was noted on these 2 instruments. The BOF was completed on 6 separate occasions. A negative trend was noted on this instrument.

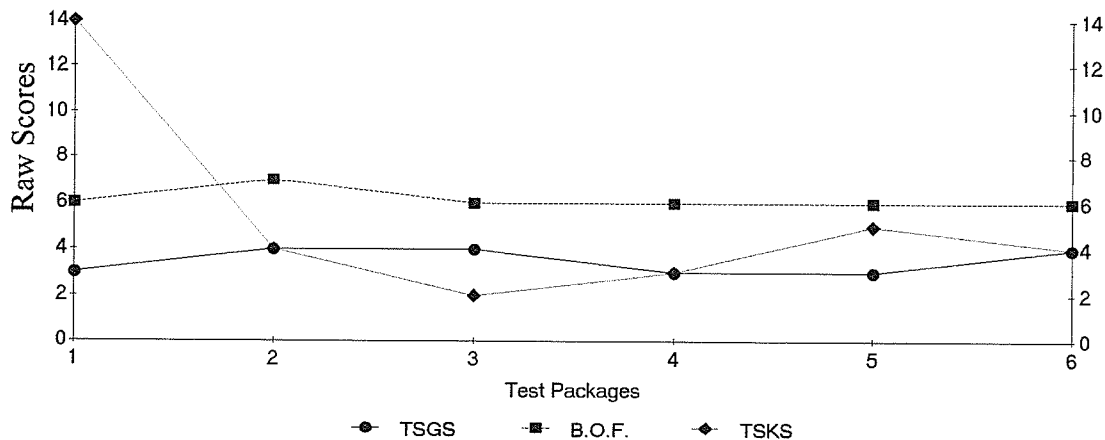


Figure-11. Subject 4: Results of 3 teacher administered tests over 6 administrations: represents the raw scores that subject 4 obtained on 3 test instruments. The teacher completed all 3 test instruments on 6 separate occasions. A positive result occurred for the TSKS. There was no change in the number of disruptions and negative social consequences as measured by the BOF. The frequency of Tics measured by the TSGS increased slightly.

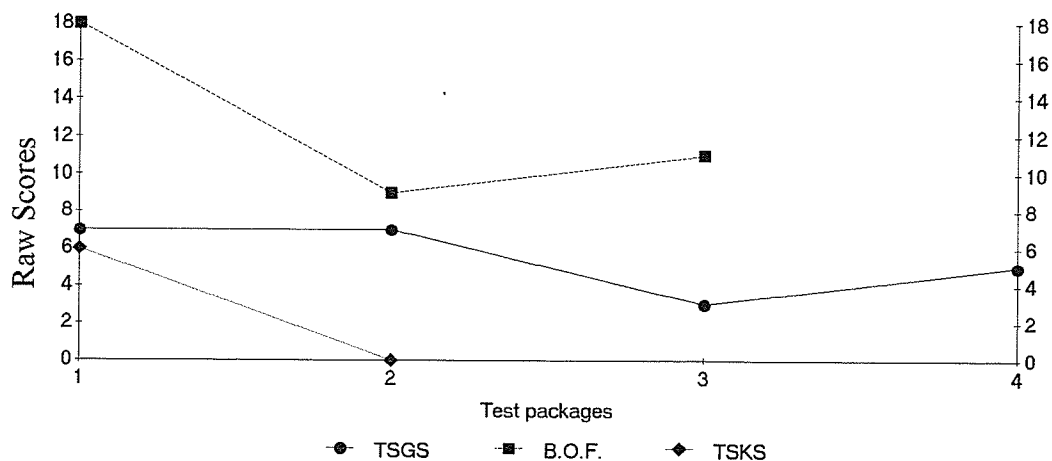


Figure-12. Subject 5: Results of 3 teacher administered tests over 4 administrations: represents the raw scores that subject 5 obtained on 3 instruments. The teacher completed 1 of these test instruments on 4 separate occasions (TSGS); another was completed on 3 separate occasions (BOF), while the 3rd instruments was completed on 2 separate occasions (TSKS). A positive trend was noted on all three instruments.

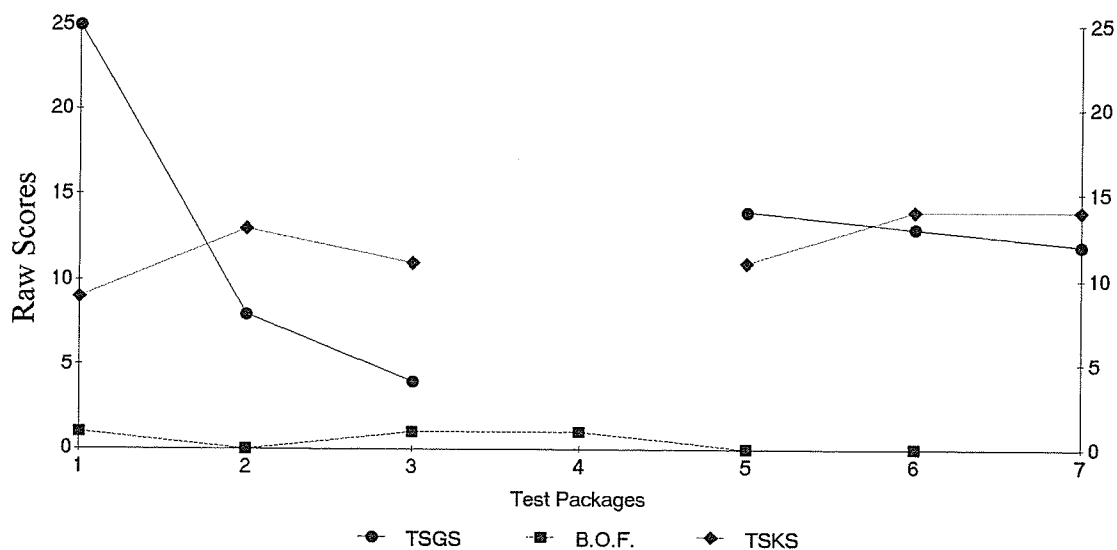


Figure-13. Subject 6: Results of 3 teacher administered tests over 7 administrations: represents the raw scores that subject 6 obtained on 3 instruments. The teacher completed all 3 test instruments on 6 separate occasions. A positive trend was noted on 2 of the test instruments (BOF and TSGS). The results of the TSKS showed a negative trend.

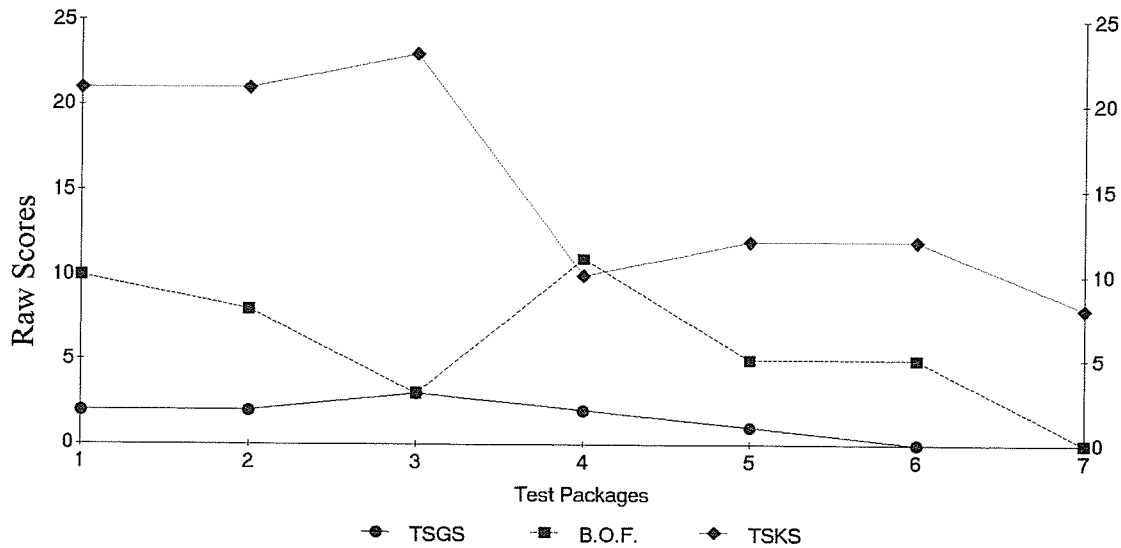


Figure-14. Subject 7: Results of 3 teacher administered tests over 7 administrations: represents the raw scores that subject 7 obtained on 3 instruments. The teacher completed all 3 test instruments on 7 separate occasions. A positive trend was noted on all 3 instruments.

Figures 8 to 14 represent the raw scores obtained by the seven subjects on 3 tests: the Tourette Syndrome Global Scale (TSGS), the Behavioral Observation Form (BOF), and the Tourette Syndrome Knowledge Survey (TSKS). Examination of the data indicates that generally there was a positive trend noted on these 3 tests.

The results show that for hypothesis 4, a decrease in the frequency of the child's tics as measured by the teacher's reports on the TSGS is supported. When the raw scores of Test 1 (the pre-test) are compared with the raw score of the last test (the post-test), the frequency of the tics expressed by the children decreased in subjects 1, 2, 3, 5, and 7, while subjects 4 and 6 experienced an increase.

The results show that for hypothesis 6, a decrease in the child's classroom disruptiveness, and negative social consequences of the child's behaviour as measured by the BOF is supported. When the raw scores of Test 1 (the pre-test) are compared to the

raw score of the last test (the post test) the decrease in disruptiveness and negative social consequences of the children's behaviour is noticed in subjects 1, 2, 3, 5, 6, and 7, while the trend for subject 4 remained stable.

The results show that for hypothesis 7, that an increase in the teacher's knowledge about, and classroom accommodation to the child's Tourette Syndrome is supported. When the raw score of Test 1 (the pre-test) is compared to the raw score of the last test (the post-test), an increase in the teachers' knowledge about Tourette Syndrome and accommodations to the children's Tourette Syndrome is noticed in subjects 1, 2, 3, 4, 5, and 7. There was a negative trend in subject 6's score.

Subject Scores--Test by Test

Data from each of the 7 subjects on each of the 7 tests is collated and represented in graphic form to be found in Appendix I.

Structured Parent Interview

The following are the results from the Structured Parent Interview and the Structured Teacher Interview. The Structured Parent Interview was conducted on the telephone. The interview consists of 8 questions.

Six of the questions relate to medication. These are asked in such a way as to elicit information regarding type of medication, changes in medication, changes in dosage, and any changes or stressful events in the family.

The questions parents were asked are:

Item1: Has subject been on medication for his/her TS. symptoms since/during...? Yes/No

Item2: If yes to #1, what medication(s) is/are s/he on?

Item3: If yes to #1, what dosage is s/he taking?

Item 3b: If yes to #1, does this represent a change in dosage since/during...? Yes/No.

Item 3c: If yes to 3b, what/how much was the change since/during...?

Item 3d: If yes to #1, does this represent a change in medication since/during...? Yes/No.

Item 4: Have there been any changes or stressful events since/during... in your family?
Yes/No.

Item 5: If so, what were they?

Results of the Structured Parent Interview show the following:

Items 1-3d--Medication:

Three subjects were not on medication at any time prior to, or during the study. Of the four subjects on medication, one began medication after the study began; three subjects were on medication prior to the study and continued throughout the study; one subject was on Haldol (0.05mg), and one subject was on Haldol (0.05mg) and Imipramine (10mg) while the other two were on Clonidine (0.75mg).

Item 4 and 5: Changes and/or Stressful Events:

All seven subjects reported changes and/or stressful events at some point during the study.

Subject 1: "negative conduct with mother."

"acting out in school yard."

"freaked out in class."

"tried to punch teacher."

Subject 2: "mother working two jobs."

"acting up at school and with baby-sitter."

Subject 3: "more subdued."

"testing limits at school."

"school difficulties."

"poor attention span."

"sleep problems."

"acting out due to frustration."

Subject 4: "three recent deaths."

"eye tics increased."

"Christmas holidays."

"new tics: vocal, and neck jerks; eye tics increasing."

Subject 5: "house for sale."

"at first going to leave community, but now will stay."

"tried out for provincial baseball team; made regular team while brother made A-team."

"stressful at school."

"teacher's aide removed due to slipped disc."

"upsetting 'event' at home with another child."

Subject 6: "last week disastrous."

"ice carnival contest-skating group."

"teacher mentioned [subject] is more wound up."

"is more wound up right after school at home."

"needs more reminders to do things."

"obstinate and stubborn."

"track and field."

Subject 7: " sibling home ill with mono--mother spoils him."

"oldest brother moved back home."

"Christmas!"

"subject is agitated--feels picked on by teachers."

Structured Teacher Interview

The Structured Teacher Interview was conducted on the telephone. The teacher of the TS subject was asked questions on the child's grades and on any interventions that may have been used to deal with the child's behavioural and/or academic difficulties.

The questions teachers were asked are:

Item 1: What were subject's grades on each test or assignments for each subject you taught since/during...?

Item 2: Are there any problems you have been having/you have had with subject's behaviour since/during...?

Item 3: If so, is there anything in particular you do? And how often do you do it?

Item 4: Are there any academic problems subject has had since/during...?

Item 5: If so, is there anything in particular you do? And how often do you do it?

Results of the Structured Teacher Interview confirm the hypotheses that the child's academic performance would improve, while the behaviour problems would decrease. The results indicate an increase in the overall performance of all 7 subjects. Data collected from the Structured Teacher Interview was assembled item by item. For Item 1 there were 39 responses for all seven subjects. Twenty-one responses--54% of the sample--indicated an increase in grades.

Item 2 had a total of 39 responses. Sixteen responses--41% of the sample--indicated a decrease in behavioural problems.

Item 3 had a total of 31 responses. Twenty-eight responses---90% of the sample--indicated an increase in the intervention by the teachers to address the behavioural problems noted in Item 2.

Item 4 had a total of 37 responses. Three responses--8% of the sample--indicated a decrease in academic problems.

Item 5 had a total of 37 responses. Twenty-two responses--60%--indicated an increase in their interventions to address the academic problems noted in Item 4.

CHAPTER V

SUMMARY AND CONCLUSIONS

The severity and frequency of the difficulties experienced by the Tourette Syndrome students in the classroom is astonishing. The behaviours displayed by these children often may be confused with wilful misbehaviours by teachers. A salient feature underlying all Tourette Syndrome symptoms is that they are involuntary. It therefore becomes of the utmost importance to "educate the educators" as to all possible aspects concerning this disorder.

This study was undertaken to evaluate the effects of information provided to the peers, teachers, and parents of the Tourette Syndrome children as well as to the TS children themselves. The information was presented to the teachers, and peers of the Tourette Syndrome child by means of a psychoeducational presentation in a multimedia format. The presentation consisted of the background, symptomatology, characteristics, and educational implications of Tourette Syndrome.

Teachers and the Tourette Syndrome children were administered instruments the purpose of which was to ascertain what changes or accommodations teachers made to the programme of the child in question. Also, information was elicited which concerned the impact of the presentations on the children's self-esteem, inappropriate behaviours, and the frequency and severity of tics.

The results obtained by this study supported 6 of the 7 proposed hypotheses:

1. The childrens' overall self-esteem, as measured by the Piers-Harris Children's Self-Concept Scale, increased; consequently this hypothesis is supported. This means that TS children responded positively to information that they can accomplish what they are willing to, and that the disorder does not adversely affect

intelligence. This information elicited support from peers and enhanced the feelings TS children have about themselves.

2. The childrens' self-esteem, as rated by the teacher on the Behavioral Academic Self-Esteem Rating Scale, increased; consequently this hypothesis is supported. This means that the TS children's self-concept increased. The TS children and their peers received information about the nature of TS and the need to assist TS children in dealing with the disorder. This led to a supportive, caring classroom environment. In turn, the TS children began to feel more positive about themselves.

3. The childrens' social acceptance, as measured by the Behavioral Academic Self-Esteem Rating Scale, did not increase or decrease; consequently this hypothesis is inconclusive. The results obtained relating to this hypothesis are not conclusive. This scale is rated by teachers. It would appear to mean that a section on social skills designed for use in the intervention may be necessary to enhance the children's social interactions with peers, teachers, and family.

4. The childrens' severity and frequency of tics, as measured by the teachers' reports on the Tourette Syndrome Global Scale, decreased; consequently this hypothesis is supported. The frequency and severity of the children's tics decreased from before the intervention to the time the last test was administered. This means that the intervention clarified problem areas for the teachers, the peers, and the children with TS thus allowing for a more supportive atmosphere leading to a higher comfort level for the TS children. This led to a reduction in frequency of tics.

5. The children's level of behavioural problems, as measured by the teacher's form of the Child Behavior Checklist, decreased; consequently this hypothesis is supported. This means that the level of behavioural problems, both interactive and personal, decreased, in severity and frequency from before the intervention to the time the last test was administered. The intervention discussed various difficulties experienced by TS children and presented strategies for dealing with these difficulties that both peers and teachers could use. The results indicate that peers and teachers implemented these strategies for dealing with the behavioural difficulties allowing for a more positive atmosphere in the school.

6. The children's classroom disruptiveness, and negative social consequences of their behaviour, as measured by the Behavioral Observation Form, decreased; consequently this hypothesis is supported. This means that the disruptive behaviours and negative social consequences arising from these behaviours decreased from before the intervention to the administration of the last test. The intervention explained the misbehaviours of the TS children were, for the most part, involuntary. This led to a decrease of the misbehaviours by the TS children and a significant decrease in retaliation or social isolation on the part of the TS children's peers.

7. Teachers demonstrated an increased knowledge about and classroom accommodation to the children's Tourette Syndrome following the school presentation as measured by the Tourette Syndrome Knowledge Survey and the Structured Teacher Interview. Consequently this hypothesis is supported. This means that the teachers of TS children learned more about the nature of, the problems of, and the strategies to deal with, Tourette Syndrome. The Tourette Syndrome Knowledge Survey and the Structured Teacher Interview indicate that

teachers approached the difficulties that TS children experience with a more positive attitude. Essentially they became more helpful and caring. They did this by modifying or altering their academic and behavioural expectations of the TS children. Generally the teachers made themselves more readily available to the TS children.

The results of this study found that psychoeducational interventions have two major effects on the teacher's treatment of children with Tourette Syndrome. Results from the TSKS and the TSI show that teachers became more accommodating of the children's special needs. Teachers spent more time with the TS child or employed more resources to meet the children's needs such as providing teacher aides, more one to one time, adapting instructions, and simply being available to the children. In class in-service presentations were requested by classroom teachers. This was perceived by the clinic team as a positive outcome resulting from the in-service given to the staff. Further, teachers met with and planned with the parents of the TS children. Thus affording a two way communication that is so essential to a proper delivery of educational services to a special needs child.

The second major effect, as noted in the TSKS and the TSI, was a reduction of stress followed by an increase in the children's academic and behaviour performance. Grades increased, and undesirable behaviour decreased. The teachers' increased attention and accommodation of the children's needs had an influence that allowed for the enhancement of these two areas of the children's school life. Teachers' accommodations generally took the form of increasing attention to the TS child's individual academic or behavioural needs

Taken together, the overall results of the study confirm that psychoeducational presentations on the history, symptomatology, characteristics, and educational implications of Tourette Syndrome have a beneficial effect for the TS child in terms of reducing stress. This reduction in stress appears to be followed by a decrease in the

frequency of tics, a decrease in behavioural and academic problems, and an improvement in self-esteem, and an increase in social acceptance.

A. Suggestions for Further Research

The results of this study have suggested some answers to some of the difficulties experienced by children with Tourette Syndrome. Some other questions have not been answered. For example, what do the fellow students of the TS child find most difficult when relating to the child. Also, a more comprehensive analysis of data obtained from the self-esteem inventory may be used to provide additional insight to the problems faced by TS children. This could then lead to an approach that could alleviate this problem. A longitudinal study with a larger sample size would be useful in confirming this study's suggested results as to what the impact psychoeducational presentations have on the Tourette Syndrome child's academic and behavioural performance. The inconclusive results obtained from the Social Attraction Subscale on the BASE indicate a need to include a section on interpersonal relationships in the psychoeducational intervention.

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APPENDIX A

STRUCTURED PARENT INTERVIEW

PROTOCOL FOR THE PARENT INTERVIEW

SESSION: _____

PARENT: _____

DATE: _____

CHILD: _____

INSTRUCTIONS TO THE INTERVIEWER:

Change the wording of each item slightly depending on whether this is the first interview (when all items will read "...since the beginning of the school year..."), the first interview following the presentation (when all items will read "...since the school presentation..."), or one of the other interviews (when all items will read "...during the past month...").

1. Has _____ been on medication for his/her TS symptoms since/during...?

____ Yes ____ No

2. If Yes to #1, what medication(s) is/are s/he on?

3. If Yes to #1, what dosage is s/he taking?

(FOR ALL INTERVIEWS EXCEPT THE FIRST ONE ALSO ASK:

- 3b. If Yes to #1, does this represent a change in dosage since/during ...?

____ Yes ____ No

- 3c. If Yes to 3b., what/how much was the change since/during...?

- 3d. If Yes to #1, does this represent a change in medication since/during ...?

____ Yes ____ No

)

PROTOCOL FOR THE PARENT INTERVIEW (continued):

4. Have there been any changes or stressful events since/during....in your family?

____ Yes ____ No

5. If so, what were they?

APPENDIX B

STRUCTURED TEACHER INTERVIEW

PROTOCOL FOR THE TEACHER TELEPHONE INTERVIEW

SESSION: _____

CHILD: _____

DATE: _____

TEACHER: _____

INSTRUCTIONS TO THE INTERVIEWER:

Change the wording of each item slightly depending on whether this is the first interview (when all items will read "...since the beginning of the school year..."), the first interview following the presentation (when all items will read "...since the school presentation..."), or one of the other interviews (when all items will read "...during the past month...").

1. What were _____'s grades on each test and/or assignment for each subject since during...?

2. Are there any problems you have been having/you have had with _____'s behaviour since/during...?

3. If so, is there anything in particular you do? And how often do you do it?

4. Are there any academic problems _____ has had since/during...?

PROTOCOL FOR THE TEACHER TELEPHONE INTERVIEW (continued):

5. If so, is there anything in particular you do? And how often do you do it?

APPENDIX C

TOURETTE SYNDROME KNOWLEDGE SURVEY

TS KNOWLEDGE SURVEY

The true-false questions below will help us to find out what you know about Tourette Syndrome (TS). Please do your best to answer them based on your current knowledge on the subject. If you do not know or are unsure of the answer to a question, please circle "Don't Know".
Do not guess.

1. There have been recent findings confirming some genetic basis to TS.

True

False

Don't Know

2. TS tics may change from time to time.

True

False

Don't Know

3. Children with TS do better in unstructured classrooms than in classrooms that are moderately structured.

True

False

Don't Know

4. Medication for TS is not likely to affect academic performance.

True

False

Don't Know

5. Taking timed tests is no more difficult for students with TS than it is for other children.

True

False

Don't Know

6. For many TS children, the academic problems they experience are due to poor motivation.

True

False

Don't Know

7. TS is contagious. You can catch it by kissing or sharing a drinking glass.

True

False

Don't Know

8. The incidence of TS in Manitoba is about 1 in 1000.

True

False

Don't Know

9. Soccer, karate and dancing may be good alternate methods of releasing tics.

True

False

Don't Know

TS KNOWLEDGE SURVEY (cont)

2.

10. Obsessions and compulsions are rarely associated with TS.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
11. Some students with TS do poorly in Phys. Ed. classes because they have a poor sense of balance.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
12. When a TS child behaves aggressively in school it is most certainly due to the TS.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
13. People with TS can stop their tics whenever they want to.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
14. To be diagnosed with TS a person has to show motor and vocal tics simultaneously.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
15. TS occurs most often in males.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
16. Learning disability is frequently associated with TS.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
17. TS does not affect intelligence.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
18. When a TS child swears it is always intentional.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
19. The majority of general practitioners have little or no knowledge of TS.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
20. Children who have TS usually show learning and behavioural problems at school because there are problems at home.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|
21. Left-handedness is more common among people with TS than in the general population.
- | | | |
|------|-------|------------|
| True | False | Don't Know |
|------|-------|------------|

TS KNOWLEDGE SURVEY (cont)

3.

22. Children with tics have TS.

True

False

Don't Know

23. Students with TS often have poor handwriting due to motor tics and/or poor fine motor control.

True

False

Don't Know

24. Children with TS are always aware of it when they are emitting a tic.

True

False

Don't Know

25. When someone with TS holds back their tics, the tics will not come out later.

True

False

Don't Know

26. TS symptoms only rarely lead people with the syndrome to be ridiculed or socially ostracized.

True

False

Don't Know

27. Whether or not TS students feel understood by other people has little effect on their overall behaviour.

True

False

Don't Know

28. Many individuals with TS also have difficulty paying attention and concentrating on their work in the classroom.

True

False

Don't Know

29. Students with TS often feel "different" from other children and tend to have social problems.

True

False

Don't Know

30. Time out of the classroom may be one method of dealing with the student's tics.

True

False

Don't Know

APPENDIX D

PIERS-HARRIS CHILDREN'S SELF-CONCEPT SCALE

Due to copyright and ethical considerations the Piers-Harris Children's Self-Concept Scale does not appear here. Interested researchers should contact:

Western Psychological Services:

12031 Wilshire Boulevard

Los Angeles, California 90025

APPENDIX E

BEHAVIOURAL ACADEMIC SELF-ESTEEM RATING SCALE

Due to copyright and ethical considerations the Behavior Academic Self-Esteem--
A Rating Scale does not appear here. Interested researchers should contact:

Consulting Psychologists Inc.

577 College Ave.

Palo Alto, California 94306

APPENDIX F

CHILD BEHAVIOUR CHECKLIST

Due to copyright and ethical considerations the Child Behavior Checklist--
Teacher's Report Form does not appear here. Interested researchers should contact:

Thomas M. Achenbach Ph.D
University of Vermont
Burlington, Vermont 05405

APPENDIX G

TOURETTE SYNDROME GLOBAL SCALE

Due to copyright and ethical considerations the Tourette Syndrome Global Scale does not appear here. Interested Researchers should consult the Journal of the American Academy of Child Psychiatry, 1984, No. 23 pp113-120.

APPENDIX H

BEHAVIORAL OBSERVATION FORM

BEHAVIORAL OBSERVATION FORM

INSTRUCTIONS: This form is to help you observe and record the reactions of other people to the behaviour of the TS child during one day. Listed below are 15 responses, some that might be made by classmates or other students, and some that might be made by you or other teachers. To complete this form, watch the TS child as unobtrusively as possible for 6 five-minute stretches picked at random over one day. Three of these times should be in the classroom, and three outside of the class (e.g., during recess or lunch). When you begin each five minute observation period, please record the time you began in the relevant column. When it ends, please write down the main activity the child was involved in during the interval. During each five minute interval when you are watching the TS child, make a check in the space marked disruptive behaviours each time the TS child does something you see as being potentially disruptive. Also, every time someone, including yourself, reacts to the TS child in one of the ways listed below, make a check mark next to it in the appropriate column.

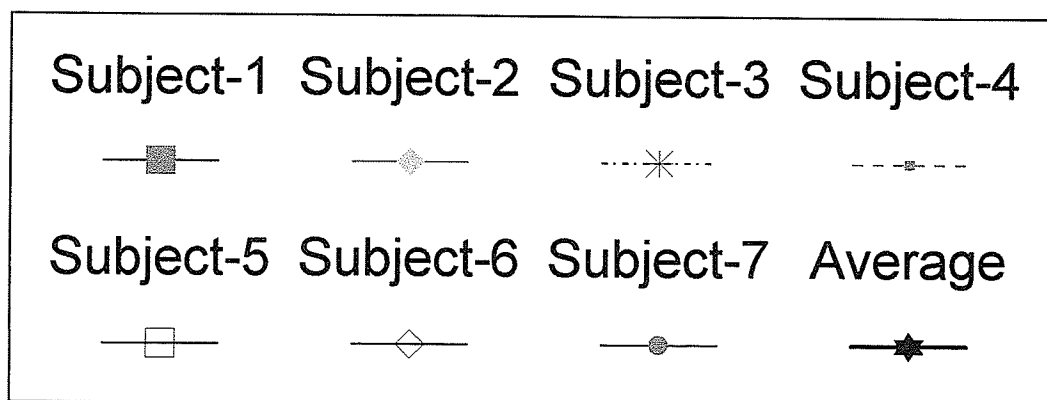
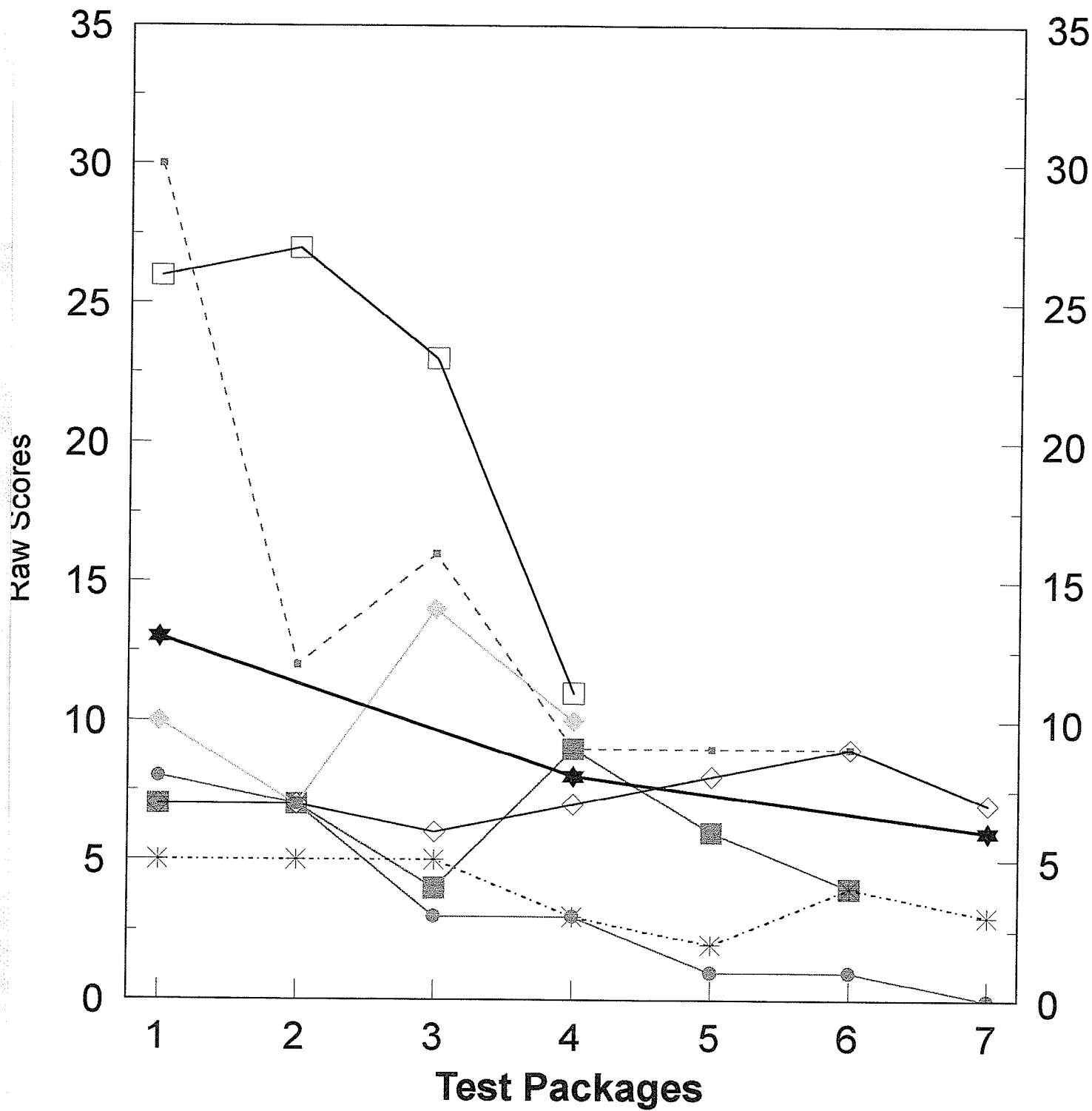
DATE: _____ **CHILD'S NAME:** _____ **TEACHER'S NAME:** _____

BEHAVIOUR	IN THE CLASSROOM			AT LUNCH OR RECESS		
	TIME: ACTIVITY:	TIME: ACTIVITY:	TIME: ACTIVITY:	TIME: ACTIVITY:	TIME: ACTIVITY:	TIME: ACTIVITY:
NUMBER OF DISRUPTIVE BEHAVIOURS						
Classmate giggles						
Classmate looks up from work						
Classmate complains to teacher						
Classmate asks TS child to stop						
Classmate ridicules TS child						
Classmate talks to another classmate about TS child						
Classmate refuses contact with TS child						
Classmate stares at TS child						
Classmate moves away from TS child						
TS child avoids classmates						
TS child asked to leave room						
Teacher stops/pauses in teaching						
Teacher asks child to stop behaviour						
Teacher disciplines TS child						
Children give no observable reaction						

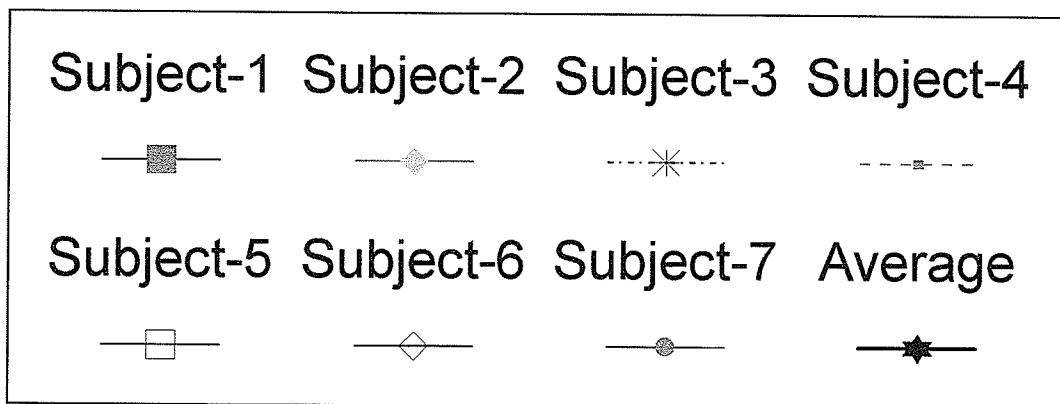
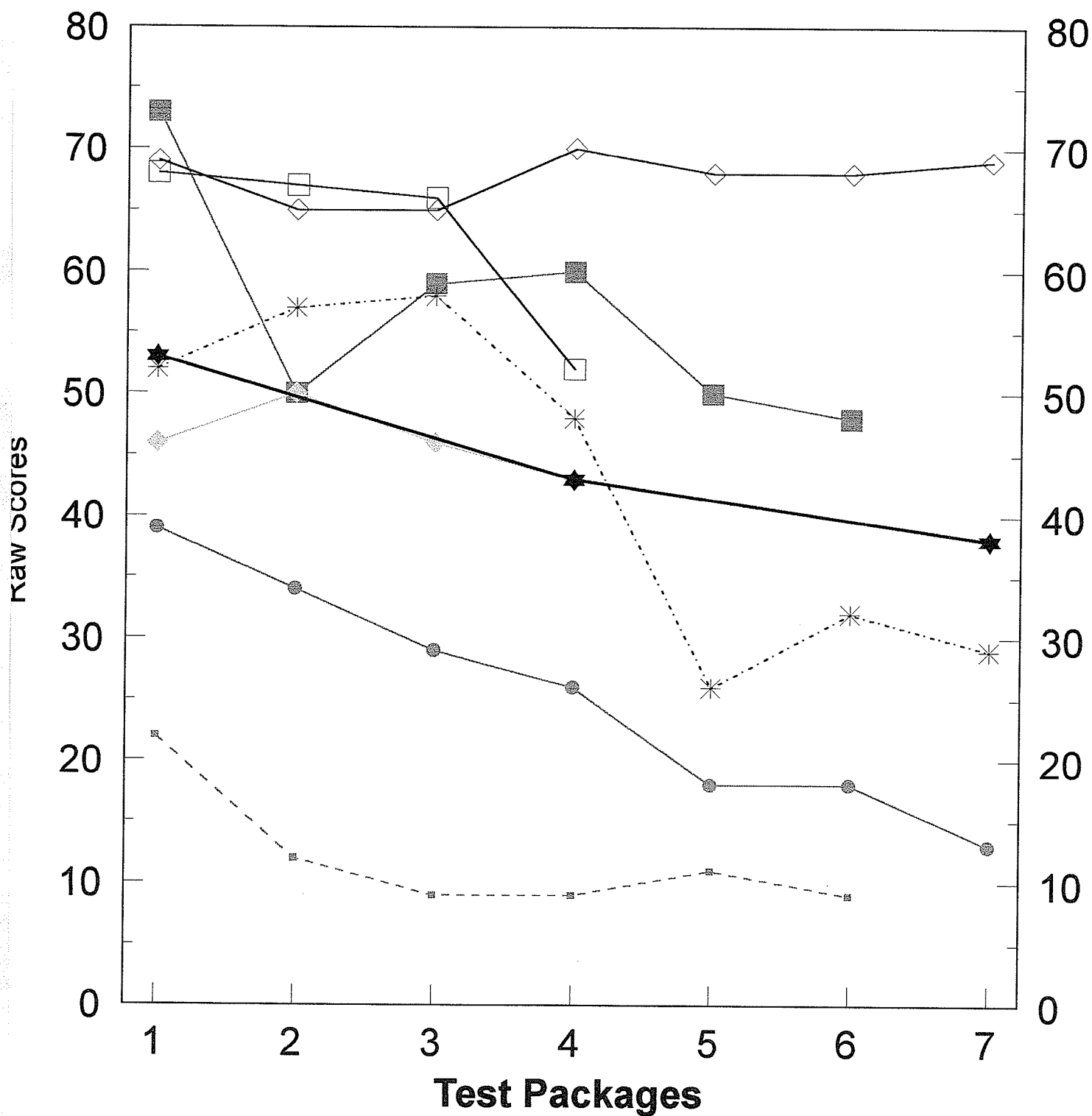
APPENDIX I

SUBJECT SCORES--TEST BY TEST

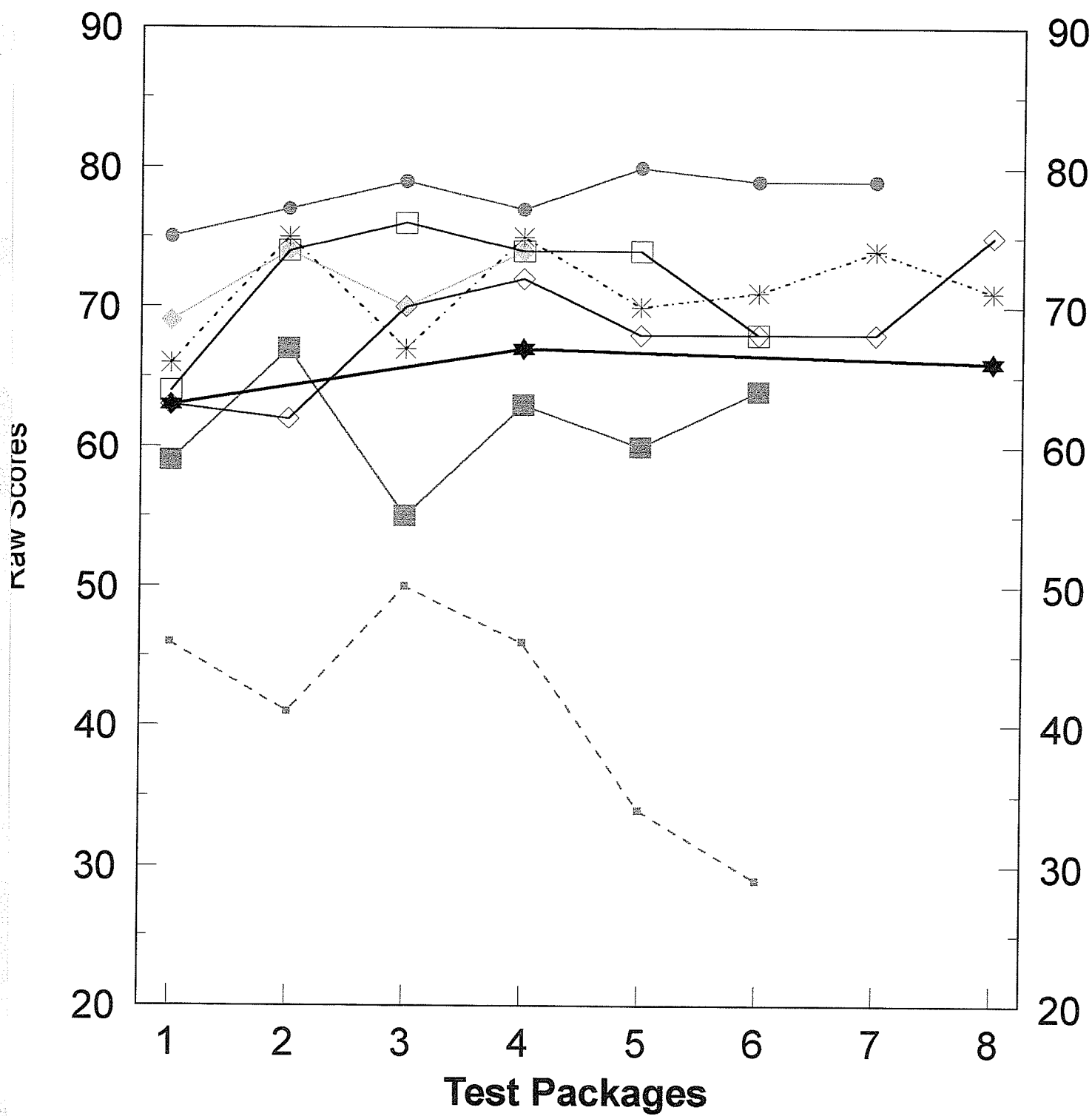
CBCL-Internalizing Subscale--7 Subjects and Average



CBCL-Externalizing Subscale--7 Subjects and Average



Piers-Harris--7 Subjects and Average



Subject-1 Subject-2 Subject-3 Subject-4

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Subject-5 Subject-6 Subject-7 Average

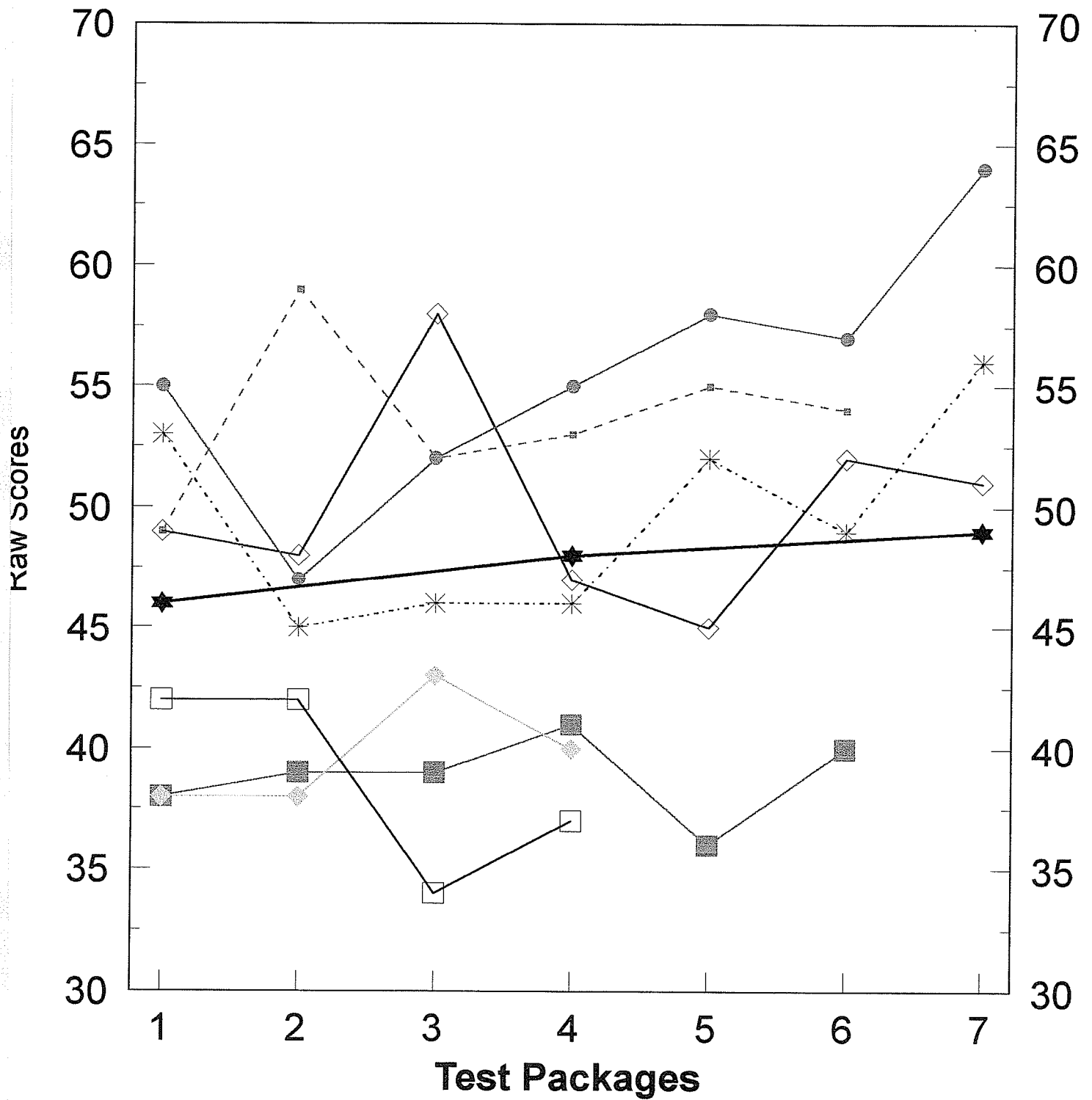
—□—

—◇—

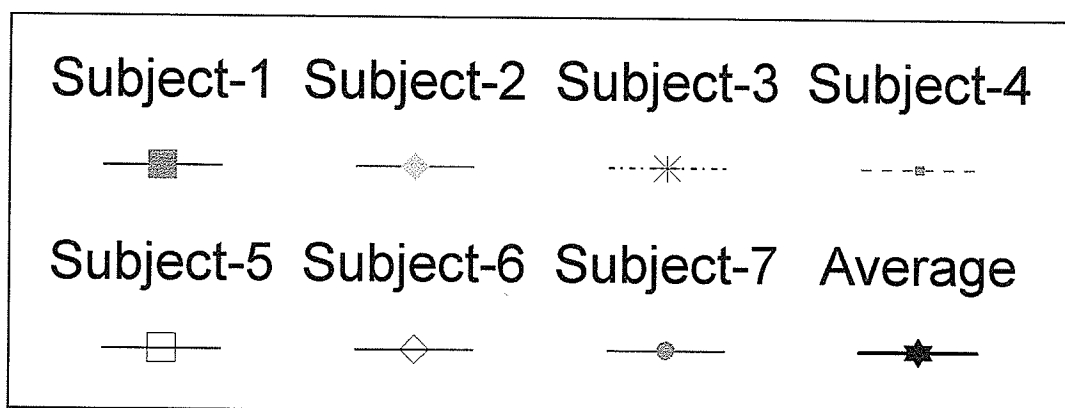
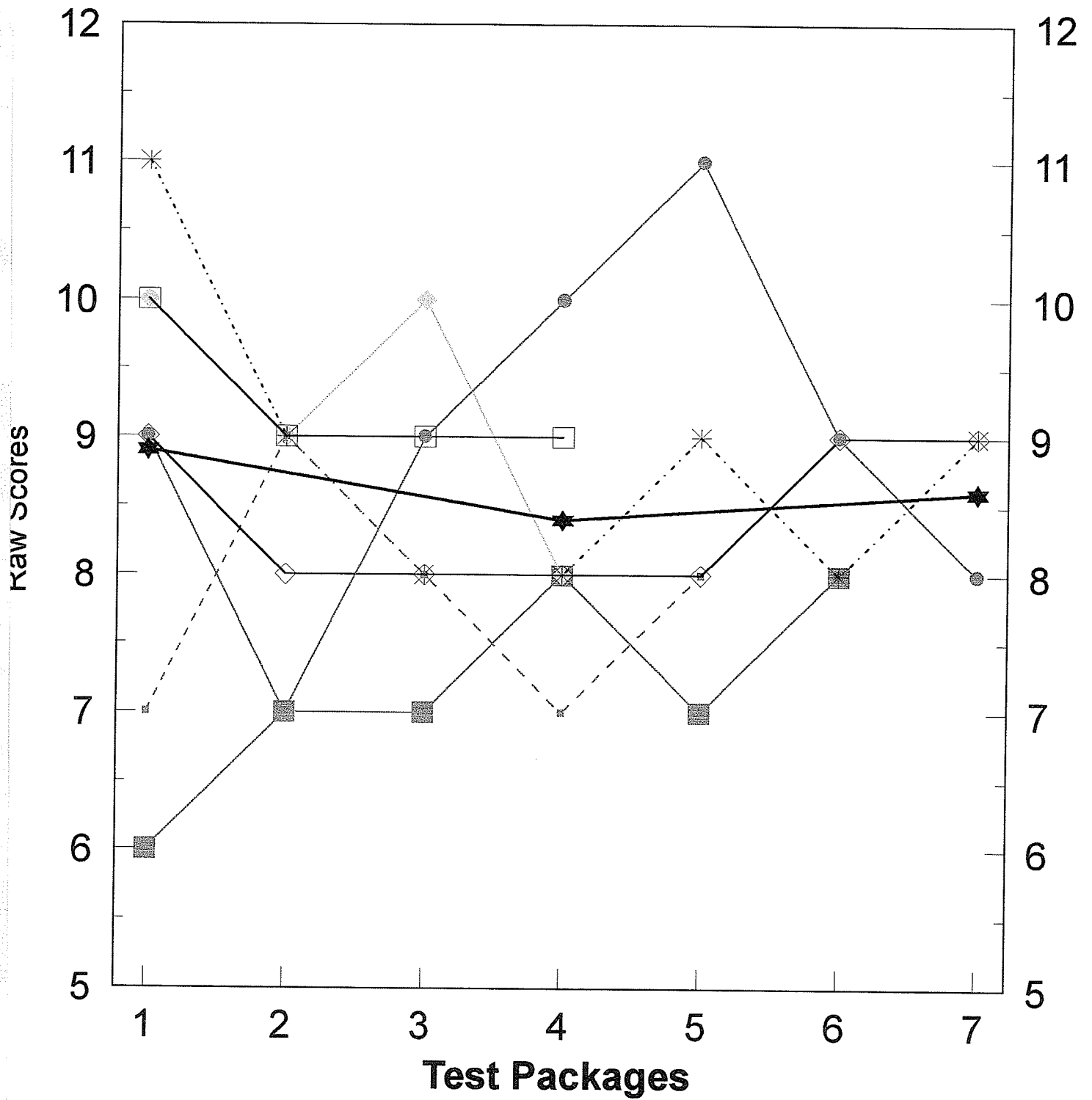
—●—

—★—

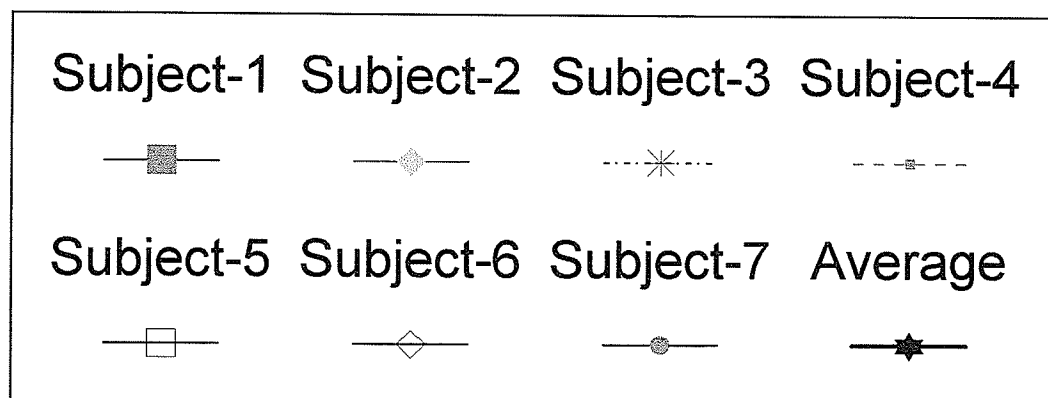
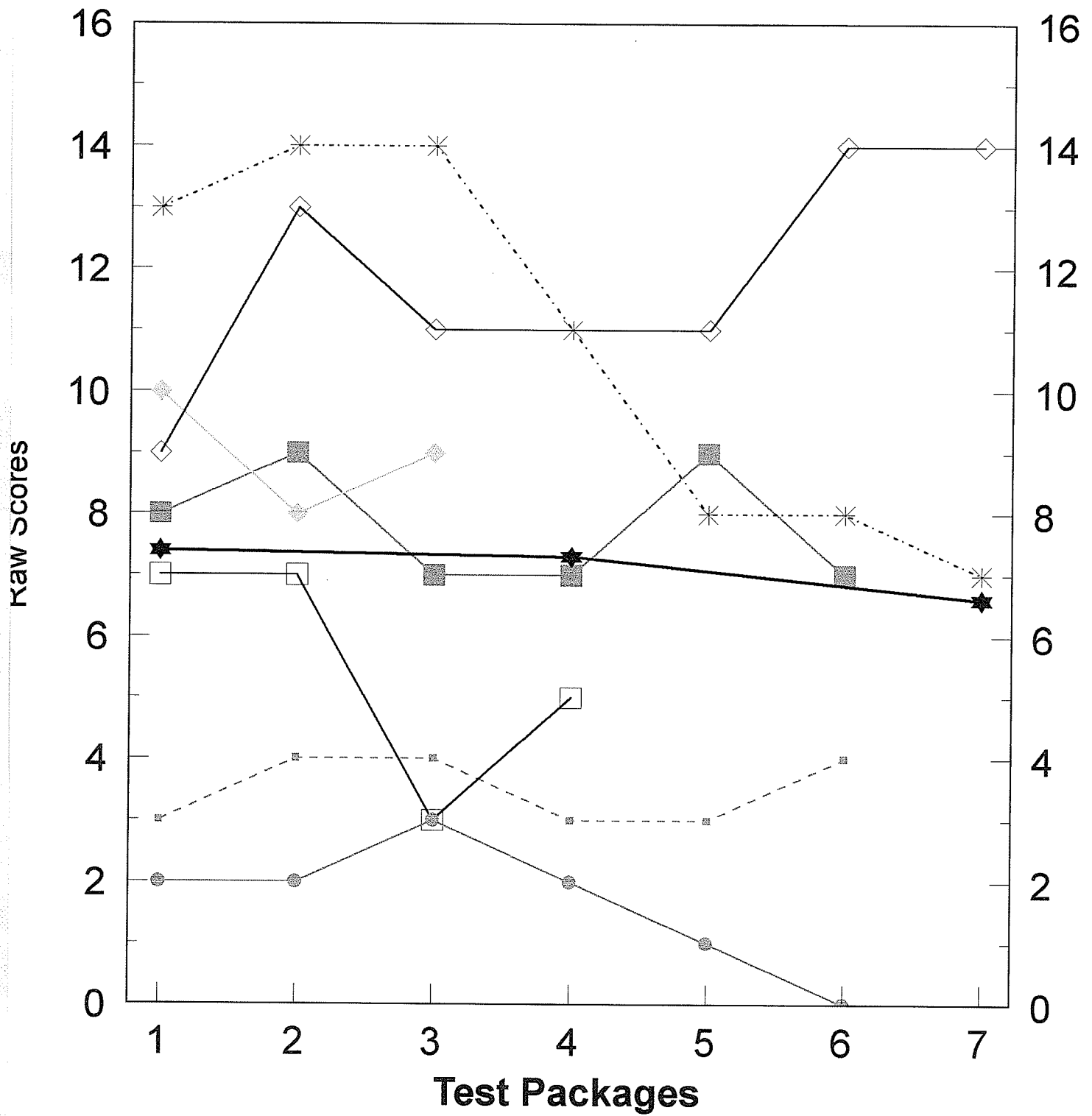
BASE-Total Scores--7 Subjects and Average



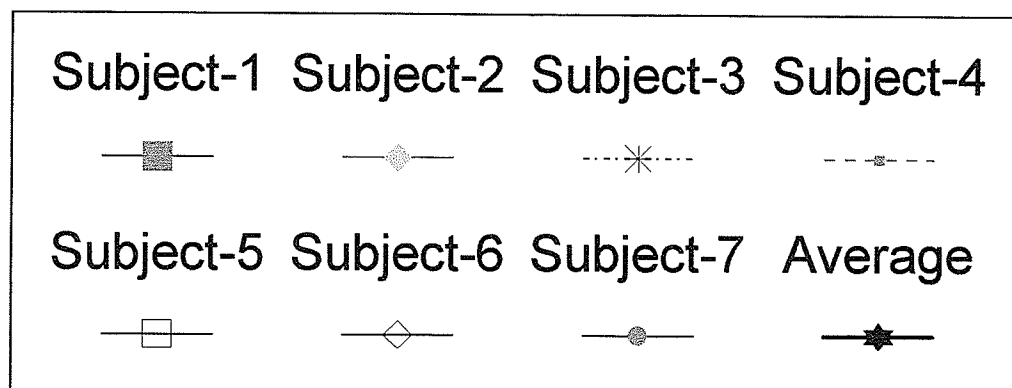
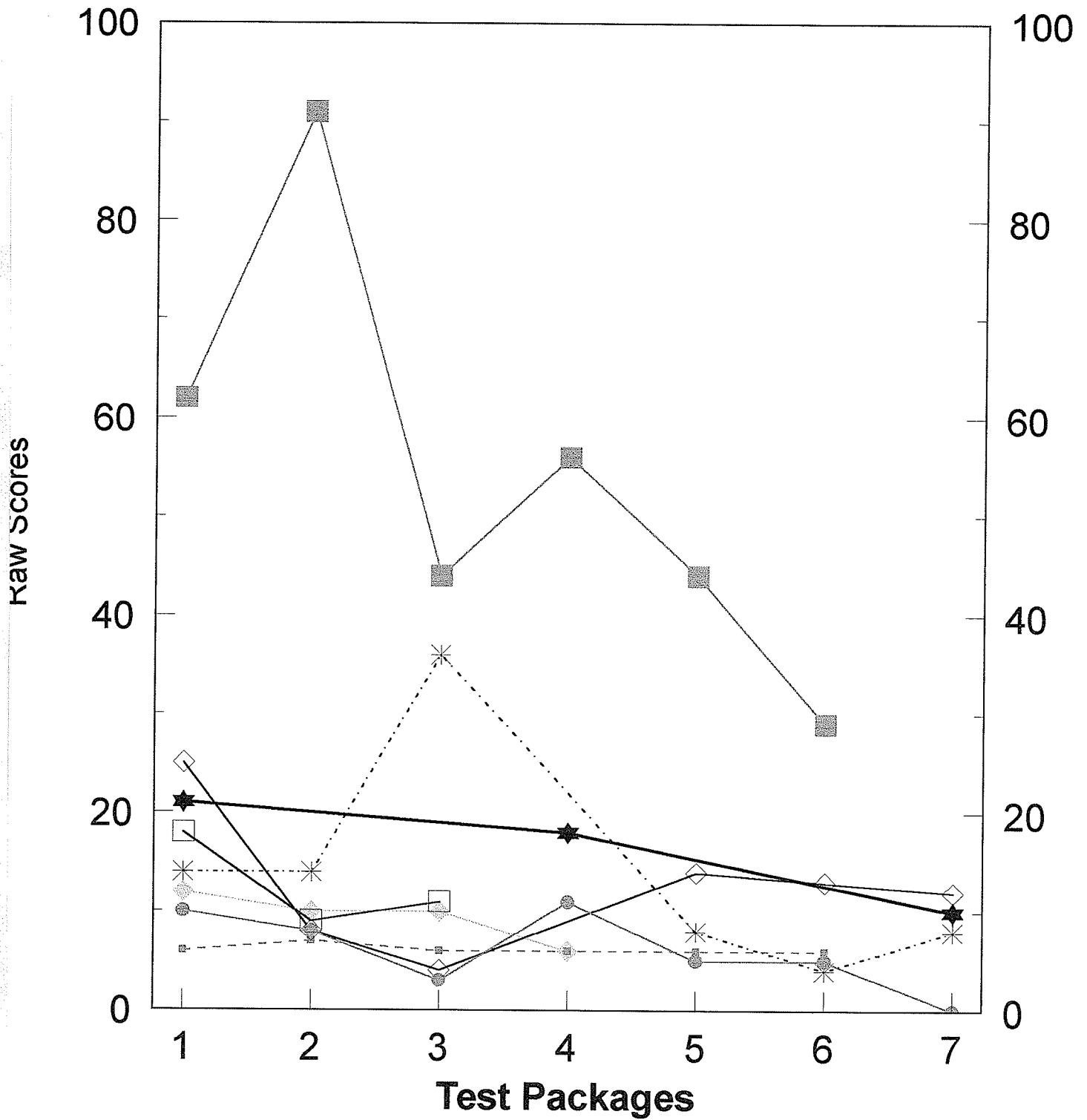
BASE-Social Attraction Subscale--7 Subjects and Average



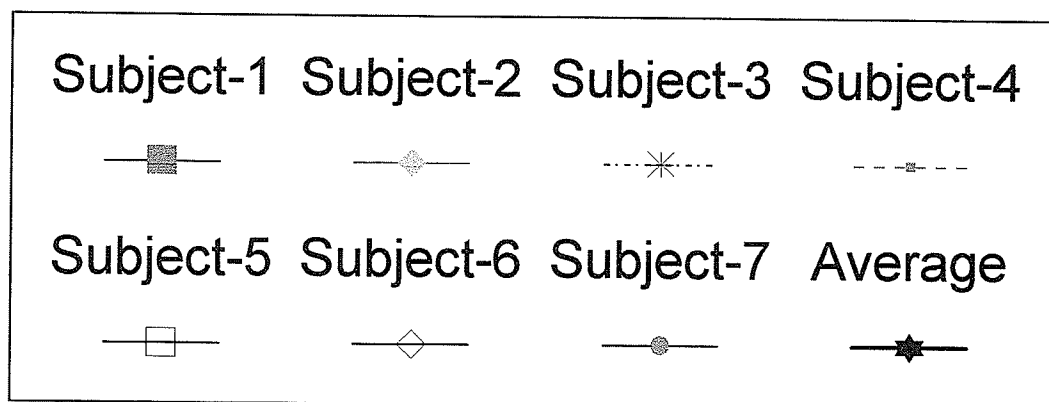
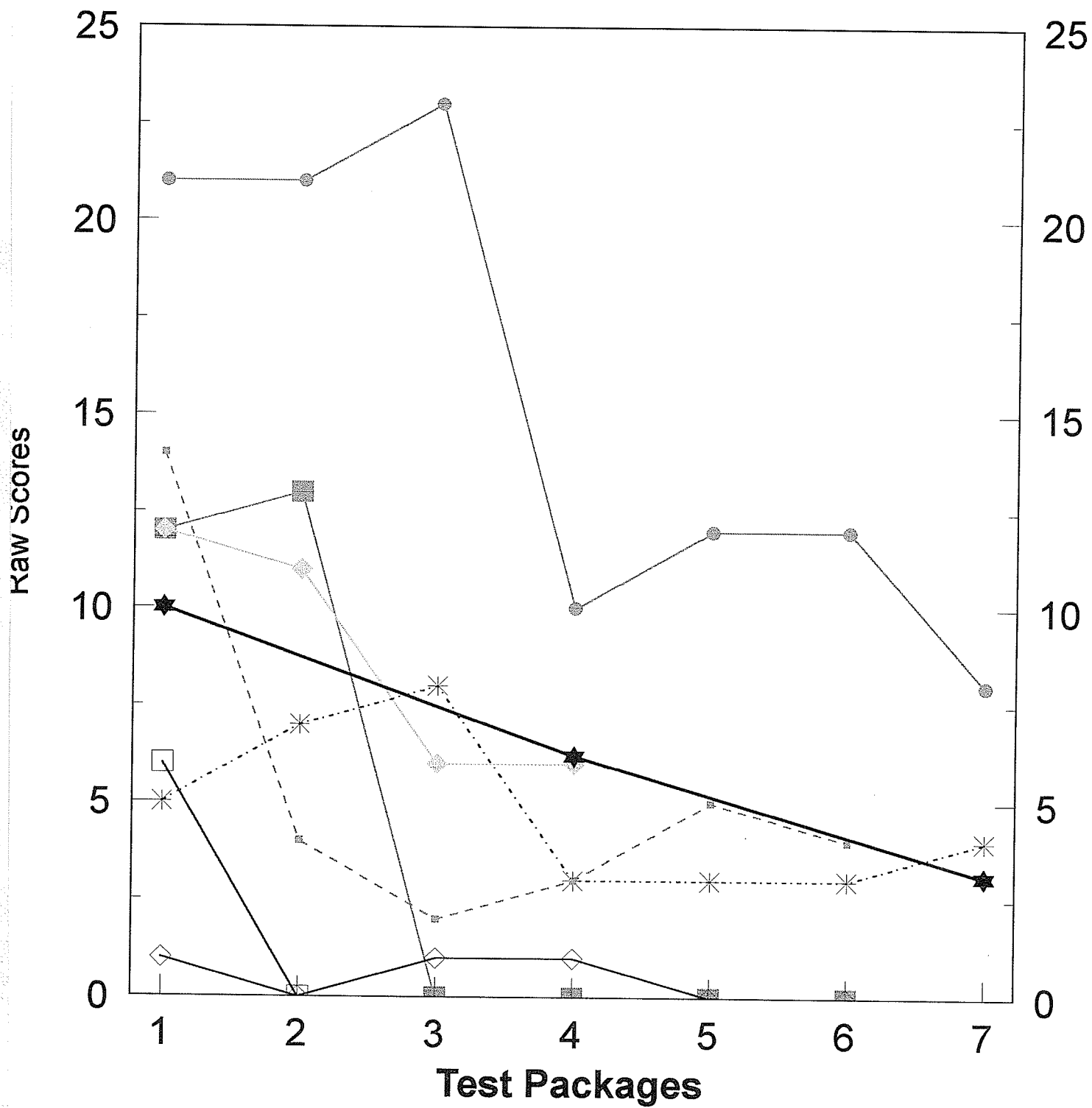
TSGS--7 Subjects and Average



BOF--7 Subjects and Average



TSKS--7 Subjects and Average



APPENDIX J

CONSENT FORMS



Hôpital Général - St. Boniface - General Hospital

409 Tache Avenue,

WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

PARENT/CHILD CONSENT FORM

Dear

Over the past few years we have made a number of presentations on Tourette Syndrome (TS) to schools attended by children and adolescents with TS. We would now like to assess the benefit of these presentations to the children and adolescents with TS and to the classroom teachers.

Specifically, we would like to know: 1) What effect, if any, the presentations had on the teacher's treatment of the children with TS and, 2) What effect, if any, the presentations had on the child's behaviour and academic performance.

For the study, we will ask your child's teacher to complete a TS information test, two behaviour checklists and some assessments of TS symptom severity that will take them 45 minutes to one hour to complete. We will also ask him/her to tell us your child's grades. We will ask your child's teacher to do this on seven occasions at approximately four week intervals over the next seven months. The first three of these times will be over the three months before we will make the presentation. This is to make sure we find out about what goes on in your child's classroom so that we can make fitting suggestions. Asking your child's teacher to monitor your child over the four months after the presentation will allow us to determine the effects of the presentation.

We will also ask that you and your child provide us with information at these same intervals. We will be asking you to let us know about your child's medication and any recent changes, as well as any stressful things that your family has experienced. We would also like your child to complete a measure of self-concept.

All data will be treated as confidential information. No individual results will be released to anyone except the parents and child unless specific permission is given to do so. Teachers will receive information about group results, unless parents and child request that individual information be shared with the teacher.

Your decision about whether or not to participate in this study will not in any way affect your standing at the TS Clinic. Presentations are not dependent on agreement to participate in this study. The other clinical staff will not be told who has and who has not agreed to participate in this study.

If you do decide to participate in this study, please sign the accompanying consent form.

Thank you for your anticipated participation.

THE EFFECT ON THE SCHOOL FUNCTIONING OF STUDENTS
WITH TOURETTE SYNDROME OF EDUCATIONAL PRESENTATIONS
MADE TO THEIR TEACHERS AND CLASSMATES

PARAPHRASE AND CONSENT FORM

1. I understand that this is a study to find out whether these presentations have made any difference as to how I do in the classroom. I understand that my parents will give you information about my medication and any recent family changes, and I will fill out a survey about how I feel about myself seven times; three times before the presentation and four times after the presentation, at about four week intervals. I understand that my teachers will also give you my recent grades and will also complete four other questionnaires at these same seven times.
2. I have the right to receive feedback about the information gathered on me even if the information is taken only as part of this study.
3. I have the right to withdraw from the study at any time. A decision to do so will not affect, in any way, my standing at the Tourette Clinic nor will it affect the type and quality of services I receive.
4. Information about me that is taken for this study will be kept in a locked filing cabinet away from clinical information. My name will not be entered onto a computer nor will it be published in any way. Individual data will not be available to clinical staff unless requested by parents and/or child.
5. I have read all of the above, or it has been read to me, and I have had a chance to ask any questions I might have. I understand I can talk to the researchers if I think of any more questions. I agree to participate in this study.

WITNESS

NAME (CHILD/ADOLESCENT)

DATE

6. I have read all of the above, or it has been read to me, and I have had a chance to ask any questions I might have. I understand I can contact the researcher if I have any further questions or concerns. I agree to participate in this study and to allow my child to participate in this study.

WITNESS

NAME (PARENT OR GUARDIAN)

DATE



Hôpital Général - St. Boniface - General Hospital
409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

TEACHER'S CONSENT FORM

Dear

Over the past few years we have made a number of presentations on Tourette Syndrom (TS) to schools attended by children and adolescents with TS. We would now like to assess the benefit of these presentations to the children and adolescents with TS and to the classroom teachers.

Specifically, we would like to know: 1) What effect, if any, the presentations have on the teacher's treatment of children with TS and, 2) What effect, if any, the presentations had on the child's behaviour and academic performance.

For the study, we will ask that you complete two behaviour checklists and two assessments of TS symptom severity which will take 45 minutes to one hour to complete. We will ask you to fill out these measures on seven occasions at approximately four week intervals over the next seven months. We will also ask you to provide us with the child's recent grades at these same times. As well, we will ask you to complete a TS information survey at two different times. Three of the seven evaluation times will be over the three months before we will make the presentation. This is to make sure that we know how the TS child behaves in the classroom and what kind of problems he/she is experiencing so that we can make fitting suggestions. The remaining four evaluation times will be at four week intervals after the presentation so that we can monitor its effects.

All data will be treated as confidential information. No individual results will be released to anyone except the parents and child unless specific permission is given to do so. Teachers will receive information about group results unless parents and child request that individual information be shared with the teacher.

Your decision about whether or not to take part in this study will not in any way affect the status of the TS student or yourself at the TS Clinic. Presentations and consultation are not dependent on your agreement to be in this study, and the other clinic staff and other school personnel will not be told who has and who has not agreed to participate.

If you do decide to participate in this study, please sign the accompanying consent form. Thank you for your anticipated participation.



Hôpital Général - St. Boniface - General Hospital
409 Tache Avenue,
WINNIPEG, MANITOBA R2H 2A6

(204) 233-8563

TEACHER'S PARAPHRASE AND CONSENT FORM

I have read all of the preceding, or it has been read to me, and I have had a chance to ask any questions I might have. I understand I can contact the researcher if I have any further questions or concerns. I agree to participate in this study.

WITNESS

NAME (TEACHER)

DATE

APPENDIX K

PRESENTATION PROTOCOL

APPENDIX K
PROTOCOL FOR THE TS SCHOOL PRESENTATIONS

The psychoeducational presentations consist of a multi-media description of the history, symptomology, characteristics, associated features, and educational implications of TS. This is imparted by slides with an accompanying lecture. This is then followed by a commercially produced video tape, "I'm A Person Too." This video is suitable for older adolescents and adults. If the target audience consists of school-age children then another video will be shown--"Stop It! I Can't." The video tapes present several examples of people with TS. After the tape is shown, the educational, symptomatological and treatment aspects of the TS are presented. Once again the lecture is presented with the assistance of slides. This concludes the presentation. At this point, questions are answered, and recommendations are made to address the difficulties shown by the specific child.

In summary, each presentation includes the following:

I. History

- Outlines the background and historical development of the disorder.
- Outlines the DSM-IV (1994) diagnostic criteria, associated features and criteria for differential diagnosis.

II. Symptomology

- Outlines the symptom picture of the TS identified in the published literature on the subject.

III. Video

- Either "I'm A Person Too." (for teachers) or "Stop It! I Can't." (for classmates).
- Provides concrete examples of a wide variety of tics, as well as descriptions given by people with TS of how they cope with the syndrome, and the difficulties created by other people's negative reactions to their symptoms.

IV. School

- Outlines the types of learning and psychological problems faced by children and adolescents with TS, and makes suggestions for ways of dealing with them in the classroom.

V. Treatment

-Outlines the psychopharmacological treatments used for TS, and their effects, side effects and impact on school functioning.

VI. TS Clinic

-Outlines the services provided by the TS Clinic at St. Boniface General Hospital.

VII. Questions and Answers, and Discussion of the Specific Child.

APPENDIX L

ETHICAL APPROVAL

UNIVERSITY OF MANITOBA

FACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Dr. Gary Shady

OUR REFERENCE: E88:123

DATE: September 27, 1988

YOUR PROJECT ENTITLED:

Efficacy of Audiovisual Presentations of Tourette Syndrome
on Teachers of Children with Tourette Syndrome.

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

Approved by Dr. Maclean on September 27, 1988.

COMMITTEE PROVISOS OR LIMITATIONS:

Approved as per your letter dated September 12, 1988.

You will be asked at intervals for a status report. Any significant changes of the protocol should be reported to the Chairman for the Committee's consideration, in advance of implementation of such changes.

** This approval is for the ethics of human use only. For the logistics of performing the study, approval should be sought from the relevant institution, if required.

Sincerely yours.

J. H. Maclean, M.D.,
Chairman,
Faculty Committee on the Use of Human
Subjects in Research

JPM/11

TELEPHONE ENQUIRIES:

788-6376 - Lorraine Lester



THE UNIVERSITY OF MANITOBA

FACULTY OF EDUCATION
Research and Ethics Committee

Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-8285
Fax: (204) 275-5962

January 9, 1995

Mr. Joe Goulet
73 Cunnington Avenue
Winnipeg, Manitoba
R2M 0W6

Dear Mr. Goulet:

On behalf of the Ethics Committee, I am pleased to inform you that the Faculty of Education Research and Ethics Committee is approving your Ethics Review Application for the research proposal, entitled, "Tourette Syndrome: A Proposal for the Study of Psychoeducational Interventions in Schools".

A copy of the approval is attached. Good luck with your research.

Yours truly,

Zana M. Lutfiyya, Ph.D.
Chair, Research and Ethics Committee

ZML/ew

Enc.

cc. J. Hughes, Advisor



Faculty of Education ETHICS APPROVAL FORM

To be completed by the applicant:

Title of Study:

Tourette Syndrome: A Proposal for the Study of Psychoeducational Interventions
in Schools.

Name of Principal Investigator(s) (please print):

Joseph Goulet

Name of Thesis/Dissertation Advisor or Course Instructor (if Principal Investigator is a student) (please print):

Dr. Jeff Hughes

I/We, the undersigned, agree to abide by the University of Manitoba's ethical standards and guidelines for research involving human subjects, and agree to carry out the study named above as described in the Ethics Review Application.

Signature of Thesis/Dissertation Advisor or Course Instructor
(if required)

Signature(s) of Principal Investigator(s)

To be completed by the Research and Ethics Committee:

This is to certify that the Faculty of Education Research and Ethics Committee has reviewed the proposed study named above and has concluded that it conforms with the University of Manitoba's ethical standards and guidelines for research involving human subjects.

Zana M. Lutfiyya

Name of Research and Ethics
Committee Chairperson

January 10, 1995

Date

Signature of Research and Ethics
Committee Chairperson