Young People's Experiences of AD/HD

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Xavier Michael Brooke

DClinPsychol

Department of Psychology

Faculty of Medicine, Health and Life Sciences

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Abstract

A review of the literature concerning young people's experiences of a diagnosis of AD/HD was conducted. The review first examines the experiences of adults with a diagnoses of mental disorders and the related topics of stigma and labelling are considered; before focussing on the experiences of young people with a diagnosis of AD/HD. The utility and validity of the existing literature is discussed, in addition to future directions for research. This is followed by an empirical paper describing a study examining the experiences of a group of young people with a diagnosis of AD/HD. Ten participants were interviewed and the data gathered were analysed using techniques from Grounded Theory. A model of these experiences, generated from the data, is given. The results of the study are discussed in relation to existing research, the clinical implications thereof, and directions for future research. The limitations of the study are also examined.

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HOW DO CHILDREN AND ADOLESCENTS EXPERIENCE A LABEL OF AD/HD? A REVIEW OF THE LITERATURE

The 'British Journal of Clinical Psychology' was used as a guide during the preparation of this literature review (See Appendix 1)

i. Abstract

The literature review discusses the experiences of young people with a diagnosis of AD/HD. Given the paucity of research in this field, the review first examines the experiences of adults with diagnoses of mental disorders, and the related topics of experiences of stigma and discrimination within this population. The review then describes AD/HD and examines some of the literature regarding the attitudes of peers and family towards young people with the diagnosis, before reviewing the existing qualitative studies investigating the experiences of the individuals who have received a diagnosis of AD/HD. Finally, directions for future research into experiences of living with mental health disorders, and the clinical relevance of such research are discussed.

How do children and adolescents experience a label of AD/HD? A review of the literature

1. Aims of the review

This review will explore children and adolescents' experiences of living with a label of AD/HD, and how this might impact upon their lives and those around them. Understanding how young people experience living with this label is important, given the increasing numbers of young people being given the diagnosis and attending services for problems attributed to AD/HD. Given the paucity of literature in this area, the review will first examine the more prevalent literature concerning adults' experiences of receiving mental health diagnoses. The majority of this limited field focuses upon experiences of stigma and discrimination in adults with a diagnosis of a mental disorder, therefore the review will first define mental disorder and then describe stigma, before turning to adults' experiences of stigma and mental disorder. The literature exploring adults' more general experiences of mental disorder will then be examined, before concluding with the literature discussing the experiences of children and adolescents with a diagnosis of AD/HD.

1.1 Search Strategies

To conduct this review of peer reviewed studies searches were conducted using computer-based databases including PsychInfo, PubMed, Web of Knowledge, Embase and the British Nursing Index, in addition to Internet search engines, such as Google. The following key words were used: Adults;

Children; Adolescents; Young People; Mental Health; Mental Disorder; Self-perception; Experiences; Perception; Stigma; Discrimination; Labeling; Diagnosis; AD/HD; Attention-Deficit / Hyperactivity Disorder; ADD; Hyperkinesis; Attention Deficit Disorder; Psychiatric; CAMHS; interviews; depression; anxiety; panic; eating disorders; OCD; psychosis; schizophrenia; conduct disorder; oppositional defiant disorder; and developmental disorder.

The literature searches produced a large number of papers. This number was scaled down for the purpose of the current review, by cross-referencing the articles, to find the most widely cited, and those deemed most important within the field; and by relevance to the question being discussed – i.e. papers that examine experiences of mental disorder, in particular qualitative papers, and those looking at children and adolescents' experiences of diagnoses of mental disorders.

In terms of how children and adolescents experience their diagnosis of AD/HD, only two studies were found that invited young people to discuss the diagnosis in interviews, which were analysed using qualitative methods.

2. Mental disorders

2.1 Diagnosis in mental health

People acting in ways not regarded as 'normal' by the society in which they live have been documented almost as far back as records of human behaviour; and were previously described as 'madness' or other such terms

(Horwitz, 2002). These descriptions were reserved for people with the most extreme behaviours. 'Formal' diagnoses in mental health have only existed, in a similar form to that which we currently use, since the late 19th Century (Horwitz, 2002). At that time there were two terms used to classify patients: 'dementia praecox' (now known as 'schizophrenia') and 'depression'. It was not until Sigmund Freud changed the way in which mental illness was conceptualised that more terms were created; widening the range of potential diagnoses (Horwitz, 2002).

The classification of different clusters of 'abnormal' behaviours continued to grow throughout the 20th Century. They were described in manuals such as the Diagnostic and Statistical Manual (DSM) which enabled psychiatrists to give an appropriate diagnosis to the range of behaviours were presented to them. These manuals continue to be updated with the addition of new disorders/diagnoses and older ones being changed or removed. The current version contains some 400 distinct diagnoses for different clusters of 'abnormal' behaviours (Horwitz, 2002).

Mental disorders are defined in the latest edition of the DSM, (DSM-IV; APA, 1994) as being,

> "conceptualized as a clinically significant behavioral [sic] or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g., a painful symptom) or

> disability (i.e. impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome must not be merely an expected and culturally sanctioned response to a particular event. Neither deviant behavior (e.g. political, religious, or sexual), nor conflicts that are primarily between the individual and society are mental disorders unless the deviance or conflict is a symptom of a dysfunction in the individual, as described above" (APA, 1994; p. xxi).

There is much controversy about the validity of diagnoses in mental health and this debate is too large an area to be covered here. However, a brief summary of the debates regarding the utility of diagnoses will now be considered.

2.2 The utility of diagnosis in mental health

Whilst some think diagnoses are potentially harmful as they may lead people to become stigmatised (see below), these categories and labels are regarded by others as being useful for a number of reasons. Kendall and Jablensky (2003) argue that although psychiatric diagnoses may not have rigorous validity, they are a useful tool for both patient and therapist:

> "Diagnostic categories can provide invaluable information about the likelihood of future recovery, relapse, deterioration, and social handicap; and they provide a wealth of information about similar

> patients encountered in clinical populations or community surveys throughout the world – their frequency and demographic characteristics, their family backgrounds and premorbid personalities, their symptom profiles and evolution over time; the results of clinical trials of several alternative therapies; and research on the aetiology of the syndrome" (Kendall & Jablensky, 2003; pp. 9 – 10)

Diagnosis provides important information to the therapist and the individual, guiding options for evidence-based treatment and their implications for the individual. Diagnosis also aids communication between professionals and client-support groups, providing a means for common understanding without necessitating a long description of an individual's difficulties (Kendall & Jablensky, 2003).

3. Stigma

In his 1963 book, the sociologist Erving Goffman stated that the word 'stigma' originates from Ancient Greece, where the term was used to describe the symbols cut or burned onto a person's body indicating that there was something "bad or unusual about the moral status of the signifier" (Goffman, 1963, p. 11). These marks would tell other people that the bearer "should be avoided, especially in public spaces" (Goffman, 1963, p. 11).

Porter (2004) summarised Goffman's conclusions, stating:

> "Stigmatising involves projecting onto an individual or group judgments about what is inferior, repugnant or disgraceful. It translates disgust into the disgusting, apprehension of danger into the dangerous. It is thus the creation of spoiled identity: first it singles out difference, next it calls it inferiority, and finally blames those who are different for their otherness" (p. 4).

Stigma has long been associated with mental disorders, as people with mental disorders have often been viewed as different, unpredictable and inferior. These perceptions have been recorded throughout history and it would not be possible to describe all accounts of stigma attached to mental disorders here.

The question of whether it is the diagnosis or the individual's behaviour that is stigmatising has long been debated in the literature (e.g. Rosenhan, 1973; Sartorius, 2002; Link, Cullen, Frank & Wozniak, 1987; Brockelman, Olney, & Williams, 2002) and, again, the topic is too large to cover within the scope of this review.

4. Attitudes towards people with mental disorders

In considering how being given a label of mental disorder is experienced, it is important to examine the attitudes of others towards people with a mental health diagnosis.

A survey conducted with approximately 1500 members of the British public by the Royal College of Psychiatrists investigated attitudes towards people with a range of mental disorders (Gelder, 2004). The survey asked a number of questions for seven different mental disorders; severe depression, schizophrenia, dementia, panic attacks, eating disorder (unspecified), alcohol addiction and drug addiction. The questions related to the following areas of interest: perceptions of dangerousness; perceptions of predictability in the individual's behaviour; how 'hard' they may be to talk to; whether the individual is to blame for their condition; and whether they could 'pull themselves together' should they want to.

The findings of the survey showed that attitudes varied widely, depending on the disorder/diagnosis that was being discussed. For example 71% of participants viewed a person with schizophrenia as 'dangerous', compared with 7% for a person with an eating disorder. Those with addictions were also highly rated as dangerous, with 74% believing people with a drug addiction to be dangerous (Gelder, 2004).

The belief that people with mental disorders "had themselves to blame" for their condition was most commonly held towards people with addictions (68% for drugs and 60% for alcohol). For severe depression, schizophrenia, dementia and panic attacks, less than 15% of participants thought that they were responsible for their condition. 35% of respondents thought that people with eating disorders were to blame for their condition (Gelder, 2004). A similar pattern was found for beliefs about whether people with mental disorders could 'pull themselves together if they wanted to'. Percentages were lowest for schizophrenia and dementia (four and eight percent respectively) and again, highest for the addictions, followed by eating disorders (Gelder, 2004).

A 2002 study (Mukherjee, Fialho, Wijetunge, Checinski, & Surgenor, 2002), examining the attitudes of 520 doctors and medical students towards people with a mental disorder found that whilst over 50% of respondents thought that patients with schizophrenia, drug addiction and alcohol problems were dangerous and unpredictable, these beliefs varied by disorder. A similar number of participants thought that people with dementia, depression and schizophrenia were 'difficult to talk to'. The majority of the participants did not feel that the individuals were to blame for their 'dangerousness' nor their communication difficulties; rather they attributed these characteristics to the nature of their disorders.

In another study of over 2000 psychiatrists' attitudes towards people with mental disorders (Kingdon, Sharma, & Hart, 2004) 59% of the respondents thought that less emphasis should be placed on public protection from people with mental disorders. However, 28% disagreed and thought that more emphasis should be given to this issue. Further, 92% of the sample thought that people with a mental disorder were 'far less of a danger' than the general public think they are, with only 2% disagreeing.

A US study (Van Dorn, Swanson, Elbogen & Swartz, 2005) set out to compare stigmatising attitudes of different groups of people who might come into contact with individuals with schizophrenia, against each other, and members of the general public. 241 people were recruited to the study; members of the general public (n=59), mental health professionals (n=85), people with a diagnosis of schizophrenia (n=104), and relatives of people with diagnosed schizophrenia (n=83). Van Dorn and colleagues (Van Dorn, Swanson, Elbogen & Swartz, 2005) found that the only significant difference between members of the general public and those who have had contact with a diagnosis of schizophrenia was in their understanding of the causes of mental disorders. The group with the most negative views of schizophrenia and people with schizophrenia were the patients themselves, although the differences between the groups were not statistically significant.

Cowan (2003) suggested that the public's negative and stigmatising attitudes towards people with mental disorders mean that communities have a 'not in my back yard' ('NIMBY') approach to the development of mental health services. Cowan stated that "In part, NIMBYism occurs as a result of the negative attitudes held by the community towards people with mental health problems" (Cowan, 2003, p. 380). In addition, Cowan (2003) stated that whilst previous research suggested that the public are willing to accept people with mental disorders into their communities, these attitudes are not borne out in practice.

To address the methodological problems in earlier research, Cowan (2003) investigated members of a Scottish public's reaction to the creation of mental health services within their community, using qualitative methods, to explore the issue of 'NIMBYism' and attitudes towards mental health. Cowan (2003) employed discourse analysis on data gathered from public documents, four group discussions and two individual interviews with those responsible for setting up the service. In the main, those who objected to the creation of the service were affronted by the lack of consultation in the planning and development of the scheme, rather than any factors relating to people with mental disorders.

There are many problems with Cowan's (2003) investigation. Firstly, the limited amount of data collected and analysed. Further, in describing the group discussions, there is no mention of the make-up of the four groups, nor how many people were in each one. Additionally, Cowan recruited people who had written letters to the newspapers to participate in the group discussions. This may have biased responses (as they were the group motivated to argue one way or the other to the press) and may not represent the views of the wider community.

In her discussion, Cowan (2003) stated, "The present study used discourse analysis to explore local people's views about people with mental health problems by examining the ways in which they were expressed when arguing for or against [the project]" (p. 383). However, despite Cowan's use of a more 'ecologically valid situation' and the utilisation of qualitative methods, she failed to explore the actual attitudes towards those with mental disorders, or to explain what those who were in opposition were actually *objecting to.*

This review has highlighted some of the difficulties when attempting to ascertain the levels of stigmatising attitudes towards mental disorders. What initially may seem a foregone conclusion – that the majority of the people hold stigmatising attitudes towards those with a label of mental disorder – is not entirely borne out by research. Attitudes appear to vary by diagnosis and population, indicating a need for more rigorous research. In the context of this review, it is important to continue by examining how those with a label of mental disorder experience having that label.

5. Experiences of mental disorders

5.1 Adults' experiences of stigma and discrimination and having a mental disorder

The experience of stigma and discrimination has only recently received attention, consequently there is little research in this area (Graf, Lauber, Nordt, Ruesch, Meyer, & Rossler, 2004). A survey of Mental Health Service users designed by the Mental Health Foundation examined issues of stigma and discrimination (De Pointe, Bird & Wright, 2000). The survey consisted of two parts, the first asking about experiences of 'mental distress' (mental disorder) and the second about experiences of discrimination. Items consisted of both open and closed questions. In total, 556 questionnaires were analysed (from a total of 4,100 distributed).

The survey found that 65% of respondents had experienced discrimination in response to their own 'mental distress' (De Pointe, Bird & Wright, 2000). Fifty six percent of respondents had experienced discrimination from within their own family. Sixty six percent of the sample stated that they would not tell some people about their own mental distress, for fear of discrimination. Seventy four percent of the respondents said that they would not disclose their mental disorder on a job application for fear of discrimination and prejudice (De Pointe, Bird & Wright, 2000).

Eighty-four percent of the sample reported that they felt able to tell their GP about their mental distress. However, 44% of the total sample reported being discriminated against in some way by their GP, for example being told "to snap out of it" or having physical symptoms explained as psychosomatic. The authors suggested that the fact that people need to talk to their GP about their mental distress, as they are the 'gateway' to many of the treatment options, may be the reason why so many could talk to their GP, despite the possibility of being faced with discrimination (De Pointe, Bird & Wright, 2000).

This survey gave an overview of the experiences of people with mental disorders in the UK, and indicated that many of them encounter situations in which they feel discriminated against. However, no demographic information was collected so it is not possible to explore whether there were any effects of these variables upon the levels of stigma and discrimination experienced. In addition, the survey does not compare how reports of discrimination are related to perceived or actual stigma. For example, the report reveals that "37% stated that they had experienced discrimination when seeking employment" (De Pointe, Bird & Wright, 2000, p. 10) but does not relate this to how those participants perceived stigma in their work place, nor are these findings referred to in the section exploring perceived stigma in relation to seeking employment (p. 11). Further, respondents reported discrimination that was not associated with their mental disorder, e.g. "Psychiatrists have been homophobic and oppressive" (De Pointe, Bird & Wright, 2000, p. 10), but the authors did not distinguish between the reasons for the discrimination.

The Mental Health Foundation also published a widely cited UK study examining the workplace experiences of people with mental disorders (Warner, 2002). The survey used a self-administered questionnaire, which mainly consisted of check boxes for the participants to tick statements that they agreed with. There were some spaces for the participants to provide their own answers. Of the 500 returned questionnaires, 411 were eligible to be analysed. 66% of participants were female. Participants were asked to describe their mental health difficulties, with over half reporting depression and 38% reporting anxiety or stress. Although the author states that some participants reported more than one presenting problem, they have not given the number of participants who did this.

In terms of discrimination, a third of participants (31%) believed that they had been turned down for a job due to their mental disorder, with a further 25% stating that this was a possibility but were unsure. This varied by mental disorder, with the majority of people with depression believing that they had not been discriminated against whilst job seeking. One in ten of the participants thought that colleagues would make negative remarks, or avoid them as a result of their mental health problem (Warner, 2002).

In terms of disclosing their mental health problems in the workplace, 90% of those in full-time employment had felt able to tell somebody at work about their difficulties. However, 27% believed that if their employer knew, they would not have their current job or would fail to get a promotion (Warner, 2002).

Whilst the report provided a number of interesting results, closer examination reveals a number of methodological problems. Firstly, the questions in the survey (see Warner, 2002, pp. 31 – 33) are closed, forcing participants to choose from a limited number of options. On the items where participants may give their own responses, they are given very little room to do so (mostly a maximum of one line). The summary tables note that statements which were given by less than 1% of the sample were excluded from the report. This means that an undisclosed number of responses were not reported for some items, and it is possible that there was a much wider range of experiences than those given in the report. Secondly, the items appear to be biased towards the participants' negative experiences such as item 12, "Do you think you have ever been turned down for a job because of your mental health?" (p. 32); and item 5 (p. 31) in which participants are given a choice of eight negative statements relating to the impact of people knowing about their mental health problems, and only four positive or neutral statements. Further, a number of items in the questionnaire do not allow the participants (nor the analysts) to distinguish between two questions of an item, for example, item 10 "Do you think your mental health problems have been caused/made worse by: (tick all that apply)" (p.32), and so it is unclear which part of the item the participants have responded to.

Perhaps the most important problem with this survey is that it presents these experiences in the workplace as if they were exclusive to people with mental health problems, but there is no way in which we can compare this populations' experiences with those of the 'general public'. It is quite possible that people without mental health problems also have beliefs about, and experiences of, being discriminated against when in the workplace, such as "feeling unsupported" by management, or believing that something about their personality has resulted in them being unfairly passed over for promotion.

Given the above problems with research using surveys with closed questions, a number of other studies utilising different methodologies to investigate the experiences of people with mental disorders will now be considered.

A qualitative study (Koivisto, Janhonen & Vaisanen, 2002) aimed to investigate the experiences of disempowerment in people with psychosis who had been admitted to a psychiatric hospital in Finland. Nine participants were recruited and interviewed about their experiences of psychosis and the interventions that they had received. The interview transcripts were examined using thematic analysis, with common themes being clustered together. The authors provided a list of the categories that they created from examining the data, such as "experience of being helped" (p. 262), and gave a few examples of extracts from the transcripts. However, despite setting out to examine the experiences of people with psychosis, Koivisto and colleagues (Koivisto, Janhonen & Vaisanen, 2002) provided few in-depth insights into feelings of disempowerment in this population. A one-paragraph descriptive summary of the common themes is given at the end of the Results section and a very brief account of their clinical relevance in the Discussion:

> "So, what is the essence of psychosis as seen by patients? The present informants described psychosis as consisting of strange experiences and feelings that caused exhaustion, fear and shame. They tried to manage these strange experiences in different ways, for example, by seeking help, discussing with friends, engaging in sporting activities, doing something or protecting themselves in some way. They wanted to understand what was happening to them, why it was

> happening and how they could manage these experiences without losing their self-control. They felt guilt and shame because of these strange experiences, which other people found difficult to understand." (Koivisto, Janhonen & Vaisanen, 2002, p. 264).

Rather than describe how these experiences might relate to existing literature, and provide suggestions for future research and clinical intervention, the authors focussed upon the advantages of using this particular qualitative methodology and how it may be applicable to nurses working with people with mental disorders. In terms of stigma and discrimination, this study suggested that people with psychosis may feel guilt and shame related to their beliefs about others' comprehension of their condition. However, the authors did not explore this issue in any depth, nor did they give any indication of the number of participants for whom this was an important experience.

Bromley and Cunningham (2004) recognised the lack of research into the experiences of stigma in people with mental health disorders, and decided to compare a UK sample of psychiatric in-patients (*n*=40) with an age and gender matched group who had been admitted for non-psychiatric medical interventions (*n*=40). The investigators were interested in the number of disclosures regarding the admission to friends and family, but they were primarily interested in gifts stating that, "Hospital admission for physical illness helps to legitimise the sick role, and the sending of 'get well' cards and flowers signals support from the patient's social network" (Bromley and Cunningham, 2004, p. 372). The researchers cited anecdotal reports that psychiatric patients received fewer gifts than medical patients and suggested that should their study demostrate this, it would provide evidence that people with a mental disorder carry a stigma from which discrimination occurs, i.e. that their relatives would not endorse the 'legitimate' nature of their condition by sending them cards or flowers.

Data were gathered using a questionnaire that asked participants the number of people in their nuclear family and how many people were in their network of friends. They were also asked about their understanding of why they had been admitted, in addition to how many family and friends they had informed of their admission and diagnosis, and if they had not informed them, the reasons for their decision. The participants were also asked to record the number of gifts and card they received during their admission.

The researchers found significant differences ($p<.001$) between the groups in terms of disclosure of diagnosis to family and friends, and for the disclosure of admission to friends (Bromley and Cunningham, 2004). The researchers did not conduct a statistical test for the disclosure of admission to family. It is likely that there were no significant differences, as the numbers of people reported as disclosing admission in the medical and psychiatric patients were similar (n=39 and n=34 respectively).

Those in the psychiatric group gave five main reasons for not wishing to disclose their diagnosis – embarrassment at not being in control of their emotions or behaviour; fear of people watching their behaviour more closely after discharge; anxieties about people treating them differently if they found out about the diagnosis; and being worried that they would lose their jobs.

Although the psychiatric patients received fewer cards and gifts, there were no significant differences between the two groups. The authors suggested that this might be attributable to the psychiatric patients having disclosed the admission to fewer people in their network of friends than those in the medical group. The authors noted that there were qualitative differences in the types of gifts received, namely that the psychiatric patients were given 'practical' gifts such as toiletries and tobacco, rather than the flowers and balloons received by the medical patients.

As with other studies cited in this review, there are a number of problems with both the method and conclusions drawn from this study. Firstly the researchers assume that the number of cards and gifts given is strongly associated with how 'legitimate' friends and family think the patient's illness is, and that measuring this would give an insight into stigma and discrimination associated with mental disorders. The authors do not acknowledge that there are a wide range of possible factors that could contribute to the number of gifts and cards given to patients (e.g. whether the patient has had previous admissions for the same problem). Further, the researchers did not take into account the impact of the length of stay upon the number of gifts received.

The researchers drew a number of conclusions from the data without considering other possible explanations. For example: "it is of interest that they [the psychiatric patients] usually receive gifts of a practical nature, which may be linked to doubts about the validity of the sick role in mental illness" (Bromley and Cunningham, 2004, p. 373). It is, however, equally possible that this difference could be accounted for by the psychiatric patients having longer admissions, and thus being more likely to need such items. Another example occurs when the investigators draw their own conclusions as to why those in the 'psychiatric' group had fewer contacts: "reduced social contact due to the effects of stigma may mean that there are fewer people to disclose admission to" (p. 372), despite not having explored this issue with the participants.

Perhaps the most interesting observation, was that a significant number of psychiatric patients perceived admission to the hospital as stigmatising and do not reveal their admission to people outside of their nuclear family.

As the previous discussion indicates, there are a limited number of published studies exploring stigma and discrimination in relation to mental health. The majority either look at one aspect and not the other (i.e. perceived stigma *or* experiences of discrimination); look at issues of stigma and discrimination but do not relate the two; are based on single cases, in which service users describe their experiences (e.g. Taylor, 2004); or use small sample sizes (e.g.

Koivisto, Janhonen & Vaisanen, 2002).

One study that attempted to address this problem was conducted in the UK by Dinos and colleagues (Dinos, Stevens, Serfaty, Weich, & King, 2004). In their study of stigma and its relationship with, and consequences for people with mental disorders, 46 participants from community mental health services completed a 45-minute interview. The authors found stigma was an issue for the majority of the participants in a number of areas. For example, 41 respondents were anxious about disclosing information about their condition to others as they thought that there was a stigma attached to their mental disorder. Following the analysis, the authors distinguished between the participants' 'subjective feelings of stigma' and the consequences thereof, and 'overt discrimination'. Dinos et al. (2004) found that all of the interviewees had experienced some level of 'subjective feelings of stigma' and had experienced consequences of this, such as avoidance of help-seeking for fear of being judged. They also found that those with depression, anxiety disorders and/or personality disorders reported experiencing a greater number of consequences, than those with other diagnoses such as psychosis (Dinos et al, 2004). The authors found that 61% of participants reported negative outcomes, such as negative emotions (e.g. guilt, embarrassment) or prevention of their recovery. 'Overt discrimination' (such as verbal and physical abuse) was more likely to be experienced by those with a diagnosis of psychosis than the other diagnostic groups and 65% of participants reported having such experiences. It is interesting to note that participants had 'subjective feelings of stigma', including those who had never experienced discrimination in relation to their disorders. Further, the authors note that some of the participants talked about positive aspects of having a mental disorder, and this aspect of the study will be examined later in this review.

Dinos and colleagues' (Dinos et al, 2004) research has a number of positive features. Firstly, the authors noted that the interviewers "avoided using the word 'stigma' so as not to lead the participants" (p. 176), and gave a description of the themes covered within their interviews, and a clear description of how the data was analysed, and categories were formed. The study also gave direct quotations from transcripts to help readers understand the results.

In terms of the limitations of this research, Dinos and colleagues (Dinos et al, 2004) do not give examples of the questions that the participants were asked, nor do they make it explicit as to whether 'open' or 'closed' questions were asked. Whilst the interviewers tried not to use the word 'stigma', the authors noted that "participants were asked to talk about the impact of their mental health problems on their work and private life", (Dinos et al, 2004, p.176) which is biased – i.e. that the mental health problem *must,* in some way, have an impact on those areas of participants' lives. As with many qualitative studies, Dinos and colleagues were unable to use triangulation of sources in order to corroborate the experiences of their participants, therefore the accounts given can only be of ‘perceived’ discrimination. Further, all participants were recruited through the local mental health service, and thus the findings cannot be generalised to a population of people with mental disorders as a whole.

Despite the limitations of this study, Dinos and colleagues (2004) have made a valuable contribution to the body of work by trying to allow participants to discuss the topics that were important to them, perhaps to a greater extent than other studies within this review.

5.2. The impact of stigma on the individual

From the above discussion, it is apparent that there is some sort of stigma felt by a proportion of people with mental disorders and those close to them. This section considers how this stigma may impact upon affected individuals.

Corrigan, Kerr and Knudsen (2005) suggested that, prior to obtaining a psychiatric diagnosis, individuals are aware of the cultural stereotypes and stigma within their society regarding mental disorders. They suggested that once a label has been received, this awareness will affect them in two ways. The authors cite the work of Link et al (1987) and Markowitz (1998; cited in Corrigan, Kerr & Knudsen, 2005) who found that in anticipation of being rejected, an individual will try to avoid others, resulting in isolation and unemployment. This in turn leads to a sense of failure, which has a negative impact upon self-esteem and self-efficacy. Further, those with a mental disorder may believe that the stigmatising attitudes and stereotypes 'fit' with their self-perception, and thus perceive themselves in a similar fashion as those who hold these stereotypes - as being of less worth than 'normal people' (Corrigan, Kerr and Knudsen, 2005). These processes are described as 'self-stigma', and previous research has found an association between levels of self-stigma and lowered levels of self-esteem and self-efficacy (Corrigan, Kerr and Knudsen, 2005). The assertion that self-stigma negatively affects an individual's quality of life has been replicated in a number of studies (e.g. Rosenfield, 1997). Further, it has been demonstrated that it can have a negative impact on interventions (e.g. Sirey, Bruce, Alexopoulos, Perlick, Friedman, & Meyers, 2001; Graf, Lauber, Nordt, Ruesch, Meyer, & Rossler, 2004).

A study of 92 outpatients with depression (Sirey, Bruce, Alexopoulos, Perlick, Raue, Friedman, & Barnett, 2001) measured participants' perceptions of stigma using a questionnaire measure on their first appointment. The researchers followed-up the participants after three months to discover whether they had continued treatment and whether they had sought intervention elsewhere. During analysis, the participants were separated by age into two groups: 18 to 64 years old (63 participants), and those who were 65 and over (29 participants), as the authors believed that their findings would be age dependent. The results showed that perceptions of stigma in older adults (65+) with a mental disorder predicted discontinuation of treatment, with no other variable being related to this outcome. Those in the younger age group reported higher levels of perceived stigma but this was not correlated with treatment outcome. Whilst this study suggests that stigma influences treatment outcome in older people, there are a number of limitations. Firstly, the authors do not state what type of treatment the participants are receiving. It is implied that it is pharmacological (by their references to 'side effects') and the reader is left unsure as to whether any psychosocial interventions were also used. Further, the authors do not state whether all participants saw the same professional, nor did they take a measure of perceived therapeutic alliance, which could have been a predictor of drop-out from intervention. The researchers do not provide sufficient explanation for differentiating between the two age groups, nor do they explain what factors may lead to differences in perceived stigma in a 64 year old, from that of a 65 year old, having distinguished between these two groups. In addition, the authors do not attempt to provide an account of why older adults perceived greater levels of stigma than those in the younger group, other than to say "the anticipated social costs may be greater for older adults and may influence their treatment adherence more directly" (Sirey et al, 2001, p. 480). However, they do not hypothesise what these anticipated social costs may be.

A number of surveys have been carried out to examine the impact of perceived stigma and discrimination. Whilst offering potentially interesting observations, e.g. 19% of respondents not being able to seek help from their G.P. for fear of stigmatising attitudes and discrimination (De Pointe, Bird &

Wright, 2000), they tend to suffer from serious methodological flaws and these have been discussed in some detail earlier in this review. In addition, the presentation of results is generally unclear and thus it is hard to know the true extent of the impact of stigma upon individuals with mental disorders.

Employing qualitative methodologies may be one way of overcoming such problems. One such study conducted in New Zealand, (Liggins & Hatcher, 2005) analysed the interviewed data from five patients referred to liaison psychiatry and five referrers in a general hospital, to investigate experiences of stigma in relation to mental illness. The patients were referred for a range of problems including, deliberate self-harm, anorexia, recurrent physical pains and delirium associated with tuberculosis. The researchers used open ended, unbiased questions during the interview for example, "How did you feel about being referred?" (p. 360). The participants' experiences were coded into categories using methods from Grounded Theory, and these included, "It's a scary business (and I don't like it)", "It's all hopeless", "She's one of them (labelling)", "You're not genuinely ill" and "Playing by the roles" (Liggins & Hatcher, 2005, p. 361). The researchers found that 'new' patients (who had just received a psychiatric diagnosis) and existing patients shared the same experiences; and that both the patients and referrers shared the same experiences, albeit from different viewpoint, i.e. the referrers as the 'stigmatizers' and the patients the 'stigmatised' (Liggins & Hatcher, 2005). The authors concluded that both patients and referrers saw mental illness as "scary, being unpredictable and emotionally demanding" (p. 363), with the patients believing that they were treated differently from others due to the psychiatric label that they had been given. This study is interesting as both stigma and discrimination arose from the data, and these experiences were shared by the patients and referrers. There are, however, limitations of the study. The researchers acknowledge that they had a small sample size given the scope of the analysis, and that they did not manage to recruit anyone with chronic psychiatric problems. In addition to the limitations cited by the authors, it should be noted that they did not disclose the beliefs and characteristics of the interviewer(s), nor did they explore whether these beliefs would be held once discharged from the hospital, or by people who are seen within the community.

5.3. Other Experiences of Mental Disorders

Much of the research described above suggests that negative experiences are the sole outcome of having a mental disorder. However, some researchers have found that participants have not reported negative experiences and, indeed, have reported positive experiences. Positive experiences of mental disorders have not been widely or explicitly investigated. It is apparent that not all consequences of having a mental disorder are negative, and whilst negative outcomes do occur, they are certainly not inevitable.

In the aforementioned study by Dinos and colleagues (Dinos et al, 2004), almost half (46%) of participants said that they had not experienced stigma, in terms of feelings of shame or anticipating negative reactions from others, whilst 39% had never experienced discrimination – either overt or perceived - and 7% of the participants thought that the public had a positive view of mental illness. The majority (85%) of participants described at least one positive aspect of having a diagnosed mental disorder with 48% describing more than one positive outcome.

The Mental Health Foundation surveys described earlier (De Pointe, Bird & Wright, 2000; Warner, 2002) also contained some positive outcomes. For example, over a third (35%) of respondents had not experienced discrimination in response to their own mental distress, and 53% had not experienced discrimination in the workplace (De Pointe, Bird & Wright, 2000). However, whilst these were presented as positive outcomes, it is possible that they are showing a lack of negative outcomes, rather than positive outcomes per se. Further, these results must be interpreted with the same caution as the 'negative outcomes' given the previously mentioned methodological problems with these studies.

Hayward and Bright (1997) found that people with a mental disorder did not experience a decrease in levels of self-esteem, even when aware of negative public perceptions of mental illness. Further, an exploratory study by Hayward, Wong, Bright and Lam (2002) found that whilst mood was significantly related to a lowering of self-esteem, perceptions of stigma were independent of this. Corrigan and Watson (2002) suggested that there are three possible reactions to stigma, but only one of these results in a lowering of self-esteem. They proposed that the first outcome was that an individual will 'self-stigmatise', resulting in a lowering of self-esteem. Alternatively, they may be indifferent to any stigma. Thirdly, perceived stigma may lead them to become 'a voice' for those within this stigmatised group, and thus become empowered. Corrigan and Watson's model is yet to be substantiated using empirical methods but is an interesting and seemingly logical hypothesis.

Given the range of experiences described above, do the experiences of children and adolescents echo those of adults? This question will now be examined, focussing specifically upon experiences of one disorder commonly diagnosed in children and young people: Attention-Deficit/Hyperactivity Disorder (AD/HD).

6. Experiences of a diagnosis of AD/HD

6.1 What is AD/HD?

AD/HD is an increasingly common condition that occurs in childhood and adolescence. The prevalence of AD/HD is believed to be between three and five percent of school aged children, with approximately 345,000 6-16 year olds with AD/HD in England. AD/HD occurs more frequently in boys than in girls (approximately 3:1; National Institute for Clinical Excellence, 2000).

AD/HD is described in DSM-IV-TR as persistent and maladaptive levels of inattention, hyperactivity, impulsivity, with some of these behaviours exhibited prior to the age of seven. In addition, the behaviours must occur in at least two settings (e.g. school and home) and cause significant impairment in social, academic or occupational functioning (American Psychiatric Association, 2000).

The cause of AD/HD is a controversial and divisive topic. There are researchers who believe that AD/HD is biological in nature, (e.g. Willis & Weiler, 2005). Some believe the disorder to be caused by psychosocial factors (e.g. Baldwin, 2000), whilst others believe AD/HD to be a social construction, pathologising normal behaviours (e.g. Law, 1997). Further, a number of investigators believe that AD/HD is the result of a combination of some, or all, of these factors (e.g. Sonuga-Barke, 2002).

6.2 Attitudes of peers and family towards young people with AD/HD

There have been a few studies that aim to explore how those with AD/HD experience the label. More commonly, studies have explored the attitudes of peers and family towards those with a diagnosis and these will be explored first.

Milich, McAninch, and Harris (1992) found that children who have a formal label of behavioural difficulties were stigmatised and discriminated against by their peers. Through observation and self-report, the researchers found that the children behaved in a consistently negative fashion towards children with these labels, when compared with peers without a diagnosis. Consequently, the child with the diagnosis becomes aware that they are being treated differently and so behaves differently. This resulted in the child with the diagnosis being rejected by their peers and having less opportunities for socialising and positive interactions.

The perceptions of peers towards children with a label of AD/HD were further explored in Law, Sinclair & Fraser's 2007 study. This study sought to explore the attitudes and behavioural intentions 11 and 12 year olds held towards peers with symptoms of AD/HD, and whether diagnostic labelling would mediate their attitudes and intentions. 120 participants were recruited through schools and were randomly allocated to one of three conditions. In each condition, the child was presented a vignette describing a gender-neutral peer with difficulties that could be described by the label 'AD/HD'. In one condition, there was no mention of the term AD/HD, in the second condition the vignette ended with "Anon has Attention Deficit Hyperactivity" (p.101) and the third ended "Anon has Attention Deficit Hyperactivity Disorder" (p.101).

Standardised questionnaires were used to elicit words the participants would use to describe 'Anon', and to gain an understanding of the range of activities in which they would be willing engage with 'Anon' (behavioural intentions). Whilst most participants perceived 'Anon' as male, over half could relate 'Anon' to someone they knew, and the majority held negative attitudes and behavioural intentions towards 'Anon'. The children did not distinguish between the three conditions in terms of their behavioural intentions or attitudes, suggesting that the inclusion of diagnostic label was not a significant factor in their perceptions. The authors concluded that the children made their negative judgements of 'Anon' based upon the externalising behaviours rather than the diagnosis itself. Although the authors acknowledge some methodological problems with this study, for example, poor response rate, that they were measuring intentions rather than actual behaviour, and perhaps most importantly, the lack of positive attributes in the vignettes; they still conclude that children hold negative attitudes towards peers with behavioural difficulties. There are, however, other problems with this study. Firstly, the authors do not explain why they choose to use 'Attention Deficit Hyperactivity', in one of the conditions, rather than an entirely fabricated 'diagnosis' or a nonsensical term. The authors did not take a measure of how many of the participants understand the word 'disorder', nor how many had actually heard of the term 'Attention Deficit Hyperactivity Disorder'; and they did not investigate whether the children had heard of other terms for the disorder (e.g. 'AD/HD, ADD, Hyperkinesis). Thus it is possible that there was no differentiation between conditions as the terms used were not part of the children's vocabulary.

A 2006 study (Dryer, Kiernan & Tyson, 2006) explored beliefs about AD/HD held by parents and professionals. The researchers recruited 670 participants, consisting of a range of professionals working with children in a range of fields (education, medical, allied health), parents with and without children with a diagnosis of AD/HD. Participants were given a 117 item questionnaire, which contained items related to the aetiology and nature of AD/HD, treatment, treatment options and prognosis of the condition. In terms of characteristics of AD/HD, the participants responses were grouped into five factors which explained 50% of variance in the data: 'Behaviour Control' (including 'Poor behaviour control and response inhibition'); 'Cognitive' (including 'poor memory', 'poor listening skills', 'poor hand-eye coordination'), 'Adjustment' (including 'being irritable and having anger outbursts', 'difficulties making friends', 'having lower IQ than peers'), 'Concentration and Attention' (including 'problems with concentration and attention'), and 'Low self-esteem'; with 'Concentration and Attention' and 'Behavioral Control' accounting for the largest variance in the data across all participant groups (Dryer, Kiernan & Tyson, 2006).

In terms of the causes of AD/HD, the analysis grouped the responses into six factors which accounted for 66.9% of the data: 'Home environment', which included 'lack of discipline', 'lack of attention', and 'maladaptive behaviours in the child' (e.g. watching too much TV); 'School environment', i.e. difficulty in adjusting to school environment / school work; [Exposure to] 'Toxins' (in utero, through poor diet or food allergies); 'Brain damage' either as a result of a birth complication or developmental delay; 'Brain function', which included chemical imbalances in the brain or problems with the way in which the brain is functioning; and 'Anxiety and depression'. Most participants attributed AD/HD to 'Brain damage' and 'Chemical imbalances in the brain', whilst 'Anxiety and depression' only accounted for 6% of the variance in the data

(Dryer, Kiernan & Tyson, 2006).

The authors concluded that professionals and parents hold similar beliefs about the characteristics and causes of AD/HD, and that these beliefs were closely related to our current knowledge of AD/HD. The authors acknowledge that the agreement between the groups in the belief that AD/HD is endogenous in nature could be cause for concern in that this may lead towards an emphasis on a pharmacological 'cure' for AD/HD, rather than considering alternatives such as behavioural intervention (Dryer, Kiernan & Tyson, 2006). The study has limitations. The analysis did not factor in the level of contact the participants had with young people with AD/HD, which may have had influenced their responses. Further, whilst it is interesting to gain an insight into the participants' beliefs about AD/HD, it is a pity that the researchers did not investigate what impact these beliefs might have on the young people and their families (e.g. the beliefs that AD/HD is caused by 'poor parenting', or 'watching too much TV'), which could suggest where any future intervention might be appropriate.

6.3 Experiences of children and adolescents with a label of AD/HD

There is a limited amount of research into the experiences of young people with a diagnosis of AD/HD, and the majority of studies have used standardised questionnaire measures to focus on self-perception. The results of these studies are varied, with some finding that children with AD/HD will give themselves inflated scores in areas of deficit (Hoza, Gerdes, Hinshaw, Arnold, Pelham et al, 2004), whilst others find that children with AD/HD will give themselves globally low scores (Dumas & Peletier, 2004). The majority agree that children and young people with AD/HD will consistently give lower self-report scores in terms of self-esteem than peers (e.g. Barber, Grubbs & Cottrell, 2005).

There is a distinct lack of qualitative studies in which young people with AD/HD are given an opportunity to discuss what it is like to have the diagnostic label from their own perspective. To date, only two such studies have been published in peer-reviewed journals. The first was conducted in the USA with 39 children aged between six and seventeen (Kendall, Hatton, Beckett & Leo, 2003), and sought to explore what sense young people with AD/HD made of the label they had been given. The researchers conducted interviews with the participants lasting between 15 and 45 minutes, which were then transcribed and analysed using methods from grounded theory. The authors identified six main themes from the analysis: 'Problems in thinking, behaving and feeling', which included 'learning and cognition problems' and 'feeling' (mad, sad, frustrated or ashamed); 'Meaning and identity', which included descriptions of behaviours associated with AD/HD forming a part of their identity; 'Pills' which included both positive and negative descriptions of taking medication; 'Mom' which included descriptions of how they perceived their mothers as being the greatest source of support; 'Causes', which included description of perceived causes of AD/HD, for example genetics, accidents or trauma; and 'Race/ethnicity', which differentiated the accounts of AD/HD by race or ethnicity. The authors also suggested that low self-esteem was present across all six themes of the analysis, and hypothesised that improving self-esteem may be important when devising interventions.

The second peer-reviewed study utilising this method recruited and interviewed 11 participants aged 13 to 19 to investigate how young people perceive and experience AD/HD (Krueger & Kendall, 2001). The interviews were transcribed and analysed using methods from grounded theory. The researchers said that they were surprised to find the core category to be centred upon the participants' descriptions of an "AD/HD-defined self" in which the experiences of AD/HD were "integrally related to their identity" (Krueger & Kendall, 2001, p. 64), i.e. that the participants did not distinguish the disorder and its related difficulties as being distinct from their sense of self. The authors state that the participants did not present their accounts as a 'failed' sense of self, rather as being misunderstood or different. The researchers concluded that the participants' accounts were likely to be a "reflection of the stigma and negative appraisals given them [sic] from society" (Krueger & Kendall, 2001, p. 68). The researchers also posited that neuro-biologically based deficits associated with AD/HD, namely self-regulation and perception, may lead to a distortion of self-perception, and that future interventions should help adolescents to address this. What the authors do not discuss is whether such distortions in self-perception are present in other young people in this age group, and whether feelings of 'being different' or 'misunderstood' might be common in typically developing adolescents.

The authors stated that the most important finding in these studies is that the participants with AD/HD appeared to have internalised their diagnoses, and as such, may not have been able to consider the effects of having a psychiatric label, as from their perspective, AD/HD was an integral part of their identity.

7. Difficulties and problems with research into the experiences of mental disorders

There is scant research into children and adolescents' experiences of AD/HD. There are a number of difficulties associated with attempting to investigate individuals' experiences of labels of mental disorders.

Research in this field often focuses upon adult populations, particularly experiences of stigma and discrimination. A major limitation of these studies is the use of self-reported measures of stigma and discrimination. It would be extremely difficult, and ethically questionable, to find evidence to corroborate individuals' accounts. One could not objectively measure the amount of stigma attached to a label, nor the discrimination an individual receives, without following them or giving them a device to record their interactions. Interviews and questionnaires, which are commonly used, rely on the participants' memory for past events, whereas real-time sampling, such as a diary, may give a more accurate account of their experiences. It is also impossible to ask people about their attitudes towards people with mental disorders, and then follow them to discover whether they had 'told the truth' or not. This raises a further issue – that people may not wish to disclose their stigmatising attitudes, or that they have engaged in discriminatory behaviour towards people with mental disorders. Further, perceived discrimination is by its very nature, subjective. Is discrimination said to have occurred when an individual has perceived it to have occurred, or is it possible to determine a threshold for what is and is not discrimination?

Another difficulty raised by Hinshaw (2005) is that it is almost impossible to distinguish what it is that actually attracts the stigma or discrimination – is it the label of a mental disorder, or the behaviours associated with the disorder? This may seem a rather trivial matter as the stigma and discrimination occur regardless of whether it was the label or behaviours that attracted it. However, it raises two important and related questions; namely does such stigma and discrimination occur in a population who display similar behaviours but have not been identified by society as being 'mentally disordered', and does the stigma and discrimination occur prior to being 'identified' as being mentally disordered? Further, are there any positive effects of having a diagnostic label, for example, might stigma actually reduce once people are given a reason for 'strange' behaviour?

A further problem appears to be connected with the audience that the research is written for, or had been funded by (i.e. the 'agenda' of the author).

This is most apparent with the presentation of the results, for example, "One in ten always or often believed that colleagues made snide or sarcastic remarks or that colleagues avoided them because of their mental health" (Warner, 2002, p. 4). The authors could have presented this as '90% of participants did not believe that colleagues made snide or sarcastic remarks....'. A further problem with the reporting of results is that there is no comparison of these beliefs with people in control groups – for example, it is possible that one in ten people in a control group believes that colleagues are talking about them in a negative way, and that these experiences are encountered by a similar proportion of the general population.

8. Conclusions & directions for future research

It is important to understand the experiences of people who have been given a diagnosis of a mental disorder so that interventions can be designed in a truly client-centred fashion. The review shows that most of the current research focuses upon adults' negative experiences of mental disorders, in particular concerning stigma and discrimination. It is important, however, to note that some of the studies have also reported positive experiences, and therefore, that the individuals' experiences may well be complex and varied.

Most current research focuses upon adults' experiences of stigma and discrimination, and much of this is methodologically flawed. There is scant research into the experiences of young people in general, and there are many questions to which we do not know the answers at present. We are unsure how children and adolescents experience having a label of mental disorder. We do not know whether they experience stigma and discrimination, and if so, to what extent, and what the processes are that lead to stigmatisation. Further, we cannot be sure to what extent perceptions of stigma and experiences of discrimination are important to children and young people with mental disorders, or how much these issues actually impact upon their quality of life. We do not know what processes occur that may lead to an individual being affected by stigma, and another individual being resilient.

What appears in much of the current literature is that the answers to these questions are driven by how the questions are posed to the participants, i.e. the researchers make an assumption that these issues are important to these populations, and formulate their methodologies based upon this assumption. Once this assumption has been made, it is almost impossible to distinguish between the researchers' beliefs and what is important to, and has an impact upon the participants.

The limited research into experiences of having a label of AD/HD seems to suggest that young people may incorporate their diagnosis into their self-identity. What is unknown, is whether this occurs for all young people with the diagnosis, or whether it was a feature of those participants. It would be interesting to discover whether 'internalising' a psychiatric diagnosis is unique to young people with AD/HD, or whether it occurs in other populations.

Given the paucity of research in this field, the large range of 'unknowns', and the difficulties in producing 'unbiased' studies, it may be fruitful for future research to adopt a 'hypothesis generating' approach such as those used by Krueger and Kendall, (2001) rather than a 'hypothesis testing' one. It may be appropriate to employ qualitative methodologies that allow participants to discuss their general experiences of mental disorders through open-ended questions. Further, these methodologies would allow the researchers to openly acknowledge their biases during analysis and to investigate what impact these beliefs may have on the results. This would afford young people with 'mental disorders' an opportunity to raise issues that are important to them, and to describe any experiences of stigma and discrimination without the influence of the researchers, thus giving an insight into how far these issues impact upon their lives.

From this basis, research questions could be designed that would explore the stigma and discrimination as part of a wider exploration of young people's experiences of labels of mental disorders, and guided by the people to whom it has the most relevance.

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Young People's Experiences of AD/HD:

A Grounded Theory study

The 'British Journal of Clinical Psychology' was used as a guide during the preparation of this empirical paper (See Appendix 1)

i. Abstract

The purpose of this study was to gain a number of insights into the experiences of young people with a diagnosis of AD/HD. Ten participants were recruited to the study through a Child and Adolescent Mental Health Service and a secondary school. Each took part in a semi-structured interview that was used to explore different aspects of their experience. The interviews were transcribed verbatim and analysed used techniques from Grounded Theory, such as microanalysis and constant comparison. The model generated from the data, centred on experiences of 'Having AD/HD bad' and 'Being in control', and the factors that influence these experiences, such as 'being stuck in boring situations' and 'Having opportunities to make choices' are described and explored using examples from the transcripts as illustrations. The study is discussed in terms of its limitations, how the analysis relates to existing research, in addition to the clinical implications arising from the study, and directions for future research.

1. Introduction

In order to understand young people's experiences of Attention Deficit /Hyperactivity Disorder (AD/HD), we must first understand what the diagnosis signifies, theoretical ideas about its aetiology, and current interventions for the disorder. Before turning to research into experiences of AD/HD we need to consider research on labelling and other studies examining experiences of mental disorder, particularly in young people.

1.1. What is AD/HD?

AD/HD is described in DSM-IV-TR as persistent and maladaptive levels of inattention, hyperactivity, impulsivity, with some of these behaviours exhibited prior to the age of seven. In addition, the behaviours must occur in at least two settings (e.g. school and home) and cause significant impairment in social, academic or occupational functioning (American Psychiatric Association, 2000).

AD/HD is an increasingly common diagnosis in children and adolescents. The prevalence of AD/HD is believed to be between three and five percent of school aged children, with approximately 345,000 6-16 year olds with AD/HD in England. AD/HD occurs more frequently in boys than in girls (approximately 3:1; National Institute for Clinical Excellence, 2000).

AD/HD is thought to affect the individual in many ways. Studies have shown that those with a diagnosis of AD/HD tend to be socially isolated from their peers, underachieve at school and display antisocial behaviours (e.g. Biederman, Faraone, Milberger, Jetton, Chen et al, 1996; Barry, Lyman, & Klinger, 2002). During their late teens, those who had a diagnosis of AD/HD as children are more likely to have deficits in academic and social functioning (Mannuzza & Klein, 2000). As adults, those with a childhood diagnosis of AD/HD are also more likely to have an antisocial personality and hold lower occupational positions (Mannuzza & Klein, 2000).

1.2. What causes AD/HD?

The cause of AD/HD is a controversial and divisive topic. There are researchers who believe that AD/HD is biological in nature, (e.g. Willis & Weiler, 2005). Some believe the disorder to be caused by psychosocial factors (e.g. Baldwin, 2000), whilst others believe AD/HD to be a social construction, pathologising normal behaviours (e.g. Law, 1997). Further, there are a number who believe AD/HD to be the result of a combination of some, or all, of these factors (e.g. Sonuga-Barke, 2002).

1.3. Interventions for AD/HD

Interventions for people with a diagnosis of AD/HD tend to be based upon the above aetiological theories, with two main types of intervention being most used: pharmacological (using methylphenidate (MPH) or drugs with a similar action) or behavioural i.e. giving parents and those with a diagnosis of AD/HD advice on how to manage the behaviours related to the disorder. As with the causes of AD/HD, intervention has also proved to be a contentious issue, both within the scientific literature and within the Media. In the UK, the National Institute for Clinical Excellence (NICE) guidelines, which are regarded as a benchmark for best practice, have recommended the use of MPH as part of a comprehensive treatment plan for AD/HD (NICE, 2000). However, the recently published findings from the large scale Multimodal Treatment Study for Children with a diagnosis of AD/HD, which has been comparing the efficacy of medication, behaviour therapy, combination and a control group, found that whilst the effects of medication were superior to other treatments or combination at 14 months, by 36 months there were no significant differences between each treatment type in terms of efficacy (Jensen, Arnold, Swanson, Vitiello, Abikoff et al, 2007).

1.4. Labelling

When exploring experiences of mental disorders, it is important to consider the effects of 'labelling' someone with such a diagnosis. Whilst this is controversial, a study conducted in 1992 by Harris and colleagues suggested that such labels could have detrimental outcomes (Harris, Millich & Corbitt, 1992). They examined the effects of labels and behaviour on children's interactions with peers. One hundred and thirty six boys, who were unknown to one another, were recruited to the study, forming 68 pairs. Within each pair was a boy with no diagnosed behavioural problems, and a second child who either had or did not have a diagnosis of AD/HD. The experimenters told half of the children that their partner had a behavioural problem (independent of whether they actually had a diagnosis) to examine the impact of this information upon the pairs' interactions. The results of the study found that both actual behavioural problems and prior knowledge of a label negatively influenced the quality of the interactions. The authors concluded that both actual behavioural presentation and peers' stigmatising interpretations of a label led to negative interactions. This could impact upon the way the 'labelled' child would behave in subsequent interactions, leading ultimately to the rejection of, and discrimination against, the labelled child by his peers.

1.5. Studies investigating experiences of AD/HD

Qualitative methodologies have been used for some time to explore people's experiences of 'mental disorder', and the majority focus upon adults (e.g. Kovisto, Janhonen & Vaisanen, 2002; Dinos, Stevens, Serfaty, Weich & King, 2004). Whilst AD/HD is a popular topic for research, focussing mainly on underlying psychological and physiological mechanisms, there is scant research into what it is like to experience AD/HD, particularly within a culture in which the label features so frequently within today's Media.

Very few studies exist that focus on the individual with a diagnosis of AD/HD. The majority investigate the experiences of parents or siblings of children with a diagnosis of AD/HD (e.g. Bussing, Gary, Mills & Garvan, 2003; Kendall 1999). There are only two studies published within peer-reviewed journals that use qualitative methodologies to explore experiences of AD/HD. The first recruited and interviewed 39 participants with AD/HD, and analysed these using methods from grounded theory (Kendall, Hatton, Beckett & Leo, 2003).

The analysis concentrated on the participants' accounts of their difficulties. In their discussion, Kendall et al. noted both that the participants had internalised their diagnosis of AD/HD and how well the accounts of AD/HD related to the DSM-IV criteria for the disorder.

The second peer-reviewed study recruited and interviewed 11 participants, aged 13 to 19, to investigate how young people perceive and experience AD/HD (Krueger & Kendall, 2001). The researchers were surprised to find the core category centred upon participants' descriptions of an "AD/HD-defined self" in which the experiences of AD/HD were "integrally related to their identity" (Krueger & Kendall, 2001, p. 64), i.e. that the participants did not distinguish the disorder and its related difficulties as being distinct from their sense of self. The authors state that the participants did not present their accounts as a 'failed' sense of self, rather as being misunderstood or different. The researchers concluded that the participants' accounts were likely to be a "reflection of the stigma and negative appraisals given them [sic] from society" (Krueger & Kendall, 2001, p. 68) and that difficulties with self-regulation and perception may lead to a distortion of self-perception in this population. The authors suggested that the most important finding is that participants with AD/HD appeared to have internalised their diagnoses, and as such, may not have been able to consider the effects of having a psychiatric label as, from their perspective, AD/HD was an integral part of their identity.

1.6. The current study

Given the controversies and the lack of research in this area, the study sought to gain insights into the above questions, and to provide an account of the perceptions of those with a diagnosis (or label) of AD/HD. The study was designed to be hypothesis-generating as opposed to hypothesis-testing. Initially, the aim of the study was to explore the meanings attached by participants to the label of AD/HD; their experiences of the process that they have been through to obtain the label; in addition to their experiences of living with the label. However, after the initial interviews had been conducted, it became apparent that all of the participants had internalised their diagnosis and it was not possible to explore the intended aims. The possible reasons for this are explored within the discussion section. Instead, the study focussed upon building a model of the participants' experiences of AD/HD from a realist perspective, i.e. "what is it like to 'have' AD/HD?"

Research Questions

To explore what it is like to experience AD/HD or the difficulties that have been described by the term AD/HD, in particular:

- To explore what difficulties the participants ascribe to having AD/HD.
- To explore the participants' perceptions of contact with services they have received in relation to AD/HD.
- To explore how the participants' perceptions and meaning fit with current understandings of AD/HD.

2. Method

2.1. Design

The study employed the methodology of 'Grounded Theory' first developed by Glaser and Strauss in 1967. Since its conception, Grounded Theory has evolved and become a widely used and well-respected qualitative methodology (Chamberlain, Camic & Yardley, 2003). Grounded Theory seeks to develop a theory of the phenomenon (in this case the participants' experiences and meanings of AD/HD), based upon the data collected from the participants, in this case using a semi-structured interview.

Grounded Theory is both an inductive and deductive methodology, and is dynamic in nature. A theory is created based upon emerging themes grounded within the data, and this theory is then tested against new and existing data, further developed and tested again using new and existing data. As part of this process, it is suggested that researchers use 'Theoretical Sampling' - the recruitment of participants of specific characteristics, often not demographic, based upon emerging themes and hypotheses, in order to 'test' the theory using data gathered from these interviews. This whole process is, ideally, repeated until 'saturation' is reached. This is the point at which the theory developed 'fits' all of the data already gathered, and with the incoming data. Due to the number of participants recruited this current study, the deductive components of Grounded Theory (e.g. theoretical sampling) could not be employed.

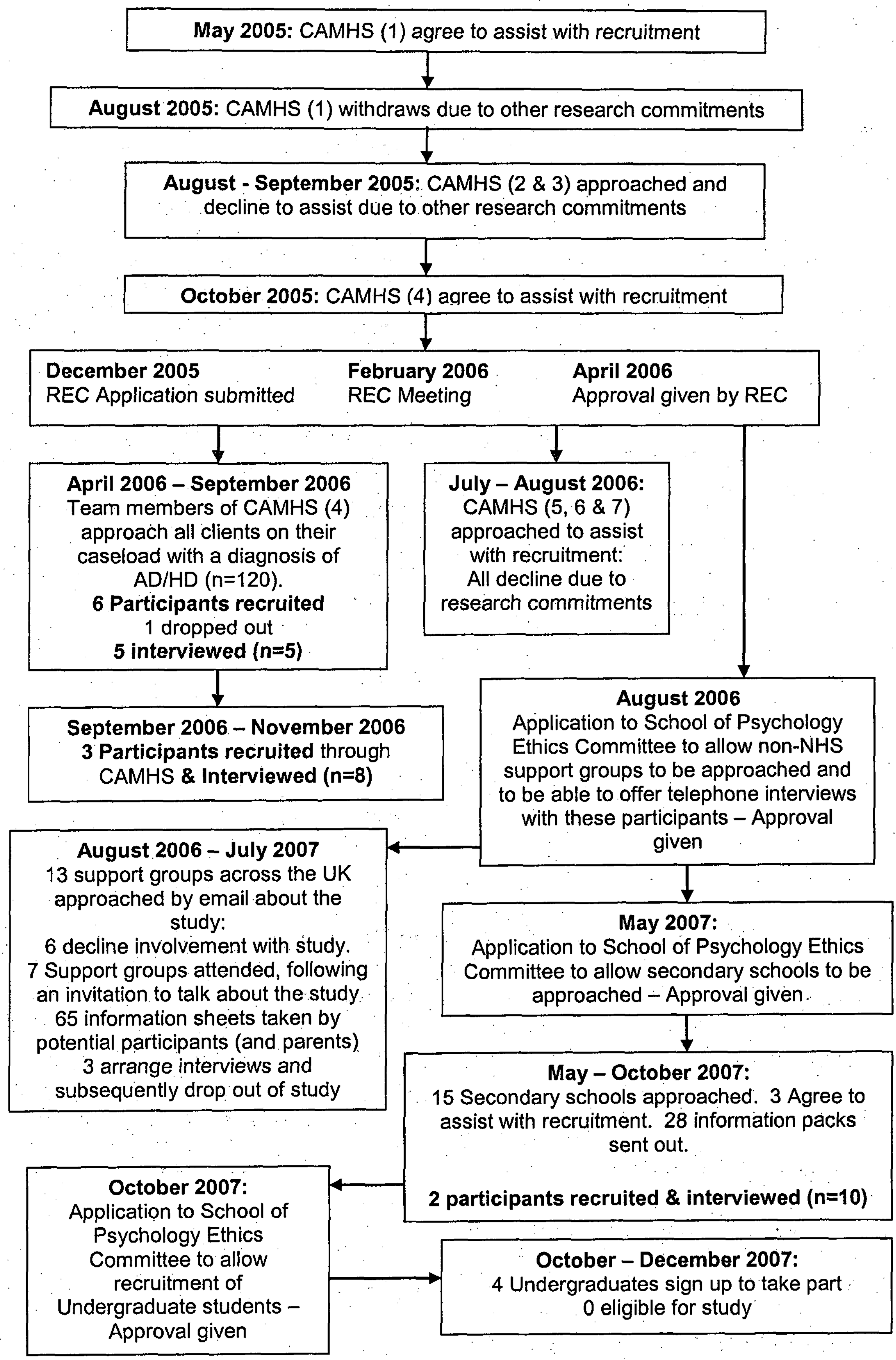
2.2. Participants

A total of ten participants completed the study, nine of which were male. Eight participants were recruited from Child and Adolescent Health Service (CAMHS) in the South of England, having been approached by team members of the service on behalf of the researcher. A further two participants were recruited through a mainstream comprehensive secondary school, having been approached by the Special Educational Needs Coordinator (SENCO). Other sources for recruitment were explored, such as non-NHS support groups and advertising through participant schemes for psychology undergraduate students, however, no participants were recruited via these means (see recruitment flowchart, Figure 1).

Participants were aged between 12 and 16, with all but one having a formal diagnosis of AD/HD. The remaining participant was being assessed for AD/HD at the time of interview, and it was thought highly likely that he would obtain a diagnosis. Six of the participants were currently taking medication for AD/HD, and three others had taken medication previously (the exception being the participant undergoing assessment). Seven participants were in full-time education in a mainstream secondary school.

One participant was employed as a labourer, having left school; one attended sixth form college and was studying A-Levels; one had been excluded from school for 12 months and the final participant attended a school for young

Figure 1. A flowchart showing the timescale of recruitment to the study



May 2005: CAMHS (1) agree to assist with recruitment

August 2005: CAMHS (1) withdraws due to other research commitments

August - September 2005: CAMHS (2 & 3) approached and decline to assist due to other research commitments

October 2005: CAMHS (4) agree to assist with recruitment

December 2005 REC Application submitted

February 2006 REC Meeting

April 2006 Approval given by REC

April 2006 – September 2006 Team members of CAMHS (4) approach all clients on their caseload with a diagnosis of AD/HD (n=120). **6 Participants recruited** 1 dropped out **5 interviewed (n=5)**

July – August 2006: CAMHS (5, 6 & 7) approached to assist with recruitment: All decline due to research commitments

September 2006 – November 2006 **3 Participants recruited** through CAMHS **& Interviewed (n=8)**

August 2006 Application to School of Psychology Ethics Committee to allow non-NHS support groups to be approached and to be able to offer telephone interviews with these participants – Approval given

August 2006 – July 2007 13 support groups across the UK approached by email about the study: 6 decline involvement with study. 7 Support groups attended, following an invitation to talk about the study. 65 information sheets taken by potential participants (and parents) 3 arrange interviews and subsequently drop out of study

May 2007: Application to School of Psychology Ethics Committee to allow secondary schools to be approached – Approval given.

May – October 2007: 15 Secondary schools approached. 3 Agree to assist with recruitment. 28 information packs sent out.

2 participants recruited & interviewed (n=10)

October 2007: Application to School of Psychology Ethics Committee to allow recruitment of Undergraduate students – Approval given

October – December 2007: 4 Undergraduates sign up to take part 0 eligible for study people with emotional and behavioural difficulties on a part-time basis having been excluded from mainstream education. All of the participants lived at home with their parents (n=8) or other members of their family (n=2).

2.3. Researcher Characteristics

The same researcher was responsible for recruitment, interviewing the participants, transcribing the audiotapes and analysing the data.

In the field of qualitative research, it has long been recognised that investigators can never achieve complete objectivity whilst undertaking an analysis (Strauss & Corbin, 1998). In order to minimise subjectivity when undertaking such an analysis researchers are recommended to take a number of actions, one of which being to recognise that their

> "understandings often are based on the values, culture, training and experiences that they bring to the research situations and that these might be quite different from their respondents" (Bresler, 1995; cited in Strauss & Corbin, 1998).

Therefore, it is important to bring into consciousness these values, experiences and beliefs, so that one may recognise when they are impacting upon the analysis. As such, a summary of the researcher's background, experiences and values is given below:

The researcher was a 29 year-old male Trainee Clinical Psychologist, undertaking his DClinPsychol at the University of Southampton. The researcher did not have a diagnosis of AD/HD, nor did he have friends or family with the diagnosis. He had become interested in the experiences of young people going through CAMHS, having worked within those systems for two years. He was particularly interested in AD/HD, having previously conducted research in this field both as part of an MSc examining perceived efficacy of early intervention and a clinical audit of this population (Thompson, Brooke, West, Johnson, Bumby, Brodrick, et al, 2004).

The researcher had also seen several families seeking assessment and diagnosis for AD/HD whilst working in a clinical capacity and noticed the growing number of cases of AD/HD entering the health system. Further, he had experience of families requesting help to claim 'Disability Living Allowance' and 'Disabled Parking Permits', citing the child with AD/HD as having the significant disability for which they were claiming. This caused the researcher to wonder what it would be like to have someone seeking a diagnosis for your behaviour, whether you would welcome this or not, and whether you would see yourself as having a 'disability'. In addition, the researcher is interested in client-centred approaches in clinical settings and had wondered how far interventions for AD/HD were for the benefit of the client (i.e. that they thought they had some sort of problem that required intervention), or for the benefit of their parents.

The researcher had also become increasingly conscious of the amount of coverage given to AD/HD in all aspects of the Media, with it even appearing in a song on the radio ("These Words" by Natasha Beddingfield), and a character being diagnosed with AD/HD and treated with medication in an episode of the popular cartoon show 'The Simpsons', (Meyer & Kirkland, 1999). Having noticed this, the researcher became curious as to how he would feel were he to have a diagnosis of AD/HD within this context.

2.4 Materials

The study employed a semi-structured interview and the interviews were recorded and transcribed using a portable cassette player, which used standard sized cassettes.

2.4.1 The Semi-Structured Interview

A semi-structured interview was designed to ensure that all topics of interest were covered by all participants (see Appendix 2). The interview schedule was designed to help the participants to talk about the issues related to the research questions. The interview started with questions about how the participants would describe themselves, and how they thought others would describe them, primarily to gain insights as to whether AD/HD or 'disability' forms a part of this, but also as a means of building rapport with the interviewee. The interview then asked whether partcipants had ever experienced finding it difficult to wait and to concentrate on something (behaviours that are usually associated with AD/HD), but without mentioning the term 'AD/HD'. The interview then asked if they had heard of 'AD/HD' and when they had first heard about it (to gain insights into their understanding of 'AD/HD'). Participants were asked whether they had seen anybody about AD/HD and what that experience was like (to gain insights into assessments and intervention). Participants were asked whether they had spoken to their family and friends about AD/HD (to gain insights into their perceptions of others' beliefs about AD/HD). At the end of the interview, the participants had an opportunity to discuss any other matters that they thought were important.

Many qualitative researchers (e.g. Rubin & Rubin, 1995; Kvale, 1996) suggest that the interview should be conversational in its style as this helps to build rapport with the interviewee, offering the best opportunity for them to give a full and rich account of their experiences. In addition, these researchers advocate the use of active listening skills such as reflection, allowing the conversations to digress from the interview schedule, so as to allow new lines of inquiry to emerge; and giving the participant time to tell their story, with only the minimal possible number of interjections from the interviewer to maintain rapport and keep the 'flow' of the interview. As such, these ideas were incorporated into the interviews.

2.5. Procedure

Information sheets were given to the young people (see Appendix 3) and their parents (Appendix 4) by CAMHS team members or the SENCO at the school. Participants registered their interest by returning a reply slip in a freepost envelope. The researcher then contacted the participants' guardians to arrange an interview at a time and location convenient to them. All participants chose to be interviewed in their own homes, and six chose to have a parent and one other their grandparents, present in the room during the interview. The remaining two participants had a parent in the house during the interview. Participants and their parents were given another information sheet, and the purpose and voluntary nature of the study explained to them. Participants and their parents then signed consent forms (see Appendix 5) before the interview commenced, and participants were reminded that they could choose not to answer questions without needing to provide a reason and that they could withdraw at any time without consequence.

After each interview had taken place the researcher wrote down thoughts about the interview and any relevant information that was given when the tape had stopped in the form of field notes (for examples see Appendix 6). The interviews were then transcribed verbatim by the researcher, during which any identifiable information (e.g. names of people, places) was anonymised and participants were each given a number by which they could be identified in the analysis. Where appropriate, the transcriptions included descriptions of participants' actions, information about their speech, such as volume or tone and pauses of three seconds or more. The completed transcript was then checked against the audiotape to ensure accuracy. The transcripts can be viewed on the enclosed data CD, saved as Microsoft Word files.

2.6. Ethics

The study was reviewed and approved by the University of Southampton School of Psychology Ethics Committee, and the Southampton and South West Hampshire Research Ethics Committee (B) (See Appendix 7).

2.7. Data analysis procedure

The data analysis procedure used techniques to develop Grounded Theory, such as those described by Strauss and Corbin (1998). Readers should note that the process of analysis is dynamic, rather than a linear sequence of steps, and there was a constant movement between the different analytic techniques described below. Supervision was used during the analysis in order to reflect upon the process and emerging theory, and to help identify areas of bias.

Immediately after each of the interviews, field notes were taken, in which initial thoughts about the interview, in addition to any information given by the participants or their guardians, were written down (see Appendix 6 for examples). The interviews were transcribed as described in the 'Procedure' section, and during this time, any further thoughts were kept as 'Analysis Memos' (see below, and examples in Appendix 8). 'Open coding' began once the first six interviews had been completed and transcribed, in order to build up a body of data for this part of the analysis. The first six interviews were then read and re-read and the audiotapes were listened to until the researcher gained familiarity with the data, and techniques of 'microanalysis' (see below) were employed.

'Analysis Memos' were kept in parallel with the analytical process. These served as a record of thought processes and decisions made, in addition to providing a space for reflections on the data and questions about the ongoing analytical process. These Memos were then consulted to stimulate thinking about the analysis and to help identify areas in which the researcher's biases and values might be impinging on the developing theory, for example,

> "What does it mean "to just lose everything" in your head? (Participant 1, p. 2, Ln 43 - 44) Is there a time when you can "get everything" in your head? When might this happen, and how? Is this an example of '*concentration*' or is it something different?".

Where Memos made reference to a section of transcript, the participant number, page and line number were given, so that they could be found subsequently. Further examples of Analysis Memos can be seen in Appendix 8. Space does not permit the inclusion of all of the analysis memos, however, these were shared and discussed during supervision, and are available upon request.

The first stage of analysis involved the process of microanalysis - a detailed and focussed line-by-line examination of the data - through which the researcher considers the broad range of possible interpretations of the data.

This forces them to focus on what the interviewees are saying, rather than imposing their own values and interpretations (Strauss & Corbin, 1998). During microanalysis, the researcher asks questions about the data, (i.e. who, what, where, when and why?) in order to assist in the discovery of codes and categories (Strauss & Corbin, 1998). These questions and thoughts arising from them were noted in the Analysis Memos, e.g.:

> "What does 'concentrate' mean? (Participant 1, p. 2, Ln 13*). What would it be like "to have to think in your head"? What would that involve? What situations would that occur in?"

Whilst conducting the microanalysis, tentative codes were noted and considered as part of 'open coding'. Open coding is a process in which meaningful chunks of data are identified and defined as 'concepts'. These concepts are given a name by which they may be indexed and referenced so that similarities and differences within the data can be more readily identified. As recommended by Strauss and Corbin (1998), the concepts in this study were given 'in vivo codes' wherever possible: giving the identified concepts names using the language of the interviewees. For example, rather than using "Inattention", the in vivo code was "not concentrating". The purpose of using in vivo codes and participants' language is to keep the emerging theory grounded within the data gained from the interviewees. Once these concepts were identified, they could then be tentatively grouped together (classified) by identifying phenomena that share meanings. As these categories started to appear, the researcher would try to gain a better understanding of them by

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* P = page number, Ln = Line Number of the transcript

seeking to describe their 'properties' (or characteristics) and 'dimensions' ("the range along which the general properties of a category vary" (Strauss & Corbin, 1998, p. 101)). As with the open coding process, the emergent categories were given names using the interviewees' own language to better reflect their experiences.

To ensure that the emerging theory remained grounded in the data and 'fitted' it well, techniques of 'constant comparison' were used throughout the analytic process. The researcher compares the data at all levels looking for similarities and differences e.g. between cases or incidents, or on a more theoretical level, between categories, and underlying meanings (Strauss & Corbin, 1998). These techniques allow the researcher to consider more possibilities about meanings within the data and reduce the possibility of accepting them at face-value or making assumptions.

Axial coding was also conducted to identify how categories and their sub-categories are related to each other. Diagrams were drawn to help examine the relationships both within and between categories.

As the categories and theory emerged, the remaining interviews were conducted and transcribed. During these interviews, more time was spent focussing upon areas of the emerging theory that lacked clarity or required more investigation. Whilst these interviews were analysed, the original open codes, categories and axial codes were re-examined and modified given the insights gained from the new data. During analysis, several categories were explored as being the 'central category', representing the main theme of the research (Strauss & Corbin, 1998). Through further analysis and constant comparison, the central theme of the analysis was identified, defined, and its relationship to the other categories explored.

As described previously, this was a dynamic process. The researcher moved between reading transcripts, open coding, and exploring the properties and dimensions of concepts as necessary. Throughout this process, facets of the analysis were modified and refined using techniques such as constant comparison, to gain new insights and to ensure it remained grounded in the data.

To ensure the rigour and validity of the analysis regular supervision was attended during the analytical process, during which the audit trail, (i.e. the analysis memos, diagrams and emerging theory) was discussed. Given the large size of the audit trail, it is not included within the appendices, but can be made available upon request.

3. Results

A Grounded Theory Analysis of Young People's Experiences of AD/HD

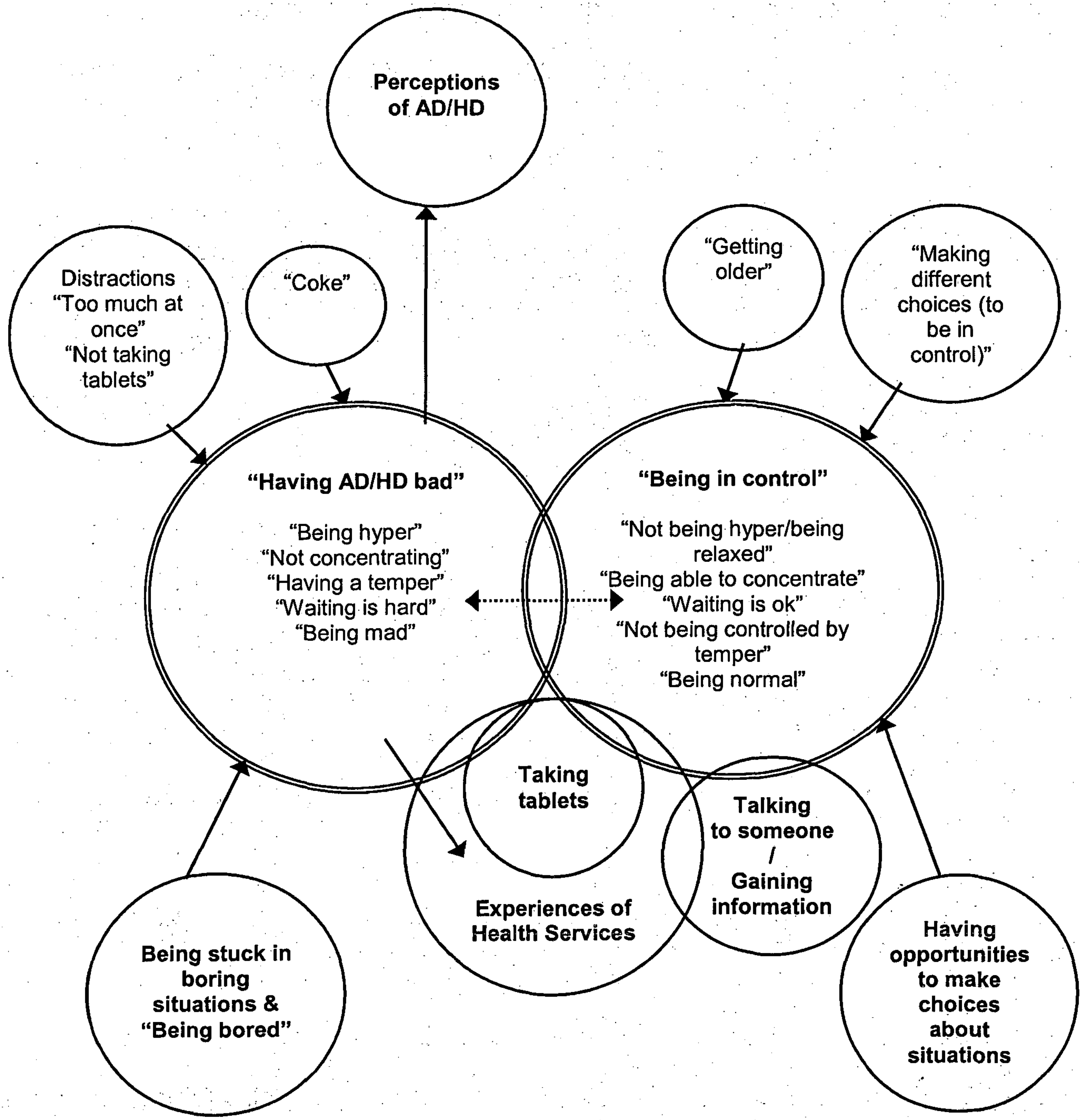
3.1. Introduction to the interpretation of the data

It is important to note that the categories that emerged during analysis provide a means of summarising the data and showing how the experiences given in the participants' accounts connect with, and impact upon one another, rather than being 'real entities' in themselves.

The key feature of the participants' accounts centres around 'Control', and is described in terms of 'Having AD/HD bad', and 'Being in control'. Definitions and descriptions of the categories and subcategories can be found in Appendix 9.

Figure 2 shows a diagrammatic representation of the participants' experiences of AD/HD. The key features of the analysis, namely 'Having AD/HD bad' and 'Being in control' are shown in concentric circles in the centre of the diagram. The dashed arrow between them represents the dimensional nature of this experience. The other circles within the diagram represent a set of the participants' related experiences that have been categorised together (as described above); the overlap between circles represents categories that are closely related to one another i.e. experiences that occur within the same context. The solid arrows show the direction of the direct influence of one set of experiences on another, from the participants' perspective.

Figure 2. A diagrammatic representation of young people's experiences of AD/HD.



In order to give a better understanding of the participants' experiences of AD/HD, the most important themes from the analysis will be described below with illustrated by examples from the transcripts.

3.2 . 'Control'

The main feature of the participants' accounts of AD/HD centred upon experiences relating to the extent to which they felt that they were in 'control' of their actions. This ranged from 'Being in control' of their actions to 'Having AD/HD bad' within which participants describe a range of actions/experiences over which they feel they have no control.

The concept of 'Control' and the constituent experiences can be thought of as both dimensional and as two discreet groups of experiences. Some participants described a range of experiences in between 'Having AD/HD bad' and 'Being in control', whereas others described having had 'AD/HD bad' but were currently 'in control'. The participants described 'moving' in both directions between 'Having AD/HD bad' and 'Being in control' over time and gave accounts of a number of experiences that impacted upon the likelihood of them experiencing 'Having AD/HD bad' or 'Being in control'.

The concepts of 'Having AD/HD bad' and 'Being in control' will be described below, in addition to examining the experiences that the participants described as influencing their experience of 'control'.

3.2.1 Having AD/HD Bad

Participants described 'Having AD/HD bad' through a number of experiences. These were characterised by situations in which participants felt that they did not have control over a range of their actions as a direct result of AD/HD. A key feature of these accounts was 'not concentrating', which included descriptions of being unable to remain focussed upon a particular task, e.g.

> "I find quite a lot of things quite easy, but concentration I find very difficult, I find it very difficult say for revising for exams, I find it difficult to sit down for half an hour in front of a book and just read it and try and learn it, and I just can't do it"
>
> (Participant 4, p. 222, Ln. 17 – 20)

in addition to being unable to retain information in mind whilst engaged in a task e.g.

> "...I've got it all in my head, and I can't think, and I just lose everything, and like, in exams, everything just goes and I can't concentrate at all"
>
> (Participant 1, p. 2, Ln 42 – 45).

Another important experience that the participants related to 'Having AD/HD bad' was 'Having a temper', which included descriptions of 'being angry', 'being aggressive', 'going crazy' and 'kicking off' where they felt they had no control over their actions, e.g.

> "if if you normally have a fight you think "I'm going to hurt them as much as possible and then step away" but with AD/HD I think it's more of a "if you hit someone you don't think you're hurting them so you go and do it again and again and again and you just keep doing it" and then suddenly when your adrenaline is gone kapooof and you're like "well why have I done this? Oh my god""
>
> (Participant 10, p. 12, Ln. 14 – 19).

Participants also spoke about 'Being hyper', including descriptions of 'having things racing through your brain' and 'having too much energy' for example:

> "I'm quite hyper, I I I, I'm always like fast at writing, fast at talking and people can't really hear me..."
>
> (Participant 2, p. 8, Ln 43 - 44).

Participants also gave accounts of finding it difficult and "annoying" to wait, for example,

> "I*: Right...so what's it like for you when you are trying to be patient?
>
> P: Very hard, I get very stressed and very annoyed, and I take it out on everyone else..."

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* I = Interviewer P = Participant

(Participant 1, pp. 3 – 4, Ln. 50 – 3).

Another feature of the participants' accounts of 'Having AD/HD bad' was of 'Being mad'. This was not as in the same sense as 'Having a temper', rather descriptions of not being 'normal' or having a mental illness, e.g.

"I: Imagine if you did, how would you explain it to somebody?

P: I'd just say I'm on pills 'cos I'm mad

I: So that's how you'd describe it?

P: Yeah 'cos I'm mad"

(Participant 6, p. 7, Ln. 30 – 36).

3.2.2. Being in control

The experiences that were categorised as 'Being in control' were those that could be viewed as being at the opposite end of the dimensions to those described within the category of 'Having AD/HD bad'.

The participants described a range of experiences in which they were 'in control' of behaviours which they had previously thought of as being outside of their control due to AD/HD; gaining control over situations which had previously been adversely affected by behaviours attributed to AD/HD; and behaviours/actions that were seen as being 'normal' for their peer group, which were previously described as symptoms AD/HD. 'Being in control' was viewed as a highly positive experience by the participants, e.g.

> "Being in control is the best feeling for someone with AD/HD 'cos you know, whatever happens you can stop it"
>
> (Participant 4, p. 15, Ln 15 – 16).

'Not being controlled by temper' was discussed by the participants as an important feature of 'being in control'

> "I just thought every time someone tried to start a fight with me, I'd think "what's the point?", if you know you can win, what's the point in fighting them 'cos you'll just make yourself look like a prat [*laughs*]...."
>
> (Participant 10, p. 5, Ln. 12 – 14).

Other features of 'Being in control' were 'Being able to concentrate' for example,

> "Yeah, I click sometimes, I click and I can concentrate"
>
> (Participant 8, p. 5, Ln. 31)

and 'Waiting is ok'

> "If I'm waiting for something like a computer game, well what can you do? It's not like you can go through the door and go "give me the computer game" you've got to wait for it, so I just don't worry 'cos there's nothing you can do about it..."
>
> (Participant 10, p. 6, Ln 36 – 39).

Participants also described experiences in which behaviours that were perceived by others to be a sign of AD/HD as 'Being normal' for their peer group, for example,

> "Well, I'm just impatient, normal impatient, just like anyone else"
> (Participant 7, p. 5, Ln. 49)

Another feature of 'Being in control' were the related experiences of 'Not being hyper' and 'Being relaxed'. The participants described these experiences as being times when there were not 'hyper' e.g.

> "…it's really low now, where it used to be I used to be jumping off walls you know, like Spiderman"
> (Participant 10, p. 11, Ln 8 – 10)

3.3. Experiences impacting upon 'Having AD/HD Bad'

During the analysis, a number of experiences emerged as having a direct impact upon 'Having AD/HD bad', and were described as exacerbating experiences such as 'being hyper' and 'not concentrating'.

Experiences in which the participants were distracted by external sources (e.g. people, noise) were commonly described as having an impact upon 'not concentrating', e.g.

> "I: What's it like when you are trying to concentrate on Playstation games?
>
> P: Really difficult [*makes 'whoooooooooooo noise'*], my brother and sister are standing there being annoying"
>
> (Participant 6, p. 5, Ln. 40 – 45).

Being asked to concentrate on several items at once was also described as having an adverse impact upon 'Not concentrating',

> "I: ….can you think of a time when it has been hard to concentrate on something?
>
> P: Like at school, when the teachers are asking me to do too much at once"
>
> (Participant 1, p. 2, Ln. 40 – 44).

'Not taking tablets' (medication) was also cited as having a negative impact upon 'Concentration', for example,

> "I have them and I still feel the same…but I do like sleep a bit better and then I can concentrate a lot more…"
>
> (Participant 3, p. 7, Ln 44 – 46).

Some participants cited fizzy drinks as having a negative impact upon 'Being hyper', for example,

> "I: When you say, "sometimes a bit hyper", can you tell me a bit more about that?
>
> P: Depends what I drink or eat, if it's like coke or anything fizzy, anything with lots of sugar in, basically I go off the wall and I can't control it."
>
> (Participant 2, p. 1, Ln. 40 – 44).

Another range of experiences that were described as having a negative impact upon the experiences associated with 'Having AD/HD bad' were 'Being bored', which describes situations within the participants' control in which they find themselves feeling bored, and 'Being stuck in boring situations' that are perceived as being beyond their control.

'Being bored' was a very common experience amongst the participants, for example,

> "I get bored easily, I do something and I get bored within 5 minutes so I just lose my concentration or I can't do it and I get frustrated, so I just get annoyed and get angry…it just winds me up…and I can't do it…." (Participant 6, p. 5, Ln 21 – 24).

Participants talked about situations that were boring, but beyond their control ('Being stuck in boring situations'), as being associated with experiences of

'Having AD/HD bad'. Examples of these experiences from the transcripts include,

> "...it feels like being in a prison cell like I feel like I've been closed in this box and I can't get out, and so I got really bored of being stuck in the cell, then really, really angry 'cos he stood in front of the door so I was waiting to get out and he said "[*name*] stand behind your place" so I did and I counted and counted and he still wouldn't let me out, and then I just burst through the door and it cut his arm a bit, 'cos when I went out the door went [*makes whooshing noise*] and got his arm, but um, I got, and sometimes when I wait and it, it depends, like if you trap me in a room and I feel that I can't get out then I get stressed quite a bit"
>
> (Participant 10, p. 6, Ln 27 – 36).

> "Like in school, when you're having a break after each question, like in school and they just talk to you for ages, and I just start losing er interest"
>
> (Participant 5, p. 5, Ln 2 – 4).

> "Like sometimes, I'm like at school and the teachers are like taking ages to give us our work, and I'm just wanna hurry up and get on with my work, and they take ages to tell us what to do..."
>
> (Participant 1, p. 3, Ln. 28 – 30).

3.4. Experiences Impacting upon 'Being in Control'

Participants gave accounts of experiences which helped them to feel 'in control' of AD/HD. The first of these concerned 'Getting older' in which participants described becoming more in control of behaviours/actions that they had associated with AD/HD as they got older, for example;

> "I've noticed that as I have got older and more mature, um it has got easier and I can do longer without tablets and I'm better without the tablets"
>
> (Participant 4, p. 8, Ln. 12 – 14).

Another factor the participants cited as helping them to 'be in control' was 'Making different choices to take control'. This factor encompassed experiences of making an active choice to avoid situations known to exacerbate 'Having AD/HD bad', or to choose a different course of action, when such an option is available, e.g.

> "if I want coke now, all I'll have now is like diet or sugar-free coke or pepsi max, all the diet fizzy drinks now, so no, they don't make me as hyper as the original stuff..."
>
> (Participant 2, p. 5, Ln. 13 – 15).

The participants also talked about having the opportunity to make choices in situations as helping them to be in control. In the examples from the transcripts below, the opportunities to make choices that increase experiences associated with 'Being in control' have been underlined:

> "I think, like yeah, knowing that you can take breaks, if you know that you're not forcefully done to do something, you have control over it, you enjoy it more and you don't get so bored, don't stop concentrating, so having a choice
>
> (Participant 10, p. 1118, Ln. 1 – 9).

> [*having discussed that background music improves their concentration*]: "if I have a bit of music I'll be like fine, you know and sometimes teachers let us listen to our MP3 and that and you know obviously then I can get on with my work better"
>
> (Participant 7, p. 7 Ln 12 – 14).

> [*Discussing clinic visits as being 'annoying'/'boring', and what would improve the experience*] "More toys, Lego actually, Lego toys that can't be taken apart, 'cos it's like, they make them up, and they should have a whole city and you could choose, like to spend an hour playing with it then an hour talking, or better than that 40 minutes playing and twenty minutes talking, and then 10 minutes play after that...... so like talk, play, talk, play, talk, play, play"
>
> (Participant 9, p. 13, Ln. 23 – 32).

3.5. Experiences of Health Services

The participants discussed a range of experiences associated with their contact with CAMHS. These were associated with their experiences of 'Having AD/HD bad', in that those experiences (e.g. 'Being hyper', 'Not concentrating') were cited as the reason for referral to CAMHS,

"P: At first my doctor didn't think I had it, but then I had to get referred to another doctor, and they said I had it...

I: And what was it like for you at that time, what was it like for you?

P: Horrible 'cos I couldn't sit still, I couldn't concentrate, and I wasn't put on any medication to help, and I found everything really hard and I wasn't concentrating properly."

(Participant 1, pp. 4 – 5, Ln 44 – 3).

3.5.1 Experiences of talking to CAMHS staff

The participants described their experiences of talking to CAMHS staff during appointments, and these ranged from 'Being bored during appointments' e.g.:

"P: It got me really bored really quick, we just sat in this room talking and talking and talking and I was like "yeah", "no", "yeah", "no", "yeah", "no" and like "oh this is pointless", and he was like "oh this is perfect" but I was like "Well not for me I'm bored" but yeah

I: And did you know why you were there or what they were talking about?

P: Well that's the thing you know it was so boring that I just didn't care, I mean even if I did know it right now, I just don't care"

(Participant 10, p. 13, Ln 28 – 36)

to 'Feeling supported by the staff' e.g.

"There's support, the psychiatrist gives you a lot of support"

(Participant 4, p. 14, Ln 37 – 42)

3.5.2. Experiences of diagnosis

The participants also talked about how they felt when they were told about the diagnosis of AD/HD. The majority of participants described feeling shocked when they were given a diagnosis of AD/HD, and this was often linked to a fear of being stigmatised, for example:

"I: So what did you think when somebody said that you might have AD/HD?

P: I thought, "you're having a fucking laugh aren't you"? I thought, "what do you think I am, some sort of nutcase"? I didn't, I mean, of course nobody wants to have it but I haven't got a choice in the matter"

(Participant 8, p. 9, Ln 25 – 30)

3.5.3. Experiences of 'taking tablets'

Nine of the participants were currently, or had previously, taken medication for AD/HD and a major feature of their contact with CAMHS teams concerned 'Taking tablets'. These experiences are described under the four headings below:

Finding out about taking medication

The participants' described their experiences of being told that they were being prescribed medication, and these ranged from 'Shock':

> "...but I was shocked and scared 'cos I thought I won't be as friendly as I normally am, and I won't be able to chat to people"
>
> (Participant 1, p. 8, Ln 8 – 9)

to 'Not being bothered' for example:

> "Didn't really care did I? Loads of other kids had to take it, so I wasn't bothered I just took it didn't I?"
>
> (Participant 6, p. 13, Ln 16 – 17).

Reasons for taking medication

The participants also described their reasons for taking the medication, and these ranged from their own desire to take the medication, for example, 'Wanting to do better at school', or 'Improving performance',

> "I'm hoping not to have the tablets... Yeah but if I have got it I have to take, but I don't mind taking them, but if they will make me better at school, then I don't mind, I'll do whatever it takes to be better at school"
> (Participant 5, p. 9, Ln 8 – 14)

to 'Pleasing others', for example:

> [To Mum] "You kept on going on at me and I said that I didn't want to take them, but you kept on at me"
> (Participant 8, p. 13, Ln 19 – 20)

Perceived efficacy of tablets

The participants also described their experiences of 'Taking tablets' in terms of how much they improved experiences associated with of 'Having AD/HD bad', and most participants described this as having some positive effects e.g.

> "If I forget to take it, I'm like mad, I don't concentrate, I can't concentrate, I can't settle down to work, I'm just like horrible [*laughs*], I can't settle down or nothing" (Participant 1, p. 7, Ln 40 - 42).

Some participants, however, described occasions when the tablets were not effective, for example:

> "Yeah and they like help with your behaviour and like when you're been on them for too long they don't"
>
> (Participant 3, p. 8, Ln 1 – 2)

and talked about their experiences of the side effects of medication

> "They used to make you puke afterwards, used to make you yak"
>
> (Participant 6, p. 12, Ln 36).

3.6. 'Talking to someone' and 'gaining information'

Participants described experiences of 'Talking to someone' and 'Gaining information' about AD/HD as being positive and were linked with experiences of 'Being in control', and also helped to alleviate fears, for example, around taking medication. From the participants' accounts, this was found to be helpful when the person giving information was perceived as being knowledgeable about AD/HD, but did not necessarily need to be a member of the CAMHS team, e.g.:

> "I was lucky my dad's a [*health professional*] and my mum's was a [*health professional*] and they'd read around it when they first realised that I had it and so any questions I had, I could ask and I could get answers, and they would explain it properly, but for other people whose parents who maybe aren't in any way medically inclined, they won't

> have that information source that I had and there's not really that much information out there, you've got your psychiatrist, and that's about it"
>
> (Participant 4, p. 14, Ln 21 – 28).

3.7. Perceptions of AD/HD

The participants described both their own perceptions of other people with a diagnosis of AD/HD and how they believe people without the diagnosis perceive people with AD/HD. These experiences will be discussed in turn below:

3.7.1. Perceptions of people with a diagnosis of AD/HD

Participants gave accounts of other people that they knew with a diagnosis of AD/HD. What is perhaps most interesting about these accounts, is that all of the participants described other people's behaviours and characteristics that they associated with 'Having AD/HD bad' as being 'worse' than their own (i.e. none said "I have the worst AD/HD out of everyone I know"), for example:

> "They're like psychos. The kids are like psychos. My auntie's got it really bad, much worse than me, she's really bad...cos like she's, like when she's, when she's really mad and she goes really mad and starts like punching walls and stuff and she's mad and like every time someone mentions it [*AD/HD*], it makes me think of that kind of person. Like my auntie."
>
> (Participant 1, p. 4, Ln 13 – 21)

The participants discussed some positive aspects of other people with AD/HD (coded as 'Good sides of AD/HD'), for example, 'Having a talent':

> "a lot of people who I've met who've got AD/HD they've always got one specific talent, I'm quite lucky, I've got quite good all round"
> (Participant 4, p. 18, Ln 44 – 46)

'Being good at work' and 'Being clever'

> "…but they are, people with AD/HD normally are clever"
> (Participant 5, p. 6, Ln 21 – 22).

and 'Being fast' or 'Being able to get an energy boost':

> "Well, some people as in rugby players, some of them have AD/HD and they control it, so instead of like getting angry with it, they only use the energetic side of it so if they're really tired of rugby they can get a big boost back and carry on playing rugby"
> (Participant 10, pp. 12 – 13, Ln 48 – 2).

The participants also talked in negative terms about other people with AD/HD using their diagnosis as an 'excuse', i.e. as a means to avoid getting into trouble, for example:

> "No..."oh I broke that cos I've got AD/HD"...yeah, whatever!"
> (Participant 6, p. 14, Ln 43)

3.7.2. Beliefs about how people without the diagnosis perceive people with AD/HD

The participants talked about how they believe those without the diagnosis perceive people with AD/HD. These perceptions were all negative, and included 'Being mad/aggressive':

> "...like I've told a few mates I've got AD/HD, and they say "oh what do you do, go mad in the classroom and hit teachers and that?" and that's what they think and that's not it, that's what their stereotype is"
> (Participant 8, p. 10, Ln 2 – 5)

and 'Being badly behaved'

> "Yeah, you hear people talking about kids in school being terribly behaved and this kid with AD/HD was suspended or whatever"
> (Participant 4, p. 11, Ln 38 – 39)

4. Discussion

The analysis shows that the participants' experiences of AD/HD are centred on experiences of 'being in control' and 'having AD/HD bad'. The analysis also describes a range of other experiences that impact upon the likelihood of the participants experiencing that they are 'in control' or 'have AD/HD bad'. Additionally, the analysis describes perceptions of people with AD/HD – those of people with a diagnosis (i.e. the participants), and how the participants believe people who do not have a diagnosis perceive them.

Before the considering the implications of the analysis, a number of issues concerning recruitment and methodology will be explored.

4.1. Recruitment and methodological issues

It is important to acknowledge that theoretical sampling could not be used in the present study. Further, whilst the data from participants nine and ten indicated that the study was close to saturation, additional participants would have been useful to confirm this. Both of these issues arose from the difficulties in recruiting participants, and this section explores possible reasons for this.

All of the other clinics in the region declined to assist with recruitment, stating that they were already engaged in research with families of children and young people with AD/HD. It is possible that many of the families who had been approached were already involved in research. Further, other Trainee

Clinical Psychologists both from the University of Southampton and elsewhere were actively engaged in recruiting young people with AD/HD in the region.

Before approaching the schools, advice was sought from researchers in Educational Psychology as to the best method for contacting them. As with the clinics, the majority of the schools approached were already engaged in research, could not commit any time to assisting with the study due to ongoing commitments, or did not feel that they would be able to identify potential participants.

Recruitment of undergraduate psychology students via an online 'research credit' system also proved unsuccessful. The four students who signed up had never had any contact with children's mental health services nor had they heard of the term 'AD/HD', and as such, they were not eligible to take part. The students said that they had signed up for the study, having seen the number of credits available, without reading through the advertisement.

The people attending the support groups (set up, but not run, by the NHS) that were approached appeared enthusiastic about the study. However many cited not having the time to commit to taking part in the study, even when offered a telephone interview. Several of the participants described taking part in after-school activities most days of the week, and it is likely other young people were similarly active. Further, it is possible, that alternative methodologies, such as self-administered questionnaire, might have been seen as fitting in more easily with the families' other commitments. This method was rejected for a number of reasons, including that interviews allow for an exploration of the participants' experiences and a questionnaire may have deterred, or even excluded, those who had difficulties with reading and/or writing.

To gain an understanding of why many young people chose not to enquire about, or take part in, the study, it is important to consider methodological issues which may have impacted upon their decision, in addition to factors that are associated with the young people themselves.

One of the main factors that may have been responsible for the young people choosing not to take part may have been the wording of the study title ("Young people's experiences of AD/HD) in addition to the information sheets (see Appendix 4) where it reads,

> "this study is trying to explore what it is like for young people to have AD/HD, or what it is like to have difficulties that are associated with AD/HD (difficulties with concentration, hyperactivity and impulsivity)".

This was changed during the ethics process and may have alienated those who disagreed with their diagnosis, had not internalised it, or found the term 'AD/HD' to be stigmatising. The wording of the information sheet was changed during the ethics process, and in hindsight, it may have been better to have used a title such as 'What young people think about AD/HD' and to have described the study in such terms.

This may also account for why those who were recruited to the study did not talk about their experiences of the label that they had been given and talked about AD/HD from a realist perspective – i.e. that they had internalised their diagnosis. This was a further limitation of the current study, as ideally, the experiences of those who had not internalised their diagnosis of AD/HD would be explored. This was also identified by Kendall and colleagues who found that the young participants with a diagnosis of AD/HD in their studies had also internalised their diagnoses (Krueger & Kendall, 2001; Kendall, Hatton, Beckett & Leo, 2003). It would be interesting to explore whether all young people with a label of AD/HD, and indeed, other diagnoses, internalise them, and whether there are any differences between those who internalise the diagnosis, and those who do not.

Developmental factors may also have had a role in the participants giving descriptions of AD/HD from a realist perspective; and their ability to fully take part in the study. Empirically-founded models of development have long shown that cognitive abilities continue to develop into late adolescence and adulthood (e.g. Piaget's 'Formal operations' period; Piaget, 1952). Cognitive abilities that are acquired and developed during adolescence and adulthood include: being able to determine logical relationships between events and experiences, thinking about abstract concepts, drawing conclusions from the available evidence, being able to consider and evaluate evidence that is contrary to one's own beliefs and perspectives (reasoning biases), being able to reflect upon one's own experience from other perspectives, and having an insight into the dimensional nature of experiences (Hetherington, Parke & Otis-Locke, 2005). In addition, adolescents are continuing to acquire and develop their expressive language skills. Given the age-range of the participants in the current study, it is quite possible that they had not yet acquired, or sufficiently developed, skills enabling them to reflect upon and communicate complex internal experiences, as demanded by the nature of the current study, and this may have impacted upon their ability to fully describe their experiences within the interviews.

Further, difficulties with attention are a feature of AD/HD, and whilst this did not appear to be a problem for the participants in the current study, it may have had an impact on their ability to fully consider the questions that were put to them.

Future studies may want to assess the abilities described above in potential participants prior to recruitment, to ensure that they will be able to understand and answer the questions put to them, ensuring that they are able to participate fully in the study.

During analysis, it appeared that the theory was close to 'saturation', as the data from participants nine and ten could be incorporated into the model that had been generated. It is possible that the participants in this study were a homogenous sub-sample of a larger group of people with diagnoses of AD/HD. This would be in-keeping with the above hypothesis for the difficulties with recruitment, and would account for the reason why all of those who took part in the study talked about AD/HD from realist perspective (i.e. that they had internalised their diagnosis, and perceive AD/HD as a 'real entity'), rather than discussing what AD/HD means to them, as was the original aim of the study.

In addition, the majority of the participants described their current experience of AD/HD as 'Being in control'. It is, therefore a possibility that the study may have only appealed to those who felt that they were 'in control' of AD/HD. Another possibility is that some of the young people did not take part as there was no tangible reward for doing so and did not see it as 'being worth their while'. The researcher investigated rewarding individuals for participating, but the LREC had made it clear that this would not be approved, for fear of young people being coerced into participating. Existing research (e.g. (Antrop, Stock, Verté, Wiersema, Baeyens, & Roeyers, 2006) suggests that people with AD/HD tend to be more sensitive to delays, and to avoid or escape from the aversive experience of delay, they will sooner choose smaller rewards in the short term, than wait for larger rewards in the long term (known as 'delay aversion'). The fact that this study asked a relatively large time commitment from participants, with no short-term, tangible reward (the only reward being to help shape future services for young people with AD/HD), may also have contributed to young people choosing not to take part.

Had more participants been recruited, theoretical sampling would have been utilised. The researcher ideally would have recruited younger participants, in particular those starting the process of diagnosis and intervention, to further explore different aspects of the analysis. Additionally, adults would have been recruited who had been through the system as children, (as well as those currently going through the system) to reflect past and current experiences of AD/HD. It would also have been interesting to recruit more females into the study to explore a possibility of different experiences between the sexes, although this may have been difficult given that males with AD/HD outnumber females by three to one (NICE, 2000).

Reflection on the study has also highlighted some other methodological issues, particularly concerning the interview schedule and process. Firstly, it would have been helpful to include a question such as "What does AD/HD mean to you?" which would have helped to explore the participants' experiences connected with the original aims of the study.

On reflection, some of the interview questions could be seen as biased, for example "Has there ever been a time when you have found it really hard to concentrate on something? Can you tell me about that?" These items would have been better phrased as "Can you tell me a bit about concentrating?"

Further, during the interviews the majority of the participants chose to be accompanied by a parent or grandparent. There were many instances within the transcripts where a parent interrupts, or where the parent is 'dominating' the conversation, and thus, some of the young person's ideas may have been 'lost', despite the researcher's attempts to minimise this. It is highly likely that participants could not be as forthright with their opinions as they might have been without their parents present, especially when discussing issues involving decisions made by parents, such as not wanting to attend a clinic or to take tablets.

It would have been interesting to triangulate the analysis, perhaps through the experiences of other family members and the participants' medical files. Further insights may have been gained if the participants had been given an opportunity to give feedback on the model of their experiences, once saturation had been reached.

With the above in mind, the impact and utility of the analysis will now be considered.

4.2. Insights from the analysis

Control

The analysis has revealed a number of interesting insights into the experiences of young people with a diagnosis of AD/HD. Firstly how 'Being in control' is important, and that 'getting in control' was a goal shared by all participants,

> "Being in control is the best feeling for someone with AD/HD cos you know, whatever happens you can stop it"
> (Participant 4, p. 15, Ln 15 – 16).

The participants had an awareness of the factors that would influence whether they experienced 'Having AD/HD bad' or 'Being in control'. One of the main factors cited as having a positive influence on 'Being in control' was 'Having opportunities to make choices about situations', as opposed to 'Being stuck in boring situations', which leads to 'Being bored and 'Having AD/HD bad'. This raises some interesting questions: Is the need to have opportunities for control over a situation any different for people with AD/HD when compared to their peers without a diagnosis? If so, what constitutes control? Would young people with AD/HD need *actual* control over the situation, or just need to *perceive* that they have control? In what way is the young people's 'perceived control over situations' correlated with their 'perceived severity of their AD/HD'? How much control over situations would young people with AD/HD wish to have? Would it be possible to for them to feel that they have too much control, and if so, is there an optimum amount of control that would help them to function at their best, and 'be in control'? Would helping young people to feel more in control of experiences that they associated with AD/HD have an effect on their general well-being, for example improving self-esteem, and if so, would these improvements in well-being be the same for a control group of peers who were given some work around empowerment?

The influence of 'Being stuck in boring situations' on 'Having AD/HD bad' (via, 'Being bored') was also described within the analysis. This may fit with existing research that suggests that behaviours associated with AD/HD such as hyperactivity are linked to, or indeed a product of, delay aversion in this population, especially in situations where there is no stimulation (Antrop, Stock, Verté, Wiersema, Baeyens, & Roeyers, 2006); and that such behaviours are a function of people with AD/HD seeking stimulation (e.g. Antrop, Roeyers, Van Oost & Buysse, 2000). Therefore, it is quite possible that when they find themselves 'stuck in a boring situation' they would be more likely to be experiencing 'Having AD/HD bad'. It would be interesting to explore through future research, whether having control over a situation that would otherwise be perceived as 'boring' would reduce the likelihood of experiences associated with 'Having AD/HD bad'.

Perceptions of AD/HD

In addition to experiences regarding 'Control', the participants discussed a range of beliefs about others' perceptions of people with AD/HD. All of the participants believed that 'AD/HD' has negative connotations for those without the diagnosis, such as 'Being mad' or 'Being badly behaved', and that those people do not hold any positive beliefs about AD/HD:

> "You never hear anything positive about it, it's only ever the negatives

that come through"

(Participant 4, p. 11, Ln 40 – 41).

The participants' experiences are echoed in several studies of teachers', parents' and siblings' understanding of AD/HD (e.g. Bussing, Schoenberg & Perwien, 1998; Carlson, Frankenberger, Hall, Totten & House, 2006; Kendall, 1999; West, Taylor, Houghton & Hudyma, 2005). In one such study (West, Taylor, Houghton & Hudyma, 2005), parents and teachers were found to be knowledgeable about the causes of AD/HD whilst having misconceptions about its characteristics and treatment.

There are also parallels between the experiences of young people in this study, and those of young adults with Asperger's Syndrome (Portway & Johnson, 2003), namely feeling 'different from normal people' and that others do not understand their difficulties. This poses a question; is this a feature of being 'labelled' with Aspeger's Syndrome or AD/HD, is it part of having a diagnosis of any 'mental disorder', or are these common experiences of adolescence in general?

What was particularly interesting about the descriptions of perceptions of AD/HD was that almost all of the participants used negative terms to describe other people with the diagnosis (e.g. "muppets", "psychos", "mad"). Further, all of the participants talked about knowing people who had more 'severe' AD/HD than they did.

Adolescents often affiliate themselves to social groups ('in groups'), and there is an increasing body of research that suggests that social identity and group behaviour is most apparent in this stage of life; given that adolescence is a period during which self-identity is defined. Group behaviour is increasingly thought to impact upon social development and feelings of self-worth (Tarrant, North, Eldridge, Kirk, Smith & Turner, 2001). Adolescents are acutely aware of the social status that is accorded to different social groups and this has an impact upon their self-evaluation; and perceiving oneself as affiliated to an unpopular or group with lower status can have a negative impact upon self esteem (e.g. Buhrmester, 1992). Evaluations of the status of social groups are thought to be made through social comparisons to other social groups, both of higher and lower status, of which one does not see themselves as a member ('out groups'). Positive evaluation of the 'in group' by its members is thought to be dependent on their comparing a range of characteristics that they perceive as defining their group, to those of the 'out groups'. When group members make these comparisons, and form a positive evaluation of the 'in group', feelings of self-worth are raised amongst the membership.

There is an increasing body of research investigating the purpose and effects of social comparison in people with mental health diagnoses. In one such study, Hedley and Young (2006) examined the relationship between social comparisons and depressive symptomatology in 36 young people aged 10 to

16 with Asperger syndrome. They found that perceived group membership to a group of people with Asperger syndrome was significantly correlated with scores of depressive symptoms.

Other studies have found that making a large number of 'upward social comparisons', in which people compare themselves to those perceived as being in a better position than they are, may be a significant factor in experiences related to depression such as low self-esteem (e.g. Bazner, Bromer, Hammelstein & Meyer, 2006).

The results from the present study suggest that there may be 'in groups' and 'out groups' within the population of young people with a diagnosis of AD/HD, and that the findings from the present study could be indicative of young people with AD/HD using 'downward social comparison' to others with the diagnosis, as a means of protecting their self-esteem by distancing themselves from a group they perceive as being stigmatised (perceived as an 'out group'). The dimensions by which these groups are defined, the nature of group membership, any social comparisons, and how these groups 'fit' with other adolescent social groups would require further investigation.

4.3. Clinical issues arising from the analysis

It is important to note that many of the participants described their experiences of CAMHS appointments as 'boring', e.g.

> "I: Oh right, and what sort of things do you talk about with them?
>
> P: Um...how does it feel? What do you do? How does it feel, what do you do, how does it feel, what do you do, how does it feel what do you do?!
>
> I: And what's it like talking about that?
>
> P: ...um, boring..."

From the participants' descriptions, 'Being stuck in boring situations' and 'being bored' lead to experiences associated with 'Having AD/HD bad', such as 'Not concentrating'. 'Boredom' and the subsequent experiences during appointments may explain how some misunderstandings about what the term AD/HD means and difficulties understanding suggested interventions might occur, e.g.

> "I hate em when they're like "oh we're going to try you on new pills", why don't you go and try it on a science rat or something, than using loads of kids as like science experiments, it fucking annoys me..."
> (Participant 6, p. 13, Ln 3 – 6)

It is therefore important to consider how we can engage young people with AD/HD in appointments so that they will not experience boredom. According to the model generated in this study, it is possible that giving the young people more control over the appointment, such as how long it will last or what they would like to talk about, may help them to concentrate and to participate in discussion. It may be, that as clinicians, we need to think about how we construct our appointments and cover the necessary topics in a more creative and stimulating way.

The participants were interested in AD/HD and wanted more information about it – which for some of the participants lead to having experiences associated with 'Being in control'. Some of the participants described feeling worried about going to the clinic to receive a diagnosis, but that these fears subsided once they had gained a better understanding of AD/HD. It is highly likely that participants are already given information about AD/HD during their appointments but for some reason they are not able to access it. It may be that it is too technical, there is too much information given at one time, or that the format in which the information is given is perceived as 'boring'. A role for the clinics would be to conduct research in order to identify what is both needed and wanted by individuals, families and the wider community (e.g. schools); what information is already being given and how useful it is; to identify the most accessible and useful format(s) for giving information; and to explore at what point having this information would be most useful (e.g. before diagnosis, after diagnosis).

The results of the current study were presented at the clinic through which the participants were recruited. One can hypothesise as to what the impact of this might be, but it is hoped that this may have stimulated thinking about the difficulties that these young people face and about providing truly client-centred interventions.

4.4. Future directions for research

The results of the current study suggest a number of future directions for research including:

- To extend the current study to a wider group of people with a diagnosis of AD/HD, particularly those who have not internalised their diagnosis if possible, in order to use theoretical sampling, and to reach saturation. This could be achieved using focus groups of families including a young person with a diagnosis of AD/HD, approaching adults and young children with diagnoses of AD/HD or accessing an on-line support forum.
- To explore whether all young people with a diagnosis of AD/HD, and other psychiatric labels, have internalised their label, and to determine what effects this might have for those who do and do not internalise their diagnosis.
- To conduct longitudinal studies of experiences, in which participants are followed from pre-assessment, through assessment, diagnosis and intervention, to explore whether participants have experiences associated with 'Having AD/HD bad' and 'Being in control' and whether these change over time.
    - To further explore issues around 'control' in situations, starting with whether the need to have opportunities for control over a situation is any different for people with a diagnosis of AD/HD when compared to peers without a diagnosis. If this were the case, it would then be

interesting to investigate the research questions posed on pages 109 and 110.

- To examine issues regarding stigma associated with a label of AD/HD.
- To explore downward social comparison with this population and what function it might serve for them.
- To explore best-practice for engaging young people in CAMHS appointments.
- To identify what information about AD/HD is wanted by the young people and their families and to find the most useful and accessible format for providing this.

4.5. Conclusions

The present study set out to explore young people's experiences of AD/HD. Recruiting participants proved difficult, as young people with AD/HD are a widely researched population. It may be that in future, researchers may wish to co-ordinate their work in order to avoid over-studying the population. Further, avoiding potentially stigmatising language in information sheets and being able to reward the participants for their time may be important in helping recruitment.

From the analysis of the participants' accounts, it appeared that their experiences of AD/HD are centred on two areas of experience concerning 'Control', termed 'Having AD/HD bad' and 'Being in control'. A number of factors influenced the participants' experience of control, including 'Being stuck in boring situations' and 'Having opportunities to make choices in situations'. The data also suggested that perceptions of AD/HD, both the participants' own, and their beliefs about other peoples' perceptions, are important in understanding how the diagnosis is experienced.

Future research in this area may first wish to extend the current study to a wider population of people with a diagnosis of AD/HD. A number of research questions for future studies were generated from the participants' accounts of AD/HD, in particular, focussing on issues concerning experiences of control; experiences of stigma; the existence and potential function of downward social comparison in this population; best practice for engaging young people in mental health services; in addition to exploring information giving for young people and their families.

Through further research, we can better understand the wants and needs of young people with a diagnosis of AD/HD and their families, and, in turn, how to give them this help in an increasingly client-centred way.

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The CD containing the interview transcripts can be found in the envelope affixed to the back of the manuscript. The interview transcripts may be viewed using Microsoft Word.

Appendix 1: Guidance for Authors, British Journal of Clinical Psychology

Notes for Contributors

The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- Papers reporting original empirical investigations
- Theoretical papers, provided that these are sufficiently related to the empirical data
- Review articles which need not be exhaustive but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications
- Brief reports and comments

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship (including personal acknowledgements and institutional affiliations) should be confined to the title page (and the text should be free of such clues as identifiable self-citations, e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at http://bjcp.edmgr.com.

First-time users: Click the REGISTER button from the menu and enter in your details as instructed. On successful

registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).
Registered users: Click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - Manuscript title page template
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions: British Journal of Clinical Psychology - Structured Abstracts Information
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.

- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For Guidelines on editorial style, please consult the *APA Publication Manual* published by the American Psychological Association, Washington DC, USA (http://www.apastyle.org).

6. Brief reports and comments

These allow publication of research studies and theoretical, critical or review comments with an essential contribution to make. They should be limited to 2000 words, including references. The abstract should not exceed 120 words and should be structured under these headings: Objective, Method, Results, Conclusions. There should be no more than one table or figure, which should only be included if it conveys information more efficiently than the text. Title, author and name and address are not included in the word limit.

7. Publication ethics

Code of Conduct - Code of Conduct, Ethical Principles and Guidelines
Principles of Publishing - Principles of Publishing

8. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

10. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

11. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs
- Tables, figures, captions placed at the end of the article or attached as separate files

Appendix 2: Semi-structured Interview Schedule

Interview schedule:

Remember that there are no wrong answers because I am interested in you and your experiences.

I would like to start by asking you about yourself.

- How would you describe yourself to someone who does not know you?
- How would other people describe you?
- Are there things that you find easy to do? Can you tell me about that?
- Are there things you find difficult to do? Can you tell me about that?
- Has there ever been a time when you have found it really hard to wait for something? Can you tell me about that?
- Has there ever been a time when you found it really hard to concentrate on something? Can you tell me about that?
- Have you ever heard of AD/HD? Can you tell me about the time when you first heard about it?
- Have you ever seen anybody about AD/HD? What do you remember about what they said or did?
- Have you talked to your family or friends about AD/HD? Can you tell me about that / those times?

Examples of prompts (to be used only when necessary):

- What did you think about that?
- Have there been other times like this?
    - Is it always this way?
    - Are there times when it is different?
- Can you tell me more about that?
- What happened next?
- Where were you?
- Were you with anyone? Who were you with?
- What did you do?
- How did you feel?
- Did you talk to anyone about it?
    - What did they do?
    - What did they say?

Appendix 3: Information Sheet for Young People

University
of Southampton

School of Psychology
Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ United Kingdom

Tel +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

PARTICIPANT INFORMATION SHEET

Young Peoples' Experiences of AD/HD

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and talk about it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study is trying to explore what it is like for young people to have AD/HD, or to have difficulties that could be described by the term AD/HD; and their experiences with clinics that they may have been to.

Why have I been chosen?

You have been chosen because this study is for young people with AD/HD, or difficulties that could be described by the term AD/HD, such as yourself.

What are the risks of taking part?

We do not expect that there will be any risks to you from taking part in this study. You may find that there are questions in the study that you do not want to answer. If this happens, you do not need to answer those questions, and you do not need to give a reason why you did not answer them.

Do I have to take part?

It is up to you and your parent/guardian to decide whether or not to take part. If you do decide to take part you will be given this information sheet and asked to sign a consent form on the day of your interview. You will get to keep a copy of both this information sheet and the consent form.

If you decide to take part you are free to change your mind at any time and you would not have to give a reason. A decision to stop the interview at any time, or a decision not to take part, will not affect the standard of care you receive now or in the future. No one will be upset if you decide not to take part.

Will I benefit from taking part?

You may, or may not, benefit directly from taking part in the study. The information that you provide us will help us to better understand young peoples' experiences of AD/HD and the clinics that they have been to. We hope that this will help us to improve the standard of care that you and others receive.

What will happen if I choose to take part?

Your parent/guardian will return the slip on their form in the envelope provided. Once this slip has been received, your parent/guardian will be contacted to arrange an interview at a time that is good for you. On the day of your interview, both you and your parent/guardian will be reminded about the purpose of the study, and asked to sign a form to show that you both give your consent to take part.

The interview will last no longer than 1 hour. If you find that this is too long, you can take a break, or the interview can be completed in two or more sessions. You will be asked questions about your experiences of AD/HD, and what it was like to go to the clinics that you may have been to. The interview will be tape-recorded (on an audio tape).

There are no wrong answers to the questions – we are interested in your experiences, and how things have been for you.

Will my taking part be kept confidential?

All information collected during the study will be kept strictly confidential. This means that the information you give will be kept private, and there will be no information that could identify you. The tape used to record the interview will be kept in a locked cabinet, and kept separate from anything that could identify you. The interview will be typed up, and any information you gave which could identify you or your family, (for example your name, address, name of your school), will be completely changed, or taken out.

What will happen to the results of the study?

A report of the study will be written. You can have a short version of the results of the study if you would like them. If you would like the results, please ask for them. Your name, and any information that could identify you or your family, will not appear in the report that is written.

Who is organising and funding the research?

The research is being organised and funded by the University of Southampton.

Who has reviewed the study?

The Local Research Ethics Committee has reviewed the study. This is a group of people who meet to decide whether a study is ok, and will not harm people who choose to take part.

Contact for further information:

If you have any questions, please contact:
Xavier M Brooke, Trainee Clinical Psychologist, Clinical Psychology, School of Psychology, Shackleton Building, Highfield Campus, University of Southampton, Highfield, Southampton, SO17 1BJ.

Or email: xmb103@soton.ac.uk

Appendix 4: Information Sheet for Parents / Letters to SENCO's & Support groups

University
of Southampton

School of Psychology
Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ United Kingdom

Tel +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

PARENT/GUARDIAN INFORMATION SHEET

Young Peoples' Experiences of AD/HD

Your child is being invited to take part in a research study. Before you and your child decide, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and talk about it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish your child to take part.

Thank you for reading this.

What is the purpose of the study?

This study is trying to explore what it is like for young people to have AD/HD, or what it is like to have difficulties that are associated with AD/HD (difficulties with concentration, hyperactivity and impulsivity). The study is interested in young peoples' experiences of these difficulties, and also their experiences of the services that they have received in relation to these difficulties. The information gathered from this study will give new insights into what the actual experience of AD/HD is like for young people, helping us to better understand the condition. In addition, the information will help to inform future developments and improvements to the services that young people receive for these difficulties. To achieve this, the results from this study will be presented to the Team at [redacted]. It is hoped that the results of this study will be published in a peer-reviewed journal.

Why has my child been chosen?

Your child has been chosen because this study is for young people with a diagnosis of AD/HD, or those whose difficulties could be described by the term AD/HD but do not have a formal diagnosis.

What are the risks of taking part?

We do not expect that there will be any risks to your child from taking part in this study. They may find that there are questions in the study that they do not want to answer. If this happens, they do not need to answer those questions, and they will not need to give a reason why they chose not answer them.

Does my child have to take part?

It is up to you and your child to decide whether or not to take part. If you both decide to take part you will both be given an information sheet and asked to sign consent forms on the day of the interview. You and your child will get to keep copies of both the information sheets and the consent forms.

If you and your child decide to take part, you and your child are still free to withdraw at any time and you would not have to give a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or your child receive now or in the future. No one will be upset with you or your child, should either of you choose not to take part.

Will I, or my child, benefit from taking part?

You and your child, may or may not, benefit directly from taking part in the study. The information that your child provides us will help us to better understand young peoples' experiences of AD/HD and their experiences of the services that they have been to. We hope that this will help us to improve the standard of care that you and your child receive.

What will happen if I, and my child, choose to take part?

If you and your child choose to take part, you will be contacted once the reply slip at the bottom of this form has been received (using the envelope provided), and your child will be asked to take part in an interview at a convenient time. On the day of the interview, both you and your child will be asked to sign forms to show that you both give consent to take part in the study.

The interview will last no longer than 1 hour. If your child finds that this is too long, they may take a break, or the interview can be completed in two or more sessions. Your child will be asked questions about their experiences of AD/HD, and what it was like to go to the clinics that they may have been to. Your child can choose not to answer certain questions, and if they do so, they do not have to give a reason for not answering. The interview will be tape-recorded (audio recording only).

There are no wrong answers – we are interested in their experiences, and how things have been for them.

Will my child's taking part be kept confidential?

All information collected during the study will be kept strictly confidential. This means that the information they give will be kept private, and there will be no information that could identify you or your child. The tape used to record the interview will be kept in a locked cabinet, and be kept in a different cabinet to the one that contains any identifiable information about you or your child.

The interview will be typed-up, and during this process, any information you gave which could identify you or you child (for example your child's name, names of other family members, your location), will be changed or removed, to protect your identities.

Should your child discuss any issues that show that they are at risk to themselves, or to others, the interview will be stopped. Your child would then been informed of the reason why the interview has been stopped. Your child's doctor at [redacted], or the duty doctor, would then be contacted to discuss the issue that has been disclosed. This would be the only case in which your child's interview would be discussed with someone else whilst they can still be identified.

What will happen to the results of the study?

A report of the study will be written, and the findings will be presented to staff at the clinic. A summary of the results will be made available to you on request. The report will not contain any names, nor will it contain the name of the service your child is currently attending.

Who is organising and funding the research?

The research is being organised and funded by the University of Southampton.

Who has reviewed the study?

The Local Research Ethics Committee has reviewed the study.

Contact for further information:

If you have any questions about the study, or wish to request a summary of the results, please contact:
Xavier M Brooke, Trainee Clinical Psychologist, Clinical Psychology, School of Psychology, Shackleton Building, Highfield Campus, University of Southampton, Highfield, Southampton, SO17 1BJ.
Or email: xmb103@soton.ac.uk

……

To arrange an interview, please return this slip in the envelope provided. Returning this slip does not mean that you have given your consent to take part – you and your child will be asked for your consent on the day of the interview. You do not need to give all of the contact details below – only the one by which you would prefer to be contacted:

Name:……………………………………………………………………

Child's Name:………………………………………………………………

Contact telephone:…………………………Email:……………………

Contact address:……………………………………………………………

ON HEADED PAPER

Head Teacher
Name of School
Address

20th June 2007

Dear [HEAD TEACHER],

For the attention of the Special Educational Needs Coordinator.

My name is Xavier Brooke and I currently finishing my Doctorate in Clinical Psychology at the University of Southampton. As part of my Doctorate, I am conducting research, looking at young peoples' experiences of AD/HD, and would to ask if you would be able to help me to contact young people who may wish to participate in this study.

I am interested in young people's experiences of difficulties associated with AD/HD (difficulties with attention/concentration, impulsive behaviours, and hyperactivity). I am also interested in their perspective of any involvement they have had with the health services. In order to gain an insight into these experiences, I am interviewing young people with AD/HD about their experiences. All information gained from the interviews will remain anonymous. The study has been reviewed by the School of Psychology Ethics Committee at the University of Southampton, and the Local Research Ethics Committee.

I am hoping that this research will provide information on what it is like to have AD/HD, and to help shape future services for people with AD/HD.

I am looking to recruit young people with a diagnosis of AD/HD, or those who have been to local services for difficulties that could be described as AD/HD (but have heard the term AD/HD used in relation to their difficulties).I have enclosed the letter for parents/guardians, in addition to information sheets for both parents/guardians and the young people, which give more details about the study. I am simply asking you to forward this information to parents of young people who meet these criteria. There is no implied endorsement by the school and the study will not impact on the school in any way. The main difficulty I have is in locating the young people I need for this study, and it is for that reason that I am asking if you would be able to help.

I would be happy to visit the school to discuss my research and answer any questions that you or the other members of staff may have.

If you would be interested in the research or would like to find out more, please do not hesitate to contact me by email: xmb103@soton.ac.uk, or by telephone 02380 xxx xxx

Many thanks in advance,

Yours sincerely

Xavier Brooke
Psychologist
University of Southampton

Appendix 5: Consent forms

University
of Southampton

School of Psychology
Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ United Kingdom

Tel +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

PARTICAPANT CONSENT FORM
Young Peoples' Experiences of AD/HD

Xavier Brooke
Department of Clinical Psychology
Highfield Campus
University of Southampton
Highfield
Southampton
SO17 1BJ

Please initial box

1. I confirm that I have read and understood the information sheet dated 12th September 2005 for the above study ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being restricted. ☐
3. I am willing for the interview to be audio-taped. ☐
4. I agree to take part in the above study. ☐

Name	Date	Signature
Researcher	Date	Signature

1 copy for Parent/Guardian, 1 for participant, 1 for researcher, 1 for medical notes

University
of Southampton

School of Psychology
Doctoral Programme in Clinical Psychology

University of Southampton
Highfield
Southampton
SO17 1BJ United Kingdom

Tel +44 (0)23 8059 5321
Fax +44 (0)23 8059 2588
Email

PARENT/GUARDIAN CONSENT FORM
Young Peoples' Experiences of AD/HD

Xavier Brooke
Department of Clinical Psychology
Highfield Campus
University of Southampton
Highfield
Southampton
SO17 1BJ

Please initial box

1. I confirm that I have read and understood the information sheet dated 12th September 2005 for the above study ☐
2. I understand that my child's participation is voluntary and that they are free to withdraw at any time without their medical care or legal rights being restricted. ☐
3. I am willing for my child's interview to be audio-taped. ☐
4. I agree to for my child to take part in the above study. ☐

Name of parent/guardian	Date	Signature
Name of participant	Date	Signature
Name of person taking Consent (if not researcher)	Date	Signature
Researcher	Date	Signature

1 copy for Parent/Guardian, 1 for participant, 1 for researcher, 1 for medical notes

Appendix 6: Examples of field notes

Examples of Field Notes

Participant 1:

Participant 1 was interviewed at home, and had just finished a long day at school and the rest of her family were busy in the room adjacent to where the interview was taking place. She seemed very eager to "get on" with the interview. I think that she found the background noise distracting at times. She appeared quite shy at first, and seemed somewhat embarrassed about the tape recorder – maybe it was because her family were around? I had suggested we find somewhere else, or meet at another time but she said she was quite happy to continue. After the first few questions, she soon chatted quite freely, and answered all questions. After the interview, I asked her if she had managed to say everything that she wanted to and she said yes. She asked me how many people were taking part and I told her that I was having difficulty with recruiting participants, and only a few people had 'signed up'. She said that it was "disgusting" and people "have no right to complain if they don't stand up for themselves and do something like this". I wonder if she has taken part as she has a story to tell? I wonder if the same might be true of the others – there is, after all, no tangible reward for taking part. I think maybe that I could do a bit more rapport building before the interview next time.

Participant 4

Participant 4 was interviewed at home with his mum and sister in a different room. He was particularly eloquent (and seemed to be academically very bright) and perhaps, because of this, he seemed particularly able to discuss his ideas fully, with little prompting. He seemed to be driven to achieve his 'full potential', in school, with his music and with his sporting activities. I found his discussions about people not understanding about AD/HD fascinating, and his anger at people promoting misconceptions about AD/HD came over strongly. After the interview, he talked some more about going to clinics and not understanding why he was there, and what exactly they were trying to do to help. He talked about finding this frustrating, and when his Mum joined us, she also described feeling that the clinic (when they first went) was a confusing and frustrating process. I really think that this participant had a story to tell – to put misconceptions about AD/HD to rest?

Participant 6

Participant 6 was interviewed at home with his Mum present. He was, as he described, a very bubbly person, who seemed excitable, and he squirmed in his seat during the entire interview. I did not get the impression that he was squirming because of the interview – I rather think he found sitting for that length of time uncomfortable. He seemed quite eager to make me laugh and crack jokes before the interview started, and I wondered whether expressions such as "pill-head" and "I take tablets because I'm mad" were to shock or entertain, or whether these were his true feelings. I think as they feature quite heavily during the interview, I may have to ponder this some more, before assuming that this is a reflection of his true feelings about having the label. After the interview he asked me about what would happen with the interviews and I explained about writing it up etc.

Appendix 7: Approval from School of Psychology Ethics Committee and Local Research Ethics Committee

NHS

SOUTHAMPTON & SOUTH WEST HAMPSHIRE
RESEARCH ETHICS COMMITTEES (B)
1ST Floor, Regents Park Surgery
Park Street, Shirley
Southampton
Hampshire
SO16 4RJ

Tel: 023 8036 2466
023 8036 3462
Fax: 023 8036 4110

Email: GM.E.hio-au.SWHRECB@nhs.net

STA/cb

18 April 2006

Mr Xavier Brooke,
Trainee Clinical Psychologist,
Clinical Psychology, University of Southampton
Highfield Campus
Highfield
Southampton
SO17 1BJ

Dear Mr Brooke

Full title of study:	**AD/HD: Young People's Experiences Of A Label, Diagnosis And Intervention**
REC reference number:	**06/Q1704/15**

Thank you for your letter of 06 April 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

Document	Version	Date
Application		09 January 2006
Investigator CV for Mr X Brooke		01 December 2005
Investigator CV for Edmund Sonuga-Barke		
Protocol	1	11 January 2006
Covering Letter		09 January 2006
Summary/Synopsis	1	11 January 2006
Letter from Sponsor		08 December 2005

Peer Review		22 January 2006
Peer Review from Catherine Brignell/Romola Bucks		
Peer Review - Lucy Yardley		05 April 2005
Compensation Arrangements		07 December 2005
Interview Schedules/Topic Guides	1	11 January 2006
Participant Information Sheet - Participant	2	03 March 2006
Participant Information Sheet - Parent/Guardian	2	03 March 2006
Participant Consent Form - Parent/Guardian	1	11 January 2006
Participant Consent Form - Participant	1	11 January 2006
Response to Request for Further Information		06 April 2006
Verbal Information to be given prior to interview	1	12 September 2005

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1704/15 **Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Raj Patel
Chair

Email: GM.E.hio-au.SWHRECB@nhs.net

Enclosures: *Standard approval conditions SL-AC2 for other studies*

Copy to:
University of Southampton
Dr. Martina Dorward, Research Governance Manager
Legal Services, University of Southampton
Highfield, Southampton

SF1 list of approved sites

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Date: Tue, 1 Nov 2005 10:45:40 -0000
From: "Smith K.M." <K.M.Smith@soton.ac.uk>
To: xmb103@soton.ac.uk
Subject: Ethics Application

Dear Xavier

Re: Young People's Experiences of ADHD: Assessment and Intervention

The above titled application was approved by the School of Psychology Ethics Committee on 31 October 2005.

Should you require any further information, please do not hesitate in contacting me. Please quote reference CLIN/03/97.

Best wishes,

Kathryn

Miss Kathryn Smith
Secretary to the Ethics Committee
School of Psychology
University of Southampton
Highfield
Southampton SO17 1BJ
Tel: 023 8059 3995 Fax: 023 8059 2606
Email: kms@soton.ac.uk

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Date: Mon, 25 Sep 2006 15:44:57 +0100
From: "Ingham R.J." <Roger.Ingham@soton.ac.uk>
To: xmb103@soton.ac.uk
Cc: "Smith K.M." <K.M.Smith@soton.ac.uk>
Subject: RE: Ethics application CLIN/03/97

Dear Xav

To avoid more work, you can consider your request (and this reply) as agreement to this proposed amendment.

I hope the recruitment situation improves as a result!

Best wishes

Roger

Professor Roger Ingham
Director, Centre for Sexual Health Research
School of Psychology
University of Southampton
Southampton SO17 1BJ, UK

tel: +44 (0)23 8059 2587
fax: +44 (0)23 8059 4597

e-mail: ri@soton.ac.uk

web: www.socstats.soton.ac.uk/cshr

From: xmb103@soton.ac.uk [mailto:xmb103@soton.ac.uk]
Sent: Mon 25/09/2006 15:31
To: Ingham R.J.
Subject: RE: Ethics application CLIN/03/97

Dear Roger,

I have ethics approval for my study which involves interviewing young people with AD/HD, and have applied for an amendment so that I can approach support groupd to recruit more participants. As I am still having difficulty recruiting, I was wondering about offering interviews over the telephone, rather than face-to-face.

Obviously, I would obtain written, informed consent from the participants and their parents, and they would be approached through the organiser of their support group; but would I need to aplpy for a further amendment before I could offer this service to the participants?

Many thanks in advance,

Xav

Xav Brooke
Trainee Clinical Psychologist

Quoting "Ingham R.J." <Roger.Ingham@soton.ac.uk>:

Dear Xav

I don't see any problem with this in principle, but I wonder whether you could please let Kathryn Smith have a copy of the letter that you would send to the groups before we approve it? She will then let me have the complete file with the requested amendment for consideration. There is no need to re-submit an application - just a brief note (like the one below) with the new material is enough.

Best wishes

Roger

Dr Roger Ingham
Reader in Health and Community Psychology
(Director, Centre for Sexual Health Research)
School of Psychology
University of Southampton
Southampton SO17 1BJ

tel: 023 8059 2587
fax: 023 8059 4597

e-mail: ri@soton.ac.uk

web: www.socstats.soton.ac.uk/cshr/

-----Original Message-----
From: xmb103@soton.ac.uk [mailto:xmb103@soton.ac.uk]
Sent: 29 June 2006 13:35
To: Roger.Ingham@soton.ac.uk
Subject: Re: Ethics application CLIN/03/97

Dear Roger,

In October 2005, the School Ethics Commitee approved my study entitled, "Young People's Experiences of ADHD: Assessment and Intervention", a qualitative study which is being supervised by Edmund Sonuga-Barke. I am still in the process of recruitment, and would like to approach non-nhs adhd support groups to see whether they may have members who may be interested in participating in the study.

I wanted to know whether my previous ethics application would allow me to go ahead with this, and Edmund suggested that I contact you.

I would be most grateful for your advice,

Many thanks in advance,

Xav

Xav Brooke

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Date: Thu, 6 Jul 2006 10:04:41 +0100
From: "Smith K.M." <K.M.Smith@soton.ac.uk>
To: xmb103@soton.ac.uk
Subject: Amendment to Ethics Application CLIN/03/97

Dear Xavier

Re: Young people's experiences of AD/HD:

Assessment and Intervention (CLIN/03/97)

The amendment you requested to make to the above titled application was approved by the School of Psychology Ethics Committee on 5 July 2006.

Should you require any further information, please do not hesitate in contacting me. Please continue to quote reference CLIN/03/97.

Best wishes,

Kathryn

Miss Kathryn Smith
Secretary to the Ethics Committee
School of Psychology
University of Southampton
Highfield
Southampton SO17 1BJ
Tel: 023 8059 3995 Fax: 023 8059 2606
Email: kms@soton.ac.uk

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Date: Tue, 16 Oct 2007 15:34:25 +0100
From: "Seiter B." <B.Speiser@soton.ac.uk>
To: xmb103@soton.ac.uk
Subject: ethics amendment

Dear Xav,

I just wanted to let you know that Roger has approved the ethics amendments you requested for your study CLIN/03/07.

Best wishes,

Barbara

Barbara Seiter

Academic Administrator

School of Psychology / Institute for Disorder of Impulse and Attention

University of Southampton

Shackleton Building (room 4041)

Highfield, Southampton

SO17 1BJ

Telephone number: 023 8059 5578

Fax number: 023 8059 2606

Email adress: bs1c06@soton.ac.uk <mailto:bs1c06@soton.ac.uk>

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Appendix 8: Examples of Analysis Memos

Examples of Analysis Memos:

Process Memos:

Open codes will be <u>underlined</u> in the transcripts[*]

The name of the code assigned to the underlined portion of the transcript will be shown in *{brackets and Italics}**. I will try to use in vivo codes where possible, so as to keep the analysis grounded in the data.

Having read and re-read the transcripts, I will do some microanalysis on transcripts 1 and 2 and note my ideas below. During this process, I will come up with some initial open codes for these transcripts and then go back to my memos and conduct further line-by-line analysis to refine these codes.

Memos from the analysis

What does 'concentrate' mean? (Participant 1, p. 2, Ln 13). What would it be like "to have to think in your head", what would that involve, what situations would that occur in?

I must explore further what "concentration" means to this and other participants. At the moment, I am thinking about the following: When does it occur/not occur? What facilitates it? What makes it harder? Is it the same as common notions of concentration e.g. "paying attention" or "listening"? Is it something more "active"? Are there times when it is a passive action? Does concentration have to occur within interactions, or can it be a solitary action? Is concentration the same as "memory" – end of interview – things to help with my memory...? I will look for other instances of concentration in the transcripts.

What does "annoyed me because I can't concentrate" mean? (participant 1, p. 3, Ln 10 - 11) Was it that that she found concentrating hard, and then became annoyed by someone else *because she couldn't concentrate*, or did she find it hard to concentrate *because someone else was annoying her*?

"The kids are like psychos" (participant 1, p. 4, Ln 13) – who are the "kids" in this situation? Does the participant include herself in this group or are they different? Is she talking about people who share the same label as her, or are the "psychos" a different group altogether? Are all "kids" psychos? There seems to be a sense of differentiation here. I need to look for instances of being the same as others, and being different from others, both with, and without a label of AD/HD.

Participant 6, talking about what it is like to concentrate: "Annoying, I get bored easily, I do something and I get bored within 5 minutes so I just lose my concentration or I can't do it and I get frustrated, so I just get annoyed and get

---

[*] This only relates to the coded versions of the transcripts, which are not included on the CD.

angry…it just winds me up…and I can't do it" (p.5, Ln 21 – 24). Getting bored easily – boredom leads to difficulties with concentration for this participant. It seems that 'how easily you get bored' determines, in some part, ability to concentrate (whilst this might seem like 'common sense', it would not be possible to report this without the participants talking about it).

"Hmmm, I can control it....sometimes" (particpant 6, P. 17, Ln 34). This participant is saying that sometime he can control (AD/HD) and this implies "sometimes not". This suggests that 'being in control' is not necessarily a stable state, and as another participant said, it might be about *trying to be in control* and that sometimes you are, and sometimes you are not. Is it then possible that only the individual would know if they were in control of their actions at a given time (and therefore responsible)?

I am still thinking about my developing theory. The open codes appear to fit under the sub-category headings, each of which is encompassed by a more abstract category, representing an interaction. Some of these categories and sub-categories interact with each other providing an insight into the experience of AD/HD. I need to draw some more diagrams and re-examine the data to gain a good understanding of how these categorised data interact with one-another.

My latest diagram shows all of the interactions between categories, but tells us nothing about the participants' experiences. Through supervision, I have thought about this, and it seems that I have only described the data so far – not actually found the more abstract concepts that over-arch these ideas. From examining the data further, I think it is more about 'Control' than anything else – could this be the central category? I need to look for evidence that would NOT support this idea.

Appendix 9: Categories, sub-categories and codes

Categories, sub-categories and codes

This document contains the final list of the categories and sub-categories identified during the analytical process. These categories have been constructed from the open coding process and further shaped by comparing the emerging model against the existing data, and new data as it was collected and transcribed. Relationships between the categories were identified by comparing the data, looking for similarities and differences and connections, and by the drawing of diagrams. Data that did not fit the emerging model was actively sought out, in order to 'test' the emerging theory. Phrases surrounded by double quotation [""] marks indicate the title of categories and sub-categories, whereas single quotation marks [''] indicate the initial open codes used in the analysis.

1. Central Category: "Control"

Definition: Experiences relating to the extent to which the participants felt that they were in 'control' of their actions and attributed this to AD/HD. This consists of two related sub-categories: 'Being in control' and 'Having AD/HD bad'. These two sub-categories can be seen as opposing ends of a dimension, and two distinct (but related) concepts.

1.1 "Having AD/HD bad"

Definition: This category consists of descriptions of behaviours and actions that they attribute to AD/HD, over which the participants feel they are not in control, and therefore are an indicator of 'having AD/HD bad'. These experiences must be described as being 'worse' than those of peers.

Includes the following sub-categories:

"Being hyper"

Definition:

Experiences in which the participants describe 'being hyper', 'having too much energy', 'can't sit still'.

"Not concentrating"

Definition:

Experiences in which the participants describe not being able to concentrate, to a greater extent than peers, or than they would expect for any given situation. Includes the codes, 'hard to concentrate', 'hard to focus'.

"Having a temper"

Definition:

Experiences in which the participants describe 'having a temper' due to AD/HD. This includes descriptions of 'being aggressive', 'shouting', 'swearing', 'throwing things', 'ADD temper', 'going mad [in context of fighting/aggression]'. These experiences must be attributed to AD/HD, and be perceived as worse than would be expected of their peers to qualify.

"Waiting is hard"

Definition:

Experiences in which the participants describe finding it difficult to wait for something. This does not include waiting for birthdays or Christmas – it is where the participants describe finding it more difficult to wait than they believe their peers would find it.

"Being mad"

Definition:

Experiences in which the participants describe being 'mad', 'crazy', 'mental' due to their label of AD/HD.

1.2 "Being in control"

Definition: Experiences in which the participants describe behaviours and actions that they attribute to AD/HD, over which the participants feel they are in control. This can be thought of as the opposite end of the dimensions of the categories described under "Having AD/HD bad".

Includes the following Sub-Categories:

"Not being hyper/being relaxed"

Definition:

Experiences in which the participants describe 'not being hyper' within the context of AD/HD. This includes 'being chilled out', 'being relaxed', 'being calm [in terms of not being hyperactive]'.

"Being able to concentrate"

Definition:

Experiences in which the participants describe 'being able to concentrate' on a task or activity. This includes 'being able to focus', 'being able to concentrate', and 'being able to get on with my work'.

"Waiting is ok"

Definition:

Experiences in which the participants describe being able to tolerate situations in which they have to wait.

"Not being controlled by temper"

Definition:

Experiences in which the participants describe being able to control their temper, where they have attributed their temper to AD/HD.

"Being normal"

Definition:

This encompasses experiences in which the participants feel that they are functioning at a level that would be expected of peers without a diagnosis of AD/HD, in areas in which they have previously had difficulty [and attributed these difficulties to AD/HD].

3. “Experiences impacting upon ‘Having AD/HD Bad’”

Definition:

Experiences which the participants describe as having a direct impact upon the experiences that are encompassed under “Having AD/HD bad”, for example, exacerbating experiences of “being hyper” or “not concentrating”.

Includes the following sub-categories and codes:

3.1 ‘Being distracted’

Definition:

Experiences in which the participants describe being distracted by others [external sources], and this exacerbating experiences associated with “Having AD/HD bad”.

3.2 ‘Too much at once’

Definition:

Experiences in which the participants describe being asked to do too many things at once.

These experiences lead to ‘not concentrating’.

3.3 *'Not taking tablets'*

Definition:

Experiences in which the participants describe either forgetting to take medication, or stopping their medication, and this exacerbating their experiences associated with "Having AD/HD bad".

This is associated with "not concentrating", "having a temper" and "being hyper".

3.4 *'Coke'*

Definition:

Experiences in which the participants describe fizzy drinks as having an adverse effect upon their experiences associated with "Having AD/HD bad".

This is associated with "being hyper".

3.5 *"Being bored"*

Definition:

Experiences in which the participants describe feeling bored and this internal state exacerbating experiences of "Having AD/HD bad".

This is associated with "being hyper", "not concentrating" and "having a temper". "Being bored" is usually (but not always) associated with "Being stuck in boring situations" (below).

3.6 "Being stuck in boring situations"

Definition:

Experiences in which the participants describe finding themselves in situations in which they feel bored, but have no opportunity to escape.

This experience leads to "being bored" and subsequently exacerbating experiences of "Having AD/HD bad".

4. "Experiences Impacting upon 'Being in Control'

Definition:

Experiences which the participants described as helping them to feel 'in control' of the behaviours and actions that they attribute to AD/HD.

Includes the following sub-categories and codes:

4.1 *'Getting older'*

Definition:

This includes descriptions in which the participants talk about becoming more in control of behaviours/actions that they had associated with AD/HD as they got older, or finding that they have more control over these behaviours/actions as a result of maturation.

4.2 *'Making different choices to take control'*

Definition:

This encompasses experiences of making an active choice to avoid situations known to exacerbate 'Having AD/HD bad' (e.g. not drinking Coke, choosing to take tablets [if they believe them to be efficacious and with no side effects]), or to choose a different course of action, when such an option is available. This does not include descriptions of having opportunities to make choices about the situations in which they find themselves.

4.3 *"Having opportunities to make choices about situations"*

Definition:

This includes descriptions of the participants having an opportunity to make choices within situations that would be expected to bring about experiences associated with "Having AD/HD bad", and these choices helping them to 'be in control'. This includes 'being able to take a break', 'being able to listen to music', 'being able to get up', 'being able to choose what you want to talk about'.

5. "Experiences of Health Services"

Definition:

Descriptions of experiences associated with contact with Child and Adolescent Mental Health Services (CAMHS).

These are associated both with experiences of "Having AD/HD bad", in that those experiences (e.g. 'Being hyper', 'Not concentrating') were cited as the reason for referral to CAMHS; and for some participants, "Being in control", either from "Taking tablets", or 'Talking to someone', and 'Gaining information [about AD/HD]'.

Includes the following sub-categories and codes:

5.1 "Talking [to CAMHS staff]"

Definition:

This includes descriptions of experiences of interacting with CAMHS staff during appointments. Includes, 'being bored during appointments', 'being listened to', 'Feeling supported by the staff', 'gaining information [about AD/HD] and 'not understanding what they're talking about'.

5.2 "Diagnosis"

Definition:

Descriptions of how the participants felt when they were first told about their diagnosis of AD/HD. This includes experiences of 'being shocked', 'feeling stigmatised/labelled', 'being scared', 'they think I'm mad' and 'they're wrong'.

5.3 "Taking tablets"

Definition:

Includes descriptions of taking medication that the participants believe is to help with difficulties associated with AD/HD.

Includes the following sub-categories:

"Finding out about taking medication"

Definition:

Includes experiences of being told that they were being prescribed medication for AD/HD.

This was a dimensional experience ranging from included, 'Shock' to 'Not being bothered'.

"Reasons for taking medication"

Descriptions of the participants' attributions for needing to take medication.

Includes, codes relating to doing it for their own benefit, including 'wanting to do better at school', 'Improving performance'; and doing it for 'pleasing others' (e.g. parents).

"How well tablets work"

Definition:

Includes descriptions of experiences of 'Taking tablets' in terms of how much the participants believed that they improved experiences associated with of 'Having AD/HD bad'.

Includes experiences of 'tablets are good/helpful', 'tablets stop working after a while', 'tablets don't work', and 'tablets make you sick / side effects'.

6. 'Talking to someone' and 'gaining information'

Definition:

Includes descriptions of experiences of 'Talking to someone' and 'Gaining information' [about AD/HD] other than people in CAMHS, although this is related to the experiences of talking to CAMHS staff.

Linked with experiences associated with "Being in control". Includes descriptions of 'finding out more about AD/HD helps', and 'finding out about the tablets helps'.

7. "Perceptions of AD/HD"

Definition:

This category consists of two sub-categories: "Perceptions of people with a diagnosis of AD/HD", and "Beliefs about AD/HD held by those without a diagnosis".

7.1. "Perceptions of people with a diagnosis of AD/HD"

Definition:

Included the participants' descriptions of their perception of people they knew with a diagnosis of AD/HD.

Includes 'They have AD/HD worse than me', 'They're bad', 'they're mad', 'they're psychos [aggressive]' and 'they're stupid'.

Also includes:

"Good sides of AD/HD"

Definintion:

Descriptions of positive aspects of other people with AD/HD – and attributing these positive aspects to their having AD/HD.

Includes: 'Having a talent', 'Being good at work' (i.e. better than peers), 'Being clever' (i.e. more so than peers), 'Being fast' and 'Being able to get an energy boost'.

"Using AD/HD as an excuse"

Definition:

Includes descriptions of other people with AD/HD using their diagnosis as an 'excuse', i.e. as a means to avoid getting into trouble.

7.2 "Beliefs about AD/HD held by those without a diagnosis"

Definition:

Includes participants' descriptions of how they believe those without a diagnosis perceive people with AD/HD.

This included 'they think we are mad', 'they think we are aggressive/psychos', 'they think we are bad [badly behaved]'.