

An evaluation of a classroom presentation
about Tourette Syndrome

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Overview

Part 1: Literature Review

This section critically appraises 22 studies examining interventions giving information (or diagnostic label) about Tourette's Syndrome (TS) and ADHD to parents, teachers and peers of individuals with the conditions. The findings suggest that providing educational information increases knowledge, positive attitudes and behaviours towards individuals with TS and ADHD whilst a diagnostic label alone appears insufficient. Further research is needed into the impact on parents, the extent to which changes are maintained over time, generalise to the population, or apply in the 'real-world.'

Part 2: Empirical Paper

In this section, a study is presented which examined the impact of a psychosocial intervention (a classroom presentation) for TS in a naturalistic setting from multiple perspectives. The study used a multiple case-study design with four sets of participants, combining primarily qualitative methods (interviews and focus groups) and quantitative questionnaires. The findings suggest that a classroom presentation about TS is perceived as a positive experience by all those concerned and leads to improvements in classmates' knowledge, attitudes, and sometimes actual behaviour, as well as the self-concept of the child with TS.

Part 3: Critical Appraisal

This section offers reflections on the research process from community psychology and practise-based evidence perspectives, methodological issues arising from the study, and how these might have been overcome.

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Part 1: Literature Review

Providing information about Tourette Syndrome
and ADHD to parents, teachers and peers: A
review of the literature

Abstract

Aims

Tourette Syndrome (TS) and Attention-Deficit/Hyperactivity Disorder (ADHD) are both stigmatised and misunderstood conditions. This review aims to identify and critically appraise studies examining interventions giving information about TS and ADHD to parents, teachers and peers of individuals with the conditions.

Method

Studies examining the impact of providing educational information (or diagnostic label) about TS and ADHD to parents, teachers and peers (child and adult) were identified by searching relevant electronic databases, reference lists and citations, and consulting colleagues.

Results

Twenty-two studies were identified, 20 of which involved teachers or peers. The studies indicate that providing educational information increases knowledge, positive attitudes and behaviours towards individuals with TS and ADHD whilst a diagnostic label alone appears insufficient. Parental education may improve treatment enrolment and adherence.

Conclusions

Whilst the findings are encouraging, there are a number of gaps in the literature including the impact on parents, the extent to which changes are maintained over time, or generalise to the population. Studies need to systematically investigate the best way to present educational information in the real world in order to improve the lives of those with TS and ADHD.

Introduction

Overview

Neurodevelopmental disorders (defined as brain-based disorders of childhood onset) such as specific learning difficulties and autism are common and affect around 20% of the paediatric population (Landgren, Petterson, Kjellman & Gillberg, 1996). Co-occurrence of neurodevelopmental conditions is the rule rather than the exception (Rothenberger, Roessner, Banaschewski & Leckman, 2007). Tourette syndrome (TS) and Attention-Deficit/Hyperactivity Disorder (ADHD) are two neurodevelopmental disorders which often co-occur and have some similarities in presentation. Children with TS and ADHD exhibit visible, externalised behaviours which may appear different to the actions of other children their age, may be disruptive in classroom settings and affect social development. In a minority of children, the symptoms continue into adulthood (Leckman, Zang, Vitale, Lahnin & Lynch, 1998). Medication and behavioural treatment approaches may be effective in reducing the severity of symptoms in some individuals with these conditions (NICE, 2008). Interventions to educate other people, such as family members, teachers and peers, about the conditions have received less research attention and are the subject of this review.

Tourette Syndrome

Tourette Syndrome is characterised by multiple motor tics and one or more vocal tics that continue for longer than a year (APA, 2000). It is estimated to affect around 1% of school-aged children (5-18 year olds) in the UK, and over three times more boys than girls (Freeman et al., 2000; Hornsey, Banerjee, Zeitlin & Robertson, 2001). The onset of TS typically occurs in middle childhood and tics peak in severity around the

age of 10-12 years (Leckman et al., 1998). In around 50% of individuals the severity of, and disability associated with, tics are significantly reduced by early adulthood (Bloch et al., 2006; Leckman et al., 1998). Tics 'wax and wane' (vary in severity and manifest in different ways) over time and can be exacerbated by stress and other contextual factors (Cornelea & Woods, 2008; Woods, Marcks & Flessner, 2007). Individuals with TS are able to suppress their tics for short periods of time (Christie & Jassi, 2003).

Consistent with the high levels of comorbidity between neurodevelopmental disorders noted above, the majority of individuals with TS also suffer from a range of additional difficulties (Freeman et al., 2000). The most commonly reported comorbid problems are ADHD and obsessive-compulsive behaviours/disorder (OCB/D) estimated to occur, respectively, in 60% and 30% of individuals. Mood/affective disorders, anxiety disorders, conduct and oppositional disorders affect up to 20% of individuals with TS. TS is also over-represented in those with learning difficulties and autistic spectrum disorder (Eapen, Robertson, Zeitlin & Kurlan, 1997; Kurlan et al., 2001).

Psychosocial impact of TS

Quality of life has found to be poorer in TS sufferers compared to the general population (Bernard et al., 2009; Cavanna et al., 2008; Cutler, Murphy, Gilmour & Heyman, 2009; Elstner, Selai, Trimble & Robertson, 2001; Storch et al., 2007b). Social, emotional and school/occupational functioning is generally more impaired than physical functioning. Both tic severity and comorbid difficulties such as OCD

and ADHD symptoms contribute a significant proportion of the variance in quality of life (Cutler et al., 2009; Storch et al., 2007b).

Increasing attention is being paid to the adverse impact of having TS on individuals' social functioning. The characteristics of TS mean that it is often stigmatised and misunderstood (Christie & Jassi, 2002). Children and adolescents with TS report that they struggle to fit into society's expectations of normal behaviour and rate social isolation and embarrassment as equally disabling as the tics themselves (Cutler et al., 2009; Wand, Matazow, Shady, Furer, & Staley, 1993). Those with tics have been found to be rated less favourably and as less socially acceptable than those without tics (Boujouk, Woods, Miltenberger & Long, 2000). Thirty-five percent of a sample of children with TS received the poorest ratings in their class by peers for withdrawal, aggression and/or likeability (Stokes, Bawden, Camfield, Backman & Dooley, 1991). Those with additional problems such as ADHD are particularly at risk of negative perceptions (Bawden, Stokes, Camfield, Camfield & Salisbury, 1998). Individuals with TS also report high rates of 'teasing', bullying or victimization by peers (Jagger et al., 1982; Shady, Fulton & Champion, 1988; Storch et al., 2007a). Teachers may also rate children with TS negatively (Stokes et al., 1991). It appears that difficulties with social relationships persist into adulthood (Champion, Fulton & Shady, 1988).

Treatments for TS

There are pharmacological and non-pharmacological treatments for TS. Some medications can help to reduce the severity of tics (Piacentini et al., 2010). However, it is not the treatment of choice for all sufferers; some do not find medication reduces

the symptoms, cannot tolerate the side-effects or do not wish to take medication long-term (Piacentini et al., 2010). There are also evidence-based psychological treatments aimed at tic reduction such as ‘Habit Reversal Training’ (Piacentini & Chang, 2006; Woods, Conelea & Himle, 2010), which combine psychoeducational information and behavioural modification techniques. Comorbid conditions may also be the target for pharmacological or non-pharmacological treatments (see section on ‘treatments for ADHD’ below). Meanwhile, the clinical literature is replete with un-researched recommendations for interventions that aim to modify the child’s environment to reduce both tics and additional difficulties (Conelea & Woods, 2008; Packer, 2005; Wilson & Shrimpton, 2003). Based on clinical anecdote rather than research evidence, it is commonly asserted that psychoeducational approaches for the child and those in their environment (such as family, teachers and other professionals) are crucial in targeting misunderstanding and stigma so that the child can access the support they require (Kepley & Conners, 2007; Stern, Burza & Robertson, 2005). In addition, there is particular emphasis on educating peers regarding TS given the social difficulties outlined above.

ADHD

Attention-deficit/hyperactivity disorder is characterised by developmentally inappropriate levels of inattention and/or hyperactivity/impulsivity. To meet DSM-IV criteria for the condition, the child must exhibit at least six inattentive or hyperactive/impulsive symptoms in more than one setting (e.g. at home and at school) for at least six months before the age of seven years, with concomitant academic and/or social impairment (APA, 2000). There are predominantly inattentive, predominantly hyperactive-impulsive and combined subtypes. It is

estimated to affect around 5% of school-aged children with a greater percentage showing symptoms that do not quite meet criteria for diagnosis (Polanczyk, de Lima, Horta, Biederman & Rohde, 2007). Boys are 2-5 times more commonly affected than girls (DuPaul, 2007). Symptoms may persist into adulthood for a significant proportion of individuals (Barkley, 2006).

Psychosocial impact of ADHD

ADHD is associated with a range of additional difficulties including oppositional-defiant disorder, conduct disorder, sleep disorder, learning disorder, and motor problems (Biederman et al., 2006). Tics occur in 20% of children with ADHD (Gillberg et al., 2004; Kadesjo & Gillberg, 2001; Robertson, 2006) Children with ADHD are also at risk of mood, anxiety, addictive and antisocial problems (Biederman et al., 2006; Biederman & Faraone, 2005). In addition, they frequently suffer from impairment in school performance; they are more likely to receive lower grades at school and leave school earlier than their peers (Mannuzza, Gittelman-Klein, Bessler, Malloy & La Padula, 1993; Merrell & Tymms, 2001). There is some evidence that ADHD is associated with impairments in social relationships (DuPaul, 2007). For example, children may enter ongoing peer activities in an abrupt, impulsive manner, or behave in a verbally or physically aggressive manner, leading their peers to reject or exclude them (Hoza et al., 2005). Teachers may also find children with ADHD difficult to manage in a classroom setting, leading to conflict in their interactions with such children (Greene, Beszterczey, Katzenstein, Park & Goring, 2002). As outlined above, ADHD may also increase the severity of impairment associated with other disorders such as TS (Banaschewski, Neale, Rothenberger & Roessner, 2007; Freeman, 2007; Rothenberger et al., 2007.)

Treatments for ADHD

There are evidence-based pharmacological and non-pharmacological approaches for ADHD. In the UK, the guidelines produced by the National Institute for Health and Clinical Excellence (NICE) state that drug treatments (stimulants such as methylphenidate or non-stimulants such as atomoxetine) should always form part of a comprehensive treatment plan that includes psychological, behavioural and educational advice and interventions (NICE, 2008). There is now an increasing body of evidence in favour of behavioural modification approaches (such as parent training) and multimodal approaches (combining medication and behavioural modification approaches in different settings as well as additional components such as social skills training) across the lifespan (Young & Amarasinghe, 2010). There is less evidence for the individual components that make up these multi-component interventions. In particular, the evidence for psychoeducation in isolation is unclear, despite the fact that this underpins many other psychological approaches to ADHD (MTA Cooperative Group, 1999; Young & Amarasinghe, 2010).

Targeting negative attitudes towards TS and ADHD

Approaches aimed at increasing the awareness and understanding of others (such as family members, teachers and peers) to reduce stigma and misunderstanding of TS and ADHD are poorly researched and under-developed, with recommendations coming largely from clinical consensus (Verdellen et al., 2011; Woods et al. 2007). However, a broader literature suggests that negative attitudes of peers towards a range of conditions such as physical disability, diabetes, cystic fibrosis, and HIV can be changed by disclosure or provision of factual information (Berlin, Sass, Davies & Hains, 2002; Berlin, Sass, Davies, Jandrisevits & Hains, 2005; Odom et al., 1999;

Wiener & Battles, 2006). Since knowledge and beliefs form the basis of attitudes, which to some extent predict behaviour (Ajzen, 1980; Favazza, Phillipsen & Kumar, 2000), it is important to use measures of knowledge, attitudes and/or behaviours as a way of determining the effectiveness of interventions aimed at educating others. Studies are beginning to evaluate this approach in TS and ADHD. In line with the drive for evidence-based practise, there is a need to review this literature to determine whether clinical recommendations are based on empirical evidence or anecdote alone.

Aims of this review

This review aims to systematically examine studies that investigate the impact of giving information as a ‘stand alone’ intervention to improve understanding and reduce the negative attitudes and behaviours of other people (peers, teachers and parents) towards individuals with TS and ADHD. Outcomes of interest include other people’s attitudes, intended behaviours, and/or knowledge about the conditions.

Method

Search strategy

The following methods were used to identify relevant papers published in English, peer-reviewed journals up to the cut off date of 27th October 2010. A search was conducted using the following electronic databases: Psychinfo, Embase, Medline, ERIC (Education Resources Information Centre), BEI (British Education Index) and AUEI (Australian Education Index). The search terms “ADHD or Tourette” were combined with “peer or classmate or parent or teacher” and each of the following (an asterix indicates the truncated term may be expanded):

- 1) (improv* or chang*) and (attitudes or knowledge or behav* intentions)
- 2) (providing or giving) and (information or advice)
- 3) (educat* or training or educational program or psychoeducation) excluding parent training
- 4) (impact or effect or evidence) and (label* or disclos*)
- 5) (stigma or prejudice or negative attitudes).

The search terms were chosen in an iterative way to be broad enough to capture the different aspects of the literature review across the clinical and educational literature whilst reducing the irrelevant papers to a manageable number to search through. Additional terms related to ADHD (such as ‘attention deficit disorder’ or ‘hyperkinetic disorder’) or TS (such as tics or tic disorder) were not used as preliminary searches indicated they did not yield additional relevant papers. Reference lists of relevant papers were examined and the citation function of Google Scholar was used to identify any further relevant papers. Experts in the fields of TS and ADHD were also approached for their input in identifying relevant papers.

Inclusion and exclusion criteria

Criteria for inclusion in the review were:

- 1) The aim of the study was to examine the impact of giving educational information about either TS or ADHD to people other than those with the disorder i.e. parents, teachers, or peers.
- 2) The study included at least one outcome measure of attitudes, intended behaviours, knowledge about the condition, or impact on the person with the condition.

- 3) The intervention being examined was primarily educational (as opposed to behaviour management).
- 4) The intervention involved giving disorder-specific information about either ADHD or TS.
- 5) The study specified what information was provided to participants.

Due to the small number of published studies in the area, no limits were placed on the developmental stage of the individual with TS or ADHD or on the age-group of peers. That is, studies of both children and adults were included since both TS and ADHD affect individuals across the lifespan. Studies examining the effects of providing a diagnostic label versus not labelling the condition were included, as it was felt these shed light on the process of disorder-specific information-giving.

Exclusion criteria were:

- 1) Studies of multi-component treatments (such as behavioural modification programmes) where it was not possible to isolate the educational component for evaluation.
- 2) Studies examining the impact of giving educational information to the person with the disorder.
- 3) Evidence from book chapters and other 'grey literature' as preliminary investigation indicated that, in this field, these sources generally yield information rooted in clinical experience or consensus rather than scientific research.

Identification of relevant papers from search results

The initial search of Psycinfo yielded a total of 235 papers. The titles and abstracts were examined to see if the article was related to the topic of the literature review. Most were excluded on the basis that the study had not examined the provision of information about (or diagnostic label of) ADHD or TS. Full papers were obtained for 20 papers, of which 12 met the inclusion criteria. A further 10 papers meeting inclusion criteria were identified through subsequent searches of the specified electronic databases (Embase, Medline, ERIC, BEI, and AUEI), reference lists and citation functions. No previous reviews covering this area were identified.

Results

The key characteristics of the 22 included studies are presented in Table 1 and Table 2. Seven studies examined the effects of providing information about TS and 15 examined the effects of providing information about ADHD; these are discussed in turn below. Within each section, the studies are organised by target audience (peers, teachers, parents).

Table 1

Summary of the TS studies included in the review

| Study (author and date) | Sample characteristics | Design | Nature of the intervention | Assessment points | Outcome measures |
|--|--|---|---|------------------------------|---|
| Friedrich et al. (1996) | 153 school children in the USA (8-11yrs; 56% female; 62% Caucasian). | TS information vs. no information vs. no TS | 100s video of a child actor briefly explaining about his TS | Post | Adjective Checklist Activity Preference Scale Foley Questionnaire Modified Foley Questionnaire |
| Holtz & Tessman (2007) | 179 school children in the USA (7-15 years; 49% female; 65% Caucasian) | TS information vs. information about drugs | 10-minute video giving educational information about TS | Pre and post | 8-item study-specific knowledge questionnaire Modified CATCH Foley Questionnaire |
| Marcks et al. (2007) | 369 adults in the USA (18-26 years; 65% university students; 59 % female; 78% Caucasian) | 2x2 design (male vs. female character; label vs. no-label of TS) | Written vignette labelling TS | Post | 32-item study-specific attitude questionnaire |
| White et al. (2010) | 144 teachers in elementary schools in the USA (22-68 years; 81% female) | Immediate vs. wait list condition | 2-hr workshop on TS, ADHD and OCD | Pre and post | 27-item investigator-derived measure of knowledge about TS ADHD and OCD |
| Woods (2002) | 112 university students studying psychology in America (mean age 20.5 years; 78% female) | 2x2 design (male vs. female character; TS education vs. no education) | 13-min video giving educational information about TS | Pre and post | Social Acceptance Scale Distance between chairs |

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| Woods et al. (2003) | 227 university students studying psychology in the USA (69% female) | 2x2x2 design (male vs. female character; mild vs. severe tics; TS education vs. no education) | Same as Woods (2002) | Pre and post | Social Acceptance Scale Tolerance Scale Distance between chairs |
| Woods & Marcks (2005) | 170 university students studying psychology in the USA (mean age 22.3 years; 75% female) | 2x3 design (male vs. female character; TS education vs. depression education vs. no education) | Same as Woods (2002) | Pre and post | Same as Woods et al. (2003) |

Note. CATCH= Chedoke-McMaster Attitudes Towards Children with Handicaps Questionnaire

Table 2

Summary of the ADHD studies included in the review

| Study (author and date) | Sample characteristics | Design | Nature of the intervention | Assessment points | Outcome measures |
|---------------------------------|--|---|--|-----------------------------|--|
| Barbarese & Olsen (1998) | 44 school teachers in the USA (75% female) | All participants received the intervention | 2 ½ -hour single session ADHD training programme | Pre and post (at 1 month) | Expanded AKS Index of Teacher Stress CAP |
| Corkum et al. (1999) | Parents of 69 newly diagnosed children with ADHD in Canada (5-12 years; 14% female; Mean age of mother 37 years) | 2x2 design (medication vs. placebo; parent training group vs. parent support group) | Parent-led once-monthly support group (parent training and medication will not be described here) | Pre and post (at 12 months) | Modified AKOS Pill counts (medication) Attendance records (parent groups) |
| Cornett-Ruiz & Hendricks (1993) | 39 primary education teachers and 81 peers (grades 4-6) in the USA | 2x2 design (ADHD label vs. no label; ADHD behaviour vs. non-ADHD behaviour) | 4½ -minute video of child actor of demonstrating either ADHD or non-ADHD behaviours; told child either had ADHD or attended regular class. | Post | Study-specific measures (First Impressions Rating Scale; Predictions Scale; Essay ratings scale) |
| Ghanizadeh et al. (2009) | 550 primary school teachers in Iran (87% female) | Same as Jastrowski et al. (2007) | Same as Jastrowski et al. (2007) | Post | 11-item study-specific attitude questionnaire |

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| Jastrowski et al. (2007) | 306 adults in the USA (67% university students; mean age 22.5 years; 56% female; 85% Caucasian) | 2x2 design (hyperactive vs. inattentive symptoms; label vs. no label of ADHD) | Written vignette labelling ADHD | Post | 16-item study-specific attitude questionnaire |
| Jones & Chronis-Tuscano (2008) | 142 teachers from 6 elementary schools in the USA (92% female; 57% Caucasian) | Immediate vs. wait list condition | Single-session ADHD training programme | Pre and post (at 1 month) | 25-item study-specific knowledge questionnaire Measure of teachers' use of classroom behaviour management strategies Intervention satisfaction measure |
| Koonce et al. (2004) | 259 university students in the USA (54% studying Education; mean age 21.5 years; 72% female; 87% Caucasian) | Video only vs. vignette only vs. video and vignette vs. video and label vs. vignette and label vs. video and vignette and label | Video or vignette of ADHD symptoms with or without labelling ADHD | Post | 17-item study-specific teacher attitudinal scale |
| Law et al. (2007) | 120 secondary school children in Britain (mean age 11.9 years; 57% female; 98% Caucasian) | ADHD label vs. ADH label vs. no label | Written vignette labelling ADHD/ADH | Post | Adjective Checklist Shared Activities Questionnaire |

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|-----------------------------|--|---|--|----------------------------|---|
| Ohan et al. (2008) | 140 primary school teachers in Melbourne, Australia (85% female; 63% Caucasian) | Male vs. female vignette character | Written vignette | Pre and post | Modified AKS 9-item study-specific questionnaire asking about attitudes and behavioural intentions |
| Saecker et al. (2010) | 62 pupils studying Psychology/Sociology in the USA (15-18 years; 63% female; 83.9% Caucasian) | ADHD facts and DPE vs. ADHD facts only | 5-7 minute video of actor providing factual information and/or disclosing that he had ADHD and giving descriptions of personal experience (DPEs) | Post | Modified KADDS Modified BIS |
| Sayal et al. (2010) | 489 children from Tymms & Merrell (2006) study | Random sampling from original study | See Tymms and Merrell (2006) | Follow-up (at 5 years) | Extended SDQ |
| Stinnett et al. (2001) | 144 university students studying Education in the USA (mean age 22 years; 81% female; 87.7% Caucasian) | 2x2 design (ADHD label vs. no label; Ritalin treatment vs. special education) | Written vignette | Post | IRP-15 Unpublished Teacher Rating Scale |
| Svanborg et al. (2009 a, b) | (Parents of) 99 stimulant-naïve children with ADHD in Sweden (19.2% female) | Atomoxetine and parental psychoeducation vs. placebo and parental psychoeducation | 4x3-hour parental education sessions on ADHD | Pre and post (at 10 weeks) | Effect size of experimental condition on core ADHD symptomatology Drop out rate |

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|------------------------|--|--|--|---------------------------------------|--|
| Syed & Hussein (2010) | 49 teachers in Karachi, Parkistan (100% female) | All participants received the intervention | 10-hour training program (2hr/day for 5 days) on ADHD | Pre, post and follow up (at 6 months) | Modified AKS |
| Tymms & Merrell (2006) | 73,367 pupils (aged 4 in 2000/01 academic year) in 2040 schools in England | Labeling vs. information on ADHD vs. labelling and information on ADHD vs. no intervention | Written information labelling children with ADHD symptoms and/or providing information on ADHD | Pre and post (at 1-2 years) | PIPS and PIPS2 18-item ADHD symptom rating scale Questionnaires to teachers |

Notes. AKOS= ADHD Knowledge and Opinions Scale
 AKS= ADHD Knowledge Scale
 BIS= Behavioural Intentions Scale
 CAP= Child Attention Problems Rating Scale
 KADDS= Knowledge of Attention Deficit Disorders Scale
 IRP-15= Intervention Rating Profile
 PIPS(2)= Performance Indicators in Primary Schools (2)
 SDQ= Strengths and Difficulties Questionnaire

TS studies

Six of the 7 studies examined the impact of educating peers about TS: two involved educating child peers and four involved educating adult peers (university students). One study examined the effects of educating teachers about TS (as well as ADHD and OCD). No studies examined the impact of giving information to parents about TS.

Overview of peer education studies

Two of the six studies on peer education involved primary school children between 7-15 years. In the remaining four studies the ‘peers’ were university (largely Psychology) students. The studies included sample sizes of 112-369 participants, who were largely Caucasian (62-75%; three studies lacked data on the ethnicity of the sample) and all took place in the USA. All the studies utilised a randomised design, with participants allocated to either experimental or control conditions. In the experimental condition, participants received information about TS, or were told the diagnostic label. The control condition was either provision of alternative information, no information (one study used both) or no diagnostic label. There were some similarities and some differences between studies regarding the outcome measures used; they generally used a combination of standardised and study-specific (investigator-derived) measures. With regards to the findings, all but one study reported some benefits of providing education to peers about TS. The main findings of each study are detailed below.

Peer education for children

Friedrich, Morgan and Devine (1996) were the first researchers to investigate the impact of providing information on the attitudes and behavioural intentions of peers towards a person with TS. They studied a sample of school children in two year groups (ages 8-9 and 10-11 years). Children watched a short video clip (60-100s) of a boy (an actor) in which the child either 1) exhibited motor tics, gave a brief personal description of himself and an explanation about his TS 2) exhibited tics and talked about himself but did not explain about TS or 3) did not exhibit tics and briefly talked about himself. Following the intervention, the participants rated the child without TS in the control condition significantly more favourably than the child in the TS conditions on a measure of personal attributes. Providing information about TS had no effect on the ratings. Boys rated the child more favourably than girls, which may have been a response to the male gender of the actor. There was no difference on a measure of behavioural intentions in the TS versus non TS conditions.

It appears that providing a brief verbal description about TS did not result in children showing more positive attitudes or behavioural intentions towards the child with TS. It may be that the information provided about TS was too brief to lead to change in attitudes/behaviours in children of this age. A strength of this study was that it attempted to overcome the social desirability effect which arises with self-report questionnaires by asking children about how they thought other children in their class would behave towards a child with TS. They found that the children reported less positive behavioural intentions for their classmates than they did for themselves,

highlighting the need for actual behavioural measures to supplement self-report measures of attitudes and behavioural intentions.

Holtz and Tessman (2007) addressed the possible limitation of the study by Friedrich et al. (1996) i.e. that providing too little information about TS was responsible for lack of attitude change. They examined the impact of showing children and young adolescents (aged 7-15 years) a 10-minute long video giving detailed information about TS, compared to a 10-minute video clip about the effects of drugs on the brain. Children who were shown information about TS showed statistically significant increases in their knowledge about TS, and their attitudes and behavioural intentions towards a child with TS compared to the group of children shown information about drugs. A limitation of this study is the lack of measure of actual behaviour towards a child with TS.

Peer education for adults

Woods and colleagues (Woods, 2002; Woods, Koch and Miltenberger, 2003; Woods & Marcks, 2005) conducted a series of three studies regarding the impact of educating US college students (hereafter referred to as university students in line with UK terminology) about TS. In the initial study, Woods (2002) showed participants a short video clip of a male or female character engaging in severe motor tics. Participants then rated how socially acceptable they found the character. Prior to the video clip, half the participants were shown a 13-minute educational video which provided information about TS and showed individuals with the condition describing their experiences. The remaining participants were not shown a video before they rated the character. Participants who received educational information about TS rated

the character as more socially acceptable than those who did not receive educational information. A subset of participants were also asked to take part in a further task. They were asked to 'make themselves comfortable' whilst they waited in a room with two chairs side-by-side for the character from the video clip to join them. The shortest distance between the two chairs was then measured. Participants who had seen the educational video about TS moved the chairs less far apart than those who had not seen the video. This study suggests that providing educational information about TS reduces negative attitudes and behaviours towards a person with the condition. The use of a measure of behaviour is a strength of this study. It may correlate with actual behaviours in real-life situations, although this remains speculative since the authors did not document the reliability and validity of this choice of behavioural measure.

Woods et al. (2003) extended the findings of Woods (2002) using a larger sample to examine whether the impact of providing educational information about TS varied as a function of the gender or tic severity of the character in the video clip. All participants completed three measures of their attitude and behaviour towards a person with TS; ratings of social acceptability and tolerance of the character and the distance they placed between the chairs. The participants who saw the educational video rated the character significantly more highly on the social acceptability and tolerance scales than participants who did not see the video, regardless of tic severity or character gender. These findings are similar to those of the original study. Unlike Woods (2002), providing educational information about TS did not generally reduce the distance between the chairs, with one exception: participants who received educational information and saw a video-clip of a male character with severe TS.

Further research would be needed to establish whether this result represents a clinically meaningful finding or occurred by chance (a type-1 error). Overall, the study suggests that providing educational information about TS may reduce negative attitudes towards male and female sufferers of both mild and severe TS, although it provides less evidence for the impact on actual behaviour.

Woods and Marcks (2005) examined the effect of a video of TS-specific educational information compared to an educational video about depression, or no video, using a similar experimental paradigm to Woods et al. (2003). The aim of this study was to examine whether the educational information provided needed to be disorder-specific or whether providing educational information about another problem would have a similar impact. Providing TS-specific information led to higher ratings of social acceptability and tolerance of a character with TS and a reduced distance between the chairs compared to providing information about depression. However, the participants who received TS-specific information only differed from the participants in the no-video condition on the social-acceptability measure. The findings provide limited evidence for the impact of condition-specific information on changing peers' attitudes. However, the decision to compare the impact of providing information on an internalising condition (such as depression) with an externalising condition (such as TS) may have impacted on the results, making it harder to draw conclusions from the study.

Marcks, Berlin, Woods and Davies (2007) examined the impact of 'disclosing' that a male or female written vignette character with tics had TS in a large sample of young adults (65% university students). In the 'disclosure' condition, the vignette said that

the character had TS; in the non-disclosure condition the vignette did not provide a diagnostic label to explain the characters unusual noises and movements. Providing a diagnostic label of TS led to less concern/anxiety about the character's behaviours, less social rejection of the character and less endorsement of the belief that the character's behaviours were due to a drug/alcohol problem (regardless of character gender) compared to not providing a diagnostic label. There was no impact on participants' views on whether the character had a psychological or medical problem. The study suggests that providing information in the form of applying a label (TS) to the character's unusual behaviours reduces negative attitudes and behavioural intentions towards the character. However, the study did not measure or control for participants' prior knowledge about TS. The majority of participants also endorsed a "moderate social philosophy," which may have led them to have more tolerant attitudes towards a labelled individual than the general population. A further limitation is that the study did not examine actual behaviours towards a person with TS, and how far the questionnaire responses predict this is unknown.

Summary of peer education studies

In summary, five of the six studies provide evidence that giving information about TS to peers results in more positive attitudes towards a person with TS, regardless of their gender or the severity of their tics, or the age of the peer group. The one study that failed to find this relationship may have provided insufficient information about TS given the age of the participants.

The strengths of the studies are their use of randomised designs, large samples and multiple outcome measures. There is less evidence that providing information about

TS leads to a change in behaviour towards the person with TS when compared with attitude change. Two of the studies examined behavioural intentions only and did not attempt to measure or control for the ‘social desirability effect.’ Reported behavioural intentions may be more positive than actual behaviours, as indicated by one study, which took this effect into account. Woods and colleagues attempted to use a measure of behaviour in the remaining three studies, with mixed findings. In addition, the reliability and validity of the measure they used is not established. To date, none of the studies have been followed up over a longer period of time to see if the shifts in attitudes are maintained. The studies are limited in their generalisability for a number of reasons. Firstly, they do not examine attitudes towards individuals with comorbid conditions (such as ADHD), which are commonly associated with TS and may influence its presentation. It may also be questioned how far the attitudes of largely white, American psychology undergraduate students elicited using artificial/laboratory-based paradigms may apply to the peer groups of people with TS in the real-world.

Teacher education studies

White et al. (2010) are the first and only researchers to investigate the impact of providing educational information about TS to teachers (144 elementary school teachers in the USA). In the experimental condition, the teachers received a two-hour, lecture-based workshop providing information on TS and associated conditions of ADHD and OCD (including definitions, clinical picture, natural history, epidemiology, manifestations in the classroom, treatment strategies and classroom management approaches). In the wait-list control condition, the teachers received the workshop six weeks later. Participants completed a 27-item, investigator-derived

measure of knowledge of TS (11 items), OCD (10 items) and ADHD (6 items) prior to and following the workshop. Overall, there was a small but significant (5%) increase in knowledge following the workshop. However, it appeared that teachers with lower scores prior to the workshop benefited most (12% increase) with no significant increase in knowledge shown by better-informed teachers. Participation in the workshop was also associated with better scores on items most commonly answered incorrectly pre-workshop. There was no impact of the type of class taught (regular, special education or other), the teacher's level of training or amount of experience working with children with the conditions.

Limitations of this study include that only a small sample of the control condition (11 participants) provided post-workshop data, limiting the power of the statistical comparisons used. The study also lacked longitudinal follow-up and behavioural measures. However, the findings suggest that teachers who lack knowledge about TS and its associated conditions may benefit from brief training on this topic.

ADHD studies

Of the 15 studies examining the effects of educating others about ADHD, nine examined the impact of educating teachers, two involved educating parents and three looked at educating peers. One study examined the impact of educating both teachers and peers.

Overview of peer education studies

Of the four studies studying peers, three studies involved children and one involved adult participants. As with the TS peer-education literature, the studies were

primarily conducted in USA (with the exception of one study which was conducted in the UK) with samples of predominantly Caucasian ethnicity (83-95%). All studies utilised a randomised design.

Peer education for children

Law, Sinclair and Fraser (2007) studied a sample of 120 children in the first three years of secondary school in the UK. They provided the children with a written vignette of a child (of unspecified gender) with symptoms of ADHD and either a label of attention-deficit/ hyperactivity disorder, attention-deficit/hyperactivity, or no label. The aim was to determine whether different types of label affected attitudes and behavioural intentions towards an individual with symptoms of ADHD. They found no differences between the three conditions on participants' adjectival ratings of the child or their behavioural intentions towards them, which were generally negative. This was unrelated to whether the participant indicated that they had met someone like the child in the vignette before; however this might have been because the level of knowledge of ADHD amongst the participants was low (only 8% reported they 'knew something' about ADHD). It may have been that a written label of ADHD/ADH provided insufficient information to change the attitudes of children of this age group. In addition, the allocation to conditions was done at a school level, introducing a number of potential confounding variables. The opt-in design also led to a very low participation rate (8%) and, consequently, a possible source of considerable participant bias.

Saecker, Skinner, Skinner, Rowland and Kirk (2010) explored the impact of disclosure in addition to providing factual information about ADHD. They studied a

sample of 62 adolescents (aged 15-18 years) studying psychology/sociology at an American high school. An actor in a video either disclosed that they had ADHD and provided descriptions of personal experience (DPEs) relating to 6 of the 12 facts they presented dispelling common myths about ADHD, or simply provided the 12 facts. The authors found that including DPEs enhanced learning of the 6 related facts but inhibited learning of the other 6 facts which did not have a DPE attached. Including DPEs did not have any impact on the behavioural intentions of participants towards a person with ADHD, which was positive in each group.

The study has a number of limitations. For example, it used a 24-year old actor who may not have been seen by the teenage participants as a 'peer'. The study also failed to control for social desirability effects (arising from participants being asked to put their names on the measures) or ceiling effects (arising from the modified measures being too easy) and did not utilise a pre-post design (it used a post measure only). A strength of this study is that it begins to examine the best way to present educational information regarding ADHD to peers. It also aimed to overcome some of the limitations of using a simple true/false knowledge measure by including a 'don't know' option (reducing the change of participants responding correctly by guessing).

Cornett-Ruiz and Hendricks (1993) contrasted both ADHD versus non-ADHD behaviours and the effects of labelling versus not labelling on the judgements of peers and teachers. The data on the peers will be presented here (see the section below for teachers' data). Eighty-one children in three grades (aged 9-11 years) in a US public school watched a 4.5-minute video of a peer exhibiting either ADHD or non-ADHD behaviours and were either told prior to watching that that the child had

ADHD or was a student in a regular class. They were given a verbal explanation of ADHD, which described how in many ways children with ADHD are similar to them. Children rated the child demonstrating ADHD behaviours more negatively on measures of their expectations of everyday behaviours and future success. Labelling the child in the video was not associated with any difference in ratings. On a task requiring them to mark an essay supposedly written by the child in the video, the children rated the unlabeled child demonstrating ADHD behaviours most negatively, and the labelled child demonstrating normal behaviours most positively. The use of a paradigm with somewhat artificial combinations of labels and behaviours may limit interpretation of this interaction effect. However, it appears that labelling may not influence general attitudes towards individuals demonstrating ADHD behaviour but may lead to lower expectations of performance on an academic task (essay writing).

Peer education for adults

Jastrowski, Berlin, Sato and Davies (2007) used an experimental design very similar to the TS study by Marcks et al. (2007) in a sample of 306 young adults in the USA (67% undergraduate students). They examined the impact of providing a written label that a vignette character (of unspecified gender) with either hyperactive or inattentive symptoms had ADHD. Labelling that the character had ADHD led to fewer socially rejecting attitudes and increased belief that the character would benefit from treatment for their problems compared to the no-label condition. The study suggests that providing information in the form of applying a label (ADHD) to the character's unusual behaviours reduces negative attitudes and behavioural intentions towards the character, regardless of the type of ADHD symptoms they are demonstrating (hyperactive or inattentive). However, the items included in the factor

'potential benefit from treatment' were diverse (e.g. ranging from "Jamie would benefit from psychotherapy" to "Jamie has trouble keeping friends") making it difficult to ascertain exactly what attitudes changed in the labelled condition. As with Marcks et al. (2007), this study did not measure or control for participants' prior knowledge about ADHD, or examine actual behaviours towards a person with ADHD.

Summary of peer education studies

The studies on the impact of educating peers about ADHD provide preliminary evidence that mirrors the TS literature. It appears that providing information about ADHD of a sufficient level of detail for the audience may lead to more positive attitudes towards the person with ADHD, whilst providing a label of ADHD alone may not be sufficient to change attitudes. All the studies made use of randomised designs. However, the small number of studies in this area make it harder to draw conclusions, particularly as they used a range of different methodologies and small samples in a majority of cases. The studies also focused on the effects of labelling in Western samples. Further studies should examine the impact of providing educational information about ADHD to both Western and non-Western peers.

Teacher education studies

The studies involving teachers used a mixture of methodologies (from randomised to uncontrolled designs) in both Western and non-Western samples. They examined a range of ways of providing information to teachers, from giving a diagnostic label, to providing written information, or giving single or multiple training sessions. Overall, the studies suggest that providing educational information to teachers improves

knowledge of the condition, whilst providing a diagnostic label may evoke negative attitudes which may be unhelpful to the child given the label. The impact of providing education on teachers' actual behaviours has yet to be examined.

Training programme studies. Barbaresi and Olsen (1998) examined the impact of a 2½-hour training session on ADHD in a small sample of 44 schoolteachers in the USA. They found that teachers' knowledge was significantly higher one month following the training than beforehand and their stress ratings were significantly reduced, although this was not correlated with increase in knowledge scores. A strength of this study is that it examined the impact of the training programme on specific knowledge items and demonstrated that specific prior misconceptions (about diet and medication in ADHD) were reduced by the training. It indicates that providing educational information may be useful, but that other factors are involved in mediating outcomes such as reduction in teacher stress (possibly effective use of behavioural modification strategies in the classroom).

Syed and Hussein (2010) examined the impact of a 10-hour training programme (2 hours/day over 5 days) in a small sample of 49 teachers from three schools in Karachi, Pakistan. The training consisted of providing factual information about ADHD as well as behavioural management techniques (although the study lacked outcome measures on the latter). The investigators found that the programme led to a significant increase in knowledge about ADHD on a true/false questionnaire measure, which was maintained at follow-up six months later. This provides preliminary evidence for the usefulness of educating teachers about ADHD in a non-Western sample.

The limitations of both of the studies above are their small sample size, lack of a control condition, confound of a small behavioural modification component, use of a true/false measure of knowledge and lack of actual behavioural measures. They fail to shed light on the impact of providing education to teachers on other outcomes such as attitudes towards children with ADHD and actual behaviours (for example, their referral of children with suspected ADHD to specialist services for assessment). This is both due to the studies' lack of outcome measures tapping these domains and also the confound of the behavioural management component, which may also impact on outcomes such as how the teacher responds to the child in the classroom.

Jones and Chronis-Tuscano (2008) aimed to address some of the limitations of Barbaresi and Olsen (1998) in a larger sample (142 American elementary school teachers) by using a randomised design and including a measure of behaviour (use of classroom management strategies). They allocated teachers to either a single-session training programme similar to that used by Barbaresi and Olsen (1998) or a wait-list control group. They found a significant increase in teachers' knowledge following the training compared to the wait-list group over the same period, giving increased confidence that the increase in knowledge about ADHD was not due to something other than the training programme. Use of classroom management strategies increased following the training for special education teachers but not regular classroom teachers. In addition, the teachers reported that they found the intervention helpful, applicable to them, and would recommend it to others. This was a somewhat more diverse sample than some other studies (57% Caucasian, 33% African American). It also suggests that it is possible to differentiate the 'active ingredients'

of such brief training programmes and to isolate the effects of educational versus behavioural management components with careful measurement. Some of the limitations regarding the two previous studies still apply, such as the lack of outcome measures of attitudes, actual behavioural and longer-term changes.

Labelling studies. Ghanizadeh, Fallahi and Akhondzadeh (2009) used the same paradigm as Jastrowki et al. (2007) to examine the impact of labelling with 550 Iranian primary school teachers. They found that providing a written label of ADHD had no impact on teachers' socially rejecting attitudes or beliefs about the potential benefit of treatment rated following the written vignette. However, the paradigm assumes prior knowledge about ADHD, which the participants may not have had (only one teacher reported receiving prior training on ADHD, and Iranian teachers' knowledge of ADHD has been rated as low in previous studies (Ghanizadeh, Bahredar & Moeini, 2006). Lack of control groups or pre-measures makes it hard to draw further conclusions about the reasons for the lack of impact of labelling as there was no comparison of attitudes towards students with ADHD versus students in general.

Cornett-Ruiz and Hendricks (1993) examined the impact of labelling and ADHD behaviours on peer and teacher judgements in a small sample of 39 teachers at three primary schools in the USA. They used the same design as for peer data described above, with the exception that a written explanation of ADHD diagnostic criteria was given instead of the more elaborate verbal explanation given to peers. They found that teachers who saw the ADHD behaviour condition rated the child more negatively in terms of expectations of everyday interactions, future success and on an

academic (essay) task. There was no impact of labelling. It may have been that too little information about ADHD was provided to teachers to alter their attitudes based on the behaviours they saw, or that the analogue design, or small sample size of teachers did not adequately tap the potential effects of labelling.

Stinnett, Crawford, Gillespie, Cruce and Langford (2001) examined the impact of providing a label of ADHD in a sample of 144 undergraduate students studying education ('pre-service teachers') in the USA. Participants read a written vignette describing a child with behavioural difficulties. The child either had a label of ADHD or no label, and was described as either taking medication (Ritalin) or being in a special educational placement. The child with the ADHD label was rated as having more attentional problems but fewer social problems than the child with no label. The child with a label in the Ritalin condition was rated as having more attentional problems than in the special education condition. These findings suggest that the label of ADHD may evoke negative expectations of increased attentional difficulties in the child, but reduce the extent to which the child's problems are labelled as social. The implications of this finding need to be investigated further, but it may be that a diagnostic label leads to a reduction in the extent to which the child is blamed or punished for their difficulties (since these may now attributed to the ADHD rather than conceptualised as behaviours under the child's control). A limitation of this study is that it uses pre-service teachers, so the extent to which the findings generalise to qualified, practising and more experienced teachers is unknown.

Koonce et al. (2004) used a similar methodology to the study by Stinnett et al. (2001) with a larger sample (259 American university students, 54% of whom were studying education). They compared the impact of labelling versus not labelling on attitudes towards a child with behavioural difficulties either shown on video, or described in a written vignette (or both). Participants who saw the video rated the child as having more social problems than those who read the written vignette. Labelling was not associated with ratings of attentional problems. The reason for this finding remains to be determined. A limitation of this study is that just under half of the sample of university students was not studying education, meaning that it may not be possible to generalise the findings to practising teachers. Nevertheless, the findings suggest that impact of video is greater than written information on evoking negative attitudes. This should be taken into account in future studies examining the impact of providing information or diagnostic labels on attitudes, and also when designing interventions to target negative attitudes.

Other approaches. Tymms and Merrell (2006) investigated the impact of sending a number of different types of information about ADHD to schools and local education authorities (LEAs) on outcomes for children with ADHD symptoms. They included a very large UK sample (over 70,000 pupils in 2040 schools) using a randomised design. Children underwent screening for ADHD characteristics in Reception year, at which time a baseline measure of their academic performance was obtained. Schools were sent one of the following: 1) names of children who scored highly on the ADHD rating scale and a description of the ADHD subtype associated with their score; 2) a book of advice of how to teach children with symptoms of ADHD; 3) both of the above; 4) neither of the above. In year two, follow up measures of the

children's academic performance, any ADHD diagnosis and management strategies were obtained. It was found that children with higher ADHD ratings made slower progress and had less positive attitudes towards school. There was a significant positive effect of providing the ADHD information book on attitudes towards school and on the children's behaviour. Providing the children's names in conjunction to the information book was associated with poorer academic performance for these children. There was no impact of providing information on the actions taken by teachers to help children with ADHD symptoms. There was no significant impact of any of the LEA level interventions.

This study provides some evidence for the use of providing educational information about ADHD directly to schools, whilst suggesting that labelling children or providing information to LEAs may be unhelpful. However, the findings were presented in a confusing, unclear fashion, which made it hard to draw conclusions. In addition, the study did not systematically measure whether there were any changes in teachers' attitudes or behaviours; the study reported that only 12.5% of Head Teachers who were sent the book said they used it. However it is not clear whether other staff used the information provided and in what manner, making it hard to understand the mechanisms by which providing information may have led to the reported outcomes.

Sayal, Owen, White, Merrell, Tymms and Taylor (2010) carried out a follow-up study of Tymms and Merrell (2006) five years later. They sent a questionnaire to the parents of a random sample of children with high or low baseline ADHD scores from a random sample of schools from the original study. They found that children who

were labelled as having ADHD in the original study were more than twice as likely to have high inattention/hyperactivity scores at follow-up compared to the group who received no intervention. There was no difference between the groups on how often children accessed specialist services. This suggests that a school-level screening programme whereby children with ADHD symptoms are identified early may be contraindicated. It may be that labelling the child could lead teachers to have negative expectations about the child's behaviour, and to treat the child in a way that increases their ADHD symptoms rather than helping them to access appropriate support. However, this conclusion is somewhat tentative due to a number of limitations of the study. For example, it utilised very different methodology to the original study, which may have influenced the ability to draw conclusions across the two. It also may have suffered from sampling bias due to the opt-in design. In addition, it does not shed any light on how the information provided in the original study was assimilated by teachers, or passed to parents, thus leaving the mechanisms resulting in change reported open to question. Nevertheless, Tymms and Merrell (2006) and Sayal et al. (2010) are the only investigators who have attempted to examine the effect of providing a diagnostic label/ educational information about the condition to other people on the individual with symptoms themselves. They also made use of longitudinal follow-up. These are important areas which are neglected across the other studies.

Ohan, Cormier, Hepp, Visser and Strain (2008) examined how prior knowledge of ADHD impacted on teachers' expectations and behavioural intentions; the study used written vignettes of children with ADHD in a sample of 140 Australian primary school teachers. The authors divided the participants into three groups based on their

responses on a true/false ADHD knowledge scale to indicate whether their prior knowledge of ADHD was 'high,' 'average' or 'low.' They found that teachers with high knowledge about ADHD were more likely to see a need for seeking professional assessment and a benefit of using classroom management strategies compared to the low knowledge group. Teachers with high or average knowledge were more likely to perceive the benefits of learning support and home-based behavioural interventions than the low knowledge group. They were also more likely to think that ADHD would have a significant impact on the child's behaviour in the classroom and with peers, and to feel less confident to manage the child's problems than the low knowledge group. Teachers with average knowledge were more likely to perceive a benefit to medication compared to the other groups. Like Barbaresi and Olsen (1998), the study also flagged up areas of strengths and misperceptions in teachers' knowledge about ADHD. For example, most teachers were aware of the different subtypes of ADHD and that its management requires a multi-modal approach. However, the majority also incorrectly assumed it could be caused by a poor diet and managed by dietary strategies. They were also often unsure of the trajectory into adolescence.

Overall, this study provides some evidence to support a role for educating teachers about ADHD, for example in preventing under-referral to specialist services, and supporting the use of appropriate management strategies. However, it also highlights the complexities of this approach, such as the need to increase teachers' belief in their ability to support children with ADHD alongside increasing their knowledge, and the need to target focus on correcting misperceptions around dietary management and enhancing knowledge of the developmental trajectory of the

condition. Limitations of the study are its correlational design and the predominantly white, female sample, which limits its generalisability. It also utilises a simple true/false measure of knowledge which may have allowed participants to guess the correct answers. Such simple measures also fail to provide detailed information about the impact of educating teachers about ADHD.

Summary of teacher education studies

There is some preliminary evidence which supports the role of educating teachers about ADHD in correcting misconceptions about the condition and fulfilling an unmet need of teachers in a range of both western and non-western countries. The research also suggests that simply providing a label without additional information is ineffective or even unhelpful to the child given the label.

It is pleasing to note that there are a number of studies examining the impact of ADHD information on relatively large samples of teachers in both Western and non-Western countries. However, different methodologies used across the ten studies and limitations of several of the studies make it hard to draw conclusions about the impact of educating teachers about ADHD. The literature appears to focus on the impact of education on teachers' knowledge about the condition and the effects of labelling on attitudes. The field would benefit from further well-designed studies (e.g. using randomised designs) examining the impact of providing educational information to teachers on their attitudes and actual behaviours towards children with ADHD. Further research also needs to consider the best way to provide information to teachers so that it avoids leading to potential negative outcomes based on labelling, corrects misconceptions and builds teachers' confidence in their ability to

support children with ADHD at school. It is particularly important for further investigation to be carried out in this area given that teachers are seen as a vital element in more comprehensive multi-modal treatments for ADHD.

Parent education studies

Only two studies examined the impact of providing parents with information (a number of studies were excluded because they examined providing information as part of a multi-component intervention). Both studies indicate that parental knowledge about ADHD may impact on enrolment in, and adherence to, both pharmacological and non-pharmacological treatments for the condition.

Corkum, Rimer, and Schachar (1999) examined the impact of parental knowledge about ADHD on enrolment and adherence over a 12-month treatment program in a sample of 81 parents of children newly diagnosed with ADHD in Canada. Parent knowledge and attitudes towards various treatments was measured prior to their child being diagnosed and prior to random allocation to either medication or placebo plus either a parent training group or parent-led parent support group (which did not include teaching of specific behavioural management strategies). Knowledge was measured again at the end of the program. Parents were more likely to enrol in both pharmacological and non-pharmacological treatments if they had a higher knowledge of ADHD and more positive view of medication. However, adherence rates were not related to baseline parental knowledge about ADHD or opinions of treatment. In addition, there was a significant increase in knowledge following the treatment, but no change in opinions of medication or parent support groups. There was a significant decrease in parents' opinion of their need for parent training, although

there was no significant difference in adherence rates between parent groups. This study suggests a complex interplay between knowledge, attitudes and behaviours that may be mediated and/or moderated by other variables such as psychological factors, the feasibility of and financial ability to comply with treatment programs. A strength of this study is that it attempts to investigate the impact of educating parents on participation in both pharmacological and non-pharmacological long-term treatment programs, which is of relevance to the real-life experiences of families.

Svanborg et al. (2009 a, b) investigated the impact of 10 weeks of drug treatment (Atomoxetine) combined with parental psychoeducation compared to placebo and psychoeducation. They studied a sample of 99 stimulant-naïve children and adolescents in Sweden using various outcome measures. They attributed the large effect size of the experimental condition and zero drop out rate compared with other Amoxetine-only trials to the interaction with parental psychoeducation (possibly due to enhanced treatment compliance). A number of considerations limit the conclusions that can be drawn from this study regarding the impact of parental psychoeducation as an intervention in its own right. Firstly, evaluating parental psychoeducation was not the main aim of the study and data on attendance of the training programme was not collected. The study also lacked 'placebo only' and 'psychoeducation only' control groups which may have added useful additional information with regards to the study's findings. The parental education programme also included behavioural management components, which may also have impacted on the outcome described.

Summary of parent education studies

There is some very preliminary evidence from two studies to suggest that providing educational information to parents may play a role in promoting enrolment in, and adherence to, a range of treatments for ADHD. Whilst both the studies examine the impact of parental education in real-life settings, the conclusions are limited by the small number of studies. Further research needs to examine this more systematically, as well as to consider other factors promoting or limiting enrolment and adherence. The lack of studies investigating the impact of providing information to parents is of concern, given that this practise underpins many of the more complex, multi-modal approaches (such as parent training) used in the management of ADHD.

Discussion

Key findings

This review identified 22 studies examining the impact of providing educational information (including providing a diagnostic label) about ADHD or TS on the attitudes, knowledge and behaviours of people other than those with the condition (i.e. parents, teachers and peers).

Eleven studies examined the impact of providing educational information, six examined the impact of providing a diagnostic label and four studies examined a combination of these (the remaining study examined the impact of pre-existing knowledge). Ten of the 22 studies examined the impact of providing educational information (or diagnostic label) about ADHD to teachers (or university students studying education). Nine studies examined providing educational information/diagnostic label regarding TS or ADHD to children (in four studies) or

adult peers (university students). One study involved both teachers and children. Only two studies examined the impact of providing educational information about ADHD to parents and no studies looked at this with regards to TS. The majority of studies reported mainly positive or mixed findings regarding the impact of providing educational information or diagnostic label. Only five studies had wholly negative findings.

The studies of TS and ADHD involving peers indicate that providing educational information can improve knowledge, attitudes and intended behaviours towards individuals with the condition (regardless of gender) in both adults and children. Providing a diagnostic label alone may reduce negative attitudes in university students but has not been shown to be effective as an intervention for child peers. It is unclear whether such changes are maintained over time or associated with changes in actual behaviours (the latter has only been found in one study).

Teacher studies of TS and ADHD show that brief training programmes about the conditions can successfully improve teachers' knowledge and correct misconceptions about the disorders. There is less evidence regarding the extent to which improvements in knowledge following training programmes are maintained over time (although two studies have reported favourably on this). Providing a diagnostic label generally appears to be unhelpful when teachers have little prior knowledge about the condition being labelled and/or additional educational information is not provided. There is some preliminary evidence that increasing teachers' knowledge may improve actual behaviours towards children with TS and ADHD, although the majority of studies did not investigate this systematically.

Only two studies examined the impact of educating parents. These studies suggest that providing educational information may help with pharmacological and non-pharmacological treatment enrolment or adherence. However, the studies also highlight that there may be other factors at play in determining treatment 'compliance' (including psychological variables, feasibility and financial issues). Further research needs to be conducted in this area, particularly as parental psychoeducation underpins many multi-component treatments for TS and ADHD which are described as evidence-based (MTA Cooperative Group, 1999; Verdellen et al., 2011; Young & Amarasinghe, 2010).

Fourteen of the studies provide some preliminary evidence regarding the best ways to provide information when targeting negative attitudes and behaviours. Six of the studies indicated that providing more detailed information is helpful in improving outcomes. Two studies indicated that information provided as video footage may be more salient than written information with regards to evoking negative attitudes. Three studies involving teachers suggested that there may be a complex interplay between the existing knowledge and the ability to alter behaviours towards children with ADHD in the classroom following educational programmes. Three studies indicated that altering the content of the educational information can alter outcome, for example, by targeting specific misconceptions about ADHD, altering the way the individual with the disorder is described, or including personal accounts of having the disorder to increase the salience of related factual information. Further research should begin to systematically investigate these effects more fully, with a view to developing the most effective intervention programmes.

The studies with negative findings involved children and teachers and suggest that providing a diagnostic label of TS or ADHD can fail to change attitudes or intended behaviours (in four studies) or lead to negative outcomes for the individual with the condition (in one study). Comparison with the studies showing positive findings suggests that it is more helpful to provide more detailed educational information (rather than a diagnostic label alone) when aiming to change attitudes towards individuals with TS or ADHD, especially when aiming to ensure there are not negative outcomes associated with disclosure for the individual involved.

Methodological strengths and limitations

Nineteen out of the 22 studies used a randomised design to allocate participants to conditions (of the remaining three studies, two did not use a control group and one utilised a correlational design), which reduces sources of variability. In addition, the majority of studies also used relatively large samples of participants (nine studies involved 100-200 participants and a further seven had samples of over 200 participants), which increases the power. Since the majority of the studies are well designed in these respects, it increases confidence in the overall conclusions that are drawn from this body of literature. Nevertheless, there are some limitations to the studies that need to be borne in mind when drawing conclusions, which are discussed below.

Sampling

Twenty of the 22 studies involved Western, predominantly Caucasian samples (14 of the studies took place in the USA). In addition, seven of the studies used university

students as participants. These characteristics of the samples may limit the extent to which the conclusions of this review generalise to the general population (which includes non-Western, non-Caucasian and non-university educated samples) since background is known to influence attitudes towards a range of variables including an ADHD label (Koonce et al., 2004; Stinnett et al., 2001). It remains open to question the degree to which university students studying predominantly Psychology or Education are similar to the peers or teachers (respectively) of those with TS or ADHD. Nevertheless, the two studies including non-Western samples in local schools in Pakistan and Iran mirror the Western literature in some respects and hence provide preliminary evidence for the applicability of the findings to different populations. Unfortunately, it was not possible to include articles published in languages other than English in this review, which may have excluded other relevant articles involving non-western samples.

Eight out of the 11 studies involving teachers used a predominantly female sample (defined as >60% of the sample being female). The remaining three studies involving teachers did not specify the gender mix but might be assumed to be predominantly female as well. A study involving more male teachers might help to establish whether the findings from studies involving predominantly female teachers generalise across all teachers. Whilst five peer studies had an approximately equal gender mix (40-60% female), four samples were predominantly female. Future studies should ensure samples are balanced in terms of gender to reduce the potential influence of gender on outcome and increase confidence in applying the findings to the general population. Both parent studies predominantly involved mothers of male

children with ADHD. It remains to be established whether the preliminary findings from these studies also apply to fathers or other carers and girls with ADHD.

Measurement

There were also a number of limitations to the types of measures used in the studies. Researchers often used examiner-derived or modified outcome measures designed specifically for that study, making it harder to draw comparisons or interpret differences in findings between studies. Fifteen of the studies used self-report measures of attitudes or behavioural intentions towards individuals with TS or ADHD, which are subject to social desirability effects (Paulhus, 1991). Eight studies used measures of knowledge about the conditions. Half of these were true/false knowledge measures, which may not be the best way to examine knowledge (since participants who do not know the answer have a 50% chance of responding correctly). None of the studies made use of any qualitative approaches in addition to quantitative outcome measures, which may provide a greater level of detail about the impact of providing information about TS or ADHD to people other than those with the condition. In addition, the findings of many of the studies, whilst statistically significant, represent small actual changes in scores on the measures. It remains to be determined whether these changes represent clinically meaningful changes. Only four of the studies used any form of longitudinal follow-up measure (over six months after the start of the study) so the stability over time of the findings from the other studies still remains to be established.

Nine studies attempted to overcome some limitations of simple, self report questionnaire measures by trying to capture actual behaviours/outcome in a real

world setting in the following ways: Two studies looked at the outcome of educating teachers on the academic performance of children with ADHD symptoms over several years. One study asked about teachers' use of classroom management strategies. Two studies examined the impact of parental education on pharmacological or non-pharmacological treatment adherence. One study examined how teachers and peers rated a child with ADHD on an essay task. Three studies by the same research team (Woods, 2002; Woods et al., 2003; Woods & Marcks, 2005) measured how far participants placed the chairs when preparing a room in which to meet a person with TS. The range of methodologies used by these studies (some of a rather artificial nature) and failure to establish the reliability and validity of the measures (as in the case of Woods and colleagues) are limitations which make it harder to draw conclusions. Nevertheless, it is important to consider whether providing educational information leads to behavioural change and better outcomes for people with the conditions in the real world when designing interventions. Overall, these studies' mixed results echo the findings of the other studies. They suggest that providing sufficient educational information may lead to positive behavioural outcomes in a way that providing a diagnostic label alone may not.

Design

In some studies (six teacher studies and two parent studies), there was a small element of behavioural modification training as well as an educational component, making it hard to draw conclusions about the impact of the latter in isolation. Fourteen studies used artificial, laboratory paradigms (written vignettes or video footage) rather than examining the process of information giving as it occurs in the real world. The majority of studies (20 out of 22) also failed to specifically address

the comorbidity that occurs between conditions in TS and ADHD, or the range of severity within the conditions, thus reducing the ecological validity of the findings.

Clinical implications

It is encouraging to find evidence that providing educational information is useful in improving negative attitudes and behaviours towards those with TS and ADHD. Such an evidence-base may encourage clinicians to suggest that individuals with TS or ADHD (and their families) tell peers and teachers about their condition, and individuals considering doing so to proceed. It also underscores the importance of designing interventions at both systemic and individual levels (i.e. which target the reactions of others towards individuals with TS and ADHD as well as reduce the symptoms themselves). A further challenge is to disseminate the findings of this review in a way that will be useful to individuals with the disorder, their families, teachers and clinicians.

The findings suggest it is important to provide sufficient disorder-specific information in conjunction with any diagnostic label to correct misconceptions and promote positive attitudes towards the labelled individual. This needs to be taken into account in any situation involving disclosure of an individual's TS or ADHD to others. The research also suggests that the way information is presented may be important. It will be useful to consider including video footage and personalised accounts when designing future educational interventions.

As noted above, many widely used, multi-component interventions for TS and ADHD are underpinned by parental psychoeducation. The lack of research

investigating stand-alone parental educational should be considered by clinicians implementing these ‘evidence-based’ interventions.

Suggestions for future research

More systematic research needs to take place into the impact of providing educational information to parents, teachers and peers. This should incorporate large, ethnically-diverse samples, randomised designs, standardised outcome measures of actual behaviour as well as knowledge and attitudes, and following up outcomes over time. Investigation using both qualitative and quantitative methods in real life settings would also provide invaluable additional information regarding the process of information giving as it occurs in the real world. It is also necessary to take into account the comorbidity of disorders, and the variety of symptom presentation when designing studies that reflect the experiences of those with the disorders. Studies to date have also failed to take into account the perspective of people with the condition when considering the impact of providing educational information, which should be addressed in future studies.

Conclusions

This review examined the body of literature investigating the effects of providing educational information about, or a diagnostic label of, TS or ADHD to the parents, teachers and peers of those with the conditions. The review provides preliminary evidence for the usefulness of providing educational information in improving knowledge and attitudes of other people towards those with the condition. It appears that diagnostic labels in isolation are not helpful. However, there remain gaps in the literature and unanswered questions, particularly with regards to the optimal way to

present information, the impact on parents and on actual behaviours towards the person with the condition, the experience of the individual with the disorder, and the process as it occurs in the real world.

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Part 2: Empirical Paper

An evaluation of a classroom presentation about
Tourette Syndrome

Abstract

Aims

This study examined the impact of a psychosocial intervention (a classroom presentation) for Tourette Syndrome (TS) in a naturalistic setting from multiple perspectives. It aimed to determine how children with TS, their parents, teachers and classmates experienced the presentation, particularly in relation to the child's peer relationships, and whether classmates' knowledge and attitudes about TS changed following the presentation.

Method

The study used a multiple case-study design with four sets of participants. It used primarily qualitative methods (interviews and focus groups) as well as questionnaires to assess change pre- to post- intervention.

Results

Thematic analysis yielded six themes. Three related to the impact on classmates – 'enabling prosocial behaviours'. Three related to the impact on the child – 'embracing having TS'. The questionnaires showed significant increases in knowledge and positive attitudes across all four schools (except for the attitudes of classmates in school three) from pre- to post-intervention.

Conclusions

The participants in this study gave positive accounts of a classroom presentation aimed at educating school children about TS. Improvements were noted in classmates' knowledge and attitudes towards TS as well as in the self-concept of the child with TS. It will be important to continue to carry out research in this area and encourage the use of such presentations across the age range outside of a research context.

Introduction

Psychosocial impact of Tourette Syndrome

Young people with Tourette Syndrome (TS)- a condition characterised by multiple motor and vocal tics which start in middle childhood and peak in severity at 10-12 years of age- are found to have poor quality of life when compared to the general population (Bernard et al., 2009; Cutler, Murphy, Gilmore & Heyman, 2009; Storch et al., 2007b). Social, emotional and school/occupational functioning is generally more impaired than physical functioning. Both tic severity and commonly occurring comorbid difficulties such as attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive behaviours/disorder (OCB/D) contribute a significant proportion of the variance in quality of life (Cutler et al., 2009; Storch et al., 2007b).

Increased attention has been paid to the adverse impact of having TS on young people's social functioning. The characteristics of TS mean that it is often stigmatised and misunderstood (Christie & Jassi, 2002). Children and adolescents with TS report that they struggle to fit in with society's expectations of normal behaviour and rate social isolation and embarrassment as equally disabling as the tics themselves (Cutler et al., 2009; Wand, Matazow, Shady, Furer & Staley, 1993). They may try hard to suppress their tics although this is only possible for short periods of time (Christie & Jassi, 2002). Young people with tics have been found to be rated less favourably and as less socially acceptable than those without tics in studies using laboratory-based paradigms with video footage (Boujouk, Woods, Miltenberger & Long, 2000; Friedrich, Morgan & Devine, 1996).

Peer relationships appear to be particularly problematic for children and adolescents with TS. In a study of classmates' attitudes towards a peer with TS, 35% of a sample of children with TS received the poorest ratings in their class by peers for withdrawal, aggression and/or likeability (Stokes, Bawden, Camfield, Backman & Dooley, 1991). Those with additional problems such as ADHD were at particular risk of poor ratings (Bawden, Stokes, Camfield, Camfield & Salisbury, 1998). Individuals with TS also report high rates of 'teasing', bullying or victimization by peers (Jagger et al., 1982; Shady, Fulton & Champion, 1988; Storch et al., 2007a). It appears that children have more difficulties with relationships within their wider social network (such as with their classmates) than with sustaining close friendships (Culter et al., 2009). These difficulties with peer relationships may persist into adulthood (Champion, Fulton & Shady, 1988).

Psychoeducational approaches in TS

The childhood onset and peak severity of TS mean that interventions regarding the child's tics are often required at this time. There are pharmacological treatments for tics, which can help to reduce their severity (Woods, Conelea & Himle, 2010). However, it is not the treatment of choice for all sufferers; some do not find medication reduces the symptoms, cannot tolerate the side-effects or do not wish to take medication long-term (Woods et al., 2010). There are also evidence-based psychological treatments aimed at tic reduction such as 'Habit Reversal Training' (Piacentini et al., 2010; Piacentini & Chang, 2006), which combine psychoeducational information and behavioural modification techniques. However, it has been found that lack of knowledge about these treatments, concerns about side effects and lack of knowledgeable treatment providers limit the utilisation of these

treatments (Woods et al., 2010). Comorbid conditions may also be the target for pharmacological and non-pharmacological treatments (NICE, 2008).

The clinical literature is replete with un-researched recommendations for interventions that aim to modify the child's environment to reduce both tics and additional difficulties (Conelea & Woods, 2008; Packer, 2005; Wilson & Shrimpton, 2003). Based on clinical anecdote rather than research evidence, it is commonly asserted that psychoeducational approaches for the child and those in their environment (such as family members, teachers and other professionals) are crucial in targeting misunderstanding and stigma so that the child can access the support they require (Kepley & Conners, 2007; Stern, Burza & Robertson, 2005). In addition, there is particular emphasis on educating peers regarding TS given the social difficulties outlined above.

Psychoeducational approaches for peers can take different forms. A leading support and research charity for people with TS and their families in the UK recommends an educational classroom presentation which is freely available on their website. This is a presentation designed for the classmates of the child with TS, describing factual information about the disorder. Despite such recommendations for psychoeducational approaches in clinical settings, there has been little research into the extent to which presentations have been used or their effectiveness, which is at odds with the current climate of 'evidence-based practice' (Darzi, 2008). Furthermore, some children (or their parents or teachers) may be reluctant to tell others about the condition; the prevalence or implications of such non-disclosure has also yet to be formally examined. Since TS is estimated to affect around 1% of

school-aged children (5-18 year olds) in the UK, a large number of children stand to benefit from further research in this area.

A small number of studies have examined the effects of interventions aimed at changing attitudes (defined as evaluations comprised of cognitive, affective and behavioural components, or beliefs, feelings/emotions and intended behaviours) of peers to TS using experimental paradigms (Friedrich et al., 1996; Holtz & Tessman, 2007; Marcks, Berlin, Woods & Davies, 2007; Woods, 2002; Woods, Koch and Miltenberger, 2003; Woods & Marcks, 2005). These have yielded somewhat mixed findings. The majority of studies have found that provision of information about TS leads to more positive attitudes towards individuals with the condition in both adults and children. In the only study (Friedrich et al., 1996) that failed to find this relationship, the intervention may have provided insufficient information about TS to lead to attitude change. In contrast to change in attitudes, the studies provide less evidence that information about TS leads to changes in behaviour towards the person with TS. Strengths of these studies include the use of randomized experimental designs, large samples (112-369 participants) and multiple outcome measures. However, the studies have a number of limitations; they did not examine the effects of interventions from the perspective of the individual with TS, measure actual behavioural change adequately, or follow up the participants to examine whether changes were maintained over the longer term. It may also be questioned how far the attitudes of predominantly white, American psychology undergraduate students elicited using artificial/ laboratory-based paradigms may apply to the peer groups of people with TS more generally.

Although research in TS is limited, the broader literature on interventions for changing attitudes suggests that negative attitudes of peers towards a range of conditions such as physical disability, diabetes, cystic fibrosis, HIV, and ADHD can be changed by disclosure or provision of factual information (Berlin, Sass, Davies & Hains, 2002; Berlin, Sass, Davies, Jandrisevits & Hains, 2005; Jastrowski, Berlin, Sato & Davies, 2007; Odom et al., 1999; Wiener & Battles, 2006). Since knowledge and beliefs form the basis of attitudes, which to some extent predict behaviour (Ajzen, 1980; Favazza, Phillipson & Kumar, 2000), it is important to study the attitudes and/or behaviours of peers to a child with TS as a way of determining the effectiveness of interventions aimed at improving peer relationships.

Aims of the study

The current study aimed to examine the impact of a psychosocial/educational intervention for TS (a classroom presentation) as it occurred in a naturalistic setting. The study examined the intervention from the perspectives of both those involved in planning and giving the presentation (the child, their parent(s) and teacher) and those hearing it (the child's classmates). It used a multiple case study design with primarily qualitative methods as this approach is appropriate for examining under-researched areas and can provide a detailed description from the perspective of the participants (Barker, Pistrang & Elliott, 2002).

The study addressed the following research questions:

1. How do children with TS, their parents, teachers and classmates experience the classroom presentation, particularly in relation to the potential impact on the child's peer relationships?

2. Do the child's classmates report greater knowledge about TS and more positive attitudes towards a child with TS following the presentation?

Methods

Overview

The study involved investigation of the effects of an intervention (a classroom presentation about TS) in a small sample of participants using a mixed-methods, multiple case study design. It used primarily qualitative methods (interview and focus groups) combined with some quantitative measures (questionnaires) to examine the impact of the presentation from the perspectives of all those involved (the child, their parent, teacher and classmates).

The intervention

The intervention comprised a presentation produced by 'Tourettes Action', a UK TS charity (through which participants were also recruited). Permission to use the presentation was obtained from the charity prior to the start of the study. It is a computer-based, slide presentation aimed at primary school aged children, containing factual information about TS produced in an age-appropriate way. For example, it describes what TS is, how common it is, and how to act towards children with the disorder. The presentation is freely available from the charity's website (<http://www.tourettes-action.org.uk/ts-presentations/>). It takes about 15-20 minutes to present (including time for questions and discussion). Suitable individuals to give the presentation to the class include the teacher, who was asked to give the presentation in the current study.

Recruitment

Participants were recruited via Tourettes Action between March 2010 and January 2011. An advert was placed on the website, included in two of the monthly newsletters and emailed to all members of the charity (primarily parents of children with TS, and individuals with the disorder). A request for participants was also made when the researcher presented the project's aims and method at the charity's annual members' conference. Parents of children with TS who were interested in taking part were invited to contact the researcher.

Once a parent contacted the researcher, an initial telephone call and/or email was used to establish whether their child met criteria for inclusion (see below). If so, the parent was provided with information sheets for themselves, their child and the child's teacher (see Appendices 2-4) and asked to contact the school to see if they would allow the study to go ahead and if the teacher would be interested in taking part. If this was met with a positive response, the researcher then contacted the teacher directly to set up the rest of the project.

Participants

Inclusion criteria

Children aged 9-11 years with a diagnosis of TS in mainstream primary school (and their parents, teachers and classmates) were eligible to take part in the study. Both boys and girls were eligible, but given that TS affects over three times more boys than girls (Freeman et al., 2000) it was expected that most of the participants with TS would be boys. Exclusion criteria for the child with TS were non-fluent English, generalised learning difficulties, a diagnosis of Autistic Spectrum Disorder, or severe

emotional/behavioural difficulties (which would prevent participation in the project). Children were also excluded if a presentation about TS had been given at school within the previous school year. There were no exclusion criteria for parents or teachers. Classmates were excluded if the teacher felt they would be unable to complete the questionnaires or participate in a discussion group lasting up to 20 minutes led by a single adult.

The aim of the study was to recruit four children in line with the multiple case study design. In total, the parents of 26 children with TS expressed an interest in participating. Of these, 22 children did not meet the study criteria or could not be included for other reasons: six were too old/ in secondary school; four were too young; four were excluded as their teacher had given a presentation within the last year; five were not included as assent/consent could not be obtained from either the child, parent or school; and three were not included as sufficient participants had already been recruited.

Characteristics of participants

All four children with TS were boys with a mean age of 9 years, 7 months (range 9 years to 10 years, 7 months). Three were of White British origin and one was of mixed ethnicity. Three of the children were in year 5 (one was in year four) and three lived with both parents (one lived with his mother).

Three of the four children were diagnosed with TS plus comorbid ADHD and OCD, or traits of these, whilst one child had 'pure' TS, reflecting the characteristics of the population of children with TS as a whole. Parental report indicated that the child

with pure TS had fewer, milder tics than the children with TS and comorbid difficulties. Parents reported that TS had a significant impact on their child's life, particularly for those children with TS plus comorbid conditions. Using the Paediatric Quality of Life Inventory (Varni Seid & Rode, 1999; described in the 'quantitative measures' section below) quality of life was rated as significantly poorer than a normative sample, particularly in the psychosocial domain (comprising emotional, social and school functioning). All the children's total and psychosocial scores fell at least one standard deviation below the mean of a normative sample. Two of the children (including the child with pure TS) were rated by their parents as having better physical functioning, within one standard deviation of the normative mean. One child had one-to-one support at school from a teaching assistant (TA) for emotional and behavioural difficulties associated with his TS and comorbid difficulties. (The TA was also interviewed as part of the research project).

Four mothers and one father took part in the project. The teachers were all female and White British. A total of 113 classmates out of 116 took part in the project (58 girls and 55 boys) with a mean age of 9 years, 2 months. The parents of two classmates did not consent for them to take part and one classmate was away during both the presentation and follow up.

Ethical approval

University College London Research Ethics Committee granted ethical approval for this study (see Appendix 1). Given that the study involved an intervention at a child's school, particular care was paid to ensuring informed consent/ assent from all parties involved (the parent, child, teacher, classmates and their parents, see

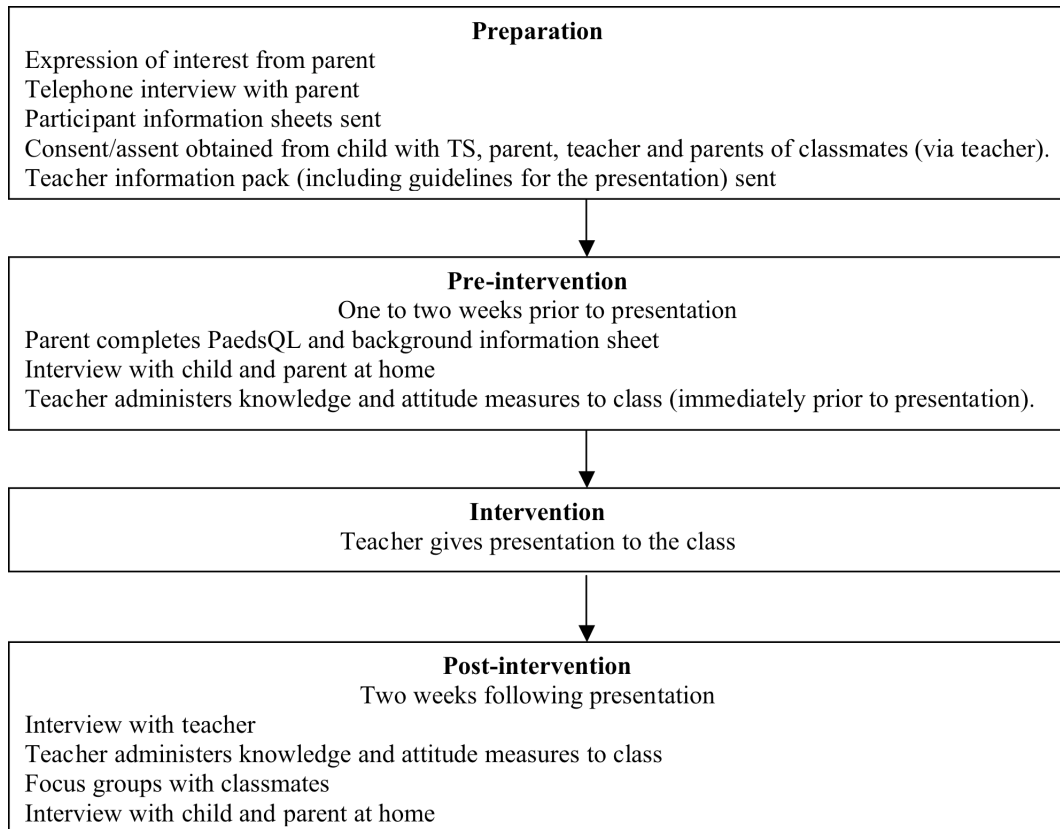
Appendices 2-8). In addition, the intervention was tailored to the wishes of the child (whether they wanted to disclose that they had TS during the presentation or not).

Procedures

The study involved a number of stages: a preparatory (recruitment) stage, a pre-presentation stage, a presentation (intervention) stage, and a post-presentation stage. The procedure is summarised in Figure 1. Approximately two weeks prior to the presentation, an initial interview was conducted with the child with TS and their parent at their home. Demographic information to characterise the sample was collected at this point and opt-out forms were sent by the teacher to classmates' parents. Two weeks later, the presentation was conducted at school; the classmates completed questionnaires immediately prior to the presentation. Two weeks after the presentation, the classmates completed the questionnaires again (in class), then took part in focus groups, and the teacher was interviewed. A follow-up interview was then conducted with the child and parent together at home. All interviews and focus groups were audio-recorded.

Figure 1

Steps involved in the research project



The intervention

The presentation was delivered by the class teacher. The children with TS were asked if and how they wished to contribute; three children chose to let their classmates know during the presentation that they had TS, and then answered some questions about this in the discussion that followed. Guidance for teachers on how to deliver the presentation was provided as part of a preparatory ‘teacher’s pack’ developed for the study (see Appendix 9). The aim was to ensure a degree of uniformity between interventions, whilst also allowing teachers to adapt the format to suit their own teaching style and the needs of their class. The pack included a sample introduction and additional background information to help teachers answer any questions classmates might have. The researcher was present in the classroom

during the presentation to support the teacher to answer questions and to help the class to complete the questionnaires correctly. This also provided an opportunity to observe how teachers made use of the presentations and guidelines, and how the presentation was received in a naturalistic setting.

Interviews and focus groups

Semi-structured interview schedules were developed for the interviews and focus groups based on discussion with the other members of the research team regarding the key areas to ask about in order to answer the research questions. The interview schedules were amended following 'piloting' with the first set of participants to include additional questions thought to be relevant. The final versions of the interview schedules are included in Appendices 10-13. The semi-structured format of the interviews allowed flexibility in how the questions were asked. It provided an opportunity for the interviewee to provide information not asked for directly, and for the interviewer to follow up on the information given, to gain in depth understanding of the interviewee's perspective.

Interviews were conducted with the child and parent together to ensure the child felt comfortable with the interview process and to enable the child and parent to expand and elaborate answers in response to each other's comments. The aim of the pre-presentation interview was to obtain the views of the child and their parent on the child's peer relationships and their expectations regarding what the presentation would achieve. The aim of the post-presentation interview was to obtain their views about the process and impact of the presentation, in particular whether there had been any changes in the child's peer relationships and how they found the experience of

the presentation. The aim of the teacher interview, conducted following the presentation, was to gain an understanding of how the presentation went and the impact on the child's peer relationships from another perspective. This was considered important because different perspectives are often neglected in the literature despite yielding useful additional information (Bawden et al., 1998).

Focus groups were conducted with classmates by dividing each class into 3-4 groups. The aim of the focus groups was to obtain the classmates' reactions to hearing the presentation and any changes in their knowledge about TS, or attitudes and intended behaviours towards a child with TS. The defining feature of focus groups, which distinguishes them from one-to-one interviews, is the interaction between the participants (Kitzinger, 1995; Wilkinson, 2003). The researcher acts to facilitate discussion between participants rather than asking questions to each participant in turn. The range of communicative processes this brings forth (including storytelling, joking, arguing, boasting, teasing, persuasion, challenge and agreement) is used to further understanding of the research topic from the participants' point of view. For example, it may help people explore and clarify views that may be less accessible in a one-to-one interview. Focus groups are a suitable method for addressing sensitive topics and the group context can be useful in facilitating personal disclosures (Farquar, 1999). This format has been suggested to help young people express their opinions without feeling that there is pressure from a more powerful adult to conform to a certain view (Cutler et al., 2009).

Thirteen focus groups were conducted with a total of 100 children (52 girls, 48 boys). Eight of the focus groups were conducted with 8 children each; the remaining

five groups were conducted with six, seven or nine children each. Thirteen children were excluded from the focus groups. In the majority of cases (n=8) this was because they were absent when the presentation or follow up took place. In one school, three classmates were unable to take part in the focus groups due to other school commitments. In another school, two children were excluded due to social communication/ behavioural difficulties.

Quantitative measures

Two questionnaires tapping classmates' attitudes and knowledge about TS were developed for the current study based on previous research in this area, and consultation with colleagues with relevant expertise. The questionnaires were administered on two occasions, once prior to the presentation and then again two weeks later. The Paediatric Quality of Life Inventory (PedsQL; Varni et al., 1999) was also completed by parents of the child with TS prior to the first interview, for descriptive purposes only.

'Attitudes about TS' measure

This 12-item questionnaire ('What I think about other people,' see Appendix 14) examined classmates' attitudes and intended behaviours towards 'John' a hypothetical child with unusual habits (tics) described in a written vignette at the start of the questionnaire. Classmates were asked to decide whether a given statement (such as 'I would stick up for John if he was being teased') was 'not true', 'somewhat true' or 'really true' for them. The items used were modified from the CATCH (Chedoke-McMaster Attitudes Towards Children with Handicaps Questionnaire; Rosenbaum, Armstrong & King, 1986) a 36-item measure used in a

previous study on children's attitudes towards TS (Holtz & Tessman, 2007). Four items were selected from each of the three domains of the CATCH (affective, behavioural and cognitive) to capture the multidimensional nature of attitudes (see 'introduction'). Items were chosen that showed reasonable factor loadings in the original study, whilst being different enough from each other to avoid redundancy, and which were felt to be of relevance to children in UK primary schools today. The items were modified to ensure the language was age-appropriate and in line with current terminology and that there was an equal number of positively and negatively-worded items, which were then ordered randomly to produce the final questionnaire. The five-item forced choice format of the CATCH was reduced to three-items, as used in other well-validated, age-appropriate measures such as the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The rationale for inclusion of the vignette was so that classmates would have a reference point in the baseline (pre-presentation) condition.

The internal consistency of the attitude measure was calculated using Cronbach's alpha on both pre- and post- intervention scores. The full scale showed good reliability overall ($\alpha=0.77$ pre and $\alpha=0.82$ post-intervention). The reliability of the individual affective, behavioural and cognitive subscales was poorer (ranging from $\alpha=0.58$ to 0.72) and therefore only the full range scale was used in the data analysis. Possible scores on the full scale range from 0-24, with higher scores indicating more positive attitudes.

'Knowledge about TS' measure

This 9-item questionnaire ('What I know about Tourette syndrome' see Appendix 15) measured classmates' knowledge about TS using a three-item response choice format. Classmates were asked to respond to a given statement (such as 'about 1 in 100 school children in England has Tourette Syndrome') by selecting 'not true', 'true' or 'don't know'. The content of the questionnaire was based on the content of the TS presentation (as used by Holtz & Tessman, 2007). The 'don't know' response option was included to reduce the likelihood of classmates answering correctly by guessing. Items were worded so that there were equal numbers of correct and incorrect facts, which were ordered randomly in the final version of the questionnaire. The internal consistency of the knowledge measure was not calculated as it was not expected that the items should necessarily 'hang together' as classmates might know some facts and not others. Possible scores ranged from 0-9 correct items, with higher scores indicating greater knowledge.

Administering the measures

Questionnaires were completed in a group format (the teacher read aloud each item and then instructed the classmates to select their individual response). It took about 10 minutes to complete both questionnaires. The questionnaires were presented in the same order to all participants (attitude measure then knowledge measure) as it was felt this would reduce the likelihood that the participants' baseline (pre-presentation) responses to the attitude measure would be influenced by association of the vignette with the label of TS.

Information about the child's TS and quality of life

Information on the child's TS (tic severity, characteristics, and comorbid diagnoses) was obtained informally via telephone interview with the child's parent prior to the study. Parents also completed the Paediatric Quality of Life Inventory (PedsQL; Varni et al., 1999) UK parent report version for children aged 8-12 years, prior to the first interview. This 23-item measure gives an indication of the child's quality of life in four domains (physical, emotional, social and school functioning). Parents rate each item (such as 'getting on with other children') on a four-point scale to indicate how much of a problem the item is for the child. All items are reversed scored so that higher scores indicate better quality of life.

Researcher's perspective

My interest in TS started when I was an assistant psychologist working at a leading national children's hospital. A colleague (subsequently the external supervisor on this project) provided psychology input to the TS clinic there and I attended several of the monthly clinics as a learning experience. I was struck by how the children with TS and their families encountered difficulties in getting other people (such as those at school) to understand the disorder, but also showed many strengths and resources in doing so. I was keen to explore this further in a research setting, especially due to the paucity of research in this field.

Due to my growing interest in this area, I co-facilitated a children's TS group, giving me some experiences of running groups with children of this age, and also talking to children with TS about their experiences. I gained experience of working with

teachers during my child placement and of interviewing adults during a number of my placements during clinical psychology training.

As a result of both reviewing the existing literature and my clinical experiences, I had some preconceptions that educating other people about TS is helpful in reducing negative attitudes towards the child with the disorder. This drove the current project (since ethical approval would not have been possible without some degree of certainty in this attitude) but also may have introduced some bias in the questions I asked to participants, although I tried to remain open-minded as far as possible when collecting and analysing data.

Data analysis

Qualitative

All interviews were transcribed verbatim by the researcher, and then analyzed using a thematic analysis approach (Braun & Clarke, 2006). In accordance with this method, a series of steps were followed; however, the approach was tailored to take into account the complex nature of the data set, which involved multiple perspectives and two time points. In describing the procedures of analysis, the term 'participant set' is used to refer to a unit composed of a child with TS, their parent, teacher and classmates. (For example, 'participant set one' refers to the first child with TS who took part in the project, their parent, teacher and classmates). The steps were as follows:

1. The transcript of the pre-intervention child/parent interview from the first participant set was read through several times. The left-hand margin was used to annotate the text when interesting or significant points were made by the

participants. These were cross-referenced where appropriate. A summary of tentative codes was written as a separate document.

2. Once the whole transcript had been read in this way, the process was repeated for the follow-up interviews (child/ parent and teacher) and focus groups.
3. Steps one and two were then repeated for participant sets two, three and four in turn.
4. Once all the data had been examined in this way, the summaries were reviewed to identify tentative domains regarding the outcome of the presentation (the child's self concept, classmates' attitudes/reactions, peer relationships/interactions). Other relevant information regarding the process of giving the presentation was noted (see 'context and background' below).
5. The interviews and focus groups were then re-read (in the same order as in steps one and two) with the domains in mind and tentative themes relating to each domain were noted in the right hand margin. Additional themes not captured by the headings above were also noted.
6. The emerging themes were listed by domain, and similar ideas were clustered together. Links to the original text were maintained by noting which interviews the themes were identified in.
7. The process was then repeated as in step three, looking for themes which were both similar and different to those from the first participant set.
8. Finally, the sets of themes were combined across perspective and participant set to produce the final super-ordinate themes discussed here.

An example of steps 1 and 5 of the analysis of participant set four is shown in Appendix 16.

Credibility checks

Credibility checks were carried out to increase confidence in the analysis (Barker & Pistrang, 2005). A second member of the research team reviewed the analysis of all the transcripts from one participant set and engaged in an extended discussion with the primary researcher about theme labels and ways of coding. In addition, triangulation was inherent in the study design, which incorporated multiple perspectives and quantitative and qualitative measures (Olsen, 2004). Perspectives were contrasted or integrated and the qualitative data were compared to those from the questionnaires.

There was overlap between the themes from different perspectives and across participant sets, which suggested that some level of saturation had been reached (Bowen, 2008). The themes that emerged did reflect the questions on the interview and focus group schedules to some extent, but they tended to focus on some areas (such as the impact on the child with TS) more than others. In addition, some themes emerged which were not asked about directly in detail (such as classmates' enthusiasm for the presentation).

Quantitative

A power analysis was conducted to establish the sample size needed for the pre and post knowledge and attitude questionnaires. Holtz and Tessman (2007) used t-tests to examine changes on knowledge and attitude measures with school children following an educational video about TS. However, it was not possible to use their prior work to inform the current study, as they did not provide the effect sizes for their findings. Therefore, a medium to large effect size (0.5-0.8) was assumed. Given that

classmates came from four different schools, a nested design was chosen to establish the number of participants needed per class. Setting power at 0.8 and alpha at 0.05, the power analysis indicated that a sample size of 15 participants per class was needed to detect a large effect and 34 participants per class to detect a medium effect.

The attitude and knowledge data were analysed using SPSS version 17.0. To answer the second research question of the study (whether classmates report greater knowledge about TS and more positive attitudes towards a child with TS following the presentation) paired-sample t-tests were used to examine the change in knowledge and attitude scores following the intervention. In total, quantitative data on 113 classmates was collected (see section on 'participants' above). The data from 15 children with incomplete data sets were excluded: nine had not completed both pre and post measures due to being absent at one time point; one was unable to complete the questionnaires due to social communication difficulties; and a further five participants (from across all four schools) had either missed items or selected two responses to a single item. Consequently, data from 98 children were included in the analysis. There were no differences between the schools in the ratio of boys to girls (determined using chi-squared tests).

Results

The data from the questionnaire measures are presented first, followed by the data from the interviews and focus groups, based on the rationale that the quantitative data provides a context for the qualitative data, which is more expansive.

Quantitative change in classmates' knowledge and attitudes

The assumptions for parametric tests were met for both the knowledge and attitude variables across the four schools individually with one exception; the change in attitude score of school three was negatively skewed and showed positive kurtosis. The data for all four schools together was negatively skewed for both variables. For non-normal data, the findings were robust across both parametric tests and their non-parametric equivalents. There were no correlations between knowledge and attitude scores except in school three, where pre-intervention knowledge was negatively correlated with pre-intervention attitude score ($r=-0.38$, $p=0.04$); that is, greater knowledge was associated with less positive attitudes.

Classmates' knowledge and attitudes about TS improved pre- to post- intervention across all four schools and in each school individually, except for the classmates in school three, who showed no change in attitudes (see Table 1).

Table 1

Change in classmates' knowledge and attitude scores pre to post intervention

| School | Mean knowledge score ^a (SD) | | | | Mean attitude score ^b (SD) | | | |
|-------------|--|-----------|-----------|--------|---------------------------------------|------------|----------|--------|
| | Pre | Post | t (df) | p | Pre | Post | t (df) | p |
| 1 | 3.4 (2.6) | 8.1 (1.3) | 9.4 (20) | <0.001 | 14.8 (3.0) | 17.3 (3.6) | 4.1 (20) | 0.001 |
| 2 | 5.6 (1.6) | 8.1 (1.1) | 6.9 (21) | <0.001 | 16.9 (4.8) | 18.6 (4.5) | 4.8 (21) | <0.001 |
| 3 | 2.2 (2.1) | 5.6 (2.4) | 8.6 (30) | <0.001 | 15.5 (5.0) | 15.9 (5.4) | 0.5 (30) | 0.627 |
| 4 | 3.9 (2.3) | 6.8 (1.9) | 4.9 (23) | <0.001 | 16.2 (3.7) | 19.5 (2.8) | 7.3 (23) | <0.001 |
| All schools | 3.6 (2.5) | 7.0 (2.1) | 13.8 (97) | <0.001 | 15.8 (4.3) | 17.7 (4.5) | 5.0 (97) | <0.001 |

^aPossible range 0-9; higher scores indicate greater knowledge. ^bPossible range 0-24; higher scores indicate more positive attitudes.

Background and context to the qualitative findings

The interviews and focus groups contained information relating to the participants' experiences of the process of the presentation being given. This provides the context for the perceived outcomes of the presentation, which were the focus of the qualitative analysis.

Expectations about the presentation

The children and their parents had positive, realistic expectations regarding the outcome of the presentation (which is likely to have been a motivating factor in their decision to take part in the research project). Participants believed that the presentation would be helpful because it would increase classmates' understanding of TS, which they felt would lead to modest behavioural changes, such as less staring and fewer questions. In all four cases, there had been attempts previously (by either the parent, teacher or child themselves) to tell classmates about the child's difference in general terms, without explaining about TS.

Disclosure

The three children with moderate to severe TS and comorbid (traits of) ADHD or OCD said they wanted their classmates to know that they had TS, so their teacher told the class this during the presentation. Their parents were supportive of this process although the parents of one child were surprised by his decision. The child with pure TS and fewer, milder tics (child two) expressed worries that other children would "laugh, giggle and talk about" him and did not want to let his classmates know that he had TS. However, he chose to have his mother in the classroom during the presentation, and was not distressed when some children guessed that he had TS. The

other children did not express any worries about negative outcomes of the presentation or disclosure at the initial interview. It appeared that the educational presentation was perceived as a context in which it was 'safe' to disclose. At the follow up interviews, parents revealed that two of the children had been somewhat nervous about the presentation closer to the time, and were relieved when it went well and there were no negative outcomes.

Peer relationships

Teacher report indicated that the children with TS were currently generally well accepted by their classmates who had either got used to the child's differences over time or generally hadn't noticed the child's tics. The child/parent interviews indicated that whilst none of the children had suffered significant teasing or bullying as a result of their TS, they were bothered and upset by other children staring at them or asking questions about their tics and felt self conscious about letting their tics out.

The process of giving the presentation

The children with TS reported that they felt comfortable during the presentation because they had their friends nearby and they were pleased the presentation had happened. They noted that the other children looked at them more once it was disclosed that they had TS, which they said felt a bit "weird," but was not distressing. The teachers also reported that they found the presentation straightforward to give and that they prepared and conducted it in a similar way to their other classroom activities. Both teachers and parents reported that the support provided by the research project was helpful in facilitating the smooth running of the presentation.

Wider context

The four children in the current study experienced a range of difficulties associated with their TS, including pain from their tics and in the majority of cases, the additional burden of comorbid ADHD and OCD. Parents reported negative reactions towards their children from adults such as some teaching staff and other parents. They described that they were constantly educating other people, which was made more difficult by the image of TS portrayed by the media. Most parents felt that the presentation was applicable beyond the child's classmates, for example in educating other teaching staff and the rest of the children in the school.

Themes from the qualitative analysis

The analysis produced two super-ordinate or overarching themes relating to perceived outcomes of the presentation, with a number of themes within each of these (see Table 2). The first super-ordinate theme relates to the impact of the presentation on the classmates; the constituent themes are drawn from the focus groups, and the follow-up interviews with the child/parent and teacher. The second super-ordinate theme relates to the impact on the child with TS; the constituent themes are drawn from the follow-up interviews with the child/ parent and teacher. The themes are illustrated with extracts from the transcripts.

Table 2

Themes from the thematic analysis of the interviews and focus groups

| Super-ordinate theme | Theme |
|---|---------------------------------|
| Impact on classmates: Enabling prosocial behaviours | 1. Curiosity about TS |
| | 2. The importance of disclosure |
| | 3. Empathy and tolerance |
| Impact on child: Embracing having TS | 4. Feeling less different |
| | 5. Increased self confidence |
| | 6. Empowerment |

As might be expected, within each theme there was some variation across participants' accounts. This was particularly true depending on whether the child with TS had disclosed that they had the condition or not. The commonalities as well as the variation are described within each theme. Where appropriate, quotes to illustrate a particular theme are drawn from within the same participant set (e.g. what child one, their parent and teacher said) to illustrate the convergence or divergence of multiple perspectives. It is then noted how this relates to the other participant sets.

The following transcription notation is used: [I:] denotes questions asked by the interviewer; (...) indicates a pause or trailing off; ... indicates omitted text; [] indicates a word such as "it" has been replaced by another word to provide clarifying or contextual information. For quotes from interviews, the initials C, P and T indicate child, parent (mother) and teacher respectively and are combined with the participant set number to uniquely identify the speaker. (For example, C1 refers to child one, T4 refers to teacher four). TA 1 refers to the teaching assistant of child one and F3 refers

to the father of child three, who were also interviewed as part of the study. For the focus groups, the gender of the speaker, denoted by B, G or U for boy, girl or unknown, is combined with the participant set and focus group number. (For example, B 2.1 indicates the quote is from a boy in school two, focus group one). The gender is omitted when the quote comes from multiple speakers within a focus group. (For example 3.3 indicates multiple speakers in school three, focus group three).

Impact on the classmates: Enabling prosocial behaviours

Theme one: Curiosity about TS

Most classmates reported that they had known little or nothing about TS prior to the presentation. Those that had heard of it said that their knowledge had come from the media (mainly television programmes), what their parents had told them and their experiences with friends or family members who had the condition. Some children remembered what they had been told previously about their classmate with TS. Following the presentation, classmates said they had learnt a lot about TS, which they demonstrated by correctly recalling facts from the presentation and its key message that children with TS do not do their tics on purpose.

“I didn’t really know that much about Tourette’s and um, I learnt quite a lot... like 100 out of, 1 in 100 every school children has Tourette’s.” (G 1.1)

“It taught us lots about what happens so now we know if you do see someone like that, you know it’s not just them doing it on purpose.” (G 2.1)

Classmates reported really enjoying learning about TS and wanted to know more. The content of the presentation appeared to hold a somewhat unique appeal for the children– “there was something about it [which] was really interesting to people” (G 2.3). Only a small number of children reported that they had found the presentation

“a bit boring” (U 3.3). Teachers also noted how engaged the classmates were during the presentation, highlighting this as something that they felt had gone particularly well.

“I think the children were, um, quite inquisitive at certain points....They weren’t just watching it, they wanted to know things...Some of them in particular seemed genuinely really interested in it.” (T3)

“Um, I think it was the response of the children actually [that went particularly well]... I think that surprised me and that was good, so that it didn’t just become me talking, it became more of a discussion at times.” (T4)

In particular, classmates were very curious about aspects of TS and engaged in lively debate at some points during the focus groups in order to try to recall, understand and explain more complex aspects of TS (such its causes and developmental course). They were keen to know “how does actually Tourette Syndrome happen to children? So, how does it make, how does it build?” (B 1.1). They also generated novel questions about TS, which had not been mentioned directly in the presentation content.

“What country has the most people with Tourette Syndrome?” (B 1.3)

“Where did it, where did it, so has it been happening since the beginning of time or is it something that has evolved with us?” (G 1.3)

The children were also interested in the ‘stories’ of people who have the condition, such as those whose photographs were included in the presentation. This interest was noted by the teachers. Classmates reported that the pictures had given them a positive perspective on children with TS. A number remarked that it would have been good to include a video or case study of a child with tics to help ‘bring the information to life’ more and help them see “someone actually doing it” (G 3.1).

“I liked when they were showing the pictures but people were not actually, they are not embarrassed to have Tourette’s.” (G 3.3)

“I liked all the pictures of the people that had tics and you could see that there are lots of people that’s got tics.” (G 4.3)

“The photos were good and it was interesting that they commented on that, didn’t they? They wanted to know about the photos of people. You know, why is that person, who is that person?” (T3)

Theme two: The importance of disclosure

Some classmates reported that they might have found the behaviours of children with TS somewhat “weird”, “odd”, or “strange” prior to the presentation, and that they would probably have assumed the behaviours were purposeful or deliberate and asked the child to stop doing them. However, others said they would not have thought anything of the behaviours or would have just tried to “ignore them” (B 3.2) or “leave them alone” (B 1.3). Generally, classmates said that they thought it was helpful to have an explanation for the behaviours of a child with TS so that they knew how to behave (or not behave) towards children with tics. Some related their comments specifically to the child with TS in their class.

“Cos he can be quite [U: annoying]. Yeah, he can be really annoying. But now I know he actually has Tourette’s so I don’t think as bad, I, as him (...)” (B 1.3)

“When [child’s name] kept on doing it, I didn’t know he had it so like sometimes I copied but I don’t know until I found out. So I stopped it cos I knew it was mean.” (B 3.3)

Children also commented how knowing about TS would enable them to stand up for a child with the condition. Some felt they had a ‘right’ to know if a child they knew had TS, so they could avoid ‘acting badly’ towards them. Others said that how they would act towards a child with unusual behaviours would depend on whether they knew if the child had TS or not.

“If like a new member of the class, came into the class and they saw [child’s name] doing his tics, they might think ‘what is he doing?’ and if he starts trying to ask him, or be a little bit horrible, we could stop him and tell him and explain about Tourette’s.” (G 4.2)

“...like kind of when they do it you don't know they've got something wrong with them, you maybe think he's quite funny and then you maybe get into trouble but it's not really your fault...Like straight away, if like, there's a new child coming to school and they've got Tourette's, I think they should tell the teacher straight away to tell the class cos like, say like, like I got up and I started dancing and all, that then everyone that start laughing, then everyone would get in trouble, that's why they should tell the whole class.” (G 3.3)

It was felt by many of the children with TS, their parents and teachers that disclosure provided an important context for the presentation.

“ I think in some ways it's quite a lot of information for them to take in, if they are not really sure why they are listening to it.” (T1)

“...If [child's name] hadn't said, I might have put it into more of a context. Do you know what I mean, and given them a bit more background about why we were doing it... so that the pressure was taken off, cos the questions did come didn't they; 'who, has anyone in our school?' (...)” (T3)

Some classmates expressed surprise that their classmate had TS, as they hadn't noticed tics in the past. In school two, the classmates were not told that the child had TS, and this led to confusion where some classmates knew or guessed that the child had TS, whereas others were unaware of the child's diagnosis. This led to instances of some classmates disclosing that the child had TS, whilst others tried to respect the child's choice not to disclose.

B: “I know someone in the class who has some... [child with TS's name]” G: He doesn't... [child with TS's name] has habits” (2.1)

G: [child with TS's name]'s got habits but- [B: He has got Tourette's.] G: Has he? Okay.” (2.2)

The teacher also felt that the impact of the presentation may have been limited by the child's decision not to disclose.

“But so, answering the question, 'have they treated him any differently?' No, probably not because we haven't said “it's [child with TS's name] and this is what we need to do to, er, help him...” (T2)

The parent whose child hadn't disclosed remarked that she felt that the classroom presentation was a suitable forum for the classmates to ask questions about TS,

particularly if classmates had ‘guessed’ that the child had TS to provide a context for the presentation.

“I thought it was great cos it gave people a lot of the opportunity to ask questions about Tourette’s...I think some of them probably guessed that... it was about [child with TS’s name], which I think was very good as well cos then it was addressing something that they were all aware of but they were then able to ask questions not directly to him but about Tourette’s.” (P2)

Theme three: Empathy and tolerance

Classmates accounts suggested the capacity to be empathic towards children with TS following the presentation. They expressed concern for how the child might be feeling, tried to understand situations from their perspective, and expressed sympathy for children who have TS. As noted in theme two, classmates appeared keen to use the knowledge they had gained about TS to behave more sensitively or tolerantly towards children with TS.

“I think [another class] wouldn’t actually like [a child with TS] much at first, then if, like, the teacher explained what was wrong or something they would probably feel really sorry or really bad and um, try to be really good friends with that person.” (B 1.3)

“Cos we saw the presentation, we know quite a lot now, but if [another class] ever see that presentation, they might learn just like us, how hard it is, having tics.” (G 4.2)

However, a minority reported less sensitive or tolerant ways they would behave towards a child with TS, for example, “I would tell them to shut up” (B 3.2).

There were also a number of instances where actual changes in classmates’ behaviour towards the child with TS were reported. In one case, both the child with TS and their teacher reported these changes.

[I: ...have you noticed any other changes over the past couple of weeks?]
“It’s mainly been in pupil reactions, the couple of boys...who would be... thinking ‘this isn’t right’ when I wasn’t talking to [child’s name] about his tics, I think they’ve been a lot more understanding, and they might have

noticed it more but they haven't given me the look or a glare like they would have before to say 'well why is he getting away with it?... And in the group as well, ... even more children as well... have understood why he's not quite as focused straight away as the other children.'" (T4)

[I: Have you noticed any other changes after the presentation?] "Yeah because no one was asking me [about my tics] and stuff. It was exactly what we were discussing last time [in the pre-presentation interview]. That people were a bit bugging me but I think that's got better now, I haven't heard a word about like 'why do you do that?' and stuff so it's going a lot better." (C4)

In another instance, additional changes were noted by the child and parent that were not observed by the teacher.

"But when it was me, cos I did get bullied in the end and he stood up for me." (C3)

"Everyone's been more supportive now haven't they?... I think they all sort of look out for him... I've seen him sometimes at lunchtime in the hall and he sometimes tics when he's sitting there eating his lunch and he takes a while to eat the food cos he has to touch it different ways and things, and they sit patiently and wait for him now instead of getting up and leaving him there and saying 'we'll see you outside [child's name]'..." (P3)

It appeared that in instances where teachers felt that no noticeable changes in classmates behaviour had occurred, this was also felt to be positive.

"...there's been no comeback from it, there's been no, nothing said to [child's name] it's all been quite calm and, you know, not a lot's changed, he's still got friendship groups, he still carries on." (TA1)

"Do you know, I think children, I think they take it in their stride, they move forward. I think there were maybe a couple more questions that people maybe asked [child's name]. But no, nothing more was said." (T3).

Two children behaved somewhat negatively towards the respective children with TS in their class following the presentation, which appeared to be related to the characteristics of these classmates, rather than a common response to the presentation. It was noticeable that the other children appeared to 'rally round' to support the child with TS in these instances.

"He doesn't get along with one little boy in class and we had a discussion on the day of the presentation actually, and we talked about the fact that him and

[boy's name] just kind of clash and we didn't-mum and myself- didn't feel it was anything to do with the Tourette's." (T3)

"[Boy's name] who is a bit, who is maybe not as thoughtful and sensitive as some of the others kept saying 'oh is this about [child with TS's name]?' you know, and the others said to him 'yeah, but you know, shush, cos it's rude to be shouting out like that'." (T2)

Impact on child: Embracing having TS

Theme four: Feeling less different

The three children who disclosed that they had TS felt "really happy and almost like really relieved" (C4) that their classmates now knew about their condition and had been accepting of this fact. As a result of the positive reactions they received following their disclosure, these children appeared to spend less time thinking about, or monitoring their classmates' reactions to their tics, and had the perception that their classmates were looking at them less.

"He doesn't tend to be looking around to see if anyone is watching him anymore, and they don't seem to take as much notice." (P1)

"I think he now assumes that everybody at school knows, so I think he's probably more relaxed in that way...and I think the fact that people do know has made him more relaxed." (TA1).

The children also felt "less alone" (C/P3) as a result of their condition. It appeared that the presentation reminded children that "other people have it as well" (C1) and also helped them to feel that they no longer had an unknown condition. They also appeared to feel more accepted or included by the other children at school following the presentation. As one parent put it "I think he probably, he feels more gelled in there, you know?" (P4). There appeared to be positive changes in the children's mood associated with feeling less different, including being happier and less anxious.

"He was [a lot happier] that night when he [came] home from school. He was very happy. It was a different [child's name] wasn't it?" (F3)

“Um, this was the first time after this half term where he hasn’t gone into what I call ‘stress mode’ ...we always have this episode of anxiety before the first day back. [I:...What’s the anxiety usually about?] Worry about going back. Who’s going to be there, who’s going to talk to him...There wasn’t any of that this time and we noticed a huge difference.” (P4)

The one child who did not disclose did not appear to benefit in the same way. The accounts of the child and parent generally lacked comments regarding perceived changes, although this child may have been slightly less conscious of other people noticing his tics following the presentation than he had been before when he felt people were “staring” at him.

Theme five: Increased self-confidence

The three children who disclosed reported, and/or were noticed by parents and teachers as, being “more comfortable” and “relaxed” about having their TS following the presentation. This manifested itself in a number of ways: “showing the tics a little bit more” (T4) and “doing better like answering questions cos I don’t feel a bit like ticcy around people that I haven’t talked to as much” (C4).

“I’ve heard that children have asked him if something he has done is one of his tics and he’s been able to say ‘yes’ whereas in the past he would have probably ignored them completely, or diffused the question so he didn’t really need an answer...” (P1)

The children seemed more able to ‘be themselves,’ which in turn appeared to enable them to get on with other activities (although this included ‘chatting’ as well as schoolwork).

“And even when his tics are quite bad, he’s not been asking to go out of the classroom as much, which is good, cos he’s in there for all the input and all the things.” (TA1)

“...He laughs when he has to do his tics a little bit more...Yesterday actually, he’s used his pass card to come outside of class, so he done his little vocal sound which is loud, it’s very high pitched and it made [the TA] jump. And she went ‘[child’s name] let me know before you do that next time’ and he laughed...and that’s a good thing. Cos before, he wouldn’t have even come

outside to do that, he would have kept it in. So, I think he's a bit more comfortable in himself." (P3)

"...On occasions now I've had to speak to him about getting on with his work and not chatting to his friends... which probably is that he's more relaxed in class...And I think he just generally feels more comfortable so I think that he feels generally more willing now to just show his pass card..." (T3).

Again, the child who did not disclose did not appear to benefit from any changes in this domain, although he reported feeling "okay" about the classmates 'guessing' that he had TS.

Theme six: Empowerment

The three children who disclosed experienced the presentation– including the decision to disclose, the actual disclosure, being more knowledgeable about TS than their classmates and being able to answer some of the questions during the presentation– as both positive and empowering.

"He was definitely questioning who knew what, and actually a lot happier that people knew. And happy that he knew more than they did." (TA1)

"And then when [child's name] came home at the end of the day he was just chuffed to bits like it had been a really special day...You know, that people had learnt and questions had been asked..." (P4)

These children appeared to feel that they had more control over their TS; as noted in theme five, they felt more able to answer questions about their tics, or to make a joke of them. It remained difficult for the children to wholly embrace their TS due to the 'socially unacceptable' nature of some of their tics, but they felt more able to manage them.

"I feel comfortable about using my pass card [to leave class to relieve tics in private] but not feeling comfortable in class." (C3)

"Cos he knows that some of his tics aren't socially acceptable...even though he can't control these things to a certain degree he can. I think that's why, when he's in a classroom with lots of children, he knows these are things he

shouldn't be doing, even if they are tics, so he goes outside to release them, but now he feels comfortable enough to be able to do that." (P3)

The children with TS were keen for other children to be told about their condition on a 'need to know' basis, such as letting the whole year group know when they had other classes with these children. Again, the child who did not disclose appeared to miss out on the empowering elements of the presentation, and remained reluctant about the idea of disclosing to other children about his tics, even when they might benefit from knowing.

Discussion

The participants in this study (children with TS, their parents, teachers and classmates) gave positive accounts of a classroom presentation aimed at educating school children about TS. With some exceptions, classmates' knowledge and attitudes towards TS improved following the presentation, and there were some indications that their actual behaviour towards the child with the condition may have also changed. Positive changes in the child with TS were noted (feeling less different, more confident and more empowered), particularly for those children who chose to disclose to the class that they had TS during the presentation.

A social-ecological model (Bronfenbrenner, 1979) offers a useful theoretical framework for understanding the relationship between the impact of the presentation on the classmates and the impact on the child with TS. This model emphasises the complex, multi-layered social context in which each child exists (family, school, wider community) and the importance of considering child development in terms of these contexts. The current findings suggest that a significant development in the

self-concept (defined here as the global view of self; Butler & Gasson, 2005) of the child with TS occurred following a change in their school environment. The perception of greater acceptance and tolerance from peers second to the presentation enable the child to gain more acceptance of their TS, linked with a sense of improved well-being (Lindberg & Swanberg, 2006). This highlights the importance of intervening within a child's social world to produce positive changes within the child themselves. In addition, intervention in one part of the system can act as a catalyst for further change, which may spread through the system over time. For example, one child in the current study became less anxious as a result of the presentation, which appeared to have improved the quality of his home life, as he no longer went into his parents' bed at night. Change in classmates' attitudes was suggested by some parents to have led to a change in the attitudes of other parents, which may potentially lead to a shift in societal attitudes over time.

The children with TS appeared more able to embrace having TS following the presentation because they felt less different, more self-confident and empowered as a result of the presentation. Disclosure seemed to facilitate these changes, since the child who chose not to disclose did not report the same improvements. Disclosure in the context of the teacher giving an educational presentation about TS which was well-received by peers, allowed the children to gain a sense of mastery over their environment, acceptance of their condition and perception of positive peer relations, all components of psychological well-being (Ryff & Keyes, 1995). It may have been that a shift in the child's attentional focus was also an important mediator of the changes in their self-concept. Cognitive biases such as inward focused attention or hypervigilance to threat have been found to be an important factor in psychological

difficulties such as anxiety (Clark, 1999). Prior to the presentation, the attention of the children with TS appeared focused on monitoring their tics, which may have led them to overestimate others' negative reactions. Following the presentation, their attentional focus may have shifted to other tasks (such as school work) leading them to have the impression that they were more accepted by others, and further enabling them to 'forget' about their TS to a degree and 'get on with' other activities.

Classmate's knowledge of TS and attitudes towards children with the condition improved following the presentation. It was clear from the focus groups and teacher interviews that most classmates felt that they had 'learnt a lot' and were engaged in the presentation material, curious and enthusiastic to know more about TS. The presentation also seemed to bring about more empathic and tolerant attitudes towards children with TS. These changes were reflected in classmates' scores on the knowledge and attitude measures, which showed significant increases pre- to post-intervention, except for the attitudes of the classmates in school three. The data do not provide sufficient information to explain the lack of change on the attitude measure for classmates in school three. It seemed from the focus groups in this school that children reported a wide range of attitudes towards children with TS, which may have impacted on the questionnaire scores. However, the child with TS and his parent reported noticing changes in classmates' attitudes and behaviours towards him, which does not appear to have been picked up on the attitude measure.

In some cases, the positive views expressed by classmates on the questionnaires and in the focus groups were accompanied by changes in their actual behaviours noted by the child with TS or their teacher. This indicates that the positive findings were not

just a product of classmates giving socially desirable answers (a common pitfall of self-report measures; Paulhus, 1991). Since knowledge is proposed to influence attitudes, which to some degree predict behaviour, provision of information may be at least partially responsible for the change in attitudes and behaviours noted (Vignes et al, 2009).

It is likely that group processes also influenced the changes in classmates' individual attitudes following the intervention. Information in the presentation (such as the slide about how to treat children with TS) may have influenced classmates' perception of what the majority's view of TS is. If each classmate holds the belief that the majority of children hold a more accepting attitude towards TS, they may also be more likely hold a more accepting view (Rivis & Sheeran, 2003). Disclosure may have also had a positive impact on classmates' attitudes since they could relate the presentation to their own experiences of having a classmate with TS (Rosenbaum, 2010). However, classmates reported that other factors would influence their behaviours towards children with TS besides their attitudes towards the condition. This included whether they were already friends with the child with TS, in line with previous studies (Vignes et al., 2009).

Methodological limitations

The findings of the study should be considered in light of the following methodological limitations:

It is unclear how far the findings may generalise to the population of children with TS. The opt-in recruitment design led to a self-selected sample of enthusiastic

participants who were positive about going ahead with the presentation. Not all children, families and schools will be so keen for the process to occur. However, the inclusion of one child who chose not to disclose provided a useful comparison, which suggested that the presentation was more successful when disclosure took place. In addition, the children with TS were all 9-10 year old boys of a largely white British demographic. The specificity of these sample characteristics means the extent to which the findings apply to girls with TS, and to children of different ages and other cultural backgrounds remains unknown. Finally, it remains unclear whether the impact of the presentation varies depending on the severity of the child's TS. The three children who disclosed in the current study had more severe TS with comorbid ADHD and OCD, whilst the child who chose not to disclose had pure TS with fewer, milder tics. It was not possible to establish whether the presentation had less impact for this child due to the lack of disclosure, milder tics or other reasons, such as the child's disposition, motivation or 'readiness for change' (Prochaska & DiClemente, 1983).

Although the study used a mixed methods design, the quantitative data were not the main focus. The questionnaires were included to provide an indicator of changes in knowledge and attitude, which were then explored more fully in the interviews and focus groups. The questionnaires used in the study were developed for the current research and had not been used previously, which means their validity remains unknown. In addition, the study did not examine whether the changes were maintained beyond the two-week follow up, and there was also no control group to provide comparison data. The study design was not appropriate for systematically

exploring the relationship between knowledge, attitudes and actual behavioural change.

There were a number of limitations to the qualitative data collection and analysis. Firstly, the age group of the participants made it challenging to conduct the focus groups. It was necessary for the researcher to impose a significant degree of structure onto the groups (such as asking participants to wait their turn to answer questions) whilst at the same time facilitating discussion between participants to ensure it did not become a 'question and answer session'. Secondly, it would have been helpful to have had more time for reflection between focus groups (which were run back-to-back) to record observations about the group processes, which could have informed the qualitative analysis. Thirdly, whilst including multiple perspectives had advantages, it also made it challenging to integrate and compare accounts from different participants.

Finally, the naturalistic study design meant that it was not possible to control for differences between the schools (such as school ethos/culture or class dynamics). The presence of the researcher in the classroom may also have influenced the outcomes of the presentation and detracted from the naturalistic study design.

Implications for research and practise

Further research with a large sample of children with TS is needed to establish the impact of educating classmates on the child's self-concept and the mechanisms underlying this. Mapping the relationship between knowledge, attitude and actual behavioural change towards children with TS following the presentation in a larger

number of schools would also be illuminating. It will also be important to evaluate the impact of presentations developed for use in secondary schools and adults' places of work. As a more ambitious goal, research is needed to investigate the impact of educational presentations on attitudes towards TS over a longer timescale at a societal level. As one parent put it "I think that [educating classmates] is going to help over the years in society. Cos, I mean, they are going to grow to be our adults and be far more understanding".

The consistency of the present findings across a large sample of classmates across four different schools is very encouraging and suggests that educational presentations have the potential to improve knowledge and attitudes towards TS. Such presentations also have the potential to impact positively on the self-concept of the child with TS, which is likely to be of interest to clinicians as well as children with TS, their families and teachers. A challenge will be to encourage the use of educational presentations across the age range outside of a research context. The effectiveness of this simple school-based presentation indicates that interventions targeting the child's social environment need to be carried out more routinely alongside or as an alternative to one-to-one therapeutic intervention. Clinicians could work with charities to support this process, using the current research as a model.

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Part 3: Critical Appraisal

Research as action and other reflections

Introduction

This critical appraisal reflects on community psychology as a conceptual underpinning of the study reported in Part 2, as well as some methodical issues related to the research.

The research experience

When reflecting on the process of carrying out my research, I initially struggled to define in words what I experienced time and again as most striking about working on the project. This was its sense of ‘liveness,’ stemming from witnessing the presentation and its impact unfold in the classroom, and then hearing it reflected upon in the focus groups and interviews. So many participants appeared genuinely and positively touched by the process in a way that seemed to go beyond a conceptualisation of research as an exploratory process somewhat removed from the ‘real world’. Classmates expressed the palpable enjoyment of both the presentation and the questionnaires and focus groups that I had observed during my visits to the schools. The following excerpts from some of the focus groups illustrate this:

“Yeah, [the presentation] really grabs your eye!” (Loudly, sounding enthusiastic, B 2.2)

“I liked it when they done the, when we done the test thing.” (B 3.3)

[I: Alright guys, I think, shall we [end the group] there?] No, no!” (Chorus from children, 3.1)

Parents and children told me that they were very grateful for the opportunity to take part in something that noticeably improved the child’s life in ways they were not necessarily expecting. As two parents put it:

“I mean I’m thrilled he’s done it because I didn’t realise that it would have such an effect on him. I’d completely underestimated that... I was happy he was doing it cos I thought it would affect everybody else and I didn’t expect

it to affect him. And it's affected him in a positive way and that is just a massive bonus." (P4)

"But he now has a pass card, which is very good so he can go out the class. So it's actually educated the whole school... because before they didn't really want to know and they wasn't listening and we were sort of ... 'he needs to be able to come out of class' ... and they weren't really listening. Now they are like 'what what does he need now?'..." (P3)

Teachers saw it as a learning opportunity, whilst one teacher even planned a sponsored event with her class afterwards to raise money for the TS charity and consolidate the experience:

[I: How did you feel about giving it before hand?] "Um, but really interested and pleased to have been able to take part really, to have that opportunity, for [child's name] and also in my SENCO role as well. It was a valuable thing to do"... [I: What prompted you to think of doing a fundraiser?] Um, I think it was just a way for the children to get more involved in the project and for them to see that they can, kind of, help people and just to recognise it a bit more. I just thought it would nicely follow on from what we'd started in the classroom [by giving the presentation]." (T4)

In addition, conducting the project in conjunction with Tourettes Action– a charity dedicated to promoting research and information about TS, and supporting those affected by TS in the UK– provided additional opportunities that felt equally meaningful or 'live.' These included presenting the preliminary findings of my research at two conferences, one to the charity's members (adults with TS and the parents of children with the condition) and one to clinicians working in the field both in the UK and abroad. I also covered the topic during a workshop for children with TS, which I co-facilitated. The Support Manager at Tourettes Action, who had produced the presentation used in the project, described how she had sat 'grinning from ear to ear' as she listened to me present the preliminary findings of my study. The charity was also receptive to suggestions arising from the project; I offered to produce guidelines to accompany the presentation to make it easier for teachers (and

parents and children) to use, and to modify the presentation content to include more case examples as suggested by participants (Claire Ball, personal communication.)

Working with the charity also afforded other opportunities. I received emails from a journalist specialising in educational needs who had seen my study advertised on the website. She went on to reference the presentation in her article on supporting children with TS in the classroom published in 'Special Children' magazine (a publication for educational professionals and parents of children with special educational needs). Dissemination of a summary of my findings via the Tourettes Action monthly electronic newsletter and on their website also enabled the research to reach a wide audience from across the UK of parents of children with TS, adults with the condition and professionals working in the area.

Whilst the drive to conduct research that was 'meaningful and valid' (applicable beyond the confines of the research setting) had been present from the project's conception, and heavily influenced my choice of study design, in the light of my research experiences, I was left wondering how to conceptualise the process that seemed to be occurring. Consultation with my internal supervisor led to a potential framework, community psychology.

Community psychology in action

Community psychology is an ideology that uses understanding of people in their social context to reduce distress and improve their well-being (Dalton, Elias & Wanderman, 2001). It involves working collaboratively with others, usually those who are marginalised, oppressed or disempowered, on strength-based collective or

societal (rather than individual or psychological) interventions, which focus on redistribution of power in the direction of the relatively powerless (www.compsy.org.uk). It integrates reflection, research and action and uses a plurality of research methods to allow engagement with individuals' subjective experience of their social world and give participants control over key dimensions of the process (Barker & Pistrang, 2005). 'Action research' is one orientation to enquiry that fits with the ideology of community psychology (Kagan, Burton & Siddiquee, 2008). It is defined as a process which "seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical [knowledge and] solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities" (Reason & Bradbury, 2001, cited in Kagan et al., 2008).

The research described in Part 2 could be seen to fit with a community psychology intervention, which empowers communities as collective identities, in line with the notion of 'sharing psychology' or 'giving psychology away' (Miller, 1969). The qualitative data indicated that participants experienced the research as empowering. The child with TS was given control over their role in the process, such as choosing whether to disclose they had TS, or answer some of their classmates' questions about their experiences. Teachers were empowered by the opportunity to practise a skill, which they might repeat again in the future. Classmates appeared to feel that being given more knowledge about TS would enable them to better select how to behave towards children with 'unusual behaviours.' The research may also have led to changes to the 'status quo' in that over 100 children in four schools in different geographical locations in England are now better informed about TS. Further

research would be needed to map any further dissemination of information or changes over time. In line with the ethos of community psychology, the research was also proactive rather than reactive; none of the children with TS had suffered significant bullying by peers or psychological difficulties requiring intervention. Nevertheless, the implemented classroom intervention appeared to lead to meaningful changes for both the child with TS and their classmates.

The research also involved collaboration with other disciplines and organisations (both educational and charitable). Working closely with the charity could be seen as an example of ‘sharing psychology’ with yet another community (with a large ‘online’ presence via its website) and is ongoing at the time of writing this reflection. ‘Sharing psychology’ with the charity also had a ‘domino’ effect in disseminating information when a journalist chose to publicize the presentations in an article accessible to the special education community.

It is likely that community psychology is not the only way to understand the research experiences outlined above. Indeed, not all aspects appear relevant to the current project (such as the key tenets of liberation and social justice). The study design lacked the involvement of participants since community psychology was only considered as a useful guiding ideology later on. However, I found it a helpful framework for conceptualising my experiences, particularly its tenet of empowerment. In addition, it appears to be a useful way to extend clinical practise in this area given the large number of individuals with TS (over 300, 000 in the UK alone) and the small number of specialist services available to support them. Collaboration between clinicians, charities and schools appears vital as an alternative

or adjunct to one-to-one therapeutic intervention. The study described in Part 2 demonstrates the effectiveness of an intervention within the school environment for changing societal attitudes, in line with previous research (Holtz & Tessman, 2007). As such it may provide a useful model to help clinicians liaise with other services to ‘transport’ the presentation into schools outside of a research context.

Methodological issues

The choice of study design incorporating mixed methods, multiple perspectives, and pre and post intervention measures, allowed for a detailed exploration of the impact of an intervention in a naturalistic setting. It also gave rise to a number of issues and limitations that will be discussed here.

Conducting focus groups

Whilst the literature suggests that it is possible to conduct focus groups with children of primary school age, it may be challenging at times and require adaptations to help the children engage (Darbyshire, MacDougall & Schiller, 2005; Morgan, Gibbs, Maxwell & Britten, 2002). This was certainly my experience, and required me to draw on skills gained from working clinically with children of this age. I found that it was important to keep the focus groups more structured, having participants wait their turn to speak and interrupting them when necessary to keep the discussion on track. This was consistent with the format the participants were perhaps most familiar with (a primary school class). However, without encouragement, many of them put their hands up or called me ‘Miss’ when answering questions in the focus groups, which automatically introduced a ‘classroom’ dynamic. Consequently, I also

had to work hard to encourage relevant discussion to open up between participants to prevent the groups resembling a teacher-led “question and answer session”.

Being the sole facilitator of a large number of relatively short focus groups conducted at the children’s schools also gave rise to a number of considerations. Interviewing a large proportion of the whole sample of available classmates (100 out of 116) generated a comprehensive range of views without introducing sampling bias by selecting a subset of classmates to participate in the focus groups. The format and length of the groups also appeared to facilitate engagement in the majority of participants. However, it was not possible to make use of a longer warm-up period and/or multimodal format to elicit the views of more reluctant participants, meaning that their views may not have been adequately represented (Darbyshire et al., 2005; Morgan et al., 2002). It would have also been helpful to systematically observe group processes; I was aware that a number of factors may have influenced participants’ responses, such as gender mix, alliances and divisions, social desirability effects, power imbalances between myself and the children, and the impact of the school setting. Unfortunately, this was not possible due to time and resource constraints, which meant the groups were run ‘back to back’ by a single facilitator without time for formal reflection or the luxury of a second researcher to observe and take field notes.

At some points, I also questioned whether it was possible to access participants’ meanings on some topics using the post-intervention focus group format. Given their age and developmental level, it was hard to gain a clear sense of classmates’ prior attitudes towards children with TS by asking them “before you saw the presentation,

what would you have thought if you had seen a child making unusual noises or movements?” For example, some replied that they would “know” that the child had TS or gave other responses, which led me to doubt whether they were able to access their prior knowledge states. It appeared more illuminating to ask them to think about what it would be like for another class of children similar to themselves if a new pupil with TS joined the class. Nevertheless, it remained hard to understand changes in attitudes and intended behaviours using a post-presentation focus group format. In addition, although the children wore nametags to allow me frequent use of participants’ names throughout each focus group, it was not possible to identify the speaker on each occasion during transcription. Thus, it was not possible to track the attitudes of individual classmates in a way that other formats (such as pre-post, one-to-one interviews) could.

Qualitative analysis

Conducting 13 interviews and 13 focus groups each at least 15 minutes long produced a vast quantity of data to transcribe and analyse. A challenge was to decide what to ‘foreground’ or prioritise as themes in the analysis, and what to include as background or contextual information. I chose to focus on the impact of the presentation on the classmates and the child with TS as this was most relevant from a psychological perspective. However, this meant that a lot of more practical information about the process and content of the presentation was consigned to the ‘background and context’ section. It is important not to overlook such practical information since it guides how the presentations are given; I am keen to make it available to teachers, individuals with TS as well as the charity and other clinicians.

Use of mixed methods

In line with ethos of action research and community psychology outlined above, I used a mixed methods approach within my study design. I drew on the quantitative data to ‘substantiate’ at least some of the themes that emerged from the qualitative data (such as those regarding the attitudes of the classmates). I also drew on the different perspectives offered by parents, children and teachers within the same participant set when determining themes. This ‘triangulation’ of both methods and perspectives was a strength of the study, increasing confidence in the findings (Olsen, 2004). However, whilst using both methods, I focused more on the qualitative component, which meant that aspects of the quantitative component were compromised as a result. The questionnaires were useful in giving an indication of improvements of classmates’ knowledge and attitudes pre- to post-intervention. However, the study design was not suitable for systematically examining the relationship between change in knowledge, attitudes and actual behaviours following the intervention, which remains an under-researched area (as indicated in Part 1).

‘Methodological pluralism’ extends beyond the mixed methods design of individual studies; it also refers to pluralism of approaches within a research programme or field of study (Barker & Pistrang, 2005). By using a naturalistic, largely qualitative design, I was also aiming to contribute to pluralism within the field of TS research, which tends to prioritise quantitative research and randomised controlled trials (RCTs) over multiple case study, naturalistic designs. Whilst RCTs and laboratory-based research offering tighter control over key variables undoubtedly have their place, research incorporating qualitative approaches can be a rich source of

information on areas such as self-concept, which may be hard to examine using quantitative methods (Cutler, Murphy, Gilmore & Heyman, 2009).

Researcher presence

I was present in the classroom when the presentation took place to observe how the teacher gave the presentation and the children's reactions firsthand. Unfortunately, I did not formally evaluate this aspect of the study, which means valuable data regarding the process of the presentation was not captured. Upon reflection, it may have been helpful to take an ethnographic approach using field notes, in order to overcome this limitation. Taking an ethnographic approach traditionally involves the researcher(s) engaging in fieldwork and immersing themselves in the lives of participants over a prolonged period of time so that the findings convey a sense of 'being there' (Borneman & Hammoudi, 2009). Typically, researchers' observations, recorded as field notes, are used to supplement interviews or focus groups to obtain a 'thick' description of the phenomena under study (Geertz, 1973). In the current study, I liaised closely with parents and teachers by telephone and email whilst setting up the project, in addition to interviewing participants at their homes and schools over the period of a month as well as visiting the school to observe the presentation taking place. It would have been useful to supplement the interview and focus group data by videotaping the presentations for analysis or taking detailed field notes rather than informal observations to 'thicken' the description of the process.

Also, my presence in the classroom is likely to have influenced the processes occurring. The children expressed curiosity at my presence, which signalled that the presentation differed from a normal classroom activity, and may have influenced the

outcome. Being observed can lead to ‘observer reactivity,’ i.e. the alteration of behaviour of those being observed (Harris & Lahey, 1982). In addition, the teachers sometimes turned to me to answer questions, which they would not have been able to do under ‘normal’ circumstances. The teachers commented how my presence had been a helpful (albeit not necessarily vital) resource when giving the presentation. Parents also commented that being part of the research project had been a ‘driving force’ in the presentation going ahead, since the researcher had been on hand to liaise with the school to set up the project and to answer any questions the child or teacher might have.

The above issues underscored the difficulties of achieving a truly ‘naturalistic’ piece of research. Nevertheless, in the course of recruitment, I received emails from parents and teachers who did not to take part in the study but wanted to let me know that they had found using similar presentations successful in the past. This feedback indicates that educational presentations about TS can lead to positive outcomes in the absence of a researcher. It appeared to me that helping parents, children and teachers to feel able to collaborate to give the presentation themselves without the ‘back up’ of the research project is a key consideration governing the use of the presentation. I hope to use my observations and experiences whilst conducting the research project to enable Tourettes Action to support this process.

Using the literature to inform the study

A significant challenge when conducting the current research was reviewing and synthesising the relevant literature in order to ask the relevant research questions and interpret the findings. Firstly, the research straddles educational and clinical literature

and reviewing these broad areas was a significant and time-consuming undertaking. It also draws on social psychology and cognitive behavioural theory in order to understand the mechanisms underlying complex issues such as attitudes and self-concept. Research into attitudes and group processes appears somewhat ‘out of vogue’ in comparison to the plethora of papers published in the 1970s and 1980s. This meant that I sometimes had to draw on somewhat ‘dated’ papers, not ideal when designing questionnaire measures or interpreting findings (e.g. Rosenbaum, Armstrong & King, 1986). In addition, due to lack of relevant research in the field of TS, I had to integrate theories and research from other areas to explain the findings. It was important to consult with more knowledgeable colleagues with expertise in the relevant fields to ensure that I had not missed key papers or considerations, and had provided a sensible synthesis of theoretical ideas in my interpretation of findings.

Conclusions

Psychosocial interventions (such as psychoeducation) in the field of TS have received little research attention (Verdellen et al., 2011). The current study took a small step towards filling this gap by providing some ‘practice-based evidence’, that is, evidence of outcomes in routine settings (Cahill, Barkham & Stiles, 2010). Such evidence complements ‘efficacy’ research i.e. that obtained from RCTs because it addresses the issue of the transportability of interventions and generates information about how an intervention actually works in the real world (Cahill et al., 2010). Future research programmes investigating psychoeducational approaches in TS would benefit from combining efficacy and practice-based research strategies. For example, brief questionnaires, such as the ones developed in the current study, could be used to routinely monitor outcomes of presentations given in schools, or adapted

for use in larger, controlled trials. It has been argued by some that it is also possible to combine practice-based research with community psychology approaches such as participatory action research (Westfall, Van Vorst, Main & Herbert, 2006). Involving individuals with TS, their families and teachers, as well as liaising closely with TS charities in designing further studies would also ensure that future research addresses areas that are most meaningful to those living with TS.

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Appendices

Appendix 1: Ethical approval

Dr Nancy Pistrang
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22 February 2010

Dear Dr Pistrang

Notification of Ethical Approval:
Ethics Application: 2233/001: An evaluation of a classroom presentation about Tourette Syndrome

I am pleased to confirm that, further to your satisfactory responses to the Committee's comments, your study has been approved by the UCL Research Ethics Committee for the duration of the study (i.e. until June 2011).

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form'.

The form identified above can be accessed by logging on to the ethics website homepage: <http://www.grad.ucl.ac.uk/ethics/> and clicking on the button marked 'Key Responsibilities of the Researcher Following Approval'.

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events.

For non-serious adverse events you will need to inform Dr Angela Poulter, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an

Yours sincerely

Sir John Birch
Chair of the UCL Research Ethics Committee

Cc: Claire Nussey

Appendix 2: Parent information sheet



An evaluation of a classroom presentation about Tourette Syndrome

Information Sheet for Parents

We are inviting you and your child to take part in this research project. You should only participate if you want to; choosing not to take part will not disadvantage your child in any way. Before you decide whether you want to take part, it is important to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

Who are we?

We are researchers from University College London and we are working together with Tourettes Action. Our contact details are at the bottom of this sheet.

What is the project about?

The purpose of this research is to get a detailed picture of how a classroom presentation of factual information about Tourette Syndrome (TS) may be helpful to young people with TS. This approach is recommended by Tourettes Action but has not been evaluated yet. This study will begin to do this by getting the views of young people with TS, their parents (you), their classmates and teacher.

Who is being invited to take part?

We are asking young people with TS to take part, as well as their parents, classmates and teacher. Ideally in order to take part, you and your child should be thinking that a classroom presentation about TS could be helpful, but it should not yet have been done. If this is not the case but you still wish to take part, we will be able to discuss this with you.

Children with TS often also have additional difficulties, such as with inattention, hyperactivity, obsessive-compulsive behaviours, specific learning difficulties (eg dyslexia) or feeling anxious, depressed or angry. If this is the case for your child, they will still be invited to take part unless after talking with you, we feel these difficulties would make it too difficult for them to participate in the study.

Unfortunately, we are not able to include you or your child in the study if your child does not speak English as their first language, has generalised learning difficulties, a diagnosis of autistic spectrum disorder, a statement of special educational needs or is not in a mainstream school.

What will my child and I be asked to do?

At the start of the study, we will ask you some questions (by telephone) to find out about your child's TS and any other difficulties. We will also ask you to fill in a brief questionnaire about your child's quality of life. We will also ask permission to contact your child's teacher to set up the rest of the study.

The main part of the study will involve your child's teacher giving a factual slide presentation about TS (produced by Tourettes Action) to the class. The presentation will be about TS in general and not about your child in particular; your child will not be named in the content of the presentation. Your child will be in the classroom, but there will be flexibility in how the presentation is done so that he/she can be involved in as much or as little of it as he/she wishes.

We will ask you and your child to take part together in two informal interviews, one within two weeks before the presentation and a second 2-4 weeks after the presentation. The researcher will come to your home or another suitable place at a time that is convenient for you to conduct these interviews, which should last no longer than one hour. The aim of these interviews is to hear about your thoughts and feelings about the presentation and whether anything has changed in how your child gets along with classmates or in other areas following the presentation.

In addition, we will be asking your child's classmates to complete brief questionnaires about their knowledge about TS and attitudes towards children with TS in general before and after the presentation. We will also conduct small discussion groups with your child's classmates following the presentation to look at these areas in more detail. The questionnaires and discussion groups will not ask about classmates' attitudes towards your child in particular. Your child will not be named in the questionnaires or discussion groups. Your child's teacher will also be invited to take part in an informal interview after the presentation to find out his/her view of how the presentation went. The discussion groups and interview will take place 2-4 weeks following the presentation.

What will happen to the information that is collected?

All the questionnaires and interviews will be made anonymous; names and any identifying information will be removed so that you and your child cannot be identified. With your permission, we will audio-record the interviews and then transcribe (write up) what was said. We will delete the recordings after they have been transcribed. All written information will be stored securely and will be destroyed five years after the project has ended. All data will be collected and stored in accordance with the Data Protection Act 1998.

Everything that you and your child tell us will be kept confidential; only the research team will have access to what has been said. The only time confidentiality would be broken is if we were worried that your child or somebody else was at risk of harm, and we would need to let the appropriate services know. However, we would try to talk to you about this before we spoke to anyone else.

Once the project is over, the results will be written up and may be submitted for publication in a professional journal. Reports will not reveal the identity of anyone who took part. They may include some anonymous quotations of things people have said during interviews which will be used to illustrate the findings. A summary of the findings will be given to those who took part in the project. You will have an opportunity to comment on the findings from the interviews conducted with you and your child before the final report is written.

Are there any benefits of taking part?

We hope that you and your child will find it interesting to talk to us about the impact of the presentation from your perspective. The research should give us a better understanding of the impact of such a presentation, and whether any changes should be made to it. Therefore, it should be helpful to Tourettes Action and to other young people with TS in the future.

Are there any risks of taking part?

It is possible that you or your child may feel uncomfortable answering questions about any difficulties he/she has experienced (e.g. problems with classmates). If this should happen, you do not have to answer the questions. We think it is unlikely that your child with TS will experience negative comments or bullying from other children following the presentation, but if this should occur we will discuss it with you (and with your child's teacher) and will be able to provide information to help deal with this.

Do my child and I have to take part?

No, neither of you has to take part. It is up to you both to decide. If you do decide to take part, you are still free to withdraw at any time without giving a reason.

What do I do now?

If you would like to take part, or if you have any questions, please contact Claire Nussey using the contact details below. Before taking part, we will ask you and your child to sign a consent form.

The researchers are:

Claire Nussey

Email: c.c.nussey@googlemail.com

Telephone: 07939 28 70 20

Dr Nancy Pistrang <n.pistrang@ucl.ac.uk>

Dr Tara Murphy <t.murphy@ich.ucl.ac.uk>

Department of Clinical, Educational and Health Psychology

University College London

Gower Street, London, WC1E 6BT

Thanks for reading this information sheet! You can keep this copy.

This study has been approved by the UCL Research Ethics Committee (Project ID number 2233/001).

Appendix 3: Child information sheet



An evaluation of a classroom presentation about Tourette Syndrome

Information Sheet for Young People with TS

We are inviting you to take part in this research project. You should only take part if you want to – if you don't want to, that's OK. Before you decide whether to take part, it's important to read this information sheet carefully (the researcher or your parent can read it out to you if you want). You can talk it over with other people too. Please ask us if there is anything you are not sure about or if you would like more information.

Who are we?

We are from University College London and we are working together with Tourettes Action. Our names are at the bottom of this sheet.

What is the project about?

We are trying to find out how a presentation (talk) telling other people in the class at school about Tourette Syndrome (TS) can help young people with TS. We want to learn about this from young people with TS themselves, and also from their parents, classmates and teachers.

Who is being invited to take part?

We are asking young people who have TS, their parents, classmates and teachers to take part. To take part in the study, it is a good idea if you are already thinking you might want your classmates to know some things about TS, like what it is, or how they should act towards someone who has it.

What will I be asked to do?

We would like to ask your teacher if he or she would give a presentation about TS made by Tourettes Action to your class. The presentation will be about TS in general and **not** about you. You would be in the classroom when the presentation is given, but you will be able to decide if you want to help with it or not. We will talk to you and your parents together before and after the presentation to find out what you think about it. Our meeting will be private between us, you and your parents and will last about an hour or less.

We will also ask your classmates to answer some questions before and after the presentation to find out what they know about TS and what they think about children who have TS. We will also talk with your teacher and to your classmates in small groups after the presentation. The questions we ask your classmates will **not** be about you. You will **not** be named in the questions.

What will happen afterwards?

Everything you, your parents, classmates and teacher tell us is anonymous; that means, no one will be asked to put their name on anything. If it is OK with you, we will audio-record our

conversations so that we have a record of what we talked about. We will then type up what was said but we will take out any information that can identify you and we will delete the recordings. We will make sure your information is kept private by using numbers instead of your name. What you tell us will be kept confidential (private). This means it is between you and us, and your parent. Your classmates and teacher won't hear about it. However, if you tell us something that makes us worry about your safety, we would have to tell other people.

When the study is over, we will write up a report and give you a short version of it. The report will not give the names of any of the people who took part in the study.

Are there any benefits of taking part?

We hope you will find it interesting to talk about what you thought of the presentation and anything that happened after it. We hope that we will learn some important things about giving presentations about TS from this study. This should help Tourettes Action and other young people with TS in the future.

Are there any risks of taking part?

We will be asking you about your feelings about how you get on with people in your class. If you feel upset at any point or do not want to continue, it is OK for you to stop. After the presentation, if anyone teases you, or says or does something hurtful, we will talk with you, your parents and your teacher about how to deal with this.

Do I have to take part?

No, you don't have to take part. It's up to you and your parent to decide.

What do I do now?

If you have any questions, please ask Claire Nussey using her email address or telephone number written below. If you decide to take part, we will ask you to sign a consent form.

The researchers are:

Claire Nussey
Email: c.c.nussey@googlemail.com
Telephone: 07939 28 70 20

Dr Nancy Pistrang <n.pistrang@ucl.ac.uk>
Dr Tara Murphy <t.murphy@ich.ucl.ac.uk>

Department of Clinical, Educational and Health Psychology
University College London
Gower Street, London, WC1E 6BT

Thanks for reading this information sheet! You can keep this copy.

This study has been approved by the UCL Research Ethics Committee (Project ID number 2233/001).

Appendix 4: Teacher information sheet



An evaluation of a classroom presentation about Tourette Syndrome

Information Sheet for Teachers

We are inviting you to take part in this research project. You should only participate if you want to; choosing not to take part will not disadvantage you. Before you decide whether you want to take part, it is important to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

Who are we?

We are researchers from University College London and we are working together with Tourettes Action. Our contact details are at the bottom of this sheet.

What is the project about?

Tourette Syndrome (TS) is a brain-based developmental disorder characterised by motor and vocal tics. The purpose of this research is to get a detailed picture of how a classroom presentation of factual information about TS may be helpful to young people with TS. This approach is recommended by Tourettes Action but has not been evaluated yet. This study will begin to do this by getting the views of young people with TS, their parents, their classmates and teacher (you).

Who is being invited to take part?

We are asking young people with TS to take part, as well as their parents, classmates and teacher. Ideally in order to take part, you, the child with TS in your class or their parent should be thinking that a classroom presentation about TS could be helpful, but this should not yet have been done. If this is not the case but you still wish to take part, we will be able to discuss this with you.

What will I be asked to do?

The main part of the study will take place at school so we will be asking for you to participate in the following ways:

The study will involve you giving a factual slide presentation about TS (produced by Tourettes Action) to the class, for example during a PSHE lesson. You will be given guidelines about how to do this. The presentation will be about TS in general and not about the particular child in your class; the child will not be named in the content of the presentation. The child will be in the classroom, but there will be flexibility in how the presentation is done so that he/she can be involved in as much or as little of it as he/she wishes. We will interview you 2-4 weeks following the presentation to find out what you thought about it. The interview will take place at school at a time that is convenient for you and will last about 20 minutes.

In addition, we will be asking the class to complete brief questionnaires about their knowledge about TS and attitudes towards children with TS in general before and after the presentation. We will also conduct small discussion groups each lasting 20 minutes with the classmates 2-4 weeks after the presentation to look at these areas in more detail. The questionnaires and discussion groups will not ask about classmates' attitudes towards the child with TS in particular; the child will not be named in the questionnaires or discussion groups. We will discuss with you the best time for classmates to carry out these tasks, for example during another PSHE lesson. We will provide you with information

sheets and parent withdrawal slips to send home to the parents of the classmates for this part of the study.

What will happen to the information that is collected?

All the questionnaires and interviews will be made anonymous; names and any identifying information will be removed so that no one taking part can be identified. With your permission, we will audio-record your interview and then transcribe (write up) what was said. We will delete the recording after it has been transcribed. All written information will be stored securely and will be destroyed five years after the project has ended. All data will be collected and stored in accordance with the Data Protection Act 1998.

Everything that you tell us will be kept confidential; only the research team will have access to what has been said. The only time confidentiality would be broken is if we were worried that you or somebody else was at risk of harm, and we would need to let the appropriate services know. However, we would try to talk to you about this before we spoke to anyone else.

Once the project is over, the results will be written up and may be submitted for publication in a professional journal. Reports will not reveal the identity of anyone who took part. They may include some anonymous quotations of things people have said during interviews which will be used to illustrate the findings. A summary of the findings will be given to those who took part in the project. You will have an opportunity to comment on the findings from your interview before the final report is written.

Are there any benefits of taking part?

We hope that you will find it interesting to give the presentation and talk to us about what it was like from your perspective. We hope that the presentation will also benefit the child with TS in your class. The research should give us a better understanding of the impact of such a presentation, and whether any changes should be made to it. Therefore, it should be helpful to Tourettes Action and to other young people with TS in the future.

Are there any risks of taking part?

If you feel uncomfortable answering any questions, you do not have to. We think it is unlikely that the child with TS will experience negative comments or bullying from other children following the presentation, but if this should occur we will discuss it with you (and with the child's parents) and will be able to provide information to help deal with this.

Do I have to take part?

No, you do not have to take part. It is up to you to decide. If you do decide to take part, you are still free to withdraw at any time without giving a reason.

What do I do now?

If you would like to take part, or if you have any questions, please contact Claire Nussey using the contact details below. Before taking part, we will ask you to sign a consent form.

The researchers are:

Claire Nussey
Email: c.c.nussey@googlemail.com
Telephone: 07939 28 70 20

Dr Nancy Pistrang <n.pistrang@ucl.ac.uk>
Dr Tara Murphy <t.murphy@ich.ucl.ac.uk>

Department of Clinical, Educational and Health Psychology
University College London
Gower Street, London, WC1E 6BT

Thanks for reading this information sheet! You can keep this copy.

This study has been approved by the UCL Research Ethics Committee (Project ID number 2233/001).

Appendix 5: Parent consent form



Informed Consent Form for Parents

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **An evaluation of a classroom presentation about Tourette Syndrome**

This study has been approved by the UCL Research Ethics Committee
[Project ID Number: 2233/001]

Thank you for your interest in taking part in this research. Before you agree to take part the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if my child or I decide at any time that we no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- understand that interviews may be audio-recorded, and consent to anonymised quotations from the interviews being used in reports.
- consent to the processing of personal information for the purposes of this research study.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me and to my child to my satisfaction, and I agree to my child and I taking part in this study.

Signed:

Date:

Appendix 6: Child consent form



An evaluation of a classroom presentation about Tourette Syndrome (TS)

Consent Form for Young People with TS

Please circle your answer to the questions below:

| | | |
|--|-------------|------------------|
| Have you read (or had read to you) the Information Sheet for Young People with TS? | Yes | No |
| Has someone explained this project to you? | Yes | No |
| Do you understand what this project is about? | Yes | No |
| Do you understand that some of things you say may be in our reports, without people knowing who you are? | Yes | No |
| Do you understand it's OK to stop taking part at any time? | Yes | No |
| Are you happy to take part? | Yes | No |
| If <u>any</u> answers are 'no' or you don't want to take part, don't sign your name! | | |
| If you would like to take part, please sign your name | | |
| Your name | Date | Signature |

This study has been approved by the UCL Research Ethics Committee [Project ID Number: 2233/001]

Appendix 7: Teacher consent form



Informed Consent Form for Teachers

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **An evaluation of a classroom presentation about Tourette Syndrome**

This study has been approved by the UCL Research Ethics Committee
[Project ID Number: 2233/001]

Thank you for your interest in taking part in this research. Before you agree to take part the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I

- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- understand that interviews may be audio-recorded, and consent to anonymised quotations from the interviews being used in reports.
- consent to the processing of personal information for the purposes of this research study.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- agree that the research project named above has been explained to me to my satisfaction, and I agree to take part in this study.

Signed:

Date:

Appendix 8: Classmate opt-in form



An evaluation of a classroom presentation about Tourette Syndrome (TS)

Information Sheet for Classmates and their Parents

Dear Parent,

We are inviting your child to take part in this research project. They should only take part if they want to – if they don't want to, that's OK. As their parent, you also need to agree for them to take part. Again, if you don't want them to, that's ok. Before you decide whether your child takes part, it's important to read this information sheet carefully and to read it to your child. You can talk it over with other people too. Please ask us if there is anything you are not sure about or if you would like more information.

Who are we?

We are from University College London and we are working together with Tourettes Action. Our names are at the bottom of this sheet.

What is the project about?

We are trying to find out how a classroom presentation about Tourette Syndrome (TS) can help young people with TS. We want to learn about this from young people with TS themselves, and also from their parents, classmates and teachers.

What will my child be asked to do?

Your child's teacher will be giving a presentation about TS made by Tourettes Action to the class. We would like your child to listen to the presentation and answer some questions before and after to find out what they know about TS and what they think about children who have TS. We will also talk with your child and their classmates in small groups, 2-4 weeks after the presentation to find out a bit more about what they think and know about TS. The discussion will last about 20 minutes.

What will happen afterwards?

The questionnaires your child completes will be anonymous (your child will not be asked to write their name on them). We will audio-record the group discussions so that we have a record of what was talked about. We will then type up what was said but we will take out any information that can identify your child and we will delete the recordings. When the study is over, we will write up a report and give you a summary of it. All written information will be stored securely and will be destroyed five years after the project has ended. All data will be collected and stored in accordance with the Data Protection Act 1998 and only the research team will have access to it. We will only break confidentiality if your child or someone else is at risk of harm and we need to let the appropriate services know. We would try to discuss this with you first.

Are there any benefits of taking part?

We hope your child will find it interesting to answer the questions and talk about what they thought of the presentation. We hope that we will learn some important things about giving presentations about TS from this study. This should help Tourettes Action and other young people with TS in the future.

Are there any risks of taking part?

We do not think that there are any risks of taking part. If your child feels upset at any point or does not want to continue, it is OK for them to stop.

What do I do now?

If you have any questions, please ask Claire Nussey using her email address or telephone number written below. If you are happy for your child to take part, you do not have to do anything and your child will automatically be included in the study. If you do **not** wish your child to take part, please complete the withdrawal slip below and return it to the class teacher.

The researchers are:

Claire Nussey
Email: c.c.nussey@googlemail.com
Telephone: 07939 28 70 20

Dr Nancy Pistrang <n.pistrang@ucl.ac.uk>
Dr Tara Murphy <t.murphy@ich.ucl.ac.uk>

Department of Clinical, Educational and Health Psychology
University College London
Gower Street, London, WC1E 6BT

Thanks for reading this information sheet! You can keep this copy.

This study has been approved by the UCL Research Ethics Committee (Project ID number 2233/001).

Parent Withdrawal Slip

If you do not want your child to take part in this study, please fill in this slip and return it to your child's teacher.

I would **not** like my child to take part in this study (please tick)

Child's Name:

School:

Appendix 9: Teacher information pack

**“An evaluation of a
classroom presentation
about Tourette
Syndrome” study**

**Teacher information pack
(electronic version)**

Thank you for agreeing to take part in this study. This pack contains information to help you to prepare for giving the presentation. Please don't hesitate to contact me, Claire Nussey, if you have any queries or concerns (c.c.nussey@googlemail.com, 07939287020). Hard copies of this pack are available upon request.

Contents of the teacher information pack

The powerpoint presentation

An electronic version has been sent to you by email with this pack. Please make sure you have saved this onto a computer that you will be able to use to give the presentation. (The presentation is also downloadable from <http://www.tourettes-action.org.uk/ts-presentations/> -select the version for primary school children).

Guidelines for teachers

These outline how to introduce the study and the presentation to the class. Please let the researcher know if there is anything that you feel is not appropriate/ applicable for your class.

Article " Managing Tourette's in the classroom"

You may like to read this to find out a little bit more background about Tourette Syndrome to help you answer any questions children may have following the presentation.

Information sheets and opt-out forms for classmates

Please distribute hard copies of these to the parents of all the children in your class (excluding the child with TS who is taking part in the study) the week before the presentation.

Copies of classmate questionnaires

You may like to take a look at the questionnaires before they are given to the children in your class. These are for your reference only- please do not give or show them to the children. This will be done by the researcher on the day of the presentation.

Information sheet and consent form- teacher version

You should have been sent a copy of the participant information sheet already and had an opportunity to discuss this with the researcher. Once you have done this, please read the consent form. If you are happy with what it says, please sign it and return it to the researcher on the day of the presentation.

"An evaluation of a classroom presentation about Tourette Syndrome" Study: Guidelines for teachers

The aim of these guidelines is to give you some examples of how to administer the questionnaires and give the presentation in the classroom to help you feel prepared and comfortable taking part in the study. The researcher will be on hand to help as needed. You may want to adapt the wording so that it feels natural and suits the needs of your class. If you have any comments or questions about these guidelines, don't hesitate to contact me, Claire Nussey (c.c.nussey@googlemail.com, 07939287020).

Before giving the presentation

You may want to check with the child with TS how they would like you to respond if another child asks if they or someone in the class has Tourette's, especially if they do not want the other children to know this. If the child has decided they want the class to know they have TS, we suggest you discuss with them at what point in the presentation you will do this. You may also want to ask the child if they wish to take part in giving the presentation in any way.

Introducing the study

Sample introduction: "Today we will be learning about ways in which children can be similar or different to each other. We have a visitor to our class today- her name is Claire. She is interested in finding out about what we are learning today. She will be coming back in a few weeks to talk to you about it a bit more."

Completing the questionnaires

Sample introduction: "We are going to start today by doing some worksheets Claire has brought along for us. It is not a test and isn't going to be marked, so just answer what you think." Give out the pack of worksheets to all the children, including the child with TS.

Continue with something like "has everyone got a worksheet? Ok, let's get started. Look at the first page of the worksheet. The first thing to do is fill in the bit at the top. In the space which says 'my initials are...' write your initials. Does anyone not know what that means? It means write the first letter of your first name and then the first letter of

your second name. Do not write your whole name, just the initials." Check that everyone has done this before continuing with something like "now write your age on the next line. So if you are 9 years old, write the number 9 in the space. Has everyone done this? Now I want you to put whether you are a boy or a girl. If you are a boy, put a circle around the word boy. If you are a girl, put a circle around the word girl. Finally, I want you to put today's date. Does everyone know the date? It's the [insert date] today so write [insert date] on the line." Check that everyone has completed all the information before continuing.

Read the instructions to first questionnaire "What I think of other people" then read aloud each item and ask the children to put their answer. Remind them not to look at other people's worksheets and that it is not a test, so to just answer what they think.

Once the children have completed the first questionnaire, ask them to turn over the page to the next worksheet. Read instructions to the second questionnaire "What I know about Tourette Syndrome" then read aloud each item and ask the children to put their answer. Give reminders as before if necessary.

Once the children have completed the second questionnaire, please check the child has put their initials at the top of each page and answered every question. The researcher will then collect the questionnaires.

The presentation

Sample introduction: "We are now going to learn about something called Tourette Syndrome. You may or may not know what this is. At the end of the presentation you will be able to ask questions." If applicable, say "[child with TS] is going to help me give this presentation because they know a lot about Tourette Syndrome." Continue by giving the powerpoint presentation. You may like to elaborate on the content of slides by asking the class questions about what certain terms mean, giving explanations or examples.

After the presentation

Ask if anyone has any questions. You may like to take 10 minutes to reinforce the main points of the presentation- what TS is and isn't, and how we should behave towards children with TS.

Two weeks later- questionnaires

Sample introduction: 'We have a visitor again today. Do you remember Claire- she came to our class a couple of weeks ago? She has come back today to find out a bit more about what we learnt the last time she was here. We are going to start by doing Claire's worksheets again.' Give out the questionnaire packs and repeat the instructions outlined in the "completing the questionnaires" section above.

Once the children have completed the second questionnaire, please check the child has put their initials at the top of each page and answered every question. The researcher will then collect the questionnaires.

Introducing the discussion groups

Sample introduction: "Now you are going to divide up into groups of 8. Some of you are going to go to [X] room to talk some more with Claire. The rest of you will stay here with me and do [topic of work] until it is your group's turn to go and talk to Claire. If any of you have any worries about doing this, come and talk to me." Please call groups of 8 children alphabetically from the register.

Teacher interview

The researcher would like to find out your views on how the presentation went. Please allow about 20 minutes for this after the discussion groups have been completed.

Appendix 10: Interview schedule for initial
child/parent interview

Interview schedule for initial child/parent interview

Background information (context):

1. We haven't met before and I don't know you, although your mum/dad has told me a bit about you. So, I was wondering... Can you tell me a bit about yourself?
 - a. [Use prompts as appropriate] How old are you? When were you born? Do you have any brothers and sisters? Who else lives at home? Which school do you go to? What year/class are you in? What is the name of your teacher? Do you have a favourite colour? Food? What do you enjoy doing? Is there anything you really don't like?
2. When did you first find out you had Tourette's?
 - a. How old were you? How did you find out? What was finding out like?
3. People have different names for their TS, what do you call it?
 - a. Is it ok to talk about it? Should I call it [their language] too?
4. What is your TS like at the moment?
 - a. How bad is it [use scaling], what type of ticks do you have, how long does a bad/good patch usually last?
5. [Does parent have anything to add?]

Impact of having TS:

6. What's it like having TS?
 - a. F/U e.g. "what makes it difficult?" Ask for examples of times when having TS makes them sad, angry...
7. When is TS most of a problem? Are there times when TS is less of a problem?
 - a. Ask for examples
8. Are there any good things about having TS?
 - a. Ask for examples e.g. what is good about having TS?
9. What do you think it would be like if you didn't have TS?
 - a. F/U e.g. what makes you think that? What do you think would be different?
10. [Does parent have anything to add?]

School:

11. Do you like going to school?
 - a. What makes you like/ not like going to school?

- b. How are you getting on with your schoolwork at the moment? [Does parent agree?]
12. Does having TS cause problems at school?
- a. Ask for examples e.g. what happens when you tic in the classroom/playground? What do other people say or do? How do you feel when that happens? E.g. angry, sad...
13. Who knows about your TS?
- a. What do they know? What do you think about that?

Peer relationships:

14. Do you have any friends?
- a. What are their names? Why do you like that person? What do you do together? Do they go to your school? Do you have friends at your school/in your class?
15. Are there any children at school you don't get along with?
- a. F/U e.g. ask them to define terms- bullies/teases/picks on? Ask what happens. Ask for examples. How often does that happen? What do you do when it happens? How do you feel when that happens? Why do you think that happens?
16. [Does parent have anything to add?]

The presentation (expectations):

17. What do you think about the presentation being given at school?
18. What do you hope will be different at school after the presentation?
19. Do you have any worries about the presentation?
- a. What are you worried about happening?
20. What do you most want the other kids in your class to know about TS from the presentation?
21. How do you think the other kids in your class will act after the presentation?
22. What do you think the best way for the presentation to be done is?
23. What do you think shouldn't happen in the presentation?
24. Do you want your teacher to tell the other children that you have TS during the presentation?
- a. Explore e.g. Can you tell me a bit about why/why not?
25. Is there anything else you want to tell me before the presentation?

26. [Does parent have anything to add?]

27. You have a choice in how much to take part in the presentation. Your teacher can do the whole thing and you can sit and watch, or you can say a bit of the presentation if you want to. What do you think you want to do?

28. [Does parent have anything to add?]

Feedback:

29. How did you find our talk today? Is there anything you think I should change for when we next meet or when I talk to the other children who are taking part in my project?

Appendix 11: Interview schedule for follow up
child/parent interview

Interview schedule for follow up child/parent interview

Content of the presentation:

1. What did you think of [teacher's name]'s presentation?
 - a. What was good about it? What was not so good about it? What do you remember best about it? Was anything left out that should have been in the presentation? How well do you think she answered the questions about Tourette's? Should she have done anything differently?

Experience of the presentation:

2. How did you feel during the presentation?
 - a. Embarrassed, worried, relaxed...?
 - b. What was making you feel like that?
 - c. What would have made you feel better about being in the classroom while your teacher was giving the presentation?
 - d. Was it the same/different to how you thought it would be? What was the same/different? Ask for examples...
3. Do you think it is a good idea for teachers to say that the presentation is being given because a child in the class has Tourette's? Do you think they should say who that child is?
 - a. What makes you think that?
4. You decided that you wanted/didn't want your teacher tell the other classmates that you have Tourette's at the end of the presentation?
 - a. What made you decide to do that?
 - b. [If applicable:] How did you feel when she told the other children? E.g. happy, worried... What made you feel like that?
5. Were you trying to keep your tics in during the presentation?
 - a. What was that like?
 - b. Did it make it harder to pay attention to the presentation?
 - c. What would have made it easier for you to manage your tics during the presentation?
6. [To parent] What did you hear about the presentation and from whom (e.g. child, teacher, TA)?
7. [To parent] What is your view of how the presentation went from what you've heard about it/ what you saw [if they were in the classroom]?
 - a. What was done well, less well, what could have been done differently?

Changes at school since the presentation:

8. What did the other kids in your class say to you immediately/straight away after the presentation?

9. Have they said anything to you about the presentation or about Tourette's over the last couple of weeks?
10. Do you think the presentation has changed what the other kids think about you? Remember it's fine to say less positive things- if you don't think the presentation has made any difference, it's important for me to know that.
 - a. Do you think it's made a difference to how they treat you/ react towards you?
 - b. In what way(s)?
11. Has anything changed at school since the presentation?
 - a. What has changed?
 - b. [To parent] has anything else changed at school since the presentation?
 - c. [To parent, if no changes] what would it take for this to change?
 - d. F/U on any specific issues mentioned by family during pre-presentation interview.
12. Has the presentation made any difference to how you feel about having TS?
 - a. To parent: Have you noticed any changes in how [child's name] thinks or feels about having TS since the presentation?
 - b. What do you make of that?

Recommending to others:

13. If another kid with TS asked you if a presentation was a good idea, what would you say?
 - a. To parent: what would you say if another parent of a child with TS asked you if a presentation was a good idea?
 - b. Would you recommend it to another kid with TS?
 - c. [Does parent agree?]
14. Is there anything that could be done differently if the presentation was given again?
 - a. Is there anything else you would have liked to have known before the presentation?
 - b. [Does parent have anything to add?]
15. Is there anything else you would like to tell me about the presentation?
 - a. [Does parent have anything to add?]

Appendix 12: Interview schedule for teachers

Interview schedule for teachers

Child's previous experience of school:

1. What has school been like for [child's name] in the past?
 - a. Do they enjoy school? Do they have any special/close/best friends? Have they been teased/picked on because of the Tourette's? What difficulties have you noticed as a result of the TS? What have past teachers said?
 - b. How have the other children reacted in the past when [child's name] did a tic in class?
2. What was your understanding of [child's name]'s difficulties before the presentation?
 - a. How did you try to manage these difficulties?

Teacher's experience of giving the presentation:

3. What was your understanding of Tourette's before the presentation?
4. How did you prepare for the presentation? Do you think this would have been different if you hadn't been taking part in this project?
 - a. In what way?
5. Did your understanding of Tourette's change as a result of giving the presentation?
 - a. If so, how?
6. How do you find giving the presentation?
 - a. How did you feel beforehand? E.g confident, nervous... What was contributing to you feeling that way?
 - b. What did you think went well?
 - c. What did you find more difficult?
7. Did you find the powerpoint presentation a helpful resource? Remember it's fine to say if you didn't!
 - a. Would you recommend any changes to it?
 - b. Did you require additional information about TS other than the powerpoint content?
 - c. Would you recommend it to another teacher who had a child in his/her class with TS?
 - d. How would you suggest they use it?
 - e. Would you do anything differently if you were giving another presentation about TS in the future?
 - f. Do you think it took place at the right time in the term/ school year? Why/ why not?

Changes since the presentation:

8. How did the class react to the presentation immediately afterwards?
 - a. Over the last two weeks?

9. Have you noticed any changes since the presentation? Again it's fine to say no!
 - a. In how [child's name] gets on with other children in the class?
 - b. In how other children behave towards [child's name]?
 - c. In how the other children respond when [child's name] does a tic in class?
 - d. Any other changes?
 - e. How do you understand/explain any changes?
 - f. Is there anything else that needs to change? What would it take for this to happen?

10. Is there any thing else you would like to tell me about the presentation?

Appendix 13: Focus group schedule

Focus group schedule

Warm up:

1. Okay, to start I'd like to go round the circle and you each to say one thing you liked or remember about the presentation...

Context:

2. Who had heard about Tourette's before the presentation? [Count number of hands]
3. What did you know about it?
4. Where did you hear about it/how did you find out about it?

Content of the presentation:

5. What did you learn about Tourette Syndrome (TS) from the presentation?
6. A couple of your classmates were away on the day the presentation was given two weeks ago. What would you tell them about Tourette's?
7. What did you like best about the presentation?
 - a. What did you like least?
 - b. Did anything surprise you about it?
 - c. Can you think of anything that would have make the presentation better?
 - d. Prompt: If your teacher gave the presentation to another class, what would you tell her to do to make it really good to listen to?
 - e. Your teacher doesn't want her presentation to be boring. What would you tell her not to do?
8. Is there anything about Tourette's you are still confused about?
9. Do you have any other questions about Tourette's that didn't get answered by the presentation?

Attitudes towards other children with Tourette's:

10. Before you saw the presentation, what would you have thought if you saw a child making unusual noises or movements? What would you have done?
11. What would you think if you saw another child making unusual noises or movements now? What would you do?
12. Has the presentation changed what you think about children with TS?
 - a. In what ways(s)?

13. Imagine there is a child called Mike. Mike is sitting really close to you when you eating your lunch. He keeps twitching his head and moving his arm about. Sometimes he makes a squeaking noise or sniffs. How do you feel about Mike sitting next to you?
 - a. Why/ what is it that makes you feel [insert feeling word]?
 - b. What will you do when Mike is sitting really close to you when you are eating your lunch?
14. Would you invite a child with tics to join in with your game? Why/why not?
15. Imagine there is a class of children a bit like you. Someone with tics is joining their class next term. What do you think it will be like for them having someone in their class with tics?
 - a. Prompt if necessary: what would be good about it? What would be less good?
16. Does anyone have anything else they want to say about any of the things we have talked about?

Appendix 14: Attitude questionnaire

MY INITIALS ARE: _____
MY AGE IS: _____ years
I AM A BOY/GIRL (circle one)

THE DATE TODAY IS: _____

What I Think of Other People

People think and feel different things about other people and that's ok. We would like to know what you think and feel about this child, John:

John is a boy about your age. You have noticed that John has unusual habits. He sniffs and grunts a lot. He often moves his head suddenly to the side.

Some sentences about John are going to be read out loud to you. Here is an example:

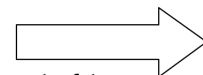
| | | Not True | Sort of True | Really True |
|---------|----------------------------------|--------------------------|-------------------------------------|--------------------------|
| EXAMPLE | I think John is as happy as I am | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |

INSTRUCTIONS:

- 1) Listen carefully to each sentence being read.
- 2) Read the sentence and the description of John again if you need to.
- 3) Tick the box to show if you think the sentence is NOT TRUE, SORT OF TRUE or REALLY TRUE for you. REMEMBER there are no right or wrong answers.

| | | Not True | Sort of True | Really True |
|---|---|--------------------------|--------------------------|--------------------------|
| 1 | I would be happy to be best friends with John | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 | I would feel happy doing a school project with John | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Turn the page to continue this set of questions



ID (Pre/post):

Page 1 of 1

MY INITIALS ARE: _____

| | | Not True | Sort of True | Really True |
|----|---|--------------------------|--------------------------|--------------------------|
| 3 | John is often sad | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 | I wouldn't talk to John | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5 | John needs lots of help to do things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | I would miss break time to keep John company | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 | John doesn't have much fun | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | I would be afraid of John | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | I would stick up for John if he was being teased | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10 | I would worry if John sat next to me in class | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11 | If John asked me to play at his house, I would not go | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12 | John wants lots of attention from adults | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

All finished? Well done!
Please wait until your teacher tells you to turn over the page.

Appendix 15: Knowledge questionnaire

MY INITIALS ARE: _____

What I know about Tourette Syndrome

Some children have something called 'Tourette Syndrome'. Some children have never heard of Tourette Syndrome whilst other children know quite a lot about it. We would like to find out what you know about Tourette Syndrome. It doesn't matter if you know lots, or nothing at all.

Some sentences about Tourette Syndrome are going to be read out loud to you. Here is an example:

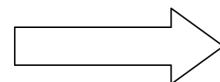
| | Not True | True | Don't know |
|---|--------------------------|-------------------------------------|--------------------------|
| EXAMPLE Some children have something called Tourette Syndrome | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |

INSTRUCTIONS: Listen carefully to each sentence being read. Read the sentence again if you need to. Tick the box to show if you think the sentence is NOT TRUE, TRUE or if you DON'T KNOW.

REMEMBER it's ok to not be sure of the answers. Don't guess- just tick "don't know" if you are not sure.

| | Not True | True | Don't know |
|--|--------------------------|--------------------------|--------------------------|
| 1 Children with Tourette Syndrome have lots of tics | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2 Tics can be small (blinking) or big (jumping) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3 Children with Tourette Syndrome make movements and noises on purpose | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4 Tics are noises and movements, a bit like habits. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Turn the page to continue this set of questions



MY INITIALS ARE: _____

| | | Not True | True | Don't Know |
|---|---|--------------------------|--------------------------|--------------------------|
| 5 | Everyone with Tourette Syndrome has the swearing tic | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6 | You can catch Tourette Syndrome from other children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7 | About 1 in 100 school children in England has Tourette Syndrome | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8 | Tourette Syndrome is equally common in boys and girls | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9 | Different tics come and go over time | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

All finished? Well done!
Please wait for your teacher to collect your forms.

Appendix 16: Example of thematic analysis



**Extract of the analysis of participant set 4 child/parent follow up interview
(page 6) with the initial codes and tentative themes by domain**

| | | | |
|---|----|---|---|
| | 1 | | |
| | 2 | I: Yeah. Alright then, yeah. And what did they | |
| | 3 | other kids in the class say to you immediately | |
| | 4 | after the presentation? If they said anything at all. | |
| | 5 | | |
| Positive interactions with the other children afterwards | 6 | C: They said, um, all the boys came over to me | Curiosity and enthusiasm Domain: classmates' attitudes/reactions |
| | 7 | and they were like crowding around saying like | |
| | 8 | that um, asking me questions and stuff. And I was | |
| | 9 | like answering them and stuff. And that went well. | |
| | 10 | And that went well. And then we just kind of | |
| | 11 | talked about the presentation a bit more and then, | |
| | 12 | and then we kind of went- I can't remember. | |
| | 13 | | |
| | 14 | M: Did you just go off any play then or? | |
| | 15 | | |
| | 16 | C: Ah, something like that I think so. | |
| | 17 | | |
| | 18 | I: Has anyone said anything to you about the | |
| | 19 | presentation or about Tourette's over the past | |
| | 20 | couple of weeks? | |
| | 21 | | |
| Positive comments from other children afterwards | 22 | C: Well the only thing I've probably, yeah, the | Enthusiasm Domain: classmates' attitudes/reactions |
| | 23 | only thing I've heard is (pause) [M: Mm] that the | |
| | 24 | presentation went really well, didn't it? | |
| | 25 | | |
| | 26 | M: Oh | |
| | 27 | | |
| | 28 | I: So people have been saying that kind of | |
| | 29 | comment to you have they? | |
| | 30 | | |
| | 31 | C: Yeah | |
| 32 | | | |
| | 33 | I: Oh okay | |
| | 34 | | |
| | 35 | C: A couple of times. | |
| | 36 | | |
| | 37 | I: Have you noticed any other changes, you know, | |
| | 38 | after the presentation. | |
| | 39 | | |
| People no longer 'bugging him'- see also page 7, lines 10-13 | 40 | C: Yeah because no one was asking me and stuff. | Enabling prosocial interactions Domain: Peer interactions/relationships |
| | 41 | It was exactly what we were discussing last time. | |
| | 42 | That people were a bit bugging me but I think | |
| | 43 | that's got better now, I haven't heard a word about | |
| | 44 | like "why do you do that" and stuff [I: mm] so it's | |
| | 45 | going a lot better. | |
| | 46 | | |

Initial list of codes generated for participant set four follow-up child/parent interview (– indicates cross-referencing of codes)

From child's comments:

Enjoyed the presentation
Thought the format made it easy to understand
No suggestions for improvements
Felt relaxed during the presentation
– Friends looking felt a bit weird but otherwise 'absolutely perfect'
– Surrounded by people he could trust
Surpassed expectations
Disclosure gives the presentation a context
A relief for others to know
– Trying to suppress tics until it was disclosed
Difficulty elaborating further [about what was good about the presentation]
Positive interactions with other children afterwards
Positive comments from other children afterwards
People no longer 'bugging him'
– Understand more now
Feel more comfortable having TS
– More able to answer questions
– Feels less ticky around less familiar people
– Letting tics out anywhere
Would recommend [the presentation] to others
Felt well-prepared for presentation

From parent's comments:

Child 'thrilled'
Child felt comfortable at school afterwards
Child felt 'it had been a really special day'
Found misunderstandings funny
Child got a lot out of it
Impact of research project
Much less anxious (no 'stress mode')
Confidence in general has grown- sharing presentation with others
Child was worried mum might embarrass him if she was there [during the presentation]
Particularly pleased about change in child- unexpected