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The Quality of Life of Children with a Diagnosis of Attention Deficit/Hyperactivity Disorder: A Comparison of Parent and Child Perspectives

THE UNIVERSITY *of* EDINBURGH

Helen Catriona Galloway

Doctorate in Clinical Psychology

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Abstract for the Research Portfolio

Objectives: Available studies largely and consistently indicate that children with Attention Deficit Hyperactivity Disorder (ADHD) experience significantly impaired quality of life (QoL). More research is required to enable an enhanced understanding of factors which contribute to the QoL of children with this diagnosis. In relation to children with ADHD, this thesis had two main aims: to review the extent to which children and their parents agree in their assessments of the child's QoL; and to examine the impact of parent stress on the child's QoL from both parent and child perspectives.

Method: A systematic review of studies reporting matched parent-proxy reported and child self-reported quantitative QoL measures is described in journal article 1. Journal article 2 presents the findings from a cross-sectional, quantitative study involving a matched sample of 45 children with a diagnosis of ADHD, and their parents. Correlation and multiple regression analyses examine the relationship between parent stress and each of the informants' ratings of the child's QoL.

Results: The findings of the systematic review indicated that in a clear majority of studies, children rated their QoL more highly than their parents. However, cautious interpretation is required as some of the studies were of poor methodological quality. In the empirical study, parent stress emerged as a significant predictor of parent proxy-ratings of child QoL, but not of self-rated QoL. Parents who rated their child's QoL lower that their children had higher perceived stress than parents who rated their child's QoL higher than their children. There were no significant differences in self-rated or parent-rated QoL between children with ADHD and children with a learning disability or with an Autism Spectrum Disorder. In line with some previous research, agreement was poorer on psychosocial domains than physical domains. However, due to the relatively small sample size, the empirical study requires replication.

Conclusions: The results of the systematic review suggest that parent and child ratings of the child's QoL are not interchangeable in the context of ADHD. Possible explanations for this trend are discussed. The empirical study suggests that parent stress negatively impacts on children with ADHD, and that it is likely that children's self-reports are affected by their impaired reflective capacity. Clinical implications and recommendations for future research are discussed in relation to both articles.

D. Clin. Psychol. Declaration of own work

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Thank you first and foremost to the children, young people and their parents and carers, who allowed me an invaluable insight into their experiences of living with ADHD. I am also highly appreciative of the individual clinical, admin and R&D staff who made it possible for me to contact them. In particular, Raymond Hamill, and to the admin team at the Child & Family Clinic at Quarry Street for receiving and protecting my precious questionnaires! I am immensely grateful to my two clinical supervisors, initially Nicola Miller, and later Clare Yuill, for their encouragement, insight, and reassurance throughout the ups and downs of the project. Thank you also to my academic supervisor, Emily Newman for patient guidance, and constructive feedback.

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My daughter Freya, now three, was born six months into my training. For the last two and a half years I have commuted 80 miles away to work, regularly having to spend nights away from home. Being separated from her has been the hardest part of my journey through clinical psychology training, and at times I have had to find immense emotional strength and courage to continue. This thesis is dedicated to Freya, who I hope, in time, will be both proud of and inspired by my work, safe in the knowledge that she will always be my greatest achievement.

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Research Portfolio Aims

This thesis is presented in portfolio format and is comprised of two journal articles which have the following aims in relation to children/young people with a diagnosis of Attention Deficit/Hyperactivity Disorder:

(1) To systematically review the relevant evidence base and compare the level of agreement between parents' assessments of their children's quality of life, and children's own assessments of their quality of life.

(2) To investigate the impact of parent stress on the child's quality of life, according to both child self-reported and parent proxy-reported quality of life measures.

Words: 24,853

Journal Article 1: Systematic Review

Is there a difference between child self-ratings and parent proxy-ratings of the quality of life of children with a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD)? A systematic review of the literature.

Helen Galloway

NHS Lanarkshire

Emily Newman

University of Edinburgh

Author's Note

Helen C. Galloway, Child & Adolescent Mental Health Services, NHS Lanarkshire. Dr Emily Newman, Clinical and Health Psychology, School of Health in Social Science, University of Edinburgh. Correspondence regarding this article should be addressed to: Helen Galloway, CAMHS for Accommodated Young People Team (CAYP), Glenshirra Building, Coathill Hospital, Hospital Street, ML5 4DN. Tel: 01236 703010. Contact: Helen.Galloway@nhs.net.
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Abstract

Objectives: There are contemporary indicators that parent-proxy ratings and child self-ratings of a child's quality of life (QoL) are not interchangeable. This review examines dual informant studies to assess parent-child agreement on the QoL of children with Attention Deficit/Hyperactivity Disorder (ADHD).

Method: A systematic search of four major databases (PsycINFO, Medline, EMBASE, and Cochrane databases) was completed, and related peer reviewed journals were hand searched. Studies which reported quantitative QoL ratings for matched parent and child dyads were screened in accordance with relevant inclusion and exclusion criteria.

Results: Key findings were extracted from thirteen relevant studies, which were rated for conformity to the recommendations of an adapted version of the STROBE statement guidelines for observational studies.

Conclusions: In the majority of studies reviewed, children rated their QoL more highly than their parents'. There was some evidence for greater agreement on the physical health domain than psychosocial domains.

Key words: quality of life; ADHD; attention deficit/hyperactivity disorder, parent-child agreement, children

Words: 9,870

Introduction

Quality of Life in Children with ADHD

ADHD has received significant attention in the media. Regular points of debate include it's under or over diagnosis, anxieties about the use of stimulant medication with children, the role of pharmaceutical companies, and whether ADHD is a 'real disorder' or a social construct. ADHD is, currently, the name given to a group of symptoms that broadly encompass inattentive, hyperactive, and impulsive behaviours (with inattentive, hyperactive/impulsive and combined subtypes). However, it remains difficult to gain professional agreement on what ADHD *is*, and how it should be managed.

What exactly causes ADHD remains an unknown. It is categorised as a neuro-developmental disorder in the Diagnostic and Statistical Manual of Mental Disorders: DSM-5™ (5th ed.) (American Psychiatric Association, 2013). MRI and PET scans show that changes in brain structure in the frontal regions are consistently found in children with ADHD (Krain & Castellanos, 2006). However, some argue that it is not possible to assess whether brain differences are caused by (rather than being the cause of) different ways of thinking. Some also argue that stimulant medications, which are undeniably effective in reducing ADHD symptoms, would improve concentration in us all. Others are concerned that we may be unnecessarily medicalizing children, and refer to ADHD as a 'cultural construct', where increasing rates of diagnosis are seen as a result of society's growing intolerance to behaviour that does not conform. For a more in depth analysis of this debate see Tammi & Taylor (2003).

Regardless of the controversies surrounding ADHD, it remains one of the most highly prevalent health diagnoses amongst children and adolescents, affecting an estimated 3% to 7% of school aged children (Daviss, 2008), with prevalence tending to be higher among

males than females (Willcutt, 2012). Symptoms usually continue into adulthood and are associated with impairments in academic, social and emotional functioning (Cantwell 1996). Comorbidity next to ADHD is the norm rather than the exception (Thompson et al., 2004) with oppositional defiant disorder (ODD), conduct disorder (CD), learning disability (LD), anxiety disorders and depression most commonly co-occurring (Biederman, Newcorn, & Sprich, 1991). Children who receive a diagnosis of ADHD tend to have poorer outcomes than control group children. They have an increased risk of low self-esteem, poor academic achievement, family and peer relationships problems, anti-social behaviour, and criminal activity (Biederman et al., 1997; Wilens, Biederman, & Spencer, 2002). Leading neuroscientist, Dr Bruce Perry, described the emotional dysregulation that often occurs between parents and their children when children with ADHD are struggling (Perry, 2014). He highlights the importance of implementing a combination of therapeutic approaches that aim to support parents to regulate themselves, and break the cycle of negative feedback.

Available studies largely and consistently indicate that children with a diagnosis of ADHD experience impaired quality of life (QoL) (Danckaerts et al. 2010). The World Health Organisation (1995, p. 1450) defined QoL as, "The individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns". However, until very recently the majority of studies in this area have reported only parent proxy measures of a child's QoL. Therefore the child's subjective experience of living with ADHD remains relatively undisclosed.

In their major review of paediatric ADHD QoL studies, Danckaerts et al. (2010) reported that of the 36 studies they reviewed, 29 included parent only ratings, three studies used only child rated measures, while only four studies utilised both parent and child ratings. The authors reported that the child self-report data was much less robust in establishing correlations between QoL and ADHD than the parent reported data. In two of the seven

studies which utilized child reported measures, children did not consider their QoL to be more impaired than healthy controls (Klassen, Miller, & Fine, 2006; Landgfuf & Abetz, 1997). Further, some of the data from the four dual informant studies indicated that there may be some discrepancies between parent and child perceptions of the child's QoL. One study found that children rated their QoL more positively than their parents across all domains except physical functioning (Klassen et al. 2006). Another reported discrepancies between child and parent ratings on the domains of physical health and home life (children rated higher), and bodily functions and positive moods (parents rated higher) (Flapper & Schoemaker, 2008).

The review authors suggested that the child reported data could in some way have been affected by the measures used. They highlight that the two studies where children did not rate their QoL differently from controls both used the Child Health Questionnaire (CHQ), while the four others (which used other QoL measures) reported reduced QoL. They also suggest that less robust ratings may be a result of children minimizing their difficulties, or an impulsive response style. Further, the authors proposed that parent ratings may be affected by the encumbrance of caring for a child with ADHD symptoms, i.e. their own QoL is affected. Indeed, some QoL studies for other conditions have reported a link between parental emotional distress and more negative perceptions of their child's QoL (Janicke et al. 2007; Kobayashi & Kamibeppu, 2011).

Measuring Paediatric Quality of Life

In relation to health conditions, the many available definitions of QoL emphasize the desired condition as one of general well-being, in which a person encounters a range of daily experiences, unconstrained by the potentially unpleasant and debilitating effects of a disorder. Studying QoL is particularly important in chronic conditions, where the focus of treatment is

often on the management of symptoms, as opposed to being curative (Ingerski et al. 2010; Varni, Limbers, & Burwinkle, 2007). When measuring the effectiveness of paediatric treatment interventions, there is an evolving realisation that it is not simply a reduction of symptoms that is important, but also children's longitudinal capacity to enjoy and participate in the multi-dimensional aspects of their daily lives. Consideration must be given to whether any illness intervention can be said to be effective if it does not improve the child's lived experience.

Generic QoL instruments are fundamentally multi-dimensional, and usually contain, as a minimum, the core domains of physical, psychological, social and cognitive functioning (Eiser & Varni, 2013). However, although the core domains are usually present, they are often defined differently, and instruments commonly break them down further into different sub-domains (Danckaerts et al. 2010). As a consequence, it is reasonable to assume that different QoL instruments may not always measure the same things, or indeed cover the necessary ground to ascertain a full understanding of QoL. In this sense, it can be challenging to compare studies which have employed differing QoL outcome measures. Some condition specific measures have been developed, such as the Pediatric Quality of Life Inventory (Peds-QL) Cancer Module (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). While these will no doubt provide detailed insight and sensitivity to the impact of a specific set of symptoms, they do not allow for comparisons with other health conditions or with normative samples.

Parent-Proxy Report in Paediatric QoL Research

The very nature of the concept of QoL as a 'lived experience' should predict that the key informant would be the individual whose QoL is in question. However, studies investigating paediatric QoL have generally utilized only parent proxy reports to provide a measure of a child's QoL. This may be problematic, as some research has shown that parent

and child reports on this concept are not interchangeable (Eiser & Morse, 2001; Klassen et al., 2006). Parent proxy measures provide, at best, an informed estimate of how a parent expects that their child to feel in many (often unobserved) contexts and, at worst, a poor and misleading judgement of the internal world of a child into whom they have little, or misconstrued, insight. This pattern has in the past been justified by the belief that children had not yet achieved a sufficient level of cognitive and linguistic development to enable self-completion of QoL measures (Upton, Lawford, & Eiser, 2008). However, several instruments designed to measure self-rated QoL in children as young as five have been developed in recent years (e.g. Paediatric Quality of Life Inventory (PedsQL), (Varni, Seid, & Rode, 1999); The Child Health Questionnaire (CHQ) (Landgraf, Abetz, & Ware, 1996); KIDSCREEN (Ravens-Sieberer et al., 2007), and research has demonstrated that children are able to reliably assess their own QoL (Cremeens, Eiser, & Blades, 2006; Varni et al., 2007).

The use of child rated measures does not render parent perceptions redundant, however. When a child is too impaired to express her views, or is unwilling, parent ratings may be the only available option. Additionally, parent accessing of healthcare and support services for their child is, in the main, predicted by their perceptions of their child's QoL (Varni, Seid, & Kurtin, 2001). Further, the level of concordance between parents and their children in assessing the child's QoL could potentially have significant clinical relevance for chronic conditions. A comparison of both perspectives could offer clinicians valuable insight into how features of the condition might affect the child's internal perceptions relative to others' external perceptions. Simply put, there may be no 'true representation' of the child's QoL, rather that both perspectives are likely to relay important information regarding the nature and impact of the condition. Assessing both perspectives may also provide insight into the nature of the relationship between parent and child and the expectations they individually possess regarding the condition and available treatments. Investigating the sources of any

discrepancies which arise between them may in turn influence clinical decision-making regarding key areas for intervention.

Parent-Child Concordance on QoL Measures

Previous reviews have investigated parent-child agreement on quality of life measures, featuring study samples of children with a range of chronic health diagnoses and healthy control groups (Eiser & Morse, 2001; Eiser & Varni, 2013; Upton et al. 2008). These reviews report consistent discrepancies between parent-proxy reports and child self-reports. It is possible that these discrepancies reflect a wider perceptual issue between self and proxy raters in general. However, studies have suggested that parents of healthy children generally rate them as having better QoL than the children rate themselves (Jozefiak, Larsson, Wichstrøm, Mattejat, & Ravens-Sieberer, 2008), while this trend is reversed in children with health conditions (Eiser & Morse, 2001; Upton et al., 2008). This would suggest there is a relationship between the child's health status and how children and their parents perceive the child's experiences.

Inter-rater agreement is often highest for objective, externalising domains like walking, running, aggression, school refusal and hyperactive behaviour, while there is generally less concordance for internalising, emotion based domains such as fatigue, pain, sadness and worry (Eiser & Morse, 2001). This suggests that parents are better at interpreting their child's observable behaviour than their internal state of mind. However, this trend can be found to be reversed in the literature both within and between different health conditions (eg. van Gent et al. 2007; Czyzewski et al. 1994).

The findings described offer valuable insights into patterns of concordance between child and parent reports across a quality of life studies for children with a range of health conditions. However, comparing samples across conditions can be problematic given that

definitions of a diagnosis can be broad (e.g. cancer) and that each condition will have its own symptoms, treatments and prognosis. Thus the individual domains of QoL measures may be affected, to a greater or lesser degree, by each condition. Potentially, this will lead to differing levels and patterns of concordance between children and their parents on QoL measures. This issue highlights a need for condition specific research which utilizes parent and child ratings of the child's QoL, so that the unique contributing factors of the associated symptomatology can be explored.

Due to the small number of studies incorporating children's views, any existing inconsistencies between parent and child perceptions of child QoL are not well studied in the context of ADHD. A focused review of further studies is necessary to explore the patterns of concordance between child and parent perceptions in detail, and to deduce what factors might underlie any discrepancies. Since Danckaerts et al.'s (2010) review, a number of additional studies have been published which have reported both child and parent rated measures of child QoL. A systematic review of this material is now warranted.

Aim of the Review

The aim of this review was to systematically examine the existing empirical data regarding the level of agreement between parent-proxy and child self-report ratings of the quality of life of children with a diagnosis of ADHD, as measured by quantitative quality of life instruments.

Method

Inclusion and Exclusion Criteria

Population.

Studies were included where the target population was children with a diagnosis of ADHD aged 0-18 years. Samples were included regardless of whether co-morbidities were present or had been purposely excluded.

Study design.

In light of the nature of the research question, it was anticipated that observational studies would be most prevalent, of cross-sectional, case control and cohort study design. However, Randomised Controlled Trials (RCTs) were not excluded from the review. Studies were included if they used a quantitative design and either compared or reported data (sample size, means and standard deviations) from quality of life measures for matched parent and child dyads. Where treatment outcome studies were included, baseline QoL measures were used. Studies which provided only child self-reports or parent/carer proxy-reports were excluded. Studies where someone other than the parent/carer was the proxy-rater (e.g. teachers or clinicians) were excluded. Studies which utilised control groups or a single group sample were included. Due to issues of generalizability and increased bias, single case studies were excluded.

Outcome measures.

Studies were included if they aimed to measure the quality of life of children with a diagnosis of ADHD, using a standardised quality of life instrument with established psychometric properties. To enable a meaningful inter-rater comparison of quality of life data, only studies which featured instruments that measured the same content and constructs for self and proxy reports, using parallel questions and rating scales were included. Quality of life measures which utilised a single item measure were not included.

Language.

Studies that were not published in the English language were excluded from the review due to a lack of translation resources available to the reviewer.

Literature Search Strategy and Study Selection

Study selection was achieved by completing literature searches of electronic databases and hand searching of specific relevant electronic journals. Reference lists from studies selected for inclusion were also reviewed (see Figure 1).

Electronic database searches.

The databases searched were PsycINFO, (1806-January 2015), EMBASE, (1974-January 2015), Medline (1946-January 2015), and Cochrane Library database (1999-January 2015). The databases were searched by entering the terms *(ADHD* OR *Attention Deficit/Hyperactivity Disorder)* AND *(Quality of Life)* within the domains of title, abstract and keyword/subject heading. A total of 153 items were returned using this search strategy after duplicates were removed.

Hand searching of selected journals.

Three journals were hand searched based on their relevance to the research area or their frequency as publishers of the studies that met the inclusion criteria from the database searches. These were: ADHD: Attention Deficit and Hyperactivity Disorders; European Journal of Child & Adolescent Psychiatry, and Journal of Attention Disorders. These journals were searched from the year 2004-2015 (January). This search returned 2 potentially relevant studies for further screening.

Reference list searches.

One further study was obtained using the snowball technique (i.e. reviewing the reference lists of studies which met the inclusion criteria) (Schei, Jozefiak, Novik, Lydersen, & Indredavik, 2013).

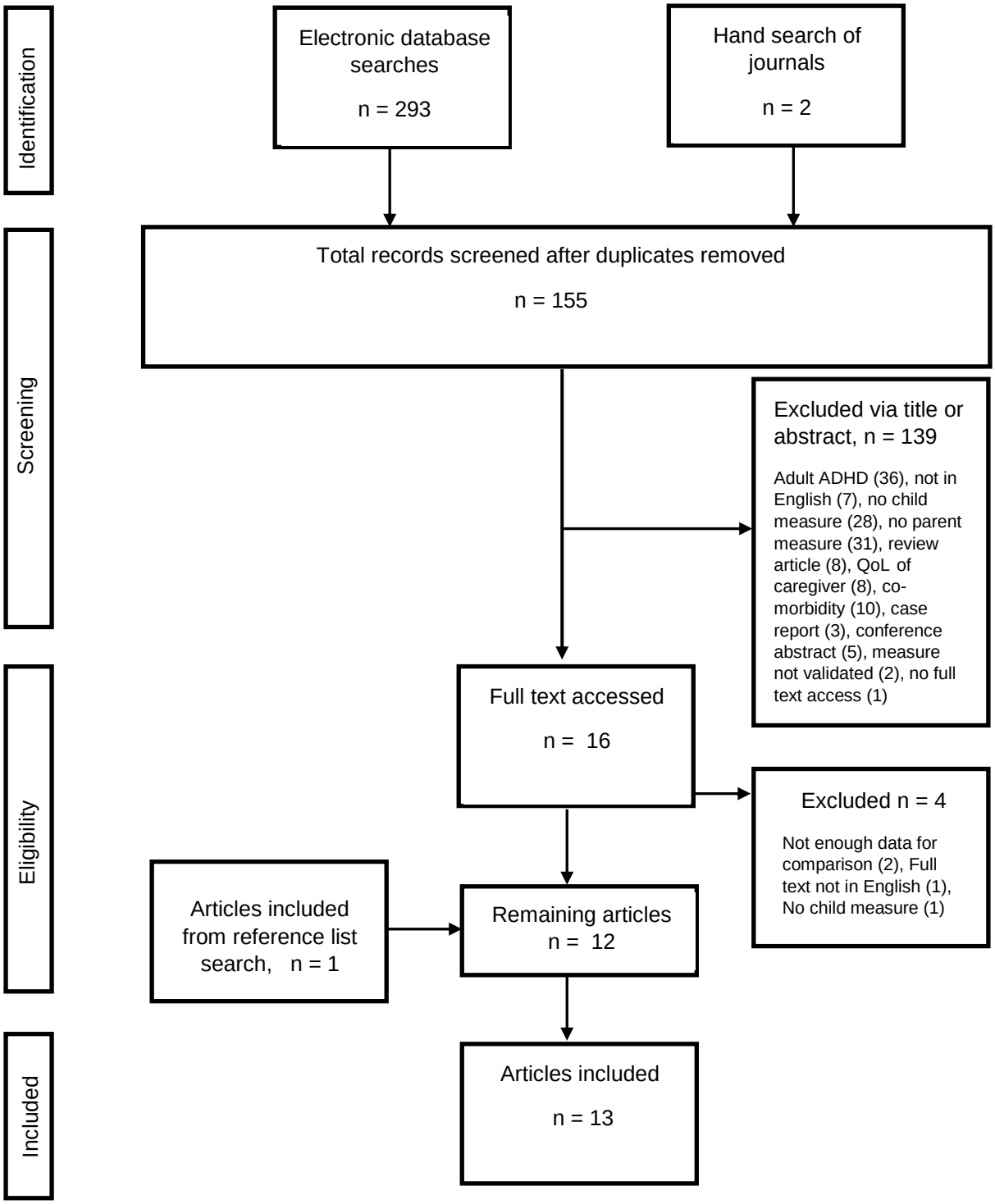

Figure 1. Flowchart detailing the study selection and exclusion process.

Study Appraisal Process

Assessing the quality of research studies and their partiality is paramount when conducting systematic reviews and meta-analyses and interpreting results. Formal quality assessment tools are increasingly well developed in the context of clinical trials and randomised controlled trials (Deeks et al., 2003). However, less consideration has been given to the use of similar instruments for appraising observational studies. Recent reviews have concluded that there is no one distinct tool advocated for this task (Jarde, Losilla, & Vives, 2012; Sanderson, Tatt, & Higgins, 2007). For the current review, the STROBE (von Elm et al., 2007) statement guidelines for observational studies have been utilized to evaluate the quality of the included studies. Although the intended purpose of STROBE was to act as a reporting guide to authors of observational studies, it has been endorsed by researchers as a starting point for the methodological appraisal of non-experimental studies (Sanderson et al., 2007). Its popularity may be attributed to the comprehensive method of its development and the presence of criteria that appear to be linked with a propensity for bias (Sanderson et al., 2007).

The quality review does not provide a comparative measure across included studies, given that each of the recommendations are not equally weighted. It does, however, provide an indication as to whether the recommended methodological and reporting aspects of the research process were present for each study. Issues relating to research methodology allow readers to assess how well a study has been designed and conducted and therefore consider how valid and generalizable the results can be assumed to be. Issues relating to reporting of research allow readers to consider how well authors have detailed, explained and/or interpreted their methods and findings. For the purpose of this review, methodological conformity to the recommendations took precedence over reporting conformity, given that it

is the results of each study, rather than their interpretation by the authors, which are most relevant to the research question.

Some adaptations were made to the criteria in order to increase their relevance to the research question. The main adaptations reduced the number of unnecessary criteria, or reworded given criteria to reflect methodological quality rather than reporting quality. The adaptations are presented in Table 1. Conformity to the items of the adapted STROBE statement guidelines was rated for each of the included studies using a binary judgement (Yes/No). A further rating of N/A (not applicable) was applied where appropriate. The recommendations comprise of six main areas (Title/Abstract, Introduction, Methods, Results, Discussion and Other Information), some of which incorporate sub-items (for the full guidelines see Appendix B). A comprehensive definition of each recommendation is detailed in (Vandenbroucke, 2007). All thirteen papers were independently coded by the first author, and a randomly generated sample of 6 papers (46.2%) were cross rated by the second author. The inter-rater reliability was found to be 0.79 ($p<.001$), indicating 'substantial' reliability (Landis & Koch, 1977).

Table 1. Adaptations to the STROBE checklist criteria

Criterion 1:	Title/Abstract - reduced to one criterion
Criterion 4:	Setting – broken down to further criteria of *(a) 'location'* and *(b) 'relevant dates'*
Criterion 8:	Measurement - Altered to indicate use of valid/reliable outcome measures appropriate to the population and for use with parent/child dyads
Criterion 9:	Bias - Altered to indicate active control for bias rather than the authors' description
Criterion 12:	Statistical Methods: parts (b), (d) and (e) removed
Criterion 13:	Participants - part (c) '*consider use of a flow diagram'* removed
Criterion 16:	Main Results – reduced to one criterion
Criterion 19:	Limitations – broken down to further criteria of *(a) 'sources of potential bias or imprecision'* and *(b) 'direction and magnitude of potential bias'*

Results

Thirteen studies that met the inclusion criteria were identified (Table 2). The studies were published across nine different countries: USA (3); The Netherlands (2); Norway (2); Iran (1); Thailand (1); Canada (1); Australia (1); Brazil (1); Turkey (1).

Characteristics of Included Studies

Table 2 lists the included studies and provides an overview of the main findings of each study as relevant to the research question. Seven were cross-sectional in design, four were case control studies, one was an open label trial, and one was a double blind, placebo controlled clinical trial.

Sample Characteristics

In total, 13 studies included 967 matched parent-child dyads, where the child had a diagnosis of ADHD. The number of dyads in each study ranged from 17 to 194. Children ranged in age from 5 to 18 years. In general, boys represented a higher proportion of the samples, ranging from 55.2% to 95.7%.

Four of the studies in the review excluded participants with conditions co-occurring with ADHD (Bastiaansen, Koot, Ferdinand, & Verhulst, 2004; Flapper & Schoemaker, 2008; Schei et al., 2013; Varni & Burwinkle, 2006) six did not exclude participants with co-morbidities at all (Klassen et al. 2006; Thaulow & Jozefiak 2012; Sciberras et al. 2011; Limbers et al. 2011a; Limbers 2011b; Gürkan et al. 2010) one study limited co-morbidities to Oppositional Defiant Disorder (ODD) (Marques et al., 2013) and two studies did not provide information about whether or not co-morbidities were excluded (Jafari, Ghanizadeh, Akhondzadeh, & Mohammadi, 2011; Pongwilairat, Louthrenoo, Charnsil, & Witoonchart, 2005).

Table 2. Characteristics of included studies.

Author (year) Country	QoL Measure	Sample characteristics (all ADHD samples include matched QoL dyads)	Design	Main findings relevant to current review (*p*-values shown where reported)	Database	Co-morbidities	Domains reported
Thaulow & Jozefiak (2012), Norway	ILC	Age range: 8-15.5 62 ADHD group, 23 girls (37.1%), 39 boys (62.9%) 49 anxiety/depression group, 20 girls (40.8%), 29 boys (59.2%) 65 healthy control group, 25 girls (38.5%), 40 boys (61.5%)	Case-control *(comparison of QoL in children with ADHD and children with anxiety/depression)*	In the ADHD group, children's self-reported QoL was significantly higher than the parent-reported QoL, (*p*<.01). The same analysis did not find a significant difference for the anxiety/depression group. Children in ADHD group rated QoL as being higher than anxiety/depression group (*p*<.05), lower than healthy controls (*p*<.05).	N/A	Not excluded	No only totals for QoL measure.
Sciberras et al (2011), Australia	Peds-QL	Age range: 8-18 47 ADHD children 45 boys, 2 girls Aged 8-12: (36) Aged 13 or over: (11)	Cross-sectional *(children's experiences of ADHD)*	Children rated their QoL higher than their parents rated them for total QoL scores and on all domains except physical functioning. Total: mean diff=-11.6, 95%CI's -18.64 to -4.70, *p*<.001. Psychosocial: mean diff=-14.64, 95%CI's-22.04 to -7.24, *p*<.01. Emotional: mean diff-14.15, 95%CI's -23.56 to -4.74, *p*<.001. Largest mean differences were in Social: mean diff: -16.49, 95%CI's -26.41 to -6.57, *p*<.001; and School: mean diff -15.11, 95%CI's -23.01 to -7.21, *p*<.001 domains.	PsycINFO	Not excluded	Yes
Marques et al (2013), Brasil	Peds-QL	Age range 8-12 45 ADHD 43 control (age & gender not specified)	Cross-sectional (with comparison group) *(parent child comparison of QoL)*	Both children and parents rated QoL as lower in ADHD group than control group on all domains. Good concordance between parents and children on all domains except school functioning, which children self-reported higher than parents (mean difference: 14.55, CI 95%: 7.77, 21.33, SD: 3.36).	Medline	Specified no co-morbidities in ADHD group except ODD	Yes
Limbers et al (2011a) USA	Peds-QL	Age range 5-18 179 children, (57 girls, 124 boys) 181 parents (177 matched dyads)	Cross-sectional *(paediatric clinic vs mental health clinic)*	Children rated QoL higher than parents for total QoL score (mean diff=8.57, *p*<.001, *d*=0.5). Children rated QoL higher across all domains except physical health. Greatest discrepancies were on school functioning (mean diff=12.06, *p*<.001, *d*=0.61), and psychosocial health (mean diff=10.18, *p*<.001, *d*=0.57).	Embase	Not excluded	Yes

Author (year) Country	**QoL Measure**	**Sample characteristics (all ADHD samples include matched QoL dyads)**	**Design**	**Main findings relevant to current review (p-values shown where reported)**	**Database**	**Co-morbidities**	**Domains reported**
Limbers et al (2011b), USA	Peds-QL	Age range 5-18 ADHD group 1: 17 general paediatric clinic (10 boys, 7 girl) and parents. ADHD group 2: (see Limbers 2011a). Healthy controls from previous sample (957 boys, 496 girls)	Case-control *(validation of Peds-QL in a sample of children with ADHD and co-morbid psychiatric disorders)*	Group 1: No statistically significant differences between parent and child rated mean QoL scores*, but sample size was small (N=17). Group 2: (see Limbers, 2011a)	PsycINFO	Not excluded	Yes
Flapper et al (2008), The Netherlands	DUX-25 and TACQOL	Age range 7-10 years 8 months ADHD + DCD (Developmental Co-ordination Disorder) 23, Control 23	Double blind placebo controlled clinical trial *(effects of methylphenidate on QoL)*	DUX-25: No sig diffs between parent and child reports for total scores but over some domains (physical $p<.001$, home $p<.004$) (children self-rated higher) TACQOL: bodily functioning ($p<.02$) and positive moods ($p<.02$) (parents rated higher) (baseline scores analysed)	PsycINFO	Excluded except for Developmental Co-ordination Disorder (DCD).	Yes
Varni & Burwinkle (2006), USA	Peds-QL	Age range 5-16 72 ADHD dyads 60 boys (83.3%), 12 girls (16.7%) 66 cancer, 57 cerebral palsy, 3,256 healthy controls	Case-control *(population based Peds-QL validation study)*	Good reliability for total scale score (Chronbach's alpha .92 child self-report, .92 parent proxy-report) and across domains. Effect sizes (parent, child): Total, .71, .70, Physical .67, .67, Psychosocial, .69, .69, Emotional .67, .66, Social .75, .75, School, .59, .59	Medline	Excluded	Yes
Klassen et al (2006), Canada	CHQ	Age range 10-17 58 dyads Male 48 (82.8%), female 10 (17.2%)	Cross-sectional *(Parent and child comparison on QoL)*	Children self-reported significantly higher QoL than parents on 4 domains: behaviour (Mean diff=22.9, 95%CI's 17.6 to 28.3, SD 19.8, $p<.001$), self-esteem (Mean diff=14.7, 95%CI's 8.2 to 21.1, SD 23.7, $p<.001$), mental health (Mean diff=6.8, 95% CI's 1.6 to 12.0, SD 19.2, $p<.01$), family cohesion (Mean diff=10.6, 95%CI's 3.7 to 17.5, SD 25.7, $p<0.01$), and worse on one: physical function (Mean diff=-4.3, 95%CI's -7.8 to -0.8, SD 13.2, $p<.01$) Discrepancies were related to co-morbid ODD, worse ADHD symptoms and psychosocial stressors.	PsycINFO	Excluded	Yes

Author (year) Country	QoL Measure	Sample characteristics (all ADHD samples include matched QoL dyads)	Design	Main findings relevant to current review (p-values shown where reported)	Database	Co-morbidities	Domains reported
Schei et al (2013), Norway	ILC	Age range 13-18 194 dyads Male 55.2%	Case-control *(impact of emotional and conduct problems on QoL in ADHD)*	For the ADHD only group adolescents reported higher total QoL scores than parents (*p*<.01). There were no significant differences between total QoL scores for parents and adolescents for the ADHD with additional emotional problems group, or the ADHD with additional conduct problems group. No subdomain scores were reported, only totals.	N/A	Excluded for direct comparison with ADHD + co-morbid conditions	No only totals
Jafari et al (2011), Iran	Peds-QL	Age range 8-17 72 dyads, 140 controls 8-12 year (75%), 13-18 years (25%)	Cross-sectional *(Parent and child comparison on QoL)*	Children rated their total QoL as higher than parents (mean diff=5.33, 95%CI's -10.6 to -0.06, *p*<.05)*. They also rated higher mean QoL scores for the school domain (mean diff=8.9, 95%CI's -16.62 to -1.2, *p*<.05)*. Parents and children in ADHD group rated QoL significantly poorer than control group across all domains.	PsycINFO	Information not provided	Yes
Pongwilairat et al (2005), Thailand	Peds-QL	46 ADHD 94 healthy control children (information not provided)	Cross sectional *(QoL of children with ADHD)*	Means show children rate their total QoL higher than parents (mean diff=146, 95% CI's 20.1 – 272.2, *p*<.05)*. Children also rated QoL higher on physical domain (mean diff=84.24, CI's 22.2 to 146.3, *p*<.01)*, however differences on other subdomains were not significant. Children and parents rated QoL poorer than healthy controls, except children self-report no significant difference in physical health domain, while parents do.	Embase	Information not provided	Yes
Bastiaansen et al, (2004), The Netherlands	Peds-QL	Age range 6-18 310 dyads 107 ADHD 57 Anxiety 28 Developmental disorders 29 mood disorders 22 other disorders 67 no diagnosis	Cross-sectional *(QoL in children with psychiatric disorders)*	For ADHD group, children self-reported higher mean QoL scores than parents across all domains. Total: Mean diff=6.6, 95%CI's 3.1 to 10.1, *p*<.001* Psychosocial: Mean diff=8, 95%CI's 3.9 to 12.1, *p*<.001* Physical: Mean diff=4, 95%CI's 0.02 to 8.0, *p*<.05* Emotional: Mean diff=6.4, 95%CI's 1.25 to 11.5, *p*<.05* Social: Mean diff=11.2, 95%CI's 7.1 to 15.3, *p*<.001* School: Mean diff=6.6, 95%CI's 2.01 to 11.9, *p*<.05*	PsycINFO	Excluded for direct comparisons with other conditions	Yes
Gurkan et al (2010)	Peds-QL	Age range 8-14 45 dyads (75.6%) 34 boys (24.4%) 11 girls	Open label trial *(psychiatric symptoms & methylphenidate)*	Children rated their QoL better than their parents for total QoL score at baseline (mean difference=5.4, 95%CI's 0.2 to 10.6, *p*<.05)*. No significant differences observed for psychosocial or physical domains.	Embase	Excluded	Yes

QoL=Quality of Life, Peds-QL=Pediatric Quality of Life Inventory 4.0 Generic Core Scales (Varni, Seid, & Rode, 1999); ILC=Inventory of Life Quality in Children & Adolescents (Mattejat et al, 2006), CHQ=Child Health Questionnaire (Landgraf, Abetz & Ware, 1996); DUX-25=Dutch-Child-AZL-TNO-Quality-of-Life (Kolsteren, Koopman & Schalekamp, 2001)' TACQOL=TNO-AZL-Child-Quality-of-Life (Vogels et al, 1998). *=denotes that statistical analysis of mean differences between groups was carried out by the author of the review based on data reported in the article.

Quality of Life Measures

Five unique QoL measures were utilized by the studies included in the review: the Paediatric Quality of Life Inventory (PedsQL) (Varni et al., 1999); the Inventory of Life Quality in Children & Adolescents (ILC) (Mattejat & Remschmidt, 2006), the Child Health Questionnaire (CHQ) (Landgraf et al., 1996); the Dutch-Child-AZL-TNO-Quality-of-Life (DUX-25) (Kolsteren, Koopman, Schalekamp, & Mearin, 2001), and the TNO-AZL-Child-Quality-of-Life (TACQOL) (Vogels et al., 1998). All of these instruments have been demonstrated to have acceptable psychometric properties. Nine (69.2%) of the studies used the Peds-QL (Bastiaansen et al., 2004; Gürkan et al., 2010; Jafari et al., 2011; Limbers et al. 2011a; Limbers et al., 2011b; Marques et al., 2013; Pongwilairat et al., 2005; Sciberras et al., 2011; James W Varni & Burwinkle, 2006), two (15.4%) used the ILC (Schei et al., 2013; Thaulow & Jozefiak, 2012), one (7.7%) used the CHQ (a F. Klassen et al., 2006), and one (7.7%) used both the DUX-25 and the TACQOL (Flapper & Schoemaker, 2008).

Statistical Analyses

A range of different statistical analyses were utilized among the included studies in order to compare parent and child ratings. Six studies used t-tests (Thaulow & Jozefiak 2012; Sciberras et al. 2011; Limbers et al. 2011a; Flapper & Schoemaker 2008; Klassen et al. 2006; Schei et al. 2013) and one study used the Bland-Altman method (Marques et al., 2013). Three studies utilized Cronbach's alpha coefficients and Pearson intra-class correlations to compare levels of concordance between parent and child rated measures (Bastiaansen et al., 2004; a F. Klassen et al., 2006; Varni & Burwinkle, 2006).

For five studies it was necessary for the author to carry out additional statistical analysis to directly compare the QoL data reported for the purpose of the review (Jafari et al. 2011; Pongwilairat et al. 2005; Limbers 2011b; Gürkan et al. 2010; Bastiaansen et al. 2004).

These studies all reported the number of participants in each comparison group, means for the total and domain QoL scores for parents and children, as well as the relevant standard deviations. With this information, the author was able to estimate whether there were statistically significant differences between the two groups of data using an online t-test calculator, Graphpad data analysis software, (http://www.graphpad.com/quickcalcs/ttest1/?Format=SD).

Quality Ratings of Included Studies

Table 3 presents an overview of how closely the thirteen reviewed studies' conformed to the recommendations from the adapted STROBE guidance statement.

The included studies varied significantly in terms of their conformity to the applied quality criteria. Two of the papers in particular did not meet a large number of the criteria (Jafari et al., 2011; Pongwilairat et al., 2005). There is some doubt therefore, as to whether these studies in particular applied the necessary methodological rigour to achieve a valid or representative result. In addition, across the range of studies, there were a number of criteria which authors commonly failed to report or address, as exemplified in the STROBE elaboration paper (Vandenbroucke, 2007). The most commonly unreported methodological issues were not providing a rationale for how study size was calculated (item 10; 12 studies did not address), not addressing how missing data were handled in the statistical analysis of results (item 12c; 9 studies did not address), not giving reasons for non-participation (item 13b; 8 studies did not address), and not providing the number of participants with missing data at each stage of the study (item 14b; 8 studies did not report). The most commonly unaddressed reporting issues were: not reporting the relevant dates/time period within which data were collected (item 5b; 6 studies did not report) and failing to discuss the direction and magnitude of the limitations reported (item 19b; 11 studies did not report). These issues,

although important, are less likely to directly impact results. Given these issues, the findings presented in this review should therefore be interpreted cautiously.

Items (Y/N)	Thaulow & Jozefiak (2012)	Sciberras et al (2011)	Marques et al (2013)	Limbers et al (2011a)	Limbers et al (2011b)	Flapper et al (2008)	Varni & Burwinkle (2006)	Klassen et al (2005)	Schei et al (2013)	Jafari et al (2011)	Pongwilairat et al (2005)	Bastiaansen et al (2004)	Gurkan et al (2010)
1.Title & Abstract	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2.Rationale	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
3.Objectives	N	Y	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
4.Study design	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y
3 (a) Location	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
(b) Relevant dates	Y	Y	N	Y	N	N	Y	Y	Y	N	N	Y	N
6. (a) Participants	N	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y
(b) Control group	Y	N/A	N	Y	N	N	Y	N/A	Y	Y	N	N/A	N/A
7.Variables	Y	N	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
8.Measurement	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
9.Bias	Y	Y	N	Y	Y	Y	Y	N	Y	N	N	N	Y
10.Study size (rationale)	N	N	N	N	N	Y	N	N	N	N	N	N	N
11.Quantitative variables	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
12. (a) Statistical methods	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
(c) Missing data	Y	N	N	N	N	N	Y	N	Y	N	Y	N	N
13. (a) Participants	Y	Y	Y	N	Y	Y	Y	Y	Y	N	Y	Y	Y
(b) Non-participation	Y	N	N	N	N	Y	N	Y	Y	N	N	N	Y
14. (a) Sample characteristics	Y	Y	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
(b) Missing data	N	N	N	Y	N	N	Y	N	Y	N	Y	Y	N
15.Outcome data	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
16.Main results	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
17.Other analyses	Y	Y	Y	Y	N/A	Y	Y	Y	N/A	N/A	N/A	Y	Y
18.Key results	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Table 3. Quality ratings of included studies.

Items (Y/N)	Thaulow & Jozefiak (2012)	Sciberras et al (2011)	Marques et al (2013)	Limbers et al (2011a)	Limbers et al (2011b)	Flapper et al (2008)	Varni & Burwinkle (2006)	Klassen et al (2005)	Schei et al (2013)	Jafari et al (2011)	Pongwilairat et al (2005)	Bastiaansen et al (2004)	Gurkan et al (2010)
19. Limitations													
(a) Sources	N	Y	Y	Y	Y	N	Y	Y	Y	N	Y	Y	N
(b) Magnitude	N	N	N	N	N	N	Y	Y	N	N	N	N	N
20.Interpretation	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
21.Generalizability	Y	Y	N	Y	Y	N	Y	Y	Y	Y	N	Y	N
22.Funding	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	Y	Y

Summary of Results

Parent child agreement on total QoL scores.

Total QoL scores were available for twelve of the thirteen included studies. Eight of the twelve studies (66.6%) reported significantly higher child self-reported total QoL scores when compared to parent proxy-reported QoL scores (Sciberras et al. 2011; Limbers et al. 2011a; Jafari et al. 2011; Pongwilairat et al. 2005; Bastiaansen et al. 2004; Gürkan et al. 2010; Thaulow & Jozefiak 2012; Schei et al. 2013). Four of the studies (33.3%) reported no statistically significant differences in total QoL scores (Marques et al. 2013; Varni & Burwinkle 2006; Limbers 2011b; Flapper & Schoemaker 2008). One study did not report a total QoL score, only domains (Klassen et al., 2006).

Parent child agreement across outcome measures.

In six of the nine studies which utilized the Peds-QL (66.6%), children rated their overall QoL significantly higher than their parents rated their QoL (Sciberras et al. 2011; Limbers et al. 2011a; Jafari et al. 2011; Pongwilairat et al. 2005; Bastiaansen et al. 2004; Gürkan et al. 2010). In the three remaining studies which used the Peds-QL, no significant differences were found between overall parent and child ratings of QoL (Marques et al. 2013; Varni & Burwinkle 2006; Limbers et al. 2011a). One of these three studies utilized a relatively small sample size compared to the others in the review (n=17) (Limbers, 2011). Both of the two studies which utilized the ILC reported that children rated their overall QoL significantly higher than their parents rated them (Schei et al., 2013; Thaulow & Jozefiak, 2012). The study which utilized the TACQOL and the DUX-25 reported no significant differences in total QoL scores (Flapper & Schoemaker, 2008). The study which utilised the CHQ did not report total QoL scores but did report significant discrepancies across domains in the direction of children rating QoL higher than their parents (Klassen et al., 2006).

Parent child agreement on QoL domains.

Across the whole sample of studies, eleven (84.6%) reported data for QoL domains. Individual domain scores were not reported by either of the ILC studies (Schei et al., 2013; Thaulow & Jozefiak, 2012). One study reported discrepancies across all domains (Bastiaansen et al., 2004). Four of the eleven studies (36.4%), all using the Peds-QL, reported higher parent-child agreement on physical health than on psychosocial domains (social, school and emotional experience) (Sciberras et al. 2011; Marques et al. 2013; Limbers et al. 2011a; Jafari et al. 2011). In one study, also using the Peds-QL, this trend was reversed, with greater agreement on psychosocial domains than physical domains (Pongwilairat et al., 2005).

Klassen et al. (2006) using the CHQ, reported that the direction of the observed discrepancies between child and parent ratings were different for physical (children rated lower) versus psychosocial domains (children rated higher), suggesting significant directional differences in parent and child perceptions according to the type of domain in question. Flapper & Schoemaker (2008) reported discrepancies across both observable and subjective domains. Children rated themselves as having better QoL in the 'physical' and 'home' domains (using the DUX-25), while they rated poorer QoL on 'bodily functioning' and 'positive moods' domains than the parent rated QoL (using the TACQOL). Varni & Burwinkle (2006); Limbers (2011b); and Gürkan et al. (2010) reported no discrepancies between parents and children across all individual domains.

Parent child agreement in comparison to normative QoL data.

Nine of the thirteen studies compared data from the ADHD group with normative data, however one of these did not compare total QoL scores, only domain scores (Klassen et al., 2006). In all of the eight studies which did compare total QoL scores, both parents and

children rated the overall QoL of the child with ADHD as poorer than the QoL of a designated healthy control group (Thaulow & Jozefiak 2012; Marques et al. 2013; Limbers et al. 2011a; Limbers 2011b; Varni & Burwinkle 2006; Jafari et al. 2011; Pongwilairat et al. 2005; Flapper & Schoemaker 2008). There were some exceptions to this on individual domains. Limbers et al (2011b) found that children did not rate their QoL as being significantly different from controls on the 'social' domain, while parents did not rate their children's physical health as being significantly poorer. Similarly Varni & Burwinkle (2006) reported that parents did not rate their child as having impaired physical health, while Pongwilairat et al. (2005), reported that children did not perceive their physical health as comparatively lacking. Klassen et al. (2006) found that children self-rated their QoL similarly to a normative sample across most domains, while their parents perceived deficits in psychosocial and family domains.

Direction of differences.

Overwhelmingly the directional trend across the range of included studies was that children reported better QoL than their parents' proxy-ratings of QoL. All eight of the studies where there were significant parent/child discrepancies in total QoL reported higher scores for self-rated QoL. The vast majority of discrepancies across individual domains followed the same directional trend as the overall scores. Children rated higher self-rated QoL than parent rated QoL on nineteen individual domains across eight studies. Parents rated higher QoL than children on only three individual domains across two studies. These were 'positive moods' and 'bodily functioning' using the TACQOL (Flapper & Schoemaker, 2008) and the 'physical' domain using the CHQ (Klassen et al., 2006).

Co-morbidities.

Two of the four studies which excluded participants with co-morbid conditions (ADHD only) found that children rated their QoL higher than their parents (Bastiaansen et al., 2004; Schei et al., 2013). Both of these studies utilised comparison groups of children with either: ADHD and other conditions (e.g. emotional/conduct disorders), (Schei et al., 2013) or other conditions without ADHD (Bastiaansen et al., 2004). Parent/child disagreement was not observed for either of these conditions as it had been in the ADHD only conditions. Four of the six studies which did not exclude co-morbid conditions reported that children rated their total QoL as being higher than their parents rated them (Thaulow & Jozefiak 2012; Limbers 2011b; Sciberras et al. 2011; Gürkan et al. 2010). The fifth study (Klassen et al., 2006) did not report overall QoL scores, but did report that children with ODD/CD were more likely to rate their QoL on 'Mental Health' and 'Behaviour' domains more favourably than their parents. Only one of the studies where co-morbidities were present found no significant differences between self and parent reported QoL (Limbers 2011b). The study which limited co-morbidities to ODD reported good concordance between parents and children for overall QoL ratings (Marques et al., 2013). Both of the studies which did not provide information about whether or not co-morbidities were excluded reported that child ratings of QoL were higher than parent ratings (Jafari et al., 2011; Pongwilairat et al., 2005).

Parent and child characteristics.

The relationship of the parent to the child (mother, father, or legal guardian) may affect inter-rater agreement, but most studies did not deviate from 'parent' as the solo descriptor of the proxy-rater. Information regarding associated variables such as parent mental and physical health status, the child's age and gender would also have been

potentially valuable. However few of the papers reported the impact of these variables on parent/child agreement in their analysis (some citing small sample sizes), so meaningful comparisons were not possible. Medication status was also of interest in this review, however its purpose was not to assess QoL of children with ADHD according to medication status or type. As most children were recruited from paediatric clinics, the rates of pharmacological intervention were high, and few studies exclusively compared parent and child QoL ratings between medicated and non-medicated children.

Discussion

Reviews comparing child self-report with parent proxy-reports of the QoL of children with chronic health conditions have found that inter-rater discrepancies are common, and that one cannot simply be substituted for the other (Eiser & Morse, 2001; Upton et al., 2008). The aim of this review was to examine the existing published data on QoL in childhood ADHD, as rated by matched parent/child dyads, in order to determine the degree and nature of any differences which occurred between them.

Agreement on Total Quality of Life Scores

In the majority of studies, there was disagreement between parents and children on the evaluation of the child's life quality. In all of the studies where discrepancies in overall QoL scores existed, children perceived their QoL as being more favourable than parents. These findings indicate that children with ADHD have a more positive view of their lives than their parents expect them to. These findings are in accordance with previous reviews which found that children with chronic conditions tend to rate their QoL more highly than their parents (Eiser & Morse, 2001; Upton et al., 2008). In the majority of cases both parents and children agreed that QoL is impaired for children with ADHD compared with healthy children. This evidence expands on Danckaerts et al. (2010) finding that QoL is impaired in children with

ADHD according to parental report. Therefore, rather than informants disagreeing on whether or not impairment in QoL exists for children with ADHD, it appears that it is the level, and/or the nature of the impairment on which there are often perceptual differences.

Several explanations have been offered for the propensity for children with ADHD to self-rate their QoL more favourably than their parents rate them. A *positive illusory bias*, which proposes that children with ADHD have overly optimistic self-perceptions, has been reported in studies exploring self-concept in ADHD (Hoza et al. 2002.; Owens & Hoza 2003). It has been hypothesized that children with this diagnosis cope with negative experiences and protect their self-image by constructing a more favourable internal representation of their competences (Ohan & Johnston, 2010). Clearly if this is the case, they do not extend this representation to equality of experience with their non-ADHD affected peers, as evidenced by their acknowledgement of comparative deficits. Sciberras et al. (2011) reported that in their sample self-worth was higher in children who reported higher QoL scores than their parents, compared with children who rated their QoL as worse than their parents, which may account for some of their apparent resilience.

Children's self-reports may also be biased by their ADHD symptomatology. Children with this diagnosis are typically impulsive and have attentional difficulties, which may cause them to record responses in haste with little deliberation. In this sense ADHD may limit their capacity to reflect on the 'bigger picture' of their life experiences, instead answering questions based on their immediate feelings. Thaulow & Jozefiak (2012) theorise that children with ADHD are more likely to focus on aspects of the present moment, while their parents are likely to focus on the child's future, concerned by problems related to school and peer relationships.

Parental perceptions are also open to bias. Some researchers have noticed a higher presence of psychopathology in parents of children with ADHD (Barkley, Fischer, Edelbrock, & Smallish, 1990; Joseph Biederman, 1992). Parents of children with ADHD also experience more parenting stress than parents of healthy controls, similar to parents of other clinically referred children (Theule, Wiener, Tannock, & Jenkins, 2010). As likely as the notion of ADHD children having overly optimistic views, is that of their highly stressed parents having their views biased by the negative thinking patterns that often underlie highly prevalent psychological problems. This hypothesis would fit with studies that have reported a link between parental emotional distress and more negative perceptions of their child's QoL for other conditions (Janicke et al., 2007; Kobayashi & Kamibeppu, 2011). Klassen et al. (2006) reported that when a psychosocial stressor was present, children rated their behaviour higher and their physical function lower compared with their parents' ratings. It is likely that both stressful life events and parental mental health issues could inhibit communication between parents and children and thus affect the degree to which they are attuned. Further, parents who are already emotionally burdened may experience more distress related to their child's ADHD behaviours, and therefore perceive them as more severe and disruptive than the child experiences them to be.

Agreement on Specific Domains

Just over one third of the studies which reported domain scores found greater parent child agreement on physical health domains as opposed to psychosocial domains (e.g social, emotional, and school experience). However, this trend should be interpreted cautiously as there were also studies where discrepancies were present across all domains or no domains. Authors of related reviews have suggested that the level of agreement on specific domains may depend on their clinical relevance to a particular disease group (Upton et al., 2008; Varni et al., 2003). They suggest that agreement is likely to be stronger on relevant domains

because parents would be more involved in this aspect of the child's healthcare. If this were the case, one might predict that in the case of ADHD, there would be greater agreement between parent and child ratings of child QoL for psychosocial rather than physical domains, since physical health is relatively unchanged by ADHD symptomatology. However, this review has found no evidence to support this theory in the context of ADHD. It may be that psychosocial domains which incorporate emotional, social and school experiences are more subjective and therefore open to parental interpretation, while physical health is easier for parents to objectively assess.

Agreement and Co-morbidities

It is difficult to make inferences regarding the impact of co-morbidities on parent-child agreement as few studies reported direct comparisons between ADHD only groups and co-morbid groups. Half of the studies which used ADHD only samples reported significant discrepancies between scores, while agreement across samples where co-morbidities had not been excluded was also variable, and samples were not homogenous in this regard. However, two potentially important findings with regards to co-morbidities were highlighted in the review. Klassen et al. (2006) found that children with co-morbid ODD/CD rate their mental health and behaviour more highly than their parents. It would thus be easy to imagine that the additional stress of co-morbidities further reduces communication and therefore agreement between parent and child. However, Thaulow & Jozefiak (2012) found that children with ADHD without co-morbidities self-rated their QoL higher than children with anxiety or depression, while there was no difference between these groups according to parent-reported ratings. This latter finding gives additional support to the theory that children with ADHD, unencumbered by co-morbid psychiatric problems have a more positive outlook on their lives than their parents expect. In contrast, children with emotional problems such as anxiety or

depression are more likely to view their lives more negatively, and more in line with their parents' expectations.

The two findings appear at first to sound contradictory, as surely if optimism is highest when ADHD is 'pure', parent child agreement would be predicted to improve as co-morbidity increases. Yet the symptoms of ODD and CD are also externalising, and rather than affecting the coping style of the young person (as an internalising emotional disorder might), they may simply be adding to the stress of the parent and/or serving to reinforce the positive illusory coping mechanism within the child, creating further discrepancy. Perhaps then, the nature of ADHD symptomatology, e.g. externalising symptoms (hyperactivity) versus internalising symptoms (negative cognitions) could, relative to other mental health problems, be a protective factor for a child's perception of their QoL. Reservedly, this hypothesis is based on the findings of only two studies. More research is needed to examine the impact of co-morbidities on parent child agreement levels. In particular, studies that utilize comparative data across different conditions and that consider their impact on both parents and children, are of interest.

Agreement Across QoL Measures

Over two thirds of the included studies used the Peds-QL as the QoL measure. A potential explanatory factor for some of the preference for this measure is that the author of the Peds-QL is also an author on three of the included studies. A clear benefit of having such a high proportion of studies utilise the same measure, was that it allowed comparisons to be made both within and between QoL measures. Upton et al., (2008) suggested that the Peds-QL has a relatively high number of items which measure observable behaviours, and that this may result in greater agreement between parents and children on this measure. The findings of this review contradict this premise, evidenced in the fact that two thirds of the Peds-QL

studies reported significant disagreement in overall QoL ratings of parents and children. Both of the ILC studies and the CHQ study reported poor concordance between raters, and the TACQOL, and DUX-25 reported discrepancies on a number of domains. Therefore, it appears that the trend of discrepancies observed across studies cannot readily be attributed to the QoL measure specified.

Of interest, in Danckaerts et al.'s (2010) review, in the two studies which utilized the CHQ, children did not rate their QoL differently from controls, while the four others (which used other QoL measures) reported reduced QoL. In the current review, a similar pattern was observed. Only one study utilized the CHQ, and it was the only one (of those who reported comparisons with normative data) which did not observe reduced QoL in children with ADHD. The eight studies which reported impaired QoL utilized other QoL measures (Peds-QL, ILC, TACQOL, and DUX-25). Thus it may be that there is something in the CHQ which less easily differentiates between the groups. However, the CHQ study utilised population norms from a different country, meaning issues such as dissimilar healthcare systems and socioeconomic status could result in key differences between the QoL of the children in the samples. However, it should also be made explicit that the (Klassen et al., 2006) study was reviewed as part of both Danckaerts et al.'s (2010) review and the current review, therefore more comparisons featuring studies which utilize CHQ self-report measures are necessary before conclusions can be drawn.

Strengths and Limitations of the Review

The search strategy utilized was comprehensive and studies were screened and included from a variety of sources. Additionally, a second rater independently appraised the conformity of a proportion of the included studies, and inter-rater reliability checks were performed, limiting appraisal bias. However, the authors acknowledge that only one

individual was responsible for selecting studies based on inclusion and exclusion criteria, and that ideally this would be cross-checked. All of the included studies utilized standardised QoL instruments with established psychometric properties, thus refining the validity and reliability of the available data.

A limitation of all survey based research is responder bias, and the lack of available comparison data regarding why some and not others partake in the research. Inconsistencies between parent and child ratings may reflect sample differences. Samples had variable inclusion and exclusion criteria, age and gender distributions, and response rates. The reviewed research studies include samples which are internationally diverse and participants are often treated within dissimilar healthcare systems. Diagnostic inconsistencies including the use of ICD-10 or DSM-IV criteria, the level of clinician experience and the use of research specific criteria in some cases, will inevitably have led to some incongruence between samples. The authors acknowledge that it would have been useful to include a section in the quality criteria relating to how ADHD diagnosis was assigned in each sample. Further, diagnostic criteria have changed over time, and the search terms may have missed studies that utilised previous terminology for ADHD.

Participants were generally recruited by convenience sampling methods with little randomisation. I addition, some samples will have a referral bias for more complex/co-morbid cases depending on the recruitment method, the stage of their treatment, and when they received a diagnosis. Some children completed questionnaires unaided or online, while researchers provided assistance to others or utilised an interview format. The method was usually based on the age of the child. Given the attentional problems associated with this population, the method of completion may have impacted on the child's QoL ratings, with children potentially being inhibited by the presence of a researcher, or by improving their attention. However, the directional impact and magnitude of each of these scenarios on the

child's QoL ratings is unknown. Notably, due the high proportions of boys within the samples, findings may not be generalizable to girls with ADHD.

Implications for Clinical Practice

In addition to their application in research, QoL measures can be of value to clinicians working with families with a child with ADHD. They might highlight specific areas where a child is having difficulty and thus where appropriate support can be sought out and targeted. Although ADHD symptoms are often reduced by medication and other psychosocial treatment interventions, it is equally important to investigate and consider areas of a child's life where there may be associated distress that might be reduced. Further, given the apparent discrepancies between parent and child perceptions of the QoL of children with ADHD found in published research, it may be helpful for clinicians to explore these differences on an individual level. Such investigations may illicit a clearer understanding of the impact of ADHD on the perceptions of the individual members of the family. If the child indicates that they experience life more positively than parents predict, this may in itself alleviate some distress in parents. It may also allow clinicians and parents to challenge or modify their own expectations in light of the child's own views.

Parents will vary in terms of their sensitivity and understanding of their child's subjective wellbeing. However, substantial discrepancies across a range of domains could signpost relational issues between a parent and child that could be further examined and potentially addressed. We recommend that dual informants are always utilised when possible, and that measures are interpreted with caution, given the potential sources of reporting bias on both parts. Further, given that the child's accessing of services is usually predicted by parental concerns regarding the child's QoL, it may be helpful for clinicians to reflect that

there is perhaps no 'true' depiction of the child's QoL, rather that both views should be valued and validated as integral contributions to clinical assessment and treatment planning.

Implications for Future Research

Studies and reviews comparing parent/child agreement across different health conditions have mostly considered children with physical health conditions. Further studies which directly compare agreement between parents and children on QoL measures across samples of children with a range of psychiatric diagnoses may aid understanding of the potential impact of each set of symptoms. For example, if levels of agreement between parents and children vary between samples of children with depression (internalising symptoms), conduct disorders (externalising symptoms), and OCD (internalising and externalising symptoms), we could learn a great deal about how children's perceptions (relative to their parents) are impacted by their condition, and perhaps learn more about how each condition affects the parent/child relationship. Further attention should be given to the potential sources of bias for both informants. Large quantitative studies investigating the specific impact of parental stress on parent and child ratings of child QoL would be of interest.

Previous research found little differences between mothers and fathers' ratings of QoL in population samples (Jozefiak et al., 2008). However this trend may be different when a child has a health condition given that one parent may be more involved with the child's health care. Therefore studies which compare proxy-raters in terms of their relationship with the child may be of interest, along with studies which explore agreement associated with child gender and age. Given the highly co-morbid nature of ADHD, more studies directly comparing agreement between ADHD only samples and samples according to type and

number of co-morbidities may also be of value. Since symptom severity is generally rated by parents in research (Danckaerts et al., 2010), such ratings may be open to the same potential sources of bias QoL ratings, and may result in erroneous correlations between ADHD symptoms and QoL. Teacher or clinician based ratings would be preferable if investigating the impact of symptom severity on agreement levels. Finally, qualitative studies considering the basis on which both sets of informants assess the child's quality of life would be highly advantageous in helping to establish the cognitive processes behind parent and child perceptions.

Conclusions

Previous related reviews have focussed on agreement across multiple diagnoses (where only one ADHD study was included) (Eiser & Morse, 2001), or have utilized mainly proxy-reports when describing child QoL (Danckaerts *et al*., 2010). Thus it had formerly been difficult to establish a clear picture of children's views of their QoL, both in relation to their non-ADHD affected peers, and to their parents. This review adds to the current evidence base by bringing together the existing published research *specific* to the quality of life of children with a diagnosis of ADHD, and by representing and comparing the views of both parents *and* children. In summary, this review found that there is consistent uni-directional evidence that children with ADHD perceive their QoL more favourably than their parents do, but less favourably than healthy controls. Thus, parent and child ratings of QoL should not be considered interchangeable when assessing the quality of life of children with ADHD. Rather both should be considered as unique and valuable perspectives for clinical and research purposes.

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Aims of the Empirical Study

The current study had two main aims in relation to children with a diagnosis of Attention Deficit/Hyperactivity Disorder.

(1) The first aim was to compare parent-proxy ratings and child self-ratings of the child's quality of life, and to examine the impact of parent stress on any observed discrepancies between the two groups of scores.

(2) The second aim was to investigate whether parent stress was a significant predictor of child QoL, according to both self-reports and parent-proxy reports, whilst controlling for other suspected predictors (co-morbidities and severity of ADHD symptoms).

Journal Article 2: Empirical Study

Title: Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives.

Helen Galloway

NHS Lanarkshire

Emily Newman

University of Edinburgh

Clare Yuill

NHS Lanarkshire

Nicola Miller

NHS Lanarkshire

Author's Note

Helen Galloway, Dr Clare Yuill & Dr Nicola Miller, Child & Adolescent Mental Health Services, NHS Lanarkshire. Dr Emily Newman, Clinical and Health Psychology, School of Health in Social Science, University of Edinburgh. Correspondence regarding this article should be addressed to: Helen Galloway, CAMHS for Accommodated Young People Team (CAYP), Glenshirra Building, Coathill Hospital, Hospital Street, Coatbridge, ML5 4DN. Tel: 01236 703010. Contact: Helen.Galloway@nhs.net. No funding was received for the review. The authors declare no conflict of interests with respect to the article.

Written with intention to submit to the *Journal of Attention Disorders*

Abstract

Objectives: There are indicators that parental psychological factors may affect how parents evaluate their child's quality of life (QoL) when the child has a health condition. This study examined the impact of parents' perceived stress on parent proxy and child self-ratings of the QoL of children with Attention Deficit/Hyperactivity Disorder (ADHD).

Method: A cross-sectional sample of 45 matched parent-child dyads completed parallel versions of the KIDSCREEN-27. Children were 8-14 years with clinician diagnosed ADHD.

Results: Parents who rated their child's QoL lower than their child had higher perceived stress scores. Parent stress was a unique predictor of child QoL from both perspectives, but explained more of the variance in parent proxy-rated QoL scores.

Conclusions: Parents' perceived stress may play an important role in their assessments of their child's QoL, meaning parent and child perspectives of QoL should be utilized wherever possible. Interventions that target parent stress may contribute to improvements in the child's QoL.

Key words: quality of life; ADHD; attention deficit/hyperactivity disorder, perceived stress, child self-ratings, parent-proxy ratings

Words: 7,869

Does parent stress predict the quality of life of children with a diagnosis of ADHD? A comparison of parent and child perspectives.

Introduction

Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most common health diagnoses of childhood, affecting an estimated 3% to 7% of school aged children (Daviss, 2008). Characterized by high levels of hyperactivity, inattention and impulsivity, it is associated with significant impairments in functioning across a range of psychosocial domains (Barkley, 2002). Children with ADHD have an increased risk of academic underachievement, poor family and peer relationships, low self-esteem, anti-social behaviour, and criminal activity (Biederman et al., 1997; Wilens, Biederman, & Spencer, 2002). ADHD is a highly co-morbid disorder and is frequently associated with: oppositional defiant disorder (ODD); conduct disorder (CD); learning disability (LD); anxiety disorders and depression (Anderson, Williams, McGee, & Silva, 1987; Biederman, Newcorn, & Sprich, 1991). Boys are more likely to be affected than girls, although girls have been found to be underdiagnosed in the community (Ramtekkar, Reiersen, Todorov, & Todd, 2010).

ADHD is categorised as a neuro-developmental disorder in the Diagnostic and statistical manual of mental disorders: DSM-5™ (5th ed.) (American Psychiatric Association, 2013). However, health professionals continue to differ in their outlook regarding the causes of and treatments for ADHD behaviours and the usefulness of classifying ADHD as a disorder. Some are convinced the symptoms have a biological basis in brain chemistry and heredity, and advocate the use of stimulant medications, which are undeniably effective in reducing symptoms. Others are aligned to more environmental explanations and solutions, and are concerned that we may be unnecessarily pathologizing children, and failing to address the underlying precipitating and perpetuating problems. Many more sit somewhere in between. ADHD is sometimes referred to as a 'cultural construct', with suggestions that

increasing numbers of children are receiving diagnoses as a result of society's growing intolerance to behaviour that does not conform. However, neuroimaging research suggests that the frontal regions of the brain, those responsible for response inhibition, delay aversion, and executive functions, are different in children with ADHD compared with control groups (Krain & Castellanos, 2006).

Leading neuroscientist, Dr Bruce Perry, recently suggested that ADHD is best thought of as a term used to describe a set of symptoms that could be the result of a range of problems (Boffey, 2014). Perry questioned the long term advantages of stimulant medication, and instead advocated the use of therapeutic approaches that aim to break the cycle of negative feedback and emotional dysregulation that often occurs between parents and children presenting with behaviours which meet the criteria for ADHD diagnosis. Related media coverage often highlights the financial interests of pharmaceutical companies, and the allocation of disability benefits to parents of some children with a diagnosis of ADHD, adding fuel to the debate. Both aside from the controversy surrounding ADHD, and in response to it, we must continue to expand our knowledge of children who have been given this diagnosis as we consider how best to improve outcomes for them.

The multi-dimensional constructs of quality of life (QoL) instruments have increasingly been applied in paediatric ADHD research to gain insight into children's daily experiences of health and wellbeing. The World Health Organisation (1995, p. 1450) defines QoL as "an individual's perception of their position in life, in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns". QoL studies of children with health conditions commonly measure and describe their functioning in core physical, social and psychological domains and compare their scores with normative population samples in order to determine the lived experience of a specific set of symptoms. Particularly in the case of ADHD, an assessment of a child's QoL can also

enable health professionals to consider the areas of a child's life which remain impaired even when symptoms are reduced.

Measuring QoL in Childhood ADHD

Paediatric QoL measures have historically been completed by parents, who have estimated their child's QoL by proxy. Only recently have children been recognised as capable of reliably assessing their own QoL (Cremeens et al., 2006; James W Varni et al., 2007) and developmentally appropriate QoL measures have been developed and utilized (e.g. Paediatric Quality of Life Inventory (PedsQL), Varni et al. 1999; The Child Health Questionnaire (CHQ), Landgraf et al. 1996; KIDSCREEN, Ravens-Sieberer et al. 2007). However, it often remains important to gather information from sources other than the child in question, especially when the child's ability to report accurately may be affected by health related impairments (Wallander, Schmitt, & Koot, 2001), and given that parent accessing of healthcare and support services for their child is, in the main, predicted by their perceptions of their child's QoL (Varni, Seid, & Kurtin, 2001).

A pattern of poor inter-rater agreement between parent and child assessments of the QoL of children with ADHD is emerging in the literature. Children with ADHD tend to self-rate their QoL significantly higher (and thus better) than their parents proxy-rate their QoL (Bastiaansen et al., 2004; Gürkan et al., 2010; Jafari et al., 2011; Limbers, Ripperger-Suhler, Heffer, et al., 2011a; Pongwilairat et al., 2005; Schei et al., 2013; Sciberras et al., 2011; Thaulow & Jozefiak, 2012). This pattern has also been observed in children with other health conditions (Eiser & Morse, 2001; Upton et al., 2008), and is in contrast with samples of healthy children, when parents generally rate children as having better QoL than the children rate themselves (Jozefiak et al., 2008). There is also some evidence within ADHD samples, that parent/child agreement is greater for physical domains compared with psychosocial

domains (Jafari et al., 2011; Limbers, Ripperger-Suhler, Heffer, et al., 2011a; Marques et al., 2013; Sciberras et al., 2011), which may be due to the more subjective nature of the latter dimension.

The majority of related studies have proposed self-protective cognitive processes within the child or ADHD symptomatology as the main explanatory factors for children rating their QoL more favourably than their parents (e.g. Hoza et al. 2002; Owens & Hoza 2003; Ohan & Johnston 2010; Thaulow & Jozefiak 2012). However, as yet, no published research has investigated how parent factors might influence this pattern of results, and authors have highlighted this as a key area for investigation (Danckaerts et al., 2010). In light of the observed discrepancies, parent and child ratings of QoL should not be considered interchangeable. Rather, both are likely to offer unique and valuable perspectives to the assessment of the QoL of children with ADHD. In clinical practice, a comparison of both perspectives could offer important insight into how features of the condition uniquely affect children and their parents and may influence clinical decision-making regarding key areas for intervention.

The QoL of Children with ADHD

There is increasingly consistent evidence that children with ADHD experience impaired QoL compared with normative population samples. A recent systematic review identified 36 studies pertaining to QoL in children and adolescents with ADHD (Danckaerts et al., 2010). Of the 36 studies included, 29 used only parent rated QoL measures, 2 included child self-reports only, and 5 included both parent and child reported ratings. The review authors concluded that there was clear evidence that, according to parental reports, children with ADHD have impaired quality of life. Across studies, parents of children with ADHD consistently rated the child's quality of life as between 1.5 and 2 standard deviations below

population norms for healthy controls (Danckaerts et al., 2010). The comparably fewer studies which utilized self-reported QoL were reported by the authors to be less robust in establishing a similar pattern of results. However, since the review's publication, a growing number of ADHD studies have utilized child reported QoL measures, and these consistently indicate that children also rate their QoL as significantly impaired when compared with healthy controls (Flapper & Schoemaker, 2008; Jafari et al., 2011; Limbers, Ripperger-Suhler, Boutton, et al., 2011a; Limbers, Ripperger-Suhler, Heffer, et al., 2011b; Marques et al., 2013; Pongwilairat et al., 2005; Thaulow & Jozefiak, 2012; Varni & Burwinkle, 2006).

Research findings generally indicate that individuals with ADHD experience impairments of psychosocial functioning that extend significantly beyond its core symptomatology of attention deficit, hyperactivity and impulsivity (Barkley, 2002; Escobar et al., 2008). Yet contextual factors which might predict a child's QoL are not well considered in relation to children with ADHD. Klassen, Miller, & Fine (2004) found some evidence that children with more ADHD symptoms have a poorer quality of life, where symptom severity was an important predictor of psychosocial health. Correlations between symptom severity and QoL are usually in the small to moderate range (Danckaerts et al., 2010), which supports the theory that they are related but distinct constructs, and that both may contribute to our understanding of the child's problems. Klassen et al.'s (2004) study also found that children with two or more co-morbid disorders had poorer QoL than children with one or no comorbidities. The study used only proxy report, although it reported large effect sizes for these differences. Another study reported that low child reported QoL was associated with co-morbid OCD, CD, and trauma related disorders, while low parent-proxy reported QoL was associated with the child's co-morbid anxiety, depression, ODD and CD (Dallos et al., 2014).

Parent Psychological Factors and QoL in Children with Health Conditions

There are some indicators that factors other than the severity or complexity of a child's impairment may influence parents' ratings of their child's QoL. White-Koning et al.'s (2007) cross-sectional study of 818 children with Cerebral Palsy found that greater severity of impairment was not always associated with poorer QoL ratings. They found that across all domains (using the KIDSCREEN), parents with higher stress levels were more likely to rate their children as having poor QoL. Similarly, Kobayashi & Kamibeppu's (2011) study of 679 Japanese school children found (using the Peds-QL) that parents' perceptions of QoL differed from the child's own perceptions of their QoL. They observed that parents who had depressive symptoms were likely to underestimate their child's QoL, irrespective of the child's own condition (i.e. depressed or not depressed). Janicke et al.'s (2007) study with 96 children attending an obesity clinic found (using the Peds-QL) that increased parent distress was associated with lower QoL according to both self-reported and parent proxy-reported ratings. Child depressive symptoms mediated the relationship between parent stress and self-rated QoL, but this was not the case for parent proxy-rated QoL.

It is possible to infer from these studies that parents whose children have poorer QoL are more impaired, and consequentially their parents have a greater burden of care and experience more distress. However, in these examples, where there is lesser association between parent stress and child rated QoL, it may indicate that the parental factors affect parents' judgements of their child's QoL. It is possible that parents who are already emotionally burdened experience more distress related to their child's health problems, and therefore perceive them as more severe than parents with low stress levels. Further, parental views may be biased by the negative thinking patterns that often underlie highly prevalent psychological problems. It is difficult to draw any directional or causal conclusions about

such associations from these results alone, and without taking into consideration other contextual variables (such as the severity and complexity of a child's condition), which might influence assessments of the child's QoL. However, these studies may relay important information about how parents and children assess QoL, and the impact parent psychological factors might have on a child's QoL.

Parent Psychological Factors and ADHD

It is yet unknown whether the same trend also exists in the context of ADHD. However, there are many established associations between child ADHD symptomatology and indicators of increased stress in parents. Stefanatos & Baron (2007) found that parents of children with ADHD are more likely to experience stress, marital problems, have more negative parenting practices, and have a mental health problem. Other researchers have also noticed a higher presence of psychopathology in parents of children with ADHD (Barkley, Fischer, Edelbrock, & Smallish, 1990; Joseph Biederman, 1992). Studies have shown that up to two-thirds of children with ADHD have a parent with a history of ADHD (Schachar & Wachsmuth, 1990), and parental ADHD has been shown to be a predictor of parental distress (Theule, Wiener, Rogers, & Marton, 2010). Studies have also shown that parents of children with ADHD experience more stress related to parenting than parents of healthy controls, similar to parents of other clinically referred children (Theule, Wiener, Tannock, & Jenkins, 2010). Further, parental problems are likely to be exacerbated by their child's ADHD behaviours (Pelham et al., 1998).

To the authors' knowledge there are currently no published studies which have analysed the effect of any parent psychological factors on the QoL of children with ADHD. Attribution theory proposes that assessing an individual's cognitive appraisal of events is fundamental when considering how they will respond to stressful situations (Cohen et al., 1983). From this perspective, situations are appraised as stressful only when the demands of

the situation outweigh the resources available to the individual. Attributions of controllability appear to consistently predict how a person will respond to, and cope with, stressful events (Harrison & Sofranoff, 2002). In this exploratory study, the term *parent stress* is utilized to indicate the global self-perceived stress of parents by assessing the extent to which they feel in control and able to cope with circumstances in their life. This is distinct from the commonly used term 'parenting stress', defined as ''the aversive psychological reaction to the demands of being a parent'' (Deater-Deckard, Dodge, Bates & Petit, 1998, p.315). Rather than exploring stress related only to the parent-child relationship, this study sought to also take into account stress from additional sources, which may not relate exclusively to parenting the child, but which are potentially important in terms of their impact on the child's QoL. In this context it seems particularly important to take a global measure of parent stress, considering that parents of children with ADHD have an elevated risk of experiencing a range of psychological and familial problems.

In the current study, parent stress was further investigated within a clinical sample of children with a diagnosis of ADHD. In order to obtain an integrated perspective, and given the discrepancies between parent and child ratings, both self-reported and parent proxy-reported QoL data were collected. This allowed for inter-rater comparisons and an analysis of any differences in the predictive power of parent stress according to both perspectives, while simultaneously controlling for suspected predictors such as symptom severity, co-morbidities and any treatment interventions undertaken. Treatment response studies have traditionally asked parents and teachers to complete behaviour rating scales to measure symptom reduction, and treatment studies that use QoL instruments have so far been very limited (Danckaerts et al., 2010). However, any study investigating predictors of QoL in childhood ADHD should also consider the impact of both pharmacological and behavioural treatment interventions and control for these if appropriate.

Study Aims

The current study had two main aims in relation to children with a diagnosis of ADHD. The first aim was to compare parent-proxy ratings and child self-ratings of the child's quality of life, and to examine the impact of the parent stress on any observed discrepancies between the two groups of scores. The second aim was to investigate whether parent stress was a significant predictor of child QoL, according to both self-reports and parent-proxy reports, whilst controlling for other suspected predictors (co-morbidities and ADHD symptom severity).

The following hypotheses were proposed:

Hypothesis 1) Children in the sample will report higher mean QoL scores than their parent's proxy-ratings of QoL. Discrepancies between parent and child ratings will be greater for subjective psychosocial domains than more observable physical domains.

Hypothesis 2) Parents who proxy-rate their child's QoL more negatively than the child self-rates their QoL will have significantly higher self-reported stress levels than parents who proxy-rate their child's QoL more positively than the child self-rates their QoL.

Hypothesis 3) High parent stress will predict lower child QoL in parent-proxy ratings, when number of co-morbidities and severity of ADHD symptoms are controlled for. However, parent stress will not predict child self-ratings of QoL.

Method

Participants

Participants were recruited from children's mental health and paediatric clinics within two NHS Scotland health boards. Participants (all active cases) were children or young people aged 8-14 with a diagnosis of ADHD, and their caregivers. The age criteria were selected in order to accommodate specific anxiety and depression measures, which were in the original design and ethics application, but which were removed from the study before it commenced, as it was felt this would require too much of the children. The age range excluded approximately 15% of the overall population of children with ADHD attending the clinics. Families were excluded where it was known that the child or parent did not speak English, or could not read or write. Where this information was available, it related to approximately 0.2% of the overall population attending clinics. Children with co-morbidities were not excluded from the study. The children in the sample received a diagnosis in clinical practice. While ADHD diagnoses are generally given according to ICD-10 criteria in Scotland, clinicians will range in experience, in the assessment methods they utilize, and in their interpretative outlook. This was apparent in the considerable differences in ADHD prevalence rates between teams operating within the same health board.

In total, 321 families were contacted by postal questionnaire. Completed questionnaires for 45 matched parent and child dyads were returned, representing a response rate of 14%. Sample characteristics are presented in Table 1. Boys composed 88.8% of the sample (n=40), which is roughly similar to patterns in the wider ADHD population. The mean age of children in the sample was 11.2 years (range 8-14). Parent/carer rated questionnaires were completed most commonly by the child's mother (n=40, 88.8%). All of the children in the sample were recorded as currently being prescribed ADHD medication. This is likely a result of the convenience recruitment method, since all of the participants

were open cases from ADHD clinics. In total, 18 parents (40%) had taken part in a behavioural intervention programme aimed at helping parents to manage their child's behaviours. Of those who had participated, 88.8% had attended more than 5 of the planned sessions. Sixty percent of children in the sample had one or more co-morbid conditions. The most common co-morbid diagnosis was Autism Spectrum Disorder (44.4%), and Learning Disability (13.6%).

Procedure

In this cross-sectional study, permission was requested from service directors in both health boards for the researcher to post questionnaire packs to all families who met the inclusion criteria in the participating teams. A representative for each team, usually a Consultant Clinical Psychologist or Consultant Psychiatrist, provided a list of names of children with a diagnosis of ADHD in their service. The representative either provided addresses and dates of birth for the children, or the researcher accessed the individual case notes to attain this information. Where the child met the inclusion criteria, the researcher posted a questionnaire pack addressed to the parent or carer of the child. This contained a cover letter outlining the purpose of the study, and an information sheet for both parents/carers and children, along with the relevant questionnaires. Inside the main envelope, the questionnaires were separated into two booklets, one marked 'to be completed by parent/carer' and one marked 'to be completed by child/young person'. The parent/carer was advised that both questionnaires must be completed to be accepted into the study, and that if their child was unable to concentrate for long enough to complete the questionnaire in one sitting, they could do so over two or three separate sittings. The parent/carer was be asked to post the completed questionnaires back to the researcher in a pre-stamped and addressed envelope.

Data Collection

Demographic Questionnaire (parent report).

This questionnaire was used to gather information about the child and their family context, allowing the researcher to give a detailed description of the sample. Information was collected regarding the child's age; gender; the number of siblings at home; age at diagnosis; the relationship of main carer to the child; a description of any physical and/or psychological co-morbidities the child had; whether the child was taking any ADHD medication (asked to state name and dosage) and whether they had taken part in a behaviour management programme (and if so how many sessions were attended).

KIDSCREEN-27 (child self-report and parent proxy-report).

Quality of life was assessed using KIDSCREEN-27 (Ravens-Sieberer et al., 2007). The KIDSCREEN instruments assess the subjective health and well-being of children and adolescents aged 8-18 years. Consideration had to be made for the concentration abilities of children with ADHD, therefore any child self-report measures had to be succinct and quick to complete, whilst also providing reliable and valid standardised measurement of the variables in question. The KIDSCREEN-27 was developed as a shorter version (27 items) of the original KIDSCREEN-52 (52 items) with a minimum of information loss and with good psychometric properties (Ravens-Sieberer et al., 2007). KIDSCREEN-27 takes approximately 10-15 minutes to complete. To enable a meaningful inter-rater comparison of quality of life data, the dependent variable measure had to have both a child self-report and a parent proxy-report version, featuring parallel questions which rated identical content and constructs. The parent-proxy version of KIDSCREEN-27 differs from the child version only in its use of developmentally appropriate language and in applying the first or third person to the questions.

The questionnaire has five individual domains: Physical Well-Being (5 items), Psychological Well-Being (7 items), Autonomy & Parents (7 items), Peers & Social Support (4 items) and School Environment (4 items). Responses are given on a 5-point scale (0=never/not at all, 1=slightly/seldom, 2=moderately/quite often, 3=very/very often, 4= always/extremely). Scores are combined both positively and inversely, with a higher score indicating a better QoL. A global index score and five separate domain scores can be calculated and t-values and percentages are available, stratified by age and gender. Internal reliability for this measure was found to be 0.92 for the parent version and 0.90 for the child version.

The Strengths and Weaknesses of ADHD Symptoms and Normal Behaviour Rating Scale (SWAN) (parent proxy-report).

The SWAN rating scale (Hay, Bennett, Levy, Sergeant, & Swanson, 2007) measures inattentive, hyperactive, and impulsive behaviours as outlined in DSM-IV criteria for ADHD diagnosis. The SWAN can be administered to parents and teachers in order to methodically acquire behavioural information about a child's ADHD symptoms. The scale effectively discriminates between children with and without ADHD, and accurately predicts subtypes. The SWAN is short and takes approximately five minutes to complete, making it an ideal measure to include in the current study. It asks informants to indicate the response that best describes the child in question over the past six months. Responses are given on a four point scale (0=not at all, 1=just a little, 2=quite a bit, 3=very much). Individual responses are then totalled to give an overall score, where a higher score is indicative of more ADHD symptoms. Its clinical value and effectiveness have been demonstrated in many studies (Arnett et al., 2013; Lakes, Swanson, & Riggs, 2012). Internal reliability for this measure was found to be 0.86.

The Perceived Stress Scale (PSS) (parent self-report).

The Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), is a widely used instrument designed to measure the degree to which respondents appraise situations in their lives as unpredictable and uncontrollable, and assess current levels of experienced stress. The questions are general rather than specific and relate to how often respondents have had certain thoughts and feelings during the last month. The scale consists of 10 items and takes around five minutes to complete. Responses are given on a 5 point scale (0=Never, 1=Almost Never, 2=Sometimes, 3=Fairly Often, 4=Very Often). In this study, parents completed the measure with reference to themselves. An overall score was obtained by summing the item scores (items 4, 5, 7, 8 are inversely scored). Higher scores indicate higher levels of stress in the parent. Cohen et al. (1983, 1988) reported that the measure had adequate validity and reliability and found correlations between the PSS and a number of stress measures, health behaviour measures, life event scores, smoking status, and help seeking behaviours. When compared with a depressive symptoms scale, they found the PSS to be an independent predictor. Internal reliability for this measure was 0.88.

Power Calculation

Harris' s (1985) formula for yielding the minimum number of participants was employed to calculate the necessary sample size. Harris suggests a rule of thumb that when a researcher applies five or fewer predictors, the number of participants should be equal to the number of predictors plus fifty. On this basis, with three predictors, at a significance level of 0.05, a minimum sample size of 53 was recommended for the current study.

Statistical Analysis

Missing data occurred on the SWAN scale for three participants, who did not fill in any of the questionnaire. This was addressed by excluding cases pairwise in the correlation and regression analyses. Paired sample t-tests were used to compare the mean scores of

parent and child ratings for the total QoL and domain scores (health, mood, family, friends, and school). Differences between total self- and parent-reported child QoL scores were calculated and the data were dichotomized to represent parents who reported higher or lower QoL than their children. A further independent samples t-test was then used to compare the mean perceived stress scores of the two groups of parents.

The second research question was addressed using a hierarchical multiple regression analysis. Prior to conducting the analyses, the relevant assumptions were considered and judged as being met. This method is useful for assessing the predictive power of a variable of interest, while simultaneously controlling for other potentially confounding variables. In this analysis, the researcher defined the order that the independent variables were entered into the regression equation to control for the group of variables which research has suggested may be predictors of QoL. In the first step, the researcher performed a multiple regression with the variables 'Symptom Severity' and 'Co-morbidities'. From this first regression model, the researcher accounted for the variance of this corresponding group of independent variables. In the second step, the variable 'Parent Stress' was added as a predictor. This allowed the researcher to examine the contribution of the new independent variable beyond the first group of independent variables. The procedure described was conducted twice, once for the child reported QoL data and once for the parent reported QoL data. Total scores were used for all measures, even where subscale scores were available. SPSS version 22 software was used.

Table 4. Characteristics of the sample

Relationship of carer to the child	Mother: 40 (88.9%), Father: 2 (4.4%), Adoptive parent: 1 (2.2%), Grandparent: 1 (2.2%), Legal guardian: 1 (2.2%)
Child's age (mean, range)	11.1, 8-14
Child's gender	Males 40 (88.9%), Females 5 (11.1%)
Age at diagnosis in years (mean, range)	7.2, 5-12
Number of siblings at home (median, range)	1, 0-5
Co-morbidities: type	Anxiety: 2 (4.4%) Attachment Disorder: 1 (2.2%) Autism Spectrum Disorder (including Asperger's) 20 (44.4%) Dyslexia: 1 (2.2%) Learning Disability: 6 (13.6%) Obsessive-Compulsive Disorder 2 (4.4%) Tic Disorder: 2 (4.4%) Tourette's Syndrome: 2 (4.4%)
Co-morbidities: number	One: 21 (46.6%) Two: 3 (6.6%) Three: 2 (4.4%) More than three: 1 (2.2%) Without co-morbidity: 18 (40%)
Behaviour management programmes: type	Triple P: 13 (28.9%) Incredible Years: 1 (2.2%) Dinosaur School: 3 (6.6%) Other: 4 (8.9%)
Behaviour management programmes: number of sessions attended	One: 1 (2.2%) Two: 0 Three: 0 Four: 1 (2.2%) Five: 0 More than five: 16 (35.5%)
Parent Stress Scores (as indicated by the Perceived Stress Scale)	
High (20+)	24 (53.3%)
Above average (14-20)	13 (28.8%)
Average or below average (0-13)	8 (17.7%)
ADHD Subtype (as indicated by the SWAN symptoms scale)	
Hyperactive/Impulsive	2 (4.4%)
Inattentive	3 (6.6%)
Combined	32 (71.1%)
Sub-clinical/symptoms controlled	4 (8.8%)
Missing	3 (%)
ADHD Medication	
Stimulant Medication	*36 (80%)*
Concerta XL	13 (28.8%)
Equasym XL	7 (15.5%)
Elvanse (Dexamphetamine)	3 (6.6%)
Medikinet	2 (4.4%)
Medikinet XL	1 (2.2%)
Methylphenidate (no brand name reported)	9 (20%)
Ritalin	1 (2.2%)
Non-stimulant Medication	*6 (13.3%)*
Strattera (Atomoxetine)	5 (11.1%)
Clonidine	1 (2.2%)
Takes medication for ADHD but name and dosage not stated	*2 (4.4%)*
Non-adherent	*2 (4.4%)*

Results

Parent Child Agreement on Child QoL

The first set of analyses investigated the difference between the self-reported ratings and parent proxy-ratings of the child's QoL (see Table 5). A global QoL index score is calculated using ten items from the KIDSCREEN-27. On the index scale, parent proxy rated QoL (*M*=41.5, *SD*=9.5) was significantly lower than child self-rated QoL (*M*=45.8, *SD*=7.1) on total QoL scores ($t(44)=4.16$, $p<.001$). Thirty three children (73.3%) rated their global QoL higher than their parents. At domain level, parents proxy-rated poorer QoL than children on 'Mood' and 'Friends' and 'School' domains, while there were no significant differences between ratings on 'Health' or 'Family', domains. The largest mean difference between parent and child ratings were observed on the 'Mood' domain. In total, 37 children (82.2%) rated higher QoL (*M*=45.3, *SD*=7.9) than their parents (*M*=38.6, *SD*=10.1) on this domain ($t(44)=5.05$, $p<.001$). On the school domain, 29 children (64.4%) rated higher scores (M=43.4, SD=10.2) than their parents (M=40.5, SD=11.7). On the 'Friends' domain, 26 children (57.7%) rated higher scores (*M*=44, *SD*=) than their parents (*M*=38.9, *SD*=14.2) ($t(44)=2.35$, $p<.05$). Cohen (1992) categorizes *d* values between .2 and .5 as representing a small effect, values between .5 and .8 as indicating a medium effect, and values greater than .8 as representing a large effect. Medium effect sizes were observed for the index and mood domains, while small effect sizes were observed for friends and school domains.

Table 5. Comparisons between parent and child QoL ratings

	Parent		**Child**						
Domain	**M**	**SD**	**M**	**SD**	**MD**	**CI 95%**	***t* value**	***p* value**	**Cohen's *d***
Index	41.5	9.5	45.8	7.1	4.4	2.3, 6.5	4.16	<0.001	0.62
Health	51.5	10.5	52.3	11.4	0.9	-3.6, 1.8	0.64	.52	
Mood	38.6	10.1	45.3	7.9	6.7	4.1, 9.4	5.05	<0.001	0.75
Family	49.0	10.4	48.2	9.6	0.8	-1.7, 3.3	0.63	.53	
Friends	38.9	14.2	44.0	12.0	5.1	0.7, 9.5	2.35	<0.05	0.35
School	40.5	11.7	43.4	10.2	2.8	0.4, 5.2	2.39	<0.05	0.36

Parent stress significantly correlated with inter-rater agreement (the difference between parent and child global QoL ratings) ($r(44)=.44$, $p<0.01$). As parent stress increased, discrepancies between parent and child ratings also increased. When the data were dichotomised, a *t*-test indicated that parents who rated their child as having poorer QoL than the children rated themselves reported significantly higher stress levels ($M=22.1$, $SD=5.9$) than parents who rated their children as having better QoL than the children rated themselves ($M=17.3$, $SD=6.4$) ($t(39)=2.17$, $p<.05$) (see Table 3). A medium effect size (.65) was calculated for the difference in scores between the two groups of parents.

Table 6. Comparison of mean parent stress ratings for parents whose proxy QoL ratings were higher or lower than their child's QoL rating.

	N	**Mean**	**SD**	**MD**	***t* value**	**CI 95%**	***p* value**	**Cohen's *d***
Group 1*	33	22.0	6.0					
Group 2*	12	15.8	6.0	6.2	3.03	2.1-10.4	<.01	.65

*Group 1=parents who rated proxy QoL lower than child, Group 2=parents who proxy rated QoL higher than child

Co-morbidities

Independent samples t-tests were carried out between children with ADHD only and children with co-morbid ASD and a co-morbid LD (see table 7). No significant differences in mean scores were observed between any of these groups for both parent rated and child rated QoL. There were also no significant differences in parent stress scores between the groups.

	ASD group	**(n=20)**	**ADHD only group**	**(n=17)**				
	M	SD	M	SD	MD	CI 95%	*t* value	*p* value
Parent rated QoL	39.7	8.4	43.8	11.0	4.06	-2.4, 10.6	1.27	.212
Child rated Qol	45.8	5.4	46.3	9.3	0.57	-4.4, 5.5	.22	.83
Parent stress score	21.9	7.0	18.9	6.2	2.9	-1.6, 7.4	1.3	.20
	LD group	**(n=6)**	**ADHD only group**	**(n=17)**				
	M	SD	M	SD	MD	CI 95%	*t* value	*p* value
Parent rated QoL	40.5	9.8	43.8	11.0	3.3	-13.9, 7.3	.64	.53
Child rated QoL	44.8	7.3	46.3	9.3	1.5	-10.2, 7.2	.41	.69
Parent stress score	18.3	5.5	18.9	6.2	.61	-6.6, 5.4	.21	.84

Table 7. Comparisons between ADHD only and co-morbid ASD and LD groups for QoL and parent stress scores

Predicting Child QoL from Parent Stress

Preliminary analysis.

Table 8 shows the inter-correlations among all major variables. Presence of co-morbidities was not significantly correlated with Parent rated QoL or Child rated QoL. Symptom Severity (where high symptom severity scores indicate fewer symptoms) negatively correlated with Parent Stress ($r(41)=-.36$, $p<.05$) and positively correlated with Parent rated QoL ($r(41)=.44$, $p<.05$), but was not correlated with Child rated QoL ($r(41)=-.20$, $p=.22$). Parent stress was also negatively correlated with both Parent rated QoL ($r(44)=-.63$, $p<.01$) and Child rated QoL scores ($r(44)=-.32$, $p<.05$). Parent rated QoL and Child rated QoL scores were positively correlated ($r(44)=.67$, $p<.01$).

Variable	Co-morbidities[a]	Symptom Severity[b]	Behavioural Intervention □	Parent Stress	Parent rated QoL	Child rated QoL
Co-morbidities[a]	-					
Symptom Severity[b]	.09	-				
Behavioural Intervention □	-.07	-.21	-			
Parent Stress	.15	-.36*	.31*	-		
Parent rated QoL	-.24	.44**	-.30*	-.63**	-	
Child rated QoL	-.15	.20	-.21	-.32*	.67**	-

Table 8. Inter-correlations between parent stress and major contextual variables.

[a] No co-morbidities was coded "0", one or more co-morbidities was coded as "1"

[b] Higher symptom severity score indicates fewer ADHD symptoms

□ Behavioural Intervention was coded "0" for not participated, "1" for have participated

*p<.05 **p<.01

Inter-correlational analysis showed that participating in a behavioural intervention was negatively correlated with parent rated QoL (r(44)=-.30, p<.05). As this was a dichotomous variable (they had either participated or not) it indicated that parents who had participated rated their child's QoL significantly lower than parents who had not. The authors reasoned that it is highly unlikely that the behavioural intervention negatively impacted on the child's QoL. A more realistic interpretation is that parents who find it harder to cope are more likely to be referred to and access such programmes. This is supported by the fact that participation in a behavioural intervention was significantly correlated with increased parent stress. There may be other factors that lead some parents to access these groups, such as lack of support at home, and poor knowledge of managing difficult behaviours. The negative

correlation suggests the behavioural intervention variable in this instance served to simply identify a group of participants who were more likely to access support. It was therefore considered to be misleading to add this variable to the regression model as an indicator of the impact of behavioural intervention programmes.

Regression analysis.

In this hierarchical multiple regression model, the variables co-morbidities and symptom severity were entered in the first step, and parent stress was entered in the second step. Co-morbidities was a dichotomous variable, where 0 indicated no co-morbidities and 1 indicated that the child had one or more co-morbidities. Symptom severity and parent stress were continuous data variables. The results of the first regression model (see table 9), with parent rated QoL as the dependent variable, revealed that at stage one, the symptom severity and co-morbidities variables contributed significantly to the regression model, (F=7.1, p<.01), accounting for 27% of the variation in parent rated QoL. Introducing the parent stress variable at stage 2 explained an additional 22% of variation in parent rated QoL and this change in R^2 was significant, (F=11.98, p<.001). Having a co-morbidity was no longer a significant predictor of parent rated QoL once parent stress had been added to the regression model. Together the three independent variables accounted for 49% of the variance in parent rated QoL.

Table 9. Hierarchal multiple regression of co-morbidities, symptom severity and parent stress on parent rated QoL.

Variables	*F*	*r*	R^2	R^2ch	Sig *F*	β
Step 1	7.1	.52	.27	.27	.002	
Co-morbidities						-5.37*
Symptom Severity						0.535**
Step 2	11.98	.70	.49	.22	.000	
Co-morbidities						-3.6
Symptom Severity						0.31*
Parent Stress						-1.73***

Note: R2ch=refers to the change in R^2 (the amount of variance added at each step). *p<.05, *p<.01 ***p<.001

The results of the second hierarchical multiple regression (see table 10), with child rated QoL as the dependent variable, revealed that at stage one, the Symptom Severity variable and the Co-morbidities variable explained 6% of the variance in child rated QoL, however these variables were not found to contribute significantly to the regression model (F=1.28, p=.29) (Table 6). Introducing the parent stress variable at stage 2 explained an additional 6% of variation in child rated QoL but this change in R^2 was not statistically significant, (F=1.74, p=.17). Together the three independent variables accounted for 12% of the variance in child rated QoL but this was not statistically significant.

Table 10. Hierarchal multiple regression of co-morbidities, symptom severity and parent stress on child rated QoL.

Variables	*F*	*r*	R^2	R^2ch	Sig *F*	B
Step 1	1.28	.25	.06	.06	.29	
Co-morbidities						-0.30
Symptom Severity						0.18
Step 2	1.74	.35	.12	.06	.17	
Co-morbidities						-1.5
Symptom Severity						0.1
Parent Stress						-0.29

Note: R^2ch refers to the change in R^2 (the amount of variance added at each step). *p<.05

Discussion

Parent Child Agreement on QoL

The first aim of this study was to compare parent and child perspectives of the child's quality of life, and to examine the impact of parents' perceived stress levels on observed discrepancies. The majority of parents in the sample rated their children's QoL more negatively than the children rated their own QoL, and these differences were found to be statistically significant. This trend suggests clear perceptual differences in the way both parties interpret the child's experiences and is in line with a growing body of paediatric research which has reported similar patterns in other samples of children with ADHD (e.g. Bastiaansen et al., 2004; Gürkan et al., 2010; Pongwilairat et al., 2005; Schei et al., 2013; Sciberras et al., 2011; Thaulow & Jozefiak, 2012), and with a range of other health conditions (Eiser & Varni, 2013; Upton et al., 2008).

Previous research has also suggested that across health conditions, parent-child agreement is often better for objective, observable domains than for more subjective domains

(Eiser & Varni, 2013; Upton et al., 2008) and the same trend was observed here. There was significant disagreement between parents and children on the mood, friends and school domains, while there were no significant inter-rater discrepancies on health and family domains. Limitations on a child's physical health are usually directly observable, and family functioning is usually accessible for a parent - as an active participant - to observe and interpret. Comparably, however, a parent's interpretation of their child's internal experiences of emotion, of school and of their peer relationships, is likely to be more subjective and may depend more on direct reports of events such as bullying.

Parent stress was not significantly correlated with bi-directional discrepancies in parent-child agreement overall; however, high parent stress was associated with more negative ratings of the child's QoL. This suggests that the direction of the difference is important to the relationship between parent stress and agreement between children and their parents. For example, parents who have lower levels of stress may still disagree with their child's assessment, but it is more likely that they will rate the child's QoL more positively than the child rates it himself. This finding may suggest that parents who experience more stress (and thus feel less in control and able to cope), perceive their child's symptoms and behaviours as more debilitating than parents who feel more in control and able to cope.

However, as the analysis does not elucidate the direction of the association, it is also feasible that features of children with poor QoL cause their parents to experience more stress. Children who have poorer QoL may have more severe ADHD symptoms and/or more co-morbid conditions. Given that ADHD behaviours are largely externalising, and that co-morbid conditions are likely to add complexity to a child's presentation, it seems reasonable to assume that the contribution of these variables to a parent's perceived stress levels may be substantial. Controlling for the complexity and severity of the child's condition enabled further delineation of the contribution of parent stress to both assessments of the child's QoL.

Predicting Child QoL from Parent-Ratings

A major finding of this study was that parent stress contributed significantly to parent ratings of the child's QoL over and above the severity or complexity of the child's condition. In line with attribution theory, this would indicate that parents who perceive that they do not have the resources to cope with the demands placed on them, assess their children as having poor QoL. This may suggest that parents' perceived stress and ability to cope acts as a source of bias in their assessments of their child's QoL. This is consistent with previous evidence that parents who report their own psychological health as poor tend to rate their children's QoL more poorly (Janicke et al., 2007; Kobayashi & Kamibeppu, 2011; White-Koning et al., 2007).

However, many authors exploring self-concept in children with ADHD have proposed that they may construct an overly optimistic perspective of their situation, in order to cope with negative experiences and protect their self-image (Hoza et al. 2002.; Owens & Hoza 2003). Thus parental assessments may be a more reliable indicator of the child's experiences, and parent stress may be a key target for clinical interventions in reducing distress in children with ADHD. In this case, because the study was cross-sectional, it was not possible to determine the causal nature and direction of the relationship between parent stress and parent-rated child QoL. Nonetheless, these findings at the very least support the need to adjust for parent stress in models of parent-reported child QoL, and to interpret parent rated measures with a degree of caution.

In line with Klassen et al.'s (2004) study, the presence of one or more co-morbidity was also found to be a predictor of parental perceptions in this study. However, this variable was no longer a predictor of parent rated QoL once parent stress had been added to the regression model. This indicates that parent stress is likely to have accounted for most of the

effect of co-morbidities on parent ratings. This is further supported by the finding that parent stress scores did not differ significantly in children with co-morbid ASD or LD. Symptom severity remained a predictor of QoL after parent stress was added to the model, suggesting symptom severity should be controlled for in future research. Were there not a significant correlation between symptoms and QoL, the relationship between ADHD and QoL would be questionable. On the other hand, if the two variables were highly correlated there may be doubts as to whether QoL offered anything additional to our understanding of ADHD. Symptoms and QoL were significantly and moderately correlated in this study, which supports the notion that QoL and symptom severity are distinct constructs, and that QoL offers additional understanding of the child's difficulties over and above the symptoms of their condition

Predicting Child QoL from Child-Ratings

None of the three variables analysed were found to be significant predictors of child rated QoL. Given the association between parent stress and uni-directional inter-rater discrepancies, it is un-surprising that it has predictive power for parent ratings but not child ratings within the sample.

Parents in the study reported high levels of perceived stress, and it is unlikely that these did not impact on their children's QoL. Considerable research has demonstrated that maternal stress negatively impacts on the nature of the mother-child relationship. Stressed mothers have been found to be less responsive and empathic with their children (Whaley, Pinto, & Sigman, 1999), show fewer positive emotions and engage in more criticism, hostility and negativity (Downey & Coyne, 1990). Children of stressed parents are ultimately at greater risk of receiving reduced emotional and practical care (Kavanaugh et al., 2006; Leiferman, Ollendick, Kunkel, & Christie, 2005). These associations may be particularly problematic for children with ADHD, who face additional psychosocial and academic

challenges, and are likely to need increased emotional and practical support from parents. Stressed parents may struggle to maintain clear boundaries and manage challenging behaviours, resulting in more negative experiences for their children. In turn this pattern may contribute to the poor outcomes which are often observed in children with ADHD.

The finding that child rated QoL scores did not differ between children with ADHD only and those with a co-morbid LD or ASD may offer some insight into why the independent variables did not predict child rated QoL. Children with other neuro-developmental disorders such as ASD and LD tend to have poor reflective capacity, which is likely to influence their self-reported QoL. Had there been clear differences in QoL scores between these groups, it may have been possible to attribute some of the discrepancies between parent and child scores to the high proportion of children with co-morbid ASD and/or LD in the sample. However, the homogenous nature of the QoL scores between these groups suggest that children with ADHD (without co-morbidity) have a similar reflective capacity to children with these additional diagnoses. Children with ADHD typically have deficits in their executive functioning which may inhibit their reflective capacity. Specifically, problems with response inhibition and metacognition are likely to affect children's ability to 'hold a thought' and 'think before they act' and organize information so that it allows for a deeper understanding.

Additionally, there may be other factors which have not yet been considered which have greater significance to the child's evaluation of their QoL, and researchers may need to think creatively to uncover what these are. Sciberras et al. (2011) found that children who rated their QoL more positively than their parents had higher self-worth than children who rated their QoL lower than their parents, while Dallos et al. (2014) found some evidence of associations between children's age and gender and their QoL. Neither age nor gender was significantly correlated with QoL within the current sample, and the postal survey design

meant that the authors chose to keep the number of child completed questionnaires to a minimum. However, these variables may provide a foundation for continuing research in this area, particularly with larger samples.

This study was an attempt to gain clearer delineation of the characteristics of children's QoL that are independent of the complexity or severity of their condition. The results expand the evidence base in three ways. Firstly, they highlight that parent stress may negatively contribute to the QoL of children with a diagnosis of ADHD. Secondly, they indicate that parent stress may affect the way parents interpret and report their child's experiences. Finally, they suggest that children with ADHD, like children with other neuro-developmental disorders, may have reduced capacity to self-reflect and accurately describe their QoL.

Limitations of the Study

The results of the current study should be interpreted with its limitations in mind. The cross-sectional nature of the study limits assumptions of causation. The sample size is relatively small, meaning replication with a larger number of participants is advisable. The age range excluded approximately 15% of the population of children with ADHD, and this may have impacted on the results. Children over the age of 14 are likely to have greater reflective capacity than the younger children in this sample and they are not represented in this study. The study did not use a control group. While it is well established that parents of children with ADHD have increased stress compared with parents of healthy children, it would be advantageous to assess the impact of parent stress on healthy children's experiences, so that comparisons could be made. A consequence of the convenience sampling method was that the study did not allow for an analysis of children with ADHD who were not taking medication. Additionally, child co-morbidities were parent-reported, meaning un-

diagnosed conditions, particularly internalising difficulties, may not be accounted for. As symptom severity was parent reported, it is thus also potentially as sensitive to the impact of parent stress as parent rated QoL. Ideally symptoms would be rated by a third party such as a clinician or teacher.

It is likely that the generalisability of the sample is affected by differences in prevalence rates and methods of diagnosis across teams and services, as well as clinicians' individual views and experience. Further, a national study carried out by NHS Quality Improvement Scotland (2008) suggested that in Scotland ADHD is significantly underdiagnosed in school aged children. Only 0.6% had a diagnosis, compared with the national prevalence rate (3-9%) (NICE, 2008). Therefore, the sample may consist of more severe cases than are observed in the wider population of children with ADHD, which raises questions about the generalisability of the results. Finally, a significant amount of the variance in QoL is left unexplained by the measures included in this study, particularly in relation to children's perspectives.

Implications for clinical practice

The study's findings further aid clinical understanding of the difficulties faced by children with ADHD and highlight a number of important issues relevant to clinical practice. That children with ADHD experience impairments in QoL further emphasises the value of incorporating QoL instruments as clinical assessment and outcome measures. Yet only half of ADHD services in Scotland use routine outcome measures (Health Improvement Scotland, 2012). Including child and parent measures is highly recommended given the trend for significant perceptual differences in their perspectives. Such differences, observed both in this study and the wider literature, are likely to benefit from exploration at an individual level. Where disagreement between a parent and child is substantial, a clinician may engage

both to consider the reasoning for their judgements, thereby eliciting important information regarding their perceptions and expectations, and the nature of the parent-child relationship. Negative parent scores may indicate stress and poor coping in the parent, and the clinician may address this directly with the parent by helping them to consider accessing sources of additional support.

Further, the study's findings may indicate that strategies other than those focussed on symptom reduction may be beneficial to children with ADHD and their parents. Services may consider incorporating stress management as a component of intervention programs that involve parents of children with ADHD, and promoting ADHD parent support groups and parent individual psychotherapy. A report published in 2012 highlighted that in Scotland, approximately 75% of parents of children with ADHD have access to behaviour management programmes (Health Improvement Scotland, 2012). However these usually cover generic behavioural and conduct problems. The same report details that behavioural interventions that are ADHD specific are likely to be more effective in supporting parents.

Implications for future research

As this was an exploratory study, further analyses of the impact of parent stress on parent and child ratings of child QoL are advisable, particularly utilizing larger sample sizes. Studies which compare the impact of parent stress on QoL across a range of clinically referred children will enable an understanding of how it might affect children differently according to the nature of their symptoms and associated impairments. Given that the symptoms of ADHD are generally externalising, and that children with ADHD have been widely inferred to have a positive outlook, comparisons with more internalising disorders such as anxiety and depression would be of considerable interest. Further, this study highlights the need for investigations into the factors which impact on the QoL of children

with ADHD, particularly from the child's perspective. Given the lack of previous research in this area, initial groundwork for this may be best achieved through qualitative analysis.

This study also highlights a need for greater understanding of *how* children and their parents make their judgements regarding the child's QoL. Davis et al. (2007) used qualitative methods to investigate the ratings of fifteen parent and child dyads on the KIDSCREEN and suggested that disagreement in scores was likely to be a result of different reasoning, rather than how they interpreted the items, which was generally very similar. The study utilized a sample of healthy children. However, considered in parallel with the results of the current study, Davis et al.'s (2007) findings may have important implications for the clinical interpretation of parent and child rated QoL measures. This is particularly relevant if child reported measures cannot be obtained and parent-proxy reported QoL is used to guide treatment decisions. Thus, in relation to ADHD, it is important for future studies to examine differences in child and parent reasoning on QoL measures, and to consider the role of parent perceived stress on such reasoning.

Conclusions

This study examined the impact of parent stress on the QoL of children with ADHD from the perspectives of children and their parents. The findings demonstrated that parents and children assessed the child's QoL differently, and increased parent stress was associated with parents rating their children's QoL as being poorer than children rated their own QoL. Further, the results suggested that parent stress negatively predicted the QoL of children with ADHD from parent perspectives, but not child perspectives. However, comparisons between children with ADHD only and children with co-morbid neuro-developmental disorders suggest that children with ADHD may have limited reflective capacity. These findings have important implications for the interpretation of parent and child rated QoL measures, and

regarding the potential impact of parent stress on the QoL of children with a diagnosis of ADHD.

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Appendix A. Submission Guidelines for the Journal of Attention Disorders

Journal of Attention Disorders (*JAD*) focuses on basic and applied science concerning attention and related functions in children, adolescents, and adults. *JAD* publishes articles including, but not limited to, diagnosis, comorbidity, neuropsychological functioning, psychopharmacology, and psychosocial issues. The journal welcomes manuscripts addressing timely, notable topics in practice, policy, and theory, as well as review articles, commentaries, in-depth analyses, empirical research articles, and case presentations or program evaluations that illustrate theoretical issues or new phenomena.

Submission

Style for all submissions must follow that of the *Publication Manual of the American Psychological Association* (6th ed.). Submission to the journal implies that the manuscript has not been published elsewhere and is not in consideration by any other journal. Submission to the Applied Research section should be no more than 30 double-spaced pages, including an abstract of 150 words or less using a sectional guideline (Objective, Method, Results, and Conclusion), a brief biographical statement for each contributing author, endnotes, references, tables, and figures, all on separate pages. Author names and affiliations should appear on a separate cover page and the manuscript should be formatted for anonymous review.

Journal of Attention Disorders only accepts submissions electronically. Electronic submissions should be sent to http://mc.manuscriptcentral.com/jad. Submissions must be in Microsoft Word. Please ensure that tables are editable files in Word or Excel, not images. Artwork should have a resolution of 300 dpi or higher. Images are best submitted separately from the text document. Please do not embed images into your file, as embedding raster image files (photographs) in Word or similar programs automatically reduces the resolution below what is needed for quality print publication.

Featured Sections

JAD features applied research. *JAD* additionally publishes unsolicited articles in three other sections: Research Into Practice, Research Briefs, and Literature Reviews. The first, Research Into Practice, should focus on well-developed areas of research with an emphasis on application and evaluation of practice. Specifically, the goal of these submissions is to illustrate how relevant conceptual and empirical principles can be implemented in evaluating and practice. Manuscripts should present theoretically sound and empirically documented principles and illustrate how these have been synthesized into practiced and proven interventions.

The journal is also interested in publishing articles in a Research Briefs section promoting the dissemination of new, novel, or otherwise important research information in a format that does not require extensive journal space. Research briefs should be substantially shorter than general articles: no longer than 15 pages, including tables, figures, and references. When submitting a manuscript for consideration as a research brief, the author should so stipulate and agree not to publish a more comprehensive version of the article in another source. Finally, the journal is interested in publishing literature reviews. These reviews should be no more than 50 double-spaced pages. Authors considering writing a literature review should consider contacting the editor before submission. JAD will also publish relevant letters describing interesting cases of developments in the field relative to clinical practice.

The journal also welcomes Letters to the Editor of no more than 300 words. Letters will be published at the editor's discretion. Opinion essays on relevant topics in ADHD are published by invitation only.

Appendix B. STROBE statement checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Appendix C. Letter of approval from the NHS Research Ethics Committee

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Bloomsbury
HRA NRES Centre Manchester
Barlow House 3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7815
Facsimile: 0161 625 7299

30 January 2014

Ms Helen Galloway
Trainee Clinical Psychologist
NHS Lanarkshire
CAMHS
194 Quarry Street
Hamilton
ML3 6QR

Dear Ms Galloway

Study title:	**Predictors of Quality of Life in Children and Young People with Attention Deficit/Hyperactivity Disorder (ADHD)**
REC reference:	**14/LO/0142**
IRAS project ID:	**138091**

Thank you for your email of 27 January 2014, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study and clarifications.

The revised documentation has been reviewed and approved by the Alternate Vice-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 Co-ordinator Dr Ashley Totenhofer, nrescommittee.london-bloomsbury@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.

Ethical review of research 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).

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.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

Additional Conditions Specified by the REC:

Please modify the Information for Staff in the following manner:

1. Under the heading 'Summary of the research' please add the following sentence 'This study has been given a favourable opinion by NRES Committee London – Bloomsbury.'
2. Under the heading 'What is the role of CAMHS staff in the study?' please add the following sentence 'The Principle Investigator within your team is [Insert the name of the local PI].'
3. Under the heading 'What is the role of CAMHS staff in the study?' please add the following after the first paragraph:
   Someone in the team will need to do the following:
   - Identify children on their caseload who has a diagnosis of ADHD
   - Address the envelopes
   - Distribute the envelopes

- Inform me of how many packs are sent out (if this is information you want)

4. Under the heading 'What is the role of CAMHS staff in the study?' please add the following sentence to the final paragraph 'The packs will be sent back to me.'
5. Under the heading 'Timeframe' please remove the first sentence.
6. Under the heading 'Timeframe' please add the following sentence after the second paragraph 'Please make sure that the packs are sent to the correct families.'

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

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 documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Investigator CV	Emily Newman	
Investigator CV	Helen Galloway	
Investigator CV	Nicola Miller	
Letter of invitation to participant	2	27 January 2014
Other: Response to Points raised by committee		
Participant Information Sheet: Staff	1	27 January 2014
Participant Information Sheet: Parent/Carer	2	27 January 2014
Participant Information Sheet: Child/Young Person	2	27 January 2014
Protocol	1	20 December 2013
Questionnaire: Depression Self-Rating Scale for Children	Validated	
Questionnaire: Demographic Questionnaires	1	12 December 2013
Questionnaire: PSS	Validated	
Questionnaire: Spence Children's Anxiety Scale	Validated	
Questionnaire: The SWAN Rating Scale for ADHD	Validated	
Questionnaire: KIDSCREEN-27 (Children and Adolescent)	Validated	
Questionnaire: KIDSCREEN-27 (Parent)	Validated	
REC application	3.5	10 December 2013
Response to Request for Further Information		27 January 2014

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

14/LO/0142	**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

Signed on behalf of:
Professor Faith Gibson
Alternate Vice-Chair

Email: nrescommittee.london-bloomsbury@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: Professor Charlotte Clarke – University of Edinburgh

Mr R Hamill - NHS Lanarkshire

Dr Emily Newman - University of Edinburgh

Dr Nicola Miller – NHS Lanarkshire

Appendix D. Letter of approval from Lanarkshire Research & Development office

Ms Helen Galloway,
Trainee clinical Psychologist
NHS Lanarkshire
CAMHS
194 Quarry Street
Hamilton
ML3 6QR

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 13 May 2014
Enquiries to Elizabeth McGonigal
R&D Facilitator
Direct Line 01236 712459
Email ElizabethMcGonigal@lanarkshire.scot.nhs.uk

Dear Galloway,

Project title: Predictors of Quality of Life in Children and Young People with ADHD

R&D ID: L13110

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

For the study to be carried out you are subject to the following conditions:

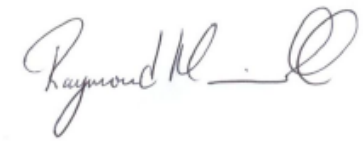
Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.show.scot.nhs.uk/cso/ or the Research & Development Intranet site: http://firstport/sites/randd/default.aspx.

- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,



Raymond Hamill – Corporate R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Professor Charlotte Clarke		Charlotte.clark@ed.ac.uk	Sponsor Contact
Dr Nicola Miller		Nicola.miller@lanarkshire,scot,nhs.uk	Named Contact

Appendix E. Letter of approval from Greater Glasgow & Clyde Research & Development (R&D) office

Coordinator/Administrator: JMcG/ LR
Direct Line: 0141 211 8548
E-mail: Joanne.McGarry@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor, 38 Church St
Glasgow
G11 6NT

30th July 2014

Ms Helen Galloway
Trainee Clinical Psychologist
CAMHS
194 Quarry Street
Hamilton
ML3 6QR

NHS GG&C Board Approval

Dear Ms Galloway

Study Title: Predictors of Quality of Life in Children and Young People with Attention Deficit/Hyperactivity Disorder (ADHD)
Chief Investigator: Ms Helen Galloway
GG&C HB site: Community
Sponsor: University of Edinburgh
R&D Reference: GN14AD294
REC Ref: 14/LO/0142
Protocol no: V2 dated 20/03/14

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information related solely to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
   a. Recruitment Numbers on a monthly basis
   b. Any change of staff named on the original SSI form
   c. Any amendments – Substantial or Non Substantial
   d. Notification of Trial/study end including final recruitment figures
   e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely

Joanne McGarry
Research Co-ordinator

CC: Dr Emily Newman, Academic Supervisor, University of Edinburgh
Dr Nicola Miller, Academic Supervisor, Belshill/Coatbridge CAMHS.
Professor Charlotte Clarke, Sponsor Contact, University of Edinburgh
NRSPCC, NHS Grampian

Appendix F. Letter of Invitation to Participants

Letter of Invitation to Participants

Dear Parent/Guardian,

You and your child are invited to take part in a research study looking at the quality of life of children with a diagnosis of ADHD. The study is taking place across NHS Lanarkshire and NHS Greater Glasgow & Clyde and is being carried out by Helen Galloway, as part of her Clinical Psychology Doctorate with the University of Edinburgh.

The details of the study are outlined in the participant information sheets provided in this pack. There is one for parents/guardians, and one for children/young people. The study is entirely voluntary, and neither you, nor your child, are obligated to take part. The care you receive from us will not be affected.

Please note that to be accepted into the study, both parents/guardians and the child/young person must complete the relevant questionnaires, as the study is investigating the paired responses of parents/guardians AND children/young people. Returned questionnaires where only the parent or only the child has completed responses will not be included in the study.

Please now turn to the relevant information sheets for more details about participating in the study.

Yours sincerely,

Example CAMHS Team

Appendix G. Participant Information sheet for Parents/Carers

Participant Information Sheet for Parents/Carers

You are invited to take part in a research study which aims to investigate the quality of life of children and adolescents with a diagnosis of Attention Deficit/Hyperactivity Disorder (ADHD).

About me

I am a Trainee Clinical Psychologist working in NHS Lanarkshire. As part of my Doctorate in Clinical Psychology at the University of Edinburgh I am carrying out a research project in collaboration with Child and Adolescent Mental Health Services (CAMHS) in a number of health boards across Scotland.

Why have you been contacted and invited to take part in the study?

You have been contacted because you care for a child with a diagnosis of ADHD.

What is the purpose of the study?

I want to find out about some things that might affect the quality of life of children living with ADHD. Previous research has shown that there is some evidence that the more severe a child's ADHD symptoms are, the poorer their quality of life will be. There is also some evidence that the more physical or mental health problems a child has, the poorer their quality of life is. I want to study whether these things have an impact on the quality of life of children with ADHD living in Scotland. I also want to study the impact of: ADHD medication; level of parental stress; and behaviour management programmes on children with ADHD. It is hoped that the findings of the study will offer a greater understanding of the difficulties faced by children with ADHD, and that it will highlight areas where appropriate support can be offered to children with ADHD and their parents/carers.

What will be involved if I take part in the study?

If you and your child would like to take part in the study, you should fill in the questionnaires which are marked for 'parent/carer'. I have included an information sheet for children/young people, which you should give to your child. If they wish to take part, they should fill in the form marked for 'child/young person'. There are five questionnaires in total, four for you and one for your child.

Once you have completed the questionnaires, you should return them in the pre-paid addressed envelope provided. Your responses would then be entered into a computer programme and analysed along with the responses from other participants.

BY RETURNING THE QUESTIONNAIRES YOU AND YOUR CHILD GIVE YOUR CONSENT TO PARTICIPATE IN THE STUDY

What about confidentiality?

All responses received from you and your child will be anonymous. You will not be asked to provide your name or your child's name or any other personally identifiable information.

Will I or my child come to any harm if we take part in the research?

I do not expect that you will come to any harm by taking part in this study. If there is anything in the questionnaires which makes you or your child feel upset, then it is recommended that you discuss how you feel with your CAMHS clinician.

What if I do not wish to participate in the study?

You do not have to take part in the study, your participation is voluntary. If you do not want to take part in the study, you can do this without giving reasons or explanations. Not taking part in the study will NOT affect your child's care.

My child has poor concentration. How will he/she be able to complete questionnaires?

The questionnaires for your child are short and only take a few minutes to complete. I am aware that your child may struggle to concentrate for much longer than this. If he or she is struggling to complete the questionnaires in one sitting, it may be easier to ask him or her to fill in each of questionnaires each day over three separate days.

What if I return my questionnaires but not my child's?

If you and your child decide to take part in the study, it is really important that BOTH the questionnaires marked 'child/young person' and the questionnaires marked 'parent/carer' are completed and returned. It is very important that ALL of the questionnaires are filled in.

How will I find out the results of the study?

A written summary of the findings from the study will be made available to all participating CAMHS services after May 2015. Please contact your CAMHS service after this date to obtain this. It is possible that results from the study will be published in a psychological research journal.

If you have any questions about the study, or about completing the questionnaires, please contact me at Helen.Galloway@lanarkshire.scot.nhs.uk or at the address below. Please return the questionnaires as soon as possible.

Helen Galloway

Trainee Clinical Psychologist

Child & Adolescent Mental Health Services

194 Quarry Street, Hamilton, ML3 6QR

Supervised by: Dr Nicola Miller, Specialist Clinical Psychologist, CAMHS, NHS Lanarkshire

Dr Emily Newman, Lecturer& Researcher, University of Edinburgh

Appendix H: Participant Information Sheet for Child/Young Person

Information Sheet for Child/Young Person

Hi. My name is Helen. I am a Trainee Clinical Psychologist. I am carrying out a research project so that I can find out more about what life is like for children and young people who have ADHD, and their families. I want to understand what things help to make life better for you, and what things can make life more difficult. I hope that this will help health professionals give the best care and support to you and your family and to other children with ADHD and their families.

What will I have to do if I want to take part?

I have made some questionnaires that will help me to find out about the way you and your family are feeling. I am asking other children with ADHD who live in this part of Scotland, and their families, to fill out the same questionnaires. There is one questionnaire for you to fill in. There are also some questionnaires for your parent or carer to fill in. Once you have filled them in your parent or carer will put them in the post box and send them to me.

How long will it take?

The questionnaire takes around 5 to 10 minutes to fill in. If you are finding it hard to do complete the questionnaire in one day, you can complete it over a few days.

What is the questionnaire like?

You won't have to do any writing. All of the questions just ask you to circle an answer. There are no right or wrong answers. Just try and choose answers that say how you feel.

What if other people find out what I have written?

Your will not be asked to write your name on the questionnaire. This means that no one will know which questionnaires have come from which person, not even me.

What if I get upset?

If there is anything in the questionnaire which makes you feel upset, then you should discuss how you feel with your CAMHS clinician.

What if I DO NOT want to take part in the study?

If you do not want to take part in the study, that's ok. You can do this without giving any reasons. Just tell your parent or carer that you don't want to take part. Not taking part will NOT affect your care.

What if I DO want to take part in the study?

If you do decide to take part, then simply fill in the questionnaire in the booklet marked 'child/young person' and give it to your parent or carer to post back to us. It is very important that ALL of the questionnaires are filled in.

How will I find out the results of the study?

The results of the study will be made available to your CAMHS service after May 2015. You or your parent or carer can contact your CAMHS service after this date to ask for a copy of this.

If you have any questions about the study, or about completing the questionnaires, you or your parent or carer can contact me at Helen.Galloway@lanarkshire.scot.nhs.uk or at the address below.

Thank you for reading and have a good day

Helen Galloway

Trainee Clinical Psychologist

Child & Adolescent Mental Health Services

194 Quarry Street

Hamilton

ML3 6QR

Appendix I. Information Sheet for Staff

INFORMATION SHEET FOR STAFF

About me

I am a Trainee Clinical Psychologist working in NHS Lanarkshire. As part of my Doctorate in Clinical Psychology at the University of Edinburgh I am carrying out a research project in collaboration with CAMHS in a number of health boards across Scotland.

Study Title: Predictors of Quality of Life in Children and Young People with ADHD

This study has been given favourable opinion by NRES Committee London – Bloomsbury. The main objective of the study is to analyse five clinical factors in order to determine their relative importance in predicting the quality of life of children and young people with a diagnosis of ADHD. I am also seeking to determine if there is a difference in self-reported and parent reported perceptions of the children's quality of life. Following an extensive review of the evidence base, the following variables have been selected:

- severity of ADHD symptoms
- level of parental stress
- number and type of co-morbidities
- participation in a parenting intervention
- current use of any ADHD medication

The effect of these five factors on quality of life will be investigated within a clinical sample of children and young people with a diagnosis of ADHD. Recruitment will take place across CAMHS teams within NHS Lanarkshire and NHS Greater Glasgow & Clyde.

It is hoped that the findings of the study will offer a greater understanding of the challenges faced by children with ADHD and their families, and assist clinical services by highlighting key areas where appropriate support can be targeted.

What is the role of CAMHS staff in the study?

I would be most grateful if your team could generate a list of names (in paper form) of **ALL** children or young people on your caseloads with a diagnosis of ADHD. On a pre-arranged date I will then visit your site and access the relevant case notes to determine whether the children fit the inclusion criteria and write the addresses on the envelopes. I will then destroy the list and post the packs out to the families.

The packs contain the following

- Letter of invitation to participate in the research
- Information sheet for caregiver
- Information sheet for child/young person
- Three standardised questionnaires will be completed by parents or carers
- One demographic questionnaire to be completed by parents or carers
- One standardised questionnaire to be completed by the child or young person
- A pre-paid envelope in which completed questionnaires will be returned

A full explanation of the study is provided for caregivers and children. The information sheets clearly state that participation in the research is voluntary, and that the care the family receives will not be affected in any way. They also state that by returning the questionnaires they give their consent to participate in the study.

The questionnaires for parents will take approximately half an hour to fill in. The questionnaire for children/young people will take five to ten minutes to complete (27 questions). Participants wishing to take part are asked to return the questionnaires as soon as possible. Information advising accessing the results of the study is also provided. The packs will be sent back to me.

I appreciate that all CAMHS teams are incredibly busy. Thank you for assisting me in collecting this important information. I hope it will be of value to CAMHS teams in the future.

If you have any questions about the study please contact me at Helen.Galloway@nhs.net or at the address below.

Helen Galloway

Trainee Clinical Psychologist

Child & Adolescent Mental Health Services

194 Quarry Street, Hamilton, ML3 6QR

Supervised by: Dr Nicola Miller, Specialist Clinical Psychologist, CAMHS, NHS Lanarkshire

Dr Emily Newman, Lecturer& Researcher, University of Edinburgh

Appendix J. Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

(TO BE COMPLETED BY THE CHILD'S MAIN CAREGIVER)

1) What is your relationship to the child? (please tick)

Mother ☐ Father ☐ Grandparent ☐ Legal Guardian ☐ Other ☐

2) How old is your child? _____

3) Is your child? Male ☐ Female ☐

4) Does your child have brothers or sisters who live in the house with them? If yes, please state how many? _____

5) How old was your child when they recieved a diagnosis of ADHD? _____

6) Has your child had a diagnosis of any of the disorders listed below?

Obsessive Compulsive Disorder (OCD)	☐	Conduct Disorder (CD)	☐
Oppositional Defiant Disorder (ODD)	☐	Learning Disability (LD)	☐
Autism Spectrum Disorder (ASD)	☐	Aspergers Syndrome	☐
Tic Disorder ☐	Anxiety ☐	Depression	☐

7) If your child has a diagnosis of any other physical or mental health problems not named above, please write the name/s here and at what age they were diagnosed.

_____

8) Does your child currently take any medication for ADHD? Yes ☐ No ☐

If yes please state the name and dosage of the medication _____

9) Have you or your child taken part in any of the following programmes that try and help manage ADHD behaviours?

Incredible Years ☐ Dinosaur School ☐ Triple P ☐ Mellow Parenting ☐

Other (please state name if possible) _____

10) How many sessions did you/your child attend?

One ☐ Two ☐ Three ☐ Four ☐ Five ☐ More than five ☐

11) Have you had support and/or advice about how to manage your child's ADHD behaviours from a CAMHS clinician? Yes ☐ No ☐

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