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YOUNG PEOPLE'S RELATIONSHIP WITH STIMULANT
MEDICATION IN THE CONTEXT OF AN ADHD DIAGNOSIS

Section A: Children and young people's accounts of stimulant medication

Word Count: 7,999 (13)

Section B: How do young people talk about stimulant medication, ADHD and
themselves: A discourse analysis

Word Count: 7,998 (389)

Overall Word Count: 15,997 (402)

A thesis submitted in partial fulfilment of the requirements
of the Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

February 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Summary

Section A provides a critical review of quantitative and qualitative literature related to children and young people's accounts of their experiences of taking stimulant medication to control symptoms associated with and ADHD diagnosis. The results were varied and contradictory. The majority of studies, both quantitative and qualitative, reported positive accounts of medication, despite acknowledging significant negative aspects, such as side effects. A minority of studies, and those focusing on adolescents highlighted an overall negative experience of medication. Identity issues related to medication were highlighted across studies, particularly in qualitative studies. The potential impact of age on medication experience is discussed, in the light of developmental theory and research.

Section B provides a discourse analysis of the accounts of thirteen young people aged 13-17, diagnosed with ADHD, related to taking prescribed stimulant medication. The young people drew on mostly positive repertoires regarding medication, in contrast to recent research with adolescent young people. Their accounts highlighted four ways of talking about medication (interpretative repertoires); *medication as transformative*, *medication as a tool*, *medication as inappropriate* and *medication as harmful*. Un-medicated selves were spoken about as 'bad', 'mad' and 'dangerous' across interviews. Dilemmas included balancing the valued 'fun' and 'lively' side the un-medicated self, with the sense of being in control and regarded as 'safe' by others when taking medication. Clinical implications and recommendations for engaging with wider meanings related to ADHD and medication are discussed.

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SECTION A: LITERATURE REVIEW

Children and young people's accounts of stimulant medication

Word Count: 7, 999 (plus additional 13 words)

Anna Tharia, BSc (Hons), MSc

January 2018

Abstract

Introduction

Attention Deficit/Hyperactivity Disorder is a common childhood mental health diagnosis and is often treated with stimulant medication. Historically, research regarding medication focused on parental views as part of an adherence agenda. Research focusing on children's ADHD experience, has suggested ambivalence and identity issues related to taking medication.

Method

This review, explored the qualitative and quantitative literature related to accounts of young people aged five to eighteen, of taking prescribed medication for ADHD symptoms. A systematic search of electronic databases was conducted. Papers were critiqued using relevant critical appraisal frameworks for qualitative and quantitative studies.

Results

Thirteen papers resulted from the search. The results of these were contradictory. While the majority of papers reported positive views and experience with medication, some qualitative studies highlighted ambivalent and negative views. Identity was a salient theme, particularly for adolescent young people.

Discussion

The potential influence of age on medication experience was discussed, and related to theories about developmental changes. The need for clinicians to involve young people in treatment decisions and engage with issues of identity were discussed. Research looking at the wider narratives around ADHD and medication, and embedding this in research with specific age groups would be valuable.

Word count: 199

Key words: ADHD, stimulant medication, psychotropic medication.

Introduction

Attention Deficit/Hyperactivity Disorder (ADHD) is a diagnosis included in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) (American Psychiatric Association, 2013) characterised by symptoms of inattention, hyperactivity and impulsivity. It is most commonly diagnosed in childhood, although increasingly adults are receiving this diagnosis (Harpin, 2005). In order for a person to meet the criteria for ADHD, symptoms must have been present before the age of twelve, should be evident in at least two settings with clear evidence that they interfere with social, academic or occupational functioning.

The rate of ADHD diagnosis varies according to region (Polanczyk et al. 2007). However, systematic reviews (e.g. Polanczyk et al., 2014) found this is largely due to differences in how the diagnosis is defined, rather than the level of symptoms. Wilcutt (2012) conducted a systematic review and meta-analysis of 86 studies of children and adolescents and found prevalence was between 5.9-7.1%.

Concepts of ADHD

Explanations for the aetiology of ADHD have been dominated by bio-medical explanations, supported by research evidencing differences in brain structure and function between those diagnosed with ADHD and controls (e.g. Curatolo, D'Agati, & Moavero, 2010). A key theory is that ADHD symptoms are caused by the dysregulation of neurotransmitter systems. In line with this theory, some genetic differences have been identified for genes implicated in neurotransmitter regulation, as well as environmental factors thought to interact with genetic factors (Kotimaa et al., 2003).

While bio-medical explanations of ADHD dominate, critics have questioned the existence of ADHD as a 'true' disorder (Timimi & Taylor, 2004; Visser & Jehan, 2009) citing the lack of

biological markers, high rate of comorbidity, higher rates of prevalence in boys and increased rate of diagnosis among deprived communities. Children who are socially disadvantaged are more likely to receive a diagnosis of ADHD (e.g. Counts, Nigg, Stawicki, Rappley, Von Eye, 2005), leading to the argument that behavioural symptoms indicating an ADHD diagnosis may have differing aetiologies, including emotional responses to stressors (Isaacs, 2006). This has implications for the treatment of ADHD, and in particular the appropriateness of medication. Other critics have suggested that ADHD is socially constructed, resulting in the medicalisation of behaviour which may be within typical range, particularly for boys, but is socially unacceptable (e.g. Timimi, 2005).

According to guidelines from the National Institute for Clinical and Health Excellence (2008), group parent training is recommended as a first line treatment for pre-school children and all children with moderate symptoms. Medication is only recommended as a first line treatment for children and young people exhibiting severe symptoms. Approximately one percent of children aged 6-12, are taking medication for ADHD in the UK (Taylor, 2014; McCarthy et al., 2012). Prescription rates have increased significantly over the past twenty years (McCarthy et al., 2009; McCarthy et al., 2012).

Medication prescribed as part of the ADHD care pathway can be non-stimulant, or stimulant, with the most common being methylphenidate. Stimulant medications increase levels of the neurotransmitters dopamine and norepinephrine by blocking their respective transporters (Heal & Pierce, 2006), and it is thought that this effect leads to the control of symptoms.

A large number of randomised controlled studies and reviews (e.g. Faraone, Biederman, Spencer, & Aleardi, 2006) have found that methylphenidate is effective at controlling the core symptoms of ADHD. However, a recent Cochrane systematic review (Storebø et al., 2015) questioned the quality of the evidence, reporting that all trials were at high risk of bias,

as researchers were able to ascertain the treatment group, due to the reporting of well-documented side effects.

Accounts of Medication

Historically, reports of medication effects, and satisfaction, have been reported by adults (e.g. Dosreis et. al., 2003; Johnstone & Fine, 1992). This is particularly noticeable for clinical trials, where the majority have used teacher and parent reports (Storebø et al., 2015), in line with the process for ADHD diagnosis. This highlights the relative absence of children and young people's perspectives about their diagnosis and medication. Studies focusing on parents' accounts of medication, outside clinical trials, have often been framed within an adherence agenda (Dosreis et al., 2006; Johnstone & Fine, 1992).

Young People's Accounts

Studies which have looked at children and young people's wider experiences of ADHD (e.g. Brady, 2014; Hallberg, Klingberg, Setsaa & Möller, 2010; Travell & Visser, 2008), have consistently highlighted the impact of medication, for young people. They suggest that children's relationship with their ADHD diagnosis and medication is complex and ambivalent (Brady, 2014), and that they are able to weigh up benefits and drawbacks of medication.

Studies have also highlighted the impact of diagnosis and medication on children and young people's sense of self. Hallberg et al. (2010) found that their teenage participants, while acknowledging that diagnosis and medication were necessary, viewed themselves as different from their peers, yet wished to be the same. They found that young people hid both their diagnosis and medication from their peers to protect themselves from the threat of stigma.

Young people's accounts of their relationship with psychotropic medication, for a number of conditions, have also highlighted an ambivalent relationship with medication. While young people spoke about the control psychotropic medication could give in terms of being able to function at a level that is expected of them (Murphy et al., 2015), they also spoke about the impact of stigma (e.g. Kranke et al., 2010) and identified behaviours that young people engaged in to protect themselves from stigma (e.g. Kranke et al., 2010; Kranke et al., 2011). These included not disclosing diagnoses and hiding evidence of medication, in line with Hallberg et al. (2010).

Childhood and Adolescent Development

Childhood is not one distinct developmental stage and children's relationship with medication (and diagnosis), including the impact on their sense of self, is likely to change over time. It is therefore not surprising that age has consistently been reported as a predictor of adherence to psychotropic medication (e.g. Hamrin, McCarthy, & Tyson, 2010; Stewart & Baiden, 2013), with adherence reducing as age increases.

Stage theorists (e.g. Erikson, 1968; Kegan, 1982; Loevinger, 1997) have proposed development as a procession through a number of stages. While these theorists have different focuses and orientations, they share similarities, in terms of the journey from childhood to adulthood being a process of individuation, separation and identity development. As different stages have different preoccupations, diagnosis of a childhood condition and taking medication for this, are likely to impact in different ways, depending on a child's age.

According to Kegan (1982) and Loevinger (1997), the youngest children, likely to be taking stimulant medication will be mostly governed by their impulses and have little sense of a self which is separate from this. In contrast, children who are at an age which corresponds to Piaget's (1932) concrete operational stage are more able to control their impulses. However,

self-interest is a primary motivator, and children at this stage are more concerned with not being found out for behaviour which might label them as ‘bad’, than with abstract ideas of personality. This corresponds with Harter’s (2012) explanation that children this age have not yet developed trait concepts of themselves, but rather impressions of their achievements and behaviours within specific domains.

Importantly, the period of adolescence has been characterised as a time of separation and identity formation (Erikson, 1968), with the key task to achieve an integrated sense of identity, where the young person’s inner sense of self is reflected back by others. During this time, young people become pre-occupied with how they appear to others, and the peer group is particularly important (Kegan, 1982) for reflecting a sense of who they are. Unlike younger children, adolescents become acutely aware if they are engaging in ‘false-self’ behaviour, that is, behaviour which presents themselves as different from their ‘true’ self (Harter, 2012). As discussed above, and in line with this, the literature concerned with adolescents’ experience of psychotropic medication, as well of studies of young people’s experience of having an ADHD diagnosis, have highlighted identity issues, and fears of the experience of stigma due to diagnosis and medication. This may have significant implications for young people, given Erikson’s suggestion that if this period is not successfully navigated this leads to identity confusion, with implications for the young person’s ability to find their role in the world as an adult.

It is important to understand children and young people’s experience of taking stimulant medication, in the context of an ADHD diagnosis. This includes the wider impact, as well as the immediate impact, and how the relationship with medication and diagnosis, may change as children develop.

Review Aims

The purpose of this report is to examine children and young people's relationship with medication, by critically reviewing the literature covering children and young people's perspectives on prescribed stimulant medication, to meet the following aims:

- 1) What do young people's own accounts tell us about their experiences of and relationship with taking medication for the symptoms of ADHD?
- 2) Is there any influence of age on young people's accounts of taking medication?

Methods

Eligibility Criteria

The eligibility criteria for this review included research papers with the following:

- Research (quantitative, qualitative and mixed-methods) into young people's self-report or accounts of taking psychotropic medication as part of their ADHD treatment.
- Study aims or research questions explicitly referred to medication, rather than treatment in general.
- Participants were aged between five and eighteen. Five was decided as the lower age limit as drug treatment is not recommended for pre-school children (NICE, 2013). Eighteen was decided as the upper age limit as the legal age of adulthood and because children are treated by distinct mental health/paediatric services.
- Children and young people's reports of medication experience formed a primary focus of the research and were analysed as a distinct group, if other accounts (e.g. parents) were included.
- Studies were published since 1998. This date range was selected because of the documented increase in prescribed medication for ADHD over this period (McCarthy et al, 2009).

Exclusion criteria

- Randomised clinical trials were excluded, to ensure that treatment was due to a clinical, rather than a randomising decision. Observational trials were included if treatment was planned as part of the child's care.

Literature Review

Five databases (PsychInfo, Medline, Pubmed, the Cochrane Library of Systematic Reviews, ASSIA) were searched on several occasions between August 2016 and January 2017.

Additionally, papers were hand searched from the references of papers.

The search terms:

‘ADHD’ OR ‘attention deficit hyperactivity disorder’ OR ‘attention deficit disorder’ OR
‘hyperkinetic disorder’

combined with (AND)

‘medication’ OR ‘drug’ OR ‘medicine’

combined with (AND)

child* OR ‘young people’ OR ‘young person’ OR ‘adolescen*’

Titles and abstracts of papers were screened for studies which met the inclusion criteria. This resulted in 13 papers.

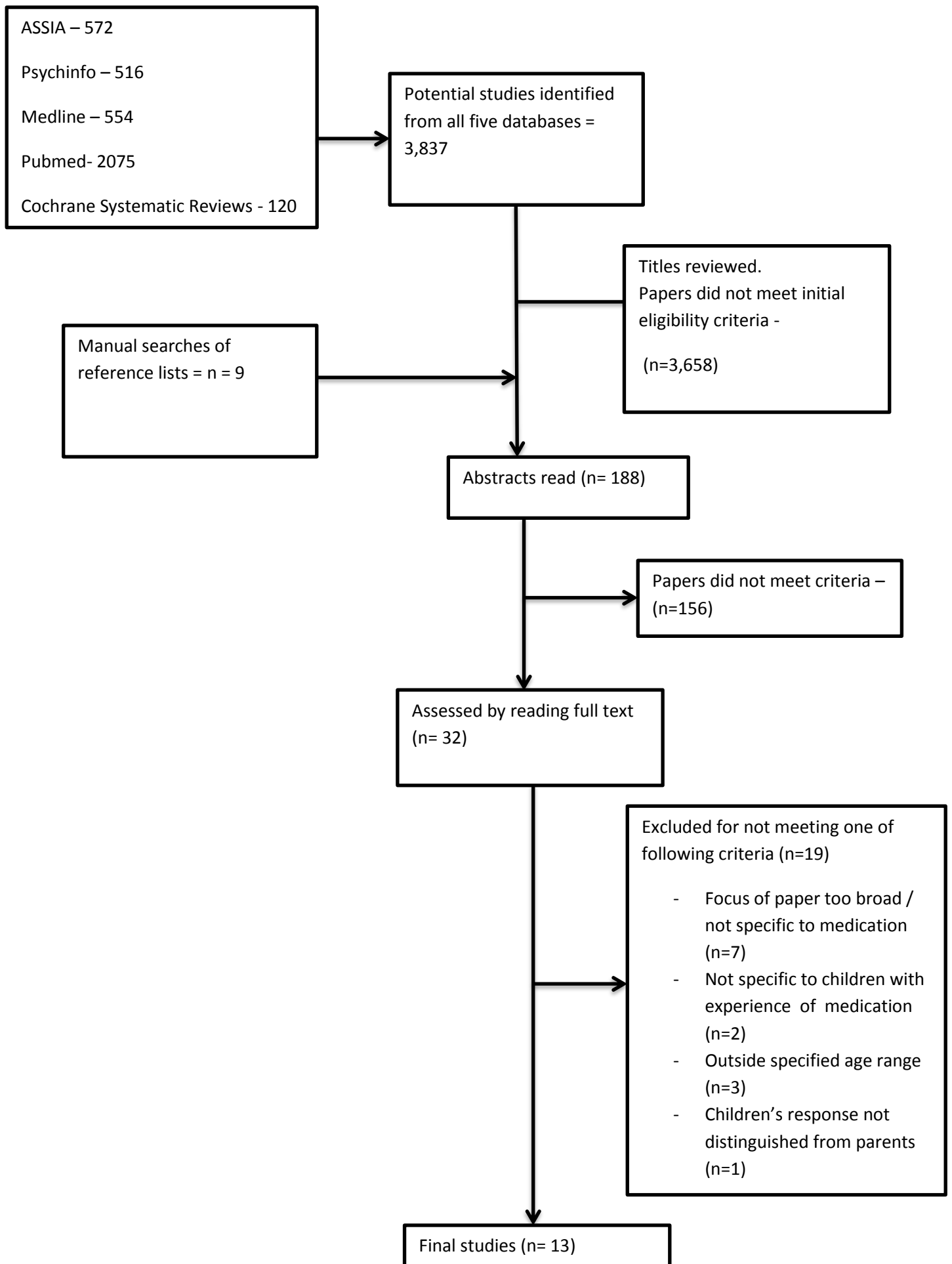


Figure 1. Flow chart illustrating literature search process

Assessing quality

The quality of each paper was critically evaluated. The qualitative papers were evaluated using Clark's (2003) RATs guidance of Relevance, Appropriateness, Transparency and Soundness. All quantitative papers were questionnaire based. Therefore the critical appraisal for a questionnaire study (Roever, 2016) was used. Outcomes of these critical appraisals are included in Appendix A and Appendix B.

Results

Thirteen papers (Table 1) were identified, six quantitative questionnaire studies, measuring satisfaction with, and attitudes towards medication, and seven qualitative studies, exploring experience of stimulant medication.

Table 1

Main Features of the Reviewed Studies

Authors	Date	Country	Participants	Design	Aim of study	Findings
Avisar & Lavie-Ajayi	2014	Israel	N=14 Age = 12.5-16.5	<u>Qualitative</u> Semi-structured interviews analysed using Interpretative Phenomenological Analysis	To explore experiences of adolescents of using stimulant medication	Young people described being passive actors in diagnostic process. Medication improved concentration but had emotional side effects, including identity loss and impacts on interpersonal relationships.
Berger, Dor, Nevo & Goldzweig	2008	Israel	Total N = 100 = 50 children and 50 parents Mean age = 12.5 SD = 2 years, 7 months)	<u>Quantitative</u> Survey design <i>Measures</i> 30 item measure designed specifically for study. Mix of forced choice, Likert-type and open questions.	To identify factors influencing attitudes toward methylphenidate treatment. To assess role of neurologist in the process.	Methylphenidate experienced as safe and effective by children and parents. Neurologist most effective factor in influencing adherence for children and parents. Children report less exposure to negative information about medication than parents and less concern about long-term effects of medication.
Brinkman et al.	2012	US	N=44 Age = 13-18	<u>Qualitative</u> Focus groups Inductive thematic analysis	To understand how young people with ADHD contribute to decisions about medication.	Adolescents have increasing role in managing medication.

Charach, Yeung, Volpe, Goodale and dosReis	2014	Canada	N=12 Age = 12-15 Also interviewed parents N=12	<u>Qualitative</u> In-depth interviews Analysed using interpretative interactionist framework	To explore beliefs and attitudes regarding use of medication and their influence on treatment decisions.	Different beliefs between adolescents and parents. Beliefs and attitudes influence treatment adherence. Input from adolescents important when making clinical decisions.
Doherty, Frankenberger, Fuhrer & Snider	2000	US	Total N = 925 = 86 children taking stimulant medication for ADHD 839 children no ADHD diagnosis Age = Mean age 13.7 (SD=1.4)	<u>Quantitative</u> Survey design <i>Measure</i> 35-item Likert scale specifically designed for study.	To examine the effects of stimulant medication on physical, academic, behavioural and social domains. To examine relationship between targeted outcomes, side effects and compliance.	Medication desirable more for social and behavioural impact than for academic. Side effects were common. Children not diagnosed with ADHD reported that they did not treat students taking stimulant medication differently.
Emillson, Gustaffson, Öhnström & Marteinsdottir	2016	Sweden	N=101 Age = 13-17	<u>Quantitative</u> Survey design <i>Measures</i> Medication Adherence Report scale (Horne & Hanks, 2004) Beliefs about Medicines Questionnaire-Specific (Horne, Weinman, & Hankins, 1999) The Brief Illness Perception Questionnaire (Broadbent, Petrie, Main & Weinman, 2006)	To increase knowledge about adherence for adolescents. To examine the influence on adherence of beliefs about medication, perceptions of ADHD, gender, age and time on medication.	Adherence was high and associated with stronger beliefs in the necessity of medication versus concerns about medication. Higher levels of adherence were also associated with less perceived side effects. There were some gender differences but no significant differences relating to age or time on medication.

Görtz-Dorten, Breuer, Hautmann, Rothenberger, Döpfner	2011	Germany	Total N = 1141 N=552 children N = 589 parents Age – 6-17	<u>Quantitative</u> Survey design <i>Measures</i> Satisfaction with medication scale (SAMS) (Görtz-Dorten et al., 2011). Correlated with ADHD symptom tracker measure Der Fremdbeurteilungsbogen für hyperkinetische Störungen (FBB-HKS) (Bruhl, Döpfner & Lehmkuhl, 2000) and Quality of Life measure (Ravens-Sieberer & Bullinger, 1998)	To analyse the psychometric properties of a new satisfaction with medication questionnaire. To report on parent and patient satisfaction with methylphenidate. To evaluate the predictive effect of ratings of ADHD symptoms and ratings of quality of life on satisfaction with medication.	Overall satisfaction with medication was high for both children and parents. Ratings of ADHD symptoms were positively correlated with medication satisfaction and negatively correlated with quality of life ratings were both. These two factors explained 36-52% of satisfaction variance.
Knipp	2006	US	N=15 Age = 14-17	<u>Qualitative</u> Semi-structured interviews analysed using thematic analysis based on Roy's modes of adaptation	To describe young people's perceptions of ADHD and medications for ADHD.	Medication was helpful at home and at school. Participants did not feel that the diagnosis or medication made them significantly different from their peers.

McNeal, Roberts & Barone	2000	US	N = 31 children N= 31 mothers Age = 7- 15	<u>Quantitative</u> Survey design <i>Measures</i> Parents' and Children's Perception of Hyperactivity Medication Questionnaires. Adapted from Baxley, Turner and Greenwold, 1978. Parent and Child Hyperactivity Medicine Side Effects Checklist (Physician's Desk Reference, 1991) Child and Parent Medication Knowledge Questionnaire designed for study	To assess children's and mothers' perceptions of stimulant medication. To test hypotheses regarding associations with, and predictors of, perceived medication benefits.	Mother's tended to perceive medication as more beneficial than their children, and had more knowledge about medication than their children.
Singh	2007	UK	N = 23 Age = 8-12	<u>Qualitative</u> Semi-structured interviews analysed using grounded theory	To explore children's moral self- understandings in the context of taking stimulant medication. To generate hypotheses about children's concepts of the authentic self.	

Singh	2013	UK/US	N=151 (A third taking medication) Age = 9-14	<u>Qualitative Mixed-methods</u> Semi-structured / structured interviews Systematic thematic analysis, discourse analysis, quantitative content analysis	To explore whether stimulant ADHD medication threatens authenticity and moral agency.	Children report that stimulants improve capacity for moral agency. Drug treatment may increase risk of threat to authenticity.
Singh, Kendall, Taylor, Mears, Hollis, Batty & Keenan	2010	UK	N=16 Age = 9-14	<u>Qualitative</u> Semi-structured interviews and focus groups analysed using deductive thematic analysis (framework approach)	To explore children's experience with stimulant medication to inform NICE guidelines	Children positive about taking medication. They reported that it reduced disruptive behaviour and improved social relationships. Stigma associated more with their behaviour than taking medication.
Thorell & Dahlström	2009	Sweden	N = 79 children N = 79 parents Age = 9-17	<u>Quantitative</u> Survey design <i>Measures</i> 18 item Likert scale designed for the study	To examine how children experience stimulant medication, in terms of positive and negative effects.	The majority of participants were positive about the effects of medication, although a minority reported a large number of negative effects. Parents and children's reports were broadly similar, although parents reported more positive effects for being more active and less angry. Parents also reported a higher level of negative effects.

Critical Review

Satisfaction with medication.

Three studies measured and compared child and parent satisfaction with medication quantitatively using questionnaires with Likert-style items. McNeal, Roberts and Barone (2000) surveyed thirty-one mother and child (age 7-15) dyads, using established measures to measure perceptions of medication. The authors found a significant difference between mothers' and children's perceived benefit of medication, using paired comparison t-tests, with mothers tending to report medication as more beneficial. Children's and mothers' scores did not differ significantly for illness concern, severity of symptoms, perceived costs and benefits, or level of side effects. Children's scores for illness concern were significantly correlated with their scores for the benefit of medication, indicating that children perceived medication more beneficial the higher their illness concern.

This study has a number of strengths including the use of established measures, adapted for ADHD medication, with good construct reliability and validity. The questions are clear and should be easily understood by both children and parents. Despite this, there are some weaknesses and limitations. The authors acknowledged that the relatively small sample size and therefore low power meant that one of their key research questions hypotheses, regarding predictor variables of perceived medicine benefit, could not be answered.

Görtz-Dorten, Breuer, Hautmann, Rothenberger, & Döpfner (2011) analysed the psychometric properties of a new satisfaction with medication 12 item measure for methylphenidate, in Germany. Children aged 6-17 years old, diagnosed with ADHD, and prescribed a long-acting formulation of the stimulant medication methylphenidate, completed the measure. Parents completed a parent version. Questionnaires were completed at three time points.

Overall the authors found over 70% of parents and 79% of children reported high satisfaction with medication, a difference which was statistically significant ($P < 0.001$). 63.0-75.6% of parents and 63.6-80.4% of children agreed or strongly agreed with the first eight items worded, all of which related to the clinical symptoms of ADHD (e.g. 'I am satisfied with how this medicine helps my child pay attention').

The large sample size of this paper, 589 parents and 582 children, is a considerable strength, as this increases the power of the calculations. In terms of reliability, the internal consistency for both parent ($\alpha = 0.96$) and child ($\alpha = 0.92$) measures were high, indicating that they were measuring the same general construct. The item total correlations were also high for parents, $r = 0.71$ to $r = 0.90$, although lower for children, in the medium to high range, $r = 0.57$ to $r = 0.77$.

A key weakness of this paper was the focus on the target symptoms of ADHD. The authors did not elicit responses for more nuanced impacts of medication, for example relating to stigma or identity issues and did not include items about side effects, despite adverse effects being well documented.

Also, the design of the questions in both of the above questionnaires is a significant weakness. For example, Görtz-Dorten et al. (2011) used an agree/disagree Likert-scale with positively worded items, as did McNeal et al. (2000) for perceived medication benefit (e.g. 'My child can sit still longer'). This lends responses to an acquiescence bias, as respondents are more likely to agree with the statement, than to disagree (Krosnick & Presser, 2010).

Additionally, the specific wording used for children 'My medicine helps me....', as opposed to parents, 'I am satisfied with...' may partly explain why children were more likely to rate medication as beneficial (Görtz-Dorten et al., 2011).

Thorell and Dahlström (2009) aimed to examine children's positive and negative experience of taking stimulant medication for ADHD, and their willingness to stop taking medication.

They compared children's and parents' responses. The authors surveyed 79 children, aged 9-17, and their parents, in Sweden, using Likert scale questionnaires, specifically designed for the study.

The authors found that most children were positive about the impact of medication on targeted symptoms, for improved concentration (83%) and for ability to sit still and do homework (over 70%). The most significant contributing factor to children's willingness to stop medication, measured using a stepwise regression model, was the belief that school was more fun when on medication. Significant differences between parents' and children's views, measured using paired *t tests* were found for the effects of getting angry less often and being less active, with parents reporting more positive effects. Parents reported significantly higher negative effects for all variables, except for not feeling like oneself when taking medication, reported by 13% of children.

One of this study's strengths is the inclusion of questions which relate to more nuanced impacts of medication. This allowed for ambivalent responses to medication to be highlighted. For example, only 20% of children wanted to stop taking medication despite almost half indicating that they were affected 'very much' or 'quite a lot' by side effects.

Other Questionnaire Studies.

Doherty, Frankenberger, Fuhrer and Snider (2000) surveyed 86 school children (US grades 6-12) taking stimulant medication and 839 children without an ADHD diagnosis in the US. Children who were prescribed stimulant medication completed a 35 item five point Likert scale questionnaire developed for the study, to measure perceptions of physical, academic and social effects of medication. Children without an ADHD diagnosis, completed a questionnaire regarding perceptions of children who took medication.

Children reported that medication was effective at helping them pay attention at school, behave better, and improve relationships. Negative effects included not feeling like themselves, the physical side effects, and reduced creativity. Approximately half the children stated they wanted to stop taking medication and half wanted to continue. Significant differences were found between the means for the three groups of achievement, social and behaviour, employing a one way repeated ANOVA. Further analysis using Tukey's honest significant difference tests identified that children rated questions about academic achievement significantly lower than those about social or behavioural functioning. The authors concluded that the study suggested that medication was more effective for behavioural and social difficulties than academic ones.

The authors asked a wide range of questions about the potential impact of medication across a number of domains, such as creativity and self, which is a strength. They also took steps to minimise common issues, such as an acquiescence bias, by including non-directional items. As the questionnaire was developed specifically for the study, it was not validated which is a weakness of the study.

Attitudes to Medication.

Two studies focused on the relationship between children's attitudes towards medication and adherence.

Berger, Dor, Nevo and Goldsweig (2008) surveyed 50 children in Israel, with a mean age of 12 years and 6 months, and their parents, to identify factors that affect attitudes to methylphenidate. Measures designed for the study covered epidemiology, source of information, common knowledge and compliance. Questions addressing attitudes asked about perceived effects, perceived safety and addictiveness. Other questions focused on what factors helped children to accept medication. Parents' and children's responses were

compared using a chi-square for non-matched comparisons and a McNemar test for matched comparisons.

The authors found the majority of parents and children, eighty percent in each group, reported a belief that methylphenidate was safe, and eighty-six percent of children reporting the belief that it was effective. A fifth reported the belief that methylphenidate is dangerous or addictive. The authors found the single factor most likely to influence attitudes towards methylphenidate for both groups was the explanation by the neurologist. Parents were significantly more likely to worry about the long-term adverse effects of medication, and reported higher exposure to negative information about medication both before and after treatment had started.

The comparison of responses in two ways, between individual parent and child, and as groups, is a key strength as it allowed the authors to assess consistency. A limitation is the narrow range of inferential statistics used. The authors could have performed correlational tests between respondents' attitudes towards medication and exposure to negative information about medication. Also, this study was situated within a compliance agenda. This is reflected in some of the wording of the questions, for example, 'Helped me in accepting medication...'. Therefore, the aims of the study, to identify what factors influence attitudes towards medication, while clinically relevant, are not clinically neutral, as the benefits of medication are already assumed.

Emilsson, Gustafsson, Öhnström, Marteinsdottir (2016) researched the influence of beliefs regarding medication, and perceptions of ADHD, on adherence. Young people in Sweden aged 13-17, completed three established measures for level of adherence, medication beliefs and illness perception. The authors used a wide range of descriptive and inferential statistics, including Mann-Whitney's U test to compare mean scores for groups, Pearson's correlation

coefficient to explore associations between variables and multiple regression models to investigate predictive variables.

Mean adherence was reported as high (88% of possible score) and positive adherence was associated with less perceived side effects, lower concerns about medication and higher scores for the perceived necessity of medication. Predictive variables of adherence included the differential between the medication necessity and concern scores, and the side effects item. Gender differences were found, with boys reporting a higher belief in their ability to control their symptoms.

This study's strength included its scope, use of measures with high reliability and validity, taking into account perceptions of ADHD, as well as medication, and the number of variables that were tested, such as gender and age.

Critique of Questionnaire Studies.

The above studies are unusual in eliciting children's views and attitudes towards medication, where adult views have traditionally informed clinicians and research. The studies range in scope, from focusing solely on the targeted effects and side effects of medication, to more wide ranging questions regarding creativity and identity. However, questionnaire studies in general fit into a positivist understanding of views and accounts and are therefore subject to criticism from a relativist position.

The assumptions behind questionnaire studies are that views and attitudes are stable positions that can be measured and located on a dimension. However, Potter and Wetherell (1987), in their work on attitudes, illustrated the importance of the context of the subject, variability in participants' responses to the same subject, and crucially the inability for the "object of thought", in this case ADHD or stimulant medication, to be distinguished from the position

on the dimension. This is illustrated most clearly by questions such as ‘Do you behave better in school when you take your medicine?’ (Doherty et al., 2000). Contained in this question are cultural understandings of what it is to behave well in school in Sweden, a western country. Additionally, as these questionnaires are completed by children and young people, who range in age from six to seventeen, the understanding of what it is to behave better, will be partly dictated by cultural expectations of behaviour at certain ages or stages. Age is also likely to affect responses to questions about the effect of medication on identity and sense of self, because the meaning of self and importance of identity changes across childhood (Harter, 2012).

Experience of Medication.

Qualitative research can allow more complex and contradictory aspects of the relationship with medication, to be explored, and there have been a number of qualitative studies which have researched aspects of this relationship. Two studies focused on exploring the experience of taking medication in general, without focusing on a particular aspect of this.

Singh et al. (2010) were commissioned by NICE to research children’s experience of stimulant medication, due to a research gap in this area. Sixteen young people aged 9-14 took part in the study, through semi-structured interviews or focus groups, analysed thematically. The process of analysis was deductive, and inductive using a coding frame.

The majority of participants spoke positively about the impact of medication across domains, including social behaviour in terms of impulse control and reduced aggression, ability to focus and a positive impact on academic achievement. Negative aspects included medication being described as ‘annoying’. The authors found that most participants saw their sense of self as unchanged by taking medication, although they also expressed ambivalence about their non-medicated self as sometimes ‘fun’, sometimes ‘annoying’. Participants related

experiences of stigma to ADHD behaviour, rather than medication, although examples of bullying included references to medication (e.g. 'tablet-boy').

This study had direct clinical relevance, as its remit was to explore children's experience of stimulant medication to address a gap in the knowledge and inform NICE guidelines. The knowledge produced directly addressed the research objectives, to explore the perceptions, knowledge and attitudes about stimulant medication among young people who were service users within the National Health Service in England.

However, there were some weaknesses and limitations, concerning clarity about the research process. While the general aim of the research was stated, there were no explicit research questions. The process for data analysis also lacked clarity. The coding frame was not included in the published study and it was not clear how the authors had brought together a deductive and inductive approach.

A key area is also the interpretation of the results. For example, the authors concluded that taking medication itself did not lead to stigmatizing attitudes from peers with stigma being more related to ADHD symptoms. However, some of the reported bullying remarks included reference to medication. An alternative interpretation could be that of a complicated picture in which symptoms, diagnosis and medication influence stigmatizing attitudes.

Avisar and Lavie-Ajayi (2014) aimed to explore Israeli adolescents' experience of using stimulant medication, and the course of diagnosis and treatment. The authors conducted semi-structured interviews with fourteen young people aged between 12.5 years and 16.5. Interpretative phenomenological analysis was employed to examine the subjective experiences of the young people interviewed.

The authors found that the participants spoke of an initial passive role during diagnosis and treatment. Young people spoke of differing impacts of medication on their academic work, with some young people reporting that medication helped with school work and exams, while others reported that it was an obstacle. The young people also spoke about the physical and emotional side-effects in terms of a loss of interest and motivation. A minority of participants spoke about medication separating themselves from others and suppressing their 'true' self. The authors noted that the majority of participants had stopped medication or started taking it selectively.

One of the key strengths of this study is the authors' acknowledgement of their own role in the research, as researchers with perspectives through which they are attempting to understand the experience of the participants. The lack of explicitly named research questions is a limitation which makes it difficult to evaluate whether the authors met their objectives. Also, despite the authors' sensitivity to the role of their own perspectives, participants accounts were treated as stable viewpoints, representative of experience, which may have limited a more complex analysis.

Sense of Authenticity.

Two studies conducted by Singh (2007; 2013) directly addressed whether children reported that medication affected their sense of authenticity, as changes in behaviour were driven by medication rather than choice.

Singh (2007) conducted semi-structured interviews in the UK with twenty-three children aged eight to twelve, and analysed these using grounded theory. Her purpose was to explore children's moral self-understanding and develop hypotheses about their concepts of a moral self, in the context of taking stimulant medication.

Singh found that while children acknowledged that medication helped them to behave better, they also consistently reported a stable sense of self, unaffected by medication. They reported this authentic self was 'bad'. Singh suggested that in light of this research, clinicians should pay attention to children's sense of self-worth and conversations about what makes a person good or bad would be helpful, to avoid children developing negative higher-trait concepts of themselves.

This research was clinically important as it addressed issues of self-esteem, identity and children's sense of responsibility for behaviour that had not been addressed in previous research. Singh also used an innovative and creative interview schedule, published with the article, using pictures of other children and dolls to explore children's views and understandings of themselves, ADHD and stimulant medication. Singh situated the research in the cultural context of Britain, by suggesting that in a culture where medication was used more widely the impact on self-worth may be less evident.

Singh (2013) drew on the large-scale VOICES (Voices on Identity, Childhood, Ethics and Stimulants) study to evaluate whether taking stimulant medication in the context of an ADHD diagnosis, threatened children and young people's sense of authenticity and moral agency. Participants were 151 children aged nine to fourteen from the UK and the USA, a third of which were diagnosed with ADHD and taking stimulant medication. Singh found that stimulant medication did not threaten the sense of authenticity for the majority of participants, with a minority (8%) reporting that it did. The majority of participants positioned medication as supporting their agency to make moral decisions, by suppressing their impulses to be 'bad'.

A limitation, rather than a weakness of Singh's studies, is the age range the research was carried out with, eight to twelve (Singh, 2007) and nine to fourteen (Singh, 2013). As

adolescence is a time of important developments in a young person's sense of self (e.g. Erikson, 1968; Loevinger, 1997), Singh's conclusions about the impact of stimulant medication on identity, is specific to middle childhood and cannot be to an adolescent population.

Young people and Decision- making.

Two studies focused on adolescence and how decisions were made about medication between young people and their families. Brinkman et al. (2012) interviewed forty young people aged 13 to 18 in focus groups to gain an understanding of young people's role in medication treatment decisions. The data was analysed using inductive thematic analysis. The authors found that with age young people take on an increasing role in medication decisions, with some beginning to use medication selectively or stop taking medication altogether. ADHD and medication had an impact on young people in several areas: school, social, personality, stigma and creativity. The authors discussed the increasing role that adolescents take in managing medication within a developmental trajectory of increasing independence.

This study addressed a clinically relevant research area, the involvement of young people diagnosed with ADHD, in treatment decisions. For a qualitative study, the project involved a large number of participants which increased the likelihood that different perspectives would be represented. The authors' sampling strategy, where equal numbers of potential participants were randomly selected from two age groups, ensured variability. The authors clearly outlined a collaborative and reflective process of analysis and interpretation which they conducted to avoid biased results.

One limitation was, despite a brief acknowledgement of the influence of group dynamics within the focus groups, young people's contributions were presented as stable viewpoints. This meant that co-construction of the topic by the young people was not fully explored, nor

was the context for young people of talking about a developmentally salient topic, increasing independence, among peers.

Charach, Yeung, Volpe, Goodale and dosReis (2014) explored the experiences of 12 young people aged 12-15 with diagnoses of ADHD and their parents about beliefs surrounding ADHD, attitudes towards stimulant medication and decision-making around medication. This involved semi-structured interviews, analysed thematically. Parents tended to support the use of medication, whereas young people reported a more complex relationship with medication, acknowledging academic and social benefits but also negative experiences including an impact on their sense of self. Half the participants reported feeling as though they were a different person when taking medication. The study also found that the majority of participants had stopped taking their medication, were in the process of stopping or envisaged stopping in the future.

This is the only qualitative study which looked at both young people's and parents' perspectives and is therefore a valuable addition to the extant literature, reflecting differences also highlighted by quantitative research. Weaknesses of the study included no clearly defined research questions and the representation of views as stable viewpoints.

Perceptions of Medication.

Knipp (2006) examined teen perceptions about ADHD and medication by interviewing fifteen teenagers aged 14-17 in the US using semi-structured interviews. She used a framework covering four domains; physiological, role functions, interdependence, self-concept/group identity. The interviews were analysed inductively using content analysis.

Knipp found that teenagers were generally positive about medication, despite finding it a 'hassle'. For example, 80% were positive about the effect of taking medication on their

school work. The majority of those interviewed reported good relationships with family, although two teenagers spoke about family conflict around medication. Teens' answers to questions about self-concept were varied, with seven reporting that diagnosis and medication did not affect their views about themselves, while five said that it did. Knipp concluded, *'Teens felt that they were everyday teenagers and that ADHD can be no big deal with the right medications.'*

There are a number of strengths to Knipp's study, including its place as an early qualitative study into young people's accounts of medication, and the focus on a particular age group. However, the use of already identified categories may have reduced the potential of the study to explore unexpected aspects of taking medication. Also, Knipp's conclusion is questionable given that a third of participants reported that medication changed their view of themselves.

Critique of qualitative studies.

The qualitative studies included in this review addressed important clinical issues, beyond the direct effect of stimulant medication. In general, the quality of the qualitative studies is strong, in terms of choosing a method which addressed the research objectives, and describing the data analytic process in detail. Studies that focused on a more targeted age group of adolescents (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014; Knipp, 2006) were able to explore the meaning and process of taking stimulant medication at a point of growing independence and changing sense of self.

However, there was a general lack of acknowledgement of the influence of the researchers on the knowledge that was produced. Research is a very particular context in which information is collected and researchers influence what is produced through their research design, research questions, interaction with participants, analysis and interpretation of the results. The majority of papers in this review did not reflect on their part in the production, or co-

production, of this knowledge, but rather presented the results as stable views and direct representations of experience. One paper stood out as an exception, by describing how the researcher is never able to get an 'insider's perspective', due to their own perspectives (Avisar & Lavie-Ajayi, 2014, p. 38).

Synthesis

The impact of taking medication.

The majority of studies included in this review found that children and young people were generally positive about medication. This was more evident in quantitative studies that measured views and satisfaction with medication, than in qualitative studies. For example, Görtz-Dorten et al., (2011) found that 79% of children reported high satisfaction with medication and Thorell & Dahlstrom (2009) reported that 83% scored 3 or 4 for improved concentration and above 70% for the ability to sit still and do homework.

The conclusions of the authors of the qualitative studies differed in terms of whether they reported that children were generally positive about medication (Singh et al. 2010; Singh, 2007; Singh, 2013; Knipp, 2006) or had a more ambivalent relationship with medication which acknowledged positive and negative aspects (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014).

In all cases, studies which compared parent and children's accounts of medication found important differences. The authors of the majority of the quantitative studies which compared parent and children's accounts found that children were less positive than parents about medication, and this was also reflected in the results of the one qualitative study which included parents' accounts (Charach et al., 2014). Only one study (Gortz-Dorten et al., 2011) found that children rated medication more positively than parents, and the results of this

study are undermined by the positive wording of questions, and the lack of questions relating to side effects or the wider impact of medication.

In terms of the wider impact of medication, only two of the quantitative studies (Thorell & Dahlstrom, 2009; Doherty, Fuhrer & Snyder, 2000) included questions related to this, such as whether the medication changed the child's sense of themselves. Thorell & Dahlstrom (2009) found that this was true for a minority of children (13%) and Doherty et al.'s (2000) figures, while unclear, suggest variability within the sample.

The qualitative research studies, which were more exploratory in nature, produced richer accounts of the wider impact of medication, including issues related to stigma and identity. Medication as a threat to the young person's sense of self was identified in a number of studies. However, there were differences in the amount of emphasis put on this impact of medication, with some studies indicating that this was mild or affected a small minority of participants (e.g. Singh et al., 2010; Singh et al., 2012) and others indicating a significant impact (Avisar & Lavie-Ajayi, 2014; Charach et al., 2014).

Factors that influence relationship with medication.

Two studies, (Emillson 2016; Berger et al., 2008) examined factors associated with adherence to medication for ADHD. Both studies reported high levels of adherence to medication among their participants, with Emillson et al. (2016) reporting that the mean score was 88% of the total possible adherence score and Berger et al. (2008) reporting that while a minority of children had stopped treatment at one point, all were now adhering to medication. However, the sample for these studies, children and young people who were currently taking medication for at least six months, meant that young people who had discontinued medication, and were therefore more likely to hold negative attitudes towards medication were not included.

Berger et al. (2008) found that the neurologists' explanation was the most important factor in the decision to start treatment for both parents and children. The authors also found that, while the main cause of negative attitudes among parents was concern about the long-term effects of medication, this was not the case for the children taking part in the study.

Emillson et al. (2016) conducted a more wide-ranging and complex study with adolescents and found that the level of adherence was associated with and predicted by high perceived necessity for medication to control symptoms, low concerns about medication, low perceived side effects of medication and higher perceived consequences of having ADHD. Gender was identified as a variable which predicted attitudes regarding the necessity of medication, with girls being more likely to rate medication as necessary.

Influence of Age.

The only study to directly examine an association between age and aspects of medication (Emillson et al., 2016), found no significant correlation between age and adherence. However, this may be partly explained because the age range of participants was already, narrow, confined to adolescents aged 13-17.

While qualitative studies are not designed to identify factors, and the qualitative studies in this review have too few participants in order for results to be transferable to the population, those studies focusing on adolescent participants, rather than younger children, were more likely to report an ambivalent relationship with medication and young people taking the decision to stop taking medication (Avisar & Lavie-Ajayi, 2014; Charach et al., 2014). These studies differed from the quantitative studies, in that they included participants who had stopped taking medication, which may partly explain this difference.

Identity issues were more prevalent in research with older participants. Identity issues were both linked with stigma regarding medication and diagnosis (Brinkman et al., 2012) and linked to the direct impact of medication, with young people describing medication as changing the way that they interacted with others, for example making them quieter (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014). Issues to do with self were also identified in the study with the youngest participants (Singh, 2007), aged eight to twelve. However, the nature of these accounts was different, so that rather than medication being seen as an obstacle to self, children identified their 'true' self as bad, and the medication as an aid to help them be 'good'.

The influence of age was also highlighted in the two studies (Brinkman et al., 2012; Charach et al., 2014) which focused on the role that adolescents take in decision making regarding medication and emerged as a theme in another study which explored the adolescent experience of medication (Avisar & Lavie-Ajayi, 2014). The young people who took part in these studies described a process of being passive in the process when younger, with decisions being led by clinicians and parents, but moving towards being an active decision-maker in the process. For some this led to conflict with parents, while for others this involved more collaborative negotiation. Their active role in decision making could involve choosing when to take medication, or for some participants choosing to stop medication altogether.

Discussion

Considering the extent that stimulant medication is prescribed to control the symptoms of ADHD, there are relatively few studies spanning the last twenty years which have examined children and young people's accounts of their relationship with medication. The small number of studies, from children and young people's perspectives, is in line with a lack of children's input in both the diagnostic process and in clinical trials of medication.

The results of the studies in this review are contradictory. The majority reported that children and young people were broadly positive about their medication, while acknowledging some drawbacks, such as side effects. Quantitative studies in particular found high satisfaction with medication and high adherence to medication. However, some of the qualitative research projects focused on adolescents (Avisar & Lavie-Ajay, 2014; Charach et al., 2014) highlighted a balance of negative aspects of medication with many participants planning or choosing to stop taking medication.

The studies in this review also highlighted identity issues related to medication. In line with research which has focused more generally on the experience of ADHD, these included experiencing stigma (Brinkman et al., 2012) and feeling different from peers. The direct impact of medication on the self, was also described by many young people, in terms of medication making them less sociable (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014). While the number of qualitative studies were few, and conclusions should be tentative, adolescent participants tended to focus more on the impact of medication as an obstacle to the 'true' self (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014). In contrast younger participants in one study viewed the medication as helping them to act better, against their 'true' self which was essentially 'bad' (Singh, 2007).

These differences may reflect differences in identity development across different stages of childhood. According to Harter (2012), children in the eight to twelve age group of Singh's (2007) study, are able to form comparisons between themselves and peers, and are therefore beginning to acknowledge negative as well as positive aspects of themselves. They are therefore likely to display 'false-self' behaviour to protect themselves and meet the expectations of others, and in particular adults. In this way, taking medication which results in children behaving in line with expectations at home and at school, could be seen as another form of 'false-self' behaviour. At this stage, however, false-self behaviour is not as distressing or threatening to children as when they reach adolescence. However, Singh (2007) has pointed out that this is the age when children are beginning to form a more global sense of self-worth, rather than appraising themselves in specific domains.. Therefore the concept of a self as 'bad' at this age, could have implications for future self-worth.

In contrast, for adolescents the role of the peer group takes on a special significance during adolescence (Kegan, 1982). According to Harter (2012) the increased importance of how others view the self during adolescence leads to 'impression management' (Harter, 2012, p. 331), which in turn creates a conflict for young people between a sense of a 'true self' and a 'false self'. The disconnection between 'true self' and 'false self', becomes distressing from early adolescence onwards. Therefore, if the experience of taking stimulant medication has the effect of separating oneself from the authentic self, and the young person feels that they must hide taking medication, in order for 'impression management', this is likely to be particularly distressing for them at a time when being authentic has become an important goal.

Limitations and strengths

To the author's knowledge, this is the first systematic literature review to examine children and young people's accounts of taking prescribed stimulant medication, in the context of an ADHD diagnosis. As such it is a valuable addition to the literature regarding young people's relationship with stimulant medication, and highlights differences, as well as similarities, between studies.

However, due to the relative scarcity of children's own accounts of medication in the literature, the author made the decision to include all studies which focused on children's and young people's relationship with medication. Therefore the thirteen papers in this review; include quantitative and qualitative studies, were conducted across different countries, and different age groups and focused on different aspects of medication experience. This means that definite conclusions are difficult to draw due to the heterogeneity of the studies in the review.

Clinical Implications

It is concerning that young people consistently refer to being passive participants in their treatment when first prescribed medication. While this is likely to be partly due to the developmental stage at which children are first prescribed medication, clinicians should be aware that young people's views about medication may be different from their parents even at a young age. They should therefore make efforts to increase children's agency during diagnosis and treatment, by seeking their views and contributions in an age appropriate way. As children develop through adolescence to young adults, it is important that clinicians continue to engage in an ongoing conversation about the meaning of an ADHD diagnosis, and the meaning and role of medication in their lives, to support the young person to make informed decisions about whether or not to stop taking medication.

Clinicians should pay particular attention to identity issues related to ADHD symptoms and to medication, and to be aware that these may have different implications depending on the age of the young person. Research in this review (Singh, 2007) suggests that younger children who are diagnosed with ADHD may have a negative self-concept of being 'bad', which remains unchanged by medication, although medication helps them to behave better. This suggests that clinicians should engage younger children in conversations about what 'goodness' or 'badness' is, to reduce the likelihood of children retaining a persistent sense of themselves as 'bad'.

For adolescents, it is more important that clinicians are aware of the potential impact of medication on the young person's sense of self and on peer relationships, which have a particular significance during adolescence. Medication may have a direct impact, by changing the way that the young person interacts with others, as it may make them feel less sociable or an indirect impact through stigma or the fear of stigma, which leads to them hiding the diagnosis and medication.

Further Research

The studies in this review have highlighted the value of focusing on different developmental stages when researching children and young people's relationship with medication. Authors of future research should consider this when deciding the sample of young people they wish research, as this will have implications for the way in which their participants make sense of diagnosis and medication, and the way in which these impact on their lives.

There is little research which connects the wider meaning of ADHD with children and young people's accounts of medication, despite indications that this is important. One of the quantitative studies in this review (Emillson et al., 2016) found that higher adherence to medication was predicted by more perceived consequences of ADHD. Qualitative research

(Charach et al., 2014; Brinkman et al., 2012) found that young people spoke of different meanings attached to ADHD, including ADHD as a disorder and as a personality trait. It is likely that the meaning of ADHD for the young person will impact the meaning of, and relationship with, medication.

Identity, and the impact of taking stimulant medication on a sense of self, was a consistent finding throughout the qualitative research and some quantitative studies. However, young people can be active participants in constructing the meaning of ADHD and medication as indicated in Charach et al.'s (2014) study, and these constructions are likely to have a real impact in terms of possibilities for their sense of self, and relationship with medication. For example, research into parents' constructions of ADHD has highlighted the implications for parents' accountability of positioning ADHD as a bio-medical or social condition (Brunton et al., 2014).

While the qualitative research included in this review had many strengths, as a body of literature, researchers tended to present the results as children's stable viewpoints. There is a need for further research which explores the discourses that young people have available to make sense of ADHD and stimulant medication, and ways in which they may actively position themselves, to negotiate their identity, successfully or otherwise, as young people with this diagnosis who take stimulant medication.

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SECTION B: EMPIRICAL RESEARCH

How do young people talk about ADHD, stimulant medication and themselves:
A discourse analysis

Word Count: 7,998 (plus additional 389 words)

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January 2018

Abstract

Introduction. Research into children and young people's experience of stimulant medication has been contradictory but suggests that adolescents may have more ambivalent views, and highlights identity issues related to this age group. There is a gap in the UK adolescent experience of stimulant medication. There is also a lack of research into the wider meaning of taking stimulant medication for an ADHD diagnosis.

Aims. The aim of this study was to research how adolescent young people talk about ADHD, medication and themselves using discourse analysis, and how available ways of understanding ADHD and medication may impact on how they make sense of themselves.

Method. This qualitative study employed a semi-structured topic schedule to guide interviews and a focus group with thirteen young people aged 13-17, analysed using discourse analysis. Additionally, leaflets available at child and adolescent services and related websites were analysed.

Results. Four different ways of conceptualising medication were identified, with implications for young people's sense of agency and control in relation to medication. The majority of participants talked about their un-medicated selves as dangerous, bad and out of control. Participants highlighted dilemmas related to balancing valued aspects of their un-medicated selves, with being in control and 'safe' when on medication.

Discussion. Clinicians should engage with the wider meanings of medication with young people, including family beliefs about medication. A focus on medication as a tool, rather than a cure, may empower young people to be decision makers. Clinicians should also be engaging young people in conversations about impact on self, in relation to medication.

Key words: ADHD, hyperkinetic disorder, stimulant medication, methylphenidate, psychotropic medication.

Introduction

This paper explores young people's discourses about taking medication for Attention Deficit Hyperactivity Disorder (ADHD). ADHD is one of the most common childhood mental health diagnoses, with the rate of diagnosis increasing significantly over the last twenty years (Polancyk, 2014). In this introduction the criteria, competing explanations and treatment recommendations for the diagnosis of ADHD will be outlined. Research focused on children and young people's experiences of ADHD medication will then be explored. Finally, the wider meanings of both diagnosis and medication will be discussed and related to theory around young people's developing identity.

ADHD diagnosis

The diagnosis of ADHD is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM V) (American Psychiatric Association, 2013). In the UK, while the term ADHD is commonly used, the diagnostic manual is the International Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organisation, 1993) and the corresponding diagnosis, which is more narrowly defined, is hyperkinetic disorder. Due to its wider usage, the term ADHD will be used throughout this paper.

As with all mental health diagnoses, ADHD or hyperkinetic disorder, as described in DSM 5 and ICD-10, are constructed categories evidenced by differences in symptoms between the two manuals. For example DSM 5 includes impulsivity as a symptom. There are no biological markers used in diagnosis as it is based on the observation of behaviours, the results of standardised questionnaires and subjective reports provided by parents and teachers. However, this does not mean that ADHD does not refer to a meaningful cluster of behaviours which cause distress for children and families.

The causes of the cluster of symptoms that make up the diagnosis of ADHD, and whether these symptoms have different aetiologies, have been a point of debate for many decades, with explanations ranging from neuro-biological (e.g. Curatolo, D'Agati, & Moavero, 2010) to ADHD as a social construction (e.g. Timimi, 2005).

ADHD and medication

While parenting interventions are recommended as first line treatment for children diagnosed with 'moderate' ADHD (NICE, 2008) medication is recommended for school aged children and young people where symptoms are severe or other interventions are ineffective. The most common medication is methylphenidate, a stimulant medication (Storebø et al., 2015) and in the UK, approximately one percent of children are taking medication for ADHD symptoms (Taylor, 2014).

Children and young people's accounts of medication

Despite the widespread use of stimulant medication as a treatment for ADHD, the number of studies focusing on children and young people's accounts of medication is relatively small. The majority of studies which have focused on children and young people's accounts have reported positive attitudes to medication, despite common side effects, such as headaches. This is particularly true for quantitative studies (e.g. Doherty-Frankenberger, Fuhrer & Snider, 2000; Gortz-Dorten et al., 2011) which found high satisfaction and adherence to medication.

A small number of qualitative studies have focused on young people's accounts of taking stimulant medication. The results are contradictory. While UK studies involving children and young people in middle childhood (Singh, 2013; Singh et al., 2010) found a broadly positive experience of stimulant medication, studies from other countries, and particularly

those with adolescent participants, highlighted negative and ambivalent views (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach, Yeung, Volpe, Goodale, & dosReis, 2014).

A salient theme to emerge across these studies are issues around identity, relating to diagnosis and medication. Singh and colleagues' research found that medication threatened a sense of authenticity in a minority of children (Singh, 2007; 2012). Other studies identified aspects of medication which had an impact on young people's sense of identity, such as personality change or stigma (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014). These studies were conducted with adolescent participants and in general their accounts reflected more ambivalent and negative views of medication than those with younger children. For example, Avisar and Lavie-Ajayi (2014) reported that participants described taking medication as a burden, due to side effects and a detrimental effect on their sense of self and 'joy of life'.

In the UK, there is a gap in research focusing on adolescent accounts of taking stimulant medication. The research that has been conducted in the UK has been conducted with younger children.

Adolescent Identity Development

Developmental theories regarding identity construction in childhood and adolescence could suggest why adolescents' relationship with stimulant medication may differ from younger children. One explanation is the salience of identity issues for young people during adolescence, which has been highlighted by a number of theorists (Erikson, 1968; Kegan, 1982; Loevinger, 1997).

Identity formation does not take place in a vacuum, and while developmental theories are universal theories, stage theorists (e.g. Erikson, 1968; Kegan, 1982; Loevinger, 1997) stress the importance of the social context for forming a coherent sense of self. According to Kegan (1982) young people are particularly sensitive to the opinions of their peers, to make sense of themselves, as they separate and transfer dependency from parents to peer relationships (Allen, 2008). This is important because it suggests that young people may be particularly vulnerable during adolescence to stigma relating both to diagnosis and medication. Goffman (1963) conceptualised stigma as spoiled identity and in line with this, research into the experience of young people taking different types of psychotropic medication suggests that they engage in strategies to protect themselves from stigma, including hiding their diagnosis and medication (Kranke et al., 2010; Kranke et al., 2011).

Additionally, Harter (2012) suggests that during adolescence the sense of a ‘true self’ becomes significant to young people, and engaging in behaviour which they perceive to be ‘false’ can be extremely distressing. This is important because changes in the way a person behaves because of medication could be experienced as ‘false-self’ behaviour, as could hiding medication. This may partly explain why the research suggests a more ambivalent attitude to medication amongst young people.

Discourses around ADHD

While studies have been valuable in focusing on the under-researched experience of taking stimulant medication, there has been less of a focus on the wider meanings of ADHD and stimulant medication in studies with young people. This includes both the impact of discourses surrounding ADHD and medication, and the ways in which young people may actively employ these to make sense of medication, and negotiate their identity. In contrast to developmental theory, this type of research approaches identity as a more flexible concept,

with different types of culturally available identity or positions, which can be taken up or rejected.

Some studies have demonstrated the impact of wider discourses surrounding ADHD. Horton-Salway (2011) analysed articles from UK newspapers referencing ADHD and identified two different ways of conceptualising ADHD. These were biological and psychosocial, with the majority of articles describing ADHD as a psychosocial phenomenon. These repertoires had implications for the identities of children diagnosed with ADHD, positioned as 'naughty' or 'sick', and their parents, as 'bad parents'. These repertoires were also evident in parents' accounts of ADHD (Brunton, McVittie, Ellison, & Whittock, 2014) with implications for parental accountability as genetic contributors or inadequate parents.

Discourses of young people

In contrast to these discourses, research focusing on online activity on Facebook by young people diagnosed with ADHD, identified mostly positive conceptions of ADHD as a 'personality enhancer' and while they accepted ADHD as a disorder, differentiated this from ADHD as a disability or disease, (Gajaria, Yeung, Goodale, & Charach, 2010). This suggests that young people with this diagnosis may draw on discursive resources other than official ones to make sense of themselves and their identity.

Treatment narratives and discourses

While discourses around illness and mental health have been explored widely (e.g. Mattingly & Garro, 2000; Yardley, 1997), research exploring the discourses and narratives around medication, for physical and mental health reasons, are less common. However, this type of approach is valuable as it allows the meanings behind medication and the impact of these to be explored. Ryan, Bissell and Morecroft (2007) argued that medication should be researched

within the context of the people's lives and wider meanings attached to their condition and treatment, and demonstrated how different constructions of medication could protect identities. Conrad's (1985) research into the meaning of medication for people with epilepsy demonstrated how what was viewed by clinicians as non-compliance, from a patient's perspective was controlling dependence and de-stigmatization. In the area of mental health, Harper's work (1999) into discourses surrounding psychiatric medication, demonstrated that the way in which clinicians and service users accounted for cases where medication was ineffective, positioned service users, for instance as resistant or problematic. From a wider treatment perspective, studies have shown that the way in which young people position themselves as service users of mental health services, can at times protect and empower them. For example, Prior (2012) found that young people accessing mental health services who took a position as virtuous problem-solver, where problems were a normal part of adolescence, were more successful in protecting themselves from stigma.

In the context of stimulant medication and ADHD diagnosis, it is important for clinicians to engage with young people's perspectives, not only about the direct effects of stimulant medication, but about the wider and personal meanings that are associated with diagnosis and medication and how this may affect their relationship with treatment. Knowledge and understanding of these wider and personal meanings for young people is particularly important given identity issues raised in the literature around stimulant medication and the salience of identity issues for adolescents highlighted by developmental theory and research. Adolescence is also the age at which young people are starting to take a more active role in their own treatment decisions, and the wider meanings associated with medication and the personal meaning of diagnosis and medication for a young person, are likely to play a role in the decisions they make. Therefore research which highlights wider meanings and discourses around ADHD medication is of direct clinical relevance.

Research Aims

This research built on the small amount of qualitative work in this area to explore the accounts of young people in the UK with an ADHD diagnosis, who take stimulant medication. The author explored discourses about ADHD and ADHD medication available to young people through published literature provided in CAMHS services. She then explored how young people draw on these discourses when talking to others about taking medication for ADHD.

Research Questions

- What discursive resources did young people have available to them to talk about themselves as people who take ADHD medication?
- How did young people who take stimulant medication further to an ADHD diagnosis, talk about ADHD, medication and themselves?
- How did young people deploy these discursive resources, in interviews and focus groups for young people with ADHD?
- What dilemmas did these discursive resources generate for young people?
- What subject positions were made available by these discursive resources, and what might that tell us about how these young people construct their identity?

Methods

Research Design and Methodology

This study employed a qualitative, non-experimental design. It involved the collection and analysis of two different types of data sources; information leaflets about ADHD and medication, and transcripts of interviews and focus groups with young people, guided by a semi-structured topic schedule (Appendix C). A qualitative design was the most appropriate design to capture the different ways in which young people talk about ADHD and medication, including contradictions and dilemmas which may be inherent in these, as well as discourse contained in resources which they may access.

Epistemological Position

Unlike the majority of studies employing discourse analysis, the data was approached from a critical realist, rather than social constructionist, position. This allowed for the acknowledgement of material, psychological and environmental reality. In the context of this study, medication is understood as having 'real' effect which may change the way a young person feels and behaves. It also acknowledges that young people are subject to societal and legal constraints, such as attending school and being under an adults' responsibility.

However, critical realism acknowledges that language is a mediator of these realities, and can construct different versions of them. These versions in turn have an impact on practice, for example how resources are allocated (Parker, 1992), and psychologically in terms of how people are positioned and the limited ways in which this allows them to be understood. There is a small tradition of critical realist work, as advocated by Carla Willig (1999).

Participants

Thirteen young people (ten males and three females) aged between 13 and 17 took part in nine interviews and one focus group. This number of participants is in line with other studies using this form of analysis. Brunton et al. (2014) interviewed twelve parents about their children's ADHD diagnosis using discourse analysis. Participants attended one of three child and adolescent mental health services (CAMHS) in one mental health trust situated in London, two generic CAMHS services and one neuro-developmental service. All participants had a diagnosis of hyperkinetic disorder according to their clinical records and were taking between 5-75mg of stimulant medication. Table 1 details participants by age, gender and interview type.

Table 1. Participants by pseudonym, age, gender and interview format.

Pseudonym	Age	Gender	Focus group or interview
Peter	13	Male	Interview
Stephen	13	Male	Interview
Denise	13	Female	Interview
Martin	14	Male	Interview
Mary	15	Female	Interview
Simon	15	Male	Interview
Danny	15	Male	Focus Group
Jack	15	Male	Focus Group
John	15	Male	Focus Group
Ellis	15	Male	Focus Group
Evie	16	Female	Interview
Ben	16	Male	Interview
Jason	17	Male	Interview

Procedure

Ethical considerations.

Ethical approval was granted by an NHS Research Ethics Committee (Appendix D), the Health Research Authority (Appendix E), The Trust Research & Development Department (Appendix F).

Data Collection.

Leaflets

In order to analyse resources that young people may access, purposeful sampling was used to collect information leaflets supplied by CAMHS services to young people and parents. These were identified by trainee clinical psychologists and psychologists working in CAMHS services covering a wide area of southern England. Inclusion criteria for leaflets was that they were information leaflets related to ADHD and ADHD treatment and that they were made available to service users, including parents and young people at CAMHS services. Leaflets which were explicitly aimed at young children were excluded. Ten leaflets were collected through this method. Websites related to ADHD and ADHD medication that were produced by the same organisations that produced the ten leaflets were also included in the analysis. Websites and materials produced by organisations unrelated to the leaflets were excluded from analysis.

Participant Recruitment

Participant recruitment took place between 01/11/2016 and 24/10/2017. Inclusion criteria was young people aged 13-17, attending one of the CAMHS services taking part in the study, who had an ADHD diagnosis (defined by an ICD-10 diagnosis of hyperkinetic disorder on their clinical records) and who were taking stimulant medication or had taken stimulant medication in the past. Exclusion criteria included any young people who were taking medication for another mental health condition. Co-morbidity did not exclude young people from taking part, as co-morbidity is the norm for ADHD (Schmidt, 2009).

Participants were recruited through two routes;

- 1) A clinician introduced the study during an appointment, providing information sheets, if the young person and their parent or carer were interested (Appendix G, H and I). The author then contacted the young person's parent, or the young person directly (if over 16 and advised by the clinician). Three participants were recruited through this route.
- 2) The Trust data service provided anonymised data for service users who met the criteria and had consented to be contacted for research. The author contacted care-coordinators to check eligibility and appropriateness for the study. Service users identified as meeting the criteria were sent a participant invitation letter (Appendix J), followed by a telephone call. Ten participants were recruited through this route.

Informed consent.

Prior to the interview or focus group the author spoke with the participant, and their parent or carer if they were aged under 16, to ensure (Appendix G, H and I) that they understood all the aspects of what they were consenting to. Young people aged younger than 16 completed an assent form (Appendix J), and a consent form was completed by a parent (Appendix L).

Young people aged 16 completed a consent form (Appendix K) and written parental consent was not sought, in line with British Psychological Society guidelines (2010), although verbal consent was given in every case.

Topic Schedule.

A semi-structured topic schedule (Ayres, 2008) (Appendix C) was developed by the author in consultation with her supervisors. It was designed to prompt young people to speak about

their experience of being diagnosed with ADHD, experience of taking stimulant medication, and the meaning of ADHD and medication. Rather than having a number of set questions, general areas were identified (what led up to taking medication, starting medication, medication now and others and ADHD / medication) with potential prompt questions.

At the time that the topic schedule was first developed there was no opportunity to pilot the schedule with service users. However, while developing the topic schedule, the author consulted with a young adult who was a service user and had been diagnosed with ADHD as an adolescent and was prescribed stimulant medication.

Schedule re-development.

After the first two interviews, and after the author's supervisors had reviewed transcripts of the interviews, the topic schedule was re-visited, as it was originally planned that the majority of participants would take part in focus groups and therefore there would be less need for prompts, as the young people would generate talk through interaction. However, most participants (nine) chose to take part in one-to-one interviews with just one focus group taking place. While the general structure remained the same, more emphasis was put on the meaning of ADHD with the inclusion of additional prompt questions, underlined in Appendix C.

Data storage and transcription.

Interviews were recorded, transferred to an encrypted, password protected memory stick, transcribed and anonymised. The audio recording was then deleted. The anonymised data will be held electronically for ten years at the sponsor university.

Data Analysis

The same form of discourse analysis (Edley, 2001) was used for the information leaflets, and transcripts. This involved identifying three analytic concepts; interpretative repertoires (Wetherell and Potter, 1988), subject positions (Davies & Harré, 1990) and ideological dilemmas (Billig et al., 1988). This type of analysis has been used in previous research focusing on ADHD, both for interviews with parents (Brunton et al., 2004) and to analyse newspaper articles (Horton-Salway, 2011).

Wetherell and Potter (1988) termed interpretative repertoires as the culturally understood ways in which subjects are spoken about or constructed. There can be many different repertoires for the same subject, for example Horton-Salway (2011) identified two common yet conflicting ways in which ADHD was constructed as a biological condition or social problem.

Subject positions are related to positioning theory (Davies & Harré, 1990) and the idea that certain ways of constructing subjects positions people in ways, which they may or may not actively take up. For example it has been argued that the construction of ADHD as biological or social positions children as either ill or naughty.

The concept of ideological dilemmas (Billig et al., 1988) points to the inherent contradictory nature and fragmentation of people's meaning making, rather than people holding coherent, cohesive ideologies and versions of events. Ideological dilemmas occur when differing repertoires contradict each other.

Transcripts

Transcripts were read several times. Each transcript was coded separately, with interpretative repertoires for ADHD and medication identified, and references to self were coded for

subject positions. Transcripts were coded a second time for subject positions implicit within interpretative repertoires and for ideological dilemmas suggested by competing repertoires.

Transcripts were compared, and patterns across transcripts identified, as well as exceptions.

Patterns were then explored within individual transcripts. Analysis was conducted by the author and checked for plausibility and alternative interpretations by a second researcher not involved in the data collection. The analytic process is outlined in Appendix O, using the medication repertoires as an example.

Results

Leaflets and related websites

The majority of leaflets (seven) were produced by pharmaceutical companies, with three leaflets produced by third sector organisations. Leaflets aimed at young children were not analysed. Websites related to these leaflets or publicised on the leaflets were also analysed. Apart from information resources produced by a charity for young people, most of the content was aimed at parents, but would be accessible to teenagers. One website contained a section specifically for teenagers.

ADHD.

Bio-medical repertoire

The dominant interpretative repertoire across these resources was one of ADHD as a bio-medical condition. There were differences between the information produced by pharmaceutical companies and those by third sector organisations, but these were in emphasis.

In the extract below, which was representative of the leaflets produced by pharmaceutical companies, the case for ADHD as a genetic, neurobiological disorder is strongly stated. After the strong statement, 'It is a neurobiological disorder', scientific information regarding neurotransmitters, is then given as evidence to strengthen the claim of ADHD as a neurobiological condition. The resources also reference and discredit two interpretative repertoires, identified in research (Brunton et al., 2012; Horton-Salway, 2011), 'naughty children' and 'bad parenting'.

*Extract 1***What causes ADHD?**

ADHD is not caused by bad parenting or lack of discipline. Nor are its origins related to excessive TV watching or a poor diet – it is a neurobiological disorder. This means that its causes are based on biological reasons that lie within the brain. Although the exact cause of the condition is not yet fully understood, it is believed to be due to an imbalance of some chemicals in the brain including noradrenaline (also known as norepinephrine) and dopamine.

In contrast leaflets from third sector organisations explicitly refer to other explanations as plausible but as contributory rather than competing explanations, with the bio-medical explanation privileged. In this extract the bio-medical repertoire is introduced as the primary explanation for ADHD, with other factors outside the child also presented as contributory factors. The fact that no gene has been identified is acknowledged but the term, ‘research is being undertaken to find this out’ suggests that it is a matter of time before this happens. The statement that a child is more likely to be diagnosed with ADHD if family members are is not explained but is likely to suggest genetic, rather than the alternative explanation of environmental causes.

Extract 2

We know that genetic (inherited) factors are important in ADHD. We don’t know which genes are the most important but research is being undertaken to find this out. However it is clear that the environment plays a part as well. If your child has a close relative who has been diagnosed with ADHD, this increases their chance of being

diagnosed with ADHD. But it does not mean that ADHD is inevitable. No single gene has been identified as causing ADHD, and it is more likely that several genes are involved, each interacting with the environment in extremely complicated ways.

Medication.

All the leaflets acknowledged that there were a number of treatments, including behavioural interventions, for the symptoms of ADHD. However, these were presented slightly differently as either a necessary or as a helpful option.

Medication as necessary.

Those leaflets produced by pharmaceutical companies presented medication in the context of neuro-biological explanations of ADHD.

Extract 3

How is ADHD managed?

Independent medical authorities, including the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) recommend a combination of medication and behavioural treatments for ADHD.

[..]

Stimulants are the main medication for ADHD and have been in use for decades.

Stimulants are not a cure for ADHD but, while children are taking them, they improve the key symptoms of inattention, hyperactivity and impulsiveness. They are effective in 70% of children with ADHD and are generally well tolerated.

*Extract 4***How does ADHD impact on a child's life if untreated?**

If ADHD is not identified and treated properly, children may be at greater risk of:

- Low self-esteem
- Academic under-performance at school
- Depression
- Friendship and relationship problems

And as an adult:

- Employment difficulties
- Criminal behaviour
- Substance abuse

In the above extracts the case for medication as part of a combined programme for the treatment of ADHD is legitimised by referring to advice from official bodies (Extract 3) and unnamed experts (Extract 4). This is inaccurate as NICE guidelines recommend medication as a first line treatment only if other interventions have not been successful (NICE, 2008). Once treatment has been framed as including medication, a number of significant present and future consequences to not treating ADHD are outlined. This interpretative repertoire of medication as necessary, therefore positions parents as damaging to their children if they decide not to give medication and children as passive recipients of medication with no part in the decision making process.

Medication as opportunity

One leaflet produced by a third sector charity presented a slightly different way of conceptualising the helpfulness of medication as transitory.

Extract 5

Medication does not cure ADHD – but it can provide a ‘window of opportunity’ in which we can help children learn to manage their own behaviour.

In the above extract, the emphasis is slightly different in terms of medication as a temporary solution, which may allow the young person to develop their own strategies. This leaflet also was the only leaflet to include a section about problems associated with medication..

Subject positions

The overall effect of the interpretative repertoires about ADHD and medication is to position parents as not responsible for their children’s difficulties through poor parenting. However, parents are positioned as responsible for the child’s life trajectory, as rejecting medication, may lead to the child not reaching their potential, or experiencing significant long-term consequences. The child is positioned away from being naughty but this then positions them as passive, not in control of biologically determined behaviour and not invited to be an active part of treatment decisions.

While the neuro-biological repertoire was a repertoire of lack and deficit throughout these leaflets, in which children are ‘very challenging and hard to manage’, there were occasional alternative and positive positioning of children. The most notable positive positioning of young people with this diagnosis was contained on a website produced by a pharmaceutical

company, aimed at young people in which 'symptoms' of ADHD were re-framed positively, for example 'I'm hyperactive' re-framed as 'I have lots of energy'.

Ideological Dilemmas

Dilemmas are presented by; the suggestion that environment may be a factor, in terms of whether and why medication is therefore indicated, and if biology is not a primary factor, whether this means that children should be regarded as 'naughty' and parents as inadequate.

Summary

The published resources suggest the main interpretative repertoire for young people to draw on was one of their condition as neuro-biological with medication as a necessary part of treatment. While this positioned them and their parents away from blame, and children away from being seen as naughty, the lack of alternative ways of thinking about their difficulties, behaviour and treatment, also positioned them as subject to their biology and therefore in a passive position as recipients of medication.

Interviews and Focus Groups

Analysis of the interviews and focus groups resulted in a number of interpretative repertoires, ideological dilemmas and subject positions being identified (Table 2).

Table 2. Interpretative repertoires, subject positions, ideological dilemmas

Interpretative repertoires – ADHD	Examples
ADHD as disorder	‘It’s a hyperactive disorder’
ADHD as normal	‘OK I thought (.) OK that’s normal’
ADHD as different for different people	‘Like it affects people in different ways’
Interpretative repertoires - Medication	
Medication as transformative	‘I’d probably be in jail or YOT’
Medication as a tool	I don’t know just (.) normal. I take medication (.) for (.) to help me (.) ‘cause it helps. So it like works and (.) it’s just like (.) a painkiller (.) so it stops the pain (.) so it stops <u>I wouldn’t</u> say it stops the ADHD but it’s like kind of (.) <u>slows</u> it down ‘It’s just knowing kind of just you know finding out what’s right with you for you to say oh this is what I like to be taking sort of thing’
Medication as inappropriate	‘Cause I’m becoming I’m becoming I’m starting to become a young man and I’m I’m not gonna think of taking medication at that age ‘cause that’s <u>ridiculous</u> ‘It just didn’t feel like (.) normal having to take something (AT: Right) to (.) get on with my day.’
Medication as harmful	‘Just putting things inside your body (.) and you don’t know like (.) what they’re doing’
Subject positions	
Unmedicated (ADHD) self as dangerous	‘I’d go mad’, ‘He was bad’, ‘I was nuts’ ‘I was bad’ ‘...so they said they’re not going to have me in the school (.) ‘cause they’re worried about people’s safety (.) so if you can’t be <u>safe</u> (.) you can’t be here without medication’
Unmedicated (ADHD) self as different, interesting and sociable	‘It would be really easy to have fun with me’ It’s like having your own your own personal disco (.) and your brain is invited to it (AT: OK) and you take the pill then suddenly it puts the sound a bit low
Medicated self as in control	‘And he said something to me but I left it’
Medicated self as being controlled	‘It just it makes me act like I’m a robot and I don’t like it. ‘Cause I thought it was going to just make you sit there. ‘Cause people told me that it just makes you sit there

Ideological Dilemma ADHD diagnosis

Understanding vs labelling

Personally I thought it was just a label as in (.) now you have this you're seen as this person.

Erm it was more like (.) it wasn't an excuse but it was more like erm OK you like (.) and understanding of why things were like happening sort of thing so yeah

Ideological Dilemmas Medication

Balancing aspects of self

'I always try not to do the bad cheeky but I do the good cheeky'

Normal vs different

Erm (.2) it's like (.3) who wants to be normal?

Interpretative Repertoires

ADHD

As the focus of this study was on medication, interpretative repertoires and subject positions for medication are the main focus of this section. However, repertoires for ADHD were also noted (see Table 1). The understandings of ADHD as a disorder, is in line with the published resources, and the understanding of ADHD as normal, fits in with previous explorations of ADHD (Charach et al., 2014). However, a third and previously unrecorded discourse for explaining ADHD as ‘different for different people’ was used by four of the participants.

Medication

Four main interpretative repertoires were identified.

- Medication as transformative
- Medication as a tool
- Medication as inappropriate
- Medication as harmful

Medication as transformative

This interpretative repertoire was evident in four interviews and by two participants in the focus group. It was used by young people to denote how medication had been instrumental in transforming many aspects of their lives and to suggest that it had affected the trajectory of their lives. It was also ascribed as a view by adults in the context of decisions being made about these young people’s lives.

Extract 6

I: So why wouldn't y(.) would you never stop? (*taking medication*)

Peter: 'Cause I want to have a good life (.) and I (.) don't want to keep getting into trouble.

Extract 7

I: OK. (.) so what what do you think it would be like if you stopped taking medication now?

John: I'd probably be in jail or YOT (.2)

In both of these extracts, the young people refer to specific feared consequences, not being in school or indeed being in jail, if they did not take the medication. Peter refers more widely to wanting to have a 'good life', implicitly suggesting that life without medication would be a bad life.

Medication as a tool

This interpretative repertoire was a generally more positive way of talking about medication, but in contrast to the interpretative repertoire of *medication as transformative*, it was more specific. Medication was spoken about more of as an aid which the young person could use or not, rather than a change to the whole person.

Extract 8

I: OK. And did you, what did you think about taking it?

Stephen: I didn't think that much, cos it never changed me that much (.) (AT: right) it just helped me to concentrate.

Conceptualising medication as a tool, rather than a necessity for an ‘ordinary’ life, allowed ADHD medication to be normalised. In the extract below Daniel states that it’s normal to take medication to help. There were other instances of medication being described as ‘no big deal’ and ‘I don’t see it as an issue’ and being likened to taking common medication, such as a painkiller. This stance may protect against potential stigma regarding medication.

Extract 9

AT: Right, OK. And what did you think when you first heard about possibly (.) taking medication.

Daniel: I don’t know just (.) normal. I take medication (.) for (.) to help me (.) ‘cause it helps.

The repertoire of medication as a tool also allowed a more flexible stance to medication. In the extract below, the young person acknowledges both the helpfulness and the drawbacks of medication. She then talks about finding the right medication or dose, using the pronoun ‘we’, demonstrating her involvement in this process, switching back to ‘I’ at the end of the extract, emphasising her role as the key decision maker regarding her medication. about what is the right medication for her.

Extract 10

I: And what’s good about it when it when it works?

Evie: You concentrate (*laugh*). It does what it I does what it does but (.) it does have (.) side effects along the way. So (.) you might be using something for so long and it stop working or you might be using like my case and you know like in my case we needed to higher it when we highered it just stopped working the way it was working with the lower it’s just knowing kind of just you know finding out what’s right with you for you to say oh this is what I like to be taking sort of thing.

An explanation of medication as a tool had implications for whether the young people considered that they would continue taking medication. Implied in the extract below is that medication is there to help the young person with specific tasks and once the need for these have gone, the medication is no longer needed.

Extract 11

After college or university (.) then yeah I don't think I'll need it after that (AT: Right)
'Cause the job I want to do you don't need to (.) like concentrate on writing and stuff (.)
it's more practical (.) which I'm good at.

Medication as inappropriate

A third repertoire of medication as inappropriate was also identified. This was related to the idea that it was not appropriate for children to be taking psychotropic medication to change their behaviour, and included ideas about the potential harm to their developing selves.

In the extracts below the young people speak about a general idea that medication is not appropriate to change the way they behave, both from their own perspective and from the perspective of others in their lives. The young people who drew on this repertoire also linked this to the idea of medication changing an integral part of themselves.

Extract 12

AT: When you first were talking about the medication and you'd got the diagnosis (Evie: Yeah) what did you think about the idea of medication?

Evie: Erm (.) I did not like it at all

AT: No?

Evie: No

AT: Why was that?

Evie: It just didn't feel like (.) normal having to take something (AT: Right) to (.) get on with my day. Like it was like (AT: Mmm) I didn't want to have to take medication every morning (.) just to go out the door

Extract 13

I: ...any other, any other reasons that you didn't like it at the time?

Ben: I was just thinking, um when I was, when I told everyone in my family they were like oh, you've always been like that though, you don't really need it. They used to say but that's just you, though, that's how you've always been, kind of thing.

Evie refers to medication as something that is not 'normal' to take. By using the phrase 'to get on with my day'. By using 'just' as a minimiser, she stresses the abnormality of taking medication to do what everybody else does without thinking. Ben presents views of family members about the inappropriateness of medication. The use of 'but that's just you' about Ben's behaviour ascribed to family members, re-frames his behaviour outside that of a disorder and more as his essential self.

There were also examples throughout the interviews of young people speaking of medication as inappropriate because it presented an obstacle to their development, and ability to develop their strategies to manage difficult situations.

Extract 14

I: Do you think you'll carry on taking medication (.) in the future?

Ellis: Nah. I'm gonna stop when I'm sixteen (AT: OK) Next year.

I: And why sixteen?

Ellis: ‘Cause I’m becoming I’m becoming I’m starting to become a young man and I’m I’m not gonna think of taking medication at that age ‘cause that’s ridiculous (.) I should be able to be independent without it (.) and be better without it.

Ellis strongly states the inappropriateness of medication once he is sixteen stressing the word ‘ridiculous’. His reasoning for this is the idea that by that age he should not have to depend on it, but on his own resources to behave appropriately, ‘..be better without it’.

Medication as harmful

The fourth repertoire related to the perceived dangers of taking medication and the impact of known and unknown side effects.

Extract 15

I: Mmm (.3) erm and so you were saying that your Dad (.) erm doesn’t like you taking medication do you know what he he why that is?

Danny: Just putting things inside your body (.) and you don’t know like (.) what they’re doing.

Subject Positions

Unmedicated (ADHD) self as dangerous.

The majority of young people interviewed (seven), described the un-medicated self as out of control and dangerous using words including ‘mad’, ‘bad’, ‘dangerous’ and ‘nuts’. This was linked to interpersonal experiences such as fighting with others and altercations with teachers. This perspective was also reflected in the views the young people ascribed to others

such as teachers, and formed part of the rationale for decisions made about their lives, such as what school they attended.

Extract 16

I: And what do you think would happen if you stopped taking your medication?

Simon: I would go nuts and I would get in trouble with any people.

Unmedicated (ADHD) self as fun and different.

In contrast to the problematic construction of self above, a positive account of self as interesting, different from others with a sociable and fun ‘personality’ was evident throughout. This was often instigated by the question, ‘What’s good about ADHD’, but also arose at other times.

Extract 17

Peter: I think it [ADHD] makes me more interesting [...]

I: So what makes a person interesting, when you talk about yourself as interesting?

Peter: They have a certain kind of personality that no-one else has.

Extract 18

I: And which do you prefer?

Ben: I think when I’m not on it. Cos when I’m not on it, (.) not that I feel free but[...]that’s when I was just more, everything was more fun if that makes sense [...] (.) I’m making more jokes in class [...] I was just, I was actually enjoying school, if that makes sense (I: right, yeah) because it was actually fun...

Medicated self – in control

With the exception of three participants, the medicated self was spoken about in terms of being in control. Being in control was related to the short term in terms of staying out of trouble, particularly in response to being provoked by others, but also to the long term in terms of achieving goals.

Extract 19

Jason: Yeah, back in school yeah. (.) It's like then I lose I lose my temper. Then like then there'd be a fight [I: right] but now when I'm in college (.) there, so I had an argument with some boy [...].

I: Yeah

Jason: And he said something to me but I left it.

Extract 20

Evie: Because I felt like it helped me a lot and I'd rather (.) get what I need to go and get rather than feeling that I can't do stuff (.) that's the that's one of the main reason why it's important to me

Medicated Self –Being controlled

While medication was spoken about as putting the young person back in control of their life for the majority of participants, for a minority of participants it was also spoken about as a form of control by others. This included the suppression of a true self as reported for a minority of participants by Singh (2013). In this position, as well as the impact of the medication, the young person was 'done to' by others and therefore was not an active decision maker. One focus group participant spoke about this particularly strongly,

mentioning it on three occasions during the focus group, referring both to his own view and the view of another family member.

Extract 21

Ellis: He doesn't like it. He doesn't want (.) He he doesn't know that I'm on it. If he knew (.2) he wouldn't like it.

I: And what do you think it is that he wouldn't like about it?

Ellis: That the medication's controlling me. Making me different. I don't like being different I like being who I am not saying that I'm a violent person but (.) even when I don't take medication I fit in with a lot of people I make friends easily. Without medication. It just it makes me act like I'm a robot and I don't like it.

However, another participant spoke about how he thought medication changed the way others saw him, in this way affecting his ability to act in social occasions as he normally would.

Extract 22

Ben:They'll probably think oh, they'll probably think, like not that I don't like them but if I'm with them and I'm just worn out just (.) they probably think oh I don't like them or something.

Ideological Dilemmas

A number of ideological dilemmas were apparent throughout the interviews, presented by the interpretative repertoires and by conceptualisations of the medicated and un-medicated selves. These dilemmas, and solutions to them, were evident in how young people negotiated their identity during the interviews and focus group.

Balancing aspects of self

A dilemma for young people taking or considering taking stimulant medication is presented by valued aspects of the un-medicated self, such as being interesting, lively and sociable, which may be affected by medication, and the aspects of the un-medicated self which are viewed as ‘dangerous’ or ‘bad’. Underlying this is how much of this aspect of themselves is acceptable before it becomes ‘over the top’ (Evie) or spills into conflict.

One participant who had recently stopped taking medication reflected this dilemma and a solution for this when describing how she tries to balance these aspects of herself.

Extract 23

Denise: (.4) I always try not to do the bad cheeky but I do the good cheeky.

The words ‘cheeky’ and ‘mischievous’ were introduced by Denise earlier in the conversation and are positive ways of describing behaviour which may not be approved of. Denise names the difference between behaviour which is acceptable ‘good cheeky’ and that which is not ‘bad cheeky’. Importantly, Denise says that she tries to do the ‘good cheeky’ showing that her intentions are good but implicit is that sometimes is ‘naughty’ and does the ‘bad cheeky’.

Normal vs different

The words both normal and different appeared across interviews related to both the diagnosis and taking medication. ‘Normal’ was used to express that diagnosis and medication did not significantly differentiate the young person from others and that these were not ‘a big deal’. However the idea that behaviour was not normal was used to express the idea that something was medically wrong, which led to seeking a diagnosis and ultimately medication. At the same time, the young people spoke about being different as positive, with attributes that

others without the diagnosis did not have. The tension between these two repertoires is expressed in the following extract from Evie.

Extract 24

Evie: Who is normal you know there isn't (.) there isn't a normal like (.) you can say being (.) blonde (.) blue eyes is normal but you know it's just standing out (.) from everyone else...

Evie emphasises the value of being different, following this by emphasising that being normal is not desirable, 'Who wants to be normal?'. However, she then questions whether normal exists, using an example of common physical traits, 'blonde (.) blue eyes', and suggesting that ADHD is just 'standing out'. In this way not being normal is not the same as being abnormal, which she has defended herself against.

Discussion

This study looked at discourse around ADHD and medication through the analysis of leaflets and websites, and the discourse of young people who take stimulant medication. The predominant repertoire from the leaflets and websites was ADHD as a neurobiological condition and medication as a treatment to target specific neurobiological deficits. Other explanations for ADHD as contributory factors were briefly mentioned in leaflets produced by third sector organisations, although in the context of a primary neurobiological explanation. This positioned children as subject to their biology which could be protective as it allowed them not be thought of as naughty but had implications in terms of children accepting medication.

Importantly, the young people who participated in this study drew on a neurobiological understanding of ADHD, but also spoke of their un-medicated selves as ‘bad’ and ‘mad’. While this may seem contradictory, it is illustrative of Billig et al.’s (1988) contention that meaning making is inherently contradictory and fragmented, rather than cohesive and coherent. It was not clear from this study whether the young people saw behaving ‘badly’ as a product of a neurobiological condition for which they were not at fault, or whether being ‘bad’ was seen as their inherent selves. However, it is possible that young people negotiate these competing explanations daily.

In contrast to recent research in other countries which found that adolescents had ambivalent views and medication was often a burden (Avisar-Lavie, 2014; Charach et al., 2014) the young people mostly drew on positive repertoires regarding medication. The difference in results between these studies, conducted in Israel and Canada, could indicate differences between cultures in discourses around diagnosis and medication. Taylor (2014) has suggested

that the differing rates in the prescribing of stimulant medication between countries, is related to cultural differences in attitudes to medication.

The young people's accounts of taking stimulant medication highlighted four ways of constructing medication; medication as transformative, medication as a tool, medication as inappropriate and medication as harmful. The first two repertoires were largely positive and used by the majority of participants. However, there were important differences. In medication as transformative, the medication is conceptualised as transformative across domains, with more implications for a sense of self. The second repertoire of medication as a tool, does not have the same implications for self. It is protective as it normalises taking stimulant medication, and allows the possibility that medication may be temporary. This repertoire positions young people as decision makers, which may counteract the power imbalance inherent in the relationship between clinician and young person.

The third repertoire 'medication as inappropriate' was a minority repertoire in young people's accounts. It was a repertoire that young people encountered outside mental health services, often attributed to trusted adults within the family. This repertoire creates a dilemma for young people in terms of taking medication which may help to some extent and make their lives easier but may be frowned upon by others.

The young people had ways of talking about ADHD and medication that were successful in terms of protecting themselves against stigma; in particular the normalisation of ADHD and medication as a tool to help. The conceptualisation of ADHD as different for different people, was also a successful way of protecting their individuality, and the threat of others pre-conceptions about ADHD.

A minority of participants spoke about medication as a type of 'false-self' behaviour, in line with Singh's (2012) findings. While this was only true for a minority of participants, given

both the salience of identity and the importance of behaving in line with a ‘true self’ (Harter, 2012) for young people of this age, this could be extremely distressing, and have implications for an ongoing sense of self.

Limitations

This study had a number of limitations. Although attempts were made to analyse difference sources, in order to explore different ways in which ADHD and medication are constructed in different forums and by different stakeholders, these were limited to publications produced by pharmaceutical companies, and third sector organisations. There may be ways of making sense of ADHD, medication and self, that were not represented. In particular, young people may draw on other resources, such as those represented by other service users, for example in social media forums and through ADHD groups and associations, and perspectives within their families and among peers at school.

A limitation is also presented by the recruitment criteria for the participants. As these were young people currently accessing CAMHS, and except for two cases, currently taking stimulant medication, it meant that the sample was less likely to represent young people who were not accessing services who may have been more likely to have strong negative feelings towards diagnosis and medication.

A further limitation is presented by the mixture of interviews and one focus group. The author originally intended that the majority of data would be collected through focus groups, as this would have allowed for interaction between young people, and the interviewer would have been less implicated in the production of discourse. Interviews are not the traditional forum for discourse analysis, as the aim is to study discourses that may be occurring naturally in other forums, although interviews have been used widely (e.g. Brunton et al., 2014).

While the interviewer is still an active participant in the production of data in focus groups,

due to interaction between the group members, the influence of the facilitator in the production of discourses should be less.

Clinical Implications

There is a lack of information resources provided by CAMHS for adolescents with an ADHD diagnosis. One of the main outcomes of the VOICES project (e.g. Singh, 2013) was a resource for children about ADHD and medication (www.adhdvoices.com). A similar resource aimed at adolescents, which incorporates a range of views and experiences could be valuable and is a potential outcome from this study.

Young people's descriptions of their un-medicated selves are concerning in terms of how they make sense of themselves. The words young people used to describe themselves before medication, included 'bad', 'mad' and 'dangerous'. The categorical nature of diagnosis is likely to restrict conversations about other explanations for 'mad' and 'dangerous' behaviour, as well as locating the issue in the person. The majority of participants were male, in line with rates of ADHD diagnosis. Timimi (2005) has written widely on the medicalisation of boys in particular, as a cultural way in which to tackle 'naughty' boys. This means that systemic factors and potential solutions including a range of intervention options may not be explored, despite evidence that behaviour associated with ADHD may have different aetiologies. While, discourses which position children away from being 'naughty' may protect young people psychologically, they also provide an obstacle to a wider exploration of reasons for an individual's behaviour and a narrowing of intervention options.

This study highlights the importance of young people being active participants in their own care. Conversations about medication as a tool, unlike a cure, may be more empowering to young people. It is likely that young people are negotiating the different culturally held meanings about diagnosis and treatment, which will have implications for their relationship

with, and choices about, medication. Therefore clinicians should engage with alternative understandings of ADHD and medication that may be held within the family. In particular, the impact of diagnosis and medication on young people's sense of self should be explored, including aspects of the self which the young person may value, such as sociability.

Further research

Further research could take a narrative approach to ADHD diagnosis and medication, to explore how young people integrate diagnosis and medication into their life stories and continuing sense of self. This approach requires rich interview data and may be more suitable to be carried out with young adults, who are also more likely to have developed a narrative about their lives.

Research which highlights how ADHD and medication are spoken about, and managed in young people's social worlds, such as with their peers at school and in their families would also be valuable. This would have the potential to highlight alternative discourses which may influence the way young people think about themselves and dilemmas between the language of clinicians and those within families.

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SECTION C: APPENDIX OF SUPPORTING MATERIAL

Appendix A

Critical Appraisal Framework for Qualitative Studies

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Appendix B

Critical Appraisal Framework for Quantitative Studies

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Appendix C

Topic Schedule

Focus Group and Interview - Topic Guide**Young people, ADHD and medication.**

Rather than having a fixed order / number of questions, the structure of the focus group or interview will remain flexible to be open to the topics and stories brought up by the participants. The questions are designed to explore accounts of ADHD diagnosis, as well as medication, as stimulant medication and the meaning of medication for young people, is situated in this context.

It is anticipated that less prompts will be needed in the focus group discussion, as participants interact with each other, and the facilitator will act more to guide the conversation.

An initial question may be, 'What can you remember about the time you first heard about ADHD?'

Through prompting, facilitators will aim to cover the following areas:

- Accounts of what led up to taking the medication.

Questions and prompts may include – *What can you remember about the first time you heard the word ADHD? What did you think? What was happening for you around that time? What did others say? How did you feel about yourself? What other words or phrases have you heard ADHD called? What do you call it?*

- Starting medication.

Questions and prompts may include - *Can you remember when medicine was first mentioned? Who mentioned it? What did they say? Can you remember what you thought / felt? Can you remember the first time that you took the medication? What did you think? What would happen if you stopped taking medication?*

- ADHD/Medication now.

Questions and prompts may include – *How do you feel about taking it now? How does the medicine itself make you feel (prompt – do you notice any differences?) How do you feel about yourself when you take the medicine? Do others notice a difference? What do they say? How important is ADHD and medication in your life? *How would you describe yourself? How does ADHD/medication fit into that? Does the medication make you feel different about yourself? Is there anything good about having ADHD?*

- Others and ADHD / medication.

Questions and prompts may include – *Who else knows that you take medication? Do your friends know about your diagnosis / that you take medication? What do they say? What have others said? What do you think about that? What do members of your family or teachers in your school say about you taking medication? Is there anybody in your life who thinks that you shouldn't take medication?*

- Medication in the future

Questions and prompts may include - *What are your thoughts about taking medication going forward? Do you think you will carry on / stop? Why do you say that?*

**Prompts added after schedule re-development*

Appendix D

Research Ethics Approval Letter

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Appendix E

Health Research Authority Approval Letter

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Appendix F

Trust Research and Development Approval

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Appendix G

Participant Information Sheet for 13-15 year olds

*University Logo**Trust Logo***Young Person Participant Information Sheet (aged 13-15)****Study Title: Young People's Experience of Medication and ADHD**

Hello. My name is Anna and I am a trainee clinical psychologist at Canterbury Christ Church University. As part of my training course I have to do a piece of research (an investigation into a topic I am interested in). I would like to invite you to take part in this study. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. Talk to others about the study if you wish.

What is the research about?

I want to hear from young people, such as you, about how you feel about taking medication and what your experiences of medication and ADHD have been. I will ask about twenty young people who attend Child and Adolescent Mental Health Services (CAMHS) to have an interview or join a focus group over the next few months, to talk about their experience and views of medicine and ADHD.

**Why have I been invited to take part?**

There is very little research about the experience of young people, aged 13 and above, who take medication after being given a diagnosis of attention deficit/hyperactivity disorder (ADHD). You have been invited to join this study because you and/or your parents agreed to be contacted about relevant research, during one of your CAMHS appointments. This particular study is relevant to you because of the medication that you take, and because you attend a CAMHS clinic where this medicine is prescribed. Your care co-ordinator or a CAMHS worker involved in your care has agreed to me contacting you about the research to see if you would like to contribute to the study, by talking about your views and experience of taking this type of medication.

Do I have to take part?

No. It is up to you. If you do want to take part, I will ask you to sign a form called an "assent" form. This means you have said yes to take part in the interview. I will also ask your parent or carer to sign something called a "consent" form to say that they have also said yes to you having an interview with me. This is really important because you are under 18. If your parents or carers say no, you cannot take part in the research study.

**What if I change my mind?**

You are free to stop taking part at any time during the research without giving a reason. If you do stop being in the study you can ask me to delete any information I have about you or anything you said to me in the interview (as long as you do this before it has already been analysed). If you decide to stop, this will not affect the service you receive at CAMHS in any way, now or in the future.

What will happen if I take part?

If you take part in the study, you will attend a group discussion with 4-5 young people, aged 13-17, who take similar medication to you, and one or two adults who will lead the discussion. We will start with some activities to help you get to know each other. Then I will ask some questions about your experiences and views of medication and ADHD.



If you don't want to be part of a group, but are still keen to have your views heard, then there is also the possibility of me carrying out an interview with you alone. In this case, we would meet in a quiet room at the CAMH service you attend. I will ask some questions about your experiences and views of medication and ADHD.

- The discussion or interview will take no longer than an hour.
- It will take place in a clinic room at the CAMH service you attend.
- I am interested in what you think and there are no right or wrong answers.
- I will use a digital recorder to record what we say so that I can listen back to it afterwards.

What are the good things about taking part?

Even though this research may not help you straight away, clinicians can use some of the information from the study to help and support young people like you in the future. Sometimes young people feel it is helpful to talk about their diagnosis and medication with a person who is not directly involved in their care as it gives them a chance to think about any issues that might be going on for them. Young people also find it helpful to meet other young people and share their experiences with them, to find out what is similar and what is different for others.

Are there any bad things about taking part?

I will be asking about what you think and feel about your medication and about ADHD, and others will be talking about their experience of medication and ADHD. I will do my best to ensure that the discussion does not upset you. However, this may be a sensitive topic for you. You should consider this before deciding to take part in the study. If you take part in the study but during the discussion there are topics you would rather not speak about, you do not have to. If at any time, you wish to stop the interview or leave the group, please let me know and I will arrange for you to do this.

Will you tell anybody what I said?

No, not unless you asked me to. I don't have to tell your parents or CAMHS workers what you say in the interview or focus group. However, there are certain situations when I would need to talk to somebody. Read the next part of the information sheet to find out more.



Will I get paid for taking part?

You will not get paid for taking part in the study. However, your travel expenses, up to the value of £10 will be reimbursed and you will receive £10 of Amazon vouchers.

Part 2 of the information sheet

When would you need to tell someone else about something I said in my interview?

The only time I have to tell someone about something you told me is if you told me that you were going to harm yourself or if someone else would be hurt if I didn't tell someone about it. I wouldn't have to tell your parents but I would need to tell a member of staff in your CAMHS team (your doctor or your psychologist or a 'duty' CAMHS worker). I wouldn't need to tell them anything else about what you said in the interview.

What will happen if I don't want to carry on with the study?

If you didn't want to be involved in the study anymore I would still like to use your interview for my research but if you want me to I can delete all of the information I have about you and your interview recording.



How will you keep all my information safe?

Information with your name or address on it will be kept in a locked cabinet. Any information about you which leaves the clinic will have your name and address taken off and all your other details changed so that no one would know it was you.

When I record your interview, I'll keep the recording on a special memory stick which uses "encryption". This means it uses a really secure password that only I can open to play the files.

I will write out your interview recording into words (this is called "transcription") and I will use a 'fake name' for you instead of your real one. I will also change the names of anyone you talk about or anything you say that might tell someone else who you are.

Three other people might ask to look at this written file with your details changed. They are the research supervisors [REDACTED]. I would not share any other details about you with the supervisors. This file is also kept in a locked cabinet at Canterbury Christ Church University for 10 years. After 10 years it all gets destroyed and deleted. No one would be able to look at it except the administrator in charge of the cabinet and the researchers, Anna Tharia and [REDACTED]. You have the right to ask me to see all the information I have about you – any time. If you thought any of it was wrong you could change it.

What will happen to the results of the research study?

The results of the study get written up into a report. The report can be read by staff in CAMHS services which have taken part in the research. I will put quotes from some of the interviews into the report but remember that your name will be changed and the details of anything you talked about so no one would know what you said. I will also send the report to a journal to be published. If this is accepted, it will be available for other psychologists to read. When the research is finished I will write a letter to you (and your parent or carer if you are under 16) to tell you about what I found out in the research.



Did anyone else check that the study is OK to do?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee. The [REDACTED] Research Ethics Committee have given this study a 'favourable opinion'. This means the committee have said that this study can go ahead.

Who is organising and funding the research?

This research will be paid for by Canterbury Christ Church University. Some of the psychologists and psychiatrists in CAMHS services in South London and Maudsley Trust are helping me to set the study up.

What if there is a problem?

What if there is a problem? If you have any problems during the interview, please let me know. If I can't sort the problem out straight away, I can talk to someone in your CAMHS team. If you feel like the problem really hasn't been sorted out, you can make a formal complaint. You can do this by contacting the Research Director for the Doctorate in Clinical Psychology: [REDACTED] Research Director, Doctorate in Clinical Psychology Salomons Centre for Applied Psychology Salomons Campus, Canterbury Christ Church University, Broomhill Road, Southborough, Kent, TN3 0TF

Do you want some more help before you make a decision?

Try talking this information sheet through with your family, a friend or your psychologist, doctor or care- coordinator.



If you want any help to understand anything in this information sheet or you want to ask some more questions, please contact me. **Anna Tharia**, Trainee Clinical Psychologist Canterbury Christ Church University, Salomons Centre for Applied Psychology, Broomhill Road, Southborough, Kent TN3 0TF.

You can leave a message for me on a **24-hour voicemail phone line at** [REDACTED]. Please say that the message is for me [Anna Tharia] and leave a contact that I can get back to you.

Alternatively, you can email me at a.tharia323@canterbury.ac.uk.

You can also look up this helpful link that explains more about research studies in [REDACTED]



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Appendix H

Participant information sheet for 16-17 year olds

Young Person Participant Information Sheet (aged 16-17)

Study Title: Young People's Experience of Medication and ADHD.

Hello. My name is Anna and I am a trainee clinical psychologist at Canterbury Christ Church University. As part of my training course I have to do a piece of research. I would like to invite you to take part in this study. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. Talk to others about the study if you wish.

What is the research about?

I want to hear from young people, such as you, about how you feel about taking medication and what your experiences of medication and ADHD have been. I will ask about twenty young people who attend Child and Adolescent Mental Health Services (CAMHS) to join a focus group or have an interview over the next few months, to talk about their experience and views of medicine and ADHD.

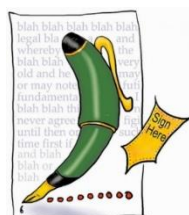


Why have I been invited to take part?

There is very little research about the experience of young people, aged 13 and above, who take medication after being given a diagnosis of attention deficit/hyperactivity disorder (ADHD). You have been invited to join this study because, during one of your CAMHS appointments, you agreed that you would be happy to be contacted about relevant research. This particular study is relevant to you because of the medication that you take, and because you attend a CAMHS clinic where this medicine is prescribed. Your care co-ordinator or a CAMHS worker involved in your care has agreed to me contacting you about the research to see if you would like to contribute to the study, by talking about your views and experience of taking this type of medication.

Do I have to take part?

No. It is up to you. If you do want to take part, I will ask you to sign a consent form. You are free to stop at any time, without giving a reason. This would not affect the standard of care you receive. Any information or interviews you had given could be taken out of the final report if you wanted.



What if I change my mind?

You are free to stop taking part at any time during the research without giving a reason. If you do stop being in the study you can ask me to delete any information I have about you or anything you said to me in the interview (as long as you do this before it has already been analysed).

If you decide to stop, this will not affect the service you receive at CAMHS in any way, now or in the future.

What will happen if I take part?

If you take part in the study, you will attend a group discussion with 4-5 young people, aged 13-17, who take similar medication to you, and one or two adults who will lead the discussion. We will start with some activities to help you get to know each other. Then I will ask some questions about your experiences and views of medication and ADHD.



If you don't want to be part of a group, but are still keen to have your views heard, then there is also the possibility of me carrying out an interview with you alone. In this case, we would meet in a quiet room at the CAMH service you attend. I will ask some questions about your experiences and views of medication and ADHD.

- The discussion or interview will take no longer than an hour.
- It will take place in a clinic room at the CAMH service you attend.
- I am interested in what you think and there are no right or wrong answers.
- I will use a digital recorder to record what we say so that I can listen back to it afterwards.

What are the good things about taking part?

Even though this research may not help you straight away, clinicians can use some of the information from the study to help and support young people like you in the future. Sometimes young people feel it is helpful to talk about their diagnosis and medication with a person who is not directly involved in their care as it gives them a chance to think about any issues that might be going on for them. Young people also find it helpful to meet other young people and share their experiences with them, to find out what is similar and what is different for others.

Are there any bad things about taking part?

I will be asking about what you think and feel about your medication and about ADHD, and others will be talking about their experience of medication and ADHD. I will do my best to ensure that the discussion does not upset you. However, this may be a sensitive topic for you. You should consider this before deciding to take part in the study. If you take part in the study but during the discussion there are topics you would rather not speak about, you do not have to. If at any time, you wish to stop the interview or leave the group, please let me know and I will arrange for you to do this.

Will you tell anybody what I said?

No, not unless you asked me to. I don't have to tell your parents or CAMHS workers what you say in the interview or focus group. However, there are certain situations when I would need to talk to somebody. Read the next part of the information sheet to find out more.

CONFIDENTIAL

Will I get paid for taking part?

You will not get paid for taking part in the study. However, your travel expenses, up to the value of £10 will be reimbursed and you will receive £10 of Amazon vouchers.

Part 2 of the information sheet

When would you need to tell someone else about something I said in my interview?

The only time I have to tell someone about something you told me is if you told me that you were going to harm yourself or if someone else would be hurt if I didn't tell someone about it. I wouldn't have to tell your parents but I would need to tell a member of staff in your CAMHS team (your doctor or your psychologist or a 'duty' CAMHS worker). I wouldn't need to tell them anything else about what you said in the interview.

What will happen if I don't want to carry on with the study?

If you didn't want to be involved in the study anymore I would still like to use your interview for my research but if you want me to I can delete all of the information I have about you and your interview recording.



How will you keep all my information safe?

Information with your name or address on it will be kept in a locked cabinet. Any information about you which leaves the clinic will have your name and address taken off and all your other details changed so that no one would know it was you.

When I record your interview, I'll keep the recording on a special memory stick which uses "encryption". This means it uses a really secure password that only I can open to play the files.

I will write out your interview recording into words (this is called "transcription") and I will use a 'fake name' for you instead of your real one. I will also change the names of anyone you talk about or anything you say that might tell someone else who you are.

Three other people might ask to look at this written file with your details changed. They are the research supervisors [REDACTED]. I would not share any other details about you with the supervisors. This file is also kept in a locked cabinet at Canterbury Christ Church University for 10 years. After 10 years it all gets destroyed and deleted. No one would be able to look at it except the administrator in charge of the cabinet and the researchers, Anna Tharia and Dr Trish Joscelyne. You have the right to ask me to see all the information I have about you – any time. If you thought any of it was wrong you could change it.

What will happen to the results of the research study?

The results of the study get written up into a report. The report can be read by staff in CAMHS services which have taken part in the research. I will put quotes from some of the interviews into the report but remember that your name will be changed and the details of anything you talked about so no one would know what you said. I will also send the report to a journal to be published. If this is accepted, it will be available for other psychologists to read. When the research is finished I will write a letter to you (and your parent or carer if you are under 16) to tell you about what I found out in the research.



Did anyone else check that the study is OK to do?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee. The [REDACTED] Research Ethics Committee have given this study a 'favourable opinion'. This means the committee have said that this study can go ahead.

Who is organising and funding the research?

This research will be paid for by Canterbury Christ Church University. Some of the psychologists and psychiatrists in CAMHS services in [REDACTED] are helping me to set the study up.

What if there is a problem?

If you have any problems during the interview, please let me know. If I can't sort the problem out straight away, I can talk to someone in your CAMHS team. You can also contact me using the information at the bottom of this sheet. If you feel like the problem really hasn't been sorted out, you can make a formal complaint. You can do this by contacting the Research Director for the Doctorate in Clinical Psychology: [REDACTED], Research Director, Doctorate in Clinical Psychology Salomons Centre for Applied Psychology Salomons Campus, Canterbury Christ Church University, Broomhill Road, Southborough, Kent, TN3 0TF

Do you want some more help before you make a decision?

Try talking this information sheet through with your family, a friend or your psychologist, doctor or care- coordinator.



If you want any help to understand anything in this information sheet or you want to ask some more questions, please contact me. **Anna Tharia**, Trainee Clinical Psychologist Canterbury Christ Church University, Salomons Centre for Applied Psychology, Broomhill Road, Southborough, Kent TN3 0TF.

You can leave a message for me on a **24-hour voicemail phone line at** [REDACTED]. Please say that the message is for me [Anna Tharia] and leave a contact that I can get back to you.

Alternatively, you can email me at a.tharia323@canterbury.ac.uk.

You can also look up this helpful link that explains more about research studies in [REDACTED]



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Appendix I

Information sheet for parents and carers

Information sheet for Parents and Carers

Study Title: Young People's Experience of Medication and attention deficit hyperactivity disorder (ADHD).

Hello. My name is Anna Tharia and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite your child to take part in a research study. Before you decide whether you are happy for your child to take part, I would like you to understand why the research is being done, and what it would involve for your child. Therefore, it is important that you read through this information sheet. Please also talk to others about the study if you wish.

Part 1 tells you the purpose of the study and what will happen if you take part.
Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

There is very little research about the experience of young people, aged 13 and above, who take medication after being given a diagnosis of attention deficit/hyperactivity disorder (ADHD). Most of the research that looks at the experience of taking this type of medication focuses on younger children. I want to hear from young people, like your child, about their experiences of medication and ADHD and how they feel about taking medication.

Why has my son or daughter been invited to take part?

Your son or daughter has been invited to join this study because they attend a Child and Adolescent Mental Health Service (CAMHS) in [REDACTED], where they are prescribed medication further to a diagnosis of ADHD. During one of your child's appointments, you and/or they agreed to be approached to take part in relevant research. Your son or daughter's care co-ordinator, or a CAMHS clinician involved in their care, has agreed for me to contact you and your child regarding this research project, to see if your son or daughter would like to contribute to the study, by talking about their views and experience of medication and ADHD.

Does my son or daughter have to take part?

No. It is up to you and your son or daughter to decide together whether they should join the study. We will describe the study and go through an information sheet with both of you. If you both agree for them to take part, we will then ask you to sign a consent form, and your child to sign an "assent form" to show that they agree to take part. They are free to withdraw at any time, without giving a reason. If they decide to stop, this will not affect the service they receive at CAMHS in any way.

What will happen if my son or daughter takes part?

If your son or daughter takes part in the study, they will attend a group discussion with 4-5 young people, aged 13-17, who take similar medication to them, and one or two adults who will lead the discussion. We will start with some activities to help them to get to know each other. Then I will facilitate a discussion by asking some questions about their experience of medication and ADHD.

If they don't want to be part of a group, but are still keen to have their views heard, then there is also the possibility of me carrying out an interview with your son and daughter alone. In this case, we would meet in a quiet room at the CAMH service they attend. I will ask some questions about their experiences and views of medication and ADHD.

- The discussion or interview will take no longer than an hour.
- It will take place in a clinic room at the CAMH service they attend.
- I will use a digital recorder to record what we say so that I can listen back to it afterwards

Expenses and payments

If they take part in the study, their travel expenses, up to the value of £10 will be reimbursed. They will also receive £10 of Amazon vouchers.

What are the possible disadvantages and risks of taking part?

I will be asking about what your son or daughter thinks and feels about their medication and about ADHD. Also, if they attend a group discussion, they will hear about the experiences of other participants. This may be a sensitive topic for them. You should consider this before deciding whether you are happy for your son or daughter to take part in the study. I will explain to them at the start of the discussion that, if at any time they wish to leave the group, or stop the interview, they should let me know and I will arrange for this to happen.

What are the possible benefits of taking part?

I cannot promise that the study will help your son or daughter. However, clinicians can use some of the information from the study to help and support young people who have been given a diagnosis of ADHD. Sometimes young people feel it is helpful to talk about their diagnosis and medication with a person who is not directly involved in their care as it gives them a chance to think about any issues that might be going on for them. Young people also find it helpful to meet other young people and share their experiences with them, to find out what is similar and what is different for others.

Will my son or daughter's part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about your son or daughter will be handled in confidence. The details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

This completes part 1. *If the information in Part 1 has interested you and you are considering your son/daughter's participation, please read the information in Part 2 before making any decision.*

Part 2

What will happen if my son or daughter does not want to carry on with the study?

If your son or daughter stops taking part in the study, we would still like to use the data collected up to that point in the final study. However, if they or you really don't want us to use this data in the study at all, you have the right to request that this is taken out and destroyed. If your son or daughter drops out of the study, their medical and legal care will not be affected in any way.

What if there is a problem?

If your son or daughter has any problems during or after their interview, I will encourage them to let me know straight away. I will make it clear that they are able to leave the discussion or stop the interview at any time should they feel uncomfortable or unwell. Before the interview, I will speak to their care co-ordinator and the clinician who is on duty on the day of the interview to ensure that a CAMHS clinician will be available, should your son or daughter need any support.

If you feel that there are any problems or you have any concerns, you should ask to speak to me and I will do my best to answer your question. CAMHS staff will have an email address and telephone number for me and can arrange for me to speak to you. Alternatively, you can contact me using the details at the end of this information sheet.

If you feel as though a concern you have raised has not been resolved and you want to complain formally, you can do this by contacting the Research Director for the Doctorate in Clinical Psychology: [REDACTED], Research Director, Doctorate in Clinical Psychology, Department of Applied Psychology, Salomons Campus, Canterbury Christ Church University, Broomhill Road, Tonbridge, Kent, TN3 0TF

When would you tell someone else about something my son or daughter said in their interview?

There are only a few special circumstances when I would need to tell anyone else about something your child told me in their interview. If your son or daughter told me that they were going to harm themselves or another person, I would be obliged to inform their care co-ordinator or the CAMHS clinician on duty that day immediately. This is the only time that I will ever share information about what your child has discussed with me (unless your child specifically asks me to do so).

Will you tell me what my son or daughter said in their interview?

By law, everyone (including children under 16) has a right to have their personal data kept confidential. This means that, unless your child asks me to share information with you, I am obliged to keep the information they shared with me private. As above, if your son or daughter tells me something that makes me concerned that they might hurt themselves, or another person, I will notify their care co-ordinator or the CAMHS clinician on duty that day. They may decide to share this information with you if they feel this is in your child's best interests.

Will what my son or daughter tells you be kept confidential?

Yes. All information with your son or daughter's name or address on it will be kept securely in a locked cabinet. They have the right to check whether the information we have is right and to correct any errors. Any information about your child which leaves the hospital will have all names and addresses removed so that they cannot be recognised.

I will record the interview and then transfer it onto an encrypted memory stick approved by the NHS Trust responsible for your son or daughter's care ([REDACTED]). The data from this interview will also be transcribed (written into words) with all of the names changed so that your child can't be identified. Your son or daughter will be given a fake name and this is the name that their data will be stored under. This data will also be encrypted and stored on a memory stick. Encrypting a file means that a password is required to open and decode it. As I am responsible for ensuring that your child's data is kept safe, I will ensure that the password is kept secure and that the data can only be accessed by me.

Other people may ask to look at the data in its anonymous form – (without your child's name on it). This may include the research supervisors [REDACTED] Your child's confidentiality will be maintained at all times if this is the case.

The anonymous data will be held securely at Canterbury Christ Church University for 10 years and destroyed after this point.

Who is organising and funding the research?

This research project forms part of the assessment for the Doctorate in Clinical Psychology training programme. The research is funded by Canterbury Christ Church University and co-organised by the Child and Adolescent Neurodevelopmental Service at [REDACTED].

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participant's interests. This group of people look at the plans of a research study before it begins and agree for the study to go ahead if it meets a good standard of keeping participants safe from any potential harm. This study has been reviewed and received a favourable ethical opinion from [REDACTED] Research Ethics Committee.

What will happen to the results of the research study?

I will write a letter to you and your child to tell you about what I found out in the research. When the research is finished it will be written up in a report which will be available to the staff in CAMHS services which have taken part. The results of the research, including some quotes from the discussion, may be published in a scientific journal. Your son or daughter will not be identified in any report or publication.

For information about this research project

If you would like any help with understanding this information sheet or you would like to ask more questions before you make a decision, please contact me.

You can email me at a.tharia323@canterbury.ac.uk.

Alternatively, you can leave a message for me on a 24-hour voicemail phone line at 03330117070. Please say that the message is for me, Anna Tharia, and leave a contact number so that I can get back to you. You can also write to me at: Anna Tharia, Canterbury Christ Church University, Salomons Centre for Applied Psychology, Christ Church Canterbury University, Runcie Court, David Salomons Estate, Broomhill Road, Southborough, Tunbridge Wells, Kent TN3 0TF.

You can also look up this helpful link that explains more about research studies in

[REDACTED]
[REDACTED]

Asking for advice - Should my son or daughter participate in this study?

You might like to talk to someone about this information and whether you should agree for your son or daughter to participate. There is a lot of information to take in and you might want to talk it through, especially if there is anything that you're unsure of or that you didn't understand.

If you are wondering whether to give your consent for this study, you might like to talk to one of the psychologists involved in the project, [REDACTED]. You can also speak to your child's care co-ordinator, or their consultant or regular doctor. You might want to talk to friends or family about it as well.

Appendix J
Assent Form for 13-15 year olds

University logo

Trust Logo

Assent form for participants aged 13-15

Title of Project: Young People’s Experience of ADHD and Medication.

Name of Researcher: Anna Tharia

Please initial box

1. I have read and understand the information sheet dated _____ (version _____) and have been able to ask questions about the research and have had these questions answered.
2. I understand that I do not have to take part in this study and that I can stop being part of the study at any time, without giving a reason, and without affecting any services I receive from South London and Maudsley NHS Trust.
3. I understand that I will take part in one group interview or a one-to-one interview for no more than one hour.
4. I agree that the interview can be recorded (sound only) and that the recording can be transcribed (typed into a written version) and checked (verified) by the researcher’s supervisors.
5. I agree that anonymous quotes from my interview may be used in published reports of the study findings and that my name will not appear in the final report.
6. I agree to be contacted after the research has taken place and invited to an event to contribute to the production of an informational leaflet for staff in CAMHS, outlining the results of the research. I understand that I am not obliged to take part in this event.
7. I agree to take part in the above study.

Name of Participant

Date of Birth

Signature

Date

Name of Person taking consent

Signature

Date

Appendix K

Consent form for 16-17 year olds

Consent form for participants 16 and over

Title of Project: Young People’s Experience of ADHD and Medication.

Name of Researcher: Anna Tharia

Please initial box

8. I have read and understand the information sheet dated _____ (version _____) and have been able to ask questions about the research and have had these questions answered.

9. I understand that I do not have to take part in this study and that I can stop being part of the study at any time, without giving a reason, and without affecting any services I receive from South London and Maudsley NHS Trust.

10. I understand that I will take part in one group interview or a one-to-one interview for no more than one hour.

11. I agree that the interview can be recorded (sound only) and that the recording can be transcribed (typed into a written version) and checked (verified) by the researcher’s supervisors.

12. I agree that anonymous quotes from my interview may be used in published reports of the study findings and that my name will not appear in the final report.

13. I agree to be contacted after the research has taken place and invited to an event to contribute to the production of an informational leaflet for staff in CAMHS, outlining the results of the research. I understand that I am not obliged to take part in this event.

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

Name of Participant

Date of Birth

Signature

Date

Name of Person taking consent

Signature

Date

Appendix L

Consent form for parents

PARENT/CARER CONSENT FORM

Title of Project: Young People’s Experience of Medication and ADHD.

Name of Researcher: Anna Tharia

Please initial box

15. I have read and understand the information sheet for parents dated _____ (version _____) and have been able to ask questions about the research and have had these questions answered.

16. I understand that my child does not have to take part in this study and that he or she can stop being part of the study at any time, without giving a reason, and without affecting any services they receive from South London and Maudsley NHS Trust services.

17. I understand that my child will take part in one group interview or a one-to-one interview for no more than one hour.

18. I agree that the interview can be recorded (sound only) and that the recording can be transcribed (typed into a written version) and checked (verified) by the researcher’s supervisors.

19. I agree that anonymous quotes from my child’s interview may be used in published reports of the study findings and I understand that their name will not appear in the final report.

20. I agree for my child to be contacted after the research has taken place and invited to an event to contribute to the production of an informational leaflet for staff in CAMHS, outlining the results of the research. I understand that my child is not obliged to take part in this event.

21. I agree for my child to take part in the above study.

Child’s name

Child’s Date of Birth

Name of Parent or Carer

Date

Signature

Name of Person taking consent

Date

Signature

Appendix M

Parent invitation letter

*University Logo**Trust Logo*

Salomons Centre for Applied Psychology
 Canterbury Christ Church University
 Runcie Court
 David Salomons Estate
 Broomhill Road
 Southborough,
 Tunbridge Wells TN3 0TF

Address1
 Address2
 Address3

Date, 2016

Dear (Name),

Research Study: Young People's Experience of Medication ADHD

Some time ago, during one of the appointments you attended with your son or daughter at Sunshine House, you agreed to be contacted about research studies, in case you or your child would like to take part in them. I am contacting you now because I would like to invite your child to take part in a piece of research. I enclose an information sheet which describes the study and provides further information about it.

As you can see, your son or daughter has been invited to join this study because of the medication that they take, and because you attend [REDACTED] where this medicine is prescribed. Your child's care co-ordinator, or a clinician involved in their care has agreed to me contacting you to see if your son would like to contribute to the study, by talking about their experience of taking this type of medication in a focus group or interview. They do not have to take part in this research if you do not want them to or if they would prefer not to.

I would like to telephone you in approximately two weeks from the date of this letter to see whether your child is interested in taking part in the study and whether you would agree to them taking part. I hope you are interested in this research. However you do not need to speak with me about the research if you don't want to. If you would prefer that I did not telephone you, please leave a message for me on a **24-hour voicemail phone line at 0333011 7070**. Please say that the message is for me [Anna Tharia] and I will not contact you further. Alternatively, you can simply let me know that you are not interested when I telephone and I will not ask any further questions or contact you again.

I hope that you find the enclosed information interesting. If you have any questions about the research you can leave a message for me (Anna Tharia) on 0333011 7070 and leave a contact number.

Yours sincerely,

Anna Tharia
Trainee Clinical Psychologist

Appendix N

Analytic process for ADHD medication interpretative repertoires

Table N1. Initial working categories for medication interpretative repertoires

Repertoire	Description
Medication transformative	Medication as changed trajectory of life
Medication as a tool	Medication useful to control symptoms but does not have wider impact
Medication as harmful	Refers to physical impact on young people including side effects and potential physical danger
Medication as suppression / threat to authenticity	Medication changes personality
Medication as normal / 'no big deal'	Medication ordinary part of life
Medication abnormal	Not normal to take medication for behaviour
Medication as right time/right place (transient)	Medication something I take now but this will change
Medication not appropriate	Questioning whether it is right to take medication for behaviour
Medication as daily intrusion	Daily impact / lived experience of taking medication

Results of discussion with researcher outside the research team.

Need to take wider view of interpretative repertoires, so these are not purely themes. Resulted in interpretation of certain repertoires as containing others (e.g. medication as a tool positioned medication as normal and medication as not appropriate to change behaviour contained threat to authenticity). This resulted in three interpretative repertoires.

Table N2. Second stage of developing interpretative repertoires

repertoires	Containing
Medication as transformative	Medication as transformative Medication as a cure
Medication as a tool	Medication as a tool Medication as normal Medication as right time/right place
Medication as inappropriate	Medication not appropriate Medication harmful Medication as suppression / threat to authenticity Medication as abnormal Medication as daily intrusion

Further discussion with supervisor and discussion regarding whether medication as harmful (ie. physical impact) was the same as inappropriate, resulting in four interpretative repertoires.

- Medication as transformative
- Medication as a tool
- Medication as harmful
- Medication as inappropriate

Appendix O

Leaflet produced by third sector organisation

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Appendix P

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Appendix Q

Research Summary Report for Research Ethics Committee

Research project: 16/LO/0697

Young People's Accounts of Self, Attention Deficit Hyperactivity Disorder and stimulant medication

Overview and Aims

The research into young people's accounts of taking stimulant medication during adolescence in the context of a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) is limited, particularly in the UK. As adolescence is a time when identity is particularly salient, it is important to know how young people make sense of themselves when taking a medication which changes the way in which they behave, and may also affect how others respond to them. Adolescence is also a time of growing independence and separation from parents and it is during this time that young people will begin to make their own decisions about their care, including whether to take, or adhere, to prescribed medications. It is important that clinicians are informed and able to engage with wider issues of importance to young people connected to taking medication, such as the impact of their sense of self, as well as the direct effect of the medication.

This qualitative research project employing discourse analysis, aimed to explore:

- How young people who take stimulant medication further to an ADHD diagnosis, talk about ADHD, medication and themselves.
- What discursive resources these young people have available to talk about themselves as people who take ADHD medication.
- How young people deploy these resources, in interaction with others in research interviews and focus groups.
- What dilemmas these discursive resources generate for young people.
- What subject positions are made available by these discursive resources.

Participants

Participants were thirteen young people aged 13-17, from diverse ethnic backgrounds, currently attending child and adolescent mental health services (CAMHS) who had a diagnosis of Attention Deficit Hyperactivity Disorder, and who were either currently prescribed and taking stimulant medication (methylphenidate) or who had stopped taking medication within the last 6 months.

Method

Participants either took part in a one-to-one interview or a focus group between December 2016 and October 2017. The interview was audio recorded and the recording was transcribed and anonymised by the chief investigator. The resulting transcripts were analysed using discourse analysis (Edley, 2001).

Ten leaflets provided to young people and their parents at CAMHS services across a wide area of Southern England, and related websites, were also analysed using the same form of discourse analysis, in order to explore some of the discursive resources that might be available to young people to make sense of stimulant medication and ADHD.

Summary of findings

The young people mostly drew on positive repertoires regarding medication, in contrast to recent research in other countries which found that adolescents had ambivalent views and that medication was often a

burden (Avisar-Lavie, 2014; Charach et al., 2014) Their accounts highlighted four ways of talking about medication, termed interpretative repertoires (Wetherell & Potter, 1988); *medication as transformative*, *medication as a tool*, *medication as inappropriate* and *medication as harmful*.

The first two repertoires were largely positive and used by the majority of participants, with important differences. The repertoire of medication as transformative had more implications for self, as it was used to refer to transformation across domains. In contrast, the repertoire of medication as a tool had less implications for a sense of self, as this repertoire presented medication as a solution to address a specific issue. This repertoire normalised stimulant medication and allowed young people to position themselves as decision makers who may or may not decide to continue to take medication in the future.

The other two repertoires, *medication as inappropriate* and *medication as harmful* were minority repertoires. The young people's accounts suggested that these repertoires were ways of talking about stimulant medication that they encountered outside mental health services, and in particular from adults within their family circle.

The way in which the young people spoke about their medicated and un-medicated selves, revealed an ideological dilemma (Billig et al., 1988) between being out of control, viewed by others as 'unsafe' and 'dangerous' but being free to be 'fun' and 'sociable' when not taking medication. The young people described medication as both putting them in control of behaviour and focusing on goals, but for some young people, this resulted in the sense that they were being controlled.

The predominant repertoire from the leaflets and websites was ADHD as a neurobiological condition and medication as a treatment to target specific neurobiological deficits. Other explanations for ADHD as contributory factors were briefly mentioned in leaflets produced by third sector organisations, although in the context of a primary neurobiological explanation. This positioned children as subject to their biology which could be protective as it allowed them not to be thought of as naughty but had implications in terms of children accepting medication.

Clinical and Research Implications

- There are few leaflets available to adolescent young people regarding stimulant medication and ADHD. Most leaflets are aimed at parents or young children. It would be valuable to produce resources aimed at an adolescent population, in line with the resources aimed at younger children by the VOICES project (www.adhdvoices.com).
- This study highlights the importance of young people being active participants in their own care. Clinicians may find that conversations about medication as a tool, rather than a cure, may be more empowering to young people.
- Clinicians should engage with young people's sense of self and the impact of both diagnosis and medication on this. In particular, young people's descriptions of their un-medicated selves ('mad', 'bad', 'dangerous') are concerning, in terms of how young people make sense of themselves, and appear to be unaffected by a neuro-biological explanation of their behaviour.
- It is likely that young people are negotiating different culturally held meanings about diagnosis and treatment, which will have implications for their relationship with, and choices about, medication. Therefore clinicians should engage with alternative understandings of ADHD and medication that may be held within the family.
- Further research which took a narrative approach to ADHD diagnosis and medication, to explore how young people integrate diagnosis and medication into their life stories and continuing sense of self would be valuable.

Appendix R

Author Guidelines for Target Peer Review Journal

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