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UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

**Left High and Dry
Healthcare Transition Experiences of Young Adults with Attention Deficit
Hyperactivity Disorder**

by

Lisa Rudgley

Thesis for the degree of Doctor of Clinical Practice

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ABSTRACT
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**HEALTHCARE TRANSITION EXPERIENCES OF YOUNG ADULTS WITH
ATTENTION DEFICIT HYPERACTIVITY DISORDER**

by Lisa Rudgley

Healthcare transition is an important area that is attracting increasing attention from policy makers and clinicians, highlighting the need for transition services to be developed for young people with continuing health needs.

This study aimed to examine the healthcare transition experiences of young adults with Attention Deficit Hyperactivity Disorder (ADHD) following their discharge from Child and Adolescent Mental Health Services at age 18, and to elicit their views about what services they would find helpful in the future.

Participants comprised four young adults with ADHD. An interview guide aimed to gain personal accounts of individual's lived experiences of transition. Data was analysed using Interpretative Phenomenological Analysis.

Four superordinate themes were identified: personal experience of ADHD diagnosis and treatment; impact on self and relationships; living with ADHD and moving on. It was evident from the participants' accounts that there were gaps in the transitional care that they had received.

Research findings were discussed with reference to existing literature relating to biographical disruption, stigma and transition theory. Despite the national priorities given to healthcare transition and recommendations about best practice, these initiatives do not appear to be translated at practice level or in service provision.

These findings suggest that clear protocols should be developed and local services commissioned to ensure young adults are able to access services to support their continuing healthcare needs.

Further research into this important area is necessary to further explore transition processes, possible options for service delivery and to determine where services should be located.

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DECLARATION OF AUTHORSHIP

I, Lisa Rudgley

declare that the thesis entitled

Healthcare Transition Experiences of Young Adults with Attention Deficit
Hyperactivity Disorder

and the work presented in the thesis are both my own, and have been
generated by me as the result of my own original research. I confirm that:

- this work was done wholly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
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- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission.

• Signed:

Date: September 2013

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Definitions and Abbreviations

ADHD.....Attention Deficit Hyperactivity Disorder

ADD.....Attention Deficit Disorder

AMH..... Adult Mental Health

AMHS.....Adult Mental Health Services

CAMH.....Child and Adolescent Mental Health

CAMHS.....Child and Adolescent Mental Health
Services

GP.....General Practitioner

HKD.....Hyperkinetic disorder

IPA.....Interpretative Phenomenological Analysis

1. Introduction

In recent years, there has been an increasing interest in what happens to young people with chronic health conditions when they reach the age of 18 and require transition to adult health services for their continuing health care needs (Department for Education and Skills [DfES] 2004; Department of Health [DH] 2004a; Singh et al. 2010a; DH 2011b).

The transition from adolescence to adulthood is an important phase of emotional, personal and social development for all adolescents as they negotiate their way to becoming independent adults who are responsible for themselves (Aylmer 1988). Challenges facing this group include: leaving school, finding employment, starting tertiary education and leaving home. For young people with continuing health needs this may inevitably add an extra complexity and stress at a time when they are simultaneously negotiating other transitions in their lives.

Some paediatric services have developed transition pathways for young people with specific long term health conditions (such as Diabetes, Crohn's Disease and Cystic Fibrosis), where they are transferred over to adult specialists for management of their 'chronic disease' (Blum et al.1993; Harden et al. 2012).

However, it was apparent from a review of the literature that this was not standard practice for all young people with chronic health conditions (Keen et al. 2000; McDonagh 2006; Pugh et al. 2006; Marcer et al. 2008; Craig et al. 2011; Doug et al. 2011). A recent audit of 10 hospital trusts (Coles et al. 2010) found that transitional care arrangements were not consistently provided for young people and that the topic was not adequately covered in health professionals' training.

This situation was replicated within the field of child and adolescent mental health (CAMH) and specifically for young people with neuro-developmental disorders such as ADHD (Royal College of Psychiatrists [RCP] 2011).

Service users and providers increasingly feel that appropriate continuing care should be provided for young adults with ADHD and their experience of transition improved (While et al. 2004; Beresford 2004). Despite this, Kennedy

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(2010) has identified that the transition process continues to be problematic for many young people with ADHD who have continuing health care needs.

1.1 Personal perspective on the research

As a practitioner working with young people with ADHD in a Child and Adolescent Mental Health Services (CAMHS) setting, I had noticed that when young people reach the age of 18, the issue of where their continuing health care needs were met became a pressing concern. There did not appear to be clear transition care pathways; making follow up patchy, with care apparently provided on an ad hoc basis by General Practitioners (GP), private psychiatrists or Adult Mental Health Services (AMHS). I was concerned that this variable process may have an adverse effect on young people's engagement with healthcare and may have negatively impacted on them fulfilling their potential and being able to achieve appropriate developmental milestones.

When I started working in CAMHS in the mid 1980's, the concept of ADHD was relatively new in the UK and there was scepticism about the validity of the diagnosis. It seemed that this was a 'disorder' of childhood and I had the impression there was a widely held belief amongst professionals that children and adolescents would 'grow out of ADHD'. However with increasing knowledge and experience it is now generally considered that the difficulties this group experiences will continue into adulthood.

From my own clinical experience, it seemed evident that as this group of young people approached 18 they were faced with a gap in service provision as there were no established referral pathways. I sensed that service users, their parents or carers and professionals all found this situation difficult and unsettling as they were uncertain how they could access appropriate support for their on-going healthcare needs. I felt that it would be useful to explore this issue in a structured way to ascertain the extent of the problem and in particular to focus on the views held by the young people. I hoped that eliciting the views of young adults might provide some insights into how services could be developed or improved.

Given, that the provision of ADHD transition and adult services are in their infancy and that there is an increasing focus on incorporating service users'

views in the development of services; I felt there was an opportunity to represent the views of young people in relation to service design.

I wondered, given the wide ranging influences that ADHD has on affected individuals, what ideas they might have about their on-going healthcare needs, where services should be based and the accessibility criteria. In addition, given the heterogeneity of ADHD I was curious about what specific aspects of the condition they felt they needed continuing intervention for.

1.2 Rationale for the study

Given the consensus amongst researchers and clinicians regarding the chronicity of ADHD and its associated poor outcomes (Weiss and Hechtman 1993; Orr and Miller 1995; Hechtman 1996; Barkley et al. 2002; Taylor et al. 2004; Asherson 2005; Steinhoff 2008; Young and Gudjonsson 2008), and the apparent lack of transition and adult services for people with ADHD; it seemed timely to consider how best to develop services for these young adults to ensure they received appropriate care as they entered adulthood.

There is a growing commitment to eliciting service users' views in the provision and delivery of healthcare (Munoz-Solomando et al. 2010); an initiative supported at national level by the 'You're Welcome' policy (Department of Health [DH] 2007; DH 2011). According to Buston (2002) young people's views should be taken into account when developing services to ensure they are fit for purpose. This seemed an important point to consider and led to the development of the following research questions.

1.3 Research Questions

This study aimed to address the following research questions:

- What are the perceptions and lived experiences of young adults diagnosed with ADHD about their on-going care following discharge from Child and Adolescent Mental Health Services?
- What do young adults diagnosed with Attention Deficit Hyperactivity Disorder believe their continuing care needs to be?

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It was expected that this exploration would yield important insights from young people about their experiences of service delivery and could inform future service and policy development.

2. Background to the study and literature review

This section aims to describe the following key areas relating to the transition experiences of young adults with ADHD:

- To establish an operational definition of ADHD: aetiology, epidemiology, assessment, diagnosis and the associated long-term impacts and outcomes for people with ADHD.
- To provide an overview of the concept of transition and its importance in terms of human development.
- To provide a synopsis of the relevant literature and an appraisal of current policy.

2.1 Defining Attention Deficit Hyperactivity Disorder

The International Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organisation [WHO] 2000) describes the three core features of ADHD as inattention, impulsivity and hyperactivity (appendix 1). According to Brown (2005a, pxviii) ADHD is a 'cluster of impairments in the management system of the mind' which manifests itself in a variety of ways; for instance, an inability to focus on tasks, disorganisation, 'prone to action without reflection' (Taylor 2007) and a higher than normal level of activity in situations where it is inappropriate. Arguably, these symptoms could be said to occur in many children and adolescents; however, it is the severity, pervasiveness and extent of impairment that will lead to a diagnosis of ADHD (Hill and Taylor 2001; Taylor et al. 2004; National Institute of Clinical Evidence [NICE] 2008; American Psychiatric Association [APA] 2013). These symptoms can have a significant impact on an individual's ability to carry out important tasks of daily living (Brown 2005b, figure 1). These features have been repeatedly observed during my own clinical experience as a nurse and systemic psychotherapist working with young people who have ADHD.

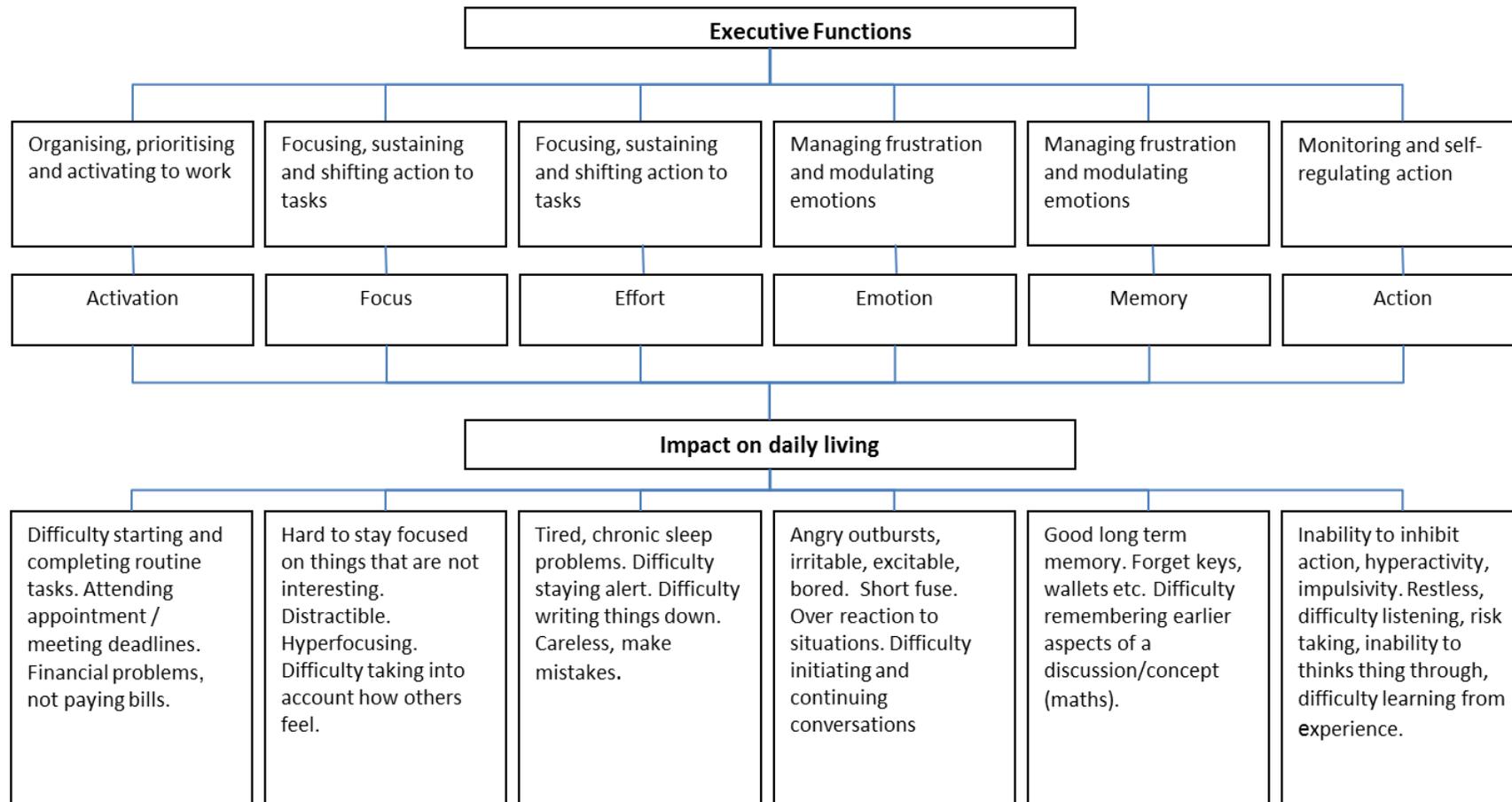


Figure 1 Impact of ADHD: Executive Functioning (adapted from Brown 2005b, p22)

2.2 Epidemiology

The prevalence of ADHD varies across different countries ranging from 2% to 19%, with an estimated worldwide pooled prevalence rate of 5.29% (Polanczyk et al. 2007). The reasons for this variation are poorly understood. Possible explanations include different assessment processes (Swanson et al. 1998), different diagnostic criteria (for example the Diagnostic Statistical Manual-V [DSM-V]; (APA 2013), is used in the United States and the ICD-10 (WHO 2000) in the UK and Europe), cultural (Timmi and Taylor 2004), demographic, geographical and physiological factors.

ADHD is a condition not confined to western society, evidence exists that shows it is found across all countries and cultures (Barkley 2006). Some clinicians are concerned that ADHD may be over-diagnosed in the UK, following a trend set in the US where the incidence of ADHD stands at 8.4% (United States Department for Health and Human Services 2011). However, the increase in diagnosis may be related to an increased awareness of the condition by parents and professionals and a shift in society's attitudes whereby disabilities are more accepted. This is supported by Taylor (2007) who reviewed evidence from the Newham (1991) and the National Morbidity Studies (2000), concluding that the incidence of ADHD has remained static but was becoming better recognised.

UK studies estimate that ADHD occurs in approximately 5-10% of school age children (Ford et al. 2003; Taylor 2007; NICE 2008) and the UK prevalence rate of ADHD in adults is estimated as 8 % (McManus et al. 2007). It is considered that at least 15- 20% of young children and adolescents with ADHD will have full symptoms as adults and as many as 65% will continue to have symptoms severe enough to interfere with their academic, social and employment functioning (Biederman et al. 2006; Mytass 2009; Wehmeier et al. 2010).

2.3 Gender distribution

ADHD in the male population is significantly higher than in females. In a study carried out in the UK of 10,348 children aged 5 to 15 years old, 3.62% (n=375)

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of boys and 0.85% (n= 88) of girls met the criteria for ADHD (Ford et al. 2003) which was consistent with the findings from several other studies (Lahey et al. 1994; Quinn and Wigal 2004; Visser and Lesesne 2005; Ramtekkar et al. 2010)

The reasons for this variation were not clear and further research into this area is indicated (Schachar and Tannock 2002). There are several possible explanations:

Firstly, the observable symptoms of ADHD present differently in boys and girls, with boys exhibiting higher levels of observable hyperactivity and conduct disorder (Brown 2005c) leading to referral to specialist clinics.

Secondly, difficulties experienced by girls such as disorganisation and poor concentration tend to be hidden and are therefore often ignored and misdiagnosed (Waite 2010).

Finally, girls are more likely to display internalising behaviours which make recognition difficult (Young 2007).

By adulthood, the gender distribution is thought to equalise (Asherson and Kooij 2007). Drawing on my clinical experience, it is possible to postulate that this is a possible sequela of untreated ADHD in women, which over time has resulted in significant impairment that has become harder to ignore and thus has led to an increased rate of contact with health services.

2.4 History of ADHD

ADHD is often perceived as a 'new' phenomenon; however it is evident from the literature that descriptions of the condition now known as ADHD (Asherson 2005) were first described as early as 1845 (Hoffman 1995) in the poem 'Fidgety Philip':

'See the naughty, restless child, growing still more rude and wild'.

In the early twentieth century, Still (1902) and Tredgold (1908) identified a group of children who had 'an abnormal defect of moral control' which they considered to be biological and constitutional in origin, rather than a result of deficient parenting practices.

Following the worldwide encephalitis outbreak in the 1920's, many children were left with impaired attention, hyperactivity and poor impulse control which supported a biological causation and was described as 'post encephalitic behaviour disorder' (Wender 1987), Adler and Chua (2002) have suggested this would now be called ADHD.

By the 1930's the term 'minimal brain dysfunction' was used to describe features of hyperkinesis, impulsivity and short attention span. In 1941, Strauss and Werner suggested that hyperactivity and behavioural problems were linked to brain damage, which in the 1950's led to the phrase 'hyperactive child syndrome' being introduced. The term 'hyperkinetic reaction of childhood' was first included in the Diagnostic and Statistical Manual of Mental Disorders in 1968 (APA).

The phrase Attention Deficit Disorder (ADD) was first used by the APA in 1980 and by 1987 this was changed to ADHD (APA 1987). When the fourth edition of the DSM was published in 1997, three sub types of ADHD were included: Inattentive, Hyperactive /Impulsive and Combined. The DSM V (APA) was published in May 2013 and now includes diagnostic criteria for adults, with an acknowledgement that ADHD continues across the life span.

2.5 Aetiology of ADHD

The literature review illuminated the lack of clarity about the exact cause of ADHD; however, there was a consensus of opinion that the heterogeneity, high levels of co-morbidity and biological and family correlates of ADHD was suggestive of a multiple developmental pathway to the disorder (Sonuga-Barke 2004; Sonuga-Barke et al. 2010; Campbell et al. 2013). This view was supported by several other researchers (Sloman and Konstatareas 1990; Pellegrini and Horvat 1995; Schachar and Tannock 2002) who proposed that a range of biological, psychological and social constructs acting together or individually may increase the risk of ADHD.

The concept of ADHD continues to generate a debate amongst clinicians, researchers and society. Questions have been raised about the validity of the diagnosis, proposing that the concept of ADHD is a social construction rather

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than a biological one and should be seen as a variation of normal functioning. Several authors have argued (Baughman 2001; Timmi and Taylor 2004) that ADHD could be better explained by the cultural contexts in which people live and the way some behaviours are perceived as unacceptable, for example 'liveliness' as 'hyperactivity'. It has been suggested that the existence of ADHD was welcomed by drug companies and clinicians, who according to several professionals (Southall 2007; Timmi and Taylor 2004; Timmi 2005; Moncrieff and Timmi 2010), regarded it as a means of making financial profit given that medication is an accepted treatment approach. Yet several researchers have challenged these views; Mytass (2009, p3) stated that:

'No evidence exists to suggest that ADHD is caused by other than neurobiological malfunctioning. Although environmental factors may influence the course of the disorder over a lifetime, they do not bring the condition about'.

This statement was supported in a position paper written by experienced researchers and clinicians in the field (Barkley et al. 2002) and is consistent with current opinion regarding the causation and validity of the diagnosis of ADHD (Taylor et al. 2004; Mytass 2009; Asherson et al. 2010).

2.6 Biological Influences

2.6.1 Genetics

ADHD is a familial and highly heritable condition. Over the last few decades investigators have sought to determine the role that genetic factors play in the development of ADHD. Although it is thought that genetic factors contribute to ADHD (Faraone and Biederman 1994; Taylor 2007), to date there has been limited success in detecting a candidate gene (Campbell et al. 2013) and more research is required to establish the link between genetic and neural processes, and the behavioural manifestations of ADHD.

Studies carried out by Faraone et al. (2001; 2005) found a 3-5% risk of ADHD occurring in first degree relatives. When the results of 18 twin studies investigating the heritability of ADHD were collated (Faraone et al. 2005;

Spencer et al. 2007) it was estimated that there was a mean heritability of 77% which was consistent with evidence from other studies (Goodman and Stevenson 1989; Asherson et al. 2010).

The mode of inheritance is currently unclear; however, it is thought that there is no specific gene for ADHD (Neale et al. 2010; Thapar et al. 2012) and given the heterogeneity of ADHD, it is likely that several genetic markers may be implicated. Research to date has identified several genes that appear to be associated with ADHD due to their effect on dopamine pathways in the brain. It is suggested that further studies using larger sample groups is required in order to explore this area further (Campbell et al. 2013).

2.6.2 Neurobiology

The exact pathophysiology of ADHD remains unclear despite growing research into its causes and the neurobiological mechanisms that mediate them. Several studies suggested a biological basis to ADHD with evidence of disturbances to the structure and function of the brain (Amen 2001; Castellanos et al. 2002; Salmon 2005; Kaplan 2008) and dysfunctional brain networks (Cortese et al. 2012). Other studies (Castellanos et al. 2002; Rubia 2005), suggested that some aspects of the development of the frontal cortex and temporal lobe regions of the brain may be delayed by up to three years and this is thought to have an impact on executive functioning controlling attention, concentration, organisation, hyperactivity and impulsiveness.

Available research was largely reliant on a bio-medical model which argued that ADHD arises from a fixed neural deficit. Sonuga-Barke and Fairchild (2012) challenged this assumption, as they did not feel it was an adequate explanation given the heterogeneity of the disorder, and advised that other factors should be taken into consideration.

2.6.3 Brain chemistry

Campbell et al. (2012) proposed that ADHD was a dopamine dysregulation disorder (partially supported by genetic, imaging and pharmacological studies) with involvement from several genes affecting the dopamine transmitter system (Kidd 2000). Neurotransmitters are associated with the ability to

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organize and prioritise, focus and sustain attention and regulate alertness; all of which are known to be significantly impaired in people with ADHD (Brown 2005b).

2.6.4 Environmental influences

The association between ADHD and behavioural disturbance has led to speculation that poor parenting is its root cause; however recent studies have given support to the theory that ADHD is a neuro-developmental condition with genetic and organic changes (Goodman and Stevenson 1989; Kidd 2000; Amen 2001; Castellanos et al. 2002).

Uncertainty still exists about the extent to which environmental factors may influence the trajectory of ADHD. It is important to bear in mind that if 50% of adults with ADHD have a child with ADHD, this will inevitably have an impact on their parenting style (Faraone et al. 2000) and consequently their potential outcomes.

There was some evidence that maternal smoking (Mick et al. 2002) and substance abuse (Chasnoff et al. 1985; Bingol et al. 1987) during pregnancy may increase the risk of ADHD. Birth weights of less than 1.5kg, obstetric complications and other pregnancy and delivery problems were associated with hyperactivity, a low IQ and higher rates of behavioural problems (Millberger et al. 1996; Mick et al. 2002). Other potential risk factors associated with ADHD type patterns of behaviour included acquired head injury, growing up in a deprived environment and taking benzodiazepines and anti-convulsants in pregnancy (Steinhausen et al. 1994).

The emerging field of epigenetics is concerned with how 'alterations in gene expression may be caused by factors other than changes in the DNA sequence'. This may eventually reveal why interacting genetic and environmental risk factors affect individuals differently and what characteristics may be influenced by the contexts in which people live (Elia et al. 2012; Campbell et al. 2013).

2.7 Diagnosis of ADHD

It is recommended that the diagnosis of ADHD should be made by an experienced clinician (NICE 2008). This should follow an assessment process which includes taking a detailed history of the presenting difficulties and gathering qualitative information from the child's parents, carers and school teachers about the child's behaviour. The Strengths and Difficulties Questionnaire (Goodman 1997) and short Conners (Conners et al. 1997) are standardised questionnaires that are completed by a young person, their parents or carers and school teacher. These are not diagnostic tools but rather provide further information about the existence of ADHD symptoms which may assist in reaching a diagnosis.

In the UK, the ICD-10 (WHO 2000) is used to make a diagnosis of ADHD. The ICD-10 is a multi-axial classification framework which is used to diagnose a variety of mental health disorders. For a diagnosis of ADHD to be made, there needs to be clear evidence of clinically significant impairment of social, academic and / or occupational functioning plus a considerable degree of inattentiveness, distractibility, impulsivity and hyperactivity (appendix 1) that is inappropriate for the developmental stage of the child. All of these symptoms must have been present for at least six months and the impairment must be pervasive, occurring across multiple settings such as school and home and be either moderate or severe (Hill and Taylor 2001; Taylor et al. 2004, NICE 2008). In addition, the symptoms should not be attributable to any other cause or explanation, such as a learning disability or anxiety disorder (Campbell et al. 2013).

2.8 Long term impact of ADHD

Until recently, it was thought most children would outgrow ADHD by mid to late adolescence. This view may have been linked to the premise that if children with mental health problems were treated early on, there would be a discontinuation of symptoms by the time they reached adulthood (Berney 2009).

Background

According to Doyle (2006), the term 'hyperkinetic disorder of childhood' may have reinforced the idea of ADHD being a childhood condition and because symptoms of hyperactivity and impulsivity appear less problematic as young people approach adulthood, this may have maintained a theory that ADHD was limited to childhood and adolescence.

The idea that ADHD could carry on into adulthood was initially proposed by Woods (1986), who described 'Attention Deficit Disorder: residual type' which correlates with the more contemporary knowledge that core symptoms of ADHD persist into late adolescence and adulthood (Bellack and Black 1992; Harpin 2005; Asherson et al. 2007; Spencer et al. 2007; Mick et al. 2011 and Buitelaar 2012).

It was reported that the symptoms of hyperactivity and impulsivity may decline at a higher rate than inattention symptoms as children grew up (Taylor 2007; Barkley 2008; Steinhoff 2008). However, there was agreement that ADHD would continue to impact on an individual's executive functioning, organisation and social and emotional functioning across the lifespan (Young and Toone 2000; Adler and Chua 2002; Barkley 2008; Young and Gudjonsson 2008).

According to Asherson (2005), in comparison with their non ADHD peers, young people with ADHD had worse long term outcomes leading to an increased risk of developing mental health problems, difficulty maintaining relationships plus educational and employment challenges. This view was consistent with the findings of several other studies (Weiss and Hechtman 1993; Hechtman 1996; Currie and Stabile 2004; Taylor et al. 2004; Lee and Hinshaw 2006; Steinhoff 2008; Lahey and Willcut 2010) which reported that young people and adults with ADHD experienced lower self-esteem, worse educational outcomes, more difficulties in the workplace and a lower socio-economic status than their non ADHD siblings. In addition, adults with ADHD often reported problems with anger management, involvement in anti-social behaviour, dissatisfaction with their relationships in general and often felt unfulfilled (Manuzza et al. 1991; Orr and Miller 1995; Rabiner 2004; Harpin 2005; Young and Gudjonsson 2008).

These findings resonated with my clinical practice, working with young people who often struggled to regulate their emotions and experienced significant difficulty in carrying out daily living activities.

2.9 Treatment approaches

The provision of treatment for children, young people and their families with ADHD was varied (NICE 2008). Treatment strategies for adults with ADHD were broadly similar to those used with children and adolescents; however there was a dearth of services nationally for adults, therefore making access to treatment difficult (NICE 2008). Current treatment approaches for ADHD could be classified as pharmacological and non-pharmacological interventions.

Psychological approaches include cognitive behavioural therapy, social skills training, family therapy and parent training such as the Webster -Stratton programme (1981). Social skills training aims to teach social interaction skills, whilst the aim of family therapy is to support families in working together to promote positive relationships in their family relationships.

In the UK, several medications are licensed for the treatment of ADHD in childhood including Methylphenidate, Atomoxetine and Dexamphetamine. Methylphenidate is a stimulant medication and was first used in children in 1957 (Conners and Eisenberg 1963) and is the preferred choice of medication for treatment of ADHD.

Currently, in the UK, Atomoxetine is licensed for the treatment of ADHD in adults if treatment was initiated in childhood and although Methylphenidate is recommended for use in adults with ADHD, it is not currently licensed (Parker 2013).

Medication for ADHD aims to reduce the core symptoms of ADHD and it is believed to act by stimulating and increasing the release of dopamine and noradrenaline within the brain and blocking or reducing their re-absorption; it is postulated that this process allows 'messages' within the brain to be more effectively transmitted and received.

2.10 Services for adults with ADHD

Over the last 20 years, across the UK services for the assessment and treatment of ADHD in children and adolescents have increased dramatically (NICE 2008; Appleton and Pugh 2011). However, this is not generally reflected in service provision for adults with ADHD and nationally there is a lack of clear referral pathways or designated services for young adults with ADHD (DH 2005a; Social Exclusion Unit 2005; Berney 2009; Royal College of Psychiatrists 2011).

Given the apparent lack of service provision for adults with ADHD, it follows that there may be a dearth of transition services for young adults leaving CAMHS. Currently, there is a considerable variation across the UK regarding the age at which transition occurs; although the NSF for children (DH 2004a; 2004b) recommends age 18, this is not consistent and may occur at any time between 16 and 19 years (Appleton and Pugh 2011).

Young et al. (2011) posited there was a need for seamless services to be developed for people with ADHD which encompassed transition from CAMHS and onwards into adult services. According to Xenitidis et al. (2007), there was an absence of commissioned specialist services for adults with ADHD despite the recommendations of the National Service Framework for long term conditions (DH 2005a). In some areas there were no pathways into further services once young adults were discharged from CAMHS (Tantum 2005). These views suggest that consideration be given to ensuring that services for people with ADHD are provided across the life span.

Three discrete groups of young adults who require access to adult services have been identified. Firstly, those who have been diagnosed with ADHD and treated in childhood who require continuing care. Secondly, people who were diagnosed in childhood but were untreated and thirdly, adults presenting to services for the first time (Asherson and Kooij 2007; NICE 2008; Young et al. 2011).

Reder et al. (2000) believed that the different eligibility criteria for accessing CAMHS and AMHS has had a negative influence on the development of adult

ADHD services, citing the need for people to have a severe and enduring mental health illness to gain access to AMHS. Asherson and Kooij (2007) suggested that despite the current knowledge that exists regarding the continuation of ADHD symptoms into adulthood, it appeared that within adult services there was a lack of knowledge and experience of working with adults who have ADHD (Lamb et al. 2008; Bolea et al. 2012; Merriman 2013).

It is hard to be precise about the prevalence of ADHD in adults in the UK, as many young people disengage from services in the transition from CAMHS to adult services (Edwin and McDonald 2007) and because it is thought that ADHD in some adults is unrecognised and untreated (Asherson 2005). However a survey of adult psychiatrists (n=197) concluded that there was a need to develop services for adults with ADHD as there was a growing demand for services (Edwin and McDonald 2007).

Feifel (2008) discussed the importance of recognising ADHD in adults, given the associated negative outcomes and argued that effective treatment of ADHD could reduce the incidence of driving accidents and substance misuse (Mason and Rahman (2011). Recent evidence suggested that with effective intervention, the negative impact of ADHD symptoms would diminish, resulting in increased self-esteem, better mental health and improved social functioning (Greener 2012).

Several studies (Young and Toone 2000; Asherson 2007 and Kooij; Ford et al. 2008) highlighted a need to develop adult ADHD services and noted that the current situation is an example of national guidance (NICE 2008) not being put into practice (Adamou 2009; Drugs and Therapeutics Bulletin 2011; Bolea et al. 2012). Several authors (Keen et al. 2000; Reder et al. 2000; Asherson 2005; Singh et al. 2010; Robb and Findley 2013) suggested that further thought was needed in order to develop services to meet the needs of this group.

2.11 Economic considerations

Given the well documented potential negative sequela for people with ADHD, it could be argued that it is a financial priority to ensure there is equity of access to healthcare services for this group (Adamou 2010).

Background

Several studies highlighted the economic burden on health and social care services made by this group (Hakkart-van Roijen et al. 2007; Barkley 2008). Evidence from a longitudinal study highlighted the increased use of health care services by people with ADHD as compared to their non-ADHD peers (Feifel 2008). Therefore, the provision of transitional and adult ADHD services might serve to ameliorate some of the impacts of ADHD on the individual and the context in which they live.

2.12 Transition

The Compact Oxford Dictionary (Soanes 2013, p1101) defines the word transition as:

‘The process or a period of changing from one state or condition to another’,

this study will use the following definition (Blum et al.1993, p570) which contextualises the above definition within the context of healthcare:

‘The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems’

Beresford (2004, p584) proposes that the aim of a transition process is:

‘a way to enable and support a young person to move towards and onto a new life stage’.

McDonagh (2006) suggested that transition be viewed as a process that takes into consideration the developmental needs of the individual which was consistent with the opinion of Munoz-Solomando et al. (2010), who argued that the individual’s personal circumstances and experiences were paramount. According to Chick and Meleis (2010) transitions were ‘invariably related to change and development’ and occurred when individuals were moving from one stable state to another.

2.13 Adolescence

Adolescence spans the ages between 13 and 19 when young people move from childhood into adulthood. Several studies have shown that adolescents are particularly vulnerable to developing an emotional or mental health disorder (Lamb et al. 2008; Buitelaar 2012; Children's Commissioner for England 2013) and it was estimated that 20% of young people aged between 16 and 24 had a mental health problem (Singh et al. 2010).

Adolescents with chronic health conditions have an increased vulnerability to experiencing stress and psychosocial problems (Shaw et al. 2004, While et al. 2004; Sawyer et al. 2007; Lamont et al. 2009) which may be exacerbated as they approach transition (While et al. 2004; DH 2008a). Additionally, they were more likely to be involved in risk taking behaviour which may impact on their motivation to access health services (Health and Social Care Advisory Service [HASCAS] and DH 2006; Sawyer et al. 2007).

2.14 Transition Theory

The transition from adolescence to adulthood is an important phase which demands that young people manage a number of simultaneous changes from psycho-social, emotional and biological perspectives. The concept of transition is embedded within developmental theory (Erikson 1963; Marcia 1967; Chick and Meleis 2010) and describes the process whereby people move from one stage to another across the lifespan. This process is often associated with a period of uncertainty as people assume new roles and status.

Meleis et al. (2000) proposed that people experiencing a transition were more vulnerable than others who were in a more stable phase, as they had to cope with several competing issues simultaneously. According to Forbes et al. (2001), for young people who had a chronic disease or disability the process was even more challenging as they also had to negotiate a healthcare transition as they moved from children's services to adult services.

Van Gennep (1960) argued that all cultures have their own particular rituals which mark the transition of an individual in their journey between leaving

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childhood and entering adulthood. This view was supported by McDonagh (2006) who suggested that transition started at puberty and ended when an individual was considered within their own culture to be an adult. Although transition was perceived as a positive stage of development (Chick and Meleis 2010), it will inevitably be experienced as a challenging time for some young adults, especially when they are negotiating other changes in their lives. Van Gennep (1960) identified three stages in the transition process:

The 'separation' phase; when young adults begin to withdraw from the familiar and prepare to move from one place to another.

The 'transition' phase; which occurs between leaving one context, experience or identity and joining the next, which may be experienced as a phase of instability and not belonging.

The 'reincorporation' phase; whereby an individual has taken on their new identity and becomes part of a new group which is associated with a change in status.

During this time, young adults will experience simultaneous parallel processes where they face significant emotional, biological and psychosocial changes; requiring them to adjust and negotiate internal and external transitions.

To some extent Van Gennep's (1960) theory described transition as a linear process, several authors (While et al 2001; Forbes et al. 2002; RCPCH 2003; Beresford 2004; Royal College of Nursing [RCN] 2004; Chick and Meleis 2010; Singh et al. 2010) argued that for some, it may be more complicated because of other factors such as chronic health conditions.

Singh et al. (2010) developed Van Gennep's (1960) definition and explained how they considered that the concept of transition incorporated two parallel processes:

The 'developmental perspective', encompasses the 'emotional, psychosocial, personal and physiological' adjustments that young people make as they become adults. This includes developmental tasks such as leaving home and school, entering the workplace and re-negotiating their relationship with their family and peers. This view was supported by Kirk (2008) who wrote that

another crucial task facing young people was the need to individuate from their parents and become autonomous, taking responsibility for their own decisions. This phase can be a challenge for many young people as they navigate their way through a number of critical events, which may result in uncertainty about their role, status and self identity.

The 'health care perspective' concerns the transition some young adults encounter as they move between healthcare services usually between the ages of 16-18 years old. This may be a particularly complex process for some young people as they may be expected to function as fully matured adults who are experienced and adept at making their own decisions about their health (Kirk 2008).

For some young people the timing of this event may not feel appropriate, because as several authors (Reiss et al. 2005; Singh et al. 2010) have commented, transition often occurs at a time that is convenient for the service rather than the individual. It has been suggested (Kirk 2008; Mills and Francis 2010) that young disabled people and those with some chronic health conditions such as ADHD and Autism Spectrum Disorder were particularly disadvantaged as often there were limited or no adult services available to transition to.

Chick and Meleis (2010, p26) proposed that there were several distinctive features associated with healthcare transition: 'process, disconnectedness, perception awareness and patterns of response' and argued that each of these areas would have a variable impact on individuals, recommending that clinicians attended to each of these domains to ensure a smooth transition between services.

The concept of 'process' described the importance of individuals being aware that that they were in transition and being informed about the impending changes they would experience. This phase in a healthcare transition was characterised by moving between services, which in combination with other transitions resulted in a disruption to familiar ways of engaging in life.

Being informed and accepting the transition was likely to influence the extent to which an individual engaged in the process and consequently led to positive

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outcomes. However this may be influenced by whether the decision to transition was the individual's choice or one that was imposed by external factors.

A necessary component of the transition process inevitably involves leaving behind 'familiar reference points' (Chick and Meleis 2010) and embracing new environments and relationships. In addition it may also mean that services previously relied on by an individual no longer exist within adult healthcare settings. This experience may leave individuals with a sense of 'disconnectedness' and may prove challenging if they are unable to access appropriate support at this time.

The word 'perception' was used to describe the individual meanings that people held about their transition experiences. Chick and Meleis (2010) considered that individuals would inevitably respond differently and argued for an individualised approach to transition planning in order to ensure the best possible outcomes.

Chick and Meleis (2010) believe that transition is a 'personal phenomenon and not a structured one'. They considered it important that individuals had an 'awareness' that they were in transition in order to successfully negotiate this important phase and thus be able to adjust to their new roles and responsibilities. They (Chick and Meleis 2010) described how the 'patterns of response' such as 'disorientation and distress' to the transition process and the subsequent 'change in self concept and role performance', would vary between individuals depending on external influences such as timing of transition, environmental, psychological and biological factors.

Within the context of healthcare and this study, transition occurs at the point when young adults are in the process of leaving a familiar CAMHS service and moving to AMHS.

2.15 Transfer and transition

Paul et al. (2013) proposed that transfer and transition were different entities and involved different processes. Their view was that 'transfer' described the

conclusion of care in a child and adolescent context and the commencement of care in adult services, whereas 'transition' was a process which 'requires therapeutic intent' and included preparation for transition and handover of care necessitating effective communication between all parties.

This view was supported by McDonagh and Kelly (2003) who proposed that the transfer of care was 'only one event' within the transition process. Viner (1999) and Vostanis (2005) agreed with this statement as they believed that in some cases the word transition simply referred to the transfer of care as a one off, administrative event between health services. Likewise, Kirk (2008) cautioned that the term transition was often used erroneously. She felt that the importance of transition as a process, which acknowledged the complex journey undertaken by adolescents as they moved into adulthood was not embedded within the way the word transition was used.

In summary transition is a 'dynamic process' (McDonagh 2006) which supports young people's move from adolescence to adulthood in a positive and empowering way. From a service perspective, the process of transition should be co-ordinated with clear aims, objectives and outcomes to ensure young people are able to achieve their full potential and needs to be mindful of other simultaneous transitions they are experiencing.

2.16 Factors supporting positive transitions

In recent years there has been an increasing amount of literature on healthcare transition generally and specific characteristics which are thought to enhance the experience of young people have been identified.

A recent study by Singh et al. (2010) reported that although key principles for effective transition have been identified, the reality was that transition protocols were not consistently implemented at service level (Hall et al. 2013). In addition it was evident that some young people continued to have negative experiences of healthcare transition. In particular, young people who had complex healthcare needs (Kirk 2008) such as learning disabilities (Townley 2004), ADHD and Autism Spectrum Disorder (Birchwood and Singh 2013; Hall et al. 2013; Matheson et al. 2013) seemed particularly poorly served. It was

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unclear why their needs appeared to have been overlooked. It may be because some conditions are now recognised as continuing into adulthood (ADHD) or because some groups who were previously overlooked now have a voice and are expressing their dissatisfaction with available service provision (Royal College of General Practitioners [RCGP] 2012).

Factors that were considered to facilitate effective transitions between healthcare services were as follows: preparation for transition (Meleis et al. 2000; Shaw et al. 2004), involvement in the transition process (Meleis et al. 2000; Singh et al. 2010) and the timing of transition (Meleis et al. 2000; Reiss et al. 2005).

Having a formal protocol, providing information, joint working between services and handing over care were all considered to be important factors (While et al. 2004; Singh et al. 2005; Meaux et al. 2009). In addition it was considered important that adult healthcare providers had sufficient training (Singh et al. 2005; Day et al. 2007) in providing continuing care to young adults. Likewise, understanding and acknowledging how young people might experience the differing environments and philosophical basis between child and adult services was seen as significant (Por et al. 2004; Townley 2006; Day et al. 2007). Finally, a phased process of involving young people in making decisions about their healthcare and consideration of to what extent families should be involved in care was recommended (Tantum 2005; Hovish and Weaver 2012).

It was beyond the scope of this study to provide a comprehensive review of transition theory or to undertake an exploration of the broader experiences of young adults transitioning from adolescence into emerging adulthood. However drawing on the above, for the purpose of this study the term transition refers to a healthcare transition involving the transfer of care between CAMHS and AMHS.

2.17 Adolescents and disengagement from services

A number of authors have raised concern about the increased likelihood of young people aged between 13 and 19 years disengaging from services in comparison to other recipients of health services (Munoz-Solomando et al. 2010).

Young adults with chronic health conditions were even more likely to drop out of services as they approached a health care transition with potentially damaging consequences to their health (DH 2001; While et al. 2004; Edwin and McDonald 2007), especially if the transition process was not well managed (Taylor et al. 2010). Buitelaar (2012) considered the period spanning adolescence and young adulthood as a crucial time in the management of ADHD and suggested that supporting this cohort to continue to access services was important, to ensure best possible outcomes for individuals.

Ferrin and Taylor (2011) suggested possible explanations for adolescents withdrawing from services. Firstly, a concern about possible medication side effects and secondly a growing need for independence. Recent evidence (McCarthy et al. 2009) showed that 95% of males aged between 15-21 have stopped medication.

Recent studies (McCarthy et al. 2009) have reported that by the age of 21 the majority of young people would no longer be accessing services; possible explanations for this were there were no clear transition pathways and a lack of service provision (Young et al. 2011). Given the existing research (Asherson 2005; Young and Gudjonsson 2008) regarding the impact of untreated ADHD on the individual and society, this situation will inevitably have an impact on an individual's health and wellbeing.

In my clinical practice, a frequent issue facing young people is the stigma associated with taking medication and attending mental health services; they report being different from their peer group, they feel they don't need medication and don't like how it 'makes them feel'. In addition, as they strive

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for independence and separation from their parents, they may decide they want to manage on their own and do not need to access services.

There is therefore a consensus of opinion that ADHD continues into adulthood and there appears to be an evident lack of available services.

3. Critical review of the literature

A review of the literature was undertaken to establish what knowledge was currently available about the topic area and to examine whether there were any particular areas that would be worthy of further exploration.

The search for and analysis of existing literature was the first stage of the research process, the South Central Literature search protocol (2007) was used to structure the search process.

3.1 Literature search area

Firstly the broad search area was identified: Attention Deficit Hyperactivity Disorder. Secondly the specific, but still preliminary research area was honed down and a question devised: What are the transition experiences of young adults with ADHD?

A SPICE (Setting, Perspective, Intervention, Comparison, Outcomes) question was formulated to focus the literature search process (table 1). This method was devised by Booth (2004) and was cited by Glasper and Rees (2013a) who described its application. They detailed how the SPICE model framework divided the broad topic into five key areas and reported that it was suitable for identifying research studies that used qualitative methodologies. Gerrish and Lacey (2006a, p96) stated that:

‘It is not necessary to identify terms for all aspects of the SPICE model to produce a list of search terms a strategy for searching’.

Therefore for the purpose of this research, a decision was made to omit the categories of comparison and evaluation as the primary interest was to identify literature that would contribute to knowledge about the transition experiences of adolescents with ADHD once they have left CAMHS rather than making comparisons, or evaluating their experiences.

Table 1 SPICE model: Key areas

Key areas	
Setting	Definition of the context which is being researched.
Perspective	What population is being studied?
Intervention	What treatment or test is being explored? What is the main intervention?
Comparison	What are you comparing with what? Variation from patient to patient.
Evaluation	What are the reasons for doing or not doing something? What are the outcomes?

3.2 Literature search key terms

Relevant words and phrases for each key area were identified: This included the use of synonyms (e.g. adolescent or teenage) and acronyms (e.g. ADHD or HKD). Possible discrepancies in terminology used across different health contexts were considered (for example CAMHS, paediatrics and AMHS). Any alternative spellings and plurals were included as were old and new terminologies (e.g. minimal brain dysfunction and HKD).

Boolean logic was used to combine different concepts using the words ‘AND’, ‘OR’ or ‘NOT’. The use of ‘AND’ meant that both terms should appear in each match that was retrieved e.g. ADHD and adolescents. Terms in the same concept group can be combined with the word ‘OR’ meaning that one of the terms must appear in each match that was retrieved, for example ‘Attention Deficit Hyperactivity Disorder’ or HKD.

Finally truncation and wildcarding techniques were used to ensure that all relevant permutations of a word were picked up. Table 2 outlines the literature search process.

Table 2 Search process using key words

Step	Search term
1	'Attention Deficit Hyperactivity Disorder'
2	ADHD
3	HKD
4	Hyperkinetic Disorder
5	'Attention Deficit Hyperactivity Disorder' or ADHD or HKD or Hyperkinetic Disorder
6	Adolescenc*
7	Teen*
8	'young people'
9	Adolescenc* or Teen* or 'young people'
10	Transition*
11	'continuity of patient care'
12	Transition* or 'continuity of patient care'
13	'Attention Deficit Hyperactivity Disorder' or ADHD or HKD or Hyperkinetic Disorder and Adolescenc* or Teen* or 'young people' and Transition* or 'continuity of patient care'

3.3 Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed (table 3) and applied to the literature search.

Table 3 Inclusion and exclusion criteria

Inclusion criteria	Exclusion Criteria	Rationale
Articles relating to adolescents, teenagers or young people.	Articles relating to children.	Research focus is on adolescents.
Transition of adolescents.	Remove anything not related to transition of adolescents.	Research about transition.
Attention Deficit Hyperactivity Disorder.	Articles not related to Attention Deficit Hyperactivity Disorder.	
Attention Deficit Hyperactivity Disorder as a chronic condition.		May provide information about service needs for this client group.
English language.	Discard any non-English language articles.	
Articles must include data.	Discard any articles which do not include data.	
	Discard any editorials or correspondence.	

3.4 Search methods used

A variety of search methods were used and included:

3.4.1 Core resources

Electronic databases comprise a collection of references which have been collated in a consistent manner. Appendix 2 details the databases scrutinised and includes information about the number of papers identified in this search process. An email alert system was set up to flag up new papers as they were published.

3.4.2 Recommended resources

A search for 'grey' literature was conducted; this includes other literature such as unpublished conference proceedings, dissertation abstracts, and published theses. Additional information was gathered by contacting relevant organisations and experts in the field by email, telephone and at conferences which provided signposting to articles not found in the literature search.

3.5 Critical appraisal

Critical appraisal was described by Burls (2009) as a process of carefully and systematically examining research to filter out unreliable, poorly formed or misleading information and to assess the validity, reliability and applicability of a study (Booth 2006, p109). There are a number of available models such as the Critical Appraisal Skills Programme (1993), Rees (2011) and Parahoo and Heuter (2013) that provide a structure to guide the process of critical appraisal. Parahoo and Heuter's model (2013) (appendix 3) was reported as being an effective and flexible framework for conducting critical reviews of qualitative and quantitative research (Glasper and Rees 2013b) and was selected to guide the review of the literature.

Available literature fell into the following categories, policy documents, descriptions of service models, clinical guidelines and transition experiences. Papers relating to the healthcare transition experiences of young people can be found in appendix 4.

3.6 Critical analysis of qualitative studies exploring the transition experiences of young people with ADHD

All the studies (appendix 5), except one, used qualitative methodologies and involved young adults. Focus groups and interviews were the most commonly used methods of data collection. The researchers argued that their rationale for using qualitative methodologies was a curiosity to develop a better understanding of the views held by young people, rather than their inferred views

Although all the studies aimed to further understand the views and opinions held by young people about transition, the specific aims of the studies were diverse. Several researchers (Patterson and Lanier 1999; Soanes and Timmons 2004; Townley 2006; Day et al. 2007; Singh et al. 2010; Hovish and Weaver 2012) were interested in understanding the transition experiences of young people moving between CAMHS and AMHS and one study (Swift et al. 2013) specifically examined the transition experiences of young people with ADHD.

Shaw et al. (2004) examined the transitional needs of adolescents with Juvenile Idiopathic Arthritis and how they might be addressed within a structured programme of care, whilst Shaw et al. (2006) focused on the quality of transitional health care by eliciting the views of young people and their parents. In the study carried out by Soanes and Timmons (2004) the views of professionals were also sought. Reiss et al. (2005) and Singh et al. (2010) hoped to identify factors that helped or hindered young people through the process of transition whilst Soanes and Timmons (2004) were keen to understand what people wanted from services and how services could be improved.

A synthesis of current transition literature from physical and mental health care contexts and the findings from qualitative studies examining transition will be presented (appendix 5). Several consistent themes emerged from the literature which will be discussed further; of particular interest is that they

were consistent with factors highlighted in published policy and practice guidelines.

3.7 Policies relating to transition

The issue of transition is very topical and important with numerous policy papers published by the Department of Health [DH] and other national agencies, highlighting the need for transition services to be developed for young people with continuing health needs (DfES 2004; DH 2004a; 2004b). The National Service Framework (NSF) for children (DH 2003) stated that transition should be guided by the young person's needs and take into account any other changes they may be experiencing. This concurred with the NSF (DH 2005a) for long term conditions that confirmed it was essential for appropriate services to be developed to meet the continuing needs of people with childhood onset disorders, in order to facilitate them achieving the best long term outcomes possible (DH 2006). These proposals were supported by the Royal College of Nursing (RCN 2004; RCN 2008) and the Royal College of Paediatrics and Child Health (RCPH 2003), who have issued position statements highlighting the importance of developing transition services and made suggestions about service configuration. In addition, the National Institute for Health and Clinical Excellence (NICE 2008) have recently published comprehensive guidelines for clinical practice which reinforce the need for appropriate transition services to be developed.

A report published by the National Coordinating Centre for the Service Delivery Organisation Research Programme (NCCSDORP 2002) suggested that many young people and their families experienced difficulties in accessing the support they needed in the transition period. This situation appears unchanged, evidence from recent government reports and guidelines (DH 2004a; DH 2008a; DH 2010a) demonstrate the continuing difficulties facing adolescents as they approach transition.

In the report 'Two Steps Forward, One Step back' (Pugh et al. 2006), attention was drawn to the fact that transition services were not universally available, with the only statutory mental health service for this age group being for

Critical review of the literature

young adults who required early intervention in psychosis [EIP]. Vostanis (2005) stated that the introduction of EIP services had led to improved standards of care and better engagement with service users and proposed that similar services should be developed for other conditions. In 2007 the Department of Health launched the 'You're Welcome' policy which identified key criteria for improving health care services for young people, including the transition of young people with continuing health needs. The policy was re-released in 2011 (DH 2011a) and reinforced the importance of involving young people in service improvement.

3.8 Description of service models

Detailed recommendations about configuring service delivery models to meet the needs of young people approaching and moving through transition were elicited from the review (Forbes et al. 2001; McDonagh 2005; Reiss et al. 2005).

Services should be age appropriate and flexible according to the needs of young people, preparation for transition should begin early to help young people develop skills in self-advocacy and increase their confidence in managing their health.

Shaw et al. (2004) recommended that individualised programmes of care should be implemented for young people, which took into account their developmental stage and suggested that professionals from children's services should be active in the transition process to ensure a smooth pathway for the young person (Shaw et al. 2004; Shaw et al. 2006; Patterson and Lanier 2009).

In addition, it was proposed that transition services should be developed with a shared responsibility between children and adult health services and clear guidelines established (Blum et al. 1993; Keen et al. 2000 DH 2004a; 2004b; RCN 2004; Singh et al. 2005; DH 2006).

'Valuing people' (DH 2001) proposed that the benefits of a well-planned transition could improve the long term outcomes and reduce the risks of non-adherence to treatment and subsequent disengagement with services. This

view was supported by Singh et al. (2005) who found that children with ADHD were at an increased risk of dropping out of services at transition. Given the knowledge that exists about the negative impact of untreated or inappropriately managed ADHD, it could be hypothesised that a significant benefit might be that by offering appropriate continuing care to this group, there will be positive outcomes in relation to their functioning. Singh et al. (2005) suggested that if such services were developed it might mean that those young people most in need, may remain engaged in services (Millard 2009).

3.9 Ideological differences between adult mental health services and Child and Adolescent Mental Health Services

A recurrent theme found in the literature was the description of the different theoretical ideas and the structure of service delivery that underpin AMH services and CAMH services which young people approaching transition found hard to understand and negotiate.

While et al. (2004) and Singh et al. (2005) discussed the differences in the way mental health problems were conceptualised, the impact of mental health difficulties and the range of interventions on offer. Historically, AMHS have provided services to people with severe and enduring mental health difficulties with a focus on diagnosis-led treatment. Whereas CAMHS have adopted a developmental approach, offering services to young people presenting with a range of difficulties without necessarily having a diagnosis (Reder et al. 2000; Singh et al. 2005; Tantum 2005; Singh et al. 2010).

In CAMHS, a systems focused approach is central, where young people are seen as part of a wider support system whose involvement is helpful, if not essential (Tantum 2005; Hovish and Weaver 2012). Ordinarily, interventions offered in CAMHS involve parents, carers and professionals from education and social care. Whereas in AMHS, treatment tends not to be offered without a diagnosis, is individually orientated and would be unlikely to include the wider network (Hovish and Weaver 2012).

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Another consistent finding was that it was often difficult to find adult services where the level of skill, expertise, resource and empathy matched those found in paediatric services (Shaw et al. 2004; Reiss et al; 2005). Paediatric services are reported by young people as being better organised and paying more attention to continuity of care (Reiss et al. 2005). Of interest, was the view held by some professionals working within AMHS that they lacked experience in managing young people and did not have sufficient knowledge about ADHD (Singh et al. 2005; Day et al. 2007).

Several authors discussed how the differing referral criteria operated by CAMHS and AMHS could leave some young people finding it hard to access services. CAMHS offer services to young people with emotional, behavioural and emerging mental health problems as well as those with more complex mental health difficulties, whereas AMHS tend to be involved with people who have a severe and enduring mental illness (Young Minds 2006; Singh et al. 2010; Brodie et al. 2011; Young et al. 2011; Hall et al. 2013). According to Singh et al. (2010) there was a lack of guidance about how to meet the needs of young adults who did not meet the criteria for accessing AMHS. Landau (1995) suggested these differences may in part, be resolved by improving communication between services; although this might prove helpful at a local level, it is likely to require further support from commissioners and service providers.

3.10 Young people's experience of Adult Mental Health and Child and Adolescent Mental Health Services

The reviewed studies highlighted the differences in the opinions held by participants about their experiences of services. Day et al. (2007) described how some young people felt paediatric staff were too child focused and some of the interventions 'childlike', whilst others felt more comfortable in an adult context and found that adult services were more flexible and able to meet their growing need for autonomy (Townley 2006). Words like 'scary' (Townley 2006)

and 'intimidated' (Day et al. 2007) were used by participants to describe adult services.

Differences in the way that staff from adult services engaged with young people were described; it was felt that they were less empathic (Shaw et al. 2004; Reiss et al. 2005) and less caring (Patterson and Lanier 1999). One participant described her experiences as:

'They should realise that someone, it's a big step, whether you are 16 or you are 18, it's still a big step, you know it's something different and if you have got depression you can't face the change' (Townley 2006, p23).

Townley (2006) suggested that staff within AMH settings might be unaware of the differences between AMHS and CAMHS which may lead to them appearing unsympathetic to young people moving into adult services. Soanes and Timmons (2004) described the impressions held by young people that adult healthcare environments appeared to be less appealing and had less to offer than child and adolescent services. In addition, the surroundings and milieu may be very different, as some adult services continue to operate from Victorian institutions, and it may be the first time that young people have come into contact with adults with severe and enduring mental illness (Townley 2006).

3.11 Views of transition held by young people with long term health conditions.

According to Kazdin (1993) and Buston (2002), research about adolescent mental health is generally a neglected area. The literature process yielded little information about the views of transition held by young people diagnosed with ADHD. Therefore the search was broadened to include related studies which described the transition experiences of young people with physical health needs or generic mental health needs. Several studies were identified: Shaw et al. (2006) (Juvenile Idiopathic Arthritis) Townley (2006) (adolescent mental health) and the Children's Commissioner for England (2007) (paediatrics) which despite being conducted in different health contexts, shared several

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common themes and suggested that healthcare transition is generally not a positive experience (Morris 1999; Shaw et al. 2004; Scott et al. 2005).

Young people described how they felt unprepared for transition, using words such as 'abandoned and dumped' to describe their feelings (Shaw et al. 2004). Although some young people commented that the knowledge and experience held by professionals in adult services was worse than in children's services; others reported positive experiences of transition (Zack et al. 2003; Soanes and Timmons 2004) and welcomed the move to adult services as they liked being treated as autonomous individuals.

A number of studies (Soanes and Timmons 2004; Reiss et al. 2005; Townley 2006) have highlighted how participants had experienced 'an abrupt ending of care' and they felt they were given inadequate information about their move to adult services and had very little choice in the process. Singh et al. (2010) described how participants viewed the process as 'complex and disturbing' and occurred at a time when they were facing several other major changes.

Evidence from Singh et al. (2010) further highlighted how there had been little preparation for the move, whilst participants from another study (Day et al. 2007) said they would have liked support with the transfer process. On the other hand, some participants commented that their planning for transition had been good and they had found it helpful (Singh et al. 2010; Hovish and Weaver 2012).

Meaux et al. (2009) described how young people seemed to have very little knowledge about what services were available and how they felt there was an expectation that they shouldn't need help. It has been shown (Tuchman et al. 2008; Harden et al. 2012) that the implementation of structured transitional programmes resulted in positive accounts of transition and continuing engagement in services by young adults.

Overall, these findings suggested that although there is a greater emphasis on the importance of ensuring effective transition between services, there was a wide variation in the experiences of young people.

3.12 Communication between child and adult services

The importance of effective communication between healthcare providers and young people was highlighted as being extremely important. Day et al. (2007) described 'shocking' communication between services with underused protocols and poor handover of care.

Participants in two studies (Patterson and Lanier 1999; Townley 2006) believed it would be helpful for adult services to be aware of service users 'narratives' prior to handover. This could potentially address the frustration raised by participants in Day et al.'s (2007) study about the repeated retelling of history. However, there was a concern that this could lead to pre conceived ideas being formed about individuals which could be detrimental in the longer term.

Participants in Townley's (2006) study made suggestions about improving communication in the transition process; they felt that regular meetings and clear explanations about the differing approaches used by CAMHS and AMHS would be helpful. This was corroborated by data from further studies (Por et al. 2004; Tuchner et al. 2008; Singh et al. 2010) which highlighted how some young people found formal planning meetings between the two services helpful in the lead up to transition.

3.13 Timing of transition

The consensus of opinion suggested that transition processes should be gradual, happen over an extended period of time and that young people should be prepared (Reiss et al. 2005; Townley 2006; Day et al. 2007). This view was supported by Soanes and Timmons (2004) and Tuchman et al. (2008) who reported that young people would like adequate preparation for transition and would like the process to be at a measured pace.

Reiss et al. (2005) proposed that transition is a developmental process, comprising several stages with specific tasks which need mastering in order for young people to move from dependence to independence and autonomy. Garcia Preto (1988) reminded us that at this point of a young person's life

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cycle there will be other important simultaneous changes they may be negotiating.

There appeared to be little consensus about the optimum age for transition (Shaw et al. 2006; Patterson and Lanier 2007). The majority of researchers agreed that using chronological age as a cut off was unhelpful, given the complexity and variability of adolescent development combined with the overlay of a chronic illness (Blum et al. 1993; While et al. 2004; Singh et al. 2005).

There is some evidence that young people with ADHD have a developmental time lag of up to three years which was consistent with Townley's (2006) view, that in having a mental health problem, the rate at which developmental changes occur may be delayed. This factor gives further weight to the proposition that the timing of transition should be congruent with the individual's needs, rather than at an arbitrary point which may be influenced by health care commissioning rather than clinical need (Reiss et al. 2005).

Participants surveyed by Day et al. (2007) felt that the decision around timing should be made by the young person anytime between the ages of 15-18 years. Participants interviewed by Shaw et al. (2004) suggested that 18 may be an appropriate time, especially given that simultaneous transitions occur at this juncture, however, they also believed that the timing should take into account other factors in the individual's life and whether the disease was well controlled. Townley (2006) argued that the timing of transition should be variable, he highlighted the opinion of participants from his study, that everyone is different and that transition should occur when the person feels ready. This was consistent with the views that emerged from several other studies (Shaw et al. 2004; Soanes and Timmons 2004; Hovish and Weaver 2012) which proposed that transition should happen at a time that is developmentally and age appropriate.

According to Shaw et al. (2004) another important factor worth considering was a preference for transition to occur when the disease is well controlled, in order to minimise disruption and anxiety to the individuals. Given the contrasting opinions expressed by young people, it would seem that an

individualised and flexible approach to the timing of transition should be implemented (Forbes et al. 2001; Shaw et al. 2004; Townley 2006).

Whilst it is encouraging that there is a consistency between policy and practice recommendations and the stated views of young people regarding the timing of transition, it appears that this is not being translated into service delivery.

3.14 Young people's relationships with health care professionals

The importance of developing effective relationships between health care workers and young people was discussed by several authors (Ginsberg et al. 1997; Buston 2002). There was a consensus of opinion about which factors were influential in the process of building effective relationships between health care workers and young people.

Continuity of care was cited as important (Shaw et al. 2004; Shaw et al. 2006; Townley 2006); young people liked to see the same professional, preferring those who were interested in them as individuals rather than as an illness. Other important factors were openness, honesty, straight talking and feeling heard (Patterson and Lanier 2006; Shaw et al. 2006; Townley 2006; Singh et al. 2010).

Trust was considered to be an important issue for young people (Shaw et al. 2004; Shaw et al. 2006; Townley 2006). Young people considered it important that they could, over time, build a trusting relationship with their health care professional (Shaw et al. 2006; Townley 2006).

Some young people had previously experienced positive relationships with professionals which had developed over an extended period of time, the loss of which (Day et al. 2007), may have contributed to the difficulty some young people had in developing trusting relationships with new professionals post transition (Patterson and Lanier 2006).

Several authors (Shaw et al. 2004; Shaw et al. 2006; Townley 2006) described how young people found it helpful if healthcare professionals had an

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understanding of what it is like to be a teenager and were aware of some of the uncertainties and issues facing them.

Although there was agreement that the quality of the relationship between service user and healthcare professionals was important, further work is required to establish what influence different healthcare contexts might have on the nature and development of professional / service user relationships.

3.15 Staff training

Several authors proposed that young people in the transition phase had specific care needs which required specialist skills in order to provide high quality care (McClure 2000; Royal College of Paediatric Child Health [RCPCH] 2003).

A key finding of the review concerned the need to provide training to adult trained healthcare professionals, thus enabling them to adequately meet the needs of young adults (DH 2004a; RCN 2004; Department for Children, Schools and Families [DFCSF]/ DH 2008a; 2008b; Royal College of Physicians of Edinburgh [RCPE] 2008; Montano and Young 2012). This could help them gain confidence and experience in working with younger adults, which was an area they had expressed concern about (DFCSF/ DH 2008ab).

Singh et al. (2010) suggested health care staff received training on the key elements of a 'good' transition alongside the development and implementation of clear transition protocols to ensure that young adults undergo successful transition processes. In addition, Singh et al. (2010) recommended that clinicians were offered focused training relating to engaging and communicating with young adults, in order to increase their confidence in working with this group.

Other literature (Asherson 2007; Ahmed et al. 2009; Merriman 2013) suggested that the identification and treatment of ADHD in AMHS and General Practice was a new challenge to professionals working in these areas. Possible explanations are that until recently ADHD was perceived as a disorder of

childhood (Rosler et al. 2010) and has only relatively recently been recognised as continuing into adulthood (Faraone et al. 2000b).

Several researchers (Berney 2009; Singh et al. 2010; Bolea et al. 2012; Montano and Young 2012; Hall et al. 2013; Matheson et al. 2013; Merriman 2013) highlighted the need for clinicians to develop their knowledge and skills in the assessment and treatment of adults with ADHD which may result in services being better able to meet the needs of this group. These findings suggested attention should be paid to ensuring that educational programmes were developed and delivered to a range of healthcare professionals to extend their knowledge base in relation to ADHD and transition.

3.16 Parental involvement

The involvement of parents or carers in the transition process received a mixed response from participants (Day et al. 2007). Some young people felt it was helpful for families to have continuing involvement (Soanes and Timmons 2004; Singh et al. 2010; Hovish and Weaver 2012) and commented on the support their families gave them (Meaux et al. 2009); whilst others acknowledged that this could impede their progression to function as autonomous individuals. Tuchman et al. (2008) described the dilemma experienced by some young adults who were concerned that if their parents were less involved then they would not have someone to 'protect' them or explain information to them.

According to Tuchman et al. (2008) and Hovish and Weaver (2012) some young adults believed their parents struggled with the concept of transition and were worried about being less involved in the health care of their adult children.

Singh et al. (2010) proposed that parental involvement in their young adults' lives inevitably changes over time as they become autonomous adults. They described an 'adaption phase' whereby young adults and parents adjust to their changing roles in relation to a number of transitional tasks, for example, financial decision as well as responsibility for healthcare decision making.

3.17 Decision making

Increased involvement in decision making processes seemed important. Some young people were keen to have clear explanations about their condition and treatment options and felt they were often uninvolved in making choices or decisions about their care (Shaw et al. 2004; Day et al. 2007; Dunn et al. 2013). Whilst others expressed a wish to become an expert in their own condition in order to make informed choices about their care. It appeared that young people felt that decisions were made for them rather than with them, despite being able to identify possible helpful solutions such as convening joint planning meetings or making information about possible options for their continuing healthcare needs more readily available to them.

Alderson and Montgomery (1996) traced the changing involvement by young people in healthcare decision making over time, describing the parallel processes in which children chronologically and developmentally become adolescents and adults and how this interfaces with their participation in decision making. They (Alderson and Montgomery 1996) described four important phases: 'being informed, expressing a view, influencing decision making' and being the 'main decision maker'.

Although it is not within the remit of this study to establish how individuals are supported to negotiate their changing responsibilities in relation to their healthcare; it would seem important for further research in this area to be undertaken to determine how this progression is managed.

Several authors (Paul 2004; RCPCH 2011; Dunn et al. 2103) argued that young people's involvement in healthcare decision making should be inherent in clinical practice. If young people were, from an early age routinely involved in making decisions about their healthcare it may increase their confidence in decision making and support them in becoming autonomous adults who are actively involved in decisions about their healthcare.

3.18 Suggestions for clinical practice

Despite the prevalence of policies outlining the need for transition services, several studies indicated that nationally there was a dearth of transition services across all specialties and young people are struggling to access appropriate care for their continuing needs (Keen et al. 2000; McDonagh 2006; Marcer et al. 2008). A recent study carried out by Oguendele and Omenaka (2012) concluded that young adults with ADHD did not experience successful transitions from CAMHS to AMHS, which supported Hall et al.'s (2013) view that attention must be paid to ensuring that transition protocols are in place and are fit for purpose.

There was a consensus of opinion that, although it was recognised that young people should receive continuing care, it was simply not happening (Patterson and Lanier 1999; Shaw et al. 2004; Reiss et al. 2005; Singh et al. 2005; Shaw et al. 2006; Day et al. 2007; Verity and Coates 2007; Marcer et al. 2008) and as a result, they were at risk of their health being compromised (While et al. 2004; Edwin and McDonald 2007).

Viner (2008) stated that young people with a range of medical and psychological conditions benefited from a process of planned transition which supported their move from child to adult services. This view was supported by Richards and Vostanis (2004) who agreed that transition services needed to be developed for young people with ADHD to ensure their healthcare needs were adequately met. Furthermore, several reports indicated that people with neuro-developmental disorders, including ADHD, were particularly disadvantaged at transition due to a lack of service provision (Beresford 2004; DH 2006; McDougall 2007; Marcer et al. 2008; RCPE 2008; Brodie et al. 2011).

Several ideas about possible changes to service delivery emerged from the literature. Participants were keen to have adequate preparation for transition (Patterson and Lanier 2006; Townley 2006); they wanted to develop skills to manage their own health care needs (Shaw et al. 2004) and become more involved in decision making relating to their health care (Patterson and Lanier 2006).

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Young people wanted easily accessible services and preferred appointments to be made at a time that did not interfere too greatly with their employment or other responsibilities (Shaw et al. 2006), it was suggested that the development of 'drop-in' clinics might be a way of addressing this issue (Shaw 2004).

Viner (2008) asserted that ensuring a safe and effective transfer of young people with chronic illness was a key quality issue for health services and Shaw et al. (2004) and Day et al. (2008) suggested that it would be useful to ask young people for their views on what they would find helpful.

It is therefore timely that research is undertaken to examine the actual experiences of young people approaching discharge from child and adolescent services and those who have left them.

3.19 Limitations of the studies critiqued

Qualitative methodologies were used in all the studies; these methods aim to explore the lived experiences of participants and to explore the subjective meanings and experiences of participants (Burls 2009).

A focus group methodology was used in four of the studies (Patterson and Lanier 1999; Shaw et al. 2004; Reiss et al. 2005; Day et al. 2007). The rationale given (Shaw et al. 2004; Day et al. 2007) for selecting focus group methodologies was that it was considered to be an effective way of eliciting information from young people. This method allows participants to interact with each other in a safe environment enabling the development and generation of ideas around a particular topic (Patterson and Lanier 1999; Shaw et al. 2004). However, disadvantages may include the possibility that participants may be unable to express their views if they are different from the majority, the potential for facilitator bias and difficulty managing group dynamics.

Interviews have the potential to elicit in-depth data about a topic; however, the researcher needs to be aware of the potential for bias in the interview process. Five studies (Soanes and Timmons 2004; Townley 2006; Singh et al. 2010;

Hovish and Weaver 2012; Swift et al. 2013) used a semi-structured interview schedule which included questions informed by broad themes drawn from the literature. Silverman (2006) considered that the use of non-directive, open-ended questions were the most effective way to gain an understanding of an individual's experiences. Townley (2006) chose this methodology because he thought the data collected would be consistent with the broad aims of his study.

In their cohort study Shaw et al. (2006) used self-completed questionnaires to collect data from participants; their rationale for their choice of methodology was not mentioned but it could be assumed it was a cost effective and appropriate method to collect data from a large group of participants.

Two of the studies (Singh et al. 2010; Swift et al. 2013) formed part of a larger research project: 'Transition from CAMHS to Adult Mental Health Services' (TRACK) (Singh et al. 2010). This study formed the basis of a report to the National Institute for Health Research Service Delivery and Organisation programme and used a mixed methodology to examine policies, protocols and service delivery relating to the transition of young adults with mental health problems and sought to elicit the views of young adults, their carers and healthcare professionals.

Purposive sampling was used by several researchers (Soanes and Timmons 2004; Townley 2006; Day et al. 2007; Singh et al. 2010; Hovish and Weaver 2012). This allows for an over representation of the topic under enquiry and enables researchers to get close to the participants' experience of the topic being studied but does mean that results are not representative. However, given that the stated intention was to give a voice to young people, rather than to present generalisable conclusions, these were appropriate sample sizes.

Opportunistic sampling was chosen by Hovish and Weaver (2012), their participants were drawn from a sample that were already involved in a larger study and had indicated that they were interested in participating in the transition study. This sample therefore was self-selected and their views were not representative.

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Because the sample sizes were small, and participants were drawn from diverse populations, it was difficult to get a sense of how the similarities or differences in their experiences were connected to their particular health difficulty or were linked to other factors. For example, young people with chronic health conditions with a high mortality rate may have very different views on the nature and quality of interpersonal relationships and the timing of transition.

The findings from the literature would have been more persuasive if the authors had included more information about the methodological challenges they encountered with their studies, for example, their experiences of recruiting sufficient numbers of young people to their studies, which was only mentioned by two researchers (Singh et al. 2010; Swift et al. 2013).

3.20 Summary

Following a critical review of the literature, it was evident there was limited knowledge about the experiences of young people in transition. Published research to date has tended to focus on professionals views on transition and little has been written about the experiences of young people. The majority of existing evidence concerned young people who had chronic physical health conditions with few papers specifically addressing transition in generic mental health and only one concerning ADHD.

It was clear from the data, that young people often had negative experiences and had strong feelings about the transition process. Available research identified a gap in transition services for young people generally which was associated with poor long term health outcomes. National recommendations argued for the development of transition services and suggestions for service models were available.

Common themes were identified which implied that regardless of disease process, the issues facing young people were similar. As the data collected was the 'lived in' experiences of the participants, the researchers did not challenge the views expressed but offered possible explanations and interpretations.

Although it was widely recognised that it is important to elicit the views of services users in the planning and development of services (Munoz-Solomando et al. 2010), there was little evidence of this happening in practice (RCN 2004; DH 2006; NICE 2008; Kennedy 2010; Brodie et al. 2011, DH 2011a; 2011b).

Given the plethora of change occurring at this stage in a young person's lifecycle (Garcia Preto 1988; DH 2008; Hovish and Weaver 2012; Joint Commissioning Panel for Mental Health 2013), it would seem imperative that consideration be given to the development of transition services that meet the individual needs of young adults in order to ameliorate the potential negative health outcomes associated with dis-engagement from services (Watson 2000).

Despite the good intentions of the Department of Health and other professional bodies to improve transition between child and adult services, it was evident from the literature this was an area that warranted further attention. Studies that have examined young people's experiences of transition have highlighted that although young people's experiences may not have been positive, they do offer insight into important factors needing consideration in the development of services. Therefore, it would seem timely to undertake research to further explore this issue with an aim of incorporating young people's views into service development. This is congruent with a national movement (DH 2011) to elicit the views of young people about healthcare provision.

4. Research Design

The aim of this chapter is to set out the research questions and provide an overview of the rationale for selecting interpretative phenomenological analysis as the chosen methodology. The gap emerging from the literature in the knowledge base and the difficulties encountered in implementing healthcare policy prompted the following research questions with which to explore the experience and meaning of transition in relation to:

What are the perceptions and lived experiences of young adults diagnosed with ADHD about their on-going care following discharge from CAMHS?

And,

What do they believe their continuing care needs to be?

4.1 Personal engagement with the method

I was naturally drawn to a qualitative method for several reasons. Firstly, as a mental health nurse and systemic psychotherapist, I am interested in the experiences and meanings that people hold about events that they have lived through (past and present) and what sense they make of them. As Pringle et al. (2011, p24) have stated the:

‘emphasis of (qualitative methodology) is on individuals accounts, which is consistent with nurses desire to offer holistic care’.

This statement was congruent with the intention of this study, which was to learn more about how young adults with ADHD understood and made sense of their experiences of transition. Secondly, a systemic approach is based upon understanding human behaviour within a relational context and focuses on patterns of interaction over time and the influence of different circumstances which is consistent with the underpinning theories of qualitative methodologies. Thirdly, given that qualitative research is reported as being an effective way to explore experiences and meanings (Silverman 2005; Lacey 2006; Finlay 2006), I felt that this method would elicit rich data that would serve to answer the research questions. Finally, as the aim of the research was

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to undertake a detailed exploration about the lived experiences of transition held by young adults with ADHD and to increase understanding about their experiences of service delivery following discharge from CAMHS, I believed that a qualitative methodology would yield rich narratives and thus allow these research questions to be expanded.

Reeves et al. (2008) hold the view that qualitative methods are useful tools for studying the delivery of patient care, as the insights they provide give practitioners a broader understanding of situations that patients face every day. This view is supported by other researchers such as Todres and Holloway (2007b), Clarke (2009) and Smith et al. (2010) and adds credence to the choice of a qualitative methodology for this study.

Given that there are a range of qualitative methods all of which have their own specific strengths and weaknesses, it was important to decide which methodology would be most appropriate to meet the aims of the study. Glasper and Rees (2013c) have stated that within nursing research the following qualitative research designs are popular: ethnography, grounded theory and phenomenology.

4.2 Ethnographic research

An ethnographic researcher aims to understand the way people behave within a particular situation. Marcus and Fisher (1986, p18) have defined ethnography as:

‘a research process in which the anthropologist closely observes, records and engages in the daily life of another culture’.

Participants are recruited by purposive sampling; therefore a particular setting or group of people is identified because they have direct experience of the topic being studied (for example patients in an acute mental health setting).

Data collection requires the researcher to become immersed in the field and is conducted by way of direct observation providing the researcher with an in-depth understanding of a particular social system (Brewer 2000; Holloway and Todres 2006a). Data is compiled from the researcher’s observations and are

recorded as field notes; in addition, interviews with group members may be undertaken. The intention is to provide a rich 'thick' description of the:

'patterns of cultural and social relationships and puts them into a context' (Holloway and Todres 2006a, p208),

with an aim to understand the experiences of people in the group from their emic or own perspective (Robson 1999; Holloway and Todres 2006a). Findings are presented as an ethnographic report which describes the researcher's observations in the field and identifies the main features of the group and setting. Throughout the research process, it is essential for the researcher to reflect on how their own social and cultural constructs influence their interpretation of the data and how the events or context being studied impact on them.

In summary, Holloway and Todres (2006a) have proposed that ethnography is the method of choice when a researcher wants to 'investigate a culture' with the intention of contributing to current theory and applying the knowledge to improve practice.

Although some aspects of ethnography appealed to me, for example, the acknowledgment of the influence that researchers may have on data collection and analysis; I did not feel that an ethnographic design would be appropriate, given that the aim of my research was to closely examine the participants' individual lived-experience as opposed to understanding their culture.

4.3 Grounded theory

Grounded theory was developed by Glaser and Strauss in the 1960's with the main aim of:

'generating a mid-range theory that is grounded in the data collected' (Stanley 2006, P64).

Grounded theory is particularly suited to researching topics that have not been widely examined or where a new perspective on a known issue is required (Holloway and Todres 2006b).

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Theoretical sampling involves recruiting participants who can provide relevant data for the generation of theory. It is a feature of this approach that the researcher will decide, as the study progresses, where the next data should be collected from, in order to develop aspects of the emerging theory (Stanley 2006).

Recruitment to the study and data collection continues until 'saturation' is reached which meaning that 'new data ceases to yield new information' (Echevarria Rafuls and Moon 1996, p69). Data collection methods include interviews, observation and the use of documents.

Data analysis begins as soon as data is collected and continues simultaneously, allowing the researcher to refine the research question and data collection procedures as the study progresses.

Grounded theory researchers are required to interpret emerging data and it is inevitable that the way in which codings are arrived at, will be influenced by the researchers own beliefs and assumptions. However Willig (2001) asserted there was insufficient recognition of this issue by grounded theorists and it was often used as a way of researchers confirming their own biases.

In summary, grounded theory is particularly suited where the researcher's intention is to:

'produce a theory that has explanatory power or modification of a theory that already exists' (Holloway and Todres 2007b, p205)

and to:

'derive a theory to therapy practice that is properly grounded in the lives of participants' (Stanley 2006, p53).

Given that the aim of my study was to understand an individual's 'lived' experience, I did not feel that grounded theory would provide the same idiographic focus as IPA. In addition I was not seeking to generate or develop a theory and therefore felt that that grounded theory would not be a suitable method to answer the identified research questions.

4.4 Phenomenology

Phenomenology is derived from the Greek: *phainómenon*: 'that which appears' and *lógos* 'study', it is a philosophical movement which developed from the ideas of Edmund Husserl in the early 20th century. Phenomenology is a branch of philosophy which is interested in how people understand and experience the world they live in and encompasses both philosophy and method. Gerrish and Lacey (2007, p538) defined phenomenology as:

'an inductive approach to qualitative research that focuses on understanding the human experience from the inside'.

To paraphrase Smith et al. (2010) phenomenology is concerned with finding out what is important to people, what meaning they make of their experiences and how they describe their relationships with things that are important to them. This definition is consistent with the idea that central to the theory of phenomenology is 'an attempt to describe phenomenon as experienced by an individual' (Wojnar and Swanson 2007).

Within the context of a research paradigm, phenomenology is the study of a phenomenon with an aim to illuminate its essence and meaning (Wojnar and Swanson 2007). Todres and Holloway (2006b) described it as:

'the gathering of examples of everyday experiences, describing them and reflecting on them'.

According to Lopez and Willis (2004) phenomenology offers a stance that is sympathetic to nursing philosophy and practice because it emphasises the importance of understanding individual's perceptions, meanings and interactions within a context. They maintained that nursing as an 'art and science' is inevitably influenced and concerned with 'human responses to actual and potential health problems'. The descriptions regarding the focus that a phenomenological position assumes and phenomenology's relevance to research and nursing practice may explain the increasing popularity of phenomenological research methods in healthcare settings (Smith et al. 2009). Although there are a range of phenomenological approaches, it appears that within the area of nursing research, the most popular methods in use are

descriptive and interpretative phenomenology (Lopez and Willis 2004; Todres and Holloway 2006b).

4.5 Descriptive Phenomenology

Descriptive phenomenology emerged from Husserlian ideas which aimed to study 'essential structures' or 'essences of phenomena as they appeared in consciousness' (Giorgi and Giorgi 2003). Descriptive phenomenology is conceptualised as a philosophical tradition and method of inquiry which draws on several principles including 'neutrality, an openness to others reality, universal truths' and the interactions between researchers and participants (Lopez and Willis 2004).

Husserl was a phenomenological philosopher who was 'interested in finding out about the essence of human experience' (Smith et al. 2010) and was curious about how people understood and gave meaning to something they had experienced.

Husserl suggested that in order to get to the 'essence' of an individual's lived experience, researchers should 'bracket off' their own assumptions and beliefs so as not to influence the meaning ascribed to the narrative.

A descriptive phenomenological approach is used when little is known about the topic with the aim being to make clear and understand the most 'essential' meaning of a phenomenon of interest from the perspective of those directly involved in it (Giorgi 1997).

Penner and Clement (2008) described the process of descriptive analysis:

'he or she analyses the descriptions given by participants and divides them into meaning-laden statements, gathering those meanings that are essential to the construct of the phenomenon being studied'

resulting in a written description illuminating the 'structure of the phenomenon' and noted that within the analysis process the researcher is not required to make interpretations.

4.6 Interpretative Phenomenological Analysis

Over the last decade IPA has become an increasingly popular choice of research method for researchers who are interested in discovering how people experience a particular phenomenon (Reid et al. 2005). There is a growing body of evidence which describes its theoretical basis, application and practice, particularly within healthcare settings (Smith et al. 1999; Smith 2004; Reid et al. 2005; Smith 2007; Eatough and Smith 2008; Smith et al. 2010). To date, studies using IPA within a mental health context have included the experiences of people with Schizophrenia (Osborne and Coyle 2002), Aspergers syndrome (Griffith et al. 2012) and alcohol addiction (Shinebourne and Smith 2009).

In Smith's seminal paper (1996), IPA was introduced as a qualitative research methodology that provided researchers with an alternative way of thinking about and analysing data. Smith et al. (2010, p40) described the aim of IPA as being:

'concerned with understanding personal lived experience and thus with exploring persons' relatedness to, or involvement in, a particular event or process'.

Smith et al. (2010, p1) defined IPA as a:

'qualitative research approach committed to the examination of how people make sense of their major life experiences'.

where attention is paid to the importance and influence of context (social, historical and culture) on the way people understand and experience a phenomenon (Eatough and Smith 2008; Smith et al. 2010).

According to Smith and Osborn (2004, p229):

'IPA recognises that different people perceive the world in very different ways, dependant on their personalities, prior life experiences and motivations. It attempts to explore, understand and make sense of the subjective meanings of events, experiences, and /or states of the individual participants themselves'

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In 2010 Smith et al. provided an overview of their current thinking on IPA. Firstly, they identified three key theoretical components of IPA: phenomenology, hermeneutics and idiography; secondly, they traced the development of IPA as an approach to qualitative research and finally, they described the influence that several philosophers had on the development of the central theoretical concepts of IPA.

Smith et al. (2010) suggested that Husserl's ideas about the way people understand and give meaning to a lived experience links to the stated aims of IPA research studies which seek:

'To understand the participants' world and to describe what it is like' (Larkin et al. 2006, p104)

and to carry out an:

'overtly interpretative analysis, which positions the initial description in relation to a wider social, cultural, and perhaps even theoretical, context' (Larkin et al. 2006, p104).

This view has contributed to the understanding of the role of the researcher in making sense of experience and links to the concept of reflexivity which is considered an important component of IPA (Smith et al. 2010).

Hermeneutics is concerned with the theory of interpretation and in relation to IPA is associated with an ability to understand something from another person's perspective, taking into account the social and cultural contexts that might have influenced their outlook; which Heidegger terms 'the person in context' as cited by Smith et al. (2010, p17) .

Smith et al. (2010, p18) described their understanding of Heidegger's work and its influence on IPA explaining that Heidegger held the view that 'people are indelibly a person in context' and that lived experience was shaped by interactions with people, things, language, relationship and culture. They described how 'our attempts to understand other people's relationship to the world are necessarily interpretative' and highlighted Heidegger's opinion that any interpretations would inevitably be influenced by the researchers assumptions and beliefs

For researchers, this implied the need to identify and own their attitudes and beliefs, in order to consider how this might influence their interpretation of participants' accounts. An associated idea is the concept of 'fore-conceptions', attributed to Heidegger and Gadamer by Smith et al. (2010), who believed that researchers may only become aware of their position on an issue when they are actually engaged in the interpretative process, stating that: 'a phenomenon can never be totally revealed' and that

'the lived experience of being a body in the world can never be completely captured' (Merleau-Ponty in Smith et al. 2010, p19).

Smith et al. (2010, p22) continued, explaining how they have incorporated Schleiermacher's ideology into their theory of IPA suggesting that:

'part of the aim of the interpretative process is to understand the writer as well as the text'

and they reflected on how this translates into practice stating that:

'I am trying to make sense of the words used but I am also trying to make sense of the person who has said those words'.

In addition, Smith et al. (2010) and Smith (2011a) identified several other key principles that IPA researchers are required to be aware of:

The 'double hermeneutic' which relates to the dynamic that occurs in the data analysis process whereby:

'The participant is trying to make sense of their personal and social world, whilst the researcher is trying to make sense of the participant trying to make sense of their personal and social world' (Smith et al. 2010, p53).

The 'hermeneutic circle', describes the 'dynamic relationship between 'the part and the whole', Smith et al. (2010, p28) explained this concept using the following example:

'If you want to understand a single episode (the part), you look to the complete life dynamic (the whole) and if you want to understand

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the whole (the complete life dynamic), you look to the single episode (the part)'.

Dynamic bracketing resonates with the concept of reflective practice, that is, it is impossible to get a definitive account of someone's lived experience because the researcher will never be able to completely put aside their own experiences which means that a 'perfect understanding will always be hidden'.

Intersubjectivity connects to the idea of 'person in context' and refers to the:

'shared, overlapping and relational nature of our engagement with the world' (Smith et al. 2010, p17).

Smith (2004) described IPA as a 'strongly idiographic' approach which aims to explore and capture the essence of an individual's personal perspective necessitating an in-depth and detailed analysis to uncover an understanding of how a person experienced something and the meaning it holds for them.

Idiographic was defined by Smith et al. (2010, p29) as 'concerned with the particular', arguing that IPA takes an alternative position to a nomothetic approach because the aim is not to make general claims from the findings but instead to provide a detailed description of what something meant to one person at one point in time.

Reid et al. (2005) asserted that IPA 'maintains an idiographic focus' as each case is analysed in its own right and in great detail before moving on to the next case. In addition, IPA researchers (Reid et al. 2005) have stated that the small sample sizes associated with IPA research are a result of the idiographic nature of the work and reject the idea that for research to be valid, larger sample sizes are necessary.

4.7 Factors influencing choice of phenomenological method

The choice of research method will inevitably determine the findings; therefore it follows that care must be taken to select a method that will provide an answer to the question being asked. Although descriptive and interpretative

phenomenological approaches share an interest in understanding human lived experience there are key differences in their objectives and philosophical foundations which will influence the research process and outcomes (Wojnar and Swanson 2007). Table 4 provides an overview of the key differences between descriptive and phenomenological studies.

Table 4 Key differences between descriptive and interpretative phenomenological studies (Wojnar and Swanson 2007)

Descriptive	Interpretative
The emphasis is on describing universal essences	The emphasis is on understanding the phenomena in context
Viewing a person as one representative of the world in which he or she lives	Viewing a person as a self interpretative being
A belief that the consciousness is what humans share	A belief that the contexts of culture, practice and language are what humans share
Descriptive	Interpretative
Self reflection and conscious 'stripping' of previous knowledge help to present an investigator-free description of the phenomenon	As pre-reflexive beings researchers actively co-create interpretations of the phenomenon
Adherence to established scientific rigour ensures description of universal essences or eidetic structures	One needs to establish contextual criteria for trustworthiness of co-created interpretations
Bracketing ensures that interpretation is free of bias	Understanding and co-creation by the researcher and the participants are what makes interpretations meaningful

Interpretive phenomenology is used when the research question aims to uncover the meaning of a phenomenon and does not require the researcher to bracket their biases instead promoting self reflexivity. Interpretive

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phenomenology goes beyond a description of core concepts and essences to look for meaning (Lopez and Willis 2004). In contrast descriptive phenomenology is useful in research where the aim is to describe the phenomenon being studied and researchers are required to 'bracket' their biases.

4.8 Epistemological and ontological approach

In relation to this study I have considered how my epistemological (how I know) and ontological (what there is to know) beliefs have led to the decision to use IPA and how these contribute to my position as a researcher and systemic psychotherapist.

The discipline of systemic family therapy has its roots in research (Jones 1995a) with many early founders of the movement coming from social science or anthropological backgrounds. Initially, family researchers were interested in how patterns of communication and relationships might contribute to the development of mental health problems; for example, communication patterns in families with schizophrenia (Bateson 1972) and interactional patterns in families with anorexia (Selvini Palazolli 1974; Dallos and Draper 2000).

A considerable amount of literature has been published on the changing theoretical and philosophical influences that underpin family therapy theory and practice (Jones 1995a; Dallos and Draper 2000; Asen et al. 2004). Jones (1995a) mapped the shift in thinking, away from a focus on how family dynamics might contribute to the development of mental health difficulties to current opinion, where the influence of context, process, relationship and the wider system are emphasised. An underlying principle is the emphasis on a collaborative approach to working with family systems. This involves understanding an individual as influencing and being influenced by the systems they are within and the therapist being seen as a part of the system, rather than external to it. This idea seems to resonate with the underlying principles of IPA.

There are several key concepts which are present in IPA and systemic family therapy and have a resonance with my clinical practice as follows:

4.8.1 **The importance of context**

Asen et al. (2004, p xi) stated that:

‘every individual is embedded in multiple contexts; physical, historical, family, financial, spiritual, cultural and other relationship contexts’.

This statement concurs with the emphasis IPA places on the importance of attending to the social and cultural contextual influences within which participants interact. This is consistent with an aim in clinical practice to gain insight into the various contexts that individuals are situated and to understand the influence this may have on their experiences and understanding. This is congruent with one of the central tenets of systemic psychotherapy that acknowledges how the beliefs and assumptions held by individuals are influenced by the systems they are part of and resonates with a constructivist perspective that knowledge and reality are subjective and shaped by factors such as cultural context, language and social relationships.

4.8.2 **Interpretivist position**

IPA and systems theory share the view there is not one reality and the way something is understood depends on the individual’s perspective which is by their beliefs, experience and knowledge (Jones 1995a; Reid et al. 2005). This concurs with my commitment in clinical practice to attempt to understand the world from another person’s point of view, recognising that there are multiple meanings and subjective realities that may be uncovered which will be important to them and will have had an impact on their current situation.

4.8.3 **Role of the researcher/clinician**

Systems theory has moved from a position whereby the therapist was seen as an expert and separate from the system with which they were working, to one of collaboration and an acknowledgment of the ‘inevitability of the observer position’ (Jones 2000a).

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Inherent in systems theory, is the importance that therapists examine their own prejudices and values and acknowledge the influence these may have on their work. This is consistent with the position taken up by IPA researchers who are required to be mindful that their pre-experience does not interfere with their ability to hear participants views (Smith et al 2010). This accords with my task as a therapist, to consider how my own belief system may affect my understanding and interpretation of what is being said.

The importance of being respectful towards the views of people is an important component of IPA (Smith et al. 2010) and family therapy (Anderson and Goolishian 1992) which resonates with my clinical practice. I believe that it is important to provide a space in which people feel able to talk openly about their ideas, thoughts and experiences and to consider the sense they have made of it. IPA advocates that researchers adopt a collaborative stance, allowing ideas and themes to emerge from the personal accounts of people rather than imposing pre-determined theories or ideas (Smith et al. 2010). This is consistent with the description of 'therapy as a conversation' (Anderson and Goolishian 1992) and resonates with the non-directive approach associated with IPA interviews.

As a clinician, I am interested in the stories people tell, the way in which they tell them and the meaning they ascribe to them which I think fits with the intention of IPA. I feel that the skills required by IPA researchers are consistent with those skills I have acquired in my practice as a family therapist and is in accordance with Sprenkle and Moon's (1992) opinion that the skills needed by phenomenologist's and family therapists are broadly similar.

Given the parallels between some of the central concepts of IPA, systems theory and my epistemological and ontological position as a clinician and researcher, I believed that IPA would be an appropriate methodological approach for this study.

4.9 Summary

In comparison to the other methods described, IPA has several advantages:

Firstly, IPA aims to provide an in depth understanding of an individual's experience of a phenomenon set within a cultural context; providing information about factors that may directly or indirectly play a part in the meaning making process (Shaw 2001).

Secondly, because IPA is concerned with the detailed examination of individuals lived experiences, it was likely that this method would elicit relevant data; furthermore, IPA has been shown to be a useful tool in health related contexts (Smith et al. 1999) which correlates with the setting where this study will take place.

Thirdly, given that IPA aims to give voice to the views of participants it could be argued that it fits well with the current NHS agenda which promotes service user involvement (Reid et al. 2005; DH 2010a).

Finally, the influence that researchers have on the data collection and analysis process and the recognition of the impact of contextual factors, is widely accepted.

In summary, IPA complemented the stated aims of the research which was to further understand the personal experiences and descriptions of the participants' journey through transition.

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5.1 Sampling

In studies using qualitative methodologies, it is essential that the sample population comprises participants for whom the research question is significant (Smith et al. 2010) and who will be able to provide rich data about their understanding and perceptions of the topics being studied (Procter and Allan 2006).

Smith and Osborn (2004) argued that heterogeneous samples could potentially make it difficult to understand the relationship between emerging patterns and contextual influences, such as the participant's age or occupation. For those reasons, the participants in this study were purposively selected to ensure a fairly homogenous sample, in order that convergences and divergences could be examined in detail (Smith and Eatough 2006)

Several authors (Procter and Allan 2006; Adler et al. 2012) have discussed the inherent difficulty in deciding on the number of participants required for qualitative research studies, proposing that there is no definitive answer and that a variety of factors need to be considered, such as the research aims, type of methodology and available resources.

Because IPA is an idiographic approach concerned with understanding a particular thing in a particular context, sample sizes tend to be small in order to facilitate a detailed analysis of the data generated. Several studies (Smith et al. 1999; Smith 2004; Smith and Eatough 2006; Smith et al 2010) have argued that smaller sample sizes and single case studies are congruent with the idiographic nature of this methodology and Reid et al. (2005, p22) suggested that:

‘IPA challenges the traditional linear relationship between number of participants and value of research’,

which was supported by Smith and Osborn (2008, p55) who described how the purpose of IPA studies is to:

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‘say something in detail about the perceptions and understandings of this particular group rather than prematurely make more general claims’.

Smith et al. (2010) have suggested that a sample of between three and six participants constitutes a reasonable sample size for a doctoral thesis.

Although the sample size might be considered small, it is important to remember that the results of this study are not intended to be representative of all young adults with ADHD. Despite the small sample size, rich data was generated by each participant that yielded new understandings of the topic from their perspective.

Given that qualitative research does not seek ‘statistical representativeness’ (Mays and Pope 1995) and taking into account the time available for carrying out interviews and data analysis, it was decided that due to the idiographic nature of IPA, this study would comprise four participants.

In order to ensure a homogenous sample, the following criteria for participation was developed (table 5).

Table 5 Sampling inclusion and exclusion criteria

Inclusion Criteria	Rationale
Aged between 18-22 years old	The study aimed to explore the experience of service delivery following discharge from CAMHS. The lower age limit of 18 years old meant that young people aged 18 years and over would have been discharged from CAMHS. The upper age limit of 22 years old was selected to draw on participants who had a relatively recent experience of transition.
Diagnosis of ADHD	Participants were required to have a diagnosis of ADHD which was made during childhood or adolescence and was unchanged up to the point of transition.
Under the care of CAMHS leading up to their 18 th birthday.	The research aimed to understand the experiences of young people who had previously accessed healthcare services for their ADHD and were in receipt of services leading up to age 18, when they were discharged from CAMHS.
Exclusion Criteria	Rationale
Participants with co-morbid Autism Spectrum Disorder (ASD).	The nature of ASD means that individuals are likely to have impaired insight and communication skills, making open ended questions orientated towards reflecting on experience difficult.
Participants with co-morbid severe and enduring mental illness.	This group was excluded from the study as they are more likely to meet criteria for referral into AMHS and thus receive a service.
Participants with a learning disability.	The data collection tool to be used in this research study has not been modified to meet the needs of young people with a learning disability. A co-morbid learning disability will reduce the ability of the researcher to make comparisons across the small sample being interviewed.
Participants whose care the researcher was directly involved in.	To avoid possible bias, this group was excluded from the study as previous contact with the researcher might impact on what participants felt able to talk about.

5.2 Recruitment of participants

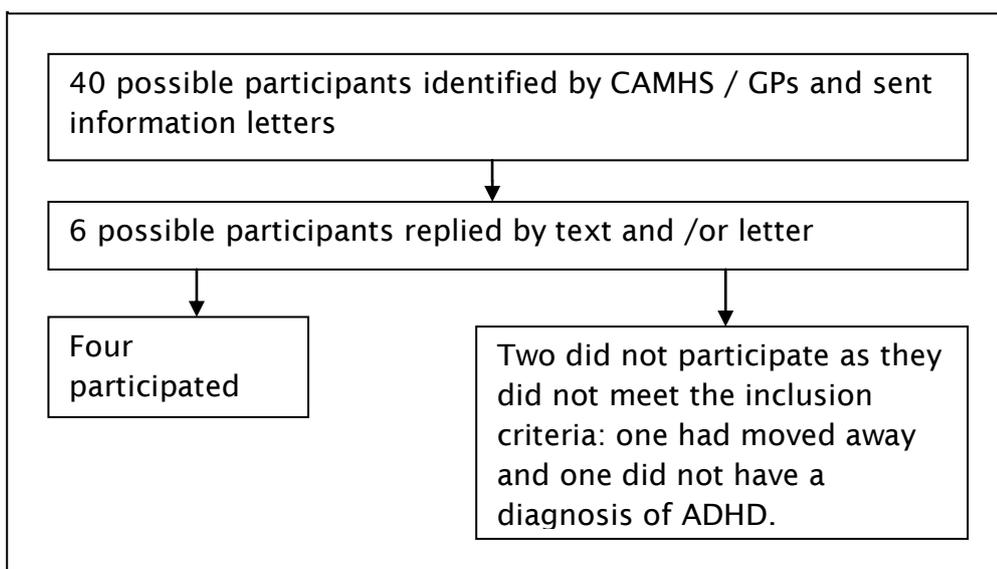
Participants were a volunteer group who had previously been under the care of a CAMH Service. Potential participants were identified by CAMHS clinicians, who had been involved in their care and were in full agreement that they could be approached by the researcher to invite them to participate in the study.

The sample in this study was self-selected and therefore subject to volunteer bias (Procter and Allan 2006), however, it is important to note that this study did not seek to extrapolate the findings to all young adults with ADHD and it is highly likely that the experiences of people who chose not to take part may be different. Instead, it sought to gain a privileged insight into the lived experience of the participants who took part.

5.2.1 Recruitment process

Individual meetings, a presentation and information leaflets were provided to CAMHS clinicians to inform them about the purpose of the study and to identify potential participants. Information letters (appendix 6) were sent to potential participants, explaining the purpose of the study and asking them to contact the researcher if they were interested in finding out more about the study (appendix 7). The process of recruitment is described in table 6.

Table 6 Recruitment process



5.3 Informing participants about the study

Consideration was given to ensuring that the information given to participants was clear. The information sheet (appendix 6) was designed using IRAS guidance but was adapted to fit the needs of young people with ADHD by ensuring that it was not too lengthy and that the information was presented in an easy to understand format using clear and accessible language.

Potential participants were contacted by a letter (appendix 6), sent to them by the researcher, inviting them to take part in the study. The letter included an introduction to the researcher, information about the nature and purpose of the study and an explanation about what was expected of participants. Given the sample age range, it was likely that some participants were no longer living at home, in which case the researcher asked parents or carers to forward the letter on.

Participants were asked to register their interest by returning the request for contact form (appendix 7), or by sending a text to the researcher. All four participants contacted the researcher by text and two of them also returned the contact form. All the participants were contacted by telephone to arrange a convenient time to meet with the researcher and to ask if they had any questions about the study. A letter confirming the interview details was sent to participants.

5.4 Consent

In general, informed consent is a pre-requisite of conducting any research study and should be given by participants prior to commencing data collection (Ballinger and Wiles 2006; Smith et al 2010). Therefore, participants were asked to complete a consent form to confirm they had read and understood the information about the study and that they agreed to participate (appendix 8). Participant's consent was requested verbally and in writing at the beginning of each interview. The participants' GPs (appendix 9) were informed that their patient was taking part in the study, in the event that any of the participants required further assessment or referral on to another agency.

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It was made clear to participants verbally and on the consent form, that they could withdraw from the study at any time without giving reason. Participants were also made aware that, if following an interview they had regrets about things they said that they would be free to withdraw their interview data.

5.5 Confidentiality

All participants' names and identifying details were changed to ensure anonymity; this was discussed verbally with participants and included in the information sheet (appendix 6). Information was given to participants about how the collected data would be stored and disposed (appendix 8).

5.6 Ethical Considerations and ethical approval

Ethical approval for this study was obtained from the Integrated Research Application System (IRAS) and the National Health Service (NHS) trust, where the research was conducted. The role of the ethics committee is to ensure that ethical standards of research practice are maintained and to protect participants. Researchers are required to describe what processes they will utilise to address issues such as informed consent, possible risks to participants and confidentiality (Ballinger and Wiles 2006, p48; Smith et al. 2010).

At the beginning of each interview, it was made explicit that the interviews were confidential with the proviso that if any safeguarding issues were raised the researcher, with the participant's knowledge, would discuss this with an appropriate professional such as their GP or social services.

Participating in research may provoke a range of responses in participants, individuals may experience the process as enlightening and affirming or they may find the process unsettling or distressing (Patton 1990; Smith et al. 2010). The researcher is an experienced therapist who is used to talking with young people about difficult issues; the researcher was mindful that the focus of the interview was for a research purpose and not therapy and aimed to end the interviews in an empowering way.

Prior to carrying out the interviews, the researcher paid attention to the process by which a participant could be signposted on to appropriate services if further support was considered necessary. However, in the event, this was not needed.

The importance of identifying strategies to support participants if they become distressed during an interview, has been highlighted by several authors (Smith and Osborn 2004; Eatough and Smith 2006); it was decided if this happened, the interview would be stopped and the participant asked if they wanted to continue. Participants were told that the researcher would be happy to meet them, following the interview, if they had any further questions or wanted to seek clarity about any other issue connected with the interviews.

A list of help lines or advice to contact the participants GP was developed and offered to all participants at the end of the interview (appendix 10).

Although the participants could be perceived as being vulnerable adults, as a consequence of having ADHD, several processes were implemented to ensure that they were able to give informed consent and were fully aware of the possible implications of participating in the study. With reference to the Mental Capacity Act (Department of Constitutional Affairs 2005) the participants were assessed as being competent to give informed consent by their key workers and the inclusion and exclusion criteria meant that people who had ADHD with co-morbid difficulties were not included in the study.

5.7 Risk assessment

The University of Southampton and NHS trust guidelines were followed.

5.8 Data collection

Interviews were arranged with participants at a date, time and venue convenient to them. Three participants chose to be interviewed in a CAMHS clinic base whilst the fourth participant preferred to be interviewed at home. Three participants were accompanied to the interview by a partner or family member; consideration was given to the possible impact this may have had on

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the data generated as the participants may have felt unable to talk openly with someone else present during the interview.

The interviews lasted between 45 minutes and one hour and 20 minutes. At the beginning of the interview, an explanation was given about the purpose of the research. In an attempt to make the participants feel comfortable, the role of the researcher and the rationale for selecting the topic area was explained. Participants were assured that the interview would be confidential unless any concerns were to emerge regarding possible risk to themselves or others, in which case, this would be discussed and a decision made regarding what action should be taken. Participants were advised that the interviews would be recorded and transcribed and were asked for their written consent, they were also offered the opportunity to ask questions about the research.

A semi-structured interview guide (appendix 11) was used to collect data. The interview guide included questions informed by themes extracted from the literature review and clinical practice. The aim of the interview schedule was to help generate qualitative data about the participant's experiences of transition. A semi structured interview schedule was chosen to ensure that the broad areas identified from clinical practice and the literature were included, whilst allowing participants to describe their own narratives about their experience. Designing the schedule allowed for reflection on the particular areas it was hoped would be covered in the interviews

The interview schedule was designed to guide the interview with the questions being used flexibly. According to Smith and Osborn (2008), the benefits of this style of interviewing are that it allows the researcher the opportunity to explore in depth any important or interesting aspects that emerge, rather than focusing purely on the researchers identified areas of interest. Consideration was given as to how the interview guide could be useful in structuring the session by providing a framework, to ensure that interviews followed the same sequence and ran to time without being overly prescriptive. In addition, it was hoped that the guide could be useful to re- focus interviews, if the young person was going off topic.

Although the interview guide was informed by the reviewed literature and the researcher's clinical experience; the intention was to be open to new ideas, generate fresh understanding of the topic area and to track any original themes, ultimately allowing participants to tell their story.

Smith et al. (2010) have suggested that interviews should start with some general questions aiming to establish a rapport between the participant and researcher so allowing space for the participant to feel comfortable, before moving onto more focused and potentially sensitive issues. Therefore, interviews were opened with broad questions such as ease of travel to the interview.

Whilst the aim was to encourage participants to tell their story about their experiences of transition in their own words. The researcher's clinical experience of working with young people with ADHD, anticipated that some of the participants might struggle to talk at length, therefore, prompts were included in the interview guide to refocus interviews and gain more detailed information.

In addition, it was thought that some participants might experience difficulty in talking for more than a few minutes at a time, they might forget the question they had been asked, lose concentration, become distracted or lose focus. Therefore prompts were introduced within a conversational dialogue and not as questions and answers; finally participants were informed they were free to get up and move around as they wished or to take a break.

As a systemic psychotherapist and nurse, the researcher is experienced at interviewing young people within a healthcare clinical context. Smith et al. (2010, p57) suggested that an IPA interview could be framed as a 'conversation with a purpose' which led to thought being given to the types of challenges that might arise in the interview process. The following areas were considered, firstly, to be alert to the possibility that the interviews did not revert to a therapeutic stance and become therapy sessions. Secondly, that the interviews would be participant led. Thirdly, that care would be taken to avoid interpretation of participants' narratives and finally to be mindful that an

'expert position' was not taken, if participants were to ask for advice about their healthcare.

5.9 Pilot study

After some deliberation, a decision was made not to conduct a pilot study, the main reason being a concern that given the sample population, it might prove difficult to recruit sufficient participants for the main study. There are conflicting opinions as to whether pilot studies are necessary, Holloway (1997) suggested that as the interviews progress, the interviewer will naturally improve upon their interview technique and will refine the interview schedule based upon their experiences of conducting the interviews. However, this view is not universally accepted and several authors maintained that pilot studies are necessary (Robson 1999; Lacey 2007) to test the data collection tool and to make any necessary refinements to the research design, before embarking on the main study.

With this in mind, the Trust's adult service user group were approached to elicit feedback regarding the wording of the interview guide and the length of the interviews. In addition, the guide was discussed with some young adults and healthcare professionals to familiarise the researcher with the layout of the guide, check that the order of the topic areas ran logically and to ask for comments on how the guide might be improved.

5.10 Data analysis

Data collected was subjected to Interpretative Phenomenological Analysis (IPA). Smith and Osborn (2009) and Smith et al. (2010) provided a detailed description of the process of IPA analysis and recommend the use of a framework to structure the data analysis which was used in this study and is described as follows:

Step 1 reading and re-reading

In order to become familiar with the original data, recordings of the interviews

were listened to several times and the transcripts were read and re-read several times. It was discovered that with repeated readings, new information, ideas and areas of interest emerged.

Step 2 initial noting

The data from the first case was re-read and initial responses recorded. Smith et al. (2010, p83) observed, 'there are no rules about what is commented on' and go on to say that the aim at this stage:

'is to develop a comprehensive and detailed set of notes and comments on the data'

Smith et al. (2010) suggested that attention be given to identifying descriptive, linguistic and conceptual comments that arise in the text as a way of getting close to the participant's life world. A comprehensive and detailed set of notes and comments about the data was devised (an extract of a transcript showing the initial noting is included in appendix 12).

Step 3 developing emergent themes

The next phase was to identify emergent themes arising from the initial notes (appendix13). Smith et al. (2010, p92) have stated that the emergent themes:

'reflect not only the participants' original words and thoughts but also the analysts' interpretation'.

Step 4 searching for connections across emergent themes

Emergent themes were initially organised chronologically. A list (appendix 14) of the emerging themes was devised which was then examined, looking for connections. Themes that seemed to fit together were clustered into master themes (appendix 15); phrases or sentences from the transcripts evidencing the themes were noted. This process was repeated for each participant.

Step 5 moving to the next case

Steps one to four were repeated for all the interviews. Smith et al. (2010) discussed the need to approach each case afresh although they concede that the researcher will inevitably be influenced by their experience of analysing the

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previous interviews. A decision was made to leave two clear days between each analysis in an attempt to separate the new case from the previous interviews findings.

Step 6 looking for patterns across cases

Once all the transcripts were individually analysed, connections between the cases were looked for and a list of superordinate themes (appendix 16) was devised, including examples from the data.

A variety of themes emerged from individual transcripts, when the same themes were present in at least three of the participants' data, these were categorised as master themes. This process sought to emphasise the idiographic perspective which is intrinsic to IPA whilst allowing consideration of any convergences and divergences between the participants' accounts.

5.11 Quality assurance in research

Lacey (2006) stated that validity and reliability are two key concepts that require consideration when evaluating the quality of research. Quality assurance in research is essential; however, it is important to ensure that the evaluation methods used are fit for purpose. Smith and Osborn (2010) argued that it is inappropriate to evaluate qualitative research using criteria developed for quantitative research; similarly Pope and Mays (1995) have proposed that the strength of qualitative research lies in its validity rather than reliability. Smith and Osborn (2010) suggested that the following areas; sensitivity to context, commitment and rigour, transparency and coherence plus impact and importance (Yardley (2000) should be used as a framework for assessing quality in qualitative research. Smith (2011 abc) has outlined how these categories have been applied specifically to IPA research papers. The steps taken to address quality assurance in this study are outlined in table 7.

Table 7 Ensuring quality in IPA research

	Sensitivity to context	
Aim	Process	Evidence
Was the analysis process consistent with IPA: phenomenological, hermeneutic and idiographic?	Audit trail to show the process of analysis, moving from initial noting to master themes.	Excerpts from transcripts (appendix 12,13,14,15,16)
Did the findings demonstrate a sufficiently in depth analysis?	Audit trail to show the process of analysis, from initial noting to master themes.	Excerpts from transcripts (appendix 12,13,14,15,16)
Were the interpretations consistent with the data collected?	Each theme evidenced with a verbatim extract.	Findings grounded in verbatim extracts (appendix 12,13,14,15,16)

	Commitment and rigour	
Aim	Process	Evidence
Was the sample appropriate to answer the research question?	Development of inclusion and exclusion criteria	Included sample comprised participants to whom the research topic was meaningful (Table 5)
Was the data collection method appropriate for the study?	Interviews were semi structured - allowing flexibility for participants to tell their story	Interview guide (appendix 11). Interview training attended.

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	Commitment and rigour	
Aim	Process	Evidence
	in their own words. An interview guide was developed as a flexible guide for interviews.	
Was the researcher clear about her role in the interview process particularly when exploring sensitive issues and where the researcher is a clinician (Field and Morse 2002)	Supervision sessions to discuss tension between being a researcher and a clinician.	Reflexivity section (sections 5.12 & 7.18)
Was the data analysis idiographic and interpretive?	Audit trail to show the process of analysis, from initial noting to master themes.	Excerpts from transcripts (appendix 12,13,14,15,16)

	Transparency and coherence	
Aim	Process	Evidence
Was consideration given to the potential influence that other factors may have on the research process?	Supervision time was used to consider the potential for bias which may arise from the researcher's own experience and knowledge.	Statement regarding researcher's personal perspective on the research (section 7.18).
Clarity about steps undertaken in data	Audit trail to show the process of analysis,	Excerpts from transcripts (appendix

	Transparency and coherence	
Aim	Process	Evidence
analysis	from initial noting to master themes.	12,13,14,15,16)
Did it make sense	Use of supervisor to check the development of themes.	Evidence of process form initial noting to development of master themes (appendix 12,13,14,15,16)
Was the study consistent with the need to show it is IPA and not a thematic analysis?	Small sample size and evidence of detailed and in depth analysis. Evidence of an interpretative process.	Verbatim extract (appendix 12).
Acknowledgement that different researchers may extrapolate different meanings from the same data	Supervisor checking of themes to ensure that they are congruent with data and that one theme is not being privileged over another.	Evidence of process form initial noting to development of master themes (appendix 12, 13,14,15,16)

	Impact and importance	
Aim	Process	Evidence
For the study to provide an insight into the meaning held by participants about their experiences of transition	Maintain an idiographic focus throughout data analysis and description of findings.	Findings do not make generalisations about transition experiences of young adults and do not make recommendations for practice.

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Collins and Nicholson (2002) have recommended that once the data has been analysed that the researcher carries out a final reading to check the interpretations are grounded in the participants' narratives. This process proved to be helpful to the researcher, leading to the identification of some additional interpretations and meanings.

The stepped analysis of the collected data was discussed in supervision; however, it is important to remember this:

‘merely produces an interpretation agreed by two people, rather than an objectivity check’ (Yardley 2000)

and that ultimately the interpretations were subjective.

The four superordinate themes which emerged from the data analysis are discussed in the findings section. It is important to note that the four identified themes were only one interpretation of the data and it is highly likely that another researcher with a different set of experiences, training, knowledge and other influencing factors could have interpreted the transcripts differently.

5.12 Reflexivity

This section will introduce the concept of reflexivity and describe why it is important for qualitative researchers. Reflexivity is a key concern for all researchers, but particularly for qualitative researchers (Yardley 2000; Dallos and Vetere 2005; Brocki and Weardon 2006; Shaw 2001; Smith et al. 2010) and is increasingly becoming an essential part of the research process. Reflexivity is defined by Finlay and Ballinger (2006, p262) as an ‘immediate, dynamic and continuing self reflection’ with the aim of critically analysing (in this instance) the research process.

According to Willig (2001, p10), the concept of reflexivity requires researchers to reflect on how their own:

‘values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research’

Reflexivity is deemed a necessary component of qualitative research practice. Several studies (Horsburgh 2003; Dallos and Vetere 2005) have highlighted the importance of researchers being self-aware, so enabling them to consider how their own life experiences, values and preconceptions may influence the way they understand or give meaning to the data they collect. This view is supported by Clarke (2009) who emphasised the importance of reflexivity for IPA researchers, arguing that it is an integral part of the methodological approach. Clarke (2009) proposed that it allows researchers to critically evaluate their position and relationship throughout the research process from inception to conclusion and so minimise their personal influence on their findings (Sin 2010).

Reflexivity is also at the core of systemic psychotherapy practice and is an integral part of the training to become a registered therapist, utilising a range of techniques such as ‘live supervision’ and ‘reflecting teams’ to support therapists to develop their skills in this area (Stratton et al. 1990; Jones 1995b; Kavner and McNab 2005). In addition, (Kavner and McNab 2005) it is important for therapists to address ‘their own inner dialogues at an emotional and cognitive level’ to support the development of reflexivity.

There is an ongoing debate (Kanuha 2000; Asselin 2003; Corbin Dwyer and Buckle 2009) concerning the extent to which researchers can be truly objective if they research topics which are close to their professional or personal lives. Given that I worked in the field of ADHD and have close experience of ADHD it could be argued that I hold an ‘insider position’, meaning that I inevitably hold some preconceived ideas about ADHD and transition. As a researcher, I needed to hold the position as an ‘outsider’ and maintain curiosity; this felt familiar, as this is the stance I adopt as a therapist allowing me to hold on to my interest about the families I work with, rather

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than sharing my own experiences with them. This seemed to accord with Smith et al.'s (2010) description of a 'dance' that IPA researchers perform as they move between looking from the point of view of the participant (insider perspective) and standing alongside the participant and looking from an interpretative position.

6. Findings

6.1 Introduction

To help with the reading of transcribed data a number of standard transcription symbols were adopted; clarifying information has been included in square brackets ([]), ellipsis points indicate material omitted (...) and brackets (()) demonstrate a pause in the conversation. The exact words spoken by the participants during the interviews were transcribed and are presented as a verbatim account.

A total of four interviews were conducted. The sample comprised two men and two women aged between 18 and 19 years old at the time of the interviews. All the participants had a diagnosis of ADHD which was made in adolescence and all of them had previously attended CAMHS.

6.2 Introduction to the participants

Caroline was an 18.5 year old woman, who was attending a college where she was studying for a qualification in beauty therapy. Caroline lived with her mum and dad and older brother in an urban area. Caroline was discharged from CAMHS when she was 18.

Daniel was a 19 year old man who was currently unemployed; he was looking for work as a handyman and had several interviews lined up. Daniel was engaged and lived with his fiancée and her family in a semi-rural area. Daniel was discharged from CAMHS when he was 18.

Mark was a 19 year old man who was employed as a grounds man; he lived with his parents and siblings in an urban area. Mark left CAMHS when he was 18.

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Rebecca was a 19 year old woman who worked in a department store and lived with her parents and older brother in an urban area. Rebecca left CAMHS when she was 17.5.

6.3 Setting the context

The intention of the interviews was twofold; firstly, to explore the lived experiences of the participants' healthcare transition following discharge from CAMHS and secondly to understand from them what their continuing health care needs might be.

In order to talk about their transition experiences, the participants seemed to find it important to talk about associated features of having ADHD. It appeared they felt these factors may have had an influence on their transition between healthcare services. It seemed as though the participants felt a need to set their transition experiences within a context; that is, their ADHD running as a continuum, susceptible to external influences as they progressed from adolescence towards early adulthood and onwards.

From the data collected, it became clear there were several important issues that concerned the participants which although not specifically related to the transition process, appeared to have a continuing impact on their lived experience of transition and their continuing healthcare needs.

Following an interpretative phenomenological analysis of the collected data about the participants' thoughts on transition, four superordinate themes were constructed. The themes have been ordered chronologically, mirroring the trajectory of the participants' relationship with ADHD over time, beginning with their diagnosis and ending with the continuing impact of ADHD across their lifespan to date. The four superordinate themes are detailed in table 8:

Table 8 Superordinate themes

Superordinate theme one	Superordinate theme two	Superordinate theme three	Superordinate theme four
Personal experience of ADHD diagnosis and treatment	Impact of ADHD on self and relationships	Living with ADHD	Moving On

6.4 Personal experience of ADHD diagnosis and treatment

The first superordinate theme concerned the participants' experiences of the events leading to them being given a diagnosis of ADHD, the types of treatment they received and the approach of professionals.

Although these aspects may not at first seem linked to transition per se, what seemed to emerge from the participants' accounts was the on-going impact these issues have on them as they move into adulthood. The continuing influence of an ADHD diagnosis and their previous experiences of accessing services may have helped them consider what services they would find useful as adults and the attributes they felt were important for healthcare professionals working with adults who have ADHD.

Five master themes were reported that underpin the superordinate theme (table 9).

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Table 9 Superordinate theme one: personal experience of ADHD diagnosis and treatment

Superordinate theme one				
Personal experience of ADHD diagnosis and treatment				
Master themes				
1	2	3	4	5
The process and timing of diagnosis	How does it feel to be told you have ADHD?	Medication and me	Attending CAMHS	Who cares and who can I trust?

These are now presented in full detail:

6.4.1 The process and timing of diagnosis

The participants described in varying detail their recollection of being referred to CAMHS. They all remembered that there had been concerns about their behaviour at school and at home for a number of years. It was clear from their responses that they had experienced significant difficulties for several years before these were framed as ADHD. Rebecca recalled how:

Everyone just thought I was naughty (3.3)...my mum always said that there was something, what I was doing wasn't right (3.28-3.30).

It emerged that all the participants were given the diagnosis of ADHD when they were teenagers. Daniel and Rebecca recounted how, despite having previously attended CAMHS as children, they had not been given a diagnosis of ADHD and in fact Daniel was told that he did not have ADHD. Daniel and Rebecca's accounts gave voice to their sense of bewilderment and frustration about why or how they had attended CAMHS for so many years without anyone making a decision about how their difficulties might be explained.

Daniel spoke of his earlier experience of being referred to CAMHS which seemed somewhat confusing:

Yeah, this is like weird. I was in primary school (), cos (), I was disruptive and that, and they got me tested by a specialist. I got tested; they said I never had it [ADHD] (2.11-2.14).

Whilst Rebecca commented that:

I was diagnosed really late which was really bad (2.23-2.24) ...I had loads of different CAMHS workers...like, I was in counselling since I was like six...I done my counselling all the way through then someone [therapist] who works here...like she diagnosed me as soon as she met me (2.25-2.30)

and:

I think the worst thing was, that I was doing it for so long, like every week I would have to come like, for so long, and then the worst bit was, that nowhere else like recognised it (19.23-19.27).

Given that Daniel and Rebecca subsequently received a diagnosis of ADHD, it would be interesting to understand what sense they made of the discrepancy between how different professionals formulated their difficulties and the potential impact this may have had on their ability to trust healthcare professionals' judgements then and going forwards.

Caroline, Mark and Rebecca commented on how their mothers had been aware of their difficulties and that this had led to a referral to CAMHS. They reported that despite being seen at CAMHS, this had not resulted in them being diagnosed with ADHD. There may be several explanations for this; their mothers may have felt disempowered in attempting to pursue their concerns further. It could be linked to a sense of maternal self blame, a feeling they

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were poor parents, a lack of self-confidence or simply their concerns were not heard by the professionals they met. Rebecca explained that:

My mum always said that there was something like, what I was doing wasn't right (3.28-3.29).

This concurred with Marks experience that it was:

My mum's (idea), Yeah, cos I wasn't concentrating in lessons or nothing (2.9).

and Caroline who reported that:

We didn't know that I had ADHD, there was talk about ADHD and my mum had a feeling that I did (), and she looked it up on the computer and there were just loads of symptoms (2.12-2.16).

Their accounts contrasted with Daniel's narrative that his school initiated the referral at the point of crisis:

I done [sic] a serious assault, so the school got me tested (2.15)...I get hyperactive and once I start getting hyperactive I get bored with that ...I just start messing about...an' that and get myself kicked out of lessons...when I start getting bored I ...start...throwing stuff about and stuff like that (2.27-2.31).

It appeared that despite Daniel having been told previously that he did not have ADHD; his school was sufficiently concerned about him that they asked for him to be seen again.

A shared experience for all the participants was the relative delay in receiving a diagnosis of ADHD, their accounts of school life clearly portrayed some of the difficulties they experienced over an extended period of time. It could be assumed that this may have had a negative influence on their self-esteem as they struggled to make sense of what was 'wrong' with them and may have impacted

on their educational success. There was a sense of regret as to what might have been, if they had received their diagnoses earlier. In Rebecca's words:

It was about three years ago [age 16], I was diagnosed really late which was really bad, because then I wouldn't have had no trouble [sic] at school (2.23-2.25).

Caroline echoed this:

Basically, I went all through school and I had a lot of trouble at school (2.12)...It was when I had just finished doing my GCSEs [age 16], (2.17)...It was when I finished school, it was like when I had just finished school (2.15-2.16).

Daniel expressed his frustration that he had been told at primary school that he didn't have ADHD when in fact he did:

So going into year ten, halfway through year ten [age 15]...and he turns round and said 'you had it since you were born'. So one specialist got it wrong and the other one said I had it since I was born (2.14- 2.18)...he said I'd had it because of the way he said 'I was disruptive' (2.25-2.26).

Despite a prevailing sense of frustration about the delay in receiving a diagnosis they did not seem to question why this happened. Mark could not remember exactly when he was told that he had ADHD. There may be several explanations for this: a longer time period had elapsed since his diagnosis which may have contributed to him not remembering or he may have felt disconnected from the process:

I don't know (), I can't remember what age I was (.) I was quite young. Yeah, I was probably about thirteen (2.2-2.10)...I can't remember back then (3.16).

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Caroline and Rebecca remembered their experience of how their diagnoses were made, in particular the use of the 'QBtest'. Rebecca described her experience, a sense of shock when she saw the results:

I remember, I done that test with the camera, I remember seeing the first one, and seeing the second one, and then actually realizing, how () much I actually could not concentrate (5.3-5.6)...mine [the graph] was all over the paper, literally the whole paper was scribbled (20.3-20.5).

Caroline also remembered doing the Qbtest:

We come here just after I finished school, cos they asked us to come in, cos we had been to the doctors and I had to do a little test on the computer () the clicking thing [QBtest]. And then they diagnosed it [ADHD] (2.18-2.22).

From these extracts it seemed as if the participants had not fully participated in the assessment process and it appears that they felt as if their diagnosis was made as a result of their performance on the computer QBtest (the QBtest provides a graph of the core symptoms of ADHD). It may be the participants were able to remember this aspect of the assessment process in greater detail because it may be easier to conceptualise ADHD symptoms that are presented visually. There was a sense that they had possibly felt uninvolved in the decision making process.

6.4.2 How does it feel to be told you have ADHD

The way in which these participants described their responses to being given the diagnosis of ADHD illustrates the dilemma other individuals may encounter when they receive a label for their condition. There may be advantages in having a diagnosis; it may for example give a framework for understanding a problem enabling individuals and their networks to better understand the challenges facing them and to feel less isolated. However, for some people,

having a mental health label may lead to feelings of isolation, of being different and feeling stigmatised by others.

It was clear from the responses given by the participants that they experienced a range of emotions when they found out that they had ADHD. Rebecca described a feeling of relief because the diagnosis helped to better understand her behaviour:

Yeah, I felt quite glad, cos, then, like, there was a reason, why I was like I was, rather than everyone just thinking that I was an attention seeker..., I was kind of, I was pretty happy, not happy to have it but happy to actually understand why I was acting like the way I was (3.21-3.26).

Daniel expressed a sense of confusion and not understanding when he was told his diagnosis, which may be because the way he experienced other people who have ADHD did not match how he saw himself:

Don't know (), what they was going on about, cos I knew what ADHD was, cos I was around people with it and he said I had it because of the way he said I was disruptive (2.21-2.25).

Rebecca appeared to blame herself and felt guilty about how she had behaved in the past; she gave a moving description about her experience of not being in control of herself and not knowing why. It sounded as if she didn't quite understand the link between her behaviour and the diagnosis and felt too preoccupied with her behaviour and feeling guilty that it did not make sense to her:

I didn't really understand it at first like, like, I couldn't, I don't know how to explain it. I would say stuff, and then I would think why the hell did I just say that but I wouldn't be able to stop it, I just thought I would never be able to sit still or anything (3.9-3.12).

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Caroline's reaction to being given a formal diagnosis was initially emotional; this may have been her realisation that there was something officially wrong with her. It seemed that understanding her behaviour fitted with the symptoms of ADHD was reassuring because it helped her understand her own behaviour:

And then they diagnosed it so, I started crying () I started crying when I found out (2.22-2.24)... I really don't know why I started crying, I think it was, just the fact I knew I had it, it was all new to me, I didn't really know what it was all about... I didn't really understand what it was but I had read it up on the internet and when you look at the symptoms on there, it's just I thought yeah, I do that, and everything (3.2-3.6).

Mark's reaction to hearing that he had been diagnosed with ADHD highlighted his sense of feeling different. Mark seemed to come to the conclusion that he needed fixing and there was something wrong with him:

I thought I'd get put on tablets...I wasn't concentrating in lessons or nothing... I was just psycho in the head (2.8-2.12).

Although Rebecca was initially upset when she was told her diagnosis, she was hopeful that it could be positive; she thought it could mean things would change for her and that she might be able to access some care, support and understanding. Even though Rebecca said that she was most upset, she was very aware of her mother's relief at being told the diagnosis. There seemed to be a gap between their two positions, specifically in relation to stages of acceptance. Rebecca's mother appeared to have moved to the next stage and was looking for solutions whilst Rebecca was still grieving about the diagnosis:

Say I didn't get diagnosed then I would still be doing that (14-13.15)...

My mum was relieved that they had actually said, and that I could get it sorted out. Yeah, I was probably the most upset (15.2-15.4).

To a certain extent the participants appeared relieved at having an explanation of what was wrong with them and seemed to accept this without question. It seemed as if some of their uncertainty stemmed from not really having understood the information given to them about the diagnosis or how being given a diagnosis might change things. They needed to not only make sense of an abstract concept but had to deal with the emotional side of being given a label. There was a sense that they were not entirely certain about what the diagnosis meant, whether it provided a helpful explanation about their behaviour or confirmed their negative self concept.

6.4.3 Medication and me

It seemed that following their diagnosis of ADHD, all the participants were prescribed ADHD medication as part of their treatment plan. Their shared accounts suggested that there were several important issues concerning the use of medication. The positive benefits of medication on their ability to engage with daily living activities was highlighted. The following extract illustrated how Mark felt medication had helped him:

I was just psycho in the head [laughs]. () As long as I take my tablets I can concentrate and just get on with what I want to do. If I don't take the tablets I do nothing (), without the tablets I lose concentration at work and everything(), Yeah and I get really angry easily () I shout a lot (2.13-2.18). Yeah, my behaviour would be naughty if I didn't take them but as soon as I got put on the tablets I noticed I was concentrating in lessons and sitting down in lessons (3.2-3.5).

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Mark's negative perception of how he behaved without medication connected with Caroline's description of herself as:

A nightmare when I don't have my medication ... especially with my mum we clash loads when I don't have it [medication] (4.13-4.17).

Caroline stressed the importance of her medication and outlined how it helped her:

If I don't take my medication and I want to (), say if I want to () um, () like it helps me, () my medication, like at school and that and at college; if I am doing tests (4.6-4.8)...Yes, it helps me hell of a lot. I don't argue with people, I concentrate on my work, I get through my college days. It does help (5.14-5.16).

Rebecca concluded that taking medication had helped her immensely, particularly in the workplace and in helping her make sense of who she is; implying that she perceived her true self as the one without symptoms of ADHD or on medication:

When I used to go to work, I would have my tablets and I could learn so much more (5.9-5.11)... I found the most helpful thing was probably the tablets. That sounds really bad. Probably the tablets because they helped me understand who I actually was (12.21-12.23).

Rebecca described her mother's positive response:

My mum was just glad that actually they could control it because I was put on that [medication] stuff and then I could actually control my actions then. But after that, I just could like sit down, like now (3.30- 4.4).

Rebecca's mother may have felt that up to then ADHD had been having a negative influence on Rebecca's life and perhaps was hopeful that with the diagnosis would come interventions that would

support Rebecca in managing her symptoms, therefore minimising their impact. Rebecca reported how she had noticed positive changes since she started taking medication. Rebecca's mother may have felt they now had a framework for understanding Rebecca's behaviour, rather than it being constructed as intentional; it was reframed as something she needed support to deal with. Interwoven with this, may have been her relief in knowing that she had not done something to directly cause Rebecca's difficulties which may have enabled her to move forwards and see things differently.

Although the participants described how medication had helped them, what emerges from their accounts was a sense that somehow their behaviour without medication was not considered socially acceptable and therefore needed changing. Mark summed up how he felt without medication:

If I don't take the tablets I do nothing (), without the tablets I lose concentration at work and everything (). Yeah, and I get really angry easily (), I shout a lot (2.15-2.18)... My behaviour would be naughty (3.2). Yeah, my behaviour would be naughty if I didn't take them [tablets] (3.22).

And Caroline said:

My mum she needs to be there to remind me [to take medication] otherwise I would be psycho by now (5.19-5.20).

Rebecca recalled her experience of medication enabling her to sit an exam at school and her mother's positive feedback:

The first time she ever said that she was actually proud of me was I took my, I took a test [taking medication], I don't remember what it was for, and I actually sat through the whole test, cos I couldn't sit though it before, I would just walk out because I would get so bored and then I actually at through the

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whole test and that was the first time she ever said she was actually proud of me (5.14-5.21).

There appeared to be a perception that without medication they were naughty, angry and lacked control. It is unclear as to where these beliefs originate but it may be that they are a consequence of experiencing continuing failure at school and in their relationships.

In contrast to the other participants, Daniel seemed ambivalent about the benefits of medication, he talked about how he liked himself the way he was, he appeared to think that taking medication changed him into a worse person. He described its effect on him:

When I'm not taking the medication I am lively and stuff like that. When I'm taking the medication, I don't, I don't talk. I don't like taking it (3.31-4.4)... I just sit there like that. Sometimes, I get the shakes when I'm on them () and I sit there and me hands go and I start twiddling around with me hands (4.9-4.12).

There was a mixed response about the practicalities of actually taking medication; Mark's pragmatic statement may be linked to his positive view about how medication supported him to work:

I take my tablets in the morning (). They are all right because I don't have to take them like three times a day, it is only once in the morning and that's it... Yeah, every morning when I wake up (2.20-2.24).

If I didn't take my tablets, it would of, cos you got to use strimmers, grass, hedge trimmers. They won't let you touch them; they won't let me do that unless I actually took the medication (8.12-8.19).

Even though Caroline and Rebecca stressed the importance medication plays in supporting them in their educational and work environments, they both commented on how they didn't actually like taking it. Caroline said:

I don't like taking it. It gets stuck in my throat (12.6)... I hate taking my medication. I don't know why (), I don't know why, I just hate taking it (5.9-5.11)

and sometimes needed reminding:

They say (mum and boyfriend), 'take the pills now and take the pills' (4.17-4.16).

This statement may confirm Caroline's unexpressed belief that people prefer the medicated Caroline or it may serve to illustrate Caroline's continuing need for support from her family in managing ADHD. Rebecca appeared to feel the same way as Caroline about the need to take medication on a regular basis:

I don't really like taking tablets...I felt quite old... taking tablets every day but I think if I didn't have the tablets then I would still be the same. Because they help you think a lot more, you can actually think. I don't know what they actually do but you can actually think before you do something (10.24-11.1).

However in Daniel's case, taking medication made him feel physically unwell, which may have influenced his view about the efficacy of medication:

It don't really get into my system, cos, once I take it I throw up. I thrown it back up, so, cos then it's kind of in me system but only a little bit (3.24-3.26).

Given that the medication prescribed for ADHD is a schedule two controlled drug and is closely monitored when used in children and adolescents, it was interesting to note that the participants currently appeared to have little or no supervision of their medication. Indeed, it seemed as if they had assumed the responsibility for the titration and ongoing use of medication which seemed to cause them a degree of concern. In Mark's words:

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I just got on with my tablets, I get my prescription for my tablets and that's it (6.17-6.18).

And Daniel's:

I () kind of don't take it [medication] (3.15-3.16) ...I still get my prescriptions; I take them on occasions but not often (3.19-3.20).

And Rebecca:

They [GP] just give me tablets, like they don't ask you why. They gave me tablets. I went in there when I was starting my new job, I was like, I might as well get the tablets in case I need them (14.29-14.31).

Caroline recalled her concern when she was approaching transition at age 18 that she would no longer be able to be prescribed medication:

I am not sure when that [the medication] will stop (7.15-7.16)... [I thought I was] going to run out of medication, and yes, I just knew it would make things difficult (8.17-8.18).

Rebecca shared this view but she had decided to stop her medication in any case:

*It's like my tablets, I couldn't have them anyway (13.5)...
You are not meant to get them when you are 18 (15.1).*

For Caroline and Mark, medication was clearly perceived as a helpful way of supporting them to engage in the day to day tasks expected of them. Daniel's opinion about medication seemed connected to his experience that it did not seem to be working and Rebecca had decided to stop medication. However, despite their different experiences there seemed to be general agreement that support for them around medication was lacking and they seemed unsure as to how this might change.

Given the continuation of ADHD symptoms across the lifespan it was interesting that Caroline and Rebecca held the belief that once they were 18 and ready for transition from CAMHS, they would not be eligible for prescribed medication.

6.4.4 Attending CAMHS

All the participants were able to describe some of their memories about attending CAMHS. It appeared that Daniel and Mark received comparable interventions, they recounted how they had been offered regular appointments to monitor their medication which included physical checks which they seemed to find helpful. Daniel explained:

They (CAMHS) would, like, send me a letter and tell me you have got to be in on this day, in this time to see us to do your weight and everything (), then, and after they done that, they would say well (), we will send you another letter or give me another appointment to come back in another six months or something like that (5.8-5.13).

which was supported by Mark who said:

I used to have to go down there and get checked every three months (), my height and my weight () how I was doing on the medication () and what it's like being on the medication (5.20-5.24).

From their accounts there was a sense that they found the predictability of their appointments reassuring, it may be that at one level there was a sense of feeling contained and held in mind.

Caroline also remembered her contact with CAMHS:

Two years I was here, yes (), six or seven (), yeah, about two and a half years. Yes. But I only come here about four or five times. Once every six months (5.22-5.24)...

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(CAMHS) spoke to me about how I was getting on. Umm (), gave me leaflet if I needed to help, if I needed help for anything (7.12-7.14).

From Caroline's account it would appear that she had regular appointments at CAMHS and felt that she could access appropriate support as necessary. Caroline recounted how she found it helpful that she could ask questions if needs be and she appeared to be confident that her therapist would know the answers:

They obviously, they know a lot about it, don't they? So yeah, talking to them about it and them answering questions and that, that helped me (7.22-7.24)...When you go to the doctors (GP) they don't know everything, do they? They don't really know a lot, so when you come here (CAMHS) they know everything (9.9- 9.12).

6.4.5 Who cares and who can I trust?

All the participants stressed the importance of being able to develop trusting and supportive relationships with their healthcare workers. It seemed important for them that they were able to trust their healthcare workers professional judgment regarding the recognition and treatment of ADHD and that professionals should have an understanding about the impact of ADHD on functioning. Specific examples of incidents which appeared to illustrate a gap in the knowledge base of some of the professionals they encountered are highlighted.

Three of the participants talked about their experience of having been in contact with services when they were younger and how at that time ADHD had been excluded. Daniel shared how he had received conflicting information about whether or not he had ADHD:

He (doctor) turns round and said 'you had it since you were born'. So, one specialist got it wrong and the other one said I had it since I was born (2.16- 2.18).

This account was similar to Rebecca's experience:

I had loads of different CAMHS workers (), like I was in counselling since I was, like six...I done my counselling, all the way through, then [therapist] someone who works here, don't think she still does, she like diagnosed me as soon as she met me (aged 15); obviously I wish I just had her all the way through, from when I was little (2.9-3.6).

And Caroline's:

My mum did take me to the doctors a couple of times and they just said that I didn't have it and she spoke to the school a few times and they said no, no (13.26-14.2).

It would be interesting to consider how they made sense of the fact that despite having been seen in CAMHS as children, their ADHD was not recognised until late adolescence; by which time they had experienced significant impairment in their relationships with others and unsatisfactory academic achievement.

Another important issue concerned their view that there was a need for professionals to have an understanding of what it is like to have ADHD. Mark made it clear that he thought that professionals should know that:

Like it's harder for me to sit there and concentrate () and that if () and that I need to (), actually () and I need to concentrate and () to be actually able to sit there and talk to people (4.15-4.18).

Daniel strongly expressed his ideas about what he thought would be helpful:

I just know they should know what they're talking about...know about ADHD, what kicks it off, and that sort of thing, so they know what to talk about (9.4-9.9)... do

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the homework on it, know everything about it, it'll be easier to talk about it (9.17-9.20).

Caroline was in agreement with Daniel's view and said that:

If they didn't know anything, no, I would not like that, I wouldn't like to sit there and they say they was counselling me or something and they didn't know anything about it (14.21-14.24).

Central to Daniel's account was the issue of medication and not understanding the rationale for how his medication was titrated. It appears he experienced the decisions made about titration as a failure of collaboration and he was not really sure how much the doctor knew about medication and the reason why it wasn't working which he illustrated with the phrase:

I think they wanted me to be a guinea pig or something (7.24).

Daniel went on to express frustration that his medication still did not appear to be effective and wondered if it should be increased:

One doctor's tried to push it down [medication], and I wanted to put it up for a reason (4.18-4.19)...Started on Ritalin, Ritalin wasn't doing nothing, so they put me on something else. I was on that for a couple of months, that one started to wear off so they put the milligram up, so that started to wear off and now I'm on these tablets (7.19-23).

Daniel believed that his medication was not working properly, he appeared uncertain that anyone knew enough about his treatment to sort it out, which left him feeling anxious and potentially less likely to comply with treatment.

The quality of the relationship with therapists was considered important by the female participants. Rebecca's account highlighted

how she appreciated being able to have one consistent therapist and she thought she would have found it difficult to change therapist:

I probably wouldn't have gone to any other counsellor other than [therapist], because I trusted her and I opened up to [therapist] more than any other counsellor I have ever had (12.14-12.18).

The importance that Rebecca placed on being able to have a continuing relationship with a therapist was borne out in Caroline's account, which highlighted the difficulty she encountered in having more than one therapist:

I didn't really know them. I had two people, yes, two different people (12.19-12.20)

Both young women appeared to have clear ideas about how they would like their therapists to be with them, which to a certain extent, seemed to have been influenced by past unhelpful experiences and had led them to consider what they would like from a therapist. Caroline proposed someone that is:

Easy to get on with, not, I did have one doctor actually, and uh it was quite hard to talk to him, and it seemed like he was not really that interested, so, yeah, it would be someone I could easily talk to and feel comfortable around (14.16-14.19).

and went on to identify specific issues that she would find unhelpful:

Someone who does not listen. Someone who just doesn't show that they are interested. Like if they are looking everywhere and doodling on their board, writing... distracted [they are], at everything or leaving the room every five or ten minutes, just two seconds. Something like that, would annoy me (15.13-15.19).

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Rebecca continued, she described her experience of seeing a number of therapists whom it appeared had therapeutic styles which she didn't feel comfortable with. Rebecca stated that she would welcome a direct approach in sessions although she recognised that this was her personal position and therefore might be different for others:

I would rather they cut straight to the point, when I used to go to other counsellors here they would drag it out, seriously they would. (18.22-18.25)... I would much prefer someone to say, look you need to grow up...I would much rather someone gets to the point (18.27-19.1).

Mark's account suggested that he found it helpful to discuss his ADHD with his therapist; from his narrative this appeared to have resulted in him developing a better understanding of his condition and consequently being less critical about himself:

Head case? (Do you still feel like that?) No, cos when I'm on the medication, I'd actually gone to see (doctor) about it and I started to understand more about it (10.7-10.10).

One interesting aspect that was highlighted by three of the participants was their opinion that it would be helpful to speak to someone who has ADHD. They felt that these individuals would have a better understanding of the issues facing them and may have had similar experiences. In other healthcare care contexts such as rheumatoid arthritis and scleroderma, it is becoming increasingly common for the skills of 'expert patients' to be utilised. From the following extracts, it seems as if this is something that the participants felt that people with ADHD might find helpful. Daniel said:

When it's someone else who's got ADHD talking to me, it's easier cos they know what they're going through (9.9-9.1).

Which connected to Mark's view that:

*They should know what it's like to be on medication (6.7)
...That they've got patience for us, and they can sit there,
and they would actually listen to you, whereas there are
those people who haven't got ADHD, so they just won't
listen, and they don't realise what you've actually got
wrong with you (7.19-7.25).*

And Rebecca's:

*Someone that has had ADHD, I'd let them tell them, cos I
think you can explain more...I think you can explain it in
their way, like...I have to put it in different ways to make
other people ()...you can say it in a different way (17.28-
18.2).*

What clearly emerges from the data was the importance for the participants to feel a connection with the services and the healthcare professionals who were supporting them in managing their ADHD. They clearly stated the value of having contact with someone who has an understanding of ADHD and is able to support them in implementing strategies to minimise the impact of their symptoms on their daily lives. The participants seemed to appreciate being contacted regularly by services to see how they were doing. If some of these issues were addressed it might support effective transition between healthcare services.

6.5 Impact of ADHD on self and relationships

The second superordinate theme concerned the impact that ADHD had had on their sense of self and its influence on their relationships with their families, peers, school and the wider society. The participants' narratives conveyed their struggles to fit in and develop positive self-affirming relationships with other people

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across a variety of contexts. This may have had a resonance with their transition experiences; weaving through their accounts was a sense of spoiled identity, disempowerment and a lack of entitlement. These factors may have influenced their ability to voice their specific healthcare needs and may have influenced their engagement with services currently and in the future. Three master themes emerged from the data (table 10).

Table 10 Superordinate theme two: impact of ADHD on self and relationships

Superordinate theme two Impact of ADHD on self and relationships		
.....Master themes		
1	2	3
Mad Bad Who am I?	You, me and everyone I know : <ul style="list-style-type: none"> • Families and how to survive them • My mum and me • School days are not the best days of your life 	‘He’s not naughty he’s got ADHD’

6.5.1 Mad? Bad? Who am I’?

The impact of ADHD on the participants’ self-image was present in all the narratives. It seemed as if the participants believed that their problems are a reflection of who they really are and they seem to find it hard to separate themselves from their ADHD. ADHD appears to have disrupted their sense of self and they seem to have constructed potentially unhelpful meanings about who they are. Their negative self-image may be shaped by their experiences of being criticised and misunderstood by people they have come into contact with over a period of time. All four participants appeared to hold the view that somehow they are different to other people and

that there is something wrong with them. The language used by these adults to describe their ADHD was extremely poignant, highlighting how they saw themselves as possibly being mad or having something wrong with them that can't be changed. They seemed unsure about what ADHD was and there was a sense of feeling embarrassed and ashamed. Caroline and Mark used the pejorative term '*psycho*' as a descriptor for themselves. In Mark's words:

I was just psycho in the head (2.12-2.13) and a head case (10.7).

and Caroline's:

I would be psycho (5.20).

Mark and Daniel seemed to think there was something wrong with their brains, their understanding of what was wrong with them may be linked to the explanations they had been given about ADHD or as a result of the questions they were asked by professionals. Mark explained that:

I would say, it's () something to do with your brain () waves (), there's something wrong with your brain waves, it's not actually stopping me working or anything (7.10-7.16)

which seemed to connect with Daniel's experience:

Doctors ask me how me head [sic] is (4.17)...I just let them think it's me (8.18)...They just think it's something, that is all in the head (8.24-8.25).

It would be interesting to understand more about what having '*something wrong with your brain*' actually meant to them and how they might have then thought about this in relation to prevailing societal views about people who have a learning disability or a mental health problem.

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The meaning that people hold about their condition will inevitably influence their sense making of who they are, in particular whether they see themselves as separate to their ADHD or whether they feel defined by it. It was striking how much the participants seemed to struggle with their self-concept, seemingly unsure of where their ADHD began and ended and whether it was something external to or an integral part of them. Looking back Caroline reflected that she was:

A nightmare (4.14)...Probably that I was just a naughty child (14.4).

She continued, seemingly expressing her uncertainty about whether it was *her* that was bad or her ADHD; there was a sense that she was unsure about who she really was:

I blame everything on everyone else. That's what I do, I didn't really think I was that bad. When I look back on it now, I do think 'oh god, I was a horrible child' (14.6-14.9).

Rebecca perceived herself as different to other people whom she described as '*normal*', which suggests that she may see herself as abnormal or damaged in some way:

Normal people just get on with it don't they? Whereas I have to think about it (8.4-8.6).

Daniel considered that his ADHD had a negative impact on how he was perceived by others and appeared frustrated that they seemed unable to separate his ADHD from the real Daniel:

But it's me ADHD what is making me [sic] be me, if you get what I mean? So I just, let um think it's just me being me. Most people think, even when you say no, it's me ADHD. They say no, you just thinking it's that. So I just let them think it's me (8.13-8.18).

Daniel seemed to have convinced himself that it was not worth trying to explain who he really is to other people; his account highlighted how ADHD had interfered in his relationships.

Rebecca described how in the past she held a negative view about herself. At some point there seems to have been a move from seeing herself as the problem to an acknowledgment that it was her behaviour that was problematic. Rebecca appeared to have moved to a position where she had objectified ADHD as the problem and was able to see herself as having a separate positive identity:

I used to think I was a bad person... because everyone, I thought everyone hated me. And I used to think, I was a really bad person but now I know that it is not actually me, it wasn't, it was never me that anyone didn't like, it was just the outbursts. Now I realise that because I can control them I am not a bad person at all (7.7-7.14).

In the following account, Rebecca vividly described her experience of not feeling in control of her behaviour: She saw herself as bad, likening herself to a 'drunk' and there was a sense that she was unsure as to whether her behaviour was intentional, uncontrollable or a medical problem. Rebecca seemed worried about being out of control and was fearful about what she might say or do; central to her narrative was a sense of powerlessness and shame:

It just takes over (ADHD) (8.25-8.26)...You don't know what you are doing. It's as if you are drunk. That's what I think, if you are drunk you know, you say things when you are drunk and you think that if you were sober you wouldn't say it. I think it is like that, you will say things and you'll think why did you do it or you would do something and you would think why did I do that, I wouldn't have done that if I had thought about it (5.36-6.5)...It's like having () Tourettes it is the way you are, you just can't control it (9.7-9.9)...It's like something you

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wouldn't normally do and you know it's wrong in your head but you can't help doing it (10.16-10.18).

The participants shared their awareness of how the impact of ADHD on their functioning was observable by others; however it appeared that rather than being able to share their experiences, they had to protect people by agreeing with their perceptions of them or hiding how they really felt. Daniel pretended that things were OK even when they were not:

I don't like talking about it ...normally I keep it to myself. The GP says how's your ADHD going or anyone says how's it going, I go all right, even if it's not (7.13-7.15).

And then went on to say how he even kept his real feelings from his mother:

How me mind works and everything [sic], she (mother) didn't know the full ...cos, I wouldn't tell her (8.8-8.10).

Rebecca had made a decision not to tell work colleagues that she had ADHD and seemed to be saying that concealing it protected her from being subject to any pre-conceived ideas they may hold about how people with ADHD behave, which may provide an external locus of control:

I don't tell anyone I have got ADHD, my work people don't know (6.16-6.17)...I think it is better if people don't know and they don't expect you to kick off or whatever (6.20-6.21).

From Mark's perspective, it seemed that he also found it helpful to avoid telling others about his ADHD and this somehow helped him keep his symptoms under control:

I ain't told none of them (), they don't need to know, and then, and then I can't take it out on them and then we've

still got a good relationship going between us all (10.13-10.14).

The desire to protect others by not feeling able to openly share their perspective may leave individuals feeling isolated and different, Rebecca summarised this:

I think it is quite a lonely thing. I don't know, it sounds really sad really but it is not horrible lonely, but once you learn, then you don't feel like anyone else knows. Well you know they know but not in the same way as you know. It's really weird (14.20-14.25).

The participants' accounts highlighted the complex interplay between their beliefs, behaviour and relationships in the context of ADHD and how they positioned their identity within this. They alluded to their sense of isolation and shame and demonstrated a desire to protect others from their reality.

6.5.2 You, me and everyone I know

It was clear from the responses made by participants that ADHD has had an impact on their relationships generally. They recounted how their behaviour was often misunderstood and that they were seen as having negative traits, they mentioned particular things that other people might notice which they felt may have impacted on their relationships. These experiences could be hugely influential in the development and maintenance of their positive self-esteem, as other people's reactions may contribute to the way in which beliefs about self-worth are constructed.

6.5.2.1 Families and how to survive them

The impact of ADHD on the relationships between the participants and their families was clearly described. It seemed that prior to the diagnosis of ADHD being made, many of the families were struggling to understand and support each other. The participants

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acknowledged the individual impact of ADHD and its subsequent affect on their relationships with their families. They were aware that at times they may have been hard to live with and that this might have challenged their families' ability to support them. Caroline described how she thought her family may have experienced her:

I can be quite, I don't know, really () nasty. Yes, I can be quite mean (). Umm, I argue a lot with my boyfriend or my mum (11.12-11.15).

And continued by explaining how she and her mum had different perceptions about her:

My mum says I can be quite horrible actually, when I don't take my medication. Don't really see it myself... I don't argue with everyone (11.9-11.11).

Mark explained that his family recognised his mood swings:

They notice I am in a bad mood (2.28-2.29).

Rebecca's behaviour was such that it appeared that her family seemed to be treading on egg shells around her:

My mum could never tell me what to do because I would have an outburst (8.10-8.11).

and in Daniel's case this resulted in his mother becoming tearful and upset:

[She] was in tears one day (10.8).

Rebecca's brother seemed confused by her unpredictable moods:

My brother never understood how I could be so happy then just start crying (16.8-16.9).

From their accounts it seemed that whilst their families were aware of their distress and were sometimes on the receiving end of their offsprings' difficult behaviour, they may have struggled to

understand the reasons for it. It seemed that there was a sense of relief for everybody when the diagnosis was made. It appeared to help other family members understand why the participants behaved in the way they did and consequently appeared to have a positive impact on their relationships together. It may be that having an explanation for bad behaviour helps people master it; knowing that bad behaviour is not intentional may create a space for families to do something different.

In the following extract Rebecca described her relationship with her mother; it seemed that they both found it hard to make sense of what was happening with Rebecca presenting herself as being left with residual feelings of shame and guilt:

Like, I would say to my mum all the time, like I would do something, and say I am sorry, like I didn't know what I was doing and she would say, how can you? Like, she didn't understand (6.1-6.6).

Some of the things I have done, it's just awful. I never wanted to put her through it....you can't help yourself when you are at that point. I hope she knows I am sorry, I am sure she does (19.8-19.14).

Daniel highlighted how his mother experienced his behaviour prior to diagnosis as difficult and challenging; the diagnosis seemed to enable her to have had a different narrative:

She [mother] thought it was just me being me and to find out it's not, it's me ADHD [sic] making me the way I am. That's what most people don't get. They think it's just me being me (8.10-8.13)...Then she [mother] knew what I had going on in my head (10.7).

Rebecca told a similar story, her mother couldn't understand what was happening, having the diagnosis seemed to help her see Rebecca's behaviour differently. There may have been a sense of

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relief that rather than Rebecca's outbursts being intentional that they were part of ADHD:

I used to have an outburst and then I would say sorry to my mum and she would never get it, she would think I couldn't control it, until I found out I had ADHD and then she understood (17.20-17.23).

Daniel and Rebecca described how post-diagnosis, things changed and their parents were better able to understand them. This process may have challenged a previously held dominant narrative of hopelessness, blame and guilt, externalising the problem may have enabled the family to recapture their hope for the future and to offer support.

Rebecca's situation deteriorated to the point where it was agreed that she would leave home, however her aunt was able to step in and offer support. Rebecca experienced this as helpful; she acknowledged that she was able to allow her aunt to set limits for her in a way that she would never have tolerated from her mother:

When I moved to [place], it wasn't my mum and then I was on the tablets and she (aunt) could just come and tell me what to do and I would do it because I would listen, rather than just start to kick off (9.9-9.13).

Following diagnosis there appeared to be a shift in family relationships which could be attributed to having an explanation of why things were difficult or may be linked to the perceived positive benefits of medication on their ADHD symptoms. Caroline's response indicated that when she took medication there were fewer arguments:

My mum, we clash loads when I don't have it (medication) (4.14-4.15).

and when her family observed behaviour which they linked to her ADHD symptoms, they encouraged her to take medication:

My mum and my boyfriend, they notice a lot and they say, 'take the pills now, take the pills' (4.17-4.18).

Rebecca talked about how her family were initially tentative regarding the changes in her behaviour and seemed to find it hard to put history behind them:

When I first started taking it, my mum was, oh god something is going to happen because she thought it was all building up and I was going to have one major outburst. ... I had learned to, to talk about things, instead of letting them all get on top of me and then for it all to come out at once, at the wrong person (11.7-11.13).

Daniel's family were also adept at noticing the difference in his behaviour when he hadn't taken medication:

I know her mum and dad [fiancé] notice when I've not taken it, cos they ask me, they go 'have you taken your tablets'? (4.6-4.8).

Rebecca's narrative focused on the improved relationship that she had with her mother:

My mother wasn't worried about what to say to me anymore, she loved it (5.24-5.35).

and described how:

We are really good friends now, and, we could, never talk, we couldn't sit in the same room together. It's really nice I have always wanted a relationship with my mum (8.16-8.19).

It would appear that the different understanding her family had constructed about why her behaviour was challenging had allowed them to develop strategies for supporting her:

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My mum knows when I walk away to leave me alone. All my family, they are really good. If I get up and walk out, they know just to leave me alone and then I will come in and say sorry, now they actually understand (6.24-28).

6.5.2.2 My mum and me

The importance of continuing family support was seen as important for several of the participants who seemed to value the input from their relatives. Caroline discussed the important role her family and in particular her mum held in her life:

Yes, I have had support; they have been there for me whenever I have ever needed, especially from my mum. I've mentioned her a lot, yer, she is always there for me. She is always there for me, she helps me through it. (4.23- 4.27)...I just come with her [mum] anyway. Mmm, I feel less nervous, if I came in here today by myself, I dunno, I don't think I would have said as much. It's comforting having her (16.28-17.2).

Mark expressed a similar sentiment to Caroline:

Most of the appointments (attended with mum). No (did not consider attending alone) (7.4- 7.7)...I think she [mum] will carry on supporting me (9.27).

Daniel also found it helpful to have the involvement of his mum; he thought that it gave her some insight into how he was managing:

It was all right that way (mum attending), cos then she knew what I had going on in me head, what it can do and what it does do (10.6-10.7)...It's easier to take someone with me, but, sometimes they don't let other people in when I'm doing them (10.11-10.12).

From their accounts, it appeared as if ADHD interfered with the usual sequence of attaining life cycle goals, it seemed as if, for

some, the process of individuation from parents was delayed, with their accounts highlighting how much they continued to value and want support from others.

The participants' accounts demonstrated their awareness of how difficult they could be to live with and how this interfered with family relationships. Family life can provide a safe environment for diffusing external tensions, given their descriptions of the challenges facing them, it maybe that they found it easier to externalise their feelings at home with people they trust. Their descriptions of their family's tenacity to stick by their children was central. However, over time this pattern may have impacted on their family's collective self-esteem, worrying that they were failing in their roles as parents, siblings or other significant relationship.

6.5.2.3 **School days are not the best days of your life**

The responses given by the participants suggested that they were aware that their peers had noticed aspects of their behaviour which made them stand out in a group and had considered how this might be experienced and understood by others. Rebecca remembered:

Everyone just thought I was naughty (3.7-3.8)... that I was an attention seeker. That is basically what they thought (3.21-3.23).

and hypothesised that:

I think they just see me as a drama queen, because I make bigger deals out of things ...emotionally (8.17-8.19).

Daniel said:

I was disruptive (2.12)

and Mark observed that his peers:

notice that I am in a bad mood (2.28-2.29).

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Rebecca described how her behaviour at times may have been experienced as confusing to her peers:

At school I could be really happy, and then I could start crying, and everyone would be, what the hell is wrong with her (16.10-16.12)

Caroline's peers appeared to be very aware of her behaviour and noticed when things seemed difficult for her:

Some of the girls at college say 'you haven't had your medication today, have you'? (4.18-4.19).

A turning point for Rebecca seemed to be when she found out that she had ADHD which appeared to enable her to externalise it and see it as something that had an influence on her but was not an integral part of her:

As soon as I found out that it wasn't actually me that they didn't like, the bullying didn't bother me anymore. ...it's not actually me, they didn't like it's the hyper behavioural stuff, it was that (8.22-8.26)

Being part of their peer group seemed important for all the participants; it seemed that they have all had different experiences of this process. Daniel acknowledged that he was part of a peer group involved in anti-social behaviour. This may have been a consequence of wanting to belong so much that it didn't matter that the group was getting into trouble, or a desire to be liked, or an inability to regulate his impulsivity and therefore joining in without considering the consequences:

I think I was around with the wrong crowd as well, so I had to (), um act more (3.10-3.12)...When you're young and you've got ADHD it's hard cos you're round in the wrong crowds, they persuade you to do stuff, cos when you've got ADHD, they can persuade you by the click of their fingers (6.4-6.8).

Mark on the other hand felt he couldn't tell his peers about his ADHD and seemed to think that concealing it would enhance his relationships:

So I ain't told none of them (), they don't need to know (), and then, and then I can't take it out on them. And then we've still got a good relationship going between us all (10.13-10.16).

In contrast to Mark, Rebecca's friends were aware that she had ADHD. Rebecca described how they told her that they liked her as she was; however, she was not so sure, perhaps because of the negative experiences she had had when her ADHD appeared to have got in the way of her fulfilling her potential and getting into trouble:

They think it's funny, they generally think it is funny, I have one good friend who was in school with me at the same time...and she was, well I preferred you when you didn't take your tablets, and I said why, and she said 'because you were so hyper all the time'...so yes she prefers me hyper, but that's not a good thing (8.7-8.13).

Caroline was unsure about the extent to which her friends were aware of her difficulties; however she thought they noticed when she had taken medication:

My calm levels. I don't think, yeah they do realise. But sometimes, like, I dunno yeah they do realise (5.2-5.4).

Their accounts highlight the influence that their peer group had on how they see and came to know about themselves, their peers seemed to act as a barometer of how socially acceptable they were to be with. There was a sense of them acting like social chameleons and adopting an 'I am what you want me to be' stance.

An important issue for all of the participants was how ADHD had affected their lives at school. There was an overwhelming sense of being misunderstood in the educational environment and they gave

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detailed descriptions of how difficult they had found it to sit still, participate in lessons and fulfil their academic potential. There was a shared experience of constantly experiencing failure and being exposed to negative criticism about their behaviour. Mark described the challenges he faced at school:

Like it's harder for me to sit there and concentrate (), and that if () and that I need to (), actually (), and I need to concentrate and () to be actually able to sit there (4.15-4.18).

Rebecca described how:

I found it really hard to concentrate, like on my school work (4.19-4.20).

Caroline simply said:

I can't concentrate (4.9-4.10).

They cited how challenging it was for them to sit still and how their behaviour was frequently perceived as disruptive:

I get hyperactive and once I start getting hyperactive, I get bored with that, I just start messing about () an' that and get myself kicked out of lessons (), when I start getting bored. I () start () throwing stuff about and stuff like that (2.8-3.1) (Daniel).

I just thought I would never be able to sit still (3.13-3.14) ...I couldn't sit in the classroom and also I was getting told off for always standing up, was always fidgeting (4.14-4.16) (Rebecca).

It appears that in this context, their behaviour seemed to have been constructed as 'bad' and unacceptable rather than part of their ADHD and therefore they were punished rather than supported; they described how they would 'act in the moment':

I used to just get up and walk out, save them kicking me out (3.5-3.6) Daniel.

Caroline described how she struggled to regulate her emotions, finding it hard to verbalise her distress; instead behaving in a way that led to her actions being misunderstood:

Yeah, like when I get angry I cry and when I went to college the other day I had not had my pills even when it was not my fault. I got on the wrong train to London and like when I got back to college she did not let me explain, she just said get out, get out of the classroom because they do not let you in if you are late and so I slammed the door and I burst out crying, you know when you cry really badly and I couldn't breathe (11.18-11.25).

Rebecca added to Caroline's statement, she described how hard she found it to concentrate and to keep her emotions in check, recalling how she found it difficult to self-regulate:

My biggest thing was concentration and my highs and lows, I would come from a high and I could literally, in two seconds, I could be on a complete low. My brother never understood how I could be so happy then just start crying. I think that was the hardest thing because at school I could be really happy and then I could start crying and everyone would be, what the hell is wrong with her, and then I don't know. Now, though I get really emotional sometimes. I don't let myself get on a high, I don't drink because I know that if I drink then I am going to, it clashes completely so I don't drink so I smoke instead which helps me (16.4-16.17).

In both Caroline and Rebecca's accounts, there was a sense of regret for how school life could have been different and a perception that they had lost the potential they might have had to succeed

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academically, both at school and even at university. Caroline believed that:

I probably, I would not have got myself in trouble so much at school and I would have stayed in school and would have probably passed all my GCSES (13.20- 13.22).

Rebecca shared this view, she felt that:

If I was diagnosed before then, I would probably have had a better school life (7.26-7.27)...I would probably be at Uni by now (19.30-20.19).

Caroline's statement seemed to encapsulate all the participants' experiences of school life:

I had a lot of trouble at school (2.12).

Given the negative accounts of their time at school, it may be the participants felt this was relevant to their healthcare transition, as moving from an educational to a work place setting is a transition in its own right. Their experiences of ADHD messing up their school career may have led them to question how they would manage in the workplace and whether they would be exposed to continuing negativity about their capacity to function effectively.

6.5.3 'He's not naughty he's got ADHD'

From their accounts it seems that there is a dominant theme that very few people have a good understanding of ADHD. ADHD is a disability which can manifest itself in socially inappropriate behaviour by people who on the surface appear not to have any difficulties. ADHD may be misunderstood by the media, the general public and a variety of professionals, leading to a misconception that ADHD is wilful and due to poor parenting. Caroline reported that she saw a posting on a social media site which suggested that ADHD is a fabrication:

I read something on the internet, I think it was on Facebook and there was a woman saying that children and young teenagers and that (), they don't have ADHD and there was no such thing and it was just attention seeking (3.9-3.13)

and she continued, explaining how this had made her feel:

It makes me angry if people say we are just doing it for attention. Like, well, I'm really not (3.18-3.20).

Caroline suspected that most people view ADHD as:

They probably just think, most people, they probably just think like, it is really hyper, children but it is a lot more than that (17.19-17.21).

Caroline's experience supports the belief that some people think that ADHD is a contrived condition. This may explain the participants' view that in order to know ADHD you have to have some sort of personal relationship with it. Mark said that:

There are those people who haven't got ADHD, () they just won't listen and they don't realise what you've actually got wrong with you (7.22-7.24).

Rebecca echoed this view:

I don't think they understand really. I don't think anyone can really understand unless they have been through it or someone tells them what it is like (10.1-10.5).

Daniel had experienced a variety of reactions to his ADHD, he discussed how, in some jobs, it was seen as a positive attribute:

The construction industry love people with ADHD. They'll take anyone () if you've got it (), because they know with hands on they'll be fine (12.1-12.4).

However, he had also experienced that:

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Some jobs, once they see you've got ADHD they don't want you (11.26-11.28).

and added that there still seemed to be an underlying concern from employers that people with ADHD might be unpredictable:

In case you turns angry or aggressive or sort of like that but most of them aren't that bothered because hands on you're fine, and stuff like that (12.11-12.12).

Rebecca summarised her view that she thought it helped if people had experience of ADHD; she discussed how her mum's understanding of the condition changed once Rebecca had received her diagnosis:

My mum understands a lot more about it because I have it. (8.26-8.27)...I think if you have ...it in your family, someone in the family, then you understand, but I don't think you can. My mum will say that you can never actually understand unless you experience it, because ... she has experienced it, then I know she understands more than someone that hasn't really experienced it, does that make sense? (15.18-15.25).

This superordinate theme gave voice to the participants' views about how ADHD had disrupted their sense of self and agency and had had a significant impact on their relationships. They described feelings of not functioning as they should, which may be based on their experience of how other people reacted to them and so influenced the opinions they had formed about themselves. They seemed to have an idea that somehow they needed to create a new and different identity in order to fit in. Going forward into adulthood these residual feelings of shame and disappointment may impact on their ability to form relationships generally and they may need continuing support to address them.

6.6 Living with ADHD

The third superordinate theme concerned the participants' experiences of living with ADHD, in particular how it had impacted on their lives personally and in their educational and work environments, then and in the past. Given that ADHD is a condition that continues throughout the lifespan, it is unsurprising that the participants considered that it had a relevance during transition and onwards. Three master themes emerged from the data (table 11).

Table 11 Superordinate theme three: living with ADHD

Superordinate theme three Living with ADHD		
Master themes		
1 Managing ADHD	2 Nobody knows me better than me	3 Decision making and responsibility

6.6.1 Managing ADHD

The participants gave detailed descriptions about the negative impact that their ADHD symptoms have had on their ability to engage on an equal footing with their peers in daily living activities. From their accounts it was possible to gain an impression about how their experiences may have negatively impacted on their self-esteem and sense of agency. They identified specific issues that they had found distressing and that had been hard to manage. Daniel and Mark mentioned their poor organisational and motivational skills which had led to them forgetting to make appointments with their GP:

I have got to make an appointment. I say I'll do it, but then I forget (5.16) (Daniel).

Findings

I have to go into town to go and see my Dr. I haven't registered with the Dr's up on the corner there (9.9-9.11) (Mark).

Daniel and Rebecca described how hyperactivity which is one of the core symptoms of ADHD manifested itself:

I get hyper (7.29) (Daniel).

*I just thought I would never be able to sit still (3.13-3.14)
...Hyper, but that's not a good thing (8.15) (Rebecca).*

Difficulty in concentration was an issue described as problematic by several of the participants. Rebecca described her struggle with focusing on a task, characterised by her difficulty in reading books and an inability to attend to detail:

I scan read it, I don't even read it, it's weird. I can't read books they just bore me. I would much rather watch TV... I think it is because when you are reading, your mind goes everywhere else...and then you don't actually know, whereas when you are watching telly you can just catch up on the story line, whereas when you are reading you are, like, 'what's going on?' (14.1-14.9).

Rebecca's account highlighted the difficulties she experienced in undertaking what would be considered an everyday task, describing the challenges that ADHD symptoms such as inattention can pose. She had found that watching television did not challenge her in the same way and therefore possibly potentially minimised her exposure to activities in which she might experience a sense of failure.

Caroline maintained that without medication her concentration was so poor that she could not carry out specific tasks:

If I don't take it [the medication] and I can't concentrate whatsoever () so that means I can't do that (4.9-4.10).

Rebecca queried whether her difficulty with maths was somehow connected to her having ADHD and wondered whether her poor concentration meant she was unable to focus enough at school to gain the necessary knowledge base:

I can't do my times tables. I don't know if that was anything to do with it, but I have never been able to concentrate on numbers (4.24-4.27).

Another key area identified by the participants was their inability to self-regulate their emotions. They described how they were unable to control their feelings and ended up shouting or lashing out, they realised that this was unacceptable but felt powerless to intervene. Rebecca's account demonstrated this:

I done [sic] some bad stuff, like I would just be sat there and then my mum would say something and I would take it completely the wrong way and then I would end up, like, throwing chairs, getting really angry, because I would not know why I was acting like it, so it made me more frustrated (4.9-4.14).

As did Caroline's:

Really bad shouting and that () and I can't seem to calm myself down and then I cry and cry and cry (11.16-11.17)

who went on to say that she was often unaware that she might be seen by others as hard to be with:

I don't, don't do it to attention seek like. Cos sometimes. I don't realise I am being irritating like I can be really loud and () sometimes I do know and other times I don't (3.14-3.16).

Findings

6.6.2 Nobody knows me better than me

All the participants expressed similar views concerning the personal responsibility they assumed for their ADHD. Despite their narratives suggesting that they often felt unsure as to how much they were in control of their ADHD and to what extent it controlled them, they generally accepted responsibility for their behaviour. Caroline was clear that that she had to take some responsibility:

I can't obviously blame it all on the ADHD (13.22-13.23).

My interpretation of the following excerpt is based on my clinical experience in the field. It is possible that having a diagnosis of ADHD might be used to explain behaviour that could be considered socially inappropriate or a way of justifying losing control. However when Daniel said:

I done a serious assault (2.15)

the way I understood this statement was, it implied Daniel accepted responsibility for his behaviour and did not seek to excuse it. Rebecca observed that it was possible to take personal responsibility, however she acknowledged that this was hard to achieve and gradually happened over a period of time:

I think I have learnt to control it a lot, just to be able to sit here and control it. Normally I would have to walk around or something (3.14-3.17)...It is something you kind of need to do on your own. You have to do it on your own otherwise you never actually understand (13.2-13.5).

Rebecca described how having stopped taking medication she had had to address the issue of self-control and described a strategy that worked for her:

I don't take the tablets any more so I try and do it on my own (4.4-4.5)... now I just walk away from anything (6.30)... You can train yourself to help it (10.9-10.10).

Mark seemed unsure about whether he could take responsibility for himself. Although he expressed his conviction that he should as an adult be able to manage himself, he actually did not feel very confident about it:

I'd have to have self-confidence not to take it (the medication) be more confident about managing (6.10-6.12).

Three of the participants continued to take medication, however Rebecca had made a decision to stop taking medication and to manage her symptoms on her own. Rebecca's knowledge about when medication could be helpful, led her to approach her GP to collect a prescription when she started a new job:

They gave me tablets, I went in there ...when I was starting my new job I was like, and I might as well get the tablets in case I need them (15.10-15.12).

Mark seemed sufficiently confident to manage his own medication and collected his prescription when he needed to. Mark seemed to believe that it was unnecessary to see a doctor without a clear reason, which may be that he felt he had enough knowledge of his condition to manage his treatment or it may be he worried (as he indicates later on in the interview) about wasting professionals' time:

I ain't needed to contact no-one about it (). I just got on with my tablets, I get my prescription for my tablets and that's it (6.16-6.18)...If I don't need to see him there is no point in going to an appointment (9.7- 9.9).

Daniel described his in-depth knowledge of how medication works and described how his body seemed to have developed a tolerance to the dose:

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When I get used to it, it wears off after about half an hour of me taking it... The capsule stays in your stomach but just releases a little bit (3.24-3.30).

Daniel would like to see his doctor for advice about the correct dosage:

Knowing if me tablets have got to go up or come down (6.28-6.29).

Daniel's account seemed to imply that he believed he had more experience of managing his medication than the professionals he met, there was a sense that he was not sure how decisions about his medication were made and wondered why:

They switched my tablets so many times (3.20-3.21).

Rebecca described how the medication gave her 'thinking' time, which may have had a positive influence on her functioning and consequently on her self-confidence and self-esteem. She had come to the conclusion that the positive changes were not necessarily solely due to medication but that she also had played a part:

When I was taking the tablets I could think, it sounds really weird but I could actually think about what I was doing, so I thought well, surely it is not just the tablets doing that, it must be me as well, thinking' (6.22-6.27).

The participants described a range of practical strategies that they had found helpful and their own unique ways of approaching the challenges facing them. Daniel observed that he managed better in situations where he could be kept busy and utilise his practical skills with good effect:

When I'm sat there doing nothing, it just comes and I get bored and once I start getting bored I get agitated, then the ADHD kicks off. I've always been that way since

school. If I was hands on I was fine. If I was sitting in classroom writing I wasn't (8.23-8.28).

Daniel was clear about the sort of employment that would not suit him:

When you're just sat in an office doing paperwork after paperwork it gets boring and that's when your ADHD kicks in (12.12-12.14).

which had influenced his decision making about the type of jobs he applied for:

The jobs I go for are hands on and when I am hands on I am all right (8.22-8.23).

Similarly Rebecca had noticed that working had had a positive impact on her symptoms, she liked being busy:

I think it is because [when] I am working it takes all my energy as well. Whereas before, I was doing nothing, it was just winding me up (3.18-3.22).

and she recommended getting involved in things, keeping busy and minimising the time available to become bored and fed up:

I think if you challenge yourself then you are not thinking about it, If you are just not doing anything, then you start thinking about it more....I will always have to be busy and get involved in stuff (7.21-7.25).

Rebecca found it helpful to establish a daily routine and that this coupled with an acceptance of having ADHD seemed to encourage her to take charge of her ADHD. Rebecca put a routine in place when she was first living on her own and described the positive benefits:

When I came off the tablets I made a routine ...then I just stuck with the routine and it has worked. ... I can still concentrate more ...I think it is because you know that

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you have got ADHD, you know that you can actually concentrate...it you just have to beat it I think (7.28-8.3).

Rebecca stressed the importance of being in a relaxing environment and having space to think things through. This strategy may have served to assist in reducing the competing stimuli which people with ADHD often struggle to manage and can lead to them feeling stressed and hyper-aroused:

It is a whole different life in [place], so much more relaxed compared to here, it helped me there wasn't so much busyness and it helped me actually understand what was going on more. I would just go to the beach and that was it ... To think about things and I had a lot more thinking time there, whereas here I was always round people. So I could never actually think about it because there would always be ...take your tablet (11.25- 12.3).

Rebecca discussed her mastery of ADHD as a continuing challenge and described her view that it was important to experience a thing in order to overcome and manage it:

Once you go through the process you understand and once you learn, you teach yourself (14.17-14.19).

Caroline, on the other hand, gave the impression that she continued to rely on her mother to modify the impact of ADHD and to alert her to it:

Mum will say, 'look stop it now, you need to calm down' (3.17-3.18).

Rebecca's account described in detail what she had learned about herself and in particular how to manage her ADHD symptoms. Rebecca described how she had identified potential triggers and moderated her behaviour accordingly:

I don't let myself get on a high, I don't drink because I know that if I drink then I am going to, it clashes completely, so I don't drink, so I smoke instead, which helps me (16.4-16.17).

she managed her hyperactivity symptoms by:

That's why I wear [bracelets], and then I just play with these...I just fidget all the time (4.17-4.19).

and her impulsivity symptoms:

I just kind of trained myself to think before I do things...you can feel when you are going to kick off. I never knew how to stop it (6.27-6.29).

The participants' knowledge of their condition did not seem to be restricted to their home and personal lives. The participants identified ideas and strategies which they felt were helpful in a school environment. Daniel described his method of coping; unfortunately it appears as if this was not acceptable in the school environment and possibly led to further criticism:

But I found a way of, like, controlling it like, is like doodling when I was in my lessons and that, drawing on pieces of paper kept me calm... Drawing on pieces of paper kept me calm, but most of the teachers didn't let me (3.1-3.5).

Rebecca had found visual learning strategies helpful. It may be that drawing something makes it more interesting and eye catching and reduces the possibility of becoming bored and distracted:

I think that if you are learning, it should be visual learning, because you get bored otherwise, if it is just a piece of paper. Like seriously, you get so bored, Even now, I don't know, I would say, like, draw things out, like do it visually, because like a piece of paper, even when I read it

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now, like I just get so bored? I just skip right to the bottom... I can't read, I can't physically read the whole thing (13.24-14.1).

And Caroline's strategy was to enlist the support of her teachers:

I can't concentrate whatsoever () so that means I can't do that () so I have to say [so] to the teacher (4.9-4.10).

This theme has demonstrated the depth of knowledge held by participants about their condition; what it was like to live with ADHD and what they had learnt about how to manage symptoms. From their accounts it seemed as though they were able to effectively manage certain aspects of their ADHD. However there appeared to be a sense that if they did need support they would not know how to access it. Although they appear to be well informed, there seemed to be an underlying concern about the depth of knowledge held by some health professionals which may have influenced their engagement with health services currently.

6.6.3 Decision making and responsibility

The extent to which participants were involved in making decisions about their healthcare was raised by several participants, this seemed to be an important issue that needs consideration leading up to and during their transition to adult orientated services. From their accounts it appeared that they held differing views and have had different experiences of this process. Mark's perspective was that he felt he had been involved as much as he wanted, however he acknowledged that this may vary between individuals:

I had enough involvement in it, yeah; I guess some people might have no involvement and some people might want lots of involvement. I had enough of it (8.27-9.1).

Rebecca felt she should make decisions for herself:

My mum wasn't involved...I had the choice of what tablets, if I wanted to be on them and I came in on my own to do the test. I didn't really need, if I wanted my mum there she would have been there, but sometimes you just have to do it on your own (20.14-20.19).

Daniel on the other hand seemed to have felt ambivalent and almost passive about his involvement in making choices about his care. In the first extract he described a session where he and his mum together made the decision to turn down medication:

They commented on me switching me tablets (), when they would tell us about me tablets, which ones they wanted to put me on and the side effects and stuff like that, then it was then, cos I think they was going to put me on ones which could make you commit suicide. So me and me mum turned round and said no, we're not going on them. So ...I just left it to them (9.24-10.1).

However, in the following extract, Daniel seemed unable to express his views about his treatment, instead allowing professionals to make the decision for him with the proviso that if they did not get it right he would not adhere to treatment:

I just left it to them, cos if it wasn't the right decision I wouldn't take me tablets [sic]. So I just left it to them to make the decisions...they would tell us about me tablets[sic], which ones they wanted to put me on (9.17-9.25)...I just left it to them (10.1).

Rebecca and Caroline described the support they required from their mums to help them to remember to take their medication:

All the time (forget to take medication), unless my mum reminds me.my mum she needs to be there to remind me (5.18-5.19): (Caroline).

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*Every day she (mum) would tell me to take my tablets
(11.3-11.4): (Rebecca).*

It seemed as if these two women were struggling to assume full responsibility for taking medication, or it may be an example of how poor organisational skills and short term memory difficulties commonly associated with ADHD impacted on their ability to make and comply with decisions they had made about their health.

One of the major decisions made by Caroline concerned whether she felt she needed continuing support post 18:

The last time I came in and they said about my ADHD and they asked, 'did I want to carry it on (accessing services) or not carry it on', 'yes', that I said, yeah (15.21-15.23).

What clearly emerged from Rebecca's account was her rationale for taking responsibility for making decisions for herself; she felt this meant she was less likely to place the blame on others when things went wrong, therefore presumably preserving relationships:

If it goes wrong you are going to blame that person...I always try and put the blame on someone else, it's not my fault. Whereas now I just admit that I am wrong. I used to always put the blame so I probably wouldn't have let my mum decide anyway. She probably wouldn't have decided (20.23-20.29).

This superordinate theme highlighted the participants perceptions about the continuing impact that ADHD had on their lives. It was clear from their responses that they had developed strategies that seemed to be helpful to them.

Their narratives highlighted the extent of their knowledge about their condition, however as they progress into adulthood and encounter different challenges it would not be unreasonable to expect that they will need support to develop and refine their

strategies for managing the negative aspects of their ADHD symptoms.

6.7 Moving On

The fourth superordinate theme concerned the participants' experiences of the process of transition. Their interview data emphasised an absence of clear processes available to support their own transition.

ADHD has a continuing impact; it doesn't allow for stops and starts which is in contrast to the provision of healthcare services, which seem to come to a pause or an ending at the point of transition into adult services. Therefore from a service user perspective, healthcare transitions which are reliant on service criteria may be experienced as an artificial situation and incongruent with the continuing nature of chronic health conditions. Several important issues were identified which the participants considered should be voiced (table 12).

Table 12 Superordinate theme four: moving on

Superordinate theme four Moving On							
Master themes							
1 Preparation for transition	2 Transition timing	3 'Mind the gap'	4 What can I do?	5 Abandoned	6 Growing out of ADHD	7 We're adult now'	8 Ideas about support

6.7.1 Preparation for transition

The participants described their experiences of being prepared to leave CAMHS and recounted what this was like. There seemed to be a consensus that preparation for this was patchy, leading to some of the participants formulating their own ideas about what the process

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would be like. Mark's example appeared to illustrate how his belief about transition stemmed from his observations of other young adults leaving CAMHS:

No (not talked to about leaving service at age 18) I knew straight away, because I knew other kids that was going there () and that's when you have to go back to the GP (4.3- 4.6).

Both Rebecca and Caroline had received letters informing them that they would be transferred to another service for continuing care. Caroline's letter seemed to suggest that her medication would be stopped and she might have to travel further afield to receive care, which clearly bothered her:

When I got the letter (), because they told you that you are not allowed to have medication past age...so obviously we was all worried [sic] about that...CAMHS told me that () because apparently you had to go to adult (), like somewhere in London (5.25- 6.3).

Rebecca's letter arrived when she was in the process of moving house. At this time Rebecca was nearly 18 with only a few months left before a formal transition into adult services would occur. Rebecca decided that:

when the letter come through [sic] I thought that I might as well try and do it on my own (11.19-11.20).

Daniel was told in person that he would be transferred to an adult service; however at the time of the interview he had not heard anything:

They said they were going to refer me to a different specialist for adults, and they haven't yet (4.22-4.24) (Daniel).

Mark was told that he would be seen by his GP; however this had not yet happened:

They (CAMHS) said to me that I was being transferred to your GP now () and that it was every six months I would get seen (3.16-3.19) (Mark).

Caroline's experience of being prepared for transition seemed to leave her with an idea that there was an adult service she could access, however she didn't seem entirely clear about how she would access the service:

I thought like, () I thought, well, like, we are not going to have CAMHS or anything like that anymore, once I was, that was it, that is what I thought and then they said that there was an adult one (10.26-10.28).

The participants' accounts highlighted confusion on the part of healthcare professionals and themselves about what services would be available, where they would be located and at what point they would be transferred.

6.7.2 Transition timing

The timing of transition was seen as an important issue. There was a consensus of opinion that the point at which transition occurs should be flexible and arranged on an individual basis. Several of the participants felt that children should get a priority over adults and they appeared to hold a belief that health services equipped to meet their needs were in short supply. They seemed concerned that younger people should be able to access the support they need, it almost seemed as if they worried about taking up too much time from services which they felt might be better used for others. Mark thought that once people were better they should be seen by their GP:

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If they've actually progressed then they could go and see their GP and let other young people get seen (5.8-5.10).

Daniel and Rebecca shared the view that priority should be given to younger people. This view may have linked to their experience of not receiving their diagnoses until adolescence, by which time they had experienced disruption to their relationships at school and at home. By accessing services at an earlier date, they may have felt that the impact of ADHD on an individual's life may have been ameliorated. Daniel stated his opinion that:

I think young people need it more (6.3).

Rebecca agreed with Daniel, making a connection between having help when you are younger and the impact on functioning across the life span:

I suppose children...should get more because that is going to help them through their whole life (13.10-13.12).

However Caroline felt that children and adults should be entitled to the same level of service:

I think they (children) should get the same support [as an adult] (8.13).

Mark felt that people should continue to access services for as long as they need and stressed the importance of seeing people who are knowledgeable about ADHD. Mark continued saying that they could be moved to a different service for their on-going care once things had improved:

If they don't progress through the years and then () I'd expect them to stay there a bit longer and actually be seen by the proper people, () then, if they've actually progressed then they could go and see their GP and let other young people get seen (5.2-5.10).

The age at which transition should occur was raised, in particular whether chronological age should inform the timing of transition. Caroline maintained that:

I definitely don't think younger (than 18), because it does help, it does help coming here. I am not too sure about it, it depends really, it depends on the person I think (7. 2-7.5).

Mark knew he would have to leave CAMHS at a certain time, which may be linked to his pragmatic response to transition:

I knew I could only stay there for a certain age () and I was seventeen/eighteen anyway (3.29-4.11).

Daniels view was that:

18 is about right (5.21).

Caroline was not sure about the age 18 cut off, she indicated that:

I think if it is just mild and they are coping alright then yeah 18's fine but if it is like me and it's really bad, like without medication um, then carry on coming. Because I think like you need it as much as you can, until, you know what I mean, until you feel like you're fine or when you feel like you're going to come off it (7.5- 7.10).

It may be that the differences in opinion were related to their own satisfaction with services they had accessed and whether they considered they needed further support. A key message seemed to concern the need for flexibility in the timing of transition which they linked to the severity of the ADHD, engagement with a therapist and their ability to control their ADHD:

*It depends on how they've actually progressed (5.3-5.8):
(Mark).*

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It depends again on the person cos people get it different don't' they? They get it milder they get it () so it really depends on that (8.11- 8.13): (Caroline).

Engagement with a therapist might be a reason for changing services. Rebecca commented on how difficult it can be to establish a rapport with a therapist and felt that preservation of a therapeutic relationship should override an arbitrary service cut off point:

I think that once you connect with a counsellor you should be able to stay with them until you are ready to leave...I think as soon as you get one you can talk to, then you shouldn't have to leave. Because I think that's wrong really, you might get someone you don't want to talk to, especially when you are in a dark place it takes a lot to open up to someone and then to be moved at eighteen (12.12-12.24).

Daniel considered that it was beneficial to see the same person; he suggested that it was helpful to know that a therapist had an understanding of an individual's specific issues which they had developed over time:

Cos if you are talking to the same person about it, they know more about you, stuff like that () and what's going on and that (11.10- 11.12).

Daniel and Rebecca's accounts suggested they would find it hard to change therapists with whom they had built up good relationships. There seemed to be an unexpressed fear that if this were to happen when they didn't feel ready, they might feel unable or find it difficult to start again with someone new.

Rebecca's proposal was for one service spanning all age groups which would render transition unnecessary and therefore any disruption to treatment:

I think age is just a number, I think it should all be one [service] (12.24-12.25).

Rebecca re-iterated Daniel's view regarding the importance of developing relationships over time and feeling understood. Rebecca found the thought of changing services so difficult that she seemed to suggest that she would prefer not to be seen anywhere:

I would rather be seen in the place that you got diagnosed. I suppose because I think that here they understand me because they know me, whereas if I went somewhere, I probably wouldn't go anywhere else (15.1-15.6).

From their accounts it seemed as if there was a view that transition should happen when the individual feels ready to move. An interesting point was made regarding whether transition needs to happen at all and whether it would be preferable to have one service spanning all age groups so as to avoid disruptions to their care.

6.7.3 Mind the gap

The transition process seemed to have been a traumatic experience for everyone. Most appeared to have been told that they would be transferred to another service but their actual experience was rather different. It appeared that all of them had yet to be contacted. Mark recounted his experience of not having heard anything:

Well, they said to me that I was being transferred to your GP now () and that it was every six months I would get seen () But I still haven't been seen by my GP about it. [One year later] (3.17-3.20).

as did Daniel (waiting 18 months) who was told that he was going to be referred to another service:

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the doctors said they were going to refer me to a specialist a couple of weeks after I left here but I've heard nothing else (6.20-6.22): (Daniel).

Caroline seemed to find it hard to remember what the process was like:

I just got a letter. The last time I come was six months before. I got a letter saying for the last time, actually, I think it was a couple of months before (6.18-6.21).

Caroline couldn't make sense of why she had not heard anything, she described how she was given information about her continuing care but since then she hadn't been in contact with anyone (waiting six months):

we come in for the last meeting and they talked to us about it and said I can carry it on and then they told me they were going to send me to [Name of place] but we haven't had anything since then and that was in [6months ago], no that was [five months ago] the day after my birthday I think and nothing really. Oh okay and that was the adult services wasn't it? But we haven't had anything since so nothing has happened, since then (6. 3-6.8).

Rebecca's experience was slightly different to the others, which may be because she was in the process of moving. It seemed as if she discussed leaving CAMHS with her therapist who then wrote her a referral letter. It appears from this extract that Rebecca took the initiative to prompt the transition process:

I had to move to [place]. I told [therapist] and that was it really, and then I went... they wrote a letter to me so that I could transfer (11.15-11.18).

There appeared to be a general sense of uncertainty amongst the participants as to why they had not been contacted by anyone since

their discharge. Caroline didn't know what to make of the situation; she was receiving medication but she hadn't met with anyone yet:

I don't know why I haven't been [to the adult service] I am not too sure, I am still getting the medication (6.13-6.14).

Caroline seemed to be under the impression that she would have a meeting with the adult team and explained that she thought she would be contacted by the new service, but this didn't seem to have happened. Caroline appeared resigned to wait until someone contacted her and it seemed that she hasn't considered that perhaps she could initiate contact for herself; which may be because she didn't know who to contact:

I have not had the meeting yet, with the adult like (8.21). They said they were going to send us a letter but like I said we have not got anything (9.3-9.4).

Rebecca's account of her experience of the transition process puts her as central to the decision to continue to access support, she seemed empowered by this:

I kind of never needed to go back which in a way to me that's my achievement rather than being told that I am too old to come. I chose to stop (11.21-11.24).

6.7.4 What can I do?

There seemed to be a sense of resignation about the lack of transition and the lack of contact they have had with services since they were discharged. The participants made some suggestions about how they might access services that could support them but they felt powerless to do this for themselves.

This might be linked to their earlier descriptions of not wanting to take up professionals' time or it might connect to their low self-esteem, not feeling worthy or important enough to make a fuss. On the other hand it may be symptomatic of their ADHD symptoms

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which lead to poor organisation, difficulty in setting priorities and poor motivation. It may be a reflection of young adults generally who may not see looking after their health as a priority or are inexperienced in navigating healthcare systems. Mark said he could:

Phone my GP up and book an appointment (9.5).

and Daniel acknowledged he did need to sort out an appointment:

I do need to contact him [GP] and sort it out (6.25-6.26).

but despite stating it, they did not appear to have been able to follow this through. Daniel then said that:

The GP doesn't even talk to me () cos I tend not to go to him () I don't like him (5.13-5.15).

This statement suggested that Daniel may not even book an appointment as he didn't really feel he had a good relationship with the doctor. Daniel thought his GP should have taken responsibility for contacting him:

I thought the GP would have sorted it out (5.5).

Caroline seemed ambivalent about whether she needed support or not, on the one hand she felt abandoned, but on the other hand she said that:

I haven't really needed to speak to anyone, not really (8.25-8.26)...I haven't needed extra support (10.22).

Mark seemed clear that he could access his GP if he needed to, he explained that he didn't see the need to go and see his GP unless there was a reason to do so:

Then I'd phone my GP up and book an appointment (), I know if I need to see him I've got that appointment. If I don't need to see him there is no point in going to an appointment (9.5- 9.9).

6.7.5 'Abandoned'

There was a dominant story of feeling alone; all the participants expressed an overwhelming sense of being left to get on with their transition themselves. Their experience seemed to have been one in which they had been forgotten and overlooked. Caroline presented herself as:

I am kind of confused (6.12-6.13).

Rebecca perceived that it was left up to her:

I think that once you leave CAMHS you either have to deal with it (20.14-20.15).

Whilst Mark seemed resigned to his situation:

I still haven't been seen by my GP about it (3.19-3.20).

Daniel account gave an impression that he seemed to be in a void:

I left this service and did nothing else...after that there was nothing (4.16-4.21).

Caroline and Daniel felt isolated and let down:

I haven't moved to the adult one, I haven't had anything, I don't really understand that (17.7-17.9) (Caroline).

They said they were going to refer me to a different specialist for adults and they haven't yet (4.22-4.24)...I've heard nothing else (6.22) (Daniel).

Mark seemed to accept that he should just get on with things and take his medication:

I just got on with my tablets, I get my prescription or my tablets and that's it (6.16-6.18)

whereas Caroline was worried that her medication would stop:

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Now I am an adult they say they are going to stop my medication (8.4- 8.5)...I was scared, I thought ()...I was scared because I thought I wasn't going to have my medication anymore (8.15-8.17)

and was terrified about the possible impact on her condition:

terrible because I thought that's it, I'm not going to have any medication anymore and I wasn't ready really to come off it (11.3-11.5).

Rebecca was concerned that protocol was not being followed and expressed her view that professionals weren't bothered about her:

You are not meant to get them (tablets) when you are eighteen and they gave me them when I was eighteen and I thought, oh well, they just don't understand I don't think, I don't think GPs care anymore (15.13-15.17).

Daniel had a sense of being in a void and had a suspicion that no one knew he was there:

After I moved out of this place here (CAMHS), I had nothing out of my GP (6.17-6.19).

And even if he were seen, he felt that his GP didn't appear interested or didn't know how to help:

You can never guarantee that they're going to be there [GP] when you want to see them and they'll just palm you off on someone else (11.3-11.6)... Talking to your GP, they are mostly on the computer trying to figure it out (11.12-11.14).

Rebecca echoed Daniel's opinion that GPs don't seem to understand:

I don't think GPs understand to be honest, because I don't like GPs. About ADHD, they really don't understand. They just give me tablets, they don't ask you why (15.7-15.10).

From their accounts Daniel and Rebecca appeared to share the view that their GPs didn't understand them and that they hadn't formed a relationship with them. The participants felt as if they had been left to manage their healthcare needs on their own. They were concerned that when they did get to see a GP that this was unsatisfactory and that their GP's did not seem to know what help they needed.

6.7.6 Growing out of ADHD

Several important issues arose in relation to the continuing influence of ADHD on the participants. It was clear from Daniel's response, that he had a belief that some people grow out of ADHD when they reach adulthood which may mean he viewed ADHD as a potentially transient part of his life:

Some people with ADHD wear out of it when they turn 18, not long lasting (5.23-5.24).

Caroline was hopeful that her ADHD would get better and described how:

I did get told that by the time I was (older), my brain, like, I don't have it anymore. So I am kind of looking forward to that (5.7-5.8).

It seemed as if Caroline had been informed that her ADHD symptoms would improve or go away in the future which she was pleased about. If her ADHD symptoms do not improve, she may struggle to cope with her feelings of disappointment, she went on to describe how she had had a test which she said confirmed that she still had ADHD:

I had to have a test [QBtest] to see what my ADHD was like again. I had to do one with my medication and one without medication and then the last time I come back,

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yes that was the last time, tests showed, a hell of lot, lines were like this, going massive (6.21-6.26).

Several of the participants described how they felt some aspects of their ADHD had improved as they had got older. Daniel said that:

I still go hyper but () not as bad () as when I was back in school (3.8-3.9).

Rebecca had also noticed an improvement:

I probably have one [outburst] every two months now rather than every day (8.28-8.29)

and she felt that her concentration had improved:

Now I can go for about two hours, that's my concentration level (19.1-19.3).

Mark recounted how he felt his ADHD was sufficiently managed:

It's not actually stopping me from working or anything (7.12-7.14)...I've still got my job at the end of the day (8.8-8.9).

There was a shared view that as they had got older that they had become more adept at controlling some aspects of their ADHD.

Rebecca reported that:

If I said to them [work place], they probably wouldn't even know, they wouldn't even notice because I've learnt to control it (6.18-6.20).

Mark also felt that he had more control:

(ADHD) not as bad... () as it used to be but I can kind of control it more as I get older... I don't think it's wearing off but I can control it more now, than what I could (7.4-7.9).

However, in a contrasting statement Rebecca expressed her frustration that as she had got older she had noticed that some aspects of her ADHD seemed harder to manage. She sounded almost scared of her potential to do damage to herself or others and seemed sad that this could negatively affect her relationships:

I think controlling your anger. That is the worst; as I have got older it's getting harder to control and I would have thought it would have got easier but to me it is getting harder because you go through more when you are older I suppose....if you don't know how to control it, when you are older you just, what's the word um, in trouble because I wouldn't have trusted myself if I couldn't... control it I wouldn't have trusted myself to live with anyone. I think it can be quite, I was getting quite dangerous, if I couldn't control it then no one would want to live with me (17.6-17.18).

From their accounts, it appeared that ADHD continued to impact on their lives, although they described some of the positive changes they had noticed in their ADHD symptoms, they clearly articulated the continuing challenges in managing their behaviour and keeping it under control.

6.7.7 'We're adult now'

As well as external transition processes, there appeared to be an internal transition as the participants moved from adolescence into adulthood. From their accounts, they seemed very clear about how their responsibilities needed to change or were expected to change as they become adults. Mark stated:

We're adult and we've got to take the responsibilities of it now (6.1-6.2).

In Rebecca's words:

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when you are older it is harder to control your emotions. When you are younger you just let them out, but when you are older you have to, work...much harder (17.24-17.27).

In these extracts there was a sense that becoming an adult necessitated being responsible and taking charge, it was perceived as hard work and challenging. It was difficult to know whether this was seen as a positive step or whether it was stressful. Mark felt that:

Adults should be able to control their ADHD better than the children should () because we're adult and we've got to take the responsibilities of it now (), our parents aren't going to be around all our lives (), adults should actually be able to do it off their own back (5.28-6.4).

This was echoed by Daniel:

When you get to an adult you can make your own decisions... adults, they, can make their own decisions (6.3-6.8).

There was a sense of having to take control of yourself and 'pull your socks up'. Daniel stated that:

You turn into an adult (), you got to kind of take control of it, stuff like that... you got to take control of it [ADHD] and sort it out yourself, like most adults have to do with themselves (5.21-5.6).

Rebecca was well aware of the expectations of her as an adult in the workplace; she knew that certain behaviours would not be tolerated:

Whereas actually being able to listen, because if I was like that at work I would not have a job. You have to listen to your boss, no matter how much she winds me up and I have to listen to her (19.11-19.15).

There seemed to be a belief that becoming an adult brought with it the expectation that individuals would automatically be able to manage themselves differently. Mark seemed to suggest that, at some point, medication for ADHD should be stopped and was almost disparaging about the notion that some people might find this difficult:

Adults should actually be able to do it off their own back... Shouldn't need help to come off the medication they've been on medication all their life, they should know what it's like to be on medication (6.3-6.8).

Rebecca's experience of leaving home seemed to have made her grow up and take responsibility for herself and seemed to have been a turning point for her; she recommended this as something that would be helpful for everyone to experience:

I grew up when I moved to [place], because I had to live on my own (2.14- 2.15).

You should be given a chance to do things on your own, live on your own, because that changes you. I think it can either make you or break you. Living on your own and even if it is just for a year, everyone should go through it (20.17-20.22).

The participants suggested that becoming an adult brings with it a set of pre-determined expectations and responsibilities. They alluded to the need to individuate from their families; to stop relying on their parents and take full responsibility for themselves, however at times there was a sense of ambivalence and fear.

6.7.8 Ideas about support

Access to continuing care seemed to be an important issue for the participants, a variety of suggestions were made regarding what

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help they think would be useful. Daniel initially expressed uncertainty about what support he might find helpful:

I don't know () I don't have a clue (5.4-5.5).

However, several specific areas which they considered might be beneficial were highlighted. Rebecca discussed the importance of equitable access to services for all people which could include assessment and treatment of ADHD:

It's like my tablets I couldn't have had them anyway, when I am eighteen you have to swap tablets... I don't see why age is different. I don't know, anyone could be hiding it and then they might want to know what actually is wrong with them...I think everyone should get the same (13.16-13.21).

Daniel and Caroline appeared to want answers and reassurance about their condition. Daniel discussed how he would value:

Knowing if me tablets have got to go up or, () I know when it had worn off, but see if it's like wearing off, me ADHD, as I'm getting older (7.1-7.2).

Caroline agreed with Daniels statement, stressing the importance of being able to have questions answered knowledgably:

You get all answers, you get all your questions answered. If you go the doctors well (), maybe they might not know anything about it so. So you feel that coming somewhere that is specialised you get good answers (9.13-9.16).

Rebecca speculated, whether being seen by someone who has had ADHD or knows someone with ADHD might be helpful as she felt this might help them understand her better:

I don't know, probably if I got a GP who has got an ADHD person, son or something, they would understand a lot more. Someone that has actually talked to someone or

something like that. I think you cannot understand it, unless you have experienced it (15.26-16.1).

Support for finding employment and helping to access benefits was also identified as important to the participants. Daniel would like support to find a job where he would not be discriminated against because of his ADHD:

Someone to help you like look for a job where the employers [are] not too fussed that you've got ADHD (11.26-11.28).

Caroline mentioned the difficulties she had had in understanding whether she was entitled to any support, she appeared confused as to whether she could access any financial support:

When we rang up, because that was when we was[sic] having money problems at home and when we rang up they said there was no point in trying for it because the letter would get rejected or something (9.26- 10.2)...To hear more about that [benefits] (10.3-10.4).

There seemed to be a desire to know that a service was there to fall back on just in case they needed it. Caroline and Rebecca seemed to value a sense of being held in mind:

*Knowing that they are still there if you need them (10-25)
(Caroline)*

*I knew they would be there if I needed to go (11.20-11.21)
(Rebecca).*

Daniel clearly valued the services he had accessed in the past and identified key aspects of the service that he had found helpful:

A bit like the service that I come to here. You've got someone to talk to about it, stuff like that (11.2-11.3)...: if you've got like a service like this you can talk to them and nine times out of ten they'll be here (11.7-11.8).

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Rebecca highlighted the need for on-going therapeutic interventions, in particular, managing the behavioural sequelae of ADHD. Rebecca appeared to feel that in order to overcome ADHD symptoms, it was important to be able to understand or set boundaries for yourself which may result in better control of symptoms:

How to control yourself that would be the main thing. As soon as you learn to control what is going on in your head then you can control your actions (18.8-18.11).

Daniel outlined his concern about getting into trouble as a result of poor decision making about peer group choices. He suggested that this was an area where support is necessary:

Just get in with the wrong people then you need more support with it () and stuff like that (6.10-6.12).

The importance of accessing on-going prescribing of medication and the ability to ask questions about medication was identified as helpful by Caroline:

Medication would be helpful and for the DLA, I would have wanted to find out more about that (12.21-12.22)... I could find out like how long I am going to be on my medication for and what it was going to be like now that I am (18.8.2-8.4).

Rebecca appeared to be slightly uncertain as to whether she should be on medication or not, there was a sense that she was not sure that her GP knew enough about her to support her in making this decision:

You are not meant to get them (tablets) when you are eighteen and they gave me them when I was eighteen and I thought, oh well. They just don't understand I don't think, I don't think GPs care anymore (15.13-15.17).

From Rebecca's account it could be surmised that access to a service where professionals are familiar with ADHD and its treatment, would be helpful. Caroline took this idea one step further, suggesting that that a service dealing just with ADHD might be useful:

Probably a service with just ADHD. When you have got everything else, like depression, and that, that is completely different to having ADHD (13.12-13.14).

Mark says that he would have found it helpful to have been able to have a meeting with his CAMHS professional and his GP (who appeared to be his new healthcare provider for ADHD), he may have had a belief that such a meeting would have helped his GP to understand the issues for him thus smoothing his transition:

We could have had a meeting with my GP and X [Dr.] at the same time () and spoke about it (4.9-4.1).

In regards to frequency of appointments, Caroline appeared to want regular appointments at fairly close intervals:

Seeing them more than once every six months I think, perhaps every three months, half the six months...I didn't really see him [professional] a lot because it was once every six months, that's not really a lot... that's twice a year, so () Yeah once every three months (12. 8- 12.14).

The following reflective statement made by Rebecca seemed to summarise the views of all the participants about the support they need:

I think you always need help; no one with ADHD can sit there and say they don't need help, day to day you need help with something. Whether it is you help yourself or someone else helps you with () ...you can't go a day without needing help (17.1-17.5).

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There seemed to be a consensus that access to a service would be helpful, however they were not entirely sure as to how best to provide this.

6.8 Summary

This section aimed to provide an understanding of the participants' views about their healthcare transition experiences and presented a detailed account of the researcher's interpretations in relation to their narratives.

The participants stated that they had wanted to participate because they hoped that it might help other young adults facing the same processes. The participants were engaging and often articulate, discussing their experiences of transition in an open and straightforward manner. In addition to their views specifically related to the transition process itself, they highlighted other sensitive issues which they considered important and seemed to have a continuing influence. For example, they mentioned how they received contradictory information relating to their diagnosis which possibly led to a sense of uncertainty about the validity of their diagnosis potentially impacting on their compliance with treatment.

In addition, they described conflicting views about medication; on the one hand noticing positive benefits on their symptoms, on the other hand it seemed as if they were possibly satisfying an unconscious desire to conform with their peers by taking the medication but also feeling a sense of loss of their real self when they have.

7. Discussion

7.1 Introduction

This study set out to understand the healthcare transition experiences of young adults with ADHD. This final chapter begins by discussing the findings in relation to the available knowledge in several interlinking fields: biographical disruption, stigma and transition theory.

The limitations and strengths of the study will be considered and a reflection on any personal bias that might have influenced the interpretation of the findings or the research process is included.

Key recommendations to inform future practice are embedded within the 'key implications for clinical practice section' (7.8).

Finally, the implications of the findings in relation to future research will be discussed

7.2 Key findings

One of the more significant findings to emerge from this study was that healthcare transition needs to take account of other important transitions in a young person's life.

This study has enhanced our understanding of healthcare transition experiences of young adults with ADHD and found that the participants did not appear to have been prepared or involved in the transition process. In fact, none of the participants had experienced a transition into adult services.

The results of this research support the idea that ADHD impacts on relationships. There is an indication that the concepts of biographical disruption (Bury 1991), transition theory (Van Genep 1960; Chick and Meleis 2010), psychosocial developmental theory

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(Erikson 1968; Marcia) and spoiled identity (Goffman 1963) may enhance our understanding of healthcare transitions.

7.3 Discussion of the findings

There is an increasing concern (DH 2004a; Pugh et al. 2006; Kennedy 2010) that young adults with chronic health care conditions are being disadvantaged in their transition between child and adult healthcare services. Previous studies (Dfes 2004; DH 2004; Reiss et al. 2005; Coles et al. 2010; Singh et al. 2010; Merriman 2013) have reported that healthcare transition is an important issue and is attracting increasing attention from policy makers, clinicians, researchers, patients and their families and/or carers across all areas of healthcare provision.

Healthcare transition is an important and complex phenomenon which usually occurs when young adults reach the age of 18 and are discharged from child and adolescent centred services and transferred to adult services. This can be a particularly vulnerable time for individuals (Vostanis 2005; Hovish and Weaver 2012; Paul et al. 2013), who may already be negotiating other internal and external transitions as they move from adolescence into adulthood.

Failure to undergo an effective transition within healthcare contexts is a serious issue given the well documented negative outcomes associated with discontinuity of healthcare (DH 2012; Montano and Young 2012). Therefore, it is essential that young people have equitable access to healthcare services (the Children's Commissioner for England 2013) and feel that their needs are being supported.

This study was designed to give voice to young adults to speak openly about their experiences and the meaning they made of them. This study therefore contributes to the existing knowledge base by capturing the participants' opinions and attitudes about this important subject.

The use of IPA allowed an exploration of the participants' perspectives about their healthcare transition experience, allowing insight into their world and thus contributing to the available knowledge and understanding about this area. To date, there are no published IPA studies which explore the healthcare transition experiences of young adults with ADHD and to date there is only one other qualitative research study (Swift et al. 2013) addressing this topic.

The primary findings of this study were the descriptive stories given by the participants of their experiences of transition and the ideas they had about how services might be developed. What emerged from the data was that their experiences and thoughts about transition were interwoven with other important issues that clearly held relevance for them.

The findings from this study indicated that the issues concerning the participants were broadly consistent with other research into this area (Shaw et al. 2004; Singh et al. 2010; Swift et al. 2013) which maintained that healthcare transition was a complex issue warranting further attention.

7.4 Superordinate theme one: personal experience of ADHD diagnosis and treatment

Although this theme may seem unrelated to the topic of transition, from the participants' perspective, it clearly held relevance for them. This was presumably, because some of these specific areas will continue to influence them as they transition into adulthood and access healthcare services.

In comparison to having a physical health difficulty, mental health is an area that is often misunderstood and may lead to the discrimination and isolation of people who have mental health

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problems (Gale 2007; Young Minds 2012). In this study, the participants did not appear to have a clear sense of what their diagnosis meant, using negative words such as 'psycho' to describe themselves. They seemed ambivalent about whether it was helpful to be told that they had ADHD and appeared to feel that their behaviour without medication was unacceptable.

A considerable amount of research has been published on the effect of labelling and its subsequent impact on individuals, particularly in the field of mental health (Gale 2006; Young Minds 2012).

According to Corrigan (2010), although having a diagnostic label may be experienced as empowering, it may also serve to identify an individual as different from their peers which during adolescence and emerging adulthood may be particularly challenging. This opinion was consistent with several other researchers (Link and Phelan 2010; Wright et al. 2011; Young Minds 2012) who argued that labelling had contradictory impacts; encouraging some individuals to access help, whilst others may have experienced it as stigmatising and were consequently less likely to seek help, which resonated with the participants reactions to their diagnoses.

A recent study carried out by Young Minds (2012) reported that many people gain their knowledge about mental health from the media and that this information often portrays people with mental health difficulties in a stigmatising and pejorative way (Shift 2008; Philo et al. 2010).

Given the age of the participants, it may be that some of their reactions were connected to the dominant narratives that exist within society about mental illness which they would inevitably have come into contact with at school, at home, on the television, internet and social media sites. If this was the case this may have had an influence on their response to their diagnoses and the way they view themselves.

A recent study (Young Minds 2010) found as people get older, their attitudes towards mental health become increasingly negative and that 67% of 17-25 year olds found it harder to talk about having a mental health problem than a physical health problem. The participants in this study were aged between 18 and 19 years old, therefore it would be reasonable to hypothesise that this may have had an impact on their willingness to talk to their friends or employers about having ADHD.

Link and Phelan (2010) and Wright et al. (2011) considered it important to differentiate personal identity from the 'problem'. This idea fits with the concept of 'externalising' which was developed by White and Epston (1990), who suggested that this approach enables individuals to counteract the effects of labelling. Epston et al. (1992) suggested it was important to establish a context where people could experience themselves as separate from the problem and allowed them to develop alternative positive narratives about themselves, reducing feelings of guilt and blame.

An interesting finding of this study which was consistent with that of Matheson et al. (2013) was the concern some participants had about being able to continue to take prescribed ADHD medication post 18. All the participants had been prescribed medication when they were attending CAMHS and were able to recall the close supervision they had received. They seemed to think that once they reached 18, their medication would stop and this worried them.

Drawing on the experiences of the participants and supported by my clinical practice and a recent review conducted by Montano and Young (2012), it appeared that there was a lack of clarity about whose responsibility it was to prescribe and supervise medication post 18. It seemed as though GPs by default, had taken on this role, even though stimulant medication for adults is not licensed in the UK (Nutt et al. 2007).

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Currently in the UK, Atomoxetine is licensed for use in adults as a continuation therapy and although Methylphenidate is not licensed for use in adults, it can be taken by adults as a continuation therapy if closely supervised by a prescriber (Parker 2013).

An implication of this is the possibility that healthcare professionals in primary care could, with the appropriate training and support, be well placed to supervise the ongoing medication aspects of ADHD treatment in adults (Nutt et al. 2007; Bolea. et al 2012; Merriman 2013).

The participants described their perception that the knowledge held by professionals about ADHD is insufficient, this concurs with Montano and Young's (2012) view that there is a need for better training for professionals about ADHD. This may, in part, account for the sense young people have (Young People's Manifesto for Change 2009) that GPs are disinterested or unsure about their role in supporting young people with mental health difficulties.

It seemed as if the participants felt that they were solely in charge of managing their ADHD, whilst this could be seen as a positive, there appeared to be an absence of any support other than from their families. This perceived lack of support may account for an interesting idea that emerged from this study, which was to meet other people with ADHD, who they believed would be more in tune with their experiences.

In 1999 the White paper 'Saving Lives: Our healthier nation' (DH) was published which heralded the introduction of the Expert Patients Programme (EPP). This placed patients with long-term health conditions at the centre of their healthcare with an intention to improve their quality of life.

Although there have been some reservations about the programme (Tattersall 2002), it is generally perceived that it has been a useful initiative (Hardy 2004) with the potential to make a real difference to the quality of life of people with a chronic illness.

Although the EPP offers support to people with mental health problems, they do not specifically offer support to people with ADHD or emerging adults in transition. Extending this initiative to include young adults, could potentially result in improved transitional healthcare outcomes and support young people to develop self-management skills.

If the EPP programme were extended to include young adults with ADHD in transition, it might go some way towards supporting their wish to meet other people with ADHD and to feel less isolated and more confident about managing their own healthcare needs.

7.5 Superordinate theme two: impact on self and relationships

This theme yielded rich data about the influence that ADHD had on the participants' relationship with themselves and others, expressing a sense of isolation from their families, peers and society. All the participants mentioned how ADHD had shaped and to a certain extent controlled their lives.

Given the chronic nature of ADHD, it is likely that it will continue to exert some influence throughout adulthood. From the participants' explanations, it seemed that ADHD had interfered in their process of moving from adolescence into emerging adulthood and the way they perceived themselves.

Adolescence could be considered to be a bridge between childhood and adulthood and is associated with a number of important developmental tasks which support this journey. It is a time when the importance of 'fitting in' and being part of a peer group takes on an increasing priority.

Adolescence in itself, could be conceptualised as a transitional process which is influenced by a number of external factors such as

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family, peer group, education and health, however, it is not necessarily a difficult phase for all adolescents.

In relation to this study, the findings suggested that all the participants had experienced some difficulty in fulfilling these goals, which may be a consequence of having ADHD or a consequence of having any chronic health condition. It would be interesting to explore the specific impact ADHD has on the timing and the way in which developmental tasks are achieved.

To date little has been written about the possible impact that having ADHD has on the construction of self identity (Shattell et al. 2008; Houck et al. 2011). What is known is that having ADHD is associated with low self esteem and is considered to have a negative impact on an individual's relationships with their family, friends and society (Gallichan and Curle 2008; Houck et al. 2011).

A wide range of theories exist (Erikson 1963; McGoldrick and Gerson 1989; Marcia 1980) which highlight the tasks adolescents need to achieve in order to become fully launched adults.

Erikson, a psychoanalytically oriented theorist, was interested in the psychological processes humans navigate as they move from childhood to older adulthood. Erikson's (1963) theory of psychosocial development comprised eight developmental stages which all individuals have to negotiate during their lives: trust versus mistrust, autonomy versus shame and doubt, initiative versus guilt, industry versus inferiority, identity versus role confusion, intimacy versus isolation, generativity versus stagnation and ego integrity versus despair.

According to Erikson (1963) each developmental stage is associated with a 'crisis' or turning point which individuals need to master in order to successfully move to the next stage. Erikson (1963) suggested that these crises are of a psychosocial nature resulting from the interaction between an individual and the context in which they are embedded.

Of interest to this study is the fifth developmental stage, 'identity versus role confusion' which occurs during adolescence and is concerned with the formation of self identity.

Erikson (1963) proposed that all adolescents between the ages of 12-18 experienced 'identity diffusion', which concerned their search for personal identity and is associated with a sense of not knowing and unease about who you are.

This is a challenging phase for most adolescents because as well as achieving a sense of identity they are also undergoing biological, psychological and contextual changes.

Eysenk's (2004) interpretation of Erikson's (1963) seminal work is supported by Cuhadaroglu-Cetin et al. (2013). They considered that a key task facing adolescents was making decisions based on their previous knowledge and experience, about who they want to be and how they want to be perceived; whilst at the same time needing to fit in and be accepted by society.

Erikson (1963) believed that in order for individuals to move to the next developmental phase it was necessary to have attained a positive sense of self identity. It is possible therefore, that if this process is disrupted or delayed, as is evidenced in the findings of this study, that this might have an impact on an individual's ability to feel valued and accepted by others.

Erikson (1963) emphasised the importance of mastering developmental stages in a sequential manner and cautioned that if this does not happen, then it may have long term consequences for the individual. These findings suggest that it might be interesting to consider whether having ADHD has interrupted this important progression and if true, then it may be important for clinicians to consider how best to support individuals and families to ensure this does not lead to difficulties in the future.

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Marcia (1967) used Erikson's (1963) theory as a basis for further exploration of the attainment of self identity in adolescence. Marcia (1967) proposed that the main task in adolescence was not about identity resolution or confusion but the extent to which an individual has explored and made a commitment to a particular identity.

Woodward (2002, p7) stated that

'Identity offers a way of thinking about the links between the personal and the social; of the meeting place of the psychological and the social, of the psyche and the society'

Marcia (1967) considered that the development of self identity involved the examination and evaluation of existing held beliefs and choices which would consequently result in a decision to assume a particular role or principle.

Erikson (1963) and Marcia (1967) agreed that individuals who had committed to an identity tended to be happier and were able to move to the next developmental phase than those who had not. In the context of this study it would be interesting to consider whether having ADHD had had an influence on the development of the participants self identity. It would have been interesting to examine any similarities or differences between participants regarding how they positioned themselves in terms of their identity statuses and their thoughts on whether they felt that this process had been delayed or disrupted as a result of having ADHD.

Kreuger and Kendall (2001) found that some people see ADHD:

'as part of their self identity and define themselves selves in terms of their ADHD symptoms'

and proposed that this may be connected to the way individuals understand ADHD and the meaning this label holds for them and others.

According to Gallichan and Curle (2008) it is not uncommon for people with ADHD to have a negative sense of self, participants in their study described themselves as 'unworthy and intrinsically bad'. This study corroborated their findings evidencing the use of negative words such as 'psycho' by the participants to describe themselves. From the available literature (Kreuger and Kendall 2001; Gallichan and Curle 2008), it appears as if there is a relationship between having ADHD and a negative sense of self.

Several authors highlighted how the ability to form and sustain intimate loving relationships is a crucial developmental stage during adolescence and that failure to do so may result in relationship difficulties going forwards (Erikson 1963; Garcia Preto 1989; Micucci 1998).

The findings of this study evidenced the difficulty the participants experienced in managing their relationships with others; it seemed as if others found them hard to tolerate at times and seemed to misunderstand their intentions. Although their relational difficulties might be part of adolescent development, it appeared that their experiences were distressing and their relationships severely compromised. They seemed to sense that others found their behaviour hard to understand or manage.

These findings were consistent with other studies (Gallichan and Curle 2008; Shattell et al. 2008) which reported how participants viewed themselves negatively in comparison to their peers and often felt misunderstood.

ADHD symptoms such as hyperactivity and distractibility are thought to have a detrimental impact on their communication and engagement with others which left individuals feeling different and isolated (Gallichan and Curle 2008; Shattell et al. 2008). Shattell et al. (2008) described how ADHD was sometimes thought by others to be an excuse for socially unacceptable behaviour.

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A key task for young people is being able to separate and individuate from their families in order to achieve independence and to establish an identity for themselves (Erikson 1963; Garcia Preto 1989; Micucci 1998).

Although developing identity is a personal process, it is inevitably influenced by the context in which individuals are situated. Erikson (1963) believed that one of the key tasks facing adolescents was the need to develop an identity of their own that was separate from their parents. Given the parallel process of transition from childhood into adulthood this is a crucial and demanding phase for all adolescents.

The participants described the important and continuing role their families play in their lives. It seemed as if their process of individuation was ongoing and associated with a feeling of ambivalence towards acknowledging, that as adults, they should be responsible for themselves whilst valuing and wanting their families and partners to continue to support them and their ADHD.

Shattell et al. (2008) reported their findings which showed how in retrospect their participants had valued the support they received from their parents. Although at times they had felt misunderstood and 'nagged', they acknowledged that they had also experienced positive feedback and support which seemed to have had a positive impact on their self construct.

All the participants gave what appeared to be an honest account of how they believed they were perceived negatively by others. They described how they felt misunderstood and seen as difficult; it seemed as if there was a tension between how they saw themselves and how they were seen by others. There was a sense of desperately trying to fit in; to the extent they seemed to feel a need to hide their 'real self' from their families and peers.

This resonated with Winnicott's (1960) concept of the true and the false self. This theory focuses on the central idea that the true self is

the original 'you' and embodies an individual's real feelings and desires.

The false self or 'adapted self' is designed to protect the 'true self' at times when it might be inappropriate or harmful, to expose the essence of ourselves to others. These are unconscious processes and stem from a desire to survive by adapting and hiding some aspects of our behaviour to fit in with others around us.

This concept seemed pertinent in relation to the participants' descriptions about their treatment with medication. Although their accounts indicated that medication had a positive influence on their interactional patterns and appeared to strengthen their relationships; they were ambivalent as they also wanted to be 'themselves', medication free and be accepted for who they were. Their indecision about which part of them they could safely expose to others may be related to their personal experience of the association between ADHD and its detrimental influence on relationships (Asherson 2005; Barkley 2008).

Loe and Cuttin (2008) discussed the notion of the 'medicated self', they described the tension some young adults with ADHD experienced between being their authentic self and the self they think others want them to be. They (Loe and Cuttin 2008) proposed that medication increases the gap between the 'perceived authentic and ideal identities'.

Loe and Cuttin (2008) explored the 'dis-ease' that was felt by individuals, on the one hand feel they are being controlled by a drug which renders them as 'inauthentic', to another where they are better able to control themselves and achieve their potential.

Gallichan and Curle (2008) found that medication seemed to help individuals adapt to their contexts, however they cautioned it may be experienced as a threat to their sense of self identity.

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This study found that the participants felt ambivalent about whether they should relinquish their medicated self, possibly risking their relationships and employment or to carry on taking medication with its perceived influence on their sense of self.

Mark mentioned how he could only meet the health and safety requirements of his employment if he took medication. Rebecca decided to request a prescription of medication in case she needed to manage her behaviour in the workplace. These findings seemed consistent with those mentioned by Gallichan and Curle (2008) and Loe and Cuttin (2008) where people felt the need to 'modify' or 'control' their behaviour to be accepted.

Erikson's (1963) seminal work on the stages of psychosocial development emphasised the importance of establishing a meaningful personal identity, he considered that this process was heavily reliant on social feedback.

Given the participants' narratives which describe their long standing exposure to negative perceptions, it is likely that this will have had an influence on the development of their sense of self and identity in a potentially unhelpful way.

This links to the work of Goffman (1963), who refers to the concept of a 'spoiled identity' where the reactions of others to what they perceive are 'abnormal traits' in another person (for example with a mental health problem) cause a person to feel stigmatised. This sense of being treated as different and unlikeable becomes internalised and individuals begin to believe that they are the 'thing' that others dislike. There was a flavour of this in the collected data, whereby the participants seemed to have convinced themselves that they were 'naughty' and 'a nightmare' and so struggled to hold onto a positive sense of self.

A strong relationship between mental health labelling and stigma has been reported (Young Minds 2012). Studies have shown (Gale 2006; Young Minds 2012) that mental health problems were

associated with higher levels of stigma than physical health problems and could have a detrimental impact on an individual's self-esteem.

According to Green et al. (2003) one of the most risky consequences occurred when the 'damaging aspects of stigma are internalised', leading to secrecy about the condition, not using services and non-adherence to treatment (Corrigan 2004).

A recent study by Woolfson (2008) tracking experiences of stigma in young people with mental health problems identified that young people had experienced verbal and physical abuse. They were excluded by their peers and did not feel supported by people who would be reasonably expected to offer support in a non-stigmatising way such as for example, mental health professionals, GPs and teachers. The consequence of this was a reluctance to seek help for their difficulties.

The findings of this study seemed consistent with those of Woolfson (2008). The participants described how they preferred not to tell others about their condition as they were concerned about the effect of this on their relationships and their experiences of other people's perceptions of them and ADHD.

Very little has been written on the impact of ADHD on self identity. Previous studies (Barber et al. 2005; Gallichan and Curle 2008; Shattell et al. 2008) have noted that people with ADHD often described themselves using negative language and seemed concerned about how others experienced and responded to them. A description of feeling different and being misunderstood was a common experience amongst the participants particularly when they were un-medicated.

Although it is thought that having a label can help individuals to make sense of and manage their health more effectively (Shattell et al. 2008), it would seem important that support is given to

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individuals to consider how they understand and make sense of their diagnosis in order to cope with negative responses.

Houck et al. (2013) suggested that an area worthy of further exploration is how an individual's experience of social relationships and contexts may give rise to negative self perceptions. More information on this issue might support the development and delivery of targeted interventions.

7.6 Superordinate theme three: living with ADHD

The findings of this study evidenced the significant influence that ADHD exerted on the participants' lives which was consistent with the literature (Asherson 2005; Young and Gudjonson 2008; Montano and Young 2012). The participants described how ADHD seemed to be 'messing up their lives', with a sense of frustration that they struggled with some aspects of daily living and in comparison with their peers were unable to achieve their potential. They seemed to see themselves as incompetent and inadequate.

Bury's (1982) concept of biographical disruption seemed a relevant theory to help in understanding the impact of ADHD on the participants' functioning. Bury (1982) has described chronic illness as a disruptive event which affects everyday life activities and impacts on how individuals see themselves and are perceived by others. Initially this idea resonated with the descriptions the participants gave about the impact ADHD has on them.

Bury (1982) has suggested that a key element of biographical disruption was the catastrophic impact that having a chronic illness had on core identity and a loss of confidence that was experienced by individuals about the functioning of their body and their sense of self. He described how this process was influenced by the meaning

that an individual held about their condition and the meaning ascribed by others.

A central idea was the difference in the way people saw themselves before and after being diagnosed with a chronic illness and how they often became focused on the long term outcomes associated with the illness, for example, increasing debilitation or death. Bury (1982) suggested that before an individual can move to a position of mastery, they needed to be able to make sense of it for themselves and be able to reframe their ideas about the positive and negative influence it had on their lives.

Considering the findings of this study, in relation to the concept of biographical disruption, it would be interesting to further explore whether some aspects of this concept are applicable to people with ADHD.

Although ADHD is not a condition that gets progressively worse over the life span, it does have a continuing impact on quality of life (Adler and Chua 2002; Asherson 2005; Lahey and Willcut 2010; Montano and Young 2012) and the way people see themselves.

The findings of this study suggest that ADHD has an impact on an individual's sense of identity; however, further study is warranted to fully investigate this area.

To date, the focus of biographical disruption has been on chronic illnesses emerging in adulthood (Williams 2000), therefore it is not known how applicable this concept is in relation to young adults diagnosed with ADHD in childhood or adolescence. Hubbard et al's (2010) statement that:

‘unless illness threatens identity then the illness may be disruptive but not biographically so’ (Hubbard et al. 2010)

is an intriguing one, which could usefully be explored in further research.

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If more were known about whether people view ADHD as biographically disruptive, it may influence the provision of clinical interventions to support the development of self-esteem and increase access to services (Hubbard et al. 2010).

This study highlighted the possibility that the biographical disruption model might be applicable to young adults with ADHD. It would be interesting to explore whether a diagnosis of ADHD changes individuals sense of self pre and post diagnosis, however given that most diagnoses are made in early childhood, this may prove challenging.

Another important finding was the participants' descriptions about how they managed and took responsibility for their ADHD; in particular their knowledge of medication and the practical strategies they utilised to ameliorate the impact of their ADHD. Although this appears to have happened by default rather than as a planned aspect of care, these findings support the recommendations outlined in national guidelines (NICE 2011; NICE 2012) that patients are encouraged to be more involved in planning and managing their care in partnership with professionals.

In their analysis of the Bristol enquiry report, Coulter and Dunn (2002) identified several areas which needed to be addressed, if patient care were to be improved. A central concept was putting patients at the centre of their care, with increased involvement in decision making and encouraging a partnership approach, resulting in improved health outcomes.

Although Coulter and Dunn (2001) claimed that health care professionals often adopted a paternalistic approach; the findings of this study suggested that participants were inadvertently placed in a position of being solely responsible for managing their own care, describing how none of them have had contact with a healthcare professional since their discharge.

In recent years, there has been an increasing drive towards involving service users in their own healthcare, including the planning and delivery of services (DH 2004c; Street and Herts 2005; HASCAS 2008). It was proposed that engaging service users would lead to improvements in quality and effectiveness, resulting in better health outcomes.

NICE recently published two reports (2011; 2012), which recommended that healthcare services robustly engaged with service users to provide better care. Specific areas were highlighted and included effective individualised care planning, support in accessing services, encouraging self-management, improved communication, involvement of families and continuity of care.

The findings of this study were not very encouraging, implying that this has not happened; the question therefore, is why despite numerous policies and guidelines (Francis 2013), it does not seem to be effecting change in clinical practice.

Given the recent Berwick report (2013) which stated the importance of engaging and empowering patients in their care, it appeared that further work was required to establish how to engage clinicians in developing collaborative partnership working with young adults in the lead up to transition, carefully supporting them to become more confident and knowledgeable about their condition.

The participants in this study had not met anyone since their discharge from CAMHS and there seemed to be a sense of confusion about how to access services. They appeared to be under the impression that their GP was the only service they could access, even though they had been told that they would be referred to a specialist service.

The participants voiced concern about their GPs knowledge of ADHD, Their impression that their GPs were not confident in managing ADHD, could be resolved if the recommendations made

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by Montano and Young (2012) and Merriman (2013) were implemented.

Montano and Young (2012) and Merriman (2013) suggested that, given the increasing recognition and treatment of ADHD and a dearth of specialist ADHD services, training should be provided for GPs to support them in providing evidence based care.

This seems a priority given the reported statistic that there has been a '4 fold increase in the UK of prescribed ADHD medications between 1998 and 2010' (Ilyas and Moncrieff 2012) which suggests, most GPs, if not all will, be involved in providing healthcare services to people with ADHD.

There was a varied response regarding the efficacy of medication with just two participants continuing to take medication regularly. It was apparent that all the participants had questions about the use of medication and it seemed they felt it would be beneficial to be able to discuss their queries with a professional.

Mullen (1997) stated the importance of engaging people in a dialogue about medication, reporting that if people were uncertain or had unanswered questions about medication then this could lead to problems with compliance. This implies that there needs to be clarity about who is responsible for the care of young adults when they leave CAMHS and decisions about their treatment, should be made in partnership between service users and professionals.

It is recommended (NICE 2008; Fabiano et al. 2009) that medication should not be the sole treatment intervention for ADHD. Therefore, if young adults are to access a range of interventions, consideration needs to be given regarding which services can realistically provide this.

Although the participants demonstrated their ability to make decisions for themselves and were 'experts' in managing their ADHD, they also experienced some anxiety about being in this

position without support. This perhaps indicates that if the recommendations of Shaw (2004) were implemented and opportunities to develop their self-management skills in conjunction with regular contact from healthcare professionals were provided, their experience of healthcare might be enhanced and better outcomes achieved.

7.7 Superordinate theme four: moving on

The final theme concerned the participants' accounts of their experience of leaving CAMHS and illuminated their ideas about their continuing healthcare needs. From the data collected, it appeared as if there were interconnected areas of importance which were interwoven across the superordinate themes and that these had particular significance when considered in the context of transition, continuing healthcare needs and service provision.

What clearly emerged from the participants' accounts was that none of them had accessed services providing specific ADHD healthcare since being discharged from CAMHS. It appeared that all of them had been left to the care of their GPs whom they criticised for not appearing to have specialist knowledge and understanding of ADHD.

Rather than transition being experienced as an empowering and contained process, it seemed as if the participants experienced an abrupt ending to their healthcare with no apparent evidence of any care planning or continuing support. The impression being that there was an expectation that they would self manage their care.

Their experience correlates with published evidence (Townley 2006; Day et al. 2007; Crowley 2011; Montano and Young 2012; Reiss 2012) and was contradictory to the national guidelines and policies (DH 2004a; DH 2006) which stressed the importance of transition and recommend processes to ensure effective pathways.

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From the findings of this study, it appeared that GPs by default, had assumed the role of providing ongoing healthcare for this group. However, no research could be found that reported GPs were aware they were the sole providers or they understood the associated expectations held by these young adults about their GP's knowledge of ADHD and their ability to adequately meet their healthcare needs.

Given that several authors (Berney 2009; Bolea et al. 2012; Montano and Young 2012; Merriman 2013) have highlighted the training needs of this professional group it would seem timely to consider their views about who is or should be responsible for providing continuing care.

Reiss (2012) has questioned why there appears to be a difficulty in implementing transition guidelines, particularly given the general consensus that this is a priority area.

The difficulties associated with implementing national guidelines within healthcare contexts has received considerable attention, particularly given there is evidence that this omission results in a 'gap' between theory and clinical practice. This inevitably has a negative impact on the provision of safe, effective and evidence based care (Haines and Donald 1998; Kelly 2004; Michie et al. 2007).

Paul et al. (2013) proposed that transfer and transition are different entities and involve different processes. Their view was that transfer described the conclusion of care in a child and adolescent context and the commencement of care in adult services, whereas transition was a process which 'requires therapeutic intent' and included preparation for transition and handover of care requiring effective communication between all parties. They recounted how some participants in their study had been transferred to new services but had not experienced good transitional care and argued that transfer of care did not necessarily imply good transitional care or that a poor transition was associated with poor outcomes.

There seems to be some confusion about what 'transition' means (Burke et al. 2008) which is consistent with my clinical experience. It seems that it is often used to refer to an event whereby a young person's care is transferred over to an adult service at age 18. However, the timing is neither flexible nor part of a holistic transition process. Therefore, it would seem that an important implication for clinicians and commissioners is to have an awareness of the importance of healthcare transition as a process, which includes the transfer of healthcare.

According to Paul et al. (2013), there were two main factors which influenced the transition / transfer process:

Firstly, young people refused to be transferred into adult services. This may be due to young adults being concerned about the potential stigmatising experience of attending AMHS or they did not feel they needed continuing care or they were reluctant to negotiate a change in care providers (Patterson and Lanier 1999; Por et al. 2004).

Secondly, CAMHS clinicians did not refer into adult services, this may be because CAMHS clinicians felt that AMHS had differing access criteria (Munoz-Solomando et al. 2010; Young et al. 2011) or there were simply no services to refer onto (Bolea et al. 2012).

It would be useful to understand the underlying beliefs which resulted in this situation in order to try and improve transition.

Reiss (2012) suggested that there was a perception by professionals that healthcare transition was 'a new and separate task'. If this hypothesis is accurate, it might explain why transition continues to be identified as an area that needs urgent attention and why guidelines do not appear to be translated into clinical practice.

There are several possible explanations for this:

Firstly, It may reflect a lack of consensus between professionals in CAMHS and AMHS about who is responsible for facilitating a good

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enough transition even though it is acknowledged as being a 'key component of care' (Crowley et al. 2011, p548).

Secondly, although it is widely acknowledged that there is a dearth of adult ADHD services nationally (DH 2005; Berney 2009; Bolea et al. 2012), there appears to be a reluctance to address this situation.

Merriman's (2013) survey of (n=122) healthcare professionals involved in the care of people with ADHD indicated there was a general agreement (95.8%) that ADHD services should be commissioned to ensure a seamless transition at the point of discharge from CAMHS. It is unclear as to why this situation has not yet been resolved, however it is possible that this is a result of national commissioning practice.

Thirdly, if transition or adult ADHD services are not available in the local area it follows that this presumably results in confusion about where young adults should be transitioned. Of interest, is Merriman's (2013) observation that in some trusts which have adult ADHD services, transition plans are used to good effect.

This clearly warrants further exploration to determine how these important areas could be addressed to provide appropriate continuing healthcare services and to ensure best possible long term outcomes. In the context of this study it appeared there was an absence of a transfer or a transition which seemed to have left the participants confused about who was co-ordinating their care and they appeared to assume their GPs were their point of contact.

The participants' accounts vividly highlight their sense of not being held in mind using words such as 'abandoned', to describe their experience. It seemed as though there was a perception they had almost been left to manage their condition on their own and there was an underlying sense of uncertainty about how they were doing and whether they were receiving appropriate treatment.

Given that transition occurs at a time when young adults are facing simultaneous changes in their lives, it would seem to be a priority that attempts are made to engage effectively with this group to ensure they continue to receive appropriate care.

Several authors (Crowley et al. 2011; Paul et al. 2103) have expressed concern regarding the potential to lose young adults to services, particularly at the point of transition. A recent study (Ogundele and Omenaka 2012) found that 73% (n=104) of young adults with ADHD transitioning from CAMHS to adult ADHD services were discharged or lost to follow up.

Montano and Young (2012) reported that the numbers of young adults with chronic health conditions engaged in healthcare services falls dramatically at this time and suggested it may be linked to difficulties in the transition process. This view is supported by Vostanis (2005) and Edwin and McDonald (2007) who wrote that, young adults had an increased likelihood of disengaging from health care services with an associated negative impact on their functioning.

Singh et al. (2010) reported that in the 16-24 age range there was a 20% increase in the likelihood of experiencing a mental health problem and an increased vulnerability to stress. It would seem crucial that efforts are made to address this situation as a priority, particularly given that treatment of ADHD produces marked benefit to patients and society (Bolea et al. 2012; Montano and Young 2013).

The findings of this study suggested that rather than participants choosing not to engage in continuing care, it actually appears they experienced an 'enforced dis-engagement' as they were not referred on or transitioned into another service.

It appears that this 'gap', in part, has been filled by their family and other close relationships; the participants talked openly about how much they valued the continuing support of their families. Vostanis

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(2005) considered that continuing parental involvement is a protective factor during healthcare transition, therefore it would be interesting to understand what happens to young adults who don't have supportive relationships or have other complex needs.

The available literature suggests that the parents of young adults facing transition feel anxious about the process and find it difficult to relinquish their involvement in their childrens' healthcare (Jivanjee and Kruzich 2011; Sonnevald 2012).

There are differing opinions between young adults as to whether they want their parents to continue being involved in their healthcare and they often feel that they are not given a choice (Tuchman et al. 2008; Hovish and Weaver 2012; Sonnevald 2012).

Although this study is unable to comment on whether the participants' parents experienced similar concerns, three of the participants clearly valued the ongoing support from their parents/partner and were happy for this to continue. This contrasted with the fourth participant whose parent had actively encouraged her to move away and had led to her assuming responsibility for her own care albeit with the support of a family member.

Although the participants stressed the importance of their families continuing involvement, this may have been related to the limited availability of other support networks. A possible disadvantage of their families continuing involvement may be that it interferes with the process of individuation and attainment of developmental tasks.

There was an overwhelming agreement between researchers (Tuchman et al. 2008; Hovish and Weaver 2012; Reiss 2012; Paul et al. 2013) which was consistent with the findings from this study, that an individualised approach to the planning and delivery of care was important. Although national guidelines and policies (DH 2006; DH 2008) strongly emphasised the importance of this, there was a clear sense that it was not currently happening.

Although none of the participants had accessed a service since their discharge from CAMHS or had any experience of transition, they offered valuable insights about areas they considered to be important. It seemed difficult for them to conceptualise exactly how they would like services to be delivered but were able to describe changes that would be helpful.

There was a consensus that the timing of transition should be flexible and take into account the individual needs of young adults which was consistent with the evidence from other studies (Patterson and Lanier 1999; Shaw et al. 2004; Soanes and Timmons 2012).

Sawicki et al. (2011) and Sonneveld (2012) proposed the use of a 'transition readiness tool' to identify when individuals are ready for transition and what self-management skills they might need to develop to facilitate their transition. Taking this idea forward, it may be that these elements could be incorporated into a 'live care plan' held by individuals documenting their needs and how these will be met.

This would link to the current agenda (NICE 2011; 2012) of putting patients at the centre of their care and would be enhanced by providing them with education about what services are available and the evidence base in order they can make informed choices about their care.

Access to and ongoing prescribing of ADHD medication was mentioned by all the participants. One participant had taken it upon herself to contact her GP for medication as she was starting a new job and felt medication might be helpful; the other three continued to be prescribed medication by their GP. However, it appeared that the supervision they received was minimal and they identified several concerns.

Bolea et al. (2012) highlighted recommendations (NICE 2008) that once medication is initiated and stabilised, the responsibility for

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prescribing should pass to the GP under a shared care agreement. However there was no mention of who would be responsible for any further titration of medication.

These findings suggest that further clarity is needed regarding prescribing responsibility. Recent evidence (Montano and Young's 2012) has stated there is a decline in prescribed ADHD medication in 95% of males aged 15-21 and by the time they reach 21 years old there will be 'complete cessation'. Possible explanations for this might include; maturity, improved ability to manage symptoms or a deficit in both young adults and professional's knowledge about the continuation of ADHD across the lifespan and prescribing knowledge (Montano and Young 2012; Merriman 2013).

One participant suggested that joint meetings prior to transition would be helpful; this was consistent with the work carried out by Townley (2006) and Crowley (2011) who described this as being an important component of transitional care.

All the participants mentioned how it would be helpful to be able to speak to professionals about some of their queries on specific areas such as medication, employment and benefits. Access to strategies to support them in managing specific ADHD symptoms was also considered important.

Given that the participants did not appear to have been informed about possible treatment options for ADHD in adulthood and were diagnosed relatively late in adolescence, it is unsurprising that they may have found it difficult to describe what treatment options they would like to be available.

This suggests that attention need to be paid to establishing processes for sharing current evidence with service users, in order that they can make informed decisions about their care.

7.8 Key implications for clinical practice

The use of a qualitative method, specifically interpretative phenomenological analysis, allowed an exploration of the participants' perspectives about their healthcare transition experience, allowing an insight into their world and thus contributing to the available knowledge and understanding about this area.

This research has produced findings which are consistent with current literature which states that healthcare transition is an important issue and that there is room for improvement.

The findings from this study highlighted several issues that were considered important by the participants and may be worthy of further consideration. Although the findings from this study are not applicable to all young adults with ADHD, they do add an additional perspective on this complex topic.

The findings have highlighted some specific issues which may be useful for clinicians to be aware of and may act as a useful starting point as they strive to meet the healthcare needs of this group. Some of the identified areas emerging from this study related to the participants sense of identity and living with ADHD, whilst others may have important implications for developing service specifications and clinical practice initiatives to better meet the continuing healthcare needs of young people with ADHD.

The focus of this study was to explore the healthcare transition experiences of young adults with ADHD and to ask their views about what they considered their continuing health care needs to be. The findings of this study suggest it would be useful to further explore how young adults would like services to be developed and in particular, where adult services should be located. In addition it would be interesting to consider whether services should fall within the remit of AMHS, primary care or a specialist ADHD services.

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The findings of this study clearly indicated that the participants wanted access to healthcare services. It was evident there were gaps in the transitional care they received. It seemed unclear as to whose responsibility it was to ensure they transitioned into adult healthcare services, or indeed where such services were located. Possible explanations for this might be, firstly, there were no available services to be transitioned to and therefore an associated absence of healthcare professionals who could support them to access continuing healthcare. Secondly, ADHD services in childhood sit variably in paediatric or CAMHS services which might make transition from a paediatric service to an AMHS confusing. If all ADHD clients were to be transitioned into AMHS, it may be the case as Berney (2009) cautions that the services could not cope with the demand. Finally, some young adults who chose to 'drop out' of services may choose to re-engage or may want a more flexible service that does not fit with the way 'traditional' healthcare services are provided.

Given that all the participants were receiving support from their GP it may be with appropriate training that GP or other members of the primary care team such as practice nurses (Montano and Young 2012; Hall et al. 2013; Merriman 2013), could develop services which would be less pathologising than an ADHD specialist service or AMHS. This would be consistent with the management of other chronic diseases

7.8.1 Transition processes

None of the participants in this study had in fact transitioned to an adult service following their discharge from CAMHS and were currently under the care of their GPs. Their experience contradicts the messages from policy initiatives such as the 'You're Welcome' policy (2011) and the Joint Commissioning Panel for Mental Health (2013) which stated that healthcare transition was important. There was a sense from the participants that they were in fact 'not

welcomed' and they felt that they had been left to get on with things on their own. It appeared that there had been a lack of preparation and lack of involvement in their transition.

As mentioned in the literature review there are a number of national guidelines which stress the importance of effective transition processes (RCN 2004; Kirk 2008; Kings Fund 2011) to enable young adults to access uninterrupted healthcare to achieve good long term outcomes (DH 2006), thus avoiding the associated negative outcomes associated with discontinuity of care (Feifel 2008; Millard 2009; Greener 2012). However, the current study has shown that these guidelines are not being translated into service configuration nor clinical practice, which is supported by other recent studies (Singh et al. 2010; RCP 2011; Lamb and Murphy 2013).

The findings from this study suggest that the participants had received minimal preparation for their transition from CAMHS to AMHS. The preparation they had experienced seemed to consist of a single conversation in which they were informed that they would be leaving CAMHS and there was a lack of clarity as to what service they would be moved on to. Their descriptions implied that transition was considered by their services to be a transfer, a one-off event, rather than part of a planned process.

These findings appear to contradict the recommendations outlined in existing transition guidelines (RCN 2004; DH 2005a; NICE 2008) and research studies which advocate standard practice should include features such as a transition plan and active involvement with AMHS prior to transition (Singh et al. 2010; Hovish and Weaver 2012; Robb and Findling 2013; Hall et al. 2013).

Recent literature (Burke et al. 2008; Robb and Findling 2013; Swift et al. 2013) supported the view that the timing of transition should be flexible and occur at a time that was appropriate for the young person and not be exclusively service led. The findings from this

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study showed that the participants were discharged from CAMHS when they reached 18, into the care of their GPs.

Given that the NICE guidelines (2008) stated that young people should have finished transition by the age of 18, there may be a case for this arbitrary age limit to be reviewed in order to enable flexibility and an individualised approach.

It is widely agreed that healthcare transitions occur at a vulnerable time for many young adults (DH 2008; Lamb et al. 2008; Singh et al. 2010), therefore it would seem that access to appropriate support is paramount. Robb and Findling (2013) stated that: 'Insufficient planning can lead to inadequate care' which potentially may result in subsequent disengagement from services at a time when young adults most need support with managing their chronic health conditions.

The results of this study and the evidence from contemporary literature indicate that it is imperative that healthcare transition arrangements and policy needs to improve. Therefore, there is a definite need for consideration of how recommendations will be translated into practice, to ensure transition protocols which are meaningful to young adults are developed and implemented.

It is important that mental health professionals understand how young people perceive services. It is hoped that one of the outcomes of the study will be that a local care pathway for young people in transition will be established and that the views of young people will be included in future service development.

An information leaflet outlining available services could be developed with support from service users, parents or carers and professionals. In particular, the development of a computer based transition care plan and the use of tele-medicine would be innovative advances in the provision of care at this crucial time.

7.8.2 Commissioning of services

One of the issues that emerged from the findings of this study concerned the provision of adult services for people with ADHD. This situation was borne out by the evidence from this study as it appeared that neither the clinicians nor participants were clear about the availability of appropriate services following discharge from CAMHS.

According to Singh et al. (2010) there is a dearth of service provision for young adults being discharged from CAMHS who do not meet AMHS access criteria. This is a particular problem for young people with neuro-developmental disorders such as ADHD (Swift et al. 2010; RCP 2011) who as evidenced by this study, end up by default under the care of their General Practitioners. The benefits of seamless continuity of healthcare for people with chronic conditions is well established (DH 2009; McGorry 2013).

Currently there is no available information about the provision of adult ADHD services nationally although there is agreement that services should be available (Marcer et al. 2008; Hall et al. 2013). Birchwood and Singh (2013) suggest that a 'thorough analysis of service design and delivery' is necessary to clarify current service availability in order to consider what further resources are required.

The results of this study indicate there is an absence of identified adult services for people with ADHD. Given the economic burden and societal impact associated with untreated ADHD (Matza et al. 2005), it seems important that this is resolved so there is equitable access to adult services for all young adults regardless of their chronic health condition.

A key area for consideration emerging from this study, concerns the need to commission services for people with ADHD and to agree on alternative service arrangements if it is felt that they do not meet criteria for accessing AMHS (NSF 2004; Lamb et al. 2008).

Discussion

This research has provided information about the views young adults hold about healthcare transition and service provision. The findings enhance our understanding of what they have found helpful and their ideas about how services could be developed.

Currently there is an emphasis on service user involvement (HASCAS 2008) in the development and provision of services within healthcare. There is therefore, a definite need to engage young adults in the planning and delivery of care which might result in more innovative approaches to service provision.

The benefits of eliciting the views of young adults about their experiences of care and their ideas about service delivery links to the recommendation made by charities such as Young Minds (2005) and HASCAS (2008) that service users should be involved in the commissioning, design and delivery of services; whilst this is a worthy initiative, attention should be paid to how this process is achieved to ensure it is not merely rhetoric.

Day (2008) wondered whether it was 'overly optimistic' to think that service users can in fact have an influence on the way in which services are developed. Therefore care is required to ensure effective and meaningful engagement with service users and transparency about the possible constraints.

7.8.3 Service delivery

The participants suggested several possibilities for service delivery, proposing a service that was provided for all people with ADHD across their life span. They highlighted the importance of accessing a service where professionals had a good knowledge of ADHD and its treatment (psychological and pharmacological) and the possibility of being able to access support and advice in relation to employment and benefits. It is possible therefore, that it would be helpful for young people, their parents or carers, clinicians and

commissioning groups to collaboratively consider options for service delivery.

These findings indicate that there are a variety of ways in which services could be provided, for example, an adult ADHD specialist service would address concerns about knowledge and competence.

This study found that GPs were the only healthcare professionals who continued to provide healthcare services to the participants; this finding has important implications for the development of services as it may be that general practice has an important role to play.

GPs are experienced in providing healthcare services to people with a range of chronic diseases requiring ongoing care such as asthma, diabetes and epilepsy. GPs are embedded within primary care teams which provide geographically accessible and non stigmatising services to all patients registered with them. In addition they work alongside a range of other professionals, including nurses, who are often specialists in the care of people with continuing healthcare needs such as diabetes.

Current research (RCN 2010) evidences the benefits for service users with continuing healthcare needs being supported by specialist nurses. It may be that a service including GPs and specialist nurses could be developed for people with ADHD, thus providing accessible, local services with professionals who have specialist knowledge and experience of their condition.

With further training (Bolea 2012; Merriman 2013) and the appropriate commissioning and development of services situated in primary care, this may be a useful option to consider. Consideration would need to be given to developing robust linkages with AMHS for complex cases, to ensure service users are able to access services suitable for their individual needs.

Discussion

By locating services within a primary care setting which is familiar to service users, there may be an additional benefit in that it may lessen the likelihood of dis-engagement with healthcare services. However, as the findings of this study cannot be extrapolated to all young adults with ADHD because, they are not representative of all young adults with ADHD further investigation into this service configuration is warranted.

Rebecca suggested that a service that covered all ages might be helpful. This idea would be worth considering. A 'life span service' would avoid the need for any transition between services and would provide continuity of care. Although these services do not appear to be widely available, there is some evidence of this approach being developed, for example there is a life span service which provides healthcare for children, adolescents and adults with Autistic Spectrum Disorders, Aspergers and learning disabilities.

A further option might be a transition service focussed on emerging adults aged flexibly between 14 and 25. A transition service could support the holistic needs of young people as they move into adulthood and would support the view that transition is a process and not a one-off event.

The findings of this study evidenced the preference expressed by the participants of having continuity in their relationships with healthcare providers, which is consistent with the literature (Shaw et al. 2004; Shaw et al. 2006; Townley 2006; Day et al. 2007). There is therefore, a definite need to take this into consideration when services are being developed.

Given the importance of keeping young adults engaged in services, consideration needs to be given to making services accessible and user friendly. In addition, relationships with other available services such as education and social care, need to be identified, to ensure that young adults have access to a range of services that would support their holistic transitional needs.

If this issue is to be moved forward, a better understanding of the views of all stakeholders is required in order to develop services that are effective, affordable and meet the needs of the population they aim to serve.

7.8.4 Families continuing involvement in healthcare

This study presents a mixed picture regarding whether or not families should be involved in their young adults' care during a healthcare transition. Although these findings differ from those of Singh et al. (2010) who found that young adults were in favour of their parents being less involved in their care, they corroborate with those of McDonagh (2004), Munoz-Salmondo et al. (2010) and Swift et al. (2013) who found that their involvement was experienced as helpful.

This study highlighted the ongoing involvement that some of the participants' parents continued to play in their lives which they seemed to find helpful. It is possible that better service provision for transitioning young adults with ADHD may mean parents and young adults feel that less parental involvement is required. Harden (2005) supports this view, she reported that if parents felt confident their adult children were receiving appropriate care, they might feel better able to reduce their involvement in their adult children's healthcare. Furthermore, it is possible that if a greater emphasis was placed on supporting young people to develop their self advocacy skills, then this might lead to a natural change in role for both parents and their adult children.

From the descriptions provided by participants in this study it seemed as if their parents were the only stable source of continuing support following their discharge from CAMHS. However given that this phase is associated with the process of individuation between young people and their parents, it is possible that continuing involvement may have a negative impact on young people becoming autonomous and independent of their families.

Discussion

An important implication of these findings is that attention should be given to supporting emerging adults in developing decision making skills. This initiative would support them to gradually take on more responsibility for making autonomous decisions about their healthcare.

7.8.5 Self concept

A further finding that emerged from this study was the impact of ADHD on self esteem and identity. It was interesting to hear the participants' explanations of how they understood ADHD. This led me to consider how clinicians deliver the diagnosis of ADHD to young people and the language they use in their explanation. It appeared that the participants believed there was a problem with their brain or more specifically their 'brain waves' (brain chemistry or neurotransmitters). This suggests that clearer explanations about ADHD at the point of diagnosis and beyond, might support the development of a positive self-identity and better understanding of ADHD.

Taking into consideration the possible influence of factors such as a spoiled identity (Goffman 1963), biographical disruption (Bury 1982), stigma and the wider transitional processes that these young adults are experiencing, it would seem appropriate that access to psychological interventions is available.

Support to reflect on the meaning of their diagnosis of ADHD and the possible stigma they experience in relation to this could be usefully addressed and may support the development of a positive self concept and build self esteem.

The findings indicated that medication was an important aspect of treatment. Although some of the participants mentioned they had accessed some psychological interventions, the extent and focus was unclear. It could be argued that medication alone may suppress

symptoms of ADHD but will not support individuals to develop appropriate strategies to manage them more effectively.

NICE (2008) proposed that access to psychological interventions might be beneficial to people with ADHD to help them manage their symptoms. Given the findings from this study suggesting the participants had experienced negative reactions by other people and considering their ambivalence about the 'real' and the 'medicated me' (Loe and Cuttin 2008), it seems important that such an opportunity is available.

Another important practical application might be the provision of psycho-educational sessions. These could be a useful component of a transition care plan to support young adults in learning how to manage their illness, understand the rationale for treatment and how to access help and information. This could be provided on a group basis led by facilitators with ADHD or knowledge of ADHD which would address the suggestion made by the participants regarding the benefits of being with people who have experience of ADHD.

7.9 Recommendations for future research

On completion of the research, it will be important to disseminate the findings. Research outcomes can be disseminated in various ways including journal articles, reports, presentation at conferences and possible inclusion in clinical guidelines (Gerrish and Lacey 2006).

At a local level, it is anticipated that the research findings will be presented at Trust academic sessions, the Trust research group and team meetings. Once the study has finished, participants will be given a written summary of the research findings.

Discussion

This study has raised several questions in need of further investigation. This study focussed on the experiences on the healthcare transition experiences of young adults with ADHD.

Further investigation into the views held by GPs, CAMHS, AMHS professionals and parents or carers in relation to their experiences and perceptions of transition, would help to establish a greater understanding of this important and concerning issue.

More information on the role GPs play in the care of young adults with ADHD and what ideas they have about where the on-going healthcare needs of this group should be situated would help inform the development of appropriate services.

More broadly, it would seem necessary to conduct a regional or national quantitative study to illuminate the extent and variety of transition needs of all young adults who have a chronic healthcare condition.

The issue of involvement by parents is an intriguing one, which could be usefully explored in further research. In particular, to elicit their views about the impact that the current absence of services has on their ability to reduce their involvement in their children's healthcare.

Further exploration of the development of self-identity in people with ADHD in relation to the concepts of biographical disruption, psychosocial development and stigma would add to the available knowledge in this area.

7.10 Limitations of the study

7.10.1 Recruitment

At the outset, it was anticipated that recruitment of young people with ADHD to the study might prove challenging and this proved to be the case. The two main difficulties were the lack of response

from potential participants who were approached directly and an insufficient pool of potential participants identified by local health services.

Patel et al. (2003) has highlighted the specific challenges that may be encountered by researchers during the recruitment process and this was also experienced as problematic in some of the critiqued literature (Patterson and Lanier 1999; Soanes and Timmons 2004; Hovish and Weaver 2012). In relation to this study, it is likely that the demographics of the required sample may have had an influence:

- Age range: The inclusion criteria of 18-22 years old meant that possible participants were young adults who were potentially negotiating a number of simultaneous transitions such as moving between school, college, employment and home. Young adults with ADHD may not be currently receiving healthcare services and may, therefore, have felt this study was not relevant to them. Furthermore, young people in this age range who have many other demands on their time may feel that participation in research is a low priority.
- Diagnosis of ADHD: The inclusion criteria requiring that potential participants have a diagnosis of ADHD only, will have therefore excluded a number of young adults who have ADHD (50-90%) with co-morbid presentations (Spencer et al. 1999; Wilens et al. 2002). Having ADHD with its associated impacts on organisation, motivation and short term memory may have had an influence on the number of responses received.

The issue of non-response from participants is consistent with Visentin et al.'s (2010) experience of conducting a study of young adults with diabetes. They suggested that a possible explanation for their recruitment difficulties was that adolescents who had not actually made a transition into adult services may have believed that

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the study was not relevant to them. It is possible therefore, that this was a factor in this study. Other possible explanations for the relatively low number of participants who were identified as meeting the inclusion criteria might include: the process of recruitment, the priority given to research within organisations, the perceived relevance of the research to clinicians and a lack of time available to identify participants.

A reasonable approach to tackle these issues might include the researcher seeking ethical approval to personally access client databases to elicit contact information, however this would need discussion with the NHS trust Caldicott Guardian to assess whether this would comply with the confidentiality, data protection and information sharing requirements as outlined in the Caldicott Guardian manual (DH 2010). An alternative approach could be to recruit participants via one of the national ADHD charities and to develop a database of people attending CAMHS who would be happy to be contacted post discharge to participate in research studies.

7.10.2 Interviews

Three of the four participants were accompanied by a family member or partner; arguably this may have had an influence on their accounts as they may have felt restricted in what they could say for fear of upsetting the person with them or embarrassment about discussing potentially sensitive issues. However, given the importance of enabling participants to feel comfortable and relaxed during the interview process, it was considered a priority that participants felt able to bring someone with them if they wished.

Initially there was a concern about the brevity of their responses; however at the analysis stage, it emerged that their answers, although relatively short and concise, provided detailed descriptions of their experiences so yielding rich data.

An interesting observation was the participants' ability to carry out several tasks simultaneously during the interviews. Initially, the researcher was concerned that allowing this might not constitute good research practice; however taking clinical experience into consideration, where it is recognised that it can be very difficult for someone with ADHD to sit still for long periods, it was felt that this would enable them to feel more comfortable and enhance their experience of the interview process. For example, during one interview, the TV was on, the participant was texting and two dogs were jumping up and down outside the window. However despite these 'distractions' the participant appeared unconcerned, he engaged well and participated fully.

7.11 Strengths of the study

A strength of this study was the use of interpretive phenomenological analysis which 'gave voice' to young adults with ADHD about their experiences of healthcare transition. Up to this point, no other young people with ADHD have been asked about their views on this topic. IPA allowed a close exploration of the insider perspective about their healthcare transition experiences, adding to the knowledge base of an area about which little is known and is therefore a novel contribution to the field of healthcare transition.

7.12 Reflection, 'there and back again'

(Tolkien 1966, p53)

'There is nothing like looking, if you want to find something. You certainly usually find something, if you look, but it is not always quite the something you were after'.

Reflective practice is considered to be an important technique for practitioners and researchers alike (Somerville and Keeling 2004; Wilding 2008), providing a framework for describing, analysing,

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reflecting and evaluating an activity that has been undertaken. Schön (1991) describes the benefits of 'reflection on action' as a way of identifying associated strengths and weaknesses and to evaluate whether any changes could be made to the process being reflected on, which might result in a different outcome.

My personal epistemology has developed over time and has been influenced by my personal narratives, experiences and training. I have worked as a general nurse and a mental health nurse; I have trained as a systemic family psychotherapist and have worked in CAMHS in the community and in-patient settings. My interest in this topic area has developed as a result of my personal and professional experiences.

I am a white British female and have three children, two of whom are young adults and I also have a family member who has ADHD. I feel comfortable talking to young adults and am curious about the views they hold about their experiences of healthcare transition and their suggestions as to how services might be provided, in particular, how these compare and contrast to mine, which may then provide insights into service enhancement.

In my clinical practice, I have found two concepts particularly helpful in developing my thinking and understanding about my own identity and how this may have influenced my therapeutic encounters. I decided to use these as a framework to guide my development as a reflexive researcher.

The 'Social GRRACCESS' (gender, race, religion, age, ability, class, culture ethnicity and sexuality) is described (Burnham 1993) as a technique to reflect on the differences and similarities that are inherent in inter-personal relationships, arguing that all these factors are important and may 'become foreground or background at different times' (Burnham and Harris 2003). I used this model to give a structure with which to reflect on their influence on me as a researcher.

A further influence on my early development as a family therapist was a clinical supervisor's use of the method she termed as the 'arc of influence'; this is a helpful tool with which to identify specific issues that potentially hold relevance for the individual, the family, the therapist and the wider system. She suggested that this facilitated the identification of specific aspects requiring attention from the therapist; to ensure they did not affect the process of therapy in an unconscious way, for example, my personal relationship with ADHD.

For the purpose of this study, I combined these ideas, which helped me explore certain areas, including those which were more prominent and required active consideration as a result of the topic area and the methodological approach, for example, the use of language (mine and participants).

From my experience as a therapist, I am familiar with the need to be reflexive about my position in a therapeutic context and continued to use strategies that I have found helpful. This included accessing regular clinical supervision and keeping a reflective diary which supported me to challenge and name my held assumptions in relation to my role as a researcher.

Throughout my career in the National Health Service, I have been interested in how to engage people in a dialogue about their impressions of the care they receive and their ideas about how services might be provided. I have noticed that whilst there appears to have been an increase in adult participation, it appears there are extra challenges associated with involving young people. I am particularly interested in how to elicit the views of young people about how services should be provided, in order that they offer meaningful support. A range of policies such as 'Creating a Patient-Led NHS' (DH 2005b) evidence the importance of patient participation in the planning and delivery of healthcare services. 'Putting Participation into Practice' (Young Minds 2005) is specific to

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CAMHS and summarised best practice initiatives aimed at increasing the participation of young people in service development.

My experiences and interest have therefore influenced my choice of topic. Together with my clinical supervisor's support I have been able to reflect on and address any pre-conceptions that may have had an influence on my interpretation of the data, with an intention of giving 'voice' (Reid et al. 2005; Larkin and Thompson 2012) to the participants' narrative.

It is considered important for qualitative researchers to keep a field diary to reflect on and add validity to the research process (Yardley 2000). Therefore a field diary was kept throughout the study which allowed me to critically appraise some of the decisions I made, the rationale behind them and provide a description of the challenges I faced. I also wanted to keep a contemporaneous record of my journey from the inception of the study to the point of completion, to reflect on the research process from a personal and methodological perspective.

The diary was used to track emerging issues, thought and ideas; the entries ranged from brief records to longer narratives about anything that captured my interest, caused me disquiet, or provided new knowledge or understandings. In addition, I recorded any relevant discussions points that arose from my membership of an IPA forum. This process has allowed me to incorporate elements of my academic, personal and professional life.

The idea to focus on the mental healthcare transition experiences of young adults with ADHD arose from my clinical experience and conversations with my supervisory team. My initial thoughts about this topic concerned my observations based on clinical practice that there appeared to be a gap in services and transition seemed to be problematic for all involved.

I was particularly interested in developing an understanding about how young adults felt about their healthcare transitions and decided

to concentrate on exploring their views regarding this important issue, especially as I believe that young people's voices about healthcare provision are generally neglected.

The literature review provided me with a broad depth of knowledge about ADHD, helping to set a context about why a careful transition is so important. Key learning points were that healthcare transitions are generally poor across all areas of healthcare and that ADHD has a continuing influence across the life span.

The following section presents my reflections on the research process and explains my rationale for decisions made about the implementation of the study and my thoughts on how successful IPA was in answering the research questions.

The sample size generated much discussion, quantitative researchers commented on the paucity of numbers asking the 'so what' question. However, qualitative researchers particularly those in the IPA 'camp' seemed more comfortable, pointing out that the sample was congruent with the idiographic approach of IPA. My personal view was that if I was to do justice to the data and carry out an in-depth analysis, any more than four participants would potentially impact on the quality of the analysis.

A small sample size was chosen for a number of reasons. Several authors (Smith 1999; Reid et al. 2005; Brocki and Weardon 2006; Smith and Osborn 2008) argued that smaller samples sizes are congruent with the idiographic intention of IPA. Smith and Osborn's (2008, p458) statement that

'the aim is not to generate large quantities of information but to gather quality information that will enable a deeper understanding of the participant's experience'

led me to consider the importance of accessing sufficient data to highlight the participants experiences whilst avoiding an excess of data that I would be unable to analyse in detail.

Discussion

Given this was a novel area of exploration, I wanted to stay 'true' to the participants' narrative and the idiographic nature of IPA. I felt that a sample of between four and six participants would allow me to undertake an in-depth exploration of the data rather than collecting a large number of descriptive themes from a larger sample. This decision was supported by several experts in the field (Smith and Osborn 2003; Smith et al. 2009; Thompson et al. 2011) who argued that larger sample sizes do not mean better results and caution that the depth of interpretative analysis may be compromised.

The issue of what constitutes an appropriate sample size is a recurrent theme amongst IPA researchers. I discussed my proposed sample size in an IPA forum and found it is an area that attracts lots of discussion. Whilst there is an agreement that small sample sizes are consistent with the idiographic emphasis of IPA (Smith and Osborn 2003; Eatough and Smith 2006; Smith et al. 2009), some researchers reported the difficulties they encountered when arguing for smaller sample sizes, despite the growing body of peer reviewed articles (Osborne and Coyle 2002; Eatough and Smith 2006) supporting this.

A further influence for me was the size of a part-time clinical doctorate study being undertaken, in particular the time available for analysis and the word count. I was keen to ensure that I did not end up with too much data which could result in a superficial analysis rather than a detailed exploration of the participants' narratives. Smith et al. (2009) state that researchers undertaking professional doctorates typically carry out between four and ten interviews which supports my decision to interview between four and six participants.

Given that the main aim of this study was to offer a detailed account of the healthcare transition experiences of young adults with ADHD, I felt that my chosen sample size would enable me to elicit the views of a hidden population and highlight their concerns. Given this is a

hard to reach population and taking into account they do not appear to be a particularly verbose group, I am satisfied with the substantiveness of the four transcripts.

In summary I consider that the sample size made methodological sense and was appropriate for the research strategy given IPA's commitment to the 'detailed examination of the particular case' (Smith et al. 2009).

Prior to commencing the study, I anticipated that recruitment might prove difficult due to the participants age and the condition being researched; what I hadn't anticipated was that it would be difficult to identify participants. On reflection, I would now utilise different strategies to address this, for example, developing a database of service users who are interested in participating in research. The difficulties I encountered in recruiting sufficient participants are consistent with the experiences of other researchers (Day 2008; Visentin et al. 2010; Hovish et al. 2012; Swift et al. 2012).

At the outset of the study, a recruitment strategy was developed; this included presenting the aims of the study and inclusion / exclusion criteria to CAMHS colleagues at an academic afternoon. In addition, several presentations were given to my professional group within CAMHS. I also telephoned, emailed and met with some CAMHS colleagues individually, to further explain the scope of the study with the aim of identifying possible participants. Although this process yielded several participants, the response rate was low. Possible explanations included: they were no longer living at the same address or they may have not been interested in taking part.

At this point a decision was made to seek ethical approval to approach three GP practices in the hope of identifying more participants. Ethical consent was given and the practices were contacted. Although this process resulted in several participants being identified only one person replied to an information letter.

Discussion

After further consideration the 'Enabling Support Service' at the University where the study was being conducted was approached, as it was felt that this might elicit more participants. Unfortunately due to issues of confidentiality, consent was not given to use this as a study site.

A discussion took place within the supervisory team regarding the possibility of approaching a national ADHD charity as a way of gaining access to more participants. However, it was decided that this strategy could pose certain challenges, for example how the diagnosis of ADHD would be validated and there were concerns about the possible associated risks in meeting unknown people in unfamiliar venues. A further round of intensive emailing, telephone calls and meetings with colleagues ensued, until a total of four participants had been interviewed.

Further discussions took place to decide whether a sample of four participants would be sufficient. The possibility of interviewing parents and professionals involved in the healthcare transitions of their young adults or service users was considered. However it was felt that triangulation of data collection would take the attention away from the focus and intention of the study which was to privilege the voices of the young adults which was a virgin area of exploration.

Although I am experienced at talking to people about sensitive issues in my professional role as a nurse and systemic psychotherapist, I have limited research interviewing skills. This was addressed by attending an interviewing skills workshop which helped me consider the differences between interviewing people as a researcher rather than a therapist.

In an early interview, I encountered a situation where the participant had the TV on and was texting. As a researcher I was uncertain how to respond and decided not to say anything. I discovered that the

participant was extremely adept at multi-tasking and despite my concerns, engaged well in the interview process.

During the process of data collection and analysis I began to wonder whether the participants had provided sufficient detail in their accounts. I discussed this with several experienced IPA researchers including one of my supervisory team. We considered the possible influence of ADHD symptoms such as poor concentration, distractibility, poor short term memory, impatience and hyperactivity might have on their responses. It was felt that it was not wholly unsurprising that they were not overly talkative, however it was thought important to judge whether their accounts were 'rich enough' and that someone with clinical experience with this group could help with this decision. However, when I began data analysis I found that although the participants' replies were fairly brief they contained rich narratives about their experiences, a view that was supported by my clinical supervisor.

There appear to be no clear guidelines about what constitutes rich data and this is ultimately a subjective decision. Given the existing literature about the difficulty of engaging young adults in research and a drive towards service user participation, it could be argued that by discounting what might be described as 'non rich' data that the very people whose narratives we seek to describe will be excluded and their voices not heard.

My sense, based on my clinical experience of working with young people with ADHD was that all the participants were engaged in the interviews. They all emphasised how they wanted to help and hoped that by sharing their experiences they might help others. I consider, that they felt, they had said what they had to say, their accounts were meaningful and they were adept at expressing themselves. There was a value and richness in their accounts and a sense of transparency.

Discussion

My experience of interviewing the participants has helped me think about my clinical practice and to consider alternative ways of engaging and establishing therapeutic relationships with this group.

Another consideration was the collection of what I initially thought to be 'irrelevant information' which didn't seem directly connected to transition. However, on further consideration, I realised that the participants were expressing something meaningful to them and were describing the psychological impact of the process of transition for them.

The possibility of using NVIVO software to carry out the analysis was discounted as it appeared counter intuitive to the intention of IPA and seemed to me to have the potential to create a disconnection from the data.

Assuming a phenomenological perspective allowed me the opportunity to explore the topic from the participants' perspective, yielding rich narratives about their ADHD and their experiences of healthcare transition.

Undertaking this study has reminded me about the positive aspects of ADHD and the associated challenges; the participants' narratives bear witness to the fact that transition is an important component of healthcare provision.

7.13 Conclusion

Healthcare transition is an important area that is attracting increasing attention from policy makers, researchers and clinicians, highlighting the need for transition services to be developed for young people with continuing health needs.

The purpose of this study was to explore the lived healthcare transition experiences of young adults who were discharged from CAMHS at the age of 18 and to understand what they believed their continuing healthcare needs to be. This research produced findings

which are consistent with current literature stating that healthcare transition is an important issue and that there is room for improvement.

Although the findings are specific to these participants, this study has provided a rich and detailed description of the healthcare transition experiences of young adults with ADHD which offer an insight into some of the issues facing young adults in healthcare transition. The challenge for professionals and policy makers is how this situation can be improved.

In the process of talking about their transition experiences, other important issues were revealed that seemed relevant, such as their sense of identity and their relationships with others. Their narratives indicate that they were left to 'get on with their own transition', which clearly needs to be addressed at national level and in service configuration and clinical practice.

This study helps us to understand and appreciate the importance of asking young adults for their views about how they think healthcare services should be provided. Suggestions were made by the participants about how services could be developed.

The findings of this study suggest that an individualised approach to healthcare transition is required. Healthcare transition should be seen as a process rather than an administrative event and needs to take account of other important transitions in a young person's life.

In Rebeccas' words:

I think you always need help, no one with ADHD can sit there and say they don't need help, day to day you need help with something. Whether it is you help yourself, or someone else helps you with () you can't go a day without needing help (17.3-17.5).

Appendices

Appendix 1 International Classification of Mental and Behavioural Disorder Criteria for ADHD (2010)

The International Classification of Mental and Behavioural Disorder [ICD] is the preferred diagnostic framework used in the UK, the most recent version ICD-10 was introduced in 2010. Although the term ADHD is not included in the ICD-10 the term hyperkinetic disorder (HKD) is broadly equivalent. Symptoms of either inattention or hyperactivity-impulsivity (or both) must have been present for at least 6 months and started before age 7. Symptoms must be pervasive and have a negative impact on school, social or occupational functioning and are not better explained by an alternative disorder such as a mood, anxiety or personality disorder.

Inattention (at least 6 symptoms)	Hyperactivity (at least 3 symptoms)	Impulsivity (at least 1 symptom)
Pays poor attention to detail, makes careless errors	Frequently fidgets with hands or finds it hard to sit still	Excessive talking
Difficulty sustaining attention on tasks or play	Often leaves their seat when expected to sit still	Blurts out answers to questions
Frequently appears not to listen	Excessive running and climbing (inappropriately) may be described as restlessness in adolescents.	Difficulty waiting for their turn
Difficulty organising activities or tasks	Persistent over activity, appears driven or 'on the go'	
Dislikes or avoids tasks which require sustained attention		
Frequently loses things		
Easily distracted by external stimuli		
Forgetful		

Appendix 2

Appendix 2 Databases searched using search terms

	Search Term	AMED	BNI	CINAHL	EMBASE	HMIC	MEDLINE	Psyc-INFO	Web of Knowledge	E - theses
1	'Attention Deficit Hyperactivity Disorder'	358	176	2363	15522	121	12270	14500	16852	113
2	ADHD	383	158	2923	16135	112	11771	15233	16030	144
3	HKD	1	0	14	111	2	84	23	111	4
4	Hyperkinetic Disorder	5	5	49	731	11	512	365	1034	8
5	1 or 2 or 3 or 4	483	207	3835	20887	149	15462	17999	21869	177
6	Adolescenc*	324	239	5128	36168	557	28322	31533	42620	586
7	Teen*	218	1042	8160	23598	1457	19567	14322	22690	572
8	'young people'	480	1689	5933	18105	4575	14163	15167	20652	2104

Appendix 2

	Search Term	AMED	BNI	CINAHL	EMBASE	HMIC	MEDLINE	Psyc-INFO	Web of Knowledge	E - theses
9	6* or 7* or 8	972	2814	18260	74462	6190	59389	57739	81990	3057
10	Transition*	1748	1197	15141	215417	2232	212621	41283	1029048	17693
11	'Continuity of patient care'	0	4	61	204	27	188	35	293	3
12	10* or 11	1748	1201	15200	215616	2258	212803	41313	1029325	17696
13	'Attention Deficit Hyperactivity Disorder' or ADHD or HKD or Hyperkinetic Disorder and Adolescenc* or Teen* or 'young people' and Transition* or 'Continuity of patient care'	1	1	7	26	1	20	34	7	3

Appendix 3

Appendix 3 Framework for critical appraisal of the literature.

(Based on Parahoo and Heuter (2013))

Title of article	Abstract	Purpose/aim of the research	Literature review	Method	Findings	Discussion
Is the precise area of study described?	Does the abstract convey enough information for readers to decide whether the article is relevant? Is the background, aim, design, method, sample and findings of the research summarised?	Are the aims of the research clearly defined?	What contribution does the article make to existing knowledge in the field? Is the reviewed literature up to date? Does the review rely on primary or sources? Is a rationale provided?	Is the process described in detail in order that the reader can understand the process? Are the research questions and objectives clearly stated? Is the design appropriate? Are data collection methods described? Sample?	Are the findings clearly presented? Is the reader able to understand how themes were extracted from the data?	Are the findings presented in the context of previous findings? Are the strengths and weaknesses of the research discussed? Are recommendations made regarding further areas for investigation? Reflections.

Appendix 4 Selected papers

Author	Year	Title	Journal
Day P Turner J Hollows A and Brooks E	2007	Bridging the gap: transitioning from child to adult services.	<i>British Journal of School Nursing</i> 2(4):146-152
Hovish K and Weaver T	2012	Transition experiences of mental health service users, parents and professionals in the United Kingdom: a qualitative study.	<i>Psychiatric rehabilitation Journal</i> 353:251-257
Patterson DL and Lanier C	1999	Adolescent health transitions: focus group study of teens and young adults with special health care needs.	<i>Family and Community Health</i> 22(2):43-58
Reiss JG Gibson RW and Walker LR	2005	Health care transition: youth family and provider perspectives.	<i>Pediatrics</i> 115 (1):112-119
Shaw KL Southwood TR and McDonagh JE	2004	Users' perspectives of transitional care for adolescents with juvenile idiopathic arthritis.	<i>Rheumatology</i> 43(3):770-778
Shaw KL Southwood TR and McDonagh JE	2006	Young people's satisfaction of transitional care in adolescent rheumatology in the UK.	<i>Child Care Health and Development</i> 33(4): 368-379

Appendix 3

Author	Year	Title	Journal
Singh SP Paul M Islam Z Weaver T Kramer T McLaren S Belling R Ford T White S Hovish K and Harley K	2010	Transition from CAMHS to adult mental health services (TRACK): A study of service organisations, policies, process and user and carer perspectives.	<i>SDO Project London: HMSO</i>
Soanes C and Timmons S	2004	Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care.	<i>Journal of Child Health Care</i> 8 (2):102-12
Swift KD Hall CL Marimuttu V Redstone L Sayal K and Hollis C	2013	Transition to adult mental health services for young people with Attention Deficit Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences.	<i>BMC Psychiatry</i> 13:74
Townley M	2006	The transition experience of young people and their families from children and young people's mental health services to adult mental health services.	Unpublished work. Gwent Healthcare NHS Trust /University of Glamorgan.
Tuchman LK Slap GB and Britto MT	2008	Transition to adult care: experiences and expectations of adolescents with a chronic illness.	<i>Child: Care, Health and Development</i> 34(5) 557-563

Appendix 5

Appendix 5 Critical review of selected literature.

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>Day P Turner J Hollows A and Brooks E (2007) Bridging the gap: transitioning from child to adult services. <i>British Journal of School Nursing</i> 2(4):146-152 UK</p>	<p>To examine the transition arrangements for young people with acute mental health needs. To explore the views of young people, families and professionals. To improve communication between staff and service users. To conduct an in-</p>	<p>Abstract not provided. Background to the study described. Databases were scrutinised to identify young people who met the inclusion criteria. Audio taped and transcribed. Limited information given about inclusion / exclusion criteria.</p>	<p>Sample comprised 6 young people aged 16-20 who were about to transition, in transition or recently transitioned. Sample was allocated to focus groups or individual interviews. 1 focus group comprising 3 females.</p>	<p>Qualitative. Case study. Data collection: Focus groups and individual interviews. Data analysis: Thematic analysis.</p>	<p>Findings: Three main issues identified. Limitations: Small sample size. Gender bias as service user participants were all women. Research was commissioned by Sheffield County Council as part of a scrutiny review into children's services which may have had an impact on the questions included. Time constraints.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
	depth analysis of working alliances and identify gaps in service.	Difficulties with the recruitment process described. Ethical approval obtained.	Interviews conducted with 3 females, 6 parents, 2 GP's and 5 key workers.		
Hovish K and Weaver T. (2012) Transition experiences of mental health service users, parents and professionals in the United Kingdom: a qualitative study. <i>Psychiatric Rehabilitation Journal</i> 35(3):251-257 UK	To describe the experiences of CAMHS service users, parents and professionals in the transition between CAMHS and AMHS.	Abstract provided a clear overview of the study. Background to the study described. Audio taped and transcribed. Informed consent.	Opportunistic sampling: drawn from 79 young people previously involved in another research study. 11 young people with a range of diagnoses, 6 parents and 9 professionals participated.	Qualitative. Data collection: Semi structured interviews conducted with young person and their parent / carer and professionals. Data analysis: Thematic analysis using NVIVO software.	Findings: Identified implications for clinical practice. Limitations: Age range of participants not stated. Recruitment difficulties - Clinicians (gatekeepers) often deemed it clinically inappropriate to contact participants. Young people refused to consent to interviews

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			Inclusion / exclusion criteria described. Recruitment process outlined. Contact made with AMHS and / or CAMHS worker to check clinically ok for young person to participate/ give informed consent.		being carried out with parents / carers / professionals. Turnover of staff meant that professionals involved in care could not be included.
Patterson DL and Lanier C. (1999) Adolescent health transitions: focus group study of teens and young	To understand the transition of young people from paediatrics to adult services.	Abstract included but lacked sufficient information about the	Volunteer sample. Age range 18-35. Inclusion / exclusion criteria	Qualitative. Data collection: Participants allocated to one of three focus	Findings: 3 emerging themes: Barriers to transition, factors that help and strategies for successful transition.

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>adults with special health care needs. <i>Family and Community Health</i> 22(2):43-58 US</p>	<p>To identify what information adolescents need and how to disseminate information.</p>	<p>contents of the paper. Background to the study described. Interviews audio taped and transcribed. Inclusion and exclusion criteria described.</p>	<p>described. Recruitment process described: Letters sent to healthcare providers asking them to give information to possible participants. 8 participants assigned to focus groups depending on criteria.</p>	<p>groups depending on criteria. Rationale given for use of focus groups. Questions generated from literature and research. Questionnaire described. Data analysis: Grounded theory - content analysis using software package.</p>	<p>Suggestions for future research. Service development information. Limitations: Difficulties with recruitment. Small sample size.2 of the focus groups comprised men / women.</p>
<p>Reiss JG Gibson RW and Walker LR (2005)</p>	<p>To examine the transition experiences of</p>	<p>Abstract included. Audio taped and</p>	<p>143 participants comprising: 49 young people, 44</p>	<p>Qualitative. Data collection: Focus group and</p>	<p>Findings: Four factors identified as impacting on transition process.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>Health care transition: youth family and provider perspectives. <i>Pediatrics</i> 115 (1):112-119. US</p>	<p>young people, families and professionals. To explore practices that facilitate successful transition.</p>	<p>transcribed. Field notes kept. Incentive of \$25 for participants</p>	<p>parents and 50 healthcare providers. The sample included young people with a range of diagnoses. Recruitment process unclear. Inclusion/exclusion criteria described in detail.</p>	<p>interviews. Participants evenly divided between focus groups in respect of role. Data analysis: Content and narrative analysis using a software package. Debrief session for facilitators post focus groups.</p>	<p>Limitations: Over representation of child healthcare providers. Wide range of healthcare needs represented therefore difficult to consider divergences and convergences in relation to specific healthcare needs.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>Shaw KL Southwood TR and McDonagh JE (2004) User perspectives of transitional care for adolescents with juvenile idiopathic arthritis <i>Rheumatology</i> 43:770-778 UK</p>	<p>To gain insight into the transitional needs of adolescents and consider how these may be addressed within a structured programme of transitional care.</p>	<p>Abstract included. Background to the study described. Ethics approval. Consent gained. Audio taped and transcribed. Set questions given to participants to generate discussion prior to focus group.</p>	<p>Purposive sampling. Volunteer group. Aged between 11-30. Parents comprised 2 of the 4 focus groups. Sample of 53 taken from 10 UK. Rheumatology centres. 11 focus groups spread across four locations. Participants assigned to one</p>	<p>Qualitative. Data collection: Focus groups, rationale for choice of method discussed. Data analysis: Interpretative phenomenological analysis. Rationale for choice of method outlined. Reflexivity discussed.</p>	<p>Findings: Identified themes are not disease specific. Key elements in transitional care described. Limitations: Small sample size. Gender predominantly females. Acknowledgment regarding limitations of the sample. Unclear whether the focus group facilitators were involved in data analysis.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			of four focus groups based on inclusion criteria. Recruitment: Phase 1 random selection from database and participants invited by letter. Phase 2 purposive selection.		
Shaw KL Southwood TR and McDonagh JE (2006) Young people's satisfaction of transitional care in adolescent Rheumatology in the UK.	To examine the quality of transitional health care from the perspective of young people with juvenile	Abstract. Background to the study described Demographic data collected at baseline and	Volunteer group 359 participants from 10 rheumatology centres 308 adolescents and 303 parents	Quantative. Data collection Self completed questionnaire prior to and 6/12 post implementation of	Findings: Adds information about aspects of service that are seen as important. Increased satisfaction following involvement in the transition

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<i>Child Care Health and Development</i> 33(4):368-379 UK	idiopathic arthritis and their parents. To examine the expectations held by participants of transitional care and satisfaction before and after an intervention programme.	described. Questionnaire developed by the authors and described. Consent given. Ethical approval obtained.	participated. Inclusion and exclusion criteria described.	structured programme of transitional care. Standardised questionnaires. Data analysis: Statistical analysis. 7 point likert scale.	programme. Provider characteristics rated as most important factors by participants. Limitations: All participants attending specialist centres may impact on results. Possible bias as data collector was also a key worker.
Singh SP Paul M Islam Z Weaver T Kramer T McLaren S Belling R Ford T White S Hovish K and Harley K (2010) Transition from CAMHS to adult mental health services	To describe the transition experiences of service users, carers and mental health professionals	Background to the study described. Description of questionnaire development. Audio taped and	Purposive sample of young people who had completed transition and their parents / healthcare	Qualitative. Data collection: Semi structured interviews. Data analysis: NVivo	Findings: Adds information about factors that hinder or support transition. 3 recommendations about preparing users for transition:

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>(TRACK): A study of service organisations, policies, process and user and carer perspectives. <i>SDO Project London: HMSO.</i></p>	<p>and investigate factors which promote and hinder successful transition.</p>	<p>transcribed. Consent given. Consent sought from young adults for their parents or healthcare professionals to be interviewed. Ethical approval obtained.</p>	<p>professionals. Sample drawn from the case note study population who were part of an earlier stage of the study (10 young adults who were engaged with AMHS and 10 young people who were not engaged with AMHS). 11 young adults interviewed. Challenges to recruitment</p>		<p>Respondent recommendations for improving transition. Limitations: Recruitment challenges.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			process described.		
Soanes C and Timmons S. (2004) Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. <i>Journal of Child Health Care</i> 8(2):102:111 UK	To examine the attitudes of young people facing transition. To understand what young people wanted from a transition service and to elicit suggestions about how to improve transition services.	Brief abstract included. Background to the study described. Ethical approval gained. Interviews audio taped and transcribed.	Purposive sample. Sample comprised 7 young people with a chronic physical illness recruited from a hospital youth club. Aged between 14-17.	Qualitative. Data collection: Semi structured interviews. Data analysis: Thematic analysis - data coded for content and then categorized into themes. Inexperienced researcher- limited discussion regarding possible impact.	Findings: 5 key themes identified. Implications for practice described Limitations: Small sample: not generalisable. Inclusion and exclusion criteria not described. How representative where the sample of wider population?

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
<p>Swift KD Hall CL Marimuttu V Redstone L Sayal K and Hollis C (2013) Transition to adult mental health services for young people with Attention Deficit Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences. <i>BMC Psychiatry</i> 13:74</p>	<p>To observe the process of transition of young people in CAMHS between the ages of 17-18 years of age. To explore the experience of young people with ADHD during transition from CAMHS to AMHS.</p>	<p>Abstract included. Background to the study described. Ethical approval gained. Interviews audio taped and transcribed.</p>	<p>Purposive sample. Part of a mixed method prospective study exploring young people's experience of transition between CAMHS and AMHS. Sample comprised 10 young people with ADHD recruited from CAMHS. 7 participants were pre - transition.</p>	<p>Qualitative. Data collection: Semi structured interviews. Data analysis: Thematic analysis Data analysis process described. Discussion about validity.</p>	<p>Findings: 4 themes identified Emerging themes consistent with those discussed in the literature. Implications for practice described Limitations: Small sample size. Participants were in the early stages of transition. Part of a larger research study which included young people with psychotic illness.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			8 of the sample had co-morbidities. Aged 17 and over		
<p>Townley M. (2006) The transition experience of young people and their families from children and young people’s mental health services to adult mental health services. Unpublished work. Gwent Healthcare NHS Trust /University of Glamorgan. UK</p>	<p>What do young people and their parents/ carers say is important to them when they transition to adult healthcare?</p>	<p>Description of the background to the study provided. Abstract not included. Ethical approval and consent were sought. Interviews audio taped and transcribed.</p>	<p>Purposive sampling. Recruitment process outlined: database search and contact by letter. 7 young people aged between 17-20 of whom 4 were interviewed with a parent. Professionals interviewed. Inclusion and</p>	<p>Qualitative study. Semi structured interviews. Identification of eight key themes. Reflexivity discussed.</p>	<p>Findings: Emerging themes consistent with those discussed in the literature. Recommendations for practice. Limitations: Small sample size. All participants were female. Parents participated in 4 out of 7 interviews. ? bias. Data analysis process not described.</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			exclusion criteria described.		
<p>Tuchman LK Slap GB and Britto MT (2008) Transition to adult care: experiences and expectations of adolescents with a chronic illness. Child: Care, Health and Development 34(5) 557-563 US</p>	<p>To describe the expectations and concerns of adolescents with chronic illnesses during transition from child to adult services. To guide service design and implementation.</p>	<p>Abstract gave a clear overview of the study. Background to the research described. Audio taped and transcribed.</p>	<p>22 adolescents with chronic physical illness, aged 15-21 and attending a children’s hospital. Part of a larger study of 155. If participants raised the issue of transition this was then discussed. 22 participants raised the theme of transition.</p>	<p>Qualitative. Longitudinal. Data collection: Questionnaire and semi structured interviews. Participants completed 1 questionnaire and attended 3 interviews over an 18 month period. Data analysis: Content and thematic analysis using Nvivo. Team of two</p>	<p>Findings: Identified specific areas of concern for young adults. Ideas regarding implementation described. Identifies areas for further research. Limitations: Study was not transition specific as set within the context of a larger study: if the participant raised the issue of transition the interview schedule allowed the researcher to</p>

Appendix 5

Author /Year /Title /Journal /Country	Aim of Study	Method	Sample	Design, data collection and analysis. Rigour, reliability and validity	Results/Limitations
			Ethical approval gained.	researchers, possible discrepancy between the data collected by different researchers not discussed.	further pursue this issue. Difficult to understand composition of the sample.

Appendix 6 Information about the research

CONFIDENTIAL

Date

Study Title: Transition Experiences of Young Adults with
Attention Deficit Hyperactivity Disorder.

Researcher: Lisa Rudgley

Ethics number: 11/SC/0228

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

My name is Lisa Rudgley. I am a part time student at The University of Southampton where I am studying for a Doctorate in clinical practice and as part of this course I am required to carry out a research study.

I would like to invite you to take part in my research study. Before you decide whether you would like to be involved, please read the following information that explains why I am doing this study and what it will involve for you. If there is anything you don't understand or if you would like more information please contact me at the address or numbers above.

Why have I been invited?

I work for the child and adolescent mental health service (CAMHS) in where you were previously seen by who suggested that you might be interested in taking part in my study.

Why is this study being carried out?

I am hoping to interview 10 young adults who have ADHD. I am interested in finding out about your experiences of accessing help for your ADHD after you left CAMHS and whether you have any ideas about which services would be helpful to you ?

Do I have to take part?

No you don't, participation is voluntary. You can decide not to take part now, or if you agree now and then change your mind, you can withdraw from the study at any time in the future without giving a reason and without it affecting any care you might receive.

What will it involve?

I would like to meet with you to carry out an interview. The interview will take about an hour and a half. With your permission the interview will be audio taped, written up and then the tape will be destroyed. The content of the interview will remain confidential unless you or I feel that we have talked about something that needs to be shared with your G.P. or another agency, if this is the case I will discuss this with you.

Your GP will be told about your involvement in the study.

Confidentiality

All information about you including your name and personal information will be kept confidential and I will use a research identification number to make sure that information collected about you is kept confidential. Information collected about you will be kept on a password protected computer file using your research identification number.

Tapes of interviews will be kept in locked filing cabinets at CAMHS and destroyed once they have been typed up. Your name and any identifying details will be changed in my project write up to ensure your anonymity. You can ask for a copy of the interview if you like.

Complaints Procedure

If you have a concern or a complaint about this study you should contact....., Research & Enterprise Services, at the Faculty of Health Sciences (Address: University of Southampton, Building 67, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 7942; Email:.....). If you remain unhappy and wish to complain formally

..... can provide you with details of the University of Southampton Complaints Procedure.

If you are interested in taking part please return the enclosed form or text me on this number I will contact you by phone to arrange the interview at a time that suits you. I can come and meet you in your home or we can meet at CAMHS in If you would find it helpful you can bring a parent/carer, key worker or a friend with you.

Reasonable expenses to cover your time (£10 HMV voucher) and any travel expenses will be reimbursed up to a maximum of £50.

If you have any questions or require any further information please contact me on this phone numberor complete the enclosed form.

Best Wishes

Lisa Rudgley

DClinP student, University of Southampton

(Protocol 1 Information about the research 11/3/2011)

Appendix 7 Request for contact by the researcher

CONFIDENTIAL

Date

Study Title: Transition Experiences of Young Adults with
Attention Deficit Hyperactivity Disorder.

Researcher: Lisa Rudgley

Ethics number: 11/SC/0228

REQUEST FOR CONTACT BY RESEARCHER

If you are interested in taking part in this study and would like me to contact you to discuss the study in more detail or to arrange an interview, please complete the following form and return it to me in the pre-paid envelope (enclosed) or you can text me, Lisa Rudgley on

Please initial the box

I am interested in taking part in this study and

I agree to Lisa Rudgley contacting me to give me more information about the study and to answer any questions that I might have before I decide to take part.

I would like to take part in this study and I agree to Lisa Rudgley contacting me to arrange an interview time. I agree to Lisa Rudgley using the contact details I have given below to contact me by telephone.

Name.....

Telephone number.....

Best time to call.....

(Protocol 1 Request for contact by the researcher 11/3/2011)

Appendix 8 Consent form

CONFIDENTIAL

Date

Study Title: Transition Experiences of Young Adults with Attention Deficit Hyperactivity Disorder.

Researcher: Lisa Rudgley

Ethics number: 11/SC/0228

CONSENT FORM

Please initial
the box

I confirm that I have read and understand the information sheet (dated ...version 1) about this study.

I have had the opportunity to think about the information sheet, ask any questions and have had these answered satisfactorily by Lisa Rudgley

I understand that I am free to withdraw from this study at any time, without having to give a reason and without affecting my future care.

I consent to my interview being audio-taped

I understand that the tapes will be written up

I understand that my name will be changed to ensure anonymity

I understand that on completion of the study that the audio tapes and transcripts will be destroyed

Appendix 8

I agree to my GP being informed of my participation in the study.

I agree to take part in the above study.

I fully understand the purpose of this study; I am clear that any information gathered will only be used in connection with this research project unless additional consent is sought from me.

Name of participant

Date

Signature

Name of person taking consent

Date

Signature

(Protocol 1 Consent form 11/3/2011)

Appendix 9 General Practitioner information sheet

CONFIDENTIAL

Date

Study title: Transition Experiences of Young Adults with Attention
Deficit Hyperactivity Disorder.

Researcher: Lisa Rudgley

Ethics number: 11/SC/0228

GENERAL PRACTITIONER INFORMATION SHEET

Dear Dr:

Re:

I am currently studying for a doctorate in clinical practice at Southampton University. Part of this course requires me to undertake a research study. The focus of my research is to explore the transition experiences of young people with ADHD when they leave Child and Adolescent Mental Health Services.

Your (above named) patient has volunteered to take part in this study. If you have any concerns about your patients involvement in this study I would be grateful if you could contact me or if you have any questions or require any further information please contact me directly at the above address.

I have enclosed a copy of the patient information sheet and consent form for your records.

Yours sincerely

Lisa Rudgley

DClinP student

(Protocol 1 GP Information sheet 11/3/2011)

Appendix 10 Information about services that can provide information and support to people with ADHD

CONFIDENTIAL

Date

Study Title: Transition Experiences of Young Adults with Attention Deficit Hyperactivity Disorder.

Researcher: Lisa Rudgley

Ethics number: 11/SC/0228

Information about services that can provide information and support to people with ADHD

Information about ADHD:

ADDISS: The National Attention Deficit Disorder Information and Support Service. 020 8952 2800. info@addiss.co.uk

AADD-UK: The 'one-stop shop' for anything relating to Adult ADHD in the UK. www.aadd.org.uk

<http://www.netdoctor.co.uk/adhd/www.livingwithadhd.co.uk>

Berkshire ADHD support: Name: contact

Counselling Services:

14-21 Time to Talk: 01635 581421

Youth Line: 01344 311200

No.5: Youth Counselling. 2-4 Sackville Street, Reading, RG1 1NT.
01189 015668

National Health Service information:

NHS direct: www.nhsdirect.nhs.uk 0845 4647

West call: Local out of hours GP service. 0118 9787811

Appendix 10

National Organisations offering a range of support, advice and information:

Alcoholics Anonymous: 0845 7697555

Connexions: Support and guidance to engage in education, training and employment. Mill Reef House, Cheap Street, Newbury, RG14 SDD. 08454085010.

CRUSE: Bereavement service 0800 4779400.

Disability Alliance: Improves living standards of disabled people. 020 2478776. www.disabilityalliance.org

Disability Law Service (DLS): 39-45 Cavell Street, London, E1 2BF. 020 7791 9800. advice@dls.org.uk

Narcotics Anonymous: 3009991212

Relate: Family relationships. 10 Oxford Road, Newbury, Berkshire, RG14 1PA. 01189 876161

Samaritans: 08457909090

Turning Point: Drug and Alcohol misuse. 1 Station Road, Newbury, Berkshire RG14 7LP. 01635 237795

(Protocol 1 Information about services that can provide information and support to people with ADHD 11/3/2011)

Appendix 11 Interview guide

Study title: Transition Experiences of Young Adult Males with
Attention Deficit Hyperactivity Disorder.

Researcher Lisa Rudgley

Ethics number: 11/SC/0228

INTERVIEW SCHEDULE

Name

Age:

Date

- 1) **I would like to start by asking you if you can tell me about yourself.**

Possible prompts: Who you live with, current occupation/ education?

- 2) **Now I'd like to ask you if you can tell me about your ADHD.**

Possible prompts: Age of diagnosis, meaning of diagnosis, description of their ADHD, impacts? Perception of others, medication.

- 3) **I'd like to ask you about your experience of leaving CAMHS; Can I take you back and ask if you can describe the process? What expectations did you have? Do you have ideas about what might have been helpful?**

Possible prompts: Looking back what age do you think transition should happen, how did you feel, preparation, help received service knowledge about ADHD, adult services , communication between services, are the needs of adolescents and adults the same or different? Age of discharge, preparation for discharge.

- 4) **I'd like you to tell me whether you have been seen in adult mental health services since you left CAMHS and if you have what that has been like for you.**

Possible prompts: help received, what's been helpful / not helpful, who have they seen, do they think they need special help, what would they find helpful, where would they like to be seen?

- 5) **I'd like you to tell me whether you have been seen in adult mental health services and if you have what that has been like for you.**

Possible prompts: Preparation, similarities or differences between care in CAMHS or AMHS, who have you they seen and what services have they received.

- 6) **Can you tell me what you think are important attributes for health care professionals /workers working with young adults.**

Possible prompts: qualities- trust, openness, honesty, straight talking, good listeners, experiences

- 7) **Can you tell me about your experience of being involved in making decisions about your health (ADHD).**

Prompts: Explanations about ADHD, treatment options and choices, parents.

Is there anything else you would like to say?

(Protocol 1 Interview Schedule 11/3/2011)

Appendix 12 Initial noting/ exploratory notes: Daniel

Initial Noting / exploratory notes	Original transcript
<p><i>Feels not wanted, dumped</i></p> <p><i>Decision taken out of his hands</i></p> <p><i>Lots of changes</i></p> <p><i>Tested - what does this mean to him?</i></p> <p><i>Process doesn't make sense.</i></p> <p><i>Behaviour problems - takes responsibility for actions</i></p> <p><i>Confusion - how does he make sense of one person getting it right and another wrong? How does this impact on trust?</i></p>	<p><i>Page 2</i></p> <p>1 did you do when you first left school?) () stuck</p> <p>2 in () have you ever heard of these places where they</p> <p>3 stick you in cos they don't want you in school and that.</p> <p>4 Yeah, they stuck me in one of them so I had to do that</p> <p>5 for two weeks and then after that I signed on for</p> <p>6 college three weeks later after that. ..When college</p> <p>7 started again after the summer I started on that () I</p> <p>8 done one set of GCSEs () never went back for the rest.</p> <p>9 (I'd like to ask you a bit about your ADHD. Looking</p> <p>10 back can remember how old you were when you</p> <p>11 were first diagnosed?) Yeah, this is like weird. I was</p> <p>12 in primary school () cos () I was disruptive and that</p> <p>13 and they got me tested by a specialist. I got tested</p> <p>14 they said I never had it. So going into year 10, halfway</p> <p>15 through year 10 I done a serious assault so the school</p> <p>16 got me tested and he turns round and said you had it</p> <p>17 since you were born. So, one specialist got it wrong</p> <p>18 and the other one said I had it since I was born. (So it</p> <p>19 sounds like you have only fairly recently had the</p>

Initial Noting / exploratory notes	Original transcript
<p><i>Sceptical of diagnosis – label stuck on him</i> <i>Knows about ADHD – observation / knowledge of others with it. Being done to.</i></p> <p><i>Identity –the real me -Can't control himself?</i></p> <p><i>School observation of difficulties- Not being understood by teachers</i></p> <p><i>Taking responsibility for behaviour-Is ADHD linked to this? Behaviour – impact of ADHD?</i></p> <p><i>Awareness of impact on him</i></p> <p><i>Identify – awareness of impact -Found a way of managing it but didn't fit with school context. Lack of understanding from others about how to help ADHD- takes matters into own hands</i></p> <p><i>Impact</i></p>	<p>20 diagnosis, what did you feel like when they said you 21 know this is ADHD?) don't know (), What they was 22 going on about, cos I knew what ADHD was cos I was 24 around people with it, then he diagnosed me with it 25 and he said I'd had it because of the way he said I was 26 disruptive. (So how would you say that ADHD 27 impacts on you, you know, what effect does it have 28 on you?) I get hyperactive, and once I start getting 29 hyperactive I get bored with that I just start messing 30 about () an' that and get myself kicked out of lessons(31 when I start getting bored I () start () throwing stuff Page 3 1 about and stuff like that...But I found a way of like 2 controlling it like, is like doodling when I was in my 3 lessons and that, drawing on pieces of paper kept me 4 calm, but most of the teachers didn't let me() so () I used 5 to just get up and walk out, save them kicking me 6 out.(Right and what about now, when you are at 7 work, do you think it has an impact now, has it 8 changed?) Yeah I still go hyper but () not as bad () as () 9 When I was back in school, I never liked school. I think</p>

Initial Noting / exploratory notes	Original transcript
<p><i>Symptoms have improved since left school -Didn't like school, Peer group- acted up to fit in with peer group - who am I?</i></p> <p><i>Doesn't like how medication affects him.</i></p> <p><i>Expert on condition</i></p> <p><i>Doesn't help for long</i></p> <p><i>Knowledge of how medication works</i></p> <p><i>Expert on managing condition</i></p> <p><i>Feels decisions made about medication not his?</i></p> <p><i>impact on compliance</i></p> <p><i>Medication makes him physically sick.</i></p> <p><i>Knowledge of how medication works.</i></p>	<p>10 that had a () thing with it, but not sure I think I was 11 around with the wrong crowd as well, so I had to () Um 12 act more.</p> <p>13 Um, what do you think about having the label of 14 ADHD. Don't bother me. (Do you take medication for 15 your ADHD?) Yeah, meant to, but I () kind of don't 16 take it, it makes me feel weird. Makes me feel like I'm 17 depressed and stuff like that, so I don't take it. (When 18 did you last take it?) About () four months ago, 19 something like that. I still get my prescriptions; I take 20 them on occasions, but not often. They switched my 21 tablets so many times I think I was on about() before I 22 come off these() seeing if they need to either put it up 23 or put it down, but never got chance to do that. cos It 24 tends, when I get used to it, it wears off after about 25 half an hour of me taking it. Yeah as well - it don't 26 really get into my system cos once I take it I throw up. I 27 thrown it back up, so cos then it's kind of in me 28 system, but only a little bit cos it's those slow releasing 29 ones. The capsule stays in your stomach but just 30 releases a little bit. (Do you think there is a difference</p>

Initial Noting / exploratory notes	Original transcript
<p><i>The real Daniel- positive description –how he wants to be seen. Describes negative impact of medication on him. Makes him act in a certain way.</i></p> <p><i>How other people see him</i></p> <p><i>Fidgety</i></p> <p><i>Experience of transition</i></p> <p><i>Dr asks how his head is but then doesn't do anything- nothing happens.</i></p> <p><i>Meaning of this – what does he think is wrong with his head?</i></p> <p><i>Hard to express himself- even to ask for an appt.</i></p>	<p>31 in how you are when you are taking medication?</p> <p><i>Page 4</i></p> <p>1 What difference do you think it makes?) When I'm not</p> <p>2 taking the medication I am lively and stuff like that.</p> <p>3 When I'm taking the medication I don't, I don't talk. So</p> <p>4 I don't like taking it. Cos I'm duff (laughs) (Do other</p> <p>5 people around you notice if you haven't taken your</p> <p>6 medication?) I know her mum and dad [fiancé] notice</p> <p>7 when I've not taken it, [laughs] cos they ask me, they</p> <p>8 go 'have you taken your tablets?' Do you notice it [asks</p> <p>9 fiancé]? [Fiancé-Yeah you go really quiet sort of thing]. I just</p> <p>10 sit there like that. Yeah sometimes I get the shakes when</p> <p>11 I'm on them () and I sit there and me hands go and I</p> <p>11 start twiddling around with me hands. Don't know why.</p> <p>12 I wondered if I could ask you a bit about what it was</p> <p>13 like, you know your experience of leaving Child and</p> <p>14 Adolescent Mental Health Services, I just wondered</p> <p>15 if you could tell me a little about what happened</p> <p>16 when you left CAMHS? I left this service and did</p> <p>17 nothing else () Doctors ask me how me head is, he's</p> <p>18 going () one doctor's tried to push it down [medication]</p>

Initial Noting / exploratory notes	Original transcript
<p><i>Feels left. Experience of transition.</i></p> <p><i>Expert on his condition</i></p> <p><i>Not responsible for his condition even though he is an expert on it and knows what helps.</i></p> <p><i>? Wanted someone else to sort out his appointment.</i></p> <p><i>Preparation for transition</i></p> <p><i>Contradicts previous statement- doesn't know what help he needs- doesn't know what will happen next. still confused waiting for something to happen</i></p>	<p>19 and I wanted to put it up for a reason – it wears off 20 after a while if you take it down to a certain level 21 ground and after that there was nothing. (So when 22 you left here did you go back to your GP?) Yeah, 23 then they said they were going to refer me to a 24 different specialist for adults, And they haven't yet.</p>

Appendix 13 Emergent themes: Daniel

Initial noting / exploratory notes	Original transcript	Emergent Themes
<p><i>Feels not wanted, dumped</i></p> <p><i>Decision taken out of his hands</i></p> <p><i>Lots of changes</i></p> <p><i>Tested – what does this mean to him?</i></p> <p><i>Process doesn't make sense.</i></p> <p><i>Behaviour problems – takes responsibility for actions</i></p> <p><i>Confusion – how does he make sense of one</i></p>	<p>Page 2</p> <p>1 did you do when you first left school?)</p> <p>2 () stuck in () have you ever heard of these places where they</p> <p>3 stick you in cos they don't want you in school and that.</p> <p>4 Yeah, they stuck me in one of them so I had to do that</p> <p>5 for two weeks and then after that I signed on for</p> <p>6 college three weeks later after that ...when college</p> <p>7 started again after the summer I started on that() I</p> <p>8 done one set of GCSEs () never went back for the rest.</p> <p>9 (I'd like to ask you a bit about your ADHD. Looking</p> <p>10 back can remember how old you were when you</p> <p>11 were first diagnosed?) Yeah, this is like weird. I was</p> <p>12 in primary school () cos () I was disruptive and that</p> <p>13 and they got me tested by a specialist. I got tested</p> <p>14 they said I never had it. So going into year 10, halfway</p> <p>15 through year 10 I done a serious assault so the school</p> <p>16 got me tested and he turns round and said you had it</p> <p>17 since you were born. So, one specialist got it wrong</p> <p>18 and the other one said I had it since I was born. (So it</p>	<p><i>Rejection</i></p> <p><i>Lack of involvement in decisions made about him</i></p> <p><i>Identity</i></p> <p><i>behaviour</i></p>

Appendix 13

Initial noting / exploratory notes	Original transcript	Emergent Themes
<p><i>person getting it right and another wrong?</i> <i>How does this impact on trust?</i> <i>Knows about ADHD - observation / knowledge of others with it.</i> <i>Sceptical of diagnosis - label stuck on him</i> <i>Being done to.</i> <i>School observation of difficulties-Not being understood by teachers</i> <i>Taking responsibility for behaviour-Is ADHD linked to this?</i> <i>Identity -the real me -Can't control himself?</i> <i>Behaviour -impact of ADHD?</i> <i>Awareness of impact on him, Identify - awareness of impact</i> <i>Found a way of managing it but didn't fit with school context.</i></p> <p><i>Lack of understanding from others about how to help ADHD- takes matters into own hands</i> <i>Impact</i></p>	<p>19 sounds like you have only fairly recently had the 20 diagnosis, what did you feel like when they said 21you know this is ADHD?) don't know (),What they was 22 going on about, cos I knew what ADHD was cos I was 24 around people with it, then he diagnosed me with it 25 and he said I'd had it because of the way he said I was 26disruptive. (So how would you say that ADHD 27 impacts on you, you know, what effect does it have 28 on you?) I get hyperactive, and once I start getting 29hyperactive I get bored with that I just start messing 30 about() an' that and get myself kicked out of lessons() 31 when I start getting bored I () start () throwing stuff <i>Page 3</i> 1 about and stuff like that...But I found a way of like 2 controlling it like, is like doodling when I was in my 3 lessons and that, drawing on pieces of paper kept me 4 calm, but most of the teachers didn't let me() so () I 5 used to just get up and walk out, save them kicking me 6 out.(Right and what about now, when you are at 7 work, do you think it has an impact now, has it 8 changed?)Yeah I still go hyper but () not as bad () as () 9 When I was back in school, I never liked school. I think</p>	<p><i>Responsibility for behaviour</i></p> <p><i>Trust</i></p> <p><i>Diagnosis</i></p> <p><i>Dis-engagement with the diagnosis</i></p> <p><i>How he sees himself - me or ADHD</i></p> <p><i>Who am I</i></p> <p><i>Impact of ADHD</i></p> <p><i>How do others see him?</i></p> <p><i>identity</i></p> <p><i>Managing behaviour</i></p>

Initial noting / exploratory notes	Original transcript	Emergent Themes
<p><i>Symptoms have improved since left school</i> <i>Didn't like school, Peer group- acted up to fit in with peer group - who am I?</i> <i>Doesn't like how medication affects him.</i></p> <p><i>Expert on condition</i></p> <p><i>Doesn't help for long</i></p> <p><i>Knowledge of how medication works</i></p> <p><i>Expert on managing condition</i></p> <p><i>Feels decisions made about medication not his?</i></p> <p><i>impact on compliance</i></p> <p><i>medication makes him physically sick.</i> <i>Knowledge of how medication works.</i></p>	<p>10 that... had a () thing with it, but not sure I think I was 11 around with the wrong crowd as well, so I had to () Um 12 act more.</p> <p>13 Um, what do you think about having the label of 14 ADHD. Don't bother me. (Do you take medication for 15 your ADHD?) Yeah, meant to, but I () kind of don't 16 take it, it makes me feel weird. Makes me feel like I'm 17 depressed and stuff like that, so I don't take it. (When 18 did you last take it?) About () four months ago, 19 something like that. I still get my prescriptions; I take 20 them on occasions, but not often. They switched my 21 tablets so many times I think I was on about () before I 22 come off these () seeing if they need to either put it up 23 or put it down, but never got chance to do that. cos It 24 tends, when I get used to it, it wears off after about 25 half an hour of me taking it. Yeah as well - it don't 26 really get into my system cos once I take it I throw up. I 27 thrown it back up, so cos then it's kind of in me 28 system, but only a little bit cos it's those slow 29 releasing ones. The capsule stays in your stomach but 30 just releases a little bit. (Do you think there is a 31 difference in how you are when you are taking</p>	<p><i>Misunderstood</i></p> <p><i>Improvement of symptoms</i></p> <p><i>Awareness of ADHD symptoms</i></p> <p><i>Peers</i></p> <p><i>Medication effects</i></p> <p><i>Makes independent decisions about medication</i></p>

Initial noting / exploratory notes	Original transcript	Emergent Themes
<p><i>The real Daniel- positive description –how he wants to be seen. Describes negative impact of medication on him. Makes him act in a certain way.</i></p> <p><i>How other people see him</i></p> <p><i>Fidgety</i></p> <p><i>Experience of transition</i></p> <p><i>Dr asks how his head is but then doesn't do anything- nothing happens.</i></p> <p><i>Meaning of this – what does he think is wrong with his head?</i></p> <p><i>Hard to express himself- even to ask for an</i></p>	<p>32 medication? <i>Page 4</i> 1 What difference do you think it makes?) When I'm not 2 taking the medication I am lively and stuff like that. 3 When I'm taking the medication I don't, I don't talk. So 4 I don't like taking it. Cos I'm duff (laughs) (Do other 5 people around you notice if you haven't taken your 6 medication?)I know her mum and dad [fiancé] notice 7 when I've not taken it, [laughs] cos they ask me, they 8 go 'have you taken your tablets?' Do you notice it? 9 [Fiancé-Yeah you go really quiet sort of thing]. I just sit 10 there like that. Yeah sometimes I get the shakes when 11 I'm on them () and I sit there and me hands go and I 12 start twiddling around with me hands. Don't know... 13 I wondered if I could ask you a bit about what it 14 was like, you know your experience of leaving Child 15 and Adolescent Mental Health Services, I just 16 wondered if you could tell me a little about what 17 happened when you left this service. I left this 18 service and did nothing else () Doctors ask me how me 19 head is, he's going () one doctor's tried to push it 20 down [medication] and I wanted to put it up for a 21</p>	<p><i>Compliance</i></p> <p><i>Not involved in decision making</i></p> <p><i>Expert on condition</i></p> <p>The real / false Daniel</p> <p>Impact on relationships</p> <p>Awareness of behaviour</p> <p>Medication effect</p> <p>Transition experience</p>

Initial noting / exploratory notes	Original transcript	Emergent Themes
<p><i>appt. Feels left. Experience of transition.</i></p> <p><i>Expert on his condition. Not responsible or his condition even though he is an expert on it and knows what helps. ?</i></p>	<p>reason – it wears off after a while if you take it down to 22 a certain level ground and after that there was nothing.</p>	<p>Concept of ADHD-</p> <p>Knows more than the Dr. Trust</p>

Appendix 14 Clustering themes: Daniel

Decision making

2.1-2.3: stuck in () have you ever heard of these places where they stick you in cos they don't want you in school and that.

Lack of involvement in decisions 2.4 Yeah; they stuck me in one of them

Not involved in decision making 3.20-3.21: they switched my tablets so many times

Not taking responsibility 5.5: I thought the GP would have sorted it out

Responsibility for decision making /compliance 9.17-9.20: I just left it to them. Cos if it wasn't the right decision I wouldn't take me tablets. So I just left it to them to make the decisions.

Passive in decision making 9.24-9.25: they would tell us about me tablets, which ones they wanted to put me on

Decision making: involvement in decision making me and me mum turned round 29 and said no, we're not going on them.

Responsibility for care 10.1: I just left it to them.

Responsibility for behaviour

Responsibility for behaviour 2.15: I done a serious assault

Managing behaviour 3.1-3.4: But I found a way of like controlling it like, is like doodling when I was in my lessons and that, drawing on pieces of paper kept me calm

Managing self 5-3.6: I used to just get up and walk out,

Managing symptoms 5.25-5.26: you got to take control of it [ADHD] and sort it out yourself, like most adults have to do with themselves.

Managing self 7.4-7.6: not as bad () as it used to be, but I can kind of control it more as I get older.

Self management: 7.8-7.9: I can control it more now could.

Shame 7.9: I can control it more now, than what I could.

Understanding of ADHD 3.4-3.5: Drawing on pieces of paper kept me calm, but most of the teachers didn't let me

Appendix 15 Master themes: Daniel

Living with ADHD

Impact on self (identity) - Is it me or ADHD?

Impact on relationships with others

Expert on the condition

Medication

Decision making and responsibility

Managing symptoms / behaviour

Involvement in care planning

Responsibility for healthcare

Internal transition - becoming an adult

Moving On

Trajectory of ADHD

Transition timing

Transition experience

Attributes of professionals

What support would they like

Services accessed

Appendix 16 Superordinate themes from the group

Personal experience of ADHD diagnosis and treatment

Process and timing of diagnosis

Emotional response to the diagnosis

Medication

Impact on self and relationships

'Mad? Bad? Who am I?' (Impact on self (identity))

'You, me and everyone I know' (Impact on relationships)

'He/she's not naughty he's got ADHD' (Perceptions of ADHD)

Living with ADHD

Managing ADHD

Being an expert on ADHD

Decision making and responsibility (Responsibility for decisions about healthcare/Involvement in care planning)

Getting Help

Experience of services prior to transition

Ideas about support

Who cares/ who can I trust? (Attributes of professionals)

Moving On

Preparation for transition

Transition timing

'Mind the gap' (Transition experience/ Transition) processes

'Abandoned' (Emotional response to transition)

Growing out of ADHD /Transition to adult hood /Internal transition – becoming an adult

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