PARENTING SKILLS TRAINING AS AN INTERVENTION FOR TIC DISORDERS

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical Psychology in the Faculty of Medical and Human Sciences

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SCHOOL OF PSYCHOLOGICAL SCIENCES
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Abstract

Tic disorders can have a significant emotional and social impact on children and their families. There is increasing support for the use of parenting programmes in childhood conditions; however research into the applicability of such programmes in tic disorders is limited. This thesis therefore aimed to investigate the topic of parenting interventions in tic disorders. The thesis presents five chapters, written as a series of self-contained papers and prepared in accordance with selected journal submission guidance.

Paper 1 is a systematic literature review of the implementation and effectiveness of behavioural parent training programmes across neurodevelopmental disorders. Twenty-two randomised controlled studies were included in the review. Neurodevelopmental disorders included attention deficit hyperactivity disorder, autistic spectrum conditions, intellectual difficulties and developmental disorders and tic disorders. Training programmes included Triple P, Barkley’s Defiant Children, Parent Child Interaction Therapy, New Forest Parenting, Parenting your Hyperactive Preschooler, Parents Plus Children, Preschoolers with Autism, Incredible Years and an idiosyncratic programme. Effects of interventions on child outcomes were examined alongside intervention characteristics and content. Results indicated robust evidence for effects of parent training on attention-deficit/hyperactivity difficulties and externalising difficulties, across neurodevelopmental disorders and training programmes. Evidence to support the effect of parent training on internalising, social and global difficulties across disorders was less robust, with fewer and inconsistent outcomes reported. Clinical and research implications resulting from the findings are discussed.

Papers 2 and 3 present empirical studies. Both studies are Q-methodological investigations into opinions on parenting interventions in tic disorders. Q-methodology is a technique which enables participants’ subjective viewpoints to be grouped using by-person factor analysis. Views on the acceptability, effectiveness, feasibility and utility of parenting interventions were explored across parents of children with tic disorders (Paper 2) and professionals (Paper 3). Across both studies, seven main factors were identified (parents four, professionals three). Findings highlighted that interventions were generally considered acceptable, justified and perceived as needed. However, important differences in opinions were found within and between parent and professional groups, highlighting key clinical considerations for possible intervention format, delivery and content. Paper 4 provides a commentary of the clinical implications of these findings when the two studies are considered together, and provides guidance to further develop and implement interventions.

Paper 5 presents a critical review, including discussion of the strengths, limitations and implications of the findings, alongside personal reflections on the research process.
Declaration
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**Dedication**
This thesis is dedicated to my Dad.

I am also eternally grateful to my Mum and Brother, who have faced our recent personal challenges with dignity, kindness and strength. Without them I would not have been able to continue with clinical training.

**Acknowledgements**
I am indebted to the participants who have donated their time and efforts to this research.

I would like to thank my supervisors Penny Bunton and Anja Wittkowski for their invaluable guidance and knowledge. I would also like to thank Hannah Butler for her advice and encouragement.

My clinical tutor, Lara Bennett, has been a continued support throughout my training and I am particularly grateful for her kindness.

Finally, I would like to thank each of my fellow trainees for their thoughtful reflections and friendship over the last three years.
Paper 1

A Systematic Review of Randomised Controlled Trials of Behavioural Parent Training Programmes for Parents of Children with Neurodevelopmental Disorders

Manuscript prepared in accordance with guidance for *Clinical Psychology Review* (Appendix 1)

Word count: 9782
Abstract
Parents and caregivers of children with neurodevelopmental disorders face significant challenges, which are exacerbated if children have additional emotional or behavioural difficulties. The current review aimed at exploring the implementation and effectiveness of behavioural parent training programmes across neurodevelopmental disorders. A systematic review of child outcomes in randomised controlled trials was undertaken. Twenty-two studies met inclusion criteria. Neurodevelopmental disorders included attention deficit hyperactivity disorder (n=10), autistic spectrum conditions (n=4), intellectual difficulties and developmental disorders (n=7) and tic disorders (n=1). Intervention programmes included Triple P (n=7), Barkley’s Defiant Children (n=2), Parent Child Interaction Therapy (n=3), New Forest Parenting (n=3), Parenting your Hyperactive Preschooler (n=1), Parents Plus Children (n=1), Preschoolers with Autism (n=1), Incredible Years (n=3) and one idiosyncratic programme.

Outcome measures were organised into five categories: attention-deficit/hyperactivity, externalising, internalising, social and global difficulties. Results indicated robust evidence for effects of parent training on attention-deficit/hyperactivity and externalising difficulties, across neurodevelopmental disorders and training programmes. Evidence to support the effect of parent training on internalising, social and global difficulties across disorders was less robust, with fewer and inconsistent outcomes reported.

In conclusion, parent training may provide a useful and effective intervention in the management of attention-deficit/hyperactivity and externalising difficulties for children with neurodevelopmental disorders.
Keywords: Behavioural Parent Training Programme, Neurodevelopmental Disorders, Outcomes, RCTs, Systematic Review.

Highlights

- Parent training programmes were evaluated across neurodevelopmental disorders
- Several programmes with many shared components have been implemented
- Transdiagnostic effects on attention/hyperactivity and externalising difficulties were robust
- Effects on internalising and social difficulties received less support
- Over-reliance on parent-rated measures was noted across studies
Introduction
The term ‘Neurodevelopmental disorder’ (NDD)\(^1\) is an umbrella diagnostic category incorporating several conditions characterised by early developmental onset and marked impairment. Within the Diagnostic and Statistical Manual-V (DSM-V) (American Psychiatric Association, APA, 2013), the main conditions falling under this heading include intellectual disabilities (ID) and learning impairments, autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), tic disorders and motor and communication disorders.

Whilst children whose disorder falls within the NDD diagnostic category are undoubtedly a heterogeneous group, it has been suggested that substantial overlaps in course, cause and epidemiology exist between conditions (Rutter, Kim-Cohen, & Maughan, 2006). Thus the parenting experiences of parents and caregivers of children with NDDs may be similar. Relative to ‘neurodevelopmentally typical’ children, those with NDDs raise different and additional challenges. Parents face heightened demands in the provision of specialised daily care and high levels of supervision and encouragement of new learning and development, attendance at medical appointments and providing advocate support (Plant & Sanders, 2007a). They often have to manage partnerships with health and school professionals (Buelow, Johnson, Perkins, Austin, & Dunn, 2013), balance employment demands (Shearn & Todd, 2000), manage their own emotional reactions to their child’s disability (Kearney & Griffin, 2001) and manage family level changes in sibling and marital relationships.

Children with NDDs also tend to exhibit higher levels of emotional and behavioural difficulties (Einfield & Tonge, 1996; Emerson & Einfield, 2010),

\(^1\)Abbreviations. NDD = Neurodevelopmental Disorder, BPTP = Behavioural Parent Training Programme, ADHD = Attention Deficit Hyperactivity Disorder, ASD = Autistic Spectrum Disorder, ID/DD = Intellectual Disability/ Developmental Disorder, CTAM = Clinical Trials Assessment Measure.
including conduct problems, self-injury, hyperactivity, social difficulties, emotional dysregulation and anxiety. Such problems have a significant impact on parents, children and wider society and they often persist into adulthood, impacting on educational, vocational and social opportunities (Einfeld et al., 2006). In addition, they are often associated with increased parental stress, depressive symptomology and negative parent-child interactions which can have mutually escalating effects on behaviour (Baker et al., 2003; Eisenhower, Baker, & Blacher, 2005; Plant & Sanders, 2007b) and can result in increased need for services and increased public healthcare costs (Einfeld et al., 2006).

Within both neurotypical and neuroatypical populations, psychological interventions in the form of behavioural parent training programmes (BPTPs) have been provided to parents of children with emotional and behavioural difficulties. Although different programmes vary in specific content, delivery and theoretical perspective, most BPTP interventions typically involve teaching parents positive strategies to manage their child’s needs, based on behavioural principles such as operant conditioning and social learning theory (Jones, Daley, Hutchings, Bywater, & Eames, 2007). Within neurodevelopmentally typical children, BPTPs have been increasingly implemented for children with conduct disorders and have demonstrated effectiveness in modifying childrens’ and parents’ behaviour within controlled trials (Michelson, Davenport, Dretzke, Barlow, & Day, 2013; Serketich & Dumas, 1996). BPTPs are now one of the most extensively used interventions for conduct difficulties and are recommended by UK national treatment guidelines (National Institute for Clinical Excellence, NICE, 2013). Given this growing evidence base for BPTPs within neurotypical groups, the current review sought to systematically examine and evaluate the use of these programmes within neuroatypical populations,
with a particular focus upon the effectiveness and implementation of BPTPs across NDDs.

Review Rationale

Although previous explorations of this research topic have been undertaken, this review aimed at extending those contributions by considering studies 1) across NDD classifications, 2) across the child lifespan, 3) across different parent training programmes, 4) involving only randomised controlled trials (RCTs) and 5) excluding multiple-component interventions.

Most previous reviews have addressed the effectiveness of BPTPs separately across sub-classifications of NDDs (e.g., ADHD: Sonuga-Barke et al., 2013; Zwi, Jones, Thorgaard, York, & Dennis, 2011; developmental disabilities: Petrenko, 2013) or have focussed on specific programmes (e.g., Parent Child Interaction Therapy: Wagner & McNeil, 2008; Stepping stones TRIPLE P: Tellegen & Sanders, 2013; Parents Plus Programme: Quinn, Carr, Carroll, & O’Sullivan, 2006). However, given commonalities across parental challenges and emotional and behavioural problems (ADHD: Waschbusch, 2002; ASD: Tonge, Brereton, Gray, & Einfeld, 1999; tic disorders: Robertson, 2008; Freeman et al., 2000; intellectual disabilities: Emerson & Einfeld, 2010; Emerson, Robertson, & Wood, 2004) these difficulties may be amenable to similar intervention methods. This review will thus examine the use of interventions from a wider perspective across programmes and across NDDs, including the often overlooked category of tic disorders. Finally, the review will examine only parent training and will exclude multiple component interventions with adjunctive child or teacher delivered elements (e.g., Fabiano et al., 2009; Lee, Niew, Yang, Chen, & Lin, 2012; Pelham & Fabiano, 2008), because
these limit attribution of effects to parent training alone (Brown, Whittingham, Boyd, & Sofronoff, 2013) and are likely to systematically differ across NDDs.

**Method**

**Search strategy**

Electronic searches were conducted using Psychinfo, EMBASE, AMED, Web of Knowledge (Web of Science and Medline) and the Cochrane library. Searches were completed in September 2013 and finalised in March 2014. Search terms involved combinations of words pertaining to disorder, intervention and design categories (see Table 1), with the Boolean operators ‘and’/‘or’ used to combine terms. Given the breadth of literature within this area, ‘near’ or ‘adjacent’ commands were also used to limit spatial parameters of multiple word combinations. Search results were limited to articles written in English and published in peer-reviewed journals. The years of publication were limited from 1990 to 2014 to reflect a period of increased popularity and increased methodological rigour in parent training evaluation research. To identify additional relevant peer-reviewed articles, manual searches were conducted using prominent parenting programme websites (Incredible Years, Triple P and Parent Child Interaction Therapy), and reference sections of selected studies and review articles.
<table>
<thead>
<tr>
<th>Disorder</th>
<th>Intervention 1</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervention 2</td>
<td>parent* intervention*, parent* training, parent* program*, parent* group*, caregiver* intervention*, caregiver* training, caregiver* program*, caregiver* group*, family intervention*,</td>
<td></td>
</tr>
</tbody>
</table>

*Note. Categories are delineated by column headings. Between category search terms were combined using the ‘and’ operator, with the exception of Intervention 1 and 2 categories which were limited using the ‘near/adjacent 15’ operator. Within category search terms were combined using the ‘or’ operator. The spatial proximity of within category multiple word phrases was limited using the ‘near/adjacent 5’ operator. Where a wildcard command (*) is presented, a database specific wildcard operator was used to denote multiple possible spellings or endings.*
Inclusion Criteria

Studies were included in the review if they 1) reported original results from an RCT, whereby a BPTP was compared to an appropriate control condition, 2) involved BPTPs which were defined as interventions with a predominant focus upon teaching parents behavioural strategies to manage emotional or behavioural difficulties, 3) involved parents/caregivers of children who were all under the age of 18 and reported to have a NDD, 4) included at least one standardised parent-rated outcome of child behaviour and provided sufficient information to calculate an effect size, 5) involved considerable face-to-face interaction with a clinician in an individual or small group setting. Studies were excluded if they 1) involved a pharmacological trial, 2) delivered additional directed intervention components to children or teachers (studies were retained if the child was involved to facilitate parent-directed naturalistic training), 3) reported the use of behavioural principles to primarily address another problem (e.g., sleep, attention, language) and not to manage child emotional or behavioural difficulties.

Data Extraction and Effect Sizes

The statistical significance of conducted analyses was obtained from the original reports. Effect sizes were calculated by the first author (GE) using sample size, pre- and post- group means and standard deviation data extracted from the original report or calculated using other information provided. For outcome measures, both total scale and subscale scores were extracted to maximise information. Effect sizes were calculated using the method reported by Tellegen and Sanders (2013), which is based on the formula provided by Morris (2008) and Carlson and Schmidt (1999). This method involves subtracting the mean pre- to post-intervention control group
change from that of the treatment group and dividing by the pooled pre-intervention standard deviation. By using both pre- and post-intervention data, this approach accounts for pre-intervention group differences and utilises all available information (Tellegen & Sanders, 2013). A correction factor was applied to account for any biases due to small sample size (Morris, 2008) and consistency in effect size direction was ensured by multiplying values by -1 where decreases in outcome scores reflected improvement. Effect sizes are denoted by $d$ and can be interpreted using the convention provided by Cohen (1992) of small (0.2), medium (0.5), and large (0.8) (Tellegen & Sanders, 2013). Where multiple treatment or control conditions were reported in a single study, effects sizes were calculated based on outcomes from the standard BPTP and waitlist control. Given variation in outcome measures, intervention delivery characteristics, and participant characteristics both within and across NDDs, a meta-analysis was considered inappropriate.

**Quality Assessment**

The Clinical Trials Assessment Measure (CTAM; Tarrier & Wykes, 2004), used to rate the quality of the identified studies, was selected given its specific applicability to controlled psychological trials. It provides structured exploration of potential sources of bias or low quality across six domains: sample, allocation, control, assessment, analysis and treatment. All papers were quality assessed by the first author (GE) and 25% were double-rated by a second independent reviewer. Interrater agreement was calculated across all CTAM items and was found to be adequate ($r=0.92$). Due to practical limitations, study authors could not be contacted to clarify details for CTAM ratings, meaning that scores may reflect issues in study reporting rather than design. Consequently, threshold interpretations of CTAM scores were
avoided (e.g., Wykes, Steel, Everitt, & Tarrier, 2008) and increased focus was placed upon the highlighted methodological strengths and weaknesses of studies rather than quantitative comparisons between studies.

**Results**

*Sample*

The initial electronic database search yielded 441 records, which was reduced to 273 after removing duplicates. Titles and abstracts were screened and 199 records were excluded because they were not relevant or did not meet inclusion criteria. The remaining 74 articles were reviewed in full along with a further 12 articles that were identified as potentially relevant, following manual screening of parenting websites and reference lists from identified reviews and papers. In all, twenty-two studies² met inclusion criteria and were included in the review. See Figure 1 for a PRISMA flow diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) demonstrating the article selection process.

²Sonuga-Barke et al. (2004) amalgamated data which combined two groups of control participants, one of which is also reported in Sonuga-Barke et al. (2001). Given independent treatment groups these studies were treated as separate.
441 records identified through database searching

273 records remaining after duplicates removed

273 records screened using titles and abstracts

199 excluded:
5 corrections
86 not original data (e.g., reviews/conference abstracts/study protocols/discussion papers/language)
22 not RCTs
46 NDD criteria
26 intervention criteria (part of medical trial)
14 multi-component intervention

86 full text articles assessed for eligibility:
- 74 from database searches
- 12 from additional sources

64 excluded:
8 design criteria (e.g., qualitative data/follow-up data/not RCT)
1 adult participants
10 NDD criteria
13 multi-component intervention
5 no standardised child outcome
13 BPTP criteria (e.g., not BPTP/behavioural principles reported but management of child behavioural or emotional problems not primary aim)
10 no appropriate comparison group
3 clinician contact (self-help, bibliotherapy, seminars)
1 insufficient data for effect sizes

22 articles included in the review

Figure 1. A flow diagram of the search process
Study Design

Table 2 presents a summary of study characteristics. All studies reported random assignment of participants to BPTP or control conditions. Control conditions consisted of waitlists, in which interventions were offered following study completion. Five studies included treatment conditions in addition of the BPTP and control. Two studies reported enhanced BPTP conditions (Bor et al., 2002; Plant & Sanders, 2007a), one study used a workshop delivery BPTP condition (Sofronoff et al., 2004), one study used a non-BPTP counselling and support treatment (Sonuga-Barke et al., 2001) and one study used an education and counselling treatment (Tonge et al., 2014). All studies completed assessments pre and post-intervention. Twelve studies completed follow-up assessments\(^3\), with durations ranging from 2 months to 1 year. Studies were completed across several countries, including Australia (N=8), U.S. (N=5), UK (N=5), Portugal (N=1), China (N=1), Puerto Rico (N=1) and the Netherlands (N=1).

\(^3\) Refers to studies in which the results of follow-up assessments were reported within the same report only.
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Prog.</th>
<th>Location</th>
<th>N(^1)</th>
<th>Conditions (N per group)</th>
<th>Diagnosis</th>
<th>NDD group</th>
<th>Behav. inclusion</th>
<th>Age limits</th>
<th>Follow up(^3)</th>
<th>CTAM score</th>
</tr>
</thead>
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<tr>
<td>Hoofdakker et al., (2007)</td>
<td>BDC(^3)</td>
<td>Netherlands</td>
<td>94</td>
<td>BPTP (47), control (47)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>no</td>
<td>4-12yr</td>
<td>6mo</td>
<td>54</td>
</tr>
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<td>Seabill et al., (2006)</td>
<td>BDC</td>
<td>America</td>
<td>24</td>
<td>BPTP (12), control (12)</td>
<td>Tic disorders</td>
<td>TSC</td>
<td>yes</td>
<td>6-12yr</td>
<td>no</td>
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<td>Unspe.</td>
<td>Australia</td>
<td>51</td>
<td>standard BPTP (18), workshop BPTP (18), control (15)</td>
<td>Asperger syndrome</td>
<td>ASD</td>
<td>no</td>
<td>6-12yr</td>
<td>3mo</td>
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<tr>
<td>Azevedo et al., (2013)</td>
<td>IY</td>
<td>Portugal</td>
<td>100</td>
<td>BPTP (52), control (48)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>no(^2)</td>
<td>3-6yr</td>
<td>no(^3)</td>
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<tr>
<td>Jones et al., (2007)</td>
<td>IY</td>
<td>Wales UK</td>
<td>79</td>
<td>BPTP (50), control (29)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>yes</td>
<td>36-48 mo</td>
<td>no</td>
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<td>McIntyre (2008)</td>
<td>IY</td>
<td>America</td>
<td>44</td>
<td>BPTP (21), control (23)</td>
<td>developmental disabilities</td>
<td>ID/DD</td>
<td>no</td>
<td>2-5yr</td>
<td>no</td>
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<td>Somua-Barke et al., (2004)</td>
<td>NFP</td>
<td>England</td>
<td>89</td>
<td>BPTP (59), control (30)</td>
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<td>ADHD</td>
<td>no</td>
<td>3yr</td>
<td>no(^3)</td>
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<td>England</td>
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<td>BPTP (30) counselling/support (28) control (20)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>no</td>
<td>3yr</td>
<td>15w</td>
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<td>NFP</td>
<td>Guernsey</td>
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<td>BPTP (17), control (13)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>no</td>
<td>preschool(2-5-6-4yr)</td>
<td>2mo</td>
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<td>America</td>
<td>31</td>
<td>BPTP (17), control (14)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>no</td>
<td>preschool</td>
<td>no</td>
<td>62</td>
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<td>Hand et al., (2012)</td>
<td>PPC</td>
<td>Ireland</td>
<td>29</td>
<td>BPTP (16), control (13)</td>
<td>mild ID (ID, ASD, Down syndrome, dyspraxia, Prader-Willi, Williams-Beuren, epilepsy, speech delay)</td>
<td>ID/DD</td>
<td>no</td>
<td>6-12yr</td>
<td>no</td>
<td>36</td>
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<td>PCTT</td>
<td>America</td>
<td>22</td>
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<td>mental retardation (mild or moderate)</td>
<td>ID/DD</td>
<td>yes</td>
<td>3.6 yr</td>
<td>no</td>
<td>59</td>
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<td>PCTT</td>
<td>Puerto Rica</td>
<td>32</td>
<td>BPTP (20), control (12)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>yes</td>
<td>4.6 yr</td>
<td>14w</td>
<td>49</td>
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<td>America</td>
<td>19</td>
<td>BPTP (10), control (9)</td>
<td>ASD</td>
<td>ASD</td>
<td>yes</td>
<td>5-12 yr</td>
<td>no</td>
<td>43</td>
</tr>
<tr>
<td>Bor et al., (2002)</td>
<td>TP</td>
<td>Australia</td>
<td>63</td>
<td>standard BPTP (21), enhanced BPTP (15), control (27)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>yes</td>
<td>36-48 mo</td>
<td>1yr</td>
<td>48</td>
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<tr>
<td>Leung et al., (2013)</td>
<td>TP</td>
<td>China</td>
<td>81</td>
<td>BPTP (42), control (39)</td>
<td>developmental disabilities (physical disability, ASD, DD)</td>
<td>ID/DD</td>
<td>no</td>
<td>preschool</td>
<td>6mo</td>
<td>52</td>
</tr>
<tr>
<td>Hoath et al., (2002)</td>
<td>TP</td>
<td>Australia</td>
<td>20</td>
<td>BPTP (9), control (11)</td>
<td>ADHD</td>
<td>ADHD</td>
<td>yes</td>
<td>5-9yr</td>
<td>12w</td>
<td>38</td>
</tr>
<tr>
<td>Plant et al., (2007)</td>
<td>TP-SS</td>
<td>Australia</td>
<td>74</td>
<td>standard BPTP (26), enhanced BPTP (24), control (24)</td>
<td>developmental disabilities (ASD, global DD, Down syndrome, chromosomal abnormality, cerebral palsy)</td>
<td>ID/DD</td>
<td>yes</td>
<td>preschool</td>
<td>1yr</td>
<td>48</td>
</tr>
<tr>
<td>Roberts et al., (2002)</td>
<td>TP-SS</td>
<td>Australia</td>
<td>47</td>
<td>BPTP (27), control (20)</td>
<td>developmental disabilities (down syndrome, genetic syndromes, cerebral palsy, accident, disease)</td>
<td>ID/DD</td>
<td>no</td>
<td>2-7 yr</td>
<td>6 mo</td>
<td>58</td>
</tr>
<tr>
<td>Roux et al., (2013)</td>
<td>TP-SS</td>
<td>Australia</td>
<td>52</td>
<td>BPTP (28), control (24)</td>
<td>developmental disabilities (ASD, down syndrome, cerebral palsy, ID)</td>
<td>ID/DD</td>
<td>no</td>
<td>2-9 yr</td>
<td>6 mo</td>
<td>50</td>
</tr>
<tr>
<td>Whittingham et al., (2009)</td>
<td>TP-SS</td>
<td>Australia</td>
<td>59</td>
<td>BPTP (29), control (30)</td>
<td>ASD</td>
<td>ASD</td>
<td>yes</td>
<td>2-9 yr</td>
<td>6 mo</td>
<td>52</td>
</tr>
<tr>
<td>Tonge et al., (2014)</td>
<td>PWA</td>
<td>Australia</td>
<td>103</td>
<td>BPTP (35), education and counselling (33), control (35)</td>
<td>ASD</td>
<td>ASD</td>
<td>no</td>
<td>2.6-5 yr</td>
<td>no(^3)</td>
<td>68</td>
</tr>
</tbody>
</table>

Note. If location of the study was not explicit the author affiliated location is provided. Behavioural inclusion refers to whether behavioural difficulties were specified in inclusion criteria. \(^1\)N refers to the number of participants contained in the analysis. \(^2\)Behavioural difficulties may have constituted inclusion criteria for some participants. \(^3\)post-intervention assessments were delayed, \(^4\)reported in reviewed article only, \(^5\)includes components from BDC and other programmes. Prog. = programme, Yr=year, mo=month, w=week, ADHD=attention deficit hyperactivity disorder, ASD=autistic spectrum disorder, ID=intellectual difficulties, DD=developmental delay, BPTP=Behavioural Parent Training Programme, BDC=Barkley’s Defiant Children Programme, PCTT=Parent Child Interaction Therapy, NFP=New Forest Parenting Programme, PYP=Parenting your Hyperactive Preschooler Programme, PPC=Parents Plus Children Programme, PWA=Preschoolers With Autism, IY=Incredible Years Programme, Unspe.=idiiosyncratic programme.
Participant Characteristics

Sample sizes\(^4\) ranged from 19 to 103 participants. All studies specified child age restrictions. The maximum age limit was 12 years, and over half of the studies only included participants under 7 years (n=14). The mean age of children was 5 years (SD=2, n=20), and approximately \(\frac{3}{4}\) of children were male (n=18).

Studies included children with a range of NDDs. These fell into four main categories: ADHD (n=10), ASD (n=4), ID/DD (n=7) and tic disorders (n=1). Unlike the other categories, the ID/DD studies contained diagnostically heterogeneous samples, often labelled ‘mixed disabilities’. Children within the ID/DD category had multiple diagnoses (e.g., ASD, Down syndrome, cerebral palsy, chromosomal/genetic abnormalities, global ID, epilepsy, speech delay, dyspraxia).

Recruitment and Diagnostic Criteria

Four studies recruited exclusively from clinical sources (Scahill et al., 2006; Sofronoff et al., 2004; Tonge et al., 2014; Hoofdakker et al., 2007), whilst the remaining studies recruited from either clinical and community sources or community sources alone.

Studies targeting children with ASD, tic disorders and ID/DD all included children with previous clinical diagnoses, or stated that children met clinician-based diagnostic criteria. Of the studies targeting children with ADHD, only two specified that children had received clinician-based diagnoses and the remainder included children that met ADHD symptom criteria at screening assessment based on parent-rated measures. Ten studies required children to exhibit elevated levels of parent-rated disruptive behaviour (ADHD=5; ASD=2; tic disorders=1; ID/DD=2).

\(^4\) Figures based on the number of participants included in analyses across all conditions.
Table 3 presents details of the interventions delivered for each study. Eight programmes were implemented across the studies: Triple P Positive Parenting (n=7), Barkley’s Defiant Children (n=2), Parent Child Interaction Therapy (n=3), New Forest Parenting (n=3), Parenting your Hyperactive Preschooler (n=1), Parents Plus Children (n=1), Preschoolers with Autism (n=1), Incredible Years (n=3) and an idiosyncratic programme for Asperger syndrome (n=1). All programmes were manualised.

All programmes implemented techniques to improve parent-child interactions, relationships/communication, promote positive child behaviour and manage negative behaviour. Five of the programmes were implemented across only one NDD category (New Forest Parenting, Parenting your Hyperactive Preschooler, Parents Plus Children, Preschoolers with Autism, idiosyncratic Asperger syndrome programme), which totalled seven studies. Four of the core programmes were implemented across several NDDs (Incredible Years, Triple P, Parent Child Interaction Therapy, Barkley’s Defiant Child), which resulted in 15 studies. Of these 15 studies, seven reported implementing modifications to the standard programme (Hoath et al., 2002; Hoofdakker et al., 2007; Matos et al., 2009; McIntrye, 2008; Scahill et al., 2006; Solomon et al., 2008; Whittingham et al., 2009). Modifications involved NDD-specific psycho-education and adaptation of standard techniques to increase applicability to specific needs, for example, completing functional assessments to identify functionally equivalent replacement behaviours and adapting play to account for children’s developmental and communication levels (McIntrye, 2008b). Despite geographic variation, only one study explicitly reported cultural adaptations to the intervention programme (Matos et al., 2009) and only one study
reported adaptations for parents’ own learning difficulties in addition to their child’s (Hand et al., 2012).

In terms of intervention delivery, 11 studies implemented individual interventions and 11 studies predominately implemented group-level delivery. The number of face-to-face intervention sessions ranged from 5 to 20, with session length ranging from 1 to 2.5 hours. Four studies provided a variable number of sessions dependent on participants’ progress (Bagner et al., 2007; Matos et al., 2009; Solomon et al., 2008; Whittingham et al., 2009). Drop-out rates from treatment ranged from 0 to 37%, although most studies reported attrition to be below 15%. Most interventions explicitly reported delivery by psychologists (n=13); however, social workers (Leung et al., 2013), health visitors (Sonuga-Barke et al., 2004; 2001) and nurses (Thompson et al., 2009) also delivered treatments across four studies.

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5 Adjunctive individual components were also provided across several group-based interventions.
## Table 3. Intervention Characteristics of the Reviewed Studies organised by Parenting Programme

<table>
<thead>
<tr>
<th>Author, year</th>
<th>NDD</th>
<th>Prog.</th>
<th>General Core Programme Content</th>
<th>Adaptations</th>
<th>Delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoofdakker et al. (2007)</td>
<td>ADHD</td>
<td>BDC²</td>
<td>Psychoeducation, techniques to positively reinforce appropriate behaviour (token economies, positive attending); discourage negative behaviour (consistent consequences, selective ignoring, time-out), promote relationships (play and communication (communicating directions effectively), generalisation (anticipate problems, manipulate settings, generalisation to other situations, public places, school behaviour). Teaching methods include role-play, modelling, corrective therapist feedback, resources (books, handouts), home assignments.</td>
<td>Increased focus on anticipating misbehaviours, manipulating antecedents, modifying parental cognitions, home assignments. Parents write weekly reports.</td>
<td>Group. 12ss, 120min.</td>
</tr>
<tr>
<td>Scahill et al. (2006)</td>
<td>TICS</td>
<td>BDC</td>
<td>Psychoeducation, traditional behaviour management techniques (interrupting, managing non-compliance), managing specific behaviour difficulties (bedtime, rigid behaviours and routines, ritualistic behaviours, literal interpretation, special interests), anxiety management, comic strip conversations and social stories. Teaching methods include workbooks, video demonstrations, interactive teaching.</td>
<td>Tics psychoeducation provided pre-randomisation.</td>
<td>Individual. 10ss.</td>
</tr>
<tr>
<td>Sofronoff et al., (2004)</td>
<td>ASD</td>
<td>Unspe.</td>
<td>Psychoeducation, addressing parent cognitions (child acceptance, feelings about behaviour, coping instances), communication (recruiting attention and eye contact, clear messages, limit setting, avoiding confrontations, routine, countdown, reminders, voice control, firmness), reinforcement of positive behaviours (praise) discourage negative behaviours (distraction, time-out). Teaching methods include naturalistic teaching, therapist observation and feedback, behavioural diaries and home assignments.</td>
<td>None</td>
<td>Individual. 6ss, 60 min. (workshop one day).</td>
</tr>
<tr>
<td>Azevedo et al., (2013)</td>
<td>ADHD</td>
<td>IY</td>
<td>Techniques to strengthen child development and relationships (play, descriptive commenting), promote positive behaviour (praise, rewards), discourage negative behaviour (ignoring, time-out, consequences, managing challenging behaviour), limit setting (household rules, routines, clear instructions, effective limit setting) and parent/family development (problem-solving, self-calming thoughts). Teaching methods include home assignments, buddy-calls, resources (books, handouts, cds), video vignettes, brainstorming, group discussions, role-play, modelling, didactic teaching.</td>
<td>None</td>
<td>Group. 14ss, 120min. weekly calls, 2 booster ss.</td>
</tr>
<tr>
<td>Jones et al., (2007)</td>
<td>ADHD</td>
<td>IY</td>
<td></td>
<td>Toddler programme adaptations used, child’s developmental level considered throughout. Additional content on blessings and challenges of NDD, functional assessment and service provision (McIntyre, 2008b).</td>
<td>Group. 12ss, 150min. weekly calls.</td>
</tr>
<tr>
<td>McIntyre (2008)</td>
<td>ID/DD</td>
<td>IY</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sonuga-Barke et al., (2004)</td>
<td>ADHD</td>
<td>NFP</td>
<td>Psychoeducation, addressing parental cognitions (child acceptance, feelings about behaviour, coping instances), communication (recruiting attention and eye contact, clear messages, limit setting, avoiding confrontations, routine, countdown, reminders, voice control, firmness), reinforcement of positive behaviours (praise) discourage negative behaviours (distraction, time-out). Teaching methods include naturalistic teaching, therapist observation and feedback, behavioural diaries and home assignments.</td>
<td>ADHD programme</td>
<td>Individual. 8ss, 60 min.</td>
</tr>
<tr>
<td>Sonuga-Barke et al., (2001)</td>
<td>ADHD</td>
<td>NFP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thompson et al., (2009)</td>
<td>ADHD</td>
<td>NFP</td>
<td>Psychoeducation of ADHD, techniques to reinforce appropriate behaviour (praise, attention, rewards), discourage negative behaviour (consequences, time out), enhance communication (effective commands) and develop children’s skills (problem solving, negotiation). Teaching methods include role-play and home assignments.</td>
<td>Revised version of programme. Targets ADHD cognitive deficits using parent-directed games to enhance children’s attention, concentration, turn taking, working memory and inhibition skills.</td>
<td>Individual. 8ss.</td>
</tr>
<tr>
<td>Author, Year</td>
<td>NDD</td>
<td>Prog.</td>
<td>General Core Programme Content</td>
<td>Adaptations</td>
<td>Delivery</td>
</tr>
<tr>
<td>------------</td>
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<td>---------</td>
</tr>
<tr>
<td>Hand et al., (2012)</td>
<td>ID/DD PPC</td>
<td>Techniques to promote relationships (play, special time), parent management skills (establishing routines, dealing with special needs, solving children’s problems), promote positive behaviour (positive instruction, encouragement, supporting homework) discourage negative behaviour (consequences, sanction systems, assertive parenting), develop children’s skills (self-esteem, problem solving), and prevention strategies. Teaching methods include role play, home assignments, weekly planning, modelling, group discussions, video-modelling.</td>
<td>Videos used from an early years programme, increased use of visual representations and one-to-one parent support from speech and language therapy for parents with ID, self-reported literacy difficulties or second language English.</td>
<td>Group. 8ss,150 min.</td>
<td></td>
</tr>
<tr>
<td>Bagner et al., (2007)</td>
<td>ID/DD PCIT</td>
<td>PCIT begins with a child directed interaction (CDI) phase and progresses through to a parent directed interaction (PDI) phase. Phase transition and programme completion is determined by skill mastery levels demonstrated during therapist observed interactions. CDI includes techniques to enhance parent-child relationships (child led play, descriptive commentary, imitation), positive parenting (praise, non-critical communication) and child social skills. PDI includes setting limits and consistent responses to behaviour (clear commands, timeout, praise, generalisation across settings). Teaching methods involve real-time coaching of parents using in-ear microphones during child interactions.</td>
<td>None.</td>
<td>Individual. 12ss (average), 60min.</td>
<td></td>
</tr>
<tr>
<td>Matos et al., (2009)</td>
<td>ADHD PCIT</td>
<td>Cultural adaptations for Puerto Rican families, pharmacological treatment psychoeducation, modification of time-out to limit force.</td>
<td>None.</td>
<td>Individual. 17ss (max), 90min.</td>
<td></td>
</tr>
<tr>
<td>Solomon et al., (2008)</td>
<td>ASD PCIT</td>
<td>ASD specific adaptations including prohibiting excessive special interest talk, significant praise for child initiated interactions, directive parent-led play when child-led play is isolating or inappropriately controlling.</td>
<td>Individual. 14ss (max).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bor et al., (2002)</td>
<td>ADHD TP</td>
<td>17 core child management strategies taught; 10 promote child competence and development (quality time, talking, physical affection, praise, attention, engaging activities, modelling, ask-say-do, incidental teaching, behaviour charts) and 7 manage misbehaviour (rules, directed discussion, ignoring, instructions, logical consequences, quiet time, time-out). Six-step planned activities routine also taught to enhance generalization of skills (planning, rules, selecting engaging activities, rewards, consequences, follow-up discussions). Teaching methods include, modelling, therapist feedback, role-play, home assignments, didactic teaching, video-modelling, resources (workbook, handouts).</td>
<td>None (enhanced condition involves partner support and coping skills content).</td>
<td>Individual. 10ss, 60-90 min (enhanced, 12ss).</td>
<td></td>
</tr>
<tr>
<td>Leung et al., (2013)</td>
<td>ID/DD TP</td>
<td>ADHD adaptations include psychoeducation, emphasis on ADHD deficits and their consequences for behaviour and parenting needs, parent relationship components (partner/social supports, problem-solving, relaxation techniques, personal coping).</td>
<td>None.</td>
<td>Group. 6ss 120min, 2 calls.</td>
<td></td>
</tr>
<tr>
<td>Hoath et al., (2002)</td>
<td>ADHD TP</td>
<td>None (enhanced condition includes content on grief issues, stress and coping, time management, professional partnerships, social supports).</td>
<td>Individual. 10ss, 60-90min (enhanced, 16ss).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plant et al., (2007a)</td>
<td>ID/DD TP-SS</td>
<td>Stepping Stones is an extension of the Triple P programme with additional content and adaptations for children with disabilities. 25 core child management strategies are taught; 14 to promote competence and development (tangible rewards, activity schedules, physical guidance, teaching backwards), and 11 to manage misbehaviour (diversion, communication, blocking, brief interruption). Teaching methods include, role-play, home assignments, didactic teaching, video-modelling, resources (workbook, handouts).</td>
<td>Partner support and coping skills content was provided to parents with additional needs.</td>
<td>Individual. 10ss, 120 min.</td>
<td></td>
</tr>
<tr>
<td>Roux et al., (2013)</td>
<td>ID/DD TP-SS</td>
<td>Additional social communication components including comic strip conversations and social stories techniques.</td>
<td>None.</td>
<td>Individual. 9ss (5 group, 4 individual)</td>
<td></td>
</tr>
<tr>
<td>Whittingham et al., (2009)</td>
<td>ASD TP-SS</td>
<td>Topics include helping parents to discuss their reactions to the diagnosis, understand autistic difficulties and their child’s developmental profile. Uses positive behaviour support principles to help parents to understand and manage difficult behaviour. Content to encourage new behaviour, support communication skills, social functioning and play. Educational content around accessing services, parental stress and grief and wider systemic reactions to autism. Teaching methods include, role-play, home assignments, didactic teaching, video-modelling, resources (workbook, handouts).</td>
<td>Additional social communication components including comic strip conversations and social stories techniques.</td>
<td>Group. 9ss (5 group, 4 individual)</td>
<td></td>
</tr>
<tr>
<td>Tonge et al., (2014)</td>
<td>ASD PWA</td>
<td>Autism specific intervention.</td>
<td>20ss alternating between group and individual.</td>
<td>60-90min.</td>
<td></td>
</tr>
</tbody>
</table>

Note. Calls refers to individual telephone calls. ss= sessions, min=minutes. 1Number of sessions varied according to participant needs. 2Includes components from BDC and other programmes. Prog.=programme, NDD=Neurodevelopmental Disorder, BDC=Barclay’s Defiant Children Programme, PCIT=Parent Child Interaction Therapy, NFP=New Forest Parenting Programme, PYHP=Parenting your Hyperactive Preschooler Programme, PPC=Parents Plus Children Programme, IY= Incredible Years Programme, Unspe.=idiosyncratic custom programme, TP=Triple P, TP-SS=Triple P-Stepping Stones, ADHD=attention deficit hyperactivity disorder, ASD=autistic spectrum disorder, ID/DD=intellectual difficulties/developmental delay, TICS=Tic disorders.
Quality Assessment

CTAM quality ratings are reported in Table 2. The CTAM measure provides scores ranging from 0 to a maximum of 100. Variability in quality ratings was considerable across studies, with overall scores ranging from 36 to 84. Only one study scored above 75 on the CTAM (i.e., within the top 25%), while 13 fell within the 50-74 range and eight had scores below 50.

In terms of highlighted strengths, CTAM scores identified that all studies completed appropriate analyses (n=22), all involved appropriately described and manualised treatments (n=22) and with the exception of one, almost all implemented treatment protocol adherence or quality assessment (n=21). However, in terms of sample characteristics, CTAM ratings identified that a large number of studies recruited from community sources and relied upon volunteering (n=10). This introduces potential bias given that participants were likely to be self-selected, motivated and results are thus less generalisable to clinical samples. Most studies also failed to report adequate power analyses or contained sample sizes less than 27 per group (n=13). Despite including only ‘gold standard’ design RCTs, most studies failed to adequately describe the process of randomisation (n=10) or to implement an independent method of randomisation (n=20). Two studies included alternative treatment control groups (Sonuga-Barke et al., 2001; Tonge et al., 2014), whilst the remainder involved only waitlist controls. As most studies did not account for non-specific effects of therapy, results may not be attributable to the specific intervention delivered.

In terms of assessments, whilst all studies included at least one standardised measure of child outcome, most did not implement blinded (n=11) or independent assessments (n=17), potentially introducing confounding effects, such as expectancy
bias. Of the studies that did report blinded assessments, none used blinding verification and only one adequately described the blinding processes, again highlighting potential bias in assessment. Although the interpretation of CTAM scores, using threshold criteria, was not considered appropriate, the quality ratings highlighted that the majority of studies did contain multiple sources of potential bias.

Study Findings

Outcome Measures

Due to the aims of the current review, only child-related outcomes were considered. However, most studies did report parent-related measures pertaining to a number of outcomes (e.g., parent stress, adjustment, competence) reflecting the parental experience.

Across the studies, child-related outcome measures varied considerably in terms of method of assessment (questionnaire, interview, and observation), informant (parent-rated, teacher-rated, clinician-rated, observer-rated), sub-scale specificity (specialised subscales vs. global total scores) and the difficulties/behaviour measured. All studies included at least one standardised parent-informed child-related outcome, eight studies included additional observer-informed outcomes (Azevedo et al., 2013; Bagner et al., 2007; Bor et al., 2002; Herbert et al., 2013; Plant & Sanders, 2007a; Roberts et al., 2006; Sounga-Barke et al., 2001; Thompson et al., 2009) and four studies included other-informed outcomes (e.g., teacher, clinician)(Azevedo et al., 2013; Hoath et al., 2002; Scahill et al., 2006; Tonge et al., 2014). Twenty-one studies calculated (M)ANCOVAs/(M)ANOVAs for primary statistical analyses and one study calculated 95% confidence intervals around group means and group change (Sonuga-Barke et al., 2004).
Data Synthesis

To facilitate synthesis of study findings given the variability in measures used, outcomes were organised into five broad categories: attention-deficit/hyperactivity (ADH) difficulties (e.g., hyperactivity), externalising difficulties (e.g., conduct), internalising difficulties (e.g., anxiety), social difficulties (e.g., peer problems) and global difficulties (e.g., total internalising and externalising scores). Within each category, outcome measures were then further classified according to informant: parent-informed, other-informed and observer-informed. This resulted in 15 outcome categories for each study, with multiple measures potentially being contained within a single category.

For each of these 15 categories, a classification of either ‘effective’, ‘not-effective’ or ‘inconsistent’ was awarded to each study. This was based on the results of the statistical comparisons for outcome measures contained within that particular category. If the BPTP condition demonstrated significant changes across the intervention period relative to the control condition for all outcome measures contained within a particular category it was deemed ‘effective’. If changes consistently failed to reach significance then a ‘not-effective’ classification was awarded. If results were inconsistent across multiple measures belonging to the same outcome category, then it was deemed ‘inconsistent’. Results are displayed in Table 4 and a summary of findings across each outcome category is described. Effect sizes and significance values for individual outcome measures are presented in Table 5.
Table 4. Study Findings within each Outcome Category organised by Parenting Programme

<table>
<thead>
<tr>
<th>Author, year</th>
<th>NDD, Prog</th>
<th>ADH</th>
<th>Externalising</th>
<th>Internalising</th>
<th>Social</th>
<th>Global</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoofdakker et al. (2007)</td>
<td>ADHD, BDC</td>
<td>N</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Schuli et al. (2006)</td>
<td>TICS, BDC</td>
<td>-</td>
<td>-</td>
<td>I</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sofronoff et al., (2004)</td>
<td>ASD, Unspe.</td>
<td>-</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Azevedo et al., (2013)</td>
<td>ADHD/TP</td>
<td>E</td>
<td>E</td>
<td>E</td>
<td>N</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Jones et al., (2007)</td>
<td>ADHD/TP</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>N</td>
<td>E</td>
</tr>
<tr>
<td>McIntyre (2008)</td>
<td>ID/DD/TP</td>
<td>N</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sonuga-Barke et al., (2004)</td>
<td>ADHD, NFP</td>
<td>N</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Sonuga-Barke et al., (2001)</td>
<td>ADHD, NFP</td>
<td>E</td>
<td>E</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Thompson et al., (2009)</td>
<td>ADHD, NFP</td>
<td>E</td>
<td>-</td>
<td>N</td>
<td>E</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Herbert et al., (2013)</td>
<td>ADHD, PYHP</td>
<td>E</td>
<td>-</td>
<td>E</td>
<td>N</td>
<td>I</td>
<td>N</td>
</tr>
<tr>
<td>Hand et al., (2012)</td>
<td>ID/DD/TP, PPC</td>
<td>E</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Bagner et al., (2007)</td>
<td>ID/DD/TP, PCIT</td>
<td>-</td>
<td>-</td>
<td>I</td>
<td>E</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Matos et al., (2009)</td>
<td>ADHD, PCIT</td>
<td>E</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Bor et al., (2002)</td>
<td>ADHD, TP</td>
<td>-</td>
<td>-</td>
<td>E</td>
<td>E</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Leung et al., (2013)</td>
<td>ID/DD/TP</td>
<td>E</td>
<td>-</td>
<td>-</td>
<td>E</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Hoath et al., (2002)</td>
<td>ADHD, TP</td>
<td>N</td>
<td>N</td>
<td>I</td>
<td>N</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Plant et al., (2007a)</td>
<td>ID/DD/TP-SS</td>
<td>-</td>
<td>-</td>
<td>E</td>
<td>E</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Roberts et al., (2006)</td>
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Note. Analysis refers to the primary relevant analysis for the presented data. Significance values of comparisons between treatment and control conditions over time were used to determine effectiveness. Significance values predominately relate to p-values <.05, however trend effects were also interpreted as evidence for effectiveness (p<.10) as they were often supported by additional significant outcomes (p<0.05). If separate analyses of mother and fathers data were provided, mothers data was reviewed. E=effective, N=not effective, I=inconsistent, P=parent, O=other, Ob=Observer. NDD=Neurodevelopmental Disorder, Parenting Programme. BDC=Barkley’s Defiant Children Programme, PCIT=Parent Child Interaction Therapy, NFP=New Forest Parenting Programme, PYHP=Parenting your Hyperactive Preschooler Programme, PPC=Parents Plus Children Programme, PWA=Parents Plus with Autism, IY=Incredible Years Programme, Unspe.=idiosyncratic custom programme, TP=Triple P, TP-SS=Triple P-Stepping Stones, ADHD=attention deficit hyperactivity disorder, ADH=attention deficit hyperactivity, ASD=autistic spectrum disorder, ID=intellectual difficulties, DD=developmental delay, TICS=Tic disorders
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Note. See page 36 for table caption
Attention-deficit/Hyperactivity Difficulties (ADH)

Eleven studies reported parent-rated ADH outcomes. Three of these found no evidence of effectiveness when treatment was compared with control conditions over time. Nine of these 11 studies targeted children with a diagnosis of ADHD. Of these, six reported consistently significant reductions in parent-rated ADH across several programmes including Incredible Years (Azevedo et al., 2013; Jones et al., 2007), New Forest Parenting (Sonuga-Barke et al., 2001; Thompson et al., 2009), Parenting your Hyperactive Preschooler (Herbert et al., 2013) and Parent Child Interaction Therapy (Matos et al., 2009). Studies involved programmes that did and did not include specific ADHD modifications or targeted programmes; effect sizes ranged from small to large (0.25 to 2.52).

Three studies did not find significant effects of interventions on ADH outcomes in ADHD samples (Hoath et al., 2002; Hoofdakker et al., 2007; Sonuga-Barke et al., 2004). Hoath et al. (2002) implemented a Triple P programme with ADHD adaptations; however, power within this study was limited given the particularly small sample size of only nine participants in the treatment condition. Hoofdakker et al. (2007) administered Barkley’s Defiant Child Programme to a clinical sample. Participants were recruited following non-response to a first phase of routine clinical care including medication; thus, the study may have involved a particularly complex sample with significant needs. Finally, Sonuga-Barke et al. (2004) delivered the ADHD specific New Forest Parenting programme using 16 randomly selected health visitors. Sonuga-Barke et al. (2004) suggest that outcomes may have been negatively influenced by these potentially less committed non-specialist therapists.
Two of the 11 studies that reported ADH outcomes did not exclusively recruit children with ADHD. Solomon et al. (2008) found consistent reductions in parent-rated ADH difficulties using Parent Child Interaction Therapy in children with ASD, although these results reached only trend levels of significance (p<0.10 to p<0.05). Hand et al. (2012) also noted consistent reductions in parent-rated ADH symptoms following participation in a Parents Plus Children programme for children with ID/DD. However, when multiple comparisons were statistically accounted for, these effects did not reach significance. Effect sizes for these studies ranged from medium to large (0.47 to 0.91).

Overall, relatively strong evidence has been found for the effect of BPTPs on parent-rated ADH difficulties, along with some evidence for the generalisability of these effects across NDDs. Unfortunately, the reporting of other-informed or observer-informed ratings was infrequent and of the studies that did provide such multi-informant measures, the results were generally mixed. Two studies reported other-informed outcomes with contradictory results (effective: Azevedo et al., 2013; not-effective: Hoath et al., 2002) and two studies reported observer-informed outcomes, again, with contradictory results (effective: Sonuga-Barke et al., 2001; not-effective: Thompson et al., 2009).

Externalising Difficulties

Eighteen studies reported outcomes pertaining to parent-rated externalising difficulties. Of these studies, 13 reported consistently significant effects, four reported inconsistent effects across outcome measures and only one study reported consistently non-significant effects.
Of the 18 studies, eight involved children with ADHD, seven of which reported consistent effects of BPTP on externalising difficulties relative to controls (Azevedo et al., 2013; Bor et al., 2002; Herbert et al., 2013; Hoofdakker et al., 2007; Matos et al., 2009; Sonuga-Barke et al., 2001; Thompson et al., 2009). Effect sizes for these studies ranged from small to large (0.32 to 2.47). The remaining study by Hoath et al. (2002) reported inconsistent findings across measures.

Three studies reported parent-rated externalising outcomes in samples of children with ASD. Two studies reported consistently significant effects (Sofronoff et al., 2004; Whittingham et al., 2009) with large effect sizes (0.81 to 1.32). Solomon et al. (2008) noted inconsistent results across measures.

Six studies reported parent-rated externalising outcomes in samples of children with ID/DD. Four of these studies reported consistently significant effects (Hand et al., 2012; Leung et al., 2013; Plant & Sanders, 2007a; Roux et al., 2013) with generally small to large effect sizes (0.13 to 0.99). Bagner et al. (2007) reported inconsistent findings across measures, whereas McIntyre (2008) reported consistently non-significant effects.

The study by Scahill et al. (2006) is the only one that exclusively involved children with tic disorders. It reported outcomes pertaining to parent-rated externalising difficulties, and found inconsistent effects across outcome measures. The study reported significant reductions in difficulties for the intervention condition relative to controls for the primary outcome measure (Disruptive Behaviour Rating Scale; Barkley, 1997). However, these effects were not sustained for another less commonly used secondary outcome measure (Home Situations Questionnaire; Barkley, 1997).
It is noteworthy that the four studies that reported inconsistent effects also specified additional parent-rated disruptive behaviour within trial inclusion criteria. This raises the possibility that relative to the majority of studies, these samples included children with more complex and severe needs given their pre-intervention levels of externalising difficulties. Furthermore, of these four studies (Bagner et al., 2007; Hoath et al., 2002; Scahill et al., 2006; Solomon et al., 2008), three utilised the same outcome measure (Eyberg Child Behaviour Inventory; Eyberg & Ross, 1978), but lacked consistency across subscale effects.

The studies that reported significant effects of BPTPs on externalising difficulties represented several intervention programmes (Barkley’s Defiant Child, Incredible Years, New Forest Parenting, Parenting Your Hyperactive Preschooler, Parent Child Interaction Therapy, Parents plus Children, Triple P, idiosyncratic Asperger syndrome programme) and included programmes that did and did not include NDD specific modifications.

Overall, evidence has been provided for either inconsistent or consistent significant reductions in parent-rated externalising difficulties when comparing BPTP to control conditions over time. However, the provision of other-informed or observer-informed outcome measures was infrequent and of the studies utilising such multi-informant approaches, the results were mixed. Only two papers reported other-rated measures (e.g., teachers) and these obtained contradictory results (effective: Azevedo et al., 2013; not-effective: Hoath et al., 2002) and six studies reported observer-informed ratings and also reported contradictory results (effective: Bagner et al., 2007, Bor et al., 2002; Plant & Sanders, 2007a; not-effective: Azevedo et al., 2013, Hebert et al., 2013; inconsistent: Roberts et al., 2006).
**Internalising Difficulties**

In contrast to the large number of studies that reported ADH and externalising difficulties outcomes, only five studies reported outcomes pertaining to internalising difficulties, of which two found consistently significant effects of BPTP compared to controls over time. McIntrye (2008) offered the Incredible Years programme to a sample of parents with children with ID/DD, while Hoofdakker et al. (2007) used the Barkley Defiant Children programme in children with ADHD. Using the same outcome measure (Child Behaviour Check List–Internalising; Achenbach, 2000) both studies reported small effect sizes (0.29 to 0.42).

Hand et al. (2012) consistently found no effects of the Parents Plus Children Programme upon internalising difficulties in children with ID/DD, whilst the remaining two studies both reported inconsistent effects of BPTPs upon internalising difficulties across outcome measures. Herbert et al. (2013) implemented a Parenting Your Hyperactive Preschooler Programme in children with ADHD, whereas Solomon et al. (2008) offered Parent Child Interaction Therapy to parents of children with ASD. The inconsistent effects reported across these two studies, however, may be attributable to the numerous and varied outcomes that each study obtained which were classified under the general internalising difficulties category in the current review in an attempt to group and summarise findings. Indeed, effects of interventions were found for emotional lability and negativity outcomes (Herbert et al., 2013) and trend effects for depression (Solomon et al., 2008), but not for anxiety (Solomon et al., 2008), emotion regulation or general internalising scores (Herbert et al., 2013).

Evidence pertaining to internalising difficulties was almost wholly derived from parent-rated measures. No studies reported other-rated measures within this
category and only one study reported observer-informed outcomes, with Herbert et al. (2013) finding no significant effects of the BPTP relative to controls using observer-informed measures.

**Social Difficulties**

Only six studies reported outcomes for social difficulties, of which, three report consistently significant effects. Azevedo et al. (2013) evaluated the Incredible Years Programme with parents of children with ADHD and found significant effects for social difficulties. Sofronoff et al. (2004) also noted significant effects for social difficulties in a sample of children with ASD using an idiosyncratic programme for Asperger disorder, which included communication specific components. Effect sizes for these studies ranged from small to large (0.38 to 1.04). Two studies implemented other- or observer-informed outcomes. Azevedo et al. (2013) noted significant effects for observer-informed measures of child prosocial behaviour but not for teacher-reported social difficulties. Using the Preschoolers with Autism Programme, Tonge et al. (2014) noted improved clinician-rated socialisation outcomes, but only for children with greater pre-test difficulties.

The three remaining studies failed to find effects of BPTPs relative to control conditions across time. These studies evaluated the Parents Plus Children programme in children with ID/DD (Hand et al., 2012), Parent Child Interaction Therapy in children with ID/DD (Solomon et al., 2008) and the New Forest Parenting programme in children with ADHD (Thompson et al., 2009).
Global Difficulties

‘Global difficulties’ as an outcome category reflects general improvement or non-specific emotional and behavioural measures. Six studies provided parent-rated outcomes and five reported consistently significant effects of BPTPs relative to control conditions over time, with small to large effect sizes (0.33 to 1.23). All five studies involved parents of children with ID/DD (Bagner et al., 2007; Hand et al., 2012; McIntyre, 2008; Roberts et al., 2006; Roux et al., 2013) and implemented a range of programmes (Incredible Years, Parents Plus Children Programme, Parent Child Interaction Therapy, Triple P). The remaining study by Tonge et al. (2014) in a sample of children with ASD, noted inconsistent effects across measures with no effects found on a measure of general behavioural and emotional difficulties (DBC-T); however, improvements were noted on a subset of Autism specific items (DBC-ASA).

No studies reported observer-informed outcomes and only one study provided other-informed outcomes, with Scahill et al. (2006) reporting significant effects of the Barkley Defiant Child programme upon clinician-rated global improvement in a tic disorder population.

Follow-up and Other Outcomes

Twelve studies implemented follow-ups, all of which reported maintenance of treatment gains. Follow-up periods were variable, with the longest at one year.

Five studies included more than one treatment condition. Plant & Sanders (2007a) and Bor et al. (2002), comparing enhanced and standard BPTP programmes, identified that the enhanced programmes were not consistently superior to the standard programmes. According to Sofronoff et al. (2004), individual weekly BPTP
was superior to a workshop format. Sonuga-Barke et al. (2001) noted that BPTP was superior to a parent counselling and support condition. Similarly, Tonge et al. (2014) reported some evidence that BPTP was superior to parent education and counselling. These results lend support to the longevity of treatment effects, the importance of delivery format, and the robustness of standard behavioural programme content.

**Discussion**

The current review evaluated the evidence regarding the effectiveness and implementation of behavioural parenting interventions for parents of children with NDDs. Twenty-two RCTs met inclusion criteria, were reviewed and their quality rated. The studies were conducted across ADHD, ID/DD, ASD and tic disorders. Some programmes were disorder-specific, while others were implemented across several NDDs, with and without modifications. Nevertheless, many shared components existed between programmes, including techniques to improve parent-child interactions, relationships/communication, promote positive behaviour and manage negative behaviour.

Quality ratings on the CTAM varied considerably across studies and most did contain multiple sources of potential bias. For the majority of studies, this included inadequate reporting of power analyses or small sample sizes, inadequate reporting or implementation of independent randomisation measures, a lack of blinded or independent assessments and the use of waitlist control groups rather than alternative therapeutic controls. However, most studies implemented appropriately described and manualised interventions and attempted to ensure treatment protocol adherence.

Given the substantial variation in the outcome measures used across the studies, outcome variables were classified into five categories: attention-deficit/hyperactivity difficulties, externalising difficulties, internalising difficulties, social
difficulties and global difficulties. With the exception of one study by Sonuga-Barke et al. (2004), all reviewed studies reported at least some evidence for the effectiveness of BPTPs relative to control conditions across at least one of these five outcomes.

The main findings can be summarised as follows: 1) There was robust evidence for the effectiveness and transdiagnostic application of BPTPs on parent-rated ADH difficulties. 2) There was also robust evidence for the effectiveness and transdiagnostic application of BPTPs on parent-rated externalising difficulties. 3) Evidence was found for the effectiveness of BPTPs on parent-rated global difficulties; however, this was derived largely from studies targeting ID/DD. This may reflect the greater applicability of this non-specific outcome to ID/DD samples, particularly given the diagnostically mixed samples within these studies, or may simply reflect convention across ID/DD research. Future studies should ensure that measure sub-scale and total scores are provided in study reports to facilitate future reviews. 4) Evidence of the effectiveness of BPTPs upon parent-rated internalising and social difficulties was limited. Few studies reported these outcomes and contradictory results were obtained across these studies. Future trials should consider evaluations of internalising and social outcomes in order to increase the evidence base for future reviews. 5) Across all outcome categories, other-informed or observer-informed outcomes were infrequently reported. The over-reliance on parent-rated outcomes across all studies may place some limitation on the reliability and validity of the results obtained, particularly given potential biases in social desirability, expectancy effects and demand characteristics. However, given the importance of changes in parental perceptions of child behaviour upon real life
familial experiences, parent-rated measures may provide the most important source of outcome information in the reviewed studies.

**Limitations**

Several methodological limitations of the studies included in the review were identified. In terms of recruitment, the majority of studies involved voluntary participants recruited via community advertisements. Thus, samples may have primarily included parents who were sufficiently motivated to seek out intervention and yet whose children did not reach a sufficient clinical threshold to have previously necessitated an intervention via the clinical route. Furthermore, only some studies confirmed clinical diagnoses via clinicians or via parent/child based screening assessments and within the ADHD sample studies, many samples included children who did not previously have a clinical diagnosis, but rather they met inclusion criteria based on parent-rated screening assessment outcomes. This introduces differences between samples in terms of anticipated experiences of clinical services, parental adjustment and severity of difficulties, which limits the applicability of results to clinical contexts, in which parents may present with more severe or complex difficulties and reduced motivation.

Several articles failed to report whether both mothers and fathers attended BPTPs and the number of sessions attended or missed. They also failed to report or statistically account for the medication status of children or the additional community based care that was received or restricted during the trial. This information may inform the optimum implementation of BPTPs in clinical practice.

Furthermore, in terms of the present review, the reduction of numerous study outcome measures into five general categories and the consideration of undoubtedly
heterogeneous samples in one review has inevitably meant that the minutiae of study findings has been neglected in favour of a more parsimonious overview of the literature.

Finally, the CTAM quality rating scale was considered to be appropriate to rate the methodological quality of these 22 RCTs. Within psychosis research, Wykes et al. (2008) have previously used a cut-off score of 65 or above to indicate adequate methodology. Four of the reviewed studies met this criterion. However, this threshold score may be viewed as arbitrary, which is why CTAM scores were presented in the current review within categories (top 25%, above 50%, etc.).

Clinical Implications

The review provides the first syntheses of study findings both across and within different neurodevelopmental disorders; an approach that is particularly relevant for clinical practice. In our clinical experience, service structure and resources mean that clinically implemented parenting interventions are not always specifically tailored to or exclusively contain parents of children with specific homogenous NDDs, and yet the diagnostic co-morbidities and parental experiences are often shared. Furthermore, the consideration of studies across disorders has highlighted several methodological limitations in diagnostic criteria, recruitment and outcomes within disorder-specific studies, which may be improved by consideration of methodologies across other NDDs rather than continued adherence to research conventions within particular disorders. Finally, the comparison of studies across disorders has also highlighted the neglect of particular NDDs within this field of research, particularly tic disorders which highlights an important area of need for future studies.
Summary

In summary, the results of the current review lend support for the effectiveness of BPTPs in parent-rated ADH and externalising difficulties across NDDs. Less support was obtained for the effectiveness of BPTPs on parent-rated internalising difficulties and social difficulties. Finally, support was obtained for the effectiveness of BPTPs on parent-rated global difficulties; however, the usefulness and generalisability of this finding across NDDs remains unclear. Despite the utilisation of several BPTP programmes across studies, shared components were considerable, adaptations were minimal and study findings were relatively consistent across programmes, lending support to the implementation and effectiveness of general BPTP models in clinical practice.

Overall, the current review has provided an important insight into the usefulness and applicability of BPTPs across neurodevelopmental disorders and has highlighted several clinical and research opportunities for the future development of this area.
References


*=Paper included in the review.
Parenting Interventions in Tic Disorders: An Exploration of Parents’ Perspectives

Manuscript prepared in accordance with guidance for Child: Care, Health and Development (Appendix 3)

Word Count: 5,000 main text, 8,148 total

Short Title: Parenting Interventions in Tic Disorders: Parents’ Perspectives

Keywords: Tic Disorder, Tourette syndrome, Parent Intervention, Parent Training, Parenting.
Abstract

Background: Parents of children with tic disorders experience multiple challenges and stresses, which can impact on family functioning, children’s well-being and could indirectly affect tic severity. Parenting interventions have been recommended in this population; however, little is known about parents’ views. Method: To further investigate this potential intervention avenue, the opinions of parents of children with tic disorders were sought. Using Q-methodology, 23 parents provided their views regarding the acceptability, effectiveness, feasibility and utility of parenting interventions. Results: Four factors emerged, representing four groups of parents with similar opinions. Whilst all factors evidenced support for parenting interventions, subtle differences emerged between factors regarding the endorsed content, barriers and delivery of interventions. Conclusion: The results indicate a perceived clinical need for parenting interventions within this population, and provide guidance to further develop and implement such interventions.

Key Message

- Parenting interventions have been recommended in tic disorder populations. The study explored parents’ opinions of such interventions.
- Interventions were generally supported by parents and considered acceptable.
- Four distinct opinions emerged across participants. These highlighted subtle differences regarding preferred intervention content and delivery format.
- The results may assist clinicians in designing interventions.
Introduction
The diagnostic category of tic disorders represents several conditions characterised by the presence of tics, defined as rapid, recurrent, non-rhythmic, motor movements or vocalizations (Robertson & Cavanna, 2008). Diagnoses include Tourette syndrome, provisional tic disorder, chronic tic disorder and unspecified tic disorder (American Psychiatric Association, 2013). Tics emerge in childhood and are accompanied by co-morbid conditions in around 90% of individuals (Cavanna et al., 2009). These include attention deficit hyperactivity disorder (ADHD), obsessive compulsive behaviours, depression, self-injurious behaviour, anxiety, conduct difficulties, autism and learning difficulties (Cavanna et al., 2009; Robertson, 2000).

Tic disorders and associated co-morbidities can have profound effects on children. Relative to ‘healthy’ controls, they are more likely to feel victimised by peers (Storch et al., 2007a), have educational problems (Debes et al., 2010) emotional difficulties (Carter et al., 2000) and a lower quality of life (Storch et al., 2007b). Therefore, tic disorders also have significant implications for families. Parents not only have to support their child’s additional needs and manage co-morbid difficulties, but they also have to adjust to the diagnosis (Chowdhury, 2004) and associated genetic implications (Rivera-Navarro et al., 2013). Consequently, parents have demonstrated increased caregiver burden and stress (Cooper et al., 2003; Schoeder & Remer, 2007; Wilkinson et al., 2008). As environmental, social and emotional factors can influence tic severity (Robertson & Cavanna, 2008), parental management and stress may inadvertently exacerbate tics, creating a reciprocal cycle of increasing difficulties. Given these parental challenges, parent-based interventions have been recommended (Cooper et al., 2003; Wilkinson et al., 2008).
Within neurodevelopmental disorders, parent training programmes are establishing an increasing evidence-base, demonstrating evidence of effectiveness across parent and child outcomes in ADHD, autism and learning difficulties (e.g., Azevedo et al., 2013; Herbert et al., 2013; Jones et al., 2007; Leung et al., 2013; Sofronoff et al., 2004; Whittingham et al., 2009). However, only one randomised controlled trial has explored the effectiveness of parent training programmes in tic disorders. Scahill et al. (2006) offered a ten-session-intervention based on the Defiant Child programme (Barkley, 1997) to parents of children with tic disorders and co-morbid oppositional behaviour. Improvements on parent-rated behavioural difficulties and clinician-rated global impressions were identified. Whilst the intervention did not impact on tic severity or parental stress, only minimal tic-specific adaptations were implemented, namely psycho-education delivered to all participants pre-randomisation.

To investigate this possible intervention approach further, the current study explored parents’ opinions of parenting interventions in tic disorders. The importance of evaluating service user views in the development of parenting interventions adheres to national guidance aimed at promoting accessible and acceptable healthcare services (Crawford et al., 2002). Consequently, parents’ perspectives on the perceived acceptability, feasibility, utility and content of such interventions were explored.
Method

Q-methodology

Q-methodology was selected because it provides a ‘qualiquantological’ approach (Watts & Stenner, 2005) that permits exploration of subjective viewpoints in a reliable, experimental and quantifiable manner (Watts & Stenner, 2012). Q-methodology is being increasingly used within healthcare research to gauge service users’ opinions of interventions (e.g., Butler et al., 2014; Westbrook et al., 2013).

Participants rank a series of statements (termed the Q-set). By allocating each statement a position within a distribution grid, participants systematically rank the statements according to their level of agreement with its content. The relative ranked position of statements enables viewpoints to emerge regarding the subject matter, and participants are grouped according to similarity of opinions.

Ethical Approval

National Health Service (NHS) Research Committee and Research and Development approval was obtained (13/NW/0213, RJ113/N190; Appendix 5-6).

Recruitment

Participants were considered eligible if they were a parent or caregiver of a child with a tic disorder. No exclusion criteria were applied. The project was advertised via a national tic disorder charity (Tourettes Action) and via a NHS specialist service for children with tic disorders (see Appendix 12-13). This specialist service had recently undertaken two small pilot parenting intervention groups, and recruitment was open to parents that had participated in the second of these groups, as well as parents that had not participated in these interventions.
Procedure

Q-set development

In developing the Q-set, the statements were derived following Watts and Stenner’s recommendations (2012). A wide variety of information sources were sampled. The academic literature was examined as were television programmes and websites relevant to tic disorders and parenting interventions. Interviews were also completed with parents who had participated in the first pilot parenting group within the specialist tic disorder service. The information that was ascertained from these multiple sources was collated to develop common themes from which representative statements were generated. An initial 244 statements were generated and reduced to 73 final statements (Appendix 16-17). The statements were reviewed and refined by the research team, and were considered to offer a balanced and representative coverage of opinions (Watts & Stenner, 2012).

Data Collection

The study was completed online via a secure website link (n=19) or via post (n=4). Telephone support was provided by the researcher if requested.

Following consent procedures (Appendix 7-9), participants provided demographic information and read a brief written summary about tic disorders and parenting interventions. Participants categorised the 73 Q-set statements into piles of either agree, neutral or disagree and then used these piles to systematically rank the statements from most agree (+6) to most disagree (-6), by placing them within a forced choice distribution grid (Figure 1). A number of free-text post-sort questions then allowed parents to provide further information about their extreme ranked statements and views of parenting interventions.
**Data Analysis**

Q-methodology involves a by-person factor analysis, whereby participants with similar opinions are grouped through similarities in their sorting patterns (Watts & Stenner, 2012). Factor analysis of the 23 Q-sorts was undertaken using PQMethod (Schmolck & Atkinson, 2012). Principal components factor analysis was conducted and factors with an eigenvalue greater than one were extracted (Guttman, 1954; Kaiser, 1960), and subjected to a varimax rotation procedure.

Q sorts with significant factor loadings were then merged using a weighted averaging procedure, to create a factor array, which represents a typical sorting pattern for that factor. The significance of factor loadings can be acceptably determined using several criteria (Watts & Stenner, 2012). One common criteria is to identify Q-sorts with loadings which exceed $p<0.01$ significance based on the Q-set.

![Figure 1. Q-sort Grid](image-url)
size (Watts & Stenner, 2012). ‘Confounded’ Q-sorts load onto more than one factor and are excluded from further analysis (Watts & Stenner, 2012). Therefore, if a p<0.01 threshold leads to multiple confounds and significant data loss, Watts and Stenner (2005) recommend raising the probability threshold to increase loading stringency. This approach was used in the current analysis.

Following determination of factor arrays, the factors were interpreted in conjunction with the demographic information and post-sort interviews. Factor-specific views were identified using statically distinguishing statements (p<0.01), extreme rankings, or assigned distinctively extreme ratings compared to other factors. Consensus views were identified using statements that did not statistically distinguish between any factors (p>0.01).

Results

Participants

Twenty-three participants completed the study; an adequate sample size for Q-methodology (Watts & Stenner, 2012). Demographic characteristics of the total sample are provided in Table 1.

All participants were parents of children with tic disorders, most of whom had a diagnosis of Tourette syndrome and multiple co-morbid conditions. Around half of parents reported having previous experience of attending a parenting intervention. Only four had taken part in the pilot parenting intervention offered by the specialist tic disorder service. The remaining parents described the parenting interventions they had attended as parent-directed individual psychology sessions, support groups, family therapy, and workshops for co-morbid conditions (e.g., dyspraxia).
Table 1: Demographic Information of Sample (n=23)

<table>
<thead>
<tr>
<th>Relationship to child:</th>
<th>Co-morbidities:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td>Behaviour/ conduct difficulties 14</td>
</tr>
<tr>
<td></td>
<td>Mood difficulties 19</td>
</tr>
<tr>
<td>Participant gender:</td>
<td>Social difficulties 13</td>
</tr>
<tr>
<td>Male</td>
<td>Anxiety 21</td>
</tr>
<tr>
<td>Female</td>
<td>OCB 14</td>
</tr>
<tr>
<td></td>
<td>Anger difficulties 18</td>
</tr>
<tr>
<td>Child gender:</td>
<td>Sleep difficulties 17</td>
</tr>
<tr>
<td>Male</td>
<td>Self-esteem difficulties 16</td>
</tr>
<tr>
<td>Female</td>
<td>Autistic spectrum disorder 3</td>
</tr>
<tr>
<td></td>
<td>ADHD 3</td>
</tr>
<tr>
<td>Child age:</td>
<td>Physical disability 3</td>
</tr>
<tr>
<td>8-11</td>
<td>Sensory disability 2</td>
</tr>
<tr>
<td>12-17</td>
<td>Learning disability 1</td>
</tr>
<tr>
<td>18+</td>
<td>Specific learning difficulty (e.g., 3</td>
</tr>
<tr>
<td>Incomplete</td>
<td>dyslexia, dyspraxia)</td>
</tr>
<tr>
<td>Mean</td>
<td>12yr</td>
</tr>
<tr>
<td>Number of siblings</td>
<td>Tic diagnosis:</td>
</tr>
<tr>
<td>0</td>
<td>Tourette Syndrome 21</td>
</tr>
<tr>
<td>1</td>
<td>Tics 2</td>
</tr>
<tr>
<td>2</td>
<td>Child ever received psychological</td>
</tr>
<tr>
<td></td>
<td>intervention for tic disorder:</td>
</tr>
<tr>
<td>3</td>
<td>Yes 13</td>
</tr>
<tr>
<td></td>
<td>No 10</td>
</tr>
<tr>
<td>3+</td>
<td>Ever attended parenting intervention:</td>
</tr>
<tr>
<td>Yes</td>
<td>Yes 11</td>
</tr>
<tr>
<td>No</td>
<td>No 12</td>
</tr>
</tbody>
</table>

OCB = obsessive compulsive behaviours, ADHD = attention deficit hyperactivity disorder.

**Factor Analysis**

Four factors were extracted and rotated, accounting for 66% of variance. Using a p<0.01 significance threshold for determining factor loadings, 16 Q sorts were confounded, loading onto more than one factor. Given this substantial potential data loss, Watts and Stenner’s (2005) recommendations were applied to increase the statistical stringency of loadings. Loadings of $\geq 0.52$ were deemed significant and
21 Q sorts loaded onto a single factor (see Appendix 23). The two remaining Q sorts did not load onto any factor and were excluded from further analysis.

Factors 1, 2 and 4 demonstrated high correlations (Factor 1 and 2=0.62: Factor 1 and 3=0.33: Factor 1 and 4=0.68: Factor 2 and 3=0.26: Factor 2 and 4=0.63: Factor 3 and 4=0.29), which indicates similar viewpoints across these factors, but with important points of disagreement (Danielson et al., 2007).

When presenting factor interpretations, relevant statements are provided alongside associated factor rankings. Quotes from post-sort questions are used to supplement factor interpretation. Participant information for each factor is presented in Table 2. Table 3 presents all statements and associated factor rankings. The presented statements used the term tic spectrum conditions (TSC)\(^6\) to refer to tic disorders.

\(^6\) This term is used because we believe that it is less stigmatising and reflects the complex range of symptoms.
Table 2: Demographic Information for Participants Loading onto each Factor

<table>
<thead>
<tr>
<th>Factor</th>
<th>Child Gender</th>
<th>Child age</th>
<th>Diagnosis</th>
<th>Co-morbidities or Additional Difficulties/Disabilities</th>
<th>Previous Service Input</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>12-17</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, anger, self-esteem</td>
<td>Child medication, yes = 7</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Anger, sleep</td>
<td>Child psychology, yes = 5</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>12-17</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td>Parent intervention, yes = 3</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>8-11</td>
<td>Tourette</td>
<td>Anxiety, OCB, self-esteem</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>18+</td>
<td>Tourette</td>
<td>ADHD, behaviour, mood, social, anxiety, OCB, sleep</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>ADHD, behaviour</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>ASD, specific learning difficulty, behaviour, mood, anxiety, OCB, anger, sleep, self-esteem</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>ASD, ADHD, behaviour, mood, anxiety, anger, sleep, self-esteem</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>12-17</td>
<td>Tourette</td>
<td>Behaviour, mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>12-17</td>
<td>Tourette</td>
<td>Behaviour, mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Sensory, specific learning difficulty, behaviour, mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>12-17</td>
<td>Tics</td>
<td>Anxiety, sleep</td>
<td>Child medication, yes = 2</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>12-17</td>
<td>Tourette</td>
<td>Physical, behaviour, mood, social, anxiety, anger, sleep, self-esteem</td>
<td>Child psychology, yes = 2</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>12-17</td>
<td>Tourette</td>
<td>Physical, behaviour, mood, social, anxiety, anger, sleep, self-esteem</td>
<td>Parent intervention, yes = 2</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>12-17</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td>Child medication, yes = 1</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>-</td>
<td>Tics</td>
<td>Behaviour, mood, anxiety, anger, sleep</td>
<td>Child psychology, yes = 1</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, self-esteem</td>
<td>Parent intervention, yes = 1</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, self-esteem</td>
<td>Child medication, yes = 3</td>
</tr>
<tr>
<td>4</td>
<td>F</td>
<td>12-17</td>
<td>Tourette</td>
<td>Mood, social, anxiety, OCB, anger, sleep, self-esteem</td>
<td>Child psychology, yes = 3</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Behaviour, mood, anxiety, OCB, anger, sleep</td>
<td>Parent intervention, yes = 3</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>8-11</td>
<td>Tourette</td>
<td>Behaviour, mood, anxiety, OCB, anger</td>
<td></td>
</tr>
</tbody>
</table>

Note. Two participants did not load onto any single factor and were excluded from the analysis. M=male, F=female. ASD=autistic spectrum disorder, ADHD=attention deficit hyperactivity disorder, OCB=Obsessive compulsive behaviours, Tourette=Tourette Syndrome.
Factor 1: ‘Parents are crucial.’

Eleven participants loaded onto Factor 1 explaining 27% of variance. Parents generally supported the notion of parenting interventions and advocated the importance of systemic factors for children, thus the factor was termed ‘Parents are crucial’. The children of these parents spanned a range of ages and co-morbidities, and whilst most children had received pharmacological interventions (n=7), very few parents had attended parenting interventions (n=3).

Parents strongly endorsed the importance of the parent-child relationship and the impact of family environments on children’s well-being (s50=+4 ‘Positive child-parent interactions are important for children’s adjustment and quality of life’; s7=+2 ‘Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC’; s49=+2 ‘Family functioning is related to children’s adjustment and quality of life’; s53=+4 ‘Children’s perception of their parent’s views towards their TSC is important’). Whilst parents endorsed the importance of effective parenting strategies (s51=+5 ‘Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence’), parents also recognised the importance of parental thoughts and feelings in moderating parenting behaviour and the role of parenting interventions in providing space to reflect on this (s3=+6 ‘Parents own thoughts and feelings affect parenting behaviour’; s2=+3 ‘Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention’).

In terms of parenting interventions, parents endorsed intervention effectiveness, reasonability and financial justification (s31=-5 ‘It is unreasonable to deliver an intervention through parents’; s37=-5 ‘Parenting interventions for TSC
are not a good use of NHS money'; s26=-6 ‘TSC are biological in origin so a parenting intervention will have no effect’; s27=-3 ‘Parent interventions for TSC would be less effective than interventions that treat the child directly’; s24=-4 ‘The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time’). Parents viewed parenting interventions as universally applicable across ages and tic severity (s43=-4 ‘Parenting interventions are more appropriate for parents of younger children with TSC’; s55=-4 ‘Parenting interventions for TSC should only be offered to parents of children with more severe tics’) and endorsed an important outcome of interventions as addressing co-morbid difficulties (s67=+4 ‘Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC’).

Post-sort question comments from parents loading onto Factor 1 demonstrated the importance of parental interactions for children’s well-being:

“Parents' attitudes, body language etc, contribute considerably to the child's good self-image. The nurturing environment is vital.”

“It is so important to children's development and self-esteem that they are accepted and validated by their parents.”

“Educating parents about their child's condition and helping them to understand and overcome some situations will definitely improve the relation with their child and help the child to feel more confident.”

Factor 2: ‘No barriers, parents would do anything to help.’

Three participants loaded onto Factor 2 explaining 14% of variance. Parents endorsed a need for interventions, they denied any proposed barriers to interventions,
and reported determination to help in any way possible. This factor was therefore termed ‘No barriers, parents would do anything to help’. Children of these parents were slightly older (12-17 years), again with a range of co-morbidities, and two parents had attended the pilot parenting intervention offered by the specialist tic disorder service.

Parents consistently refuted statements outlining potential barriers to interventions. They strongly contested service-driven barriers such as inadequate research and knowledge (s61=-5 ‘The lack of research in parenting interventions for TSC is a barrier to treatment’; s73=-5 ‘A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC’).

Parents also disagreed with parent-driven barriers to implementing techniques taught within parenting interventions (s19=-4 ‘Parents would be worried that changing parenting techniques would make things worse’; s22=-4 ‘It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal)’; s21=+3 ‘If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics’; s13=+4 ‘Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC’).

Parents strongly endorsed increased stresses and again noted the importance of the parent-child relationship (s1=+6 ‘Parents of children with TSC experience more stress than parents of children without TSC’; s50=+5 ‘Positive child-parent interactions are important for children’s adjustment and quality of life’). Parents endorsed the importance of parenting interventions in providing space to discuss
concerns, and in addressing children’s co-morbid conditions (s4=+4 ‘Giving parents
time to talk about the worries they have about their child’s TSC is important in a
parenting intervention’; s67=+5 ‘Changing children’s common co-morbid
difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important
outcome of parenting interventions for TSC’).

Parents particularly endorsed the applicability of interventions to adolescents,
possibly due to the older ages of their children (s44=+4 ‘Transition to adolescence
can be difficult so parenting interventions should be offered to parents of
adolescents with TSC’). Again parents viewed interventions as financially justified
and appropriate across tic severity (s37=-6 ‘Parenting interventions for TSC are not
a good use of NHS money’; s55=-4 ‘Parenting interventions for TSC should only be
offered to parents of children with more severe tics’).

Post-sort question comments highlighted parents’ determination to help their
children, perhaps explaining their refusal of any barriers to intervention:

“Anything that will be helpful to my child I would do.”

“As a parent you do anything to help.”

**Factor 3: ‘Worried but parents need social support.’**

Only two participants loaded onto Factor 3, and it explained 8% of variance. Parents
endorsed considerable worries, both about their child generally and specifically
about parenting interventions. Parents did, however, advocate support for parenting
interventions, particularly in providing social benefits and space to voice their
worries; thus, the factor was termed ‘Worried but parents need social support’.

In contrast to other factors, parents highlighted several concerns about the
intervention. Parents endorsed concerns that parent-implemented techniques could
make things worse or negatively affect relationships ($s_{22}=+3$ ‘It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal)’; $s_{19}=+2$ ‘Parents would be worried that changing parenting techniques would make things worse’). Consequently, parents would not implement these techniques ($s_{21}=-5$ ‘If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics’).

The perceived importance of parenting interventions appeared to be in providing space to discuss worries ($s_{4}=+6$ ‘Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention’). In contrast to all other factors, parents did not endorse the importance of developing positive parent-child relationships or a focus on changes to children’s co-morbid difficulties ($s_{7}=-4$ ‘Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC’; $s_{67}=-2$ ‘Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC’).

Consistent with this function of providing space to discuss worries, parents particularly supported group-based interventions and gaining support from other parents and professionals ($s_{52}=-6$ ‘Parents are less likely to participate in group-based parenting interventions than individual parenting interventions’; $s_{40}=+3$ ‘Social support from other parents is an important benefit of a group-based parenting intervention’; $s_{60}=+4$ ‘It is important that parents have a positive relationship with the professionals that lead parenting interventions’).
Whilst appearing pessimistic, parents did in fact support the notion of parenting interventions, believing they would be effective and that family, friends and teachers should attend ($s71=+5$ ‘Parenting interventions for TSC would be effective’; $s72=+4$ ‘Family members, friends, and teachers should be invited to attend parenting interventions for TSC’).

Post-sort question comments from parents loading onto Factor 3 emphasised the importance of social support and sharing worries:

“Meeting others with similar experience would be supportive.”

“Listening to others stories and advice would be useful to parents.”

“Gives parents a chance to get their concerns off their chest. To be able to talk to other parents to see if they have the same concerns. To get re-assurance.”

**Factor 4: ‘Parents have specific needs.’**

Five participants loaded onto Factor 4, explaining 17% of variance. Parents endorsed a need for interventions to meet their specialist requirements, in terms of tic-specific needs, professional expertise and convenience; thus, the factor was termed ‘Parents have specific needs’. Children of these parents were predominately younger (8-11 years, $n=4$), and again had a range of co-morbidities. Two parents had participated in the pilot parenting intervention delivered by the specialist tic disorder service.

Parents supported parent-directed psychological interventions ($s31=-5$ ‘It is unreasonable to deliver an intervention through parents’). However, they also viewed themselves as having clear and different intervention needs compared to parents of children without tic disorders ($s1=+6$ ‘Parents of children with TSC experience more stress than parents of children without TSC’; $s28=-6$ ‘Parents of
children with and without TSC have similar needs so interventions just for children with TSC are unnecessary’).

Consistent with these specialist requirements, the importance of professional expertise and convenience were also endorsed (s59=+5 ‘Professionals who run parenting groups for TSC must be experts in the treatment of tics’; s45=-4; ‘Shorter, weekly meetings are better than longer, monthly meetings in a parenting intervention for TSC’). Compared to other factors, parents were also less supportive of groups over individual interventions, again possibly due to their perceived specialist needs (s52=+1 ‘Parents are less likely to participate in group-based parenting interventions than individual parenting interventions’; s46=+2 ‘Parents need to discuss their child’s difficulties on an individual basis’).

In terms of intervention content, the importance of addressing both tic-management techniques and co-morbid difficulties was endorsed over that of more general parenting skills, again consistent with specialist needs (s13=+4 ‘Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC’; s22=-5 ‘It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal); s67=+5 ‘Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC’).

Post-sort question comments highlighted parents’ need for specialist input and convenience:

“Having a specialised resource available is fundamental in ensuring that the right information is given to parents.”
“[My attendance] would depend on who was offering it and when. I would need to be convinced that the professional offering [it] was properly trained.”

“I would like to see more specialised sessions.”

Consensus Statements

The analysis identified 17 consensus statements that did not statistically distinguish between factors (p>0.01)(Table 3). In describing consensus statements, those with more extreme rankings were focused on, and all four factor rankings are presented, in the order of Factor 1 (F1), Factor 2 (F2), Factor 3 (F3) and Factor 4 (F4).

Across all factors, parents generally endorsed the acceptability of parenting interventions, reporting that parents would not feel criticised or wary of attending (s20: F1=-2, F2=-2, F3=0, F4=-2 ‘Inviting parents to attend a parenting intervention for TSC would make them feel criticised’; s23: F1=-2, F2=-3, F3=-3, F4=-2 ‘Parents would be wary about a parenting intervention for TSC’) and would undertake the necessary demands (s32: F1=-3, F2=-1, F3=-4, F4=-2 ‘Parents would not complete homework as part of a parenting intervention because they are too stressed’; s33: F1=-3, F2=-2, F3=-1, F4=-4 ‘Parents would not complete homework as part of a parenting intervention because they lack motivation’).

Parents also endorsed the wide applicability of interventions (s36: F1=-2, F2=-4, F3=-3, F4=-2 ‘Only a small number of people would need a parenting intervention for TSC’) and did not endorse medication over psychological interventions (s70: F1=-2, F2=-2, F3=-4, F4=-4 ‘Medication is more effective than psychological interventions for TSC’).
Regarding intervention content, parents generally endorsed the need for tic-specific education and skills to manage children’s anger and anxiety (s15: F1=2, F2=3, F3=0, F4=2 ‘Providing education about tics is important in a parenting intervention for TSC’; s5: F1=4, F2=4, F3=2, F4=4 ‘Learning skills to manage children’s anger is important in a parenting intervention for TSC’; s6: F1=5, F2=2, F3=3, F4=4 ‘Learning skills to manage children’s anxiety is important in a parenting intervention for TSC’). Outcomes pertaining to parents feelings were also endorsed, with increased perceived control, and acceptance of tics agreed across all factors (s65: F1=2, F2=3, F3=4, F4=3 ‘Helping parents to feel more in control of their child’s difficulties is an important outcome of parenting interventions for TSC’; s14: F1=3, F2=1, F3=4, F4=3 ‘Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC’).
Table 3: Factor Arrays showing Statements and Associated Rankings across each Factor

<table>
<thead>
<tr>
<th>Statement</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents of children with TSC experience more stress than parents of children without TSC.</td>
<td>-1</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention.</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Parents own thoughts and feelings affect parenting behaviour. Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention.</td>
<td>6*</td>
<td>0</td>
<td>-2</td>
<td>1</td>
</tr>
<tr>
<td>Learning skills to manage children’s anger is important in a parenting intervention for TSC.</td>
<td>3</td>
<td>4</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Learning skills to manage children’s anxiety is important in a parenting intervention for TSC.</td>
<td>4</td>
<td>4</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC.</td>
<td>2*</td>
<td>-1</td>
<td>-4</td>
<td>0</td>
</tr>
<tr>
<td>Learning skills to give children positive attention, praise and rewards is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Learning skills in giving and enforcing clear commands to children is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
<td>-3</td>
<td>-2</td>
</tr>
<tr>
<td>Learning skills to pay less attention to children’s negative behaviours is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>Learning skills to apply consequences for negative behaviour (e.g., time out, grounding) is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
<td>-2</td>
<td>-2</td>
</tr>
<tr>
<td>Learning skills to manage children’s mood is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>3</td>
<td>-1*</td>
<td>2</td>
</tr>
<tr>
<td>Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>4</td>
<td>-3*</td>
<td>4</td>
</tr>
<tr>
<td>Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC.</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Providing education about tics is important in a parenting intervention for TSC. Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Helping parents to develop children’s social skills is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Making parents feel valued by providing a comfortable environment (e.g., snacks, breaks, resources) is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>-1</td>
</tr>
<tr>
<td>Parents would be worried that changing parenting techniques would make things worse.</td>
<td>-2</td>
<td>-4</td>
<td>2*</td>
<td>-3</td>
</tr>
<tr>
<td>Inviting parents to attend a parenting intervention for TSC would make them feel criticised.</td>
<td>-2</td>
<td>-2</td>
<td>0</td>
<td>-2</td>
</tr>
<tr>
<td>If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics.</td>
<td>1</td>
<td>3</td>
<td>-5*</td>
<td>3</td>
</tr>
<tr>
<td>It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal).</td>
<td>-3</td>
<td>-4</td>
<td>3*</td>
<td>-5</td>
</tr>
<tr>
<td>Parents would be wary about a parenting intervention for TSC. The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time.</td>
<td>-2</td>
<td>-3</td>
<td>-3</td>
<td>-2</td>
</tr>
<tr>
<td>Learning generalizable skills is important in a parenting intervention for TSC. TSC are biological in origin so a parenting intervention will have no effect. Parent interventions for TSC would be less effective than interventions that treat the child directly.</td>
<td>-4*</td>
<td>-1</td>
<td>1</td>
<td>-2</td>
</tr>
<tr>
<td>Parents of children with and without TSC have similar needs so interventions just for children with TSC are unnecessary.</td>
<td>-6*</td>
<td>0</td>
<td>0</td>
<td>-2</td>
</tr>
<tr>
<td>-3*</td>
<td>2</td>
<td>-1</td>
<td>0</td>
<td></td>
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</tr>
<tr>
<td>29</td>
<td>Child and Adolescent Mental Health Services (CAMHS) should offer parenting interventions for TSC.</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>30</td>
<td>Practical issues make it too difficult for parents to attend parenting interventions.</td>
<td>-2</td>
<td>-1</td>
<td>-3</td>
</tr>
<tr>
<td>31</td>
<td>It is unreasonable to deliver an intervention through parents.</td>
<td>-5</td>
<td>-1</td>
<td>-1</td>
</tr>
<tr>
<td>32</td>
<td>Parents would not complete homework as part of a parenting intervention because they are too stressed.</td>
<td>-3</td>
<td>-1</td>
<td>-4</td>
</tr>
<tr>
<td>33</td>
<td>Parents would not complete homework as part of a parenting intervention because they lack motivation.</td>
<td>-3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>34</td>
<td>Diagnosing TSC is a barrier to parents accessing interventions.</td>
<td>-2</td>
<td>-2</td>
<td>0</td>
</tr>
<tr>
<td>35</td>
<td>Parents would need repeated follow-ups to continue using the skills learned in a parenting intervention.</td>
<td>-1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>36</td>
<td>Only a small number of people would need a parenting intervention for TSC.</td>
<td>-2</td>
<td>-4</td>
<td>-3</td>
</tr>
<tr>
<td>37</td>
<td>Parenting interventions for TSC are not a good use of NHS money.</td>
<td>-5</td>
<td>-6</td>
<td>-1</td>
</tr>
<tr>
<td>38</td>
<td>Parents would only attend a parenting intervention if it involved other parents with children with TSC.</td>
<td>-1</td>
<td>-2</td>
<td>-4</td>
</tr>
<tr>
<td>39</td>
<td>Meeting other parents of children with TSC would increase parents worry about their own child.</td>
<td>-3</td>
<td>-2</td>
<td>1</td>
</tr>
<tr>
<td>40</td>
<td>Social support from other parents is an important benefit of a group-based parenting intervention.</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>41</td>
<td>Between six and ten parents in a group parenting intervention group is a good size.</td>
<td>0</td>
<td>-1</td>
<td>0</td>
</tr>
<tr>
<td>42</td>
<td>Parents should be offered a parenting intervention shortly after their child is first diagnosed with TSC.</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>43</td>
<td>Parenting interventions are more appropriate for parents of younger children with TSC.</td>
<td>-4</td>
<td>-1</td>
<td>-1</td>
</tr>
<tr>
<td>44</td>
<td>Transition to adolescence can be difficult so parenting interventions should be offered to parents of adolescents with TSC.</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>45</td>
<td>Shorter, weekly meetings are better than longer, monthly meetings in a parenting intervention for TSC.</td>
<td>-1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>46</td>
<td>Parents need to discuss their child’s difficulties on an individual basis.</td>
<td>-1</td>
<td>-2</td>
<td>-2</td>
</tr>
<tr>
<td>47</td>
<td>If NHS resources are limited it is better for more parents to be seen in a group-based parenting intervention.</td>
<td>0</td>
<td>-3</td>
<td>-1</td>
</tr>
<tr>
<td>48</td>
<td>Group-based parenting interventions for TSC are cost effective.</td>
<td>0*</td>
<td>-1</td>
<td>2</td>
</tr>
<tr>
<td>49</td>
<td>Family functioning is related to children’s adjustment and quality of life. Positive child-parent interactions are important for children’s adjustment and quality of life.</td>
<td>2*</td>
<td>-1</td>
<td>-1</td>
</tr>
<tr>
<td>50</td>
<td>Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence.</td>
<td>4</td>
<td>5</td>
<td>0*</td>
</tr>
<tr>
<td>51</td>
<td>Parents are less likely to participate in group-based parenting interventions than individual parenting interventions.</td>
<td>5*</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>52</td>
<td>Children’s perception of their parent’s views towards their TSC is important. It is not children’s tics that cause most concern to parents, but common co-morbid conditions (e.g., anxiety, mood, anger, behavioural difficulties). Parenting interventions for TSC should only be offered to parents of children with more severe tics. The differences in children’s TSC related difficulties are a barrier to group-based parenting interventions. All main caregivers of a child need to attend a parenting intervention for it to be effective.</td>
<td>-2</td>
<td>-3</td>
<td>-6*</td>
</tr>
<tr>
<td>53</td>
<td>Parents would accept and attend a parenting intervention for TSC. Professionals who run parenting groups for TSC must be experts in the treatment of tics. It is important that parents have a positive relationship with the professionals that lead parenting interventions. The lack of research in parenting interventions for TSC is a barrier to treatment. If a parenting intervention for TSC was in book form, professionals would be more likely to offer it. Siblings of children with TSC would benefit from their parents attending a parenting intervention.</td>
<td>0*</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>54</td>
<td></td>
<td>2</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>55</td>
<td></td>
<td>0</td>
<td>0</td>
<td>-5*</td>
</tr>
<tr>
<td>56</td>
<td></td>
<td>0*</td>
<td>-3</td>
<td>-3</td>
</tr>
<tr>
<td>57</td>
<td></td>
<td>1</td>
<td>0</td>
<td>-5*</td>
</tr>
</tbody>
</table>
Discussion

The opinions of 23 parents regarding parenting interventions in tic disorders were explored using Q-methodology. Four distinct factors, or opinions, emerged. Three factors were highly correlated (Factors 1, 2 and 4) indicating that these parents shared generally similar views, but with important points of disagreement (Danielson et al., 2007).

Across all factors, parents endorsed the acceptability of, and indicated general support for, parenting interventions. For example, Factor 1 endorsed them as effective, reasonable, financially justified and universally applicable across ages and tic severity, Factor 2 endorsed them as financially suitable and applicable across tic severity and in adolescents, Factor 3 endorsed them as effective and useful for children’s friends and teachers, and Factor 4 agreed that it is reasonable to deliver interventions through parents.
Although these similarities in opinion did exist, distinct viewpoints were also found across the four factors. Factor 1 explained the most variance and was termed ‘Parents are crucial’. This factor strongly endorsed the importance of parent-child relationships and parents’ cognitions in relation to children’s well-being. It endorsed the importance of teaching parents effective parenting strategies to develop children’s competence, teaching skills to strengthen parent-child relationships, and providing a space for parents to reflect upon their own thoughts and feelings.

Factor 2 was termed ‘No barriers, parents would do anything to help’. Parents strongly refuted any barriers to implementing parenting interventions and techniques, such as service-based inadequate knowledge or parent-based concerns about implementing techniques. Parents agreed that they experienced heightened stress relative to parents of children without tic disorders, and supported a need for space to discuss their worries about their child’s condition. This factor may represent parents with a more idealistic approach to interventions, denying any potential barriers or negative consequences to embrace help.

Factor 3 loaded the fewest parents, and was termed ‘Worried but parents need social support’. In contrast to all other factors, parents were worried about changing parenting, and implementing tic-management techniques. Unlike all other factors, parents did not endorse the importance of parent-child relationships or changing co-morbid difficulties, instead simply needing a space to discuss their worries and to receive social support from other parents. Such concerns may be indicative of parents’ lowered self-efficacy or personal-agency; self-regulation deficits that can negatively impact parenting interventions (Sanders & Mazzucchelli, 2013). Additional support and reassurance may be needed to motivate these parents to implement parenting techniques (see Sanders & Mazzucchelli, 2013), and they
may prefer support groups with no active treatment components, or brief seminar-based group interventions (e.g., Sofronoff et al., 2011) in the first instance.

Factor 4 was termed ‘Parents have specific needs’. Parents viewed themselves as having specialist needs different from other parents; they strongly endorsed the need for professional expertise, and unlike all other factors were less supportive of group-based interventions, requiring individual consultations. This factor seemingly represents parents who are searching for specific answers from perceived experts, they may benefit from clinicians’ explicit demonstrations of expertise to facilitate engagement, and may prefer individual interventions, or at least individual sessions within a group-based format (e.g., Whittingham et al., 2009).

Limitations
Q-methodology enabled the opinions of parents with differing experiences of service input, and with children of different ages and co-morbid conditions, to be explored. Parents were however self-selected volunteers, and were thus likely to be particularly motivated to participate. Such motivation may be due to their children having particularly severe difficulties, or these parents feeling in particular need of support. Whilst this places some limitations on conclusions, given their motivation, these parents may also be particularly likely to seek out such interventions and support from clinicians, and their opinions are therefore particularly important to explore in the current research. Whilst the expression of viewpoints through researcher generated statements can be criticised as restrictive compared to purely qualitative approaches, Q-methodology may have been more appealing to parents with little previous experience around this topic; perhaps more appropriately reflecting the large and more varied sample from which the data was derived.
Clinical implications

Results have obvious clinical implications for tic disorders. Given support in this sample, there appears to be a clinical justification for further development, implementation and evaluation of parenting interventions within this population. Results also indicate that parenting interventions were considered appropriate across ages and tic severity. Finally, the four parents that had previously participated in a tic-specific parenting intervention loaded onto Factors 2 and 4, which both endorsed continued support for interventions, suggesting that interventions are well-received in clinical practice.

The study also provides general guidance around possible intervention content based on parents’ majority views. Psycho-education is a key component of psychosocial interventions in tic disorders (Verdellen et al., 2011) and parenting interventions should provide parents with tic-specific information, including psycho-education, and tic-management techniques, as endorsed by most parents. The potential reservations in using tic-management techniques should be addressed, however, given the concerns expressed across Factor 3.

Addressing co-morbid difficulties was endorsed by most parents, particularly management of anxiety and anger difficulties. Aside from Factor 3, all other factors agreed the need to change children’s co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties), and ranked this more highly than providing tic-management techniques. Indeed, parents generally disagreed that changing tics was an important intervention outcome; which fits with our clinical experience of this population. Anxiety issues in tic disorders can include obsessive compulsive behaviours, social anxiety, general anxiety, panic disorder and specific phobias (Chowdhury, 2004; Roberston 2000). Anger difficulties are also common (Budman
et al., 2000; Sukhodolsky et al., 2003), and can be experienced by caregivers as uncontrollable and potentially dangerous (De Lange & Olivier, 2004). Intervention content addressing co-morbid difficulties is thus supported.

The importance of providing a reflective space for parents to discuss their worries, thoughts and feelings was also endorsed across all factors. Rivera-Navarro et al. (2013) identified that children with tic disorders viewed their parents as more worried by the tics than they were themselves. Space to discuss parents’ worries should thus form a fundamental component of interventions, and stress management and coping strategies may also reduce potentially detrimental effect of parents’ concerns on their children. Parental perceptions of control and acceptance and adjustment to their child’s difficulties were viewed as important outcomes and should also be addressed. Topics around issues of grief and loss have been incorporated into parenting interventions for developmental disabilities (e.g., Plant & Sanders, 2007), and may be applicable to tic populations with adaptations, given that such parental feelings can be experienced following tic disorder diagnosis (Chowdhury, 2004).

In terms of intervention delivery, most parents endorsed the importance of at least some professional expertise in tic disorders, highlighting that training in non-specialist services may be necessary to parents. Most parents also supported group-based interventions, however, given that Factor 4 perceived individual consultations as necessary, some individual contact within group-based programmes should be considered.

Whilst general intervention guidance can be extrapolated from the present results, the factors demonstrate that parents will have different expectations and beliefs about parenting interventions. Clearly, these must be assessed to tailor the
intervention accordingly, as with any clinical intervention in any population. For most parents these different viewpoints are likely to be subtle, and most would endorse and engage with parenting interventions, however, Factor 3 has demonstrated that differences may also be marked and clinicians’ awareness of this type of parental viewpoint is crucial in facilitating engagement.

Summary

The study examined parents’ views of parenting interventions in tic disorders using Q-methodology. All factors evidenced some support for parenting interventions, and most parents generally endorsed tic-specific content, content to address co-morbid conditions, and the provision of space for parents to discuss their concerns. These results inform the further development of parenting interventions, and future research should implement and evaluate these within randomised controlled trials. The findings highlight the potential benefits of interventions both directly for parents and indirectly for children, as one parent summarised:

“It is very stressful for the parents seeing your child have tics and sometimes more stressful for the parent than the child! If the parent is stressed the child may feel even more stressed and tic more.”

Acknowledgements

The authors would like to thank Mr Martin Woods for his administrative assistance in recruitment and Tourettes Action (www.tourettes-action.org.uk) for advertising the research to parents. We would also like to express our gratitude to all the parents who participated; we are grateful for their support of this study.
References


Debes, N., Hjalgrim, H. & Skov, L. (2010) The presence of attention-deficit hyperactivity disorder (ADHD) and obsessive-compulsive disorder worsen


Paper 3

Parenting Interventions for Children with Tic Disorders: Professionals’ Perspectives

Manuscript prepared in accordance with guidance for

*Child and Adolescent Mental Health,*

*Original Article* (Appendix 4)

Word count: 5500 main body with references

Running Head: Parenting Interventions for Children with Tic Disorders
Acknowledgements

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Abstract

**Background:** Tic disorders can have an emotional and social impact on children and families, which can in turn have a reciprocal impact on tics. Research into parenting interventions within this population is limited. **Method:** Twenty-five professionals’ views on the acceptability, effectiveness, feasibility and utility of parenting interventions were explored using Q-methodology. **Results:** Three highly correlated factors emerged, indicating three viewpoints with discrete elements that were underpinned by similar general perspectives. All factors endorsed a psychological approach, the importance of parenting practices, and theoretical and clinical justifications for parenting interventions. Discrete elements of the viewpoints debated the advocated focus, barriers and audience of interventions. **Conclusions:** Multidisciplinary professionals endorsed parenting interventions as a therapeutic tool within tic disorders. Results provide suggestions to further develop and implement interventions.

**Keywords:** Tourette syndrome, tic disorders, parenting, parent intervention
Key Practitioner Message:

- The study explored professionals’ views of parenting interventions in tic disorders. Interventions were generally considered effective, acceptable and theoretically and clinically justifiable.
- Identified intervention components included teaching positive parenting skills, addressing parental cognitions, providing techniques to manage children’s anxiety and social skills, and ensuring skill generalisability.
- A need for increased training in non-specialist services and research-evidence was highlighted. Current results may assist clinicians in designing interventions.
Introduction
Tics are recurrent, non-rhythmic, motor movements or vocalisations. Tics themselves are relatively common and are mildly and transiently experienced by around 10% of children (Verdellen et al., 2011). Tics are, however, also characteristic of tic disorders. Prevalence across tic disorders varies from 0.77% for Tourette syndrome to 2.99% for transient tic disorder (Knight et al., 2012). Co-morbid conditions occur in around 90% of individuals (Robertson & Cavanna, 2008), and include attention deficit hyperactivity disorder (ADHD), obsessive compulsive behaviours, depression, anxiety, conduct difficulties, autism and learning difficulties (Robertson, 2000; Robertson & Cavanna, 2008).

Tic disorders and co-morbidities significantly affect children and families. Children may experience social, cognitive and emotional difficulties (Robertson & Cavanna, 2008; Storch et al., 2007), while parents may experience increased stress and negative life events (Cooper, Robertson, & Livingston, 2003; Robertson & Cavanna, 2008). Furthermore, environmental, social and emotional factors can influence tic severity (Robertson & Cavanna, 2008), thus, parental management and problematic family functioning may inadvertently contribute to tic exacerbation, which may heighten familial stress; creating a reciprocal cycle.

First-line recommended psychosocial interventions for tic disorders include child-directed behavioural interventions (Verdellen et al., 2011); however, family interventions also seem justified given the familial implications. Despite recognition of the importance of family education and support (Verdellen et al., 2011), this area is under-researched. Within a randomised controlled trial design, only one study by Scahill et al. (2006) evaluated parent training for children with tic disorders and conduct difficulties. Although tics did not reduce, effects on disruptive behaviour
were promising, indicating potential valuable clinical utility for co-morbid
difficulties.

Given the limited research, the current study aimed to explore professionals’
views of parenting interventions within tic disorders, with particular consideration to
perceived acceptability, feasibility, effectiveness and utility.

Method
Design
The study used Q-methodology, whereby, participants systemically rank
statements according to agreement and the relative ranked positions reflect emergent
viewpoints. Q-methodology permits subjective opinions to be captured reliably and
quantifiably (Watts & Stenner, 2012), and is being increasingly used within
healthcare research to explore staff opinions of interventions (e.g., McIntosh et al.,
2012).

Ethical Approval
National Health Service (NHS) Research Committee and Research and Development
approval was obtained (13/NW/0213, RJ113/N190; Appendix 5-6).

Participants
Participants were recruited via email and web-based advertisements. The project was
advertised through a tic disorders charity (Tourettes Action), specialist tic disorders
service and a paediatric interest mailing group (Appendix 14). Participants with
experience of working professionally with tic disorders and/or delivering parenting
interventions were included. No exclusion criteria were applied.
Q-Methodology Procedure

Q-set Development

The statements that are systematically ranked in Q-methodology are termed the Q-set. Information to develop the Q-set was derived from various sources (Watts & Stenner, 2012). Academic literature, television programmes and websites were searched and interviews were completed with parents of children with tic disorders who had previously participated in a pilot parenting group at one of the study recruitment sites. Themes were extracted and representative statements generated (n=244) which were reviewed and refined by the research team to produce 73 final statements (Appendix 16-17), considered to offer a balanced and representative coverage of opinions (Watts & Stenner, 2012).

Data Collection

Q-sorts were completed via a secure website link. Participants firstly categorised the 73 statements as agree, neutral or disagree and then ranked statements from most agree (+6) to most disagree (-6), using a forced choice distribution grid (Figure 1). Free-text, post-sort questions then elicited further information about the statements ranked at the extreme ends of the Q-sort grid, as well as general views about parenting interventions in tic populations.
Data Analysis

Factor analysis was undertaken using PQMethod (Schmolck & Atkinson, 2002). Q-methodology involves by-person factor analysis (Watts & Stenner, 2012), identifying factors upon which participants load due to similar sorting patterns (Watts & Stenner, 2005). A principal components factor analysis was conducted: factors with an eigenvalue >1 were extracted and subjected to varimax rotation. Qsorts with significant factor loadings were merged using a weighted averaging procedure to create a factor array, or representative sorting pattern. Significant factor loadings can be determined using several criteria (Watts & Stenner, 2012). Commonly, a p<0.01 threshold is used, however, should this result in multiple confounding Qsorts (which load significantly onto more than one factor and are
excluded from analyses), increasing the loading stringency by raising the significance threshold is recommended (Watts & Stenner, 2005).

Factors were interpreted using factor arrays, demographic information and post-sort questions. Factor-specific views were identified using statements that were statistically distinguishing (p<0.01) or assigneddistinctively extreme ratings compared to other factors. Shared views were explored using consensus statements and statements placed at extreme rankings across all factors.

Results
Participant Information

Twenty-five professionals participated, a sufficient sample size for Q-methodology (Watts & Stenner, 2012). Table 1 presents demographic characteristics.
<table>
<thead>
<tr>
<th>Question</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional role:</td>
<td></td>
</tr>
<tr>
<td>Charity Worker</td>
<td>3</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>7</td>
</tr>
<tr>
<td>Research Assistant Psychologist</td>
<td>1</td>
</tr>
<tr>
<td>Medic</td>
<td>1</td>
</tr>
<tr>
<td>Paediatric Neurologist</td>
<td>1</td>
</tr>
<tr>
<td>Psychiatrist</td>
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</tr>
<tr>
<td>Trainee Clinical Psychologist</td>
<td>8</td>
</tr>
<tr>
<td>Primary Mental Health Worker</td>
<td>1</td>
</tr>
<tr>
<td>Trainee Psychotherapist</td>
<td>1</td>
</tr>
<tr>
<td>Worked professionally with children and parents:</td>
<td></td>
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<tr>
<td>Yes</td>
<td>25</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>Professional involvement in parenting groups/interventions:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Frequency of involvement (if answered yes):</td>
<td></td>
</tr>
<tr>
<td>Very frequently</td>
<td>6</td>
</tr>
<tr>
<td>Frequently</td>
<td>8</td>
</tr>
<tr>
<td>Occasionally</td>
<td>5</td>
</tr>
<tr>
<td>Rarely</td>
<td>1</td>
</tr>
<tr>
<td>Professional involvement with children with tic disorders and parents:</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td>Frequency of involvement (if answered yes):</td>
<td></td>
</tr>
<tr>
<td>Very frequently</td>
<td>4</td>
</tr>
<tr>
<td>Frequently</td>
<td>7</td>
</tr>
<tr>
<td>Occasionally</td>
<td>6</td>
</tr>
<tr>
<td>Rarely</td>
<td>0</td>
</tr>
</tbody>
</table>
Factor Analysis

Three factors were extracted and rotated, accounting for 68% of study variance. Twenty-two Q sorts were ‘confounded’ using a p<0.01 loading threshold (critical value >+0.30). To minimize data loss, this significance threshold was systematically increased (Watts & Stenner, 2005), and factor loadings of >+0.52 were deemed significant (Appendix 24). Twenty-three Q-sorts loaded onto a factor, with the two remaining Q-sorts excluded.

The factors were highly correlated (Factors 1 and 2=0.79: Factors 1 and 3=0.71: Factor 2 and 3=0.75), indicating that although distinct aspects of opinion existed, there were substantial shared opinions.

Factor interpretations are presented by reporting the relevant statement and associated factor ranking. The presented statements used the term tic spectrum conditions (TSC)\(^7\) to refer to tic disorders. Quotes from post-sort questions are provided to supplement findings. Table 2 presents factor-specific participant information and Table 3 presents factor arrays.

---

\(^7\) This term is used because we believe that it is less stigmatising and reflects the complex range of symptoms.
Table 2. Participant Information for each Factor

<table>
<thead>
<tr>
<th>Factor</th>
<th>Profession</th>
<th>Experience of parenting groups/interventions</th>
<th>Experience of working with tic disorders</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Charity Worker</td>
<td>Yes, very frequently</td>
<td>Yes, very frequently, tic disorders training</td>
</tr>
<tr>
<td>1</td>
<td>Clinical Psychologist</td>
<td>Yes, very frequently, delivered IY</td>
<td>Yes, frequently, Neurology service</td>
</tr>
<tr>
<td>1</td>
<td>Clinical Psychologist</td>
<td>Yes, frequently, delivered parenting interventions</td>
<td>No</td>
</tr>
<tr>
<td>1</td>
<td>Clinical Psychologist</td>
<td>Yes, frequently, delivered IY</td>
<td>No</td>
</tr>
<tr>
<td>1</td>
<td>Trainee Clinical Psychologist</td>
<td>Yes, rarely, delivered IY</td>
<td>Yes, occasionally, one case</td>
</tr>
<tr>
<td>1</td>
<td>Trainee Clinical Psychologist</td>
<td>Yes, occasionally, delivered IY</td>
<td>No</td>
</tr>
<tr>
<td>1</td>
<td>Paediatric Neurologist</td>
<td>No</td>
<td>Yes, frequently, Neurology service</td>
</tr>
<tr>
<td>1</td>
<td>Primary Mental Health Worker</td>
<td>Yes, very frequently, delivered various parenting programmes</td>
<td>Yes, occasionally, several clinical cases</td>
</tr>
<tr>
<td>2</td>
<td>Charity Worker</td>
<td>No</td>
<td>Yes, frequently, support role.</td>
</tr>
<tr>
<td>2</td>
<td>Clinical Psychologist</td>
<td>Yes, very frequently</td>
<td>Yes, very frequently</td>
</tr>
<tr>
<td>2</td>
<td>Clinical Psychologist</td>
<td>Yes, very frequently, delivered ADHD parenting interventions</td>
<td>Yes, occasionally</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Clinical Psychologist</td>
<td>No</td>
<td>Yes, frequently, research-based</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Clinical Psychologist</td>
<td>Yes, occasionally, delivered ADHD parenting interventions</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Clinical Psychologist</td>
<td>Yes, occasionally, delivered IY</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Clinical Psychologist</td>
<td>Yes, frequently, delivered IY</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Clinical Psychologist</td>
<td>No</td>
<td>Yes, occasionally</td>
</tr>
<tr>
<td>2</td>
<td>Trainee Psychotherapist</td>
<td>Yes, frequently, accredited IY group leader</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Medic</td>
<td>Yes, frequently, delivered sleep-related programmes</td>
<td>Yes, frequently</td>
</tr>
<tr>
<td>Role</td>
<td>Experience</td>
<td>Impact</td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>------------------------</td>
<td>-------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Charity Worker</td>
<td>No</td>
<td>Yes, occasionally, delivered psychological interventions</td>
<td></td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>Yes, frequently</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Trainee Clinical Psychologist</td>
<td>Yes, occasionally, delivered IY</td>
<td>Yes, frequently, research-based</td>
<td></td>
</tr>
<tr>
<td>Research Assistant Psychologist</td>
<td>Yes, occasionally</td>
<td>Yes, very frequently, Neuropsychiatry/tic disorder clinic</td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>Yes, very frequently</td>
<td>Yes, very frequently, Neuropsychiatry clinic</td>
<td></td>
</tr>
</tbody>
</table>

Note. Two ‘confounded’ Q sorts are excluded. IY=Incredible Years Programme (Webster-Stratton, 2006).
Consensus Statements

Consensus statements are those with similar rankings that do not distinguish between factors. Although three distinct opinions were identified, there was a high level of shared overall agreement between the factors. The Q-analysis identified 32 statistically non-distinguishing consensus statements (p>0.01)(Table 3). A further two statements were consistently awarded an extreme ranking across all factors (ranking >±3). In describing consensus statements, focus is placed on those with more extreme rankings, and all three factor rankings are reported, ordered Factor 1 (F1), Factor 2 (F2) and Factor 3 (F3).

All professionals agreed the importance of parenting practices on children’s well-being (e.g., Statement 50: ‘Positive child-parent interactions are important for children’s adjustment and quality of life’; F1=+4, F2=+6, F3=+4), and identified positive parenting skills as an intervention target (s8: ‘Learning skills to give children positive attention, praise and rewards is important in a parenting intervention for TSC’; F1=+3, F2=+3, F3=+4). Professionals agreed with the importance of parents’ internal experiences in changing parenting practices (s3: ‘Parents own thoughts and feelings affect parenting behavior’; F1=+3, F2=+5, F3=+4), such that an important intervention outcome was perceived parental control (s65: ‘Helping parents to feel more in control of their child’s difficulties is an important outcome of parenting interventions for TSC’; F1=+2, F2=+2, F3=+2).

Professionals strongly endorsed the acceptability of parents as the agents for change, (s31: ‘It is unreasonable to deliver an intervention through parents’; F1=-6, F2=-5, F3=-5) and (s22: ‘It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal)’; F1=-3, F2=-4, F3=-6). Parent-based
motivation or worry were not seen as barriers (s33: ‘Parents would not complete homework as part of a parenting intervention because they lack motivation’; F1=-3, F2=-3, F3=-3) and (s19: ‘Parents would be worried that changing parenting techniques would make things worse’; F1=-2, F2=-2, F3=-2). Group implementation was endorsed given social benefits, (s40: ‘Social support from other parents is an important benefit of a group-based parenting intervention’; F1=+3, F2=+4, F3=+5).

In terms of effectiveness, professionals disagreed that biological or pharmacological approaches to tic disorders negates the effectiveness of psychological interventions (s26: ‘TSC are biological in origin so a parenting intervention will have no effect’; F1=-5, F2=-6, F3=-5), and (s70: ‘Medication is more effective than psychological interventions for TSC’; F1=-4, F2=-3, F3=-3). The effectiveness of parenting interventions was agreed, (s71: ‘Parenting interventions for TSC would be effective’; F1=+1, F2=+3, F3=+2), (s24: ‘The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time’; F1=-4, F2=-3, F3=-3) and (s27: ‘Parent interventions for TSC would be less effective than interventions that treat the child directly’; F1=-2, F2=-2, F3=-3). All professionals endorsed a need and financial justification for tic-specific interventions (s28: ‘Parents of children with and without TSC have similar needs so interventions just for children with TSC are unnecessary’; F1=-4, F2=-3, F3=-4), and (s37: ‘Parenting interventions for TSC are not a good use of NHS money’; F1=-5, F2=-4, F3=-4).
Distinguishing Factor Viewpoints

Factor 1: Reflecting, Accepting and Knowing

Eight professionals loaded onto Factor 1, explaining 25% of the variance. As this factor represented the importance of parental cognitions and tic-specific education, it was termed ‘Reflecting, Accepting and Knowing’. Professionals included a range of professions, most had psychological training and reported considerable experience of parenting interventions. The focus on parental cognitions may therefore be underpinned by their systemic and reflective training backgrounds alongside common issues experienced through delivering parenting interventions across different populations.

Responses loading onto this factor particularly endorsed the importance of family environments and parental views on children’s well-being, (s49: ‘Family functioning is related to children’s adjustment and quality of life’; +4) and (s53: ‘Children’s perception of their parent’s views towards their TSC is important’; +5).

Professionals viewed parenting interventions as providing a reflective environment within which parents could explore and re-evaluate their cognitions to facilitate acceptance, adjustment and hope. Professionals strongly agreed with the following statements: (s4: ‘Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention’; +3), (s14: ‘Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC’; +6), (s2: ‘Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention’; +5) and (s68: ‘Helping parents to feel more positive about the future is an important outcome of parenting interventions for TSC’; +4). Indeed, these parent-based
outcomes were endorsed over tic modification (s66: ‘Changing children’s tics is an important outcome of parenting interventions for TSC’; -3).

The need for providing specific tic-related knowledge to parents was agreed, (s15: ‘Providing education about tics is important in a parenting intervention for TSC’; +3), and (s16: ‘Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC’; +2), and a lack of professional knowledge around tic disorders was perceived as an intervention obstacle (s73: ‘A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC’; +4).

In terms of attendants, delivering parenting interventions regardless of tic severity and to parents-only was endorsed, consistent with the advocated focus on parental cognitions, (s55: ‘Parenting interventions for TSC should only be offered to parents of children with more severe tics’; -4) and (72: ‘Family members, friends, and teachers should be invited to attend parenting interventions for TSC’; -3).

Comments provided by professionals loading onto Factor 1 highlighted the importance of parental cognitions:

“Parents who found it most hard to accept the disorder, and therefore their child, struggled the most and could not support their child.”

“Parental awareness, understanding, attitude, modelling and support are fundamental to a successful outcome in most cases. Regardless of tic severity.”

“Children pick a lot on their parents perceptions and this will influence their self confidence and perception of themselves.”


**Factor 2: Skilling-up!**

Ten participants loaded onto Factor 2, explaining 23% of the variance. Factor 2, termed ‘Skilling-up!’, reflected a skills-based approach to parenting interventions. Professionals again encompassed a range of professions. Most had psychological backgrounds; however, many were still undertaking professional training. The value placed on delivering functional strategies to parents may therefore reflect their training stage, with perhaps greater focus on relaying learnt techniques.

Professionals strongly agreed the importance of effective parenting strategies on children’s well-being, (s51: ‘Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence’; +4). The value of parenting interventions was therefore viewed as providing practical skills to parents, (s7: ‘Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC’; +5), and (s6: ‘Learning skills to manage children’s anxiety is important in a parenting intervention for TSC’; +4). Professionals did endorse the importance of considering parents’ internal experiences in parenting interventions, (s2: ‘Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention’; +4), perhaps given the perceived impact of internal experiences on parenting practices. These systemic intervention outcomes were again advocated over tic modification (s66: ‘Changing children’s tics is an important outcome of parenting interventions for TSC’; -3).

In direct contrast to Factor 1, whilst professionals disagreed with the provision of medication information, (s16: ‘Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC’; -3), they did not deny the importance of acknowledging the medical underpinnings of the
disorder, strongly disagreeing that (s34: ‘Diagnosing TSC is a barrier to parents accessing interventions’; -5).

Responses also supported group-based delivery of interventions on resource and clinical grounds (s47: ‘If NHS resources are limited it is better for more parents to be seen in a group-based parenting intervention’; +3), (s39: ‘Meeting other parents of children with TSC would increase parents worry about their own child’; -4), and (s52: ‘Parents are less likely to participate in group-based parenting interventions than individual parenting interventions’; -4).

Comments from professionals highlighted the perceived importance of parental strategies and group-based support:

“Likely to be beneficial both in terms of information and strategies for parents, and the social support parents may gain from a group.”

“A group has the potential to inform parents, provide social support, destigmatise Tourettes, and provide guidance.”

**Factor 3: Generalisability**

Five participants loaded onto Factor 3, explaining 21% of the variance. Factor 3, termed ‘Generalisability’, represented the universality of skills and attendants. Again the factor encompassed several professions, most with psychological training. Several professionals worked within specialist neuropsychiatry and tic disorder clinics and several held tic-related research roles. Consequently, the focus on generalisability may reflect increased awareness of the wider clinical needs of families alongside awareness of demands on specialist services.

Professionals strongly endorsed the importance of providing general skills, (s25: ‘Learning generalisable skills is important in a parenting intervention for
The importance of nurturing parental hope and children’s social skills were also advocated, (s68: ‘Helping parents to feel more positive about the future is an important outcome of parenting interventions for TSC’; +5), and (s17: ‘Helping parents to develop children’s social skills is important in a parenting intervention for TSC’; +3).

Consistent with the importance of generalisability, professionals disagreed that variability in children’s difficulties would be detrimental to interventions or that interventions should be limited to those with more severe tics, (s56: ‘The differences in children’s TSC related difficulties are a barrier to group-based parenting interventions’; -4) and (s55: ‘Parenting interventions for TSC should only be offered to parents of children with more severe tics’; -4). Professionals did not strongly advocate the need for tic-specific professional expertise or for individual interventions, (s59: ‘Professionals who run parenting groups for TSC must be experts in the treatment of tics’; -3) and (s46: ‘Parents need to discuss their child’s difficulties on an individual basis’; -3).

Group-based interventions were supported on financial grounds, (s48: ‘Group-based parenting interventions for TSC are cost effective’; +6), and professionals encouraged wide attendance of significant others (s72: ‘Family members, friends, and teachers should be invited to attend parenting interventions for TSC’; +2).

The current lack of research was, however, identified as an obstacle to implementation (s61: ‘The lack of research in parenting interventions for TSC is a barrier to treatment’; +3), perhaps given professionals increased familiarity with research evidence in tic disorders.
Comments provided by professionals reflected the importance of general skills and research evidence:

“It can provide parents with generalisable skills and confidence in supporting their children and nurture family interactions and functioning.”

“They are enjoyable for the parents and they gain a lot [of] skills which they can use, either on their child with TS or on their siblings.”

“Unfortunately the evidence base is weak but clinically this a key component of good care.”
<table>
<thead>
<tr>
<th>Statement</th>
<th>Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents of children with TSC experience more stress than parents of children without TSC.</td>
<td>0 -1 1</td>
</tr>
<tr>
<td>Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention.</td>
<td>5 4 1*</td>
</tr>
<tr>
<td>Parents own thoughts and feelings affect parenting behaviour.</td>
<td>3 5 4</td>
</tr>
<tr>
<td>Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention.</td>
<td>3 2 0</td>
</tr>
<tr>
<td>Learning skills to manage children’s anger is important in a parenting intervention for TSC.</td>
<td>-1 1 0</td>
</tr>
<tr>
<td>Learning skills to manage children’s anxiety is important in a parenting intervention for TSC.</td>
<td>2 4 0</td>
</tr>
<tr>
<td>Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC.</td>
<td>2 5 3</td>
</tr>
<tr>
<td>Learning skills to give children positive attention, praise and rewards is important in a parenting intervention for TSC.</td>
<td>3 3 4</td>
</tr>
<tr>
<td>Learning skills in giving and enforcing clear commands to children is important in a parenting intervention for TSC.</td>
<td>-1 -1 0</td>
</tr>
<tr>
<td>Learning skills to pay less attention to children’s negative behaviours is important in a parenting intervention for TSC.</td>
<td>1 1 -1</td>
</tr>
<tr>
<td>Learning skills to apply consequences for negative behaviour (e.g., time out, grounding) is important in a parenting intervention for TSC.</td>
<td>0 0 -1</td>
</tr>
<tr>
<td>Learning skills to manage children’s mood is important in a parenting intervention for TSC.</td>
<td>1 0 1</td>
</tr>
<tr>
<td>Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC.</td>
<td>2 2 0</td>
</tr>
<tr>
<td>Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC.</td>
<td>6* 2 2</td>
</tr>
<tr>
<td>Providing education about tics is important in a parenting intervention for TSC.</td>
<td>3 2 0</td>
</tr>
<tr>
<td>Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC.</td>
<td>2* -3* -1*</td>
</tr>
<tr>
<td>Helping parents to develop children’s social skills is important in a parenting intervention for TSC.</td>
<td>1 1 3*</td>
</tr>
<tr>
<td>Making parents feel valued by providing a comfortable environment (e.g., snacks, breaks, resources) is important in a parenting intervention for TSC.</td>
<td>1 3 0</td>
</tr>
<tr>
<td>Parents would be worried that changing parenting techniques would make things worse.</td>
<td>-2 -2 -2</td>
</tr>
<tr>
<td>Inviting parents to attend a parenting intervention for TSC would make them feel criticised.</td>
<td>-1 -2 -2</td>
</tr>
<tr>
<td>If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics.</td>
<td>0 -1 -1</td>
</tr>
</tbody>
</table>
It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal).

22. Parents would be wary about a parenting intervention for TSC.
23. The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time.
24. Learning generalisable skills is important in a parenting intervention for TSC.
25. TSC are biological in origin so a parenting intervention will have no effect.
26. Parent interventions for TSC would be less effective than interventions that treat the child directly.
27. Parents of children with and without TSC have similar needs so interventions just for children with TSC are unnecessary.
28. Child and Adolescent Mental Health Services (CAMHS) should offer parenting interventions for TSC.
29. Practical issues make it too difficult for parents to attend parenting interventions.
30. It is unreasonable to deliver an intervention through parents.
31. Parents would not complete homework as part of a parenting intervention because they are too stressed.
32. Parents would not complete homework as part of a parenting intervention because they lack motivation.
33. Diagnosing TSC is a barrier to parents accessing interventions.
34. Parents would need repeated follow-ups to continue using the skills learned in a parenting intervention.
35. Only a small number of people would need a parenting intervention for TSC.
36. Parenting interventions for TSC are not a good use of NHS money.
37. Parents would only attend a parenting intervention if it involved other parents with children with TSC.
38. Meeting other parents of children with TSC would increase parents worry about their own child.
39. Social support from other parents is an important benefit of a group-based parenting intervention.
40. Between six and ten parents in a group parenting intervention group is a good size.
41. Parents should be offered a parenting intervention shortly after their child is first diagnosed with TSC.
42. Parenting interventions are more appropriate for parents of younger children with TSC.
43. Transition to adolescence can be difficult so parenting interventions should be offered to parents of adolescents with TSC.
44. Shorter, weekly meetings are better than longer, monthly meetings in a parenting intervention for TSC.
45. Parents need to discuss their child’s difficulties on an individual basis.
46. If NHS resources are limited it is better for more parents to be seen in a group-based parenting intervention.
<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Score1</th>
<th>Score2</th>
<th>Score3</th>
</tr>
</thead>
<tbody>
<tr>
<td>48</td>
<td>Group-based parenting interventions for TSC are cost effective.</td>
<td>1</td>
<td>0</td>
<td>6*</td>
</tr>
<tr>
<td>49</td>
<td>Family functioning is related to children’s adjustment and quality of life.</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>50</td>
<td>Positive child-parent interactions are important for children’s adjustment and quality of life.</td>
<td>4</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>51</td>
<td>Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence.</td>
<td>2</td>
<td>4</td>
<td>1</td>
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<tr>
<td>52</td>
<td>Parents are less likely to participate in group-based parenting interventions than individual parenting interventions.</td>
<td>-1</td>
<td>-4*</td>
<td>-2</td>
</tr>
<tr>
<td>53</td>
<td>Children’s perception of their parent’s views towards their TSC is important.</td>
<td>5</td>
<td>3</td>
<td>1*</td>
</tr>
<tr>
<td>54</td>
<td>It is not children’s tics that cause most concern to parents, but common co-morbid conditions (e.g., anxiety, mood, anger, behavioural difficulties).</td>
<td>-1</td>
<td>-1</td>
<td>1</td>
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<tr>
<td>55</td>
<td>Parenting interventions for TSC should only be offered to parents of children with more severe tics.</td>
<td>-4</td>
<td>-2</td>
<td>-4</td>
</tr>
<tr>
<td>56</td>
<td>The differences in children’s TSC related difficulties are a barrier to group-based parenting interventions.</td>
<td>-3</td>
<td>-2</td>
<td>-4*</td>
</tr>
<tr>
<td>57</td>
<td>All main caregivers of a child need to attend a parenting intervention for it to be effective.</td>
<td>-2</td>
<td>0*</td>
<td>-2</td>
</tr>
<tr>
<td>58</td>
<td>Parents would accept and attend a parenting intervention for TSC.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>59</td>
<td>Professionals who run parenting groups for TSC must be experts in the treatment of tics.</td>
<td>0</td>
<td>-2</td>
<td>-3</td>
</tr>
<tr>
<td>60</td>
<td>It is important that parents have a positive relationship with the professionals that lead parenting interventions.</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>61</td>
<td>The lack of research in parenting interventions for TSC is a barrier to treatment.</td>
<td>-1</td>
<td>0</td>
<td>3*</td>
</tr>
<tr>
<td>62</td>
<td>If a parenting intervention for TSC was in book form, professionals would be more likely to offer it.</td>
<td>0</td>
<td>0</td>
<td>-1</td>
</tr>
<tr>
<td>63</td>
<td>Siblings of children with TSC would benefit from their parents attending a parenting intervention.</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>64</td>
<td>It is important to consider parents’ cultural differences in a parenting intervention for TSC.</td>
<td>3</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>65</td>
<td>Helping parents to feel more in control of their child’s difficulties is an important outcome of parenting interventions for TSC.</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>66</td>
<td>Changing children’s tics is an important outcome of parenting interventions for TSC.</td>
<td>-3</td>
<td>-3</td>
<td>0*</td>
</tr>
<tr>
<td>67</td>
<td>Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC.</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>68</td>
<td>Helping parents to feel more positive about the future is an important outcome of parenting interventions for TSC.</td>
<td>4</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>69</td>
<td>Parents prefer psychological interventions to medication for TSC.</td>
<td>-2</td>
<td>-1</td>
<td>2*</td>
</tr>
<tr>
<td>70</td>
<td>Medication is more effective than psychological interventions for TSC.</td>
<td>-4</td>
<td>-3</td>
<td>-3</td>
</tr>
<tr>
<td>71</td>
<td>Parenting interventions for TSC would be effective.</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>72</td>
<td>Family members, friends, and teachers should be invited to attend parenting interventions for TSC.</td>
<td>-3*</td>
<td>-1*</td>
<td>2*</td>
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<tr>
<td>73</td>
<td>A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC.</td>
<td>4*</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

^ = statistically consensus statements (p<0.01). *= statistically distinguishing statement factor (p<0.01).
TSC = Tic spectrum condition/ tic disorder, NHS = National Health Service.
Discussion
The study explored twenty-five professionals’ opinions on parenting interventions in tic disorders. Using Q-methodology, three factors were identified. Some shared views existed, with all factors endorsing a biopsychosocial approach, the importance of parenting practices for children’s well-being, and increased parental feelings of control. Given the range of participating professionals, this highlights the interdisciplinary recognition of systemic considerations and importance of multidisciplinary approaches within this population. Interventions were agreed to be needed, reasonable, effective, financially justifiable and well-received by parents across all factors, possibly reflecting practitioners increasing familiarity with popular parenting programmes (e.g., Webster-Stratton, 2006).

Whilst shared general opinions were identified, factor-specific viewpoints also emerged. Factor 1 ‘Reflecting, Accepting and Knowing’ particularly endorsed the importance of providing a reflective environment to facilitate parental acceptance, adjustment and hope, alongside providing specialist tic-related information. Factor 2 ‘Skilling-up!’ particularly endorsed the importance of teaching parents effective parenting strategies, whereas Factor 3 ‘Generalisability’ particularly endorsed teaching generalisable skills.

Methodological Limitations
The online Q-methodology paradigm enabled geographically dispersed professionals to participate. The expression of opinions through researcher-generated statements can be criticised as restrictive and reductionist. However, this methodology opens participation to professionals who may not consider themselves to have particularly strong views or pre-existing expertise in this area to be able to discuss their opinions at length. This is important for tic disorders, given that prevalence and co-
morbidities would suggest that children’s presentation within non-specialist services is likely, and therefore children may indeed present to those professionals who do not consider themselves to be particularly knowledgeable or opinionated about interventions in tic disorders.

**Clinical and Research Implications**

Results hold obvious clinical implications for parenting interventions in tic disorders. A clear clinical justification for further development, implementation and evaluation of parenting interventions was identified. Lack of specialist knowledge and research evidence were endorsed as obstacles, identifying increased research and training needs in non-specialist services. Group interventions were endorsed as clinically appropriate and beneficial for financial, resource and social reasons. The study also provides guidance around intervention content, identifying important components as teaching positive parenting skills, addressing parental cognitions and providing techniques to manage children’s anxiety and social skills. Surprisingly, intervention components directed at behavioural control were not strongly endorsed, despite the high co-morbidity and impact of behavioural difficulties on child and family functioning (Sukhodolsky et al., 2003).

The study also highlighted areas of contention among factors. Firstly, diagnosis was viewed as both a barrier (Factor 1) and facilitator (Factor 2) to interventions. The issues surrounding the complexity of diagnosis of tic disorders are well-documented (Robertson & Cavanna, 2008) and divergence in professional opinion may reflect this wider debate. Similarly, the provision of medication information was endorsed (Factor 1) as well as contested (Factor 2). This highlights an important consideration and further research should explore parental opinions.
Finally, attendance of significant others (e.g., teachers, friends) was contested (Factor 1) and endorsed (Factor 3). Previous parenting programmes in other populations have varied in terms of audience (e.g., Lee et al., 2012). Further research should determine the benefits and disadvantages in tic populations.

In conclusion, professionals generally agreed that interventions were theoretically and clinically justified but differences emerged in the advocated focus, barriers, and audience. Results hold clinical implications, and may aid development of a future programme, which could be implemented and evaluated within randomised controlled trials.
References


Paper 4

Innovations in Practice

Professionals’ and Parents’ Viewpoints on Parenting Interventions in Tic Disorders: Clinical Implications

Manuscript prepared in accordance with guidance for

*Child and Adolescent Mental Health,*

*Innovations in Practice Article* (Appendix 4)

Running Head: Parenting Interventions in Tic Disorders: Clinical Implications

Word count: 2500 main body with references
Abstract

Background: Parent-directed psychosocial interventions in tic disorders are endorsed by clinical guidelines and research. However, further guidance around the form of such interventions is still lacking. Method: Parents’ and professionals’ views were explored using Q-methodology and results have been previously reported across two studies. The current paper discusses these findings together to inform clinical interventions. Results: Important differences in opinions were found within and between parent and professional groups; however, majority viewpoints permitted recommendations around possible intervention format, delivery, and content. Conclusion: Intervention characteristics are suggested based on parent and professional views. Future research should implement and further evaluate such interventions.

Keywords: Tourette syndrome, tic disorders, parent, parenting
Key Practitioner Message:

• Guidance and research around parenting interventions in tic disorders is limited.

• Professionals’ and parents’ viewpoints were explored across two previously reported studies. This paper considers the clinical implications of these findings.

• Interventions were generally considered acceptable, justified and needed.

• Majority viewpoints enabled suggestions around possible intervention format, delivery and content.

• Endorsed intervention components included psychoeducation, positive parenting skills, parental cognition content, techniques to manage co-morbid difficulties and tic-modification elements.
**Introduction**

Tic disorders are characterised by rapid, recurrent, non-rhythmic, motor movements or vocalisations which commonly onset during childhood (Robertson & Cavanna, 2008). Tic disorders are frequently accompanied by co-morbid conditions, including attention deficit hyperactivity disorder (ADHD), obsessive compulsive behaviours, depression, anxiety, conduct issues (Robertson, 2012) and can negatively impact children’s quality of life (e.g., Storch et al., 2007).

Tic disorders can also negatively impact on parents’ quality of life, increasing risks of caregiver stress, burden and mental health difficulties (Cooper, Robertson, & Livingston, 2003; Wilkinson, Marshall, & Curtwright, 2008). Given environmental influences on tic severity (Robertson & Cavanna, 2008), such parental difficulties may negatively and reciprocally impact children’s functioning.

European clinical guidelines for tic disorder treatment recommend psychosocial interventions to modify the child’s environment through parents (Verdellen et al., 2011). Provision of parental support is also endorsed across the literature (e.g., Cooper et al., 2003; Wilkinson et al., 2008). There is, however, no further guidance about the precise form and content of such interventions. Across two studies we explored parents’ and professionals’ opinions of parenting interventions in tic disorders. As results are discussed in detail elsewhere (Evans et al., 2014a, 2014b), the current paper considers the findings from these two studies together, focussing on the majority opinions and clinical implications, to inform recommendations for possible intervention delivery, structure and content.
Method
Professionals who had worked clinically with tic disorders, or delivered parenting interventions, and parents of children with tic disorders were recruited through specialist tic disorder services, professional interest groups and tic disorder charities. Participants completed an internet or postal-based Q-methodological study.

Q-methodology requires participants to systematically rank statements according to agreement, and the relative ranked position of statements reflects emergent viewpoints (Watts & Stenner, 2012). Seventy-three statements were systematically ranked from most agree (+6) to most disagree (-6), using a forced-choice distribution grid (Appendix A). Post-sort interview questions were also completed. Statements were particularly focused on the perceived acceptability, effectiveness, feasibility and utility of interventions.

Using by person-factor analyses for both professionals and parents, participants were grouped, and a factor array was produced to represent typical statement configurations. Each emergent factor, or viewpoint, was then interpreted using the factor arrays, demographic information and post-sort question responses. Further methodological, procedural and analytic details are provided elsewhere (Evans et al., 2014a, 2014b).

Results
Twenty-five professionals and twenty-three parents participated. Three factors, or viewpoints, emerged across professionals and four factors emerged across parents. Factor correlations were high for each study, indicating similar opinions but with distinct areas of disagreement. Detailed factor interpretations, associated clinical implications and participant information are provided in Evans et al. (2014a, 2014b);
the current paper presents a general overview of findings across both studies with a specific focus on majority opinions. Results are organised under clinically relevant sub-headings, with specific statement numbers (Appendix B) reported alongside narrative discussions.

Perceived Acceptability

Across all factors for parents and professionals, participants agreed that parents would not be wary of parenting interventions (*statement s23*), they would undertake associated demands (*s32, s33*), and parent-directed interventions were endorsed as reasonable (*s31*). All professional and parent factors also disagreed that interventions would only be necessary for a small group of people (*s36*) and would not be a good use of money (*s37*).

Across all professional factors and three of the four parent factors, tic-specific interventions were deemed necessary (*s28*), and it was contested that parents would feel criticised or wary of changing parenting techniques (*s19, s20*). Parents, who contributed to the incongruous parent factor (Factor 3), indicated some concerns about implementing intervention techniques. However, this factor offered a clear minority viewpoint, totalling only two parents and explaining the least amount of variance.

Thus, most professionals and parents perceived interventions as acceptable, needed and justified. However, given some parents’ concerns, a thorough assessment of perceived needs, expectations and potential barriers will be important for intervention planning.
Perceived Effectiveness

All professional and parent factors disagreed that medication is more effective than psychological interventions in tic disorders \((s70)\). However, whilst all professionals also strongly contested that parenting interventions would be ineffective because tic disorders are biological in origin \((s26)\), some parents indicated neutral views. Similarly, whilst all professionals disagreed that parenting interventions would be less effective than child-directed interventions \((s27)\), parents indicated mixed views.

In some centres, medication is considered the mainstay of tic disorder treatment \((\text{Robertson}, 2012)\) and although parents did not support medication over psychological interventions, this dominant medical model may influence parental views of aetiology. Some parents’ may therefore have concerns about the effectiveness of parent-directed interventions given biological attributions. Clinicians should provide early and explicit justifications for parent-directed interventions, within a biopsychosocial model of tic disorders. Multi-disciplinary approaches to diagnosis and treatment are also considered to be the optimal way of managing many children.

Group-based Format

Across professionals and parents, most factors agreed that group-based parenting interventions would provide important social support to parents \((s40)\), and most disagreed that parents would be less likely to participate in group-based interventions relative to individual interventions \((s52)\). An incongruous parent factor emerged (Factor 4), whereby five parents appeared less supportive of group interventions, advocating a need to discuss children’s difficulties on an individual basis \((s46)\).
Thus, professionals and parents generally endorsed group-based interventions; however, the perceived individual needs of some parents may support consideration of adjunctive individual consultations. Across other neurodevelopmental conditions, group-based parenting interventions have been combined with individual consultations or telephone calls (see Evans et al., 2014c). This model is likely to be appropriate for tic disorders.

**Delivering Interventions**

Most professional factors and three parent factors agreed on the importance of a positive parent-professional relationship (s60), further supporting the known value of the therapeutic alliance. Whilst professionals either disagreed or appeared neutral regarding the need for professionals to be experts in tic disorder treatments (s59), three parent factors strongly endorsed this need. These conflicting findings identify a potential intervention barrier, and whilst expert-level training for non-specialist professionals may not be clinically necessary, demonstration of some expertise may facilitate parental engagement.

**Audience**

Across all factors, professionals and parents disagreed that parenting interventions should only be offered to those with more severe tics (s55) or younger children (s43). Views regarding whether the child’s extended network (e.g., teachers, friends) should attend interventions (s72) produced particularly mixed views. For professionals, this was both sometimes contested and sometimes endorsed across factors, and for parents this was strongly and weakly endorsed. These findings
indicate a perceived general utility of interventions, but no clear guidance on the attendance of significant others was derived.

**Intervention Components**

**Education**

All parent and professional factors either agreed or indicated neutral opinions regarding the provision of tic-related education in interventions (s15). Parents also indicated either neutral views or agreed with the provision of medication-related information (s16), however, two professional factors contested this. Overall, some psychoeducation appears warranted, but given the mixed views, information content should be determined based on a thorough assessment of parents’ needs and expectations alongside professionals’ preferences.

**Positive Parenting Skills**

All professionals and three parent factors endorsed the importance of positive parent-child interactions for children’s well-being (s50). However, positive parenting skills as an intervention target (e.g., learning skills to give positive attention, developing parent-child relationships) were less strongly endorsed by parents relative to professionals (s7, s8). This disparity may present a barrier to interventions, and clinicians should provide clear justifications for positive parenting skills.

**Parental Thoughts and Feelings**

Across all parent factors and two professional factors, the importance of providing a space for parents to talk about their worries (s4) was agreed. For most professionals and parents, helping parents to feel more in control of their child’s difficulties (s65),
accept and adjust to these difficulties (s14), and feel more positive about the future (s68) were important intervention outcomes.

The importance of parents’ own internal experiences in relation to their parenting practices and the role of interventions in helping parents to consider these effects (s2, s3) was also agreed across all professional factors. For parents, however, only one factor (Factor 1) shared these views, with the remaining three parent factors exhibiting relatively neutral or contradictory views.

Whilst professionals and parents endorsed the importance of sharing and addressing parental concerns about their child’s difficulties, parents were less supporting of the impact of these concerns upon parenting practices. This difference may be attributable to professionals’ training, and ensuring socialisation to cognitive components of an intervention may prove crucial.

*Managing Co-morbid Conditions*

All professional factors and three parent factors more strongly endorsed changing children’s co-morbid conditions relative to changing tics (s66, s67). Most professionals and parents agreed on the importance of providing techniques to manage children’s anxiety (s6). Whilst professionals were relatively neutral about providing techniques to manage children’s anger and mood (s5, s12), most parents more strongly endorsed these components. Addressing co-morbid difficulties is thus a particularly important component of parenting interventions, and clinicians should maintain awareness of potential discrepancies between professionals’ and parents’ perceived co-morbidity related needs.
Managing Tics

Three parent factors strongly endorsed the provision of information about tic modification techniques, such as exposure and response prevention and habit reversal training (s13), and agreed that they would use these techniques (s21). In contrast, all professional factors expressed disagreement or uncertainty about whether parents would implement tic-modification techniques, although they contested that implementation would negatively affect parent-child relationships (s22).

Consequently, tic-modification techniques should be addressed by interventions, either through educational components alone or if clinically appropriate, through parent-supported implementation of techniques, perhaps alongside individual child-directed sessions.

Discussion

Professionals’ and parents’ opinions of parenting interventions in tic disorders were explored across two studies (Evans et al., 2014a, 2014b). This paper considered these findings together, with specific focus upon clinical practice implications.

Most professionals and parents perceived interventions as generally acceptable, needed and justified. Results supported the universal application of parenting interventions across tic severity and age. Consistent with European clinical guidelines for tic disorder treatment (Verdellen et al., 2011), group-based interventions were generally endorsed, although some parents may require additional individual consultations.

In contrast to professionals’ views, parents endorsed tic-related professional expertise, highlighting a potential professional training need and the importance of
clinicians’ perceived knowledge on parental engagement. Mixed views were highlighted regarding whether significant others (e.g., teachers, extended family) should attend interventions. Further investigation through clinical evaluation is needed. However, as qualitative investigations have indicated parental feelings of stigmatisation by extended family members and a lack of understanding from teachers (Rivera-Navarro, Cubo, & Almazan, 2013), at least some direct or indirect involvement of others appears warranted. This may include the attendance of significant others at interventions, clinician-directed provision of psychoeducational material to others, or helping parents to communicate information and model skills to others.

Results also identified possible intervention components. Psychoeducation regarding tic-related issues should be provided and tailored to parents’ expectations and needs. Content should address positive parenting skills and encourage recognition of how parental cognitions impact parenting behaviours. Space for parents to express their worries and cognitive restructuring techniques may be helpful to increase parents perceived control, acceptance, adjustment and hope. Given parents’ perceived importance of expressing worries, clinicians may direct parents to adjunctive external support groups, or help maintain social contact following interventions. Components to manage children’s anxiety, anger and mood difficulties should be provided according to parents’ needs. Finally, clinicians could consider content relating to tic-modification techniques, however, further exploration of professionals’ perceived barriers to parent-directed implementation may be necessary.

This overview has permitted identification of general recommendations. These are, however, limited given that they are based on majority viewpoints.
Detailed consideration of the priorities, similarities and differences between each emergent factor across both studies (see Evans et al., 2014a, 2014b) will be important for clinicians implementing interventions to further consider potential barriers and necessary adjustments. Clearly, interventions must be planned and delivered following a complete clinical assessment and formulation of family needs. However, the current research has provided some initial intervention guidance, which can be further developed in clinical practice. Future studies should evaluate interventions using controlled research designs, perhaps across specialist and non-specialist tic disorder services. Parenting interventions have demonstrated positive outcomes across neurodevelopmental disorders (Evans et al., 2014c), the present findings may contribute to ensuring that such intervention opportunities are increasingly available to those with tic disorders.

Acknowledgements

The authors declare no competing or potential conflicts of interest. Many thanks go to participants, Martin Woods for administrative assistance in recruiting parents and Tourettes Action (www.tourettes-action.org.uk) for advertising the research.
References


## Appendix A: Forced Choice Distribution Grid

Disagree

<table>
<thead>
<tr>
<th></th>
<th>-6</th>
<th>-5</th>
<th>-4</th>
<th>-3</th>
<th>-2</th>
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<th>0</th>
<th>+1</th>
<th>+2</th>
<th>+3</th>
<th>+4</th>
<th>+5</th>
<th>+6</th>
</tr>
</thead>
</table>

Agree
Appendix B: Factor Arrays showing Statements and Associated Rankings across each Factor

<table>
<thead>
<tr>
<th>Statement</th>
<th>Parent Factor</th>
<th>Professional Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>01 Parents of children with TSC experience more stress than parents of children without TSC.</td>
<td>-1</td>
<td>6</td>
</tr>
<tr>
<td>02 Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention.</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>03 Parents own thoughts and feelings affect parenting behaviour.</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>04 Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention.</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>05 Learning skills to manage children’s anger is important in a parenting intervention for TSC.</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>06 Learning skills to manage children’s anxiety is important in a parenting intervention for TSC.</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>07 Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>-1</td>
</tr>
<tr>
<td>08 Learning skills to give children positive attention, praise and rewards is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>09 Learning skills in giving and enforcing clear commands to children is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>10 Learning skills to pay less attention to children’s negative behaviours is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>11 Learning skills to apply consequences for negative behaviour (e.g., time out, grounding) is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>12 Learning skills to manage children’s mood is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>13 Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC.</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Providing education about tics is important in a parenting intervention for TSC.</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>2</td>
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<tr>
<td>Helping parents to develop children’s social skills is important in a parenting intervention for TSC.</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Making parents feel valued by providing a comfortable environment (e.g., snacks, breaks, resources) is important in a parenting intervention for TSC.</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>19 Parents would be worried that changing parenting techniques would make things worse.</td>
<td>-2</td>
<td>-4</td>
</tr>
<tr>
<td>20 Inviting parents to attend a parenting intervention for TSC would make them feel criticised.</td>
<td>-2</td>
<td>-2</td>
</tr>
<tr>
<td>If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics.</td>
<td>-2</td>
<td>-2</td>
</tr>
<tr>
<td>21 It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal).</td>
<td>-1</td>
<td>3</td>
</tr>
<tr>
<td>22 Parents would be wary about a parenting intervention for TSC.</td>
<td>-3</td>
<td>-4</td>
</tr>
<tr>
<td>23 The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time.</td>
<td>-2</td>
<td>-3</td>
</tr>
<tr>
<td>24 Learning generalizable skills is important tin a parenting intervention for TSC.</td>
<td>-4</td>
<td>-1</td>
</tr>
<tr>
<td>25 TSC are biological in origin so a parenting intervention will have no effect.</td>
<td>-1</td>
<td>1</td>
</tr>
<tr>
<td>26 Parent interventions for TSC would be less effective than interventions that treat the child directly.</td>
<td>-6</td>
<td>0</td>
</tr>
<tr>
<td>27 Parents of children with and without TSC have similar needs so interventions just for children with TSC are unnecessary.</td>
<td>-3</td>
<td>2</td>
</tr>
<tr>
<td>28 Child and Adolescent Mental Health Services (CAMHS) should offer parenting interventions for TSC.</td>
<td>-4</td>
<td>-3</td>
</tr>
<tr>
<td>29 Practical issues make it too difficult for parents to attend parenting interventions.</td>
<td>1</td>
<td>0</td>
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<tr>
<td>31</td>
<td>It is unreasonable to deliver an intervention through parents.</td>
<td>-5</td>
</tr>
<tr>
<td>32</td>
<td>Parents would not complete homework as part of a parenting intervention because they are too stressed.</td>
<td>-3</td>
</tr>
<tr>
<td>33</td>
<td>Parents would not complete homework as part of a parenting intervention because they lack motivation.</td>
<td>-2</td>
</tr>
<tr>
<td>34</td>
<td>Diagnosing TSC is a barrier to parents accessing interventions.</td>
<td>-3</td>
</tr>
<tr>
<td>35</td>
<td>Parents would need repeated follow-ups to continue using the skills learned in a parenting intervention.</td>
<td>-2</td>
</tr>
<tr>
<td>36</td>
<td>Only a small number of people would need a parenting intervention for TSC.</td>
<td>-5</td>
</tr>
<tr>
<td>37</td>
<td>Parenting interventions for TSC are not a good use of NHS money.</td>
<td>-1</td>
</tr>
<tr>
<td>38</td>
<td>Parents would only attend a parenting intervention if it involved other parents with children with TSC.</td>
<td>-3</td>
</tr>
<tr>
<td>39</td>
<td>Meeting other parents of children with TSC would increase parents worry about their own child.</td>
<td>1</td>
</tr>
<tr>
<td>40</td>
<td>Social support from other parents is an important benefit of a group-based parenting intervention.</td>
<td>0</td>
</tr>
<tr>
<td>41</td>
<td>Between six and ten parents in a group parenting intervention group is a good size.</td>
<td>3</td>
</tr>
<tr>
<td>42</td>
<td>Parents should be offered a parenting intervention shortly after their child is first diagnosed with TSC.</td>
<td>-4</td>
</tr>
<tr>
<td>43</td>
<td>Parenting interventions are more appropriate for parents of younger children with TSC.</td>
<td>3</td>
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<tr>
<td>44</td>
<td>Transition to adolescence can be difficult so parenting interventions should be offered to parents of adolescents with TSC.</td>
<td>-1</td>
</tr>
<tr>
<td>45</td>
<td>Shorter, weekly meetings are better than longer, monthly meetings in a parenting intervention for TSC.</td>
<td>-1</td>
</tr>
<tr>
<td>46</td>
<td>Parents need to discuss their child’s difficulties on an individual basis.</td>
<td>0</td>
</tr>
<tr>
<td>47</td>
<td>If NHS resources are limited it is better for more parents to be seen in a group-based parenting intervention.</td>
<td>0</td>
</tr>
<tr>
<td>48</td>
<td>Group-based parenting interventions for TSC are cost effective.</td>
<td>2</td>
</tr>
<tr>
<td>49</td>
<td>Family functioning is related to children’s adjustment and quality of life.</td>
<td>4</td>
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<tr>
<td>50</td>
<td>Positive child-parent interactions are important for children’s adjustment and quality of life.</td>
<td>5</td>
</tr>
<tr>
<td>51</td>
<td>Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence.</td>
<td>2</td>
</tr>
<tr>
<td>52</td>
<td>Parents are less likely to participate in group-based parenting interventions than individual parenting interventions.</td>
<td>-3</td>
</tr>
<tr>
<td>53</td>
<td>Children’s perception of their parent’s views towards their TSC is important.</td>
<td>1</td>
</tr>
<tr>
<td>54</td>
<td>It is not children’s tics that cause most concern to parents, but common co-morbid conditions (e.g., anxiety, mood, anger, behavioural difficulties).</td>
<td>-4</td>
</tr>
<tr>
<td>55</td>
<td>Parenting interventions for TSC should only be offered to parents of children with more severe tics.</td>
<td>-3</td>
</tr>
<tr>
<td>56</td>
<td>The differences in children’s TSC related difficulties are a barrier to group-based parenting interventions.</td>
<td>-1</td>
</tr>
<tr>
<td>57</td>
<td>All main caregivers of a child need to attend a parenting intervention for it to be effective.</td>
<td>0</td>
</tr>
<tr>
<td>58</td>
<td>Parents would accept and attend a parenting intervention for TSC.</td>
<td>0</td>
</tr>
<tr>
<td>59</td>
<td>Professionals who run parenting groups for TSC must be experts in the treatment of tics.</td>
<td>2</td>
</tr>
<tr>
<td>60</td>
<td>It is important that parents have a positive relationship with the professionals that lead parenting interventions.</td>
<td>0</td>
</tr>
<tr>
<td>61</td>
<td>The lack of research in parenting interventions for TSC is a barrier to treatment.</td>
<td>0</td>
</tr>
<tr>
<td>62</td>
<td>If a parenting intervention for TSC was in book form, professionals would be more likely to offer it.</td>
<td>1</td>
</tr>
<tr>
<td>63</td>
<td>Siblings of children with TSC would benefit from their parents attending a parenting intervention.</td>
<td>-1</td>
</tr>
<tr>
<td>64</td>
<td>It is important to consider parents’ cultural differences in a parenting intervention for TSC.</td>
<td>2</td>
</tr>
<tr>
<td>65</td>
<td>Helping parents to feel more in control of their child’s difficulties is an important outcome of parenting interventions for TSC.</td>
<td>-1</td>
</tr>
<tr>
<td>66</td>
<td>Changing children’s tics is an important outcome of parenting interventions for TSC.</td>
<td>4</td>
</tr>
<tr>
<td>67</td>
<td>Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC.</td>
<td>3</td>
</tr>
</tbody>
</table>
Parents prefer psychological interventions to medication for TSC.
Medication is more effective than psychological interventions for TSC.
Parenting interventions for TSC would be effective.
Family members, friends, and teachers should be invited to attend parenting interventions for TSC.
A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rank 6</th>
<th>Rank 5</th>
<th>Rank 4</th>
<th>Rank 3</th>
<th>Rank 2</th>
<th>Rank 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>69  Parents prefer psychological interventions to medication for TSC.</td>
<td>-1</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>-2</td>
<td>-1</td>
</tr>
<tr>
<td>70  Medication is more effective than psychological interventions for TSC.</td>
<td>-2</td>
<td>-2</td>
<td>-4</td>
<td>-4</td>
<td>-3</td>
<td>-3</td>
</tr>
<tr>
<td>71  Parenting interventions for TSC would be effective.</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>72  Family members, friends, and teachers should be invited to attend parenting interventions for TSC.</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>-3</td>
<td>-1</td>
</tr>
<tr>
<td>73  A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC.</td>
<td>2</td>
<td>-5</td>
<td>0</td>
<td>3</td>
<td>-4</td>
<td>0</td>
</tr>
</tbody>
</table>

The table presents each statement and associated ranking for each factor across both studies. Rankings are derived from the weighted averaging of Q-sorts loading onto that factor. TSC= Tic spectrum Condition/ Tic Disorders. NHS = National Health Service. Statements were placed into a forced choice grid distribution where rankings ranged from -6 (disagreement) to +6 (agreement).
Critical Evaluation and Reflections

Word count: 7314 with references
Critical Evaluation and Reflections

This paper discusses the research process in its entirety, reflecting on its strengths, limitations and challenges, and the wider implications for clinical practice and future research.

Choice of Research Area

Before clinical training my research experiences were largely within adult neuropsychology. My previous research involved undertaking assessments with adults who had neurological difficulties with the aim of understanding relationships between specific impairments in cognitive functioning and structural neurological damage. Through developing relationships with participants over the three years of the project, I became increasingly interested in the wider emotional, social and systemic impacts of impaired cognitive functioning. These experiences led me to clinical training.

During clinical training I developed particular interests in developmental neuropsychology and neurodevelopmental disorders, which influenced my choice of research project and specialist placements. Tic conditions are conceptualised as developmental neuropsychiatric disorders (Robertson & Cavanna, 2008) with unique symptoms that “seemingly mock the divisions between neurology, psychiatry and psychology (i.e. motor, behavioural and cognitive symptoms)” (Cavanna & Rickards, 2013, p. 1008). Given the unique nature of tic disorders, and the clear role that psychology may offer within this population, I was keen to undertake the research project.
Literature Review

Topic Rationale

Several topics were considered for the literature review, including those specific to tic disorders (e.g., parenting experiences in tic disorders). However, it seemed important to select a topic which would permit integration of tic disorder research into a wider clinical context. Given the unique nature of tic disorders they may be perceived as distinct conditions which require interventions within specialist services. The number of children who will evidence tics, however, has been estimated to be as high as 10-20% (e.g., Bennett, Keller, & Walkup, 2013; Verdellen, Griendt, Hartmann, & Murphy, 2011). Furthermore, around 90% of those with tic disorders will experience co-morbid difficulties, such as attention deficit hyperactivity disorder (ADHD), obsessive compulsive behaviours, depression, anxiety, conduct issues and self-injurious behaviours (Robertson, 2012). Given these factors, it is likely that some children will present to local services. Therefore, grounding tic disorder research within a more general clinical context may promote accessibility of the review to general clinicians and thus increase its clinical utility.

Although reviews have been undertaken for specific neurodevelopmental disorders (e.g., ADHD; Sonuga-Barke et al., 2013) and specific parenting interventions (e.g., Triple-P; Tellegen & Sanders, 2013), these previous reviews have not integrated research across neurodevelopmental disorders, across parenting interventions and have also included tic disorders. The topic of parenting interventions across neurodevelopmental disorders met both a clinical and research need.
Search Terms

In deriving the search terms and inclusion criteria, a primary consideration was the issue of determining which conditions fall under the heading of neurodevelopmental disorders. Within the Diagnostic and Statistical Manual-V (DSM-V; American Psychiatric Association, 2013), the main conditions falling under this heading include intellectual disabilities, learning difficulties, autistic spectrum conditions, ADHD, motor disorders and communication disorders. Given limitations in the ability to generate search terms for each specific condition that is incorporated within each of these categories, it was important to balance search term specificity and sensitivity. Terms were identified through exploration of other reviews, existing literature, associated database terms and discussions with supervisors. A large number of search terms representing neurodevelopmental disorders and parenting interventions were therefore used (Paper 1, Table 1), and quantitative limits were added to ensure spatial proximity of multiple search terms. This approach was necessary because initial searches returned an unmanageable amount of papers that were not all relevant. Manual searches of reference lists and reviews revealed very few additional papers that met inclusion criteria, indicating that the search strategy was adequate.

Search Limits

The studies included in the review were limited to randomised controlled trial (RCT) designs. Non-randomised studies were considered, however initial searches identified many papers with considerable variability in methodological quality, programme delivery and outcome measures. The review was also limited to papers that were published in peer reviewed journals and published in English. Although
publication and language biases can be minimised by including relevant published and unpublished studies (CRD; Centre for Reviews and Dissemination, 2009), and obtaining papers from across languages (CRD, 2009), this was beyond the resources of the current research.

Inclusion/Exclusion Criteria

Given the breadth of the review a number of inclusion and exclusion criteria were employed to maximise homogeneity between studies and enhance comparability (Paper 1, Figure 1). Several papers that delivered seminar-based or remotely delivered interventions were excluded as they were not deemed comparable to those involving considerable face-to-face contact. Several papers that delivered additional training components to children or teachers were excluded as the factors responsible for change could not be determined (Brown, Whittingham, Boyd, & Sofronoff, 2013). Finally, several papers were excluded given that they used behavioural principles to primarily address another problem (e.g., sleep, attention, language) rather than child emotional or behavioural difficulties. The process of excluding papers was particularly time-consuming. Whilst a second reviewer would have increased the reliability of exclusions, this was not possible within the confines of available resources and instead papers were discussed amongst the research team until consensus was reached regarding exclusions.

Quality Rating

Assessing the quality of studies included in a systematic review helps to evaluate the strength of presented evidence and facilitates recommendations for future research (CRD, 2009). Several quality rating tools were considered (e.g., Downs & Black,
The Clinical Trial Assessment Measure (CTAM; Tarrier & Wykes, 2004, Appendix 2) was selected because it was developed for psychological trials (Tarrier & Wykes, 2004), it has shown adequate face validity, inter-rater agreement, internal consistency and concurrent validity (Tarrier & Wykes, 2004), and it provides quantitative outcomes.

Nevertheless, several limitations of the CTAM were noted during its application. Firstly, inadequacies in reporting rather than the methodology can lead to lower CTAM ratings. For example, marks are awarded for ‘adequate’ descriptions of the randomisation process and treatment. Aside from the inherent subjectivity in what is deemed ‘adequate’, discrepancies in journal word counts and conventions across date and place of publication could impact on reporting. Contacting study authors may have permitted discrimination between reporting and quality inadequacies (Tarrier & Wykes, 2004); however this was not possible given the time limitations. In addition, this approach could have led to rating outcomes that were confounded by authors’ availability to reply to correspondence.

A second limitation lies in the applicability of the measure across different areas of research. The CTAM has been predominately used in psychosis studies, and although it has been applied across other clinical disorders (e.g., tinnitus; Hesser, Weise, Reif, & Andersson, 2011), it was necessary to explicitly clarify some of the more ambiguous CTAM questions in order to ensure its consistent application and relevance within RCTs of parenting programmes. For example, whilst the CTAM awards quality ratings based on ‘the main outcome’, in the reviewed parenting research most papers reported multiple outcome measures and did not explicitly report which was primary. Consequently, the main outcome in the review was
considered to be any of the measures related to child behavioural/ emotional symptoms.

Whilst the double-ratings of a subset of papers indicated adequate inter-rater reliability, given these CTAM challenges, I became increasingly concerned about using absolute quantitative ratings as a comparative marker of methodological rigour. Wykes, Steel, Everitt and Tarrier (2008) used a cut-off point of 65 out of 100 to indicate appropriate methodological quality; however, given the outlined limitations this arbitrary marker was not considered to be appropriate. Upon reflection, the value of the CTAM was in the process of considering study strengths and weakness rather than the quantitative outcome, and this would be considered when choosing quality rating scales for future research.

Data Synthesis

Each of the 22 studies had multiple outcomes derived from various measures. Presenting these results in a simple and meaningful way was particularly challenging. Outcome measures were grouped according to category of difficulty (attention-deficit/hyperactivity, externalising, internalising, social and global difficulties) and were then awarded a single label representing the evidence across this category (effective, not effective, inconsistent). This approach could be criticised as reductionist. It involves grouping together measures with different psychometric properties and different purposes and it neglects the potential relationships between different categories. However, this approach does allow a large number of outcomes to be interpreted holistically and comparatively within a single paper; thus it was considered adequate for the purposes of the review.
Limitations

Several limitations of the review have already been discussed including the necessary search term limitations, the necessary inclusion and exclusion criteria, the quality rating challenges and the difficulties in coherently grouping various outcomes and outcome measures (see discussion section of Paper 1 for further limitations).

The review could also be criticised for presenting several neurodevelopmental disorders within a single paper, given the diversity of conditions and interventions reviewed. Arguably, the outcomes of children with ADHD and intellectual disabilities are very different. Similarly, an individual 17-session intensive parent child interaction therapy intervention (e.g., Matos, Bauermeister, & Bernal, 2009) is very different from a six-session group intervention (e.g., Roux, Sofronoff, & Sanders 2013). Clearly, reviewing multiple conditions and interventions leads to some heterogeneity across studies. However, this approach also has a number of advantages. Firstly, the review permits comparison of methodological rigour across neurodevelopmental disorders (e.g., diagnosis verification), allowing methodological conventions within single disorders to be challenged for the purposes of improving future research. Secondly, the approach permits the similarities and differences across interventions and disorders to be identified, thereby holding clinical utility for practitioners in designing and implementing programmes. Finally, given the co-morbid difficulties and complex presentations of children in clinical practice, a more general review may reach a wider audience of clinicians; increasing its potential clinical utility.

The review may also be limited given the exclusion of multiple-component interventions. Parenting interventions can incorporate adjunctive child or teacher
delivered elements in addition to parent-directed components (e.g., Fabiano et al., 2009; Lee, Niew, Yang, Chen, & Lin, 2012; Pelham & Fabiano, 2008). In the current review, interventions with such additional training components were excluded. Given the breadth of the review, this exclusion maximised the homogeneity between the delivered interventions and it enhanced comparability between studies. This approach also meant that the factors responsible for change in the presented studies were more determinable (Brown et al., 2013), and thus the conclusions of the review were clearer and more easily interpreted. However, the inclusion of multiple-component interventions may have permitted conclusions to be made regarding the comparative effectiveness of different elements of interventions (e.g. parent, teacher and child-directed components), and may have thus enabled recommendations for clinical practice. Nevertheless, the scope of such a review was considered beyond the resources of the current project and it therefore remains an area to be addressed in future work.

**Future Reviews**

Several avenues for future reviews exist. Firstly, a more fine-grained division of fewer child-related outcome categories could be implemented to provide greater detail around specific aspects of particular difficulties. Secondly, although the inclusion/exclusion criteria aimed to maximise homogeneity and enhance comparability between studies, following on from this initial review, future studies may use a wider, more inclusive approach to evaluate the effectiveness of different modes of delivery (see Lee, Niew, Yang, Chen, & Lin, 2012), or different intervention components (see Kaminski, Valle, Filene, & Boyle, 2008). Finally, given that outcomes were child-specific, future reviews could evaluate parent-related
outcomes (e.g., self-efficacy, parental stress). Parenting practices can be influenced by parental variables such as self-efficacy (Jones & Prinz, 2005). Parenting children with neurodevelopmental and behavioural difficulties is also associated with increased parental stress (Baker et al., 2003; Plant & Sanders, 2007b), thus exploring the impact of interventions on parental stress, and the impact of this on parenting practices may provide guidance for future interventions. Indeed, the provision of targeted stress management components to parents during parenting interventions may be beneficial. Exploring the potential impact of parenting programmes and specific intervention components on parent-related changes, including both psychological changes and changes in parenting practices, and investigating how such outcomes may differ across neurodevelopmental conditions or parenting programmes could provide important guidance for future interventions.

**Empirical papers**

**Background to the Research**

There is increasing awareness of the impact of tic disorders on children’s wider emotional, social, and systemic functioning (e.g., Cutler, Murphy, Gilmour, & Heyman, 2009; Eddy et al., 2011; Storch et al., 2007). There is also increasing recognition of the impact of tic disorders and associated co-morbidities on parents’ quality of life, including increased stress, caregiver burden and mental health difficulties (Cooper, Robertson, & Livingston, 2003; Lee, Chen, Wang & Chen, 2007; Wilkinson, Marshall, & Curtwright, 2008). Emotional and social difficulties can influence tics (Robertson & Cavanna, 2008), and thus parental difficulties and negative systemic interactions may reciprocally exacerbate tics, which may also
negatively impact co-morbid difficulties (e.g., increase social difficulties, anxiety, depression). Furthermore, parental difficulties and negative interactions may also directly and reciprocally influence co-morbid difficulties, and indeed positive parenting styles have been shown to offer a protective factor for co-morbid difficulties in tic disorders (Cohen, Sade, Benarroch, Pollak, & Gross-Tsur, 2008). Given this reasoning, it follows that parenting interventions could provide an appropriate intervention within this population.

Indeed, this logic led to a service development project that was completed within the Tics and Neurodevelopmental Movements service (TANDeM) in St Thomas’ Hospital London. The service development project aimed at implementing and evaluating a pilot parenting intervention group for parents of children with tic disorders. Two intervention groups were delivered across 2-3 days and were based on the Incredible Years programme (Webster-Stratton, 2006), with adapted educational content for tic disorders. The intervention was delivered by the research supervisor (PB) and I was involved in attending the sessions and helping to administer and collect outcome data. Short semi-structured interviews were also completed with several attendants during the first intervention group. Unfortunately, response rates to the psychometric measures were poor, despite repeated attempts to follow-up participants and reduce missing data. The poor response rate was attributed to the large number of administered outcome questionnaires given the exploratory nature of the project. Indeed, the intervention appeared to be well received by parents; however, it was clear that further information was needed to inform future implementation of the intervention, both within the specialist service and within other clinical contexts. Literature within this field was scarce, and provided no further guidance, with only one randomised controlled trial previously
targeting tic populations (Scahill et al., 2006). However, the importance of offering parent-directed interventions had been suggested across several research papers and treatment guidelines (e.g., Cooper et al., 2003; Lee et al., 2012; Verdellen et al., 2011; Wilkinson et al., 2008).

The current research was therefore developed to explore opinions around parenting interventions within this population. Whilst consideration of the general perceived effectiveness and acceptability of interventions was necessary, further exploration was also needed of the content and focus of interventions, barriers to implementation in specialist and non-specialist services and practicalities of delivery. We aimed at ascertaining the opinions of parents that had and had not been involved in the intervention delivered within the TANDeM service, and identifying the opinions of professionals with and without specific expertise in tic disorders; in order to provide a range of perspectives on this issue from those whose ‘viewpoints matter’ (Watts & Stenner, 2012).

**Wider Context**

The research was considered particularly relevant within the current clinical context, given the increasing popularity of parent training programmes across varied clinical populations (e.g., Morawska, Calam, & Fraser, 2014). Parent training programmes are developing an increased evidence-base (e.g., Michelson, Davenport, Dretzke, Barlow, & Day, 2013; Serketich & Dumas, 1996), they are included in national treatment guidance (NICE, 2013) and in the national curriculum of the Child and Young People’s Improving Access to Psychological Therapies initiative (CYP IAPT, 2013). The research is also consistent with the increased recognition of consumer participation in the development and implementation of treatments. Patient
involvement in service provision is a key element within National Health Service (NHS) values (NHS constitution, Department of Health, 2013). Furthermore, in implementing parenting programmes, Sanders and Kirby (2012) advocate that collaborative engagement between parents, practitioners and researchers is necessary to increase responsivity to parents’ needs, to produce better outcomes, and improve population reach.

**Q-Methodology**

Q-methodology was selected over questionnaire or interview approaches. Questionnaires may have lacked the detail to meaningfully explore opinions and would need large participant numbers, which is challenging within tic disorder populations given the lack of specialist services from which to recruit. As interviews rely on participants to generate an extensive narrative of their opinions or experiences, they may have attracted only those who were particularly knowledgeable or opinionated around the topic. Q-methodology, on the other hand, allows opinions to emerge dynamically in a less invasive way. It also allows for the structured exploration of opinions across participants with varied pre-existing knowledge; indeed, the parents who may be invited to participate in parenting interventions. Q-methodology offered a ‘qualiquantological’ balance (Watts & Stenner, 2005), providing a structured, reliable and quantifiable approach to explore subjective viewpoints (Watts & Stenner, 2012).

Q-methodology is being increasingly implemented within healthcare research to explore opinions of interventions across differing populations, such as staff, patients and relatives (e.g., Absalom-Hornby, Hare, Gooding, & Tarrier, 2012; Butler, Walker, Hare, Wieck, & Wittkowski, 2014; McIntosh, Westbrook, Sheldrick,
The method also permits collection of data using multiple approaches (e.g., face-to-face, via post, via the internet), which was particularly important given the geographical spread of professionals and parents. Q-methodology was therefore considered a timely, practical approach that would allow comparable exploration of opinions across both professionals and parents.

**Ethics Process**

The ethics process presented a surprising challenge, with the ethics committee requiring several revisions and clarifications to the original application. Many of these clarifications were related to misunderstandings about Q-methodology and queries about the practicalities of the online task. However, several of the requested revisions had a significant impact on the research design. For example, it was originally proposed that parents recruited from the TANDeM service could complete the study face-to-face with the researcher in clinic, however, the ethics panel requested formal provision of childcare which was not possible given cost implications and resource limitations. These changes and clarifications meant that obtaining ethical approval took longer than anticipated, confirming the importance of early application and appropriate planning for potential delays (see Appendix 5-6 for ethics approvals, Appendix 7-11 for participant information sheets and consent forms and Appendix 12-15 for research advertisements).

**Q-Sort Statements**

Deriving the Q-sort statements is one of the most difficult and time-consuming aspects of Q-methodology (Watt & Stenner, 2012). Although “the perfect Q-set is
probably a thing of fantasy” (Watts & Stenner, 2012, p.63), the statements should provide a balanced and representative coverage of opinions (Watts & Stenner, 2012). The ethics committee requested to see the statements, thus the Q-set had to be developed and reviewed by the research team within a relatively limited amount of time. Despite these external time pressures, it was crucial to ensure the statements were derived appropriately through the process of thorough sampling of various relevant materials.

The Q-sort statements were created to address various topics relevant to parenting interventions, including theoretical justifications, practical delivery, barriers, acceptability, effectiveness, and content. Following recommendations from Watts and Stenner (2012), a wide variety of information sources were sampled to generate the statements (Appendix 16). The academic literature around parenting interventions and tic disorders was examined, relevant television programmes and websites were reviewed and the information ascertained from the interviews completed with parents who had participated in the first pilot parenting group was also considered. An initial 244 statements were generated and reduced to a representative set of 73 statements by grouping themes and removing redundant items. The statements were reviewed and refined by the research team, which included clinical psychologists and researchers with expertise in tic disorders, parenting interventions and Q-methodology.

The Q-set of 73 statements is relatively large (Appendix 17), falling at the upper limit of recommendations (40 to 80; Watts & Stenner, 2012). This may be attributable to the breadth of topics covered by the statements. The Q-sort task was consequently very time-consuming, and it is possible that the large Q-set resulted in participants taking less time to consider statement rankings or perhaps terminating
the study prior to completion. Given the knowledge acquired from the current research, future studies could narrow the topic focus to reduce participant demands.

**Q-Sort Distribution**

Several factors were considered in selecting the Q-sort distribution (Appendix 18). A symmetrical distribution is standard (Watts & Stenner, 2012), a 13-point (-6 to +6) distribution was selected based on the Q-set size (e.g., Brown, 1980) and a steeper distribution was chosen to reduce extreme ranking decisions, thereby reducing participants’ potential anxieties (Watts & Stenner, 2012). A forced-choice distribution was also selected over a free-choice distribution (which allows assignment of any number of statements to any ranking value). Forced-chances provide more convenient and readily processed data (Block, 2008), however, they can be experienced as frustrating and restrictive by participants (Watts & Stenner, 2012), which was indeed indicated by several parents’ comments.

**Remote Data Collection**

Q-sorts were completed remotely, via post and secure website link. These methods held several disadvantages over face-to-face administration. Several participants abandoned attempts to complete the study, potentially given the need to maintain motivation during a lengthy task. Participants also had to undertake considerable self-directed efforts to understand the complex nature of the Q-sort task, and although succinct written instructions and instructional videos were created, it cannot be ensured that participants completed the task exactly as instructed (see Appendix 19-22 for task instructions). Despite close consultation with a computer technician and thorough piloting of the programme across systems, unpredictable technical
issues also impacted some participants’ attempts to complete the online task. These difficulties were frustrating, resulted in data loss, and impacted on perceptions of the research both for participants and the charity organisation promoting the study. Finally, participant narratives during task completion were not obtained, which may have provided a valuable insight into the dynamic emergence of opinions. Despite these disadvantages, remote data collection enabled participants across a large geographical area to complete the study at their own convenience, and given limited resources made the research feasible.

Recruitment of Professionals

The aims of Q-methodology recruitment are to invite participants whose ‘viewpoints matter’ whilst avoiding an overly homogenous sample (Watts & Stenner, 2012). It was anticipated that recruitment of professionals would provide a sample of multi-disciplinary professionals with a range of experiences in tic disorders, including those from specialist services and those with limited specialist experiences but who potentially encountered children with tics within local clinical services. Professionals were largely recruited using web-based and email advertisements (Appendix 14). Demographic information suggested that professionals with a range of expertise in tic disorders and parenting interventions had participated, thus recruitment aims were met. However, most professionals were from a clinical psychology training background, possibly due their over-representation in recruitment sources or awareness of the doctoral research demands. Although participants’ general stage of professional training was indicated (e.g., assistant, trainee, qualified), information about professionals’ years of experience was not obtained. This may have been
particularly useful for factor interpretation, and should be considered in future research.

During recruitment, several professionals contacted me to express their agreement with the project and to request information regarding study outcomes, indicating support for the clinical utility of the study.

**Recruitment of Parents**

It was also anticipated that recruitment of parents would provide a sample of caregivers, who had and had not been involved in the parenting intervention delivered within the TANDeM service, and who had various previous experiences of general parenting interventions and service input.

Recruitment of parents was particularly challenging. The research was advertised via the TANDeM service to parents that had and had not participated in the pilot parenting intervention, via the Tourettes action website, and via tic disorder support groups (Appendix 12-13). A general interest article was also written for Tourettes Action in collaboration with a colleague and was published in their newsletter (Appendix 15). It was not possible to frequently travel to St Thomas’ Hospital in London to advertise the research in person, which might have increased participation. Only four parents from the TANDeM pilot intervention completed the Q-sort task, possibly due to the time that had elapsed between the intervention and recruitment.

Parents’ demographic information indicated that recruitment aims had been met. Only two children did not have a formal diagnosis of Tourette Syndrome, indicating that most children had relatively significant and enduring tic presentations. It would have been helpful to formally collate information on the time
since diagnosis or onset of difficulties. Administering measures to explore the perceived severity of tics, or perceived impact of difficulties on children and families (e.g., parent tic questionnaire: Chang, Himle, Tucker, Woods, & Piacentini, 2009; Peds-QL-Proxy: Varni, Seid, & Rode, 1998) could have also aided factor interpretation; however, this approach would have further increased participant demands.

Given the challenges of recruitment, it may be helpful for researchers within the field of tic disorders to develop a confidential registry of participants. This approach is being increasingly adopted within other neurodevelopmental disorders to promote participant access.

Sample Size

The 25 professionals and 23 parents provide adequate participant numbers (Danielson, Webler, & Tuler, 2007; Watts & Stenner, 2012). More participants might have increased reliability of factors, but further recruitment was restricted by time and financial limitations.

Empirical Papers

Two distinct analyses were completed for parents and professionals, leading to two core empirical papers (Paper 2 and Paper 3) and a commentary paper (Paper 4). Of course, a single paper could have been produced which would have reduced the time demands associated with writing multiple publications. However, providing full factor interpretations of all the emergent viewpoints across both studies within the confines of journal word counts was considered potentially detrimental to the findings. The separate presentation and discussion of professional and parent results
permitted a more in-depth analysis of these two different groups whilst allowing findings to be disseminated to a wider audience. The commentary paper was necessary to provide a general overview of the clinical implications and potential utility of these results.

**Factor Analysis, Extraction and Rotation**

Q-sort data can be analysed in multiple ways, and although programmes such as PQMethod provide valuable automation, the researcher is still required to make important decisions at each stage of the analysis (Watts & Stenner, 2005). A principal components analysis (PCA) with varimax rotation was selected because this offers the single, mathematically best solution (Watts & Stenner, 2012). It is also recommended for novice Q-methodologists, and it is recognisable to wider audiences who are more familiar with factor analysis. Although several criteria could have been used to determine factor extraction (see Watts & Stenner, 2012), it was decided that eigenvalues greater than 1 (Guttman, 1954; Kaiser, 1960) would be used as this offers a standard objective approach (Watts & Stenner, 2005), identifying a threshold below which factors serve no data-reductive purposes (Watts & Stenner, 2005) and the criterion is again likely to be recognised by wider audiences familiar with factor analysis.

**Factor Loadings**

Significant factor loadings can be determined using several criteria. These include using the PQMethod pre-flagging algorithm (Schmolck & Atkinson, 2012), taking Qsorts (or participants) with loadings greater than 0.60 on a selected factor and less
than 0.40 on all other factors (Jordan, Capdevila, & Johnson, 2005), or identifying loadings that exceed significance thresholds (whereby thresholds are equal to 2.58 (p<0.01) divided by the square root of the Q-set size) (Brown, 1980). As this latter criterion is implemented in most studies, it was selected for the current research, but it resulted in a considerable number of ‘confounded’ Q sorts (which load onto more than one factor). These confounds are potentially attributable to the considerable shared perspectives across factors, as indicated by high factor correlations. Watts and Stenner (2005) propose an approach to avoiding the data loss resulting from confounded Q sorts, which involves incrementally increasing the loading threshold to a point whereby data loss is minimised and loadings are maximised. Although this approach may be criticised as data-driven, it maximises data use and actually results in a more statistically stringent criterion being applied. It also increases array reliability by allowing all possible significant factor loadings to contribute, albeit weighted according to their loading (see Appendix 23-24 for factor loadings).

With the exception of Watts and Stenner (2005), the wider Q-sort literature offers little further guidance around managing high numbers of confounding Q sorts. Furthermore, many Q-sort studies fail to report the number of confounding Q sorts, the number of Q sorts which do not load onto a factor, or the criteria used to determine significant factor loadings (Dziopa & Ahern, 2011). Clearly, better reporting of analyses is needed to provide greater consensus around analytic approaches for future Q-sort studies.

**Factor Interpretation**

Q-methodology allows the systematic assessment of qualitative data (Dziopa & Ahern, 2011), and as such, factor interpretation is a subjective process dependent on the researcher’s aims (Brown, 1980). Across the literature, there are many different
approaches to factor interpretations and presentation of findings (Dziopa & Ahern, 2011). Some researchers appear to focus more on the highest and lowest rankings (e.g., McIntosh et al., 2012), others focus on the statistically distinguishing items (e.g., Akhtar-Danesh, Dehghan, Morrison, & Foneska, 2011) and some researchers explicitly report a mixture of these approaches (e.g., Excel, Graaf, & Brouwer, 2007). Watts and Stenner (2012) also stress the importance of a holistic interpretation which examines the entire item configuration, interrelations and cross-factor comparisons.

A holistic approach was important in the initial conceptualisation and understanding of factors; however, it is not possible to report such full factor interpretations within the limits of journal word counts. Presented interpretations therefore focussed particularly on statements that were statistically distinguishing, extremely ranked (e.g., \( \geq +3 \) ranking) or ranked noticeably differently to the other factors. Factor arrays were interpreted within the context of post-sort comments (see Appendix 25-26) and demographic information. Due to the qualitative nature of factor interpretation, potential researcher bias is possible. To reduce this potential limitation, researchers both internal and external to the research team were consulted during interpretations and full factor arrays were presented within empirical papers. Potential bias might have also been reduced by obtaining feedback on the accuracy of factor interpretation from participants. However, this was not possible given anonymous data collection, and the benefits for factor interpretation are arguably limited given that participants are unlikely to ever conform to a factor’s opinion across the entire statement configuration (Danielson et al., 2007).

**Study Limitations**
Several limitations of the presented research have been discussed including those that resulted from the remote nature of data collection, the limitations in sample size and sample demographics, generalisability of results, the large number of statements presented, and the potential subjectivity in factor interpretation and presentation (see discussion section of Paper 2, Paper 3 and Paper 4 for further limitations). Despite these limitations, Q-methodology permitted the views of a range of professionals and parents to be explored within the limited resources of the current project, and has led to findings which have implications for future research and clinical practice.

**Future Directions**

Several areas of further research are possible. Given the perceived clinical need and utility of parenting programmes within tic disorders, future research should implement a programme that is informed by the results of the current studies. Evaluation of the programme should be undertaken using controlled trials, with outcomes including more formal standardised tic related and co-morbidity related child outcomes, parental outcomes and outcomes to explore perceived intervention usefulness, satisfaction and acceptability. Continued follow-ups could be used to explore the longevity of outcomes. Qualitative interviews could also be used to explore the experiences of parents who have participated in such an intervention, along with the experiences of their children. Implementing programmes across specialist and local services may permit any differences or challenges arising from these delivery contexts to be identified, including any additional training needs for practitioners within local services. The effects of different modes of delivery (e.g., group-based, remote delivery, attendance of teachers) could also be evaluated. Further research may also consider clinicians’ perceptions of their own competency.
in managing tic disorders within clinical practice, or could further investigate parents’ experiences of parenting within this population.

**Personal Challenges and Reflections**

Having considered the project in its entirety, it is possible to reflect on several personal challenges that resulted from the research process. Firstly, the need to balance both clinical and research work was a novel experience, and the skills that I have developed in time management, prioritising and planning have equipped me to undertake future research within clinical practice. A related challenge was in managing the boundaries between research and clinical roles. During attendance at support groups I met many children and adults with tic disorders and their families. Several parents approached me to request advice around clinical issues, accessing specialist services or to express their views on healthcare professionals. Ensuring clear boundaries between research and clinical roles, whilst validating parents’ experiences and maintaining the supportive nature of the group was challenging; however, again this is a skill which will prove important for future research. Finally, maintaining appropriate communication across several organisations was also challenging. Given the distance to St Thomas’ Hospital London from Manchester, it was imperative to maintain close communication with the service. It was also necessary to maintain close communication with research co-ordinators within Tourettes Action, and to ensure that their primary organisational value of providing support to those with tic disorders was upheld throughout the project. Whilst maintaining these relationships was at times challenging, the skills developed in liaising across organisations will be beneficial for future clinical roles.
Conclusion
As evidenced throughout this paper, despite its challenges, the research process has provided many opportunities to develop skills and knowledge which will inform my future research and clinical practice. The research has encouraged me to take a broader perspective when considering intervention innovations, it has allowed me to gain an insight into the processes underpinning intervention development and to understand the importance of implementing and evaluating novel applications of existing evidence-based approaches within clinical settings. Finally, the research has provided an opportunity to increase my knowledge of tic disorders and to gain a privileged insight into the challenges and clinical needs of children and parents affected by this unique condition.
References


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Appendices
Appendix 1: Submission Guidelines for Clinical Psychology Review

Submission guidelines for Clinical Psychology Review are provided. Guidance is extracted from http://www.elsevier.com/journals/clinical-psychology-review/0272-7358/guide-for-authors.
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Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color on the Web (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article. Please indicate your preference for color: in print or on the Web only. For further information on the preparation of electronic artwork, please see http://www.elsevier.com/artworkinstructions.

Please note: Because of technical complications which can arise by converting color figures to ‘gray scale’ (for the printed version should you not opt for color in print) please submit in addition usable black and white versions of all the color illustrations.
Figure captions
Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (not on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

Tables
Number tables consecutively in accordance with their appearance in the text. Place footnotes to tables below the table body and indicate them with superscript lowercase letters. Avoid vertical rules. Be sparing in the use of tables and ensure that the data presented in tables do not duplicate results described elsewhere in the article.

References
Citations in the text should follow the referencing style used by the American Psychological Association. You are referred to the Publication Manual of the American Psychological Association, Sixth Edition, ISBN 1-4338-0559-6, copies of which may be ordered from http://books.apa.org/books.cfm?id=4200067 or APA Order Dept., P.O.B. 2710, Hyattsville, MD 20784, USA or APA, 3 Henrietta Street, London, WC3J 8LU, UK. Details concerning this referencing style can also be found at http://humanities.byu.edu/linguistics/Hennichsen/APA/APA01.html

Citation in text
Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

Web references
As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

References in a special issue
Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

Reference management software
This journal has standard templates available in key reference management packages EndNote (http://www.endnote.com/support/enstyles.asp) and Reference Manager (http://refman.com/support/rmstyles.asp). Using plug-ins to wordprocessing packages, authors only need to select the appropriate journal template when preparing their article and the list of references and citations to these will be formatted according to the journal style which is described below.

Reference style
References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters "a", "b", "c", etc., placed after the year of publication. References should be formatted with a hanging indent (i.e., the first line of each reference is flush left while the subsequent lines are indented).


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3D neuroimaging
You can enrich your online articles by providing 3D neuroimaging data in NIfTI format. This will be visualized for readers using the interactive viewer embedded within your article, and will enable them to: browse through available neuroimaging datasets; zoom, rotate and pan the 3D brain reconstruction; cut through the volume; change opacity and color mapping; switch between 3D and 2D projected views; and download the data. The viewer supports both single (.nii) and dual (.hdr and .img) NIfTI file formats. Recommended size of a single uncompressed dataset is 100 MB or less. Multiple datasets can be submitted. Each dataset will have to be zipped and uploaded to the online submission system via the ‘3D neuroimaging data’ submission category. Please provide a short informative description for each dataset by filling in the ‘Description’ field when uploading a dataset. Note: all datasets will be available for downloading from the online article on ScienceDirect. If you have concerns about your data being downloadable, please provide a video instead. For more information see: http://www.elsevier.com/3DNeuroimaging.

Submission checklist
The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:
One author has been designated as the corresponding author with contact details:
• E-mail address
• Full postal address
• Phone numbers
All necessary files have been uploaded, and contain:
• Keywords
• All figure captions
• All tables (including title, description, footnotes)
Further considerations
• Manuscript has been 'spell-checked' and 'grammar-checked'
• References are in the correct format for this journal
• All references mentioned in the Reference list are cited in the text, and vice versa
• Permission has been obtained for use of copyrighted material from other sources (including the Web)
• Color figures are clearly marked as being intended for color reproduction on the Web (free of charge) and in print, or to be reproduced in color on the Web (free of charge) and in black-and-white in print
• If only color on the Web is required, black-and-white versions of the figures are also supplied for printing purposes
For any further information please visit our customer support site at http://support.elsevier.com.

AFTER ACCEPTANCE

Use of the Digital Object Identifier
The Digital Object Identifier (DOI) may be used to cite and link to electronic documents. The DOI consists of a unique alpha-numeric character string which is assigned to a document by the publisher upon the initial electronic publication. The assigned DOI never changes. Therefore, it is an ideal medium for citing a document, particularly 'Articles in press' because they have not yet received their full bibliographic information. Example of a correctly given DOI (in URL format; here an article in the journal Physics Letters B):
http://dx.doi.org/10.1016/j.physletb.2010.09.059
When you use a DOI to create links to documents on the web, the DOIs are guaranteed never to change.

Online proof correction
Corresponding authors will receive an e-mail with a link to our ProofCentral system, allowing annotation and correction of proofs online. The environment is similar to MS Word: in addition to editing text, you can also comment on figures/tables and answer questions from the Copy Editor. Web-based proofing provides a faster and less error-prone process by allowing you to directly type your corrections, eliminating the potential introduction of errors.
If preferred, you can still choose to annotate and upload your edits on the PDF version. All instructions for proofing will be given in the e-mail we send to authors, including alternative methods to the online version and PDF.
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Appendix 2: Clinical Trial Rating Measure (CTAM)


<table>
<thead>
<tr>
<th>Clinical Trials Assessment Measure (CTAM)</th>
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</thead>
<tbody>
<tr>
<td>Sample—two questions: maximum score = 10</td>
</tr>
<tr>
<td>Q1: is the sample a convenience sample (score 2) or a geographic cohort (score 5), highly selective sample, e.g., volunteers (score 0)</td>
</tr>
<tr>
<td>Convenience sample—e.g., clinic attenders, referred patients or Geographic cohort—all patients eligible in a particular area</td>
</tr>
<tr>
<td>Q2: is the sample size greater than 27 participants in each treatment group (score 5) or based on described and adequate power calculations (score 5)</td>
</tr>
<tr>
<td>Allocation—three questions: maximum score = 16</td>
</tr>
<tr>
<td>Q3: is there true random allocation or minimisation allocation to treatment groups (if yes score 10)</td>
</tr>
<tr>
<td>Q4: is the process of randomisation described (score 3)</td>
</tr>
<tr>
<td>Q5: is the process of randomisation carried out independently from the trial research team (score 3)</td>
</tr>
<tr>
<td>Assessment (for the main outcome)—five questions: maximum score = 32</td>
</tr>
<tr>
<td>Q6: are the assessments carried out by independent assessors and not therapists (score 10)</td>
</tr>
<tr>
<td>Q7: are standardised assessments used to measure symptoms in a standard way (score 6), idiosyncratic assessments of symptoms (score 3)</td>
</tr>
<tr>
<td>Q8: are assessments carried out blind (masked) to treatment group allocation (score 10)</td>
</tr>
<tr>
<td>Q9: are the methods of rater blinding adequately described (score 3)</td>
</tr>
<tr>
<td>Q10: is rater blinding verified (score 3)</td>
</tr>
<tr>
<td>Control groups—one question: maximum score = 16</td>
</tr>
<tr>
<td>Q11: TAU is a control group (score 6) and/or a control group that controls for non-specific effects or other established or credible treatment (score 10)</td>
</tr>
<tr>
<td>Analysis—two questions: maximum score = 15</td>
</tr>
<tr>
<td>Q12: the analysis is appropriate to the design and the type of outcome measure (score 5)</td>
</tr>
<tr>
<td>Q13: the analysis includes all those participants as randomised (sometimes referred to as an intention to treat analysis) (score 6) and an adequate investigation and handling of drop outs from assessment if the attrition rate exceeds 15% (score 4)</td>
</tr>
<tr>
<td>Active treatment—three questions: maximum score = 11</td>
</tr>
<tr>
<td>Q14: was the treatment adequately described (score 3) and was a treatment protocol or manual used (score 3)</td>
</tr>
<tr>
<td>Q15: was adherence to the treatment protocol or treatment quality assessed (score 5)</td>
</tr>
</tbody>
</table>

where the criterion is not reached for any question score = 0
Total score: maximum score = 100
Appendix 3: Submission Guidelines for Child: Care, Health and Development

A summary of the relevant aspects of the submission guidelines for Child: Care, Health and Development is provided. Guidance is extracted from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2214/homepage/ForAuthors.html

Child: Care, Health and Development

© John Wiley & Sons Ltd

Edited By: Stuart Logan
Impact Factor: 1.7
ISI Journal Citation Reports © Ranking: 2012: 35/65 (Psychology Developmental); 48/122 (Pediatrics)
Online ISSN: 1365-2214

GENERAL
Child: Care, Health and Development is an international, peer-reviewed journal which publishes papers dealing with all aspects of the health and development of children and young people. We aim to attract quantitative and qualitative research papers relevant to people from all disciplines working in child health. We welcome studies which examine the effects of social and environmental factors on health and development as well as those dealing with clinical issues, the organization of services and health policy. We particularly encourage the submission of studies related to those who are disadvantaged by physical, developmental, emotional and social problems. The journal also aims to collate important research findings and to provide a forum for discussion of global child health issues.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in Child: Care, Health and Development. Authors are encouraged to visit Wiley-Blackwell Author Services for further information on the preparation and submission of articles and figures.

To allow double blinded review, please submit (upload) your main manuscript and title page as separate files.
Please upload:
• Your manuscript without title page under the file designation 'main document'
• Figure files under the file designation 'figures'
• The title page, Acknowledgements and Conflict of Interest Statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review in the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

**MANUSCRIPT TYPES ACCEPTED**

Original Articles: Articles reporting original scientific data based quantitative or qualitative research are particularly welcomed. Articles should begin with a structured abstract and should ideally be between 2,000 and 3,000 words in length excluding tables and references. In the case of complex qualitative research reports, the editors may be prepared to extend the word limit to 5000 words.

**MANUSCRIPT FORMAT AND STRUCTURE**

Format
Spelling should conform to that used in *The Concise Oxford Dictionary*, published by Oxford University Press. Language: The language of publication is English.

Structure
The following checklist should be used to check the manuscript before submission. Articles are accepted for publication at the discretion of the Editor. A manuscript reporting original research should ideally be between 2000 and 3000 words. In the case of complex qualitative research reports, or systematic reviews, the editors may in some circumstances be prepared to extend the word limit to 5000 words. The manuscript should consist of the sections listed below.

Title Page: The title page should give both a descriptive title and short title. The title should be concise and give a brief indication of what is in the paper. Authors are required to detail in full: qualifications, current job title, institution and full contact details. Also a word count for the article and keywords should be given on the title page.

To allow double-blinded review, please submit (upload) your main manuscript and title page as separate files as explained in section 3.4.

Abstract: Structured abstracts, not more than 300 words, including background, methods, results and conclusions are preferred.

Main Text: Generally, all papers should be divided into the following sections and appear in this order: Abstract (structured abstracts, not more than 300 words, including background, methods, results and conclusions are preferred); Introduction; Methods; Results; Discussion; Acknowledgements (these should be brief and must include references to sources of financial and logistical support); References; Tables; Figures.

Key Messages: A key messages box should be provided with each manuscript. This should include up to 5 messages on key points of practice, policy or research.
References: References cited in the text should list the authors' names followed by the date of their publication, unless there are three or more authors when only the first author's name is quoted followed by et al. References listed at the end of the paper should include all authors' names and initials, and should be listed in alphabetical order with the title of the article or book, and the title of the Journal given in full as shown:


Work that has not been accepted for publication and personal communications should not appear in the reference list, but may be referred to in the text (e.g. 'A. Author, unpubl. observ.' or 'B. Author, pers. comm.').

Tables, Figures and Figure Legends: Always include a citation in the text for each figure and table. Any abbreviations used in figures and tables should be defined in a footnote.
Appendix 4: Submission Guidelines for Child and Adolescent Mental Health

Original Articles and Innovations in Practice Articles

A summary of the relevant aspects of the submission guidelines for Child and Adolescent Mental Health Original Articles and Innovations in Practice articles is provided. Guidance is extracted from http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1475-3588/homepage/ForAuthors.html

Child and Adolescent Mental Health

© Association for Child and Adolescent Mental Health

Edited By: Tamsin Ford, Crispin Day, Jane Barlow and Kapil Sayal
Impact Factor: 0.635
ISI Journal Citation Reports © Ranking: 2012; 92/114 (Psychology Clinical); 103/121 (Psychiatry (Social Science)); 104/122 (Pediatrics); 112/135 (Psychiatry)
Online ISSN: 1475-3588
Associated Title(s): Journal of Child Psychology and Psychiatry

Author Guidelines

Contributions from any discipline that further clinical knowledge of the mental life and behaviour of children are welcomed. Papers need to clearly draw out the clinical implications for mental health practitioners. Papers are published in English. As an international journal, submissions are welcomed from any country. Contributions should be of a standard that merits presentation before an international readership. Papers may assume any of the following forms: Original Articles; Review Articles; Measurement Issues; Innovations in Practice.

Original Articles: These papers should consist of original research findings.
Review Articles: These papers are usually commissioned; they should survey an important area of interest within the general field.
Measurement Issues: These are commissioned review papers that aim to evaluate evidence-based measurement issues in child mental health disorders and services.
Innovations in Practice: Submission to this section should conform to the specific guidelines, given in full below.

Summary: Authors should include a structured Abstract not exceeding 250 words
under the sub-headings: Background; Method; Results; Conclusions.

**Keywords:** Please provide 4-6 keywords.

**Key Practitioner Message** (in the form of 3-6 bullet points) should be given below the Abstract, highlighting what's known, what's new and the direct relevance of the reported work to clinical practice in child and adolescent mental health.

Papers submitted should be concise and written in English in a readily understandable style, avoiding sexist and racist language. **Original Articles should not exceed 5,500 words, including References and Tables.** Occasionally, longer articles may be accepted after negotiation with the Editors. Authors should include a word count of their paper.

Authors who do not have English as a first language may choose to have their manuscript professionally edited prior to submission.

**Headings:** Original articles should be set out in the conventional format: Methods, Results, Discussion and Conclusion. Descriptions of techniques and methods should only be given in detail when they are unfamiliar. There should be no more than three (clearly marked) levels of subheadings used in the text.

All manuscripts should have an **Acknowledgement** section at the end of the main text, before the References. This should include statements on the following:

**Study funding:** Please provide information on any external or grant funding of the work (or for any of the authors); where there is no external funding, please state this explicitly.

**Conflicts of interest:** Please disclose any conflicts of interest of potential relevance to the work reported for each of the authors. If no conflicts of interest exist, please include an explicit declaration of the form: "The author(s) have declared that they have no competing or potential conflicts of interest".

**Contributorships:** Please state any elements of authorship for which particular authors are responsible, where contributions differ between the author group. (All authors must share responsibility for the final version of the work submitted and published; if the study includes original data, at least one author must confirm that he or she had full access to all the data in the study, and takes responsibility for the integrity of the data and the accuracy of the data analysis). Contributions from others outside the author group should also be acknowledged (e.g. study assistance or statistical advice) and collaborators and study participants may also be thanked.

For referencing, **CAMH** follows a slightly adapted version of APA Style [http://www.apastyle.org/](http://www.apastyle.org/). References in running text should be quoted showing author(s) and date. For up to three authors, all surnames should be given on first citation; for subsequent citations or where there are more than three authors, 'et al.' should be used. A full reference list should be given at the end of the article, in alphabetical order.
References to journal articles should include the authors' surnames and initials, the year of publication, the full title of the paper, the full name of the journal, the volume number, and inclusive page numbers. Titles of journals must not be abbreviated. References to chapters in books should include authors' surnames and initials, year of publication, full chapter title, editors' initials and surnames, full book title, page numbers, place of publication and publisher.

Tables: These should be kept to a minimum and not duplicate what is in the text; they should be clearly set out and numbered and should appear at the end of the main text, with their intended position clearly indicated in the manuscript.

Figures: Any figures, charts or diagrams should be originated in a drawing package and saved within the Word file or as an EPS or TIFF file. Titles or captions should be clear and easy to read. These should appear at the end of the main text.

Footnotes should be avoided, but end notes may be used on a limited basis.

**Innovations in Practice**

*Child and Adolescent Mental Health (CAMH)* promotes evidence-based practice, intervention and service models. Innovations in practice, intervention and service provision may arise through careful and systematic planning, while others are responsive to need, evolution of existing services, or simply arise because of changing circumstances or technology. In this rapidly evolving field, the Editors of *CAMH* warmly welcome short *Innovations in Practice* papers which aim to allow authors to share with our wide international multidisciplinary readership knowledge and initial impact of new and interesting developments.

Manuscripts submitted as *Innovations in Practice* submissions should follow the standard format for *Original Articles* but be **no more than 2500 words**, including references and tables. They should briefly set out the aims and detail of the innovation, including relevant mental health, service, social and cultural contextual factors; the evaluation methods used; relevant supporting evidence and data; and conclusions and implications.

Submissions may describe formal pilot and feasibility studies or present findings based on other evaluative methods. Contributions outlining important innovations with potential significant impact may be considered even in the absence of evaluative data. Close attention should be paid in all submissions to a critical analysis of the innovation.
Appendix 5: Research Ethics Committee Approval

06 June 2013

Dr Gemma Evans
Trainee Clinical Psychologist
University of Manchester ClinPsyD Programme
2nd Floor, Zochonis Building
University of Manchester
Brunswick Street
Manchester
OL2 5YQ

Dear Dr Evans,

Study title: Feasibility and acceptability of a group-based parent training programme for parents of children with tic disorders.

REC reference: 13/NW/0213
IRAS project ID: 119616

Thank you for your letter of 30 May 2013, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Assistant Co-ordinator Miss Nicola Burgess, nrescommittee.northwest-gmsouth@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advertisement</td>
<td>1c PTP_NHS_Advert</td>
<td>30 May 2013</td>
</tr>
<tr>
<td>Advertisement</td>
<td>PTP_Tourettes_Action_draft_advert</td>
<td>30 May 2013</td>
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<tr>
<td>Advertisement</td>
<td>PTP_NHS_advert_staff_1c</td>
<td>30 May 2013</td>
</tr>
</tbody>
</table>
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.
Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/NW/0213 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee’s best wishes for the success of this project.

Yours sincerely

Burgess

PP:
Professor Sobhan Vinjamuri
Chair

Email:nrescommittee.northwest-gmsouth@nhs.net

Copy to: Miss Catherine Barrow
Ms Karen Ignatian, Guy’s And St Thomas’ NHS Foundation Trust
Appendix 6: Research and Development Approval

Guy's and St Thomas' NHS Foundation Trust

Dr Tammy Hedderly
Guy's and St Thomas' NHS Foundation Trust
TANDeM, Children's Neuroscience Centre
1st Floor, Staircase D, South Wing,
St Thomas' Hospital,
Westminster Bridge Road,
London
SE1 7EH

18/07/13

Dear Dr Hedderly,

Title: Feasibility and Acceptability Study of a parent training intervention

In accordance with the Department of Health’s Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

- Ethics Number: 13/NW/0213
- Sponsor: University of Manchester
- Funder: Clinical Psychology training programme
- End Date: 01/07/2014
- Protocol: Version 1b (05/05/2013)
- Site: St Thomas’ Hospital
- R&D Approval Date: 18/07/13
- Chief Investigator: Dr Gemma Evans

NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion letter dated 06/06/2013. I am pleased to inform you that we are approving the work to proceed within Guy’s and St Thomas' NHS Foundation Trust and that the study has been allocated the Trust R&D registration number RJ113/N190. I can confirm that from the SSI application form you have agreed to recruit 17 previous participants and 15 patients who have not attended the groups within 1 year.

Whilst the Trust takes on non funded research without charge for sponsorship, research management and governance or research costs we encourage all research to be funded and particularly encourage UKCRN portfolio eligible research. Prior to your next research proposal please contact the R&D department about portfolio eligibility and how to gain funding for research so as to ensure that the study can gain appropriate funding prior to your research application.
Conditions of Approval:
- The principal investigator must ensure that the recruitment figures are reported.
- The principal investigator must notify R&D of the actual end date of the project.
- R&D must be notified of any changes to the protocol prior to implementation.
- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

Data Protection:
Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

Amendments:
Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

ISRCTN registration:
If appropriate it is recommended that you register with the Current Controlled Trials website http://isrctn.org/. Find out more about registering for an International Standard Randomised Controlled Trial Number (ISRCTN) as part of the Portfolio application process. Non-commercial studies with an interventional component that are eligible for NIHR CRN support can register for an ISRCTN for free via the Portfolio Database.

Should you require any further information please do not hesitate to contact us. Thank you for registering your research project.

Yours sincerely
Joanna Peel
Research Facilitator

cc: Miss Catherine Barrow (Catherine.barrow@manchester.ac.uk)
cc: Dr Gemma Evans
Title of project: **A parent training programme for parents of children with tic disorders; the feasibility and acceptability of a group-based intervention.**

Name of researcher: **Gemma Evans**

*We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please contact the researcher if there is anything that is not clear.*

The study hopes to investigate attitudes towards parenting interventions for parents of children with a tic spectrum disorder. This will involve performing a Q-sort task. This is a task where you will read some statements and organise them into piles of whether you agree or disagree with the statement. You will then be asked to give some comments about why you have placed the statements in the piles that you have. If you have taken part in a group you may also be asked some questions about your experiences.

**What is the purpose of the study?**

We hope to look at parents attitudes towards this type of group intervention in order to understand whether it is considered acceptable and feasible and what factors may effect this. We are hoping to ask three groups of people to complete the Q-sort: 1) Parents who have taken part in a specific parenting group for their child with a tic spectrum disorder 2) Parents who have a child with a tic spectrum disorder but have not taken part in a specific parent group 3) NHS Staff who work with children with tic spectrum disorders and their parents.

**Why have I been invited?**

You have been invited to participate because you are in the first of these categories and have participated in a previous group held at St. Thomas hospital. We are hoping for around 10-15 people from each of these three categories to participate in the study.

**Do I have to take part?**

It is up to you to decide to join the study. We will describe the study in this information sheet. If you agree to take part, we will then ask you to give consent using a consent form. You are free to withdraw at any time during the study, without giving a reason. This would not affect any care you or your child may receive now or in the future.
What will happen to me if I take part?
If you decide to take part then you will be asked to complete the Q-sort. This can be done online or via post. The task usually takes around 20-25 minutes to complete but this will depend on how much information you give us in the comments. The task will involve reading some statements and then arranging these into piles of agree-disagree. After the Q-sort you will be asked to give some comments about your decisions.

Online completion:
If you would like to participate online then please follow this website address {WEBSITE ADDRESS}. If you begin to complete the Q-sort online and feel that you would like more support to complete it online then you will be able to email or ring the researcher and arrange a time to complete it with her over the telephone. If you do not feel that you need any additional support then you can complete the Q-sort alone and in your own time.

Post completion:
If you would like to participate via post then please tick the option on the letter and return in the envelope provided. We will then send the task through the post with instructions about how to complete it.

Expenses and payments
As a token of appreciation for your time you will be offered a £5 high street shop voucher following completion of the task. If you complete the Q-sort online and wish to receive the voucher then you will be asked to provide your name and address in order for you to arrange to receive the vouchers via post. If you do not wish to receive the voucher then you will not be required to provide this information. If you complete the Q-sort via mail then the vouchers will be sent via post following receipt of the completed Q-sort. To ensure that participants only complete the Q-sort on one occasion, each home address will only be able to receive two vouchers and we will only be able to send each voucher once.

What are the possible disadvantages and risks of taking part?
Usually there are no risks associated with studies like this one. Your child’s treatment will not be affected in any way, whether you agree to take part or not. The statements are unlikely to be upsetting. However if you did become upset then you could decide whether you wished to carry on, to have a break, to postpone or to terminate the task.

What are the possible benefits of taking part?
You may find it helpful to give us your views about this type of group. We hope that the research will help to develop the intervention further which will help other parents in the future.

Will my information be kept confidential?
The answers that you type after the statements will be analysed by the researcher. Any information which may identify you in any way will be removed. These and
your statements will be anonymised so they are identifiable by number. If you provide the researcher with your name and address to receive a voucher then the researcher will keep your address details until the high street vouchers have been distributed. It will be kept securely and then destroyed from the researcher’s records. Your name and address will never be given to anyone else and will hosted on university servers managed by university IT staff and using industry standard security protocols. Your details will not be used to link to your Q-sort responses and will be used only to distribute the vouchers.

**What will happen to my results?**
All data gained from the study will be destroyed in 5-10 years’ time. The research may be published but your name will not be given. The publication may include quotes of comments that were made by you and this may be linked to demographic information that you may have provided however all names will be removed.

**What if there is a problem?**
Complaints
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

**Who has reviewed the study?**
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Greater Manchester South NRES Committee (13/NW/0213).

**Who is organising and funding the research?**
The research has been organised and funded by the University of Manchester. The research is taking place as part of an education project for the qualification of Doctorate in Clinical Psychology. If you would like any more information on the research, please contact Gemma Evans (gemma.evans@postgrad.manchester.ac.uk).

**Further Project Information**
If you would like any more information about the research project please contact Dr Gemma Evans (trainee clinical psychologist) or Dr Penny Bunton (clinical psychologist):

<table>
<thead>
<tr>
<th>Gemma Evans</th>
<th>Penny Bunton</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Psychology Department</td>
<td>Clinical Psychology Department</td>
</tr>
<tr>
<td>2nd floor Zochonis Building</td>
<td>2nd floor Zochonis Building</td>
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<tr>
<td>University of Manchester</td>
<td>University of Manchester</td>
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<tr>
<td>M13 9PL</td>
<td>M13 9PL</td>
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<tr>
<td><a href="mailto:gemma.evans@postgrad.manchester.ac.uk">gemma.evans@postgrad.manchester.ac.uk</a></td>
<td><a href="mailto:penny.bunton@manchester.ac.uk">penny.bunton@manchester.ac.uk</a></td>
</tr>
</tbody>
</table>
Further General Support
Should you require further support or experience any distress then you may wish to contact your own or your child’s GP or you may find the following contacts helpful:

Tourettes Action UK:
www.tourettes-action.org.uk
Helpline: 0300 777 842

SANE:
www.sane.org.uk
0845 767 8000

MIND:
www.mind.org.uk
0300 1233 393

Samaritans:
www.samaritans.org
0845 790 9090

To participate online please go to the following website address:
Appendix 8: Q-study Parents
Information Sheet General

Participant Information Sheet: Q-sort_2

Title of project: A parent training programme for parents of children with tic disorders; the feasibility and acceptability of a group-based intervention.
Name of researcher: Gemma Evans

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please contact the researcher if there is anything that is not clear.

The study hopes to investigate attitudes towards parenting interventions for parents of children with a tic spectrum disorder. This will involve performing a Q-sort task. This is a task where you will read some statements and organise them into piles of whether you agree or disagree with the statement. You will then be asked to give some comments about why you have placed the statements in the piles that you have.

What is the purpose of the study?
We hope to look at parent attitudes towards this type of group intervention in order to understand whether it is considered acceptable and feasible and what factors may effect this. We are hoping to ask three groups of people to complete the Q-sort: 1) Parents who have taken part in a specific parenting group for their child with a tic spectrum disorder 2) Parents who have a child with a tic spectrum disorder but have not taken part in a specific parent group 3) NHS Staff who work with children with tic spectrum disorders and their parents.

Why have I been invited?
You have been invited to participate because you are in the second of these categories. You are a parent of a child who has a tic spectrum condition. You may have participated in general parenting groups but you will not have participated in the specific parenting group that has been provided as part of this study. Alternatively you may not have ever participated in any general parenting groups. You do not need to have any prior knowledge about these types of groups to take part. You may have responded to an advert either in the department at St. Thomas hospital or on-line via Tourette’s action. We are hoping for around 10-15 people from each of these three categories to participate in the study.
Do I have to take part?
It is up to you to decide to join the study. We will describe the study in this information sheet. If you agree to take part, we will then ask you to give consent using a consent form. You are free to withdraw at any time during the study, without giving a reason. This would not affect any care you or your child may receive now or in the future.

What will happen to me if I take part?
If you decide to take part then you will be asked to complete the Q-sort. This can be done online. The task usually takes around 20-25 minutes to complete but this will depend on how much information you give us in the comments. If you begin to complete the Q-sort and feel that you would like more support to complete it online then you will be able to email the researcher and arrange a time to complete it with her over the telephone. If you do not feel that you need any additional support then you can complete the Q-sort alone and in your own time.

The task will involve reading some statements and then arranging these into piles of agree-disagree. After the Q-sort you will be asked to give some comments about your decisions.

Expenses and payments
As a token of appreciation for your time you will be offered a £5 high street shop voucher following completion of the task. If you complete the Q-sort online and wish to receive the voucher then you will be asked to provide your name and address in order for you to arrange to receive the vouchers via post. If you do not wish to receive the voucher then you will not be required to provide this information. To ensure that participants only complete the Q-sort on one occasion, each home address will only be able to receive two vouchers and we will only be able to send each voucher once.

What are the possible disadvantages and risks of taking part?
Usually there are no risks associated with studies like this one. Your child’s treatment will not be affected in any way, whether you agree to take part or not.

The statements are unlikely to be upsetting. However if you did become upset then you could decide whether you wished to carry on, to have a break, to postpone or to terminate the task.

What are the possible benefits of taking part?
You may find it helpful to give us your views about this type of group. We hope that the research will help to develop the intervention further which will help other parents in the future.

Will my information be kept confidential?
The answers that you type after the statements will be analysed by the researcher. Any information which may identify you in any way will be removed. These and your statements will be anonymised so they are identifiable by number. If you
provide the researcher with your name and address to receive a voucher then the researcher will keep your address details until the high street vouchers have been distributed. It will be kept securely and then destroyed from the researcher’s records. Your name and address will never be given to anyone else and will hosted on university servers managed by university IT staff and using industry standard security protocols. Your details will not be used to link to your Q-sort responses and will be used only to distribute the vouchers.

**What will happen to my results?**
All data gained from the study will be destroyed in 5-10 years’ time. The research may be published but your name will not be given. The publication may include quotes of comments that were made by you and this may be linked to demographic information that you may have provided however all names will be removed.

**What if there is a problem?**
Complaints
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

**Who has reviewed the study?**
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Greater Manchester South NRES Committee (13/NW/0213).

**Who is organising and funding the research?**
The research has been organised and funded by the University of Manchester. The research is taking place as part of an education project for the qualification of Doctorate in Clinical Psychology. If you would like any more information on the research, please contact Gemma Evans (gemma.evans@postgrad.manchester.ac.uk).

**Further Information**
If you would like any more information about the research project please contact Dr Gemma Evans (trainee clinical psychologist) or Dr Penny Bunton (clinical psychologist):

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Department</th>
<th>Building</th>
<th>Phone</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gemma Evans</td>
<td>Clinical Psychology</td>
<td>Clinical Psychology</td>
<td>University of Manchester</td>
<td>07543204608</td>
<td><a href="mailto:gemma.evans@postgrad.manchester.ac.uk">gemma.evans@postgrad.manchester.ac.uk</a></td>
</tr>
<tr>
<td>Penny Bunton</td>
<td>Clinical Psychology</td>
<td>Clinical Psychology</td>
<td>University of Manchester</td>
<td>0161 2758093</td>
<td><a href="mailto:penny.bunton@manchester.ac.uk">penny.bunton@manchester.ac.uk</a></td>
</tr>
</tbody>
</table>
Further General Support
Should you require further support or experience any distress then you may wish to contact your own or your child’s GP or you may find the following contacts helpful:

Tourettes Action UK:
www.tourettes-action.org.uk
Helpline: 0300 777 842 open Monday to Friday 9am-5pm

SANE:
www.sane.org.uk
0845 767 8000

Samaritans:
www.samaritans.org
0845 790 9090

MIND:
www.mind.org.uk
0300 1233 393
Appendix 9: Q-study Parents Consent Form

CONSENT FORM: Q-sort parents

Title of project: A parent training programme for parents of children with tic disorders; the feasibility and acceptability of a group-based intervention.
Name of researcher: Gemma Evans

Please tick all boxes

1. I confirm that I have read and understand the Q-sort participant information sheet (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my own or my child’s medical care or legal rights being affected.

3. I agree to take part in the above study.

4. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data.

5. I agree to the use of anonymous quotations in the study.

Name of Participant __________________________  Date ________________  Signature __________________________

Name of Person taking consent __________________________  Date ________________  Signature __________________________

Where possible a copy of this consent form will be sent to the participant and one will be kept by the researcher.

Version 1b
05/05/2013
Appendix 10: Q-study Information

Participant Information Sheet: Q-sort_3

Title of project: A parent training programme for parents of children with tic disorders; the feasibility and acceptability of a group-based intervention.

Name of researcher: Gemma Evans

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please contact the researcher if there is anything that is not clear.

The study hopes to investigate attitudes towards parenting interventions for parents of children with a tic spectrum disorder. This will involve performing a Q-sort task. This is a task where you will read some statements and organise them into piles of whether you agree or disagree with the statement. You will then be asked to give some comments about why you have placed the statements in the piles that you have.

What is the purpose of the study?
We hope to look at parents and clinician attitudes towards this type of group intervention in order to understand whether it is considered acceptable and feasible and what factors may effect this. We are hoping to ask three groups of people to complete the Q-sort: 1) Parents who have taken part in a specific parenting group for their child with a tic spectrum disorder 2) Parents who have a child with a tic spectrum disorder but have not taken part in a specific parent group 3) NHS Staff or other clinicians who may work with children with tic spectrum disorders and their parents.

Why have I been invited?
You have been invited to participate because you are in the third of these categories and are a staff member who may have previously or may potentially work with children with tic spectrum disorders or you may have previously been involved in general parenting interventions. We are hoping for around 10-15 people from each of these three categories to participate in the study.

Do I have to take part?
It is up to you to decide to join the study. We will describe the study in this information sheet. If you agree to take part, we will then ask you to give consent using a consent form. You are free to withdraw at any time during the study, without giving a reason.
What will happen to me if I take part?
If you decide to take part then you will be asked to complete the Q-sort. This can be done online. The task usually takes around 20-25 minutes to complete but this will depend on how much information you give us in the comments. If you begin to complete the Q-sort and feel that you would like more support to complete it online then you will be able to email the researcher and arrange a time to complete it with her over the telephone. If you do not feel that you need any additional support then you can complete the Q-sort alone and in your own time.

What are the possible disadvantages and risks of taking part?
Usually there are no risks associated with studies like this one.

The statements are unlikely to be upsetting. However if you did become upset then you could decide whether you wished to carry on, to have a break, to postpone or to terminate the task.

What are the possible benefits of taking part?
You may find it helpful to give us your views about this type of group. We hope that the research will help to develop the intervention further which will help parents in the future.

Will my information be kept confidential?
The answers that you type after the statements will be analysed by the researcher. Any information which may identify you in any way will be removed. These and your statements will be anonymised so they are identifiable by number.

What will happen to my results?
All data gained from the study will be destroyed in 5-10 years’ time. The research may be published but your name will not be given. The publication may include quotes of comments that were made by you and this may be linked to demographic information that you may have provided however all names will be removed.

What if there is a problem?
Complaints
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Greater Manchester South NRES Committee (13/NW/0213).
Who is organising and funding the research?
The research has been organised and funded by the University of Manchester. The research is taking place as part of an education project for the qualification of Doctorate in Clinical Psychology. If you would like any more information on the research, please contact Gemma Evans (gemma.evans@postgrad.manchester.ac.uk).

Further Project Information
If you would like any more information about the research project please contact Dr Gemma Evans (trainee clinical psychologist) or Dr Penny Bunton (clinical psychologist):

Gemma Evans
Clinical Psychology Department
2nd floor Zochonis Building
University of Manchester
M13 9PL
gemma.evans@postgrad.manchester.ac.uk
07543204608.

Penny Bunton
Clinical Psychology Department
2nd floor Zochonis Building
University of Manchester
M13 9PL
penny.bunton@manchester.ac.uk

Further General Support
Should you require further support or experience any distress then you may wish to contact your GP, or you may find the following contacts helpful:

Tourettes Action UK:
www.tourettes-action.org.uk
Helpline: 0300 777 842

MIND:
www.mind.org.uk
0300 1233 393

SANE:
www.sane.org.uk
0845 767 8000

Samaritans:
www.samaritans.org
0845 790 9090
Appendix 11: Q-study Professionals Consent Form

CONSENT FORM: Q-sort_staff

Title of project: A parent training programme for parents of children with tic disorders; the feasibility and acceptability of a group-based intervention.
Name of researcher: Gemma Evans

Please tick all boxes

1. I confirm that I have read and understand the Q-sort participant information sheet (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I agree to take part in the above study.

4. I understand that relevant sections of data collected during the study may be looked at by responsible individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in the research.
I give permission for these individuals to have access to this data.

5. I agree to the use of anonymous quotations in the study.

Name of Participant ___________________________ Date ____________ Signature ______________

Name of Person taking consent ___________________________ Date ____________ Signature ______________

Where possible a copy of this consent form will be sent to the participant and one will be kept by the researcher.

Version 1b
05/05/2013
PARENTS and CAREGIVERS!

We want your views.
We would like your views on what you would think about attending a parent group for parents of children with tic disorders.

You will not attend a group as part of this study, but we are interested in hearing your opinions about whether you think such groups might be helpful. You do not need to have any prior knowledge about these types of groups to take part.

What will happen to me if I take part? You will be asked to perform a computer task. This can be done online. The task usually takes around 20-25 minutes to complete. You will be given a short explanation about parenting groups. The task will involve reading some statements. The statements will contain opinions about the groups. You will be asked to arrange these statements into piles of agree or disagree. After this task you will be asked to type some comments about your views should you wish.

What is the purpose of the study? We hope to look at parents attitudes towards parent groups in order to understand whether they would be considered acceptable and feasible and what factors may affect this. This information will help to decide whether parenting groups would be useful for parents of children with tic disorders.

Expenses and payments. You will be able to complete the task on the internet whenever you choose. You will be offered a high street voucher as a small token of appreciation for your time following completion of the task. You will be given the option of providing the researcher with your name and address to receive this voucher. We would like 30-45 participants to complete the task.

Further Project Information
If you would like any more information about the research project please contact Dr Gemma Evans (trainee clinical psychologist);
gemma.evans@postgrad.manchester.ac.uk, 07543204608.

How do I take part? If you would like to take part please visit this website. If you prefer to complete the task via post please contact Gemma Evans.

{WEBSITE ADDRESS}
Appendix 13: Research Link via Tourettes Action


Researchers at the University of Manchester are carrying out research on whether parents and caregivers would attend parent groups.
Researchers would like the views of parents and caregivers on what they would think about attending a parent group for parents of children with tic disorders. The research is being carried out by the University of Manchester with the support of Tourettes Action and Guys and St Thomas’ hospital.

Participants will not attend a group as part of this study, but we are interested in hearing your opinions about whether you think such groups might be helpful. You do not need to have any prior knowledge about these types of groups to take part.

Who can take part?
Any parent/caregiver of a child with a tic disorder.

What will happen to me if I take part?
You will be asked to perform an online computer task, it takes approximately 30 minutes to complete. You will be given a short explanation about parenting groups. You will be asked to arrange statements about parenting groups into piles of agree or disagree. You can leave comments if you wish.

What is the purpose of the study?
We hope to look at parents attitudes towards parent groups in order to understand whether they would be considered acceptable and feasible and what factors may affect this.

Expenses and payments.
You will be able to complete the task on the internet whenever you choose. You will be offered a high street voucher as a small token of appreciation for your time following completion of the task. We would like 30-45 participants to complete the task in total.

Further Project Information & help.
If you would like any help or have questions about completing the online tasks the more please email Dr Gemma Evans (trainee clinical psychologist) or call 07543204608 at any time.

How do I take part?
You can take part online now. Or, if you would prefer to complete the task via post please contact Gemma Evans.
For more details on Tourettes Action research projects, please contact Research Manager, Seonaid Anderson.
Appendix 14: Q-study Advertisement
for Professionals

Clinicians

We would like your views on what you would think about parenting groups for parents of children with tic disorders.

We are interested in the views of professionals who have previously worked or currently work with children with tic disorders, or professionals who may have currently or previously been involved in parenting interventions.

What will happen to me if I take part? You will be asked to perform a computer task. This can be done online. The task usually takes around 20-25 minutes to complete. You will be given a short explanation about parenting groups. The task will involve reading some statements. The statements will contain opinions about parenting groups. You will be asked to arrange these statements into piles of agree or disagree. After this task you will be asked to type some comments about your views should you wish.

What is the purpose of the study? We hope to look at professionals attitudes towards parent groups in order to understand whether they would be considered acceptable and feasible and what factors may affect this. This information will help to decide whether parenting groups would be useful for parents of children with tic disorders.

You will be able to complete the task on the internet whenever you choose. We would like 30-45 participants to complete the task in total.

Further Project Information
If you would like any more information about the research project please contact Dr Gemma Evans (trainee clinical psychologist) or Dr Penny Bunton (clinical psychologist):

Gemma Evans
gemma.evans@postgrad.manchester.ac.uk
07543204608

Penny Bunton
penny.bunton@manchester.ac.uk

How do I take part? If you would like to take part please visit this website. If you prefer to complete the task via post please contact Gemma Evans.
What do psychologists do?

Posted on 17 October 2013 by Seonaid Anderson

Two Trainee Clinical Psychologists from the University of Manchester answer questions about psychological therapy.

What do psychologists do?
Psychologists support people and try to improve their well-being, often through talking therapies.

What will happen when I first go to meet a psychologist?
Therapy often starts with a ‘getting to know you’ period, where the psychologist might ask questions about how things are for you, your background and detail about your tics and the impact of these. You and the psychologist then usually decide together whether a talking therapy may be helpful and what type of therapy would be suitable.

What happens in therapy?
There are lots of different therapies that have been found to be helpful for tic spectrum conditions. For example, you may have heard of habit reversal therapy, exposure response prevention, or cognitive behavioural therapy. Each one of these is a little bit different but generally they work by finding strategies for managing your tics or the impact that tics might have.

Do I have to lie on a couch and talk about dreams?
There are many stereotypes about psychology. You might have seen in lots of films someone lying on a couch talking to a therapist. Usually psychologists don’t use a couch – just a couple of chairs in a room to sit and have a friendly conversation about the things that are important to you.

Can a psychologist read my mind?
It would make our job a lot easier if they could. But no, psychologists cannot read your mind. It is up to you how much or little you feel comfortable to talk about and want to share.

Are talking therapies helpful for tics?
Research has shown talking therapies can be useful in helpful people to manage tics and other common difficulties associated with tics (for example anxiety, low mood, attention-deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), or other social difficulties like bullying).
Who sees a psychologist?
Lots of different people are seen by psychologists. For example, we see people of all ages and from all backgrounds. There are lots of reasons people might have therapy, for example they might be struggling to cope because of negative life events, medical difficulties or thoughts or feelings that become too overwhelming.

What’s the difference between psychologists and psychiatrists?
The main difference is that psychologists do not administer medication, and they go through different training. Psychologists and psychiatrists often work closely together. Also, other professionals like counsellors can provide talking therapies.

What training do clinical psychologists have?
Most clinical psychologists have a couple of degrees, and all are trained to a doctoral level, with three years of training. They usually have a wide variety of clinical experience and research experience.

Why is research important?
Research is a really important part of being a psychologist. Through research, psychologists can better understand what difficulties people might have, why this might be and they can develop the best possible ways of helping them with such difficulties.

Both of us are currently working on research projects:
Heather: I am currently carrying out research and looking to speak with young people who have had a helpful or successful experience of a talking therapy for their tics. This is to find out what helps and why it helps, so that we can capture such stories and share them with other professionals.

Gemma: I am looking for parents of children or young people with tics to help with my research. Parents will be asked to complete a statement sorting task online or by post to find out whether parents think that parenting groups would be a helpful thing for psychologists to offer. Parents do not need to have any prior knowledge about these types of groups to take part.

Do you think seeing a psychologist might be helpful for you or someone you know?
If you want to see a psychologist we recommend you speak to your GP about the available local services and ask to be referred. Alternatively contact Tourettes Action for further information.

This article was written by Heather Smith and Gemma Evans, two trainee clinical psychologists currently on the University of Manchester Clinical Psychology Doctorate programme.
Appendix 16: Q-set Development Process

A figure to show the statement generation process.

Journal Articles
- Parenting programmes
- Tic disorders
- Parents and tic disorders
- Parent programmes parent views

Books
- Parenting programmes
- Tic disorders

Television Programmes
- Tic disorders
- Parenting techniques

Websites
- Tic disorders
- Parenting programmes

Interviews
- Parents from first pilot parenting group

Quotes, key phrases and information taken from materials

Sorted into themes

Initial statements generated (n=244)

Sorted into further themes, removed duplicated and redundant items

Reviewed and revised with the research team

Final statements obtained (n=73)
Appendix 17: Q-set Statements

1. Parents of children with TSC experience more stress than parents of children without TSC.

2. Helping parents to think about their own thoughts and feelings about their child’s difficulties is important in a parenting intervention.

3. Parents own thoughts and feelings affect parenting behaviour.

4. Giving parents time to talk about the worries they have about their child’s TSC is important in a parenting intervention.

5. Learning skills to manage children’s anger is important in a parenting intervention for TSC.

6. Learning skills to manage children’s anxiety is important in a parenting intervention for TSC.

7. Learning skills to develop a parent-child relationship through play, warmth, praise and attention is important in a parenting intervention for TSC.

8. Learning skills to give children positive attention, praise and rewards is important in a parenting intervention for TSC.

9. Learning skills in giving and enforcing clear commands to children is important in a parenting intervention for TSC.

10. Learning skills to pay less attention to children’s negative behaviours is important in a parenting intervention for TSC.

11. Learning skills to apply consequences for negative behaviour (e.g., time out, grounding) is important in a parenting intervention for TSC.

12. Learning skills to manage children’s mood is important in a parenting intervention for TSC.

13. Providing information about techniques to manage children’s tics (e.g., exposure response prevention, habit reversal training) is important in a parenting intervention for TSC.

14. Helping parents accept and adjust to their child’s difficulties is important in a parenting intervention for TSC.

15. Providing education about tics is important in a parenting intervention for TSC.
16. Providing information about medication (e.g., benefits, side effects) is important in a parenting intervention for TSC.

17. Helping parents to develop children’s social skills is important in a parenting intervention for TSC.

18. Making parents feel valued by providing a comfortable environment (e.g., snacks, breaks, resources) is important in a parenting intervention for TSC.

19. Parents would be worried that changing parenting techniques would make things worse.

20. Inviting parents to attend a parenting intervention for TSC would make them feel criticised.

21. If parents were given knowledge about psychological techniques (e.g., exposure response prevention, habit reversal) they would use these techniques to manage children’s tics.

22. It would negatively affect the parent-child relationship if parents tried to change children’s tics using psychological techniques (e.g., exposure response prevention, habit reversal).

23. Parents would be wary about a parenting intervention for TSC.

24. The difficulties of children with TSC frequently change so a parenting intervention would not be effective over time.

25. Learning generalizable skills is important in a parenting intervention for TSC.

26. TSC are biological in origin so a parenting intervention will have no effect.

27. Parent interventions for TSC would be less effective than interventions that treat the child directly.

28. Parents of children with and without TSC have similar needs so interventions just for children with TSC are unnecessary.

29. Child and Adolescent Mental Health Services (CAMHS) should offer parenting interventions for TSC.

30. Practical issues make it too difficult for parents to attend parenting interventions.

31. It is unreasonable to deliver an intervention through parents.
32. Parents would not complete homework as part of a parenting intervention because they are too stressed.

33. Parents would not complete homework as part of a parenting intervention because they lack motivation.

34. Diagnosing TSC is a barrier to parents accessing interventions.

35. Parents would need repeated follow-ups to continue using the skills learned in a parenting intervention.

36. Only a small number of people would need a parenting intervention for TSC.

37. Parenting interventions for TSC are not a good use of NHS money.

38. Parents would only attend a parenting intervention if it involved other parents with children with TSC.

39. Meeting other parents of children with TSC would increase parents worry about their own child.

40. Social support from other parents is an important benefit of a group-based parenting intervention.

41. Between six and ten parents in a group parenting intervention group is a good size.

42. Parents should be offered a parenting intervention shortly after their child is first diagnosed with TSC.

43. Parenting interventions are more appropriate for parents of younger children with TSC.

44. Transition to adolescence can be difficult so parenting interventions should be offered to parents of adolescents with TSC.

45. Shorter, weekly meetings are better than longer, monthly meetings in a parenting intervention for TSC.

46. Parents need to discuss their child’s difficulties on an individual basis.

47. If NHS resources are limited it is better for more parents to be seen in a group-based parenting intervention.

48. Group-based parenting interventions for TSC are cost effective.

49. Family functioning is related to children’s adjustment and quality of life.
50. Positive child-parent interactions are important for children’s adjustment and quality of life.

51. Teaching parents the most effective parenting strategies will help to strengthen children’s social, emotional and academic competence.

52. Parents are less likely to participate in group-based parenting interventions than individual parenting interventions.

53. Children’s perception of their parent’s views towards their TSC is important.

54. It is not children’s tics that cause most concern to parents, but common co-morbid conditions (e.g., anxiety, mood, anger, behavioural difficulties).

55. Parenting interventions for TSC should only be offered to parents of children with more severe tics.

56. The differences in children’s TSC related difficulties are a barrier to group-based parenting interventions.

57. All main caregivers of a child need to attend a parenting intervention for it to be effective.

58. Parents would accept and attend a parenting intervention for TSC.

59. Professionals who run parenting groups for TSC must be experts in the treatment of tics.

60. It is important that parents have a positive relationship with the professionals that lead parenting interventions.

61. The lack of research in parenting interventions for TSC is a barrier to treatment.

62. If a parenting intervention for TSC was in book form, professionals would be more likely to offer it.

63. Siblings of children with TSC would benefit from their parents attending a parenting intervention.

64. It is important to consider parents’ cultural differences in a parenting intervention for TSC.

65. Helping parents to feel more in control of their child’s difficulties is an important outcome of parenting interventions for TSC.

66. Changing children’s tics is an important outcome of parenting interventions for TSC.
67. Changing children’s common co-morbid difficulties (e.g., anxiety, anger, mood, behavioural difficulties) is an important outcome of parenting interventions for TSC.

68. Helping parents to feel more positive about the future is an important outcome of parenting interventions for TSC.

69. Parents prefer psychological interventions to medication for TSC.

70. Medication is more effective than psychological interventions for TSC.

71. Parenting interventions for TSC would be effective.

72. Family members, friends, and teachers should be invited to attend parenting interventions for TSC.

73. A lack of training and knowledge about TSC is a barrier to non-specialist services offering parenting interventions for TSC.
### Appendix 18: Q-sort Grid

<table>
<thead>
<tr>
<th>-6</th>
<th>-5</th>
<th>-4</th>
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<th>0</th>
<th>+1</th>
<th>+2</th>
<th>+3</th>
<th>+4</th>
<th>+5</th>
<th>+6</th>
</tr>
</thead>
</table>

Disagree

Agree
Appendix 19: Pre-Task Information

Pre-task Information

Please read this information carefully.

Definitions of terms we use in the Q-sort task

Parent
We use the word 'parent' but this can be replaced with the word 'caregiver' if it is more appropriate to you.

Tic Spectrum Condition or TSC
We use the term "tic spectrum condition" or TSC to mean any condition that involves tics.
Tics are involuntary, repetitive movements or sounds. For example, a movement tic may be eye rolling or limb jerking, and a sound tic may be throat clearing or saying phrases.
The term "tic spectrum condition" covers several tic conditions like Tourette's syndrome, chronic motor or vocal tic disorder and transient tic disorder.
Tic spectrum conditions can also often occur with other difficulties such as obsessive compulsive behaviour, anxiety, mood difficulties, sleep difficulties, behavioural difficulties and attention deficit hyperactivity disorder (ADHD).

Parenting Intervention
We use the term "parenting intervention" in the task, however you may have also heard this called a 'parenting group' or a 'parenting program'. Parenting interventions usually involve a group of parents and are run by a Psychologist.

The only thing that you need to know about parenting interventions before completing the Q-sort is that they teach parents skills to help parents to manage their children's difficulties; the psychologist does not usually work with the child directly but works through their parents.

In a parenting intervention, psychological techniques or skills are taught to parents. You may have seen some of these techniques on television programs about parenting, like 'supernanny', 'Jo frost: extreme parental guidance', 'nanny 911', or 'driving mum and dad mad'.

The psychological techniques usually involve teaching parents the best ways to play with, praise, set limits and apply consequences with their children but can also involve skills to help with more specific difficulties like children's anxiety, mood or sleep problems and even tics.

Parenting interventions aim to help parents to increase children's positive behaviours and reduce children's negative behaviours or their distress. In the Q-sort task we will ask your opinion about what you think would be important skills to be taught in a parenting intervention.
Appendix 20: Parents Post-Sort Free Text Questions

Please answer the following questions.

- Please explain why you agree most with the statement you have placed below "-6".

- Please explain why you agree least with the statement you have placed below "+6".

- What is your overall view of parenting interventions for parents of children with tic spectrum conditions?

- Would you attend a parenting intervention if it was offered to you and why?
Appendix 21: Professionals Post-sort Free Text Questions

Please answer the following questions.

- Please explain why you agree most with the statement you have placed below "+6".

- Please explain why you agree least with the statement you have placed below "+6".

- What is your overall view of parenting interventions for parents of children with tic spectrum conditions.

- In your professional role, would you consider delivering a parenting intervention for parents of children with tic spectrum conditions and why?
Appendix 2: Instructions for Postal Q-sort Task

The materials provided for this section are

- Envelope containing 73 statement cards on pink paper
- Sheets containing the words AGREE, DISAGREE, NEUTRAL on green paper
- Envelope containing 13 ranking cards ranging from -6 to +6 on brown paper
- Sheet containing a small blank q-sort grid on blue paper

**Step A:**
Find an area to carry out the task, you may need quite a large area, about the size of a table. If all else fails then use the floor!

**Step B:**
Take the three green sheets containing the words AGREE, NEUTRAL, DISAGREE and place them spaced out in-front of you.
Take the pile of pink 73 statement cards. Read each pink statement carefully and place it into one of three piles:
- a pile for statements you definitely disagree with
- a pile for statements you definitely agree with
- and a pile for the rest, called the ‘neutral’ pile. Although it is called the neutral pile, this pile might include statements that you less strongly agree or disagree with, or it could include statements that you feel indifferent, unsure of or have mixed feelings about.

It will be helpful for step C of the task if you try and put roughly the same number of statements in each of the three piles (around 20 to 25 statements), although this doesn’t have to be exact. If you find that you are placing most of the statements in the agree or disagree piles, then you might want to start putting some of the statements you feel less strongly about in the neutral pile.

If you place each pile on-top of one of the three sheets (AGREE, NEUTRAL, DISAGREE) this may help you to remember which pile is which.
Step C:

Setting up the q-sort grid:

1) You should now have three distinct piles of pink statement cards. Keep your three piles separate from each other, but set them aside for the moment.

2) Next take the envelope containing 13 brown ranking cards ranging from -6 to +6 and lay out the cards horizontally at the top of your sorting area, as far away from you as your area will allow. Lay out the cards in order ranging from -6 on your left to +6 on your right. Leave a centimetre or two in between each so they look like this:

   
   -6  -5  -4  -3  -2  -1  0  +1  +2  +3  +4  +5  +6

3) Take the blue q-sort grid.

   The Q-sort task involves arranging your statements from the pink piles under the brown ranking cards so that there are the same number of statements under each as there are empty boxes on the small blue q-sort grid. It is as if you are creating a large pink and brown version of the blue q-sort grid. So under -6 you should have one pink statement, under -1 ten pink statements and so on.

To decide which statements should go where, follow the instructions below.

Completing the q-sort grid:

4) First take the pink statements from the "AGREE"-pile ONLY. Leave the DISAGREE and NEUTRAL piles for now. Spread out the pink AGREE statements so you can see each one.

5) Your job is to allocate each pink statement a place under one of the brown ranking cards. Pink cards under the highest ranking positions (towards the highest positive numbers e.g. +6 or the right side) should be the ones which you agree with most strongly.

   Select the pink statement you most agree with out of your AGREE pile and place it below the "+6". Next, take the two statements you second most agree with and place them under "+5". Next, take the four statements you third most agree with and place them under “+4”. So on for the “+3” and “+2” columns. Use the small
blue q-sort grid to check that you are putting the correct number of statements under each ranking card.

Follow this procedure for all statements in the AGREE pile. If you have lots of statements in the AGREE pile you might need to put some under the negative numbers in the grid. Please don’t worry about this, you just need to place the statements you most strongly agree with towards the more positive end of the grid (closer to +6). Don’t worry about whether items are placed on top of or below each other in the grid.

6) After all your pink cards in the AGREE pile have a position under a brown ranking card, pick up the pink cards in your DISAGREE pile. Repeat the above instructions for the statements in this pile. The statements that you disagree with most strongly should be placed towards the lowest ranking positions (towards the highest negative numbers e.g. -6, or the left side) in the grid.

Select the statement you most disagree with and place it below the “-6”. Next, take the two statements you second most disagree with and place them under the “-5”. Carry on like this, just as you did with the agree statements. Again you just need to place the statements you most strongly disagree with towards the more negative end of the grid (closer to -6).

7) When all your pink statements from the AGREE and DISAGREE piles are placed under a brown ranking card pick up the NEUTRAL pile of pink statements and follow the same procedure. The further towards the middle of the grid you place statements (closer to 0), the more neutral you feel about this statement relative to the others, but you might still agree or disagree with it.

You can swap statements around after you have put them in a position in the large grid if you change your mind.

Keep going until all the pink statements from the AGREE, NEUTRAL and DISAGREE piles are placed under a brown ranking card. Remember the large pink and brown grid must be the same shape as the blue grid.
The full task usually takes around 30 minutes, so try to not spend too much time deciding on the position of individual statements, we just need a general sense of your opinion.

**STEP D:**

8) Your large pink and brown grid should now look like the small blue q-sort grid but with pink statements replacing each blank square. Look over your large pink and brown grid once more and shift any statements if you want to.

9) Next take the small blue q-sort grid. Next to each pink statement in your large pink and brown grid there is a number. Please write that number in the corresponding position in the blue grid, so that I can see the position of your statements using just the small blue version.

Congratulations, you have now finished the Q-sort task! Once you have written the corresponding numbers in the small blue q-sort grid you can collect the pink, brown and green cards and throw them away.

**WHEN YOU HAVE WRITTEN A NUMBER IN EACH BOX PLEASE RETURN THE BLUE Q-SORT GRID SHEET TO ME IN THE ENVELOPE PROVIDED.** (please do not return the pink, brown or green cards)

Thank you very much for taking part!
### Appendix 23: Factor Loadings for Parents

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X= loading onto a particular factor
## Appendix 24: Factor Loadings for Professionals

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X= loading onto a particular factor
Appendix 25: Parents’ Post-sort Comments about Ranking Decisions

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<td>(-6; s70) “The effectiveness of medication on tics is variable. Although my son feels that the tics themselves are the biggest problem, we can see that it is how he feels about the tics and himself that actually create the biggest problems for him. Psychological interventions have given him back some of the control that TS takes away.”</td>
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<tr>
<td></td>
<td>(+6; s53) “My own experience of my own child is that he is better when he feels comfortable in himself. Parents' attitudes, body language etc, contribute considerably to the child's good self-image. The nurturing environment is vital. He looks to us for answers - we need to be confident in what we say and how we say it.”</td>
</tr>
<tr>
<td>1</td>
<td>(-6; s22) “Parents need to work with their children in a positive way and this can only happen if they are educated about tics and interventions.”</td>
</tr>
<tr>
<td></td>
<td>(+6; s3) “It is so important to children's development and self-esteem that they are accepted and validated by their parents. Parents don't understand tics and if their children's behaviour isn't explained it can be misinterpreted as naughty, bad or plain mad”.</td>
</tr>
<tr>
<td>1</td>
<td>(-6; s28) “Although all parents have issues surrounding how best to bring up their child, I feel that this is too generalised and that parents of children with TSC have very different needs in addition to those faced by other parents”.</td>
</tr>
<tr>
<td></td>
<td>(+6; s51) “The most important thing for me as a parent is for my son to meet his full potential in whatever he chooses to do. Without self confidence, friendships and emotional stability I feel that this would not be possible. I want him to grow into a happy, confident adult regardless of his difficulties”.</td>
</tr>
<tr>
<td>1</td>
<td>(-6; s37) “I believe are not true, parents need a lot of support”.</td>
</tr>
<tr>
<td></td>
<td>(+6; s71) “This is based on my opinion for the needs I found important and necessary for me as the parent and my child. We could do with lots of support.”</td>
</tr>
<tr>
<td>1</td>
<td>(-6; s70) “Every case is different what works for one individual will not necessarily be right for another. Therefore I disagree as a general statement, that one is more effective than the other. It is trial and error for each individual case.”</td>
</tr>
<tr>
<td></td>
<td>(+6; s14) “To be accepted for who you are, and have adjustments made so you are not always wrong, negative or inappropriate, can only be a more positive outcome for any child or adult. If everything you do is wrong then the response is always negative. Acceptance and a positive response is by far a better environment to be in.”</td>
</tr>
<tr>
<td>1</td>
<td>(-6; s19) “Usually parents want the best for their children, if the change of parental techniques can bring the family together and have a better time, it is essential to put changes in place.”</td>
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<td>---</td>
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</tr>
<tr>
<td>(+6; s50)</td>
<td>“It is the essence when dealing with a special need child.”</td>
</tr>
<tr>
<td>(-6; s31)</td>
<td>“Educating parents about their child's condition and helping them to understand and overcome some situations will definitely improve the relation with their child and help the child to feel more confident.”</td>
</tr>
<tr>
<td>(+6; s45)</td>
<td>“We understand that tics are involuntary movements, but what makes the day to day life difficult is all the behavioural problems revolving around TS. It affects the whole family. And as a parent, I often feel lost.”</td>
</tr>
<tr>
<td>(-6; s23)</td>
<td>“Some would be because of a group of parents.”</td>
</tr>
<tr>
<td>(+6; s45)</td>
<td>“Because if any new problems arise you can sort straight away.”</td>
</tr>
<tr>
<td>(-6; 28)</td>
<td>“This is probably the biggest &quot;battle&quot; we have faced as a family - persuading schools teachers clinicians consultants that the child with TS has MORE THAN JUST TICS. That their needs, socially, emotionally, educationally and in terms of treatments are different than those of the child without TSC. There is a common misconception amongst NHS, CAMHS, schools, local authorities that the tics are the only issue, but we have found that the TS child has a host of different needs, driven by a complex syndrome of neurodevelopmental problems.”</td>
</tr>
<tr>
<td>(+6; 1)</td>
<td>“Stress has been a major factor of our lives and of every other parent of a TS child we have met, even though we are perfectly accepting of --- condition and behaviours. For us the stresses gave been around getting appropriate acceptance/ education for ---, or treatments other than medication from NHS/ CAMHS. It is a stress borne of frustration from the lack of help available.”</td>
</tr>
<tr>
<td>(-6; 34)</td>
<td>“Why is it a barrier to accessing interventions can’t see that would be a problem, diagnosed or not”</td>
</tr>
<tr>
<td>(+6; 21)</td>
<td>“Because if I actually had a professional person to give me advice on how to help my child positive things we could do then that would be fantastic. I didn’t know that you could reverse or help tics. As a parent you do anything to help. That would be very useful to me.”</td>
</tr>
<tr>
<td>(-6; 37)</td>
<td>“When you have a child with TS you appreciate all the help, without NHS I'd be lost as a parent”</td>
</tr>
<tr>
<td>(+6; 1)</td>
<td>“We as parents do have stress issues, higher than a child without TS. This is due to behaviour, anger, anxiety, OCD, tics etc.”</td>
</tr>
<tr>
<td>(-6; 37)</td>
<td>“It is a very good use of nhs money.”</td>
</tr>
<tr>
<td>(+6; 67)</td>
<td>“It is important to learn how to cope and deal with the co-morbid difficulties as this is a major issue with our son.”</td>
</tr>
<tr>
<td>(-6; s37)</td>
<td>“Parenting interventions for TSC would be a good use of money if it helped the children develop emotionally and socially.”</td>
</tr>
<tr>
<td>(+6; s40)</td>
<td>“Parents often feel isolated and unsure whether behaviours are because of TS or not. Meeting others with similar experience would be supportive.”</td>
</tr>
<tr>
<td>(-6; s52)</td>
<td>“I think parents would prefer a group based parenting intervention so they can get more of an understanding of the wide variety and severity of children’s tics, listening to others stories and advice would be useful to parents. Some parents may find talking to other parents easier then talking to professionals.”</td>
</tr>
<tr>
<td>Rank</td>
<td>Parent Comment</td>
</tr>
<tr>
<td>------</td>
<td>----------------</td>
</tr>
<tr>
<td>4</td>
<td>“Gives parents a chance to get their concerns off their chest. To be able to talk to other parents to see if they have the same concerns. To get re-assurance.”</td>
</tr>
<tr>
<td>-6</td>
<td>“More help should be given by the NHS as tic disorders have a HUGE impact on children’s' lives.”</td>
</tr>
<tr>
<td>+6</td>
<td>“It is very stressful for the parents seeing your child have tics and sometimes more stressful for the parent than the child! If the parent is stressed the child may feel even more stressed and tic more. Also I am answering this question as a parent so from my point of view.”</td>
</tr>
<tr>
<td>-6</td>
<td>“Having met up with other families I find talking to them helps more than worries me.”</td>
</tr>
<tr>
<td>+6</td>
<td>“Anxiety is a massive part of the condition and often more damaging than the tic disorder.”</td>
</tr>
<tr>
<td>-6</td>
<td>“My partner [identifiable information] and does only a small amount of the parenting. It would be nice if he could come, but it is not a barrier if he can't. Even if he could the cost of babysitting (£s and in terms of disruption) might prevent either of us from attending.”</td>
</tr>
<tr>
<td>+6</td>
<td>“Since he developed TS, I have been repeatedly attacked by my wonderful, clever son who was a completely caring, loving child for [identifiable] years. It has become incredibly isolating and difficult to talk about. Medical profs. Seem to think I could whip him into shape with some &quot;1, 2, 3 Magic&quot; or similar and don't acknowledge to unpredictability and neurological roots of Tics2.”</td>
</tr>
<tr>
<td>-6</td>
<td>“No actual medication specifically for tourettes, psychological interventions are known not be much more successful in the long term treatment of tics.”</td>
</tr>
<tr>
<td>+6</td>
<td>“There is such a variety of info available that not all of it is correct or relevant therefore having a specialised resource available is fundamental in ensuring that the right information is given to parents. Tourettes is a long term condition therefore parents need to be equipped to deal and help support their child with it.”</td>
</tr>
<tr>
<td>-6</td>
<td>“Problems appear to get worse with age, from age 8 onwards parents should be given access to intervention groups.”</td>
</tr>
<tr>
<td>+6</td>
<td>“We have 2 children and our child with tourettes definitely causes more stress within the family than our other [child] and we can see it is because of the behaviours that are caused by tourettes ie. Anger, ocd, lack of concentration, frustration.”</td>
</tr>
</tbody>
</table>

Note. The table contains ranking comments provided by the parents that were included in the analysis. Two parents did not provide ranking comments. Comments from the two parents that did not load significantly onto a factor are not presented.
### Appendix 26: Professionals’ Post-sort Comments about Ranking Decisions

<table>
<thead>
<tr>
<th>Factor</th>
<th>Comment</th>
</tr>
</thead>
</table>
| 1      | (-6; s31) “Of course it is reasonable!”
|        | (+6; s73) “There appear to be very few psychologists - or even non-clinical professionals such as social workers - or even volunteers such as "expert parents" - who are either sufficiently interested or sufficiently trained in tic disorders in order to deliver specifically tailored parenting interventions. Almost all parents of children with tic disorders I have come into contact with who have had "general" parenting interventions have found these unsatisfactory.” |
| 1      | (-6; s26) “Whether they are or aren't biological a parenting intervention is always likely to be beneficial.”
|        | (+6; s3) “Parents cognitions are probably the most important target for any intervention so that they are better adjusted to managing their child.” |
| 1      | (-6; s31) “Parents are with children most and know their children best so it is logical that they are best placed to deliver the interventions. Also parent training has best evidence base.”
|        | (+6; s3) “Parents often are not aware that their management strategies are often affected by their own mood and attributions about the child’s behaviour. This can undermine relationships and the effectiveness of strategies if not dealt with.” |
| 1      | (-6; s31) “Parents have a direct and causal impact on the development of their child. Consequently, delivering interventions through parents (possibly the most important adult in child's life) is entirely appropriate, and backed up by an extensive research base.”
|        | (+6; s50) “Early parental bonds establish a child's attachment patterns, not only within childhood but through their entire life. Child-parent relationships and interactions can have an extensive impact on the development of the individual child, from developing their sense of self worth and identity in childhood to their ability to form long-lasting, stable and positive relationships within adulthood.” |
| 1      | (-6; s37) “Is a significant condition with long term morbidity.”
|        | (+6; s67) “Because they are often as disabling as the tic.” |
| 1      | (-6; s26) “I didn't think that TSC were necessarily biological in origin but, even if they are, parenting interventions could still be effective in helping the family to support the child more effectively, which would have an impact on the TSC and also the child and family's well-being. As I understand it, TSC can increase under conditions of stress and anxiety, therefore a psychological parenting intervention would seem appropriate and likely to be effective.” |
| 226 | (+6; s49) “The family environment is the most important factor in a child's well-being and quality of life.” |
| 1 | (-6; s43) “I think the provision should be about impact on functioning not age and that it is appropriate when it is appropriate. Also parents of different age children can help and support one another.” (+6; s14) “This is probably based on the assumption that the social and emotional impact for the child and the parent of tics significant/severe enough to require a parenting intervention are likely to be a major issue. Also in my clinical experience those parents who found it most hard to accept the disorder, and therefore their child, struggled the most and could not support their child with negative consequences on the child.” |
| 2 | (-6; s26) “It seems there is a lot of scope for changing the support and environment around a child and how their tics are managed and responded to, and their sense of themselves, their identity and mood, which in turn will have a positive impact on their wellbeing (a focus that seems more important than reducing the frequency/severity of tics).” (+6; s50) “This seems a fundamental and necessary basis for adjustment and QOL - I think children can be supported to deal with very difficult things if their relationship with their parents/caregivers is positive and secure.” |
| 2 | (-6; s34) “Diagnosis can help to access treatment.” (+6; s50) “Parents are key to our development in all ways.” |
| 2 | (-6; s22) “This has been shown to be beneficial not negative within the research and clinical experience.” (+6; s48) “Good value for money, more children and parents seen at one time.” |
| 2 | (-6; s16) “Too child specific, idiosyncratic, and may lead to assumption that all children will be treated with medication.” (+6; s6) “Many other problems and co-morbidities stem from poorly managed anxiety. By focussing on child's anxieties parents will help their own anxieties.” |
| 2 | (-6; s22) “Research would indicate the opposite - e.g. behavioural techniques can improve behaviours, thus decreasing stress in the family and improving relationships.” (+6; s13) “This feels like it would give good face validity to the intervention for parents and give a good foundation to the overall parenting intervention. E.g. increasing a parent's understanding of the condition will hopefully lead to greater acceptance and understanding of behaviours and enable them to better access the behavioural techniques.” |
| 2 | (-6; s26) “Biopsychosocial model - tics might be influenced by psychosocial factors and so parenting techniques addressing these issues would be useful.” (+6; s3) “This is true - children pick a lot on their parent’s perceptions and this will influence their self confidence and perception of themselves. Children rely on their parents and attachment with their parents for their own self worth and belief system.” |

226
<table>
<thead>
<tr>
<th></th>
<th>(-6; s31) “Parenting interventions are likely to be effective because parents spend far more time with children than a professional ever will. I think it is reasonable to ask parents to implement an intervention that will benefit their child. Parents are also likely to have need for support and information, which parenting interventions also address to some extent.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>(+6; s50) “The parent-child relationship is one of the most important influences on children's wellbeing - it is a key source of support, way in which children learn and develop, source of self esteem etc. Role of attachment.”</td>
</tr>
<tr>
<td></td>
<td>(-6; s31) “Parents spend the most time with the child so it is crucial that they are on board with any intervention and makes sense that they deliver it”</td>
</tr>
<tr>
<td>2</td>
<td>(+6; s8) “Because this is the basis of positive parenting which will help children to feel secure.”</td>
</tr>
<tr>
<td></td>
<td>(-6; s26) “I believe they are anxiety related more than biological.”</td>
</tr>
<tr>
<td>2</td>
<td>(+6; s50) “This is true for all children and we know this and it’s very fundamental.”</td>
</tr>
<tr>
<td></td>
<td>(-6; s31) “I don't agree with this as I think it can be very helpful. However it is research that will show whether an intervention via parents is effective or not. Is it unreasonable? I am not sure I understand the use of the word unreasonable? Unfair on the parents? I don't think so.”</td>
</tr>
<tr>
<td>3</td>
<td>(+6; s68) “I think this is one of the most important messages for parents to take away. If they feel more positive this should in turn have a positive effect on their child and family.”</td>
</tr>
<tr>
<td></td>
<td>(-6; s26) “Parenting interventions are often effective at empowering the parents, and psychoeducation around tics and reducing stress in the home through better parenting can lead to reduction in tics as stress is a well known driver of TSCs.”</td>
</tr>
<tr>
<td>3</td>
<td>(+6; s50) “It is crucial for the child to feel loved and have that positive bedrock - that way when they need disciplining/enforcing, the child knows that the parent cares for them but their behaviour itself is unacceptable. Also important if the child has tics to have someone they are close to seek support and advice from, and if they receive it to involve in therapy.”</td>
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<tr>
<td></td>
<td>(-6; s26) “Parenting interventions have been shown to be effective in a number of domains, cultures, difficulties etc. It would seem naively reductionist to simply consider it ineffective due to a 'biological' origin, as this neglects the holistic context for example the impact of tics; distress, anxiety, social stigma and others perceptions/reactions which may lead to avoidance and low mood or further exacerbated anxiety or an increase in tics potentially. The psychosocial functioning must be considered, perhaps with a 'biopsychosocial' approach.”</td>
</tr>
<tr>
<td>3</td>
<td>(+6; s71) “Parenting interventions could provide an extremely valuable contributions the YP and family's well being and functioning - it is not necessarily defined by a change in tic frequency or severity etc..”</td>
</tr>
<tr>
<td></td>
<td>(-6; s31) “Parents are often key in helping children with difficulties such as tsc.”</td>
</tr>
</tbody>
</table>
Parenting interventions are an essential part of therapy in tic disorders in children. This is a well established research finding in many childhood conditions. It is fundamental.

Note. The table contains ranking comments provided by the professionals that were included in the analysis. Two professionals did not provide ranking comments. Comments from the two professionals that did not load significantly onto a factor are not presented.