

Experiences of healthcare transitions for young people with attention deficit hyperactivity
disorder: a systematic review of qualitative research

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Abstract

Background: Attention deficit hyperactivity disorder (ADHD) is a neurodevelopmental disorder characterised by hyperactivity, inattention and impulsivity. Up to two thirds of young people with ADHD may experience symptoms into adulthood, yet the limited literature available suggests that many young people with ongoing needs do not transfer from child to adult healthcare services. Although worldwide and NICE guidelines recognise the importance of supported transition, evidence suggests for ADHD this is poorly managed and variable. Little is known about how transition is experienced by those involved. We aimed to synthesise existing peer reviewed literature to understand views and experiences of young people, carers and clinicians on transitioning between child and adult ADHD services.

Method: Five databases were searched and all articles published between 2000 and up until January 2017 considered. Four key search areas were targeted; *ADHD, Transition, Age* and *Qualitative Research*. Quality appraisal was conducted using Wallace criteria. Findings from included studies were synthesised using thematic analysis. **Results:** Eight papers, six from the UK, and one each from Hong Kong and Italy, were included. Emerging themes centred on difficulties transitioning; hurdles that had to be negotiated, limitations of adult mental health services, inadequate care and the impact of transition difficulties. **Conclusions:** Healthcare transition for this group is difficult in the UK, because of multiple challenges in service provision. In addition to recommendations in NICE guidelines, respondents identified a need for better provision of information to young people about adult services and what to expect, greater flexibility around age boundaries and the value of support from specialist adult ADHD services. More research is needed into ADHD healthcare transition experiences, especially in countries outside the UK, including accounts from carers and clinicians.

Keywords: ADHD, Transition, Systematic Review, Qualitative Methods, Health, Experiences, Adolescence

Key practitioner message:

- Lack of healthcare provision in the UK results in inadequate care, such as keeping young people on at CAMHS, weaning off medication prematurely and discharging to GP without specialist management, which can leave young people feeling abandoned, under intense distress and unable to cope.
- In addition to the information transfer between healthcare services recommended in the NICE guidelines, clinicians, carers and young people want accurate and sufficient information before and during transition, which should include information about where adult services are and how to access them.
- Differences in thresholds between child and adult mental health services in the UK leave some young people unable to access adult ADHD services.
- Parents and carers want to continue to be involved when the young person transitions, which is often outside the normal patterns of adult mental health service provision.
- There was no consensus about the necessity of age boundaries or the ideal age / stage for transition to adult health services.

Experiences of healthcare transitions for young people with attention deficit hyperactivity disorder: systematic review of qualitative research

Attention Deficit Hyperactivity Disorder (ADHD) is a lifespan neurodevelopmental disorder characterised by hyperactivity, inattention and impulsivity (Gibbins & Weiss, 2007; Kooij et al., 2010). Reviews of prevalence suggest ADHD affects 5.9-7.1% of children (Willcutt, 2012). Up to two thirds of young people continue to experience symptoms into adulthood (Agnew-Blais et al., 2016; Faraone et al., 2006). The proportion of young people who access treatment declines at a greater rate than age related decrease in symptoms, implying some young people with ADHD do not receive the care they need as adults (Coghill, 2016; Newlove-Delgado et al., 2017).

Getting healthcare transitions right for young people with ADHD is crucial. Transitional healthcare is defined as *“the purposeful, planned movement of adolescents with chronic physical and mental conditions from child-centred to adult-orientated health care systems”* (Blum et al., 1993, p. 570). This review defines transitional healthcare for young people with ADHD broadly, to include transfer to adult mental health services, referral to General Practitioner (GP) and ceasing to access health services (Paul et al., 2015). For all young people with mental health needs the move into adult health services occurs at a very vulnerable stage in their lives, with potentially many other challenging transitions; such as changing school, moving out of home, or starting work (Schulenberg et al., 2004). This stage of development is particularly challenging for young people with ADHD because the combination of impulsivity, inattention and hyperactivity make organising and managing change difficult (Baric et al., 2016; Gotlieb & Gotlieb, 2009; Wolraich et al., 2005).

National and international guidelines on ADHD recognise the importance of this healthcare transition (Seixas et al., 2011). In the UK, the National Institute for Health and Clinical Excellence (NICE) guidelines (2008, 2016a) recommend the move from child and

adolescent mental health services (CAMHS) to adult mental health services (AMHS) for young people with ADHD takes place as a managed transition. Current quantitative and qualitative evidence suggests that healthcare transitions for young people with ADHD are poorly managed, highly variable and little is known about the experience of those involved (Coghill, 2016; Hall et al., 2014; Hall et al., 2013). Consequently, levels of drop out from services are high (McCarthy et al., 2009; Ogundele, 2013; Wong et al., 2009). Without adequate ongoing treatment, long term consequences can include disrupted social relationships, education, and work, as well as increased high risk behaviours such as drug taking and criminal activity (Montano & Young, 2012). Knowing more about how young people, their parents/carers and clinicians experience transition may help identify barriers and facilitators, and could help inform future transition protocols and service development. Considering that there are effective treatments for ADHD (Banaschewski et al., 2006; Bolea-Alamañac et al., 2014; Sonuga-Barke et al., 2013), reducing drop out and improving transitions into adult health services are key aims to reduce costs to society and to improve the wellbeing of young people with ADHD.

Existing literature on healthcare transitions for young people with mental health disorders includes three recent systematic reviews (Embrett et al., 2016; Mulvale et al., 2015; Paul et al., 2015). Conclusions are limited by scarcity of data but indicate patchy provision, a need for accessible and age-appropriate services, need to tackle stigma, unhelpful cultural differences between CAMHS and AMHS, and parents wanting more involvement (Mulvale et al., 2015; Paul et al., 2015). Literature specific to ADHD healthcare transition is even more limited. It includes a scoping review published in 2013 (Swift, Sayal, et al.) confirming the lack of research and a literature review that described a number of barriers to continuity of care (Montano et al., 2012). To our knowledge no systematic review has been conducted on ADHD healthcare transitions since NICE guidelines were published in 2008. Findings of

previous reviews have been useful but mainly descriptive in nature. This systematic review synthesises existing peer reviewed qualitative literature to answer the following research question: What are the experiences and perceptions of young people with ADHD, their parents/carers, and treating clinicians related to the transition between CAMHS and AMHS?

Methods

Methods followed University of York guidance for undertaking reviews in health care (Tacconelli, 2010). As we aimed to synthesise the experiences of key stakeholders to inform future service design, we used thematic analysis, inductive methods and an iterative approach in line with critical realist perspectives (Braun & Clarke, 2006).

Inclusion and Exclusion Criteria

The search was limited to peer-reviewed publications written in English, due to language limitations. Articles were included if they reported qualitative data about young people with a diagnosis of ADHD aged 14-25 years before, during or after a transition to adult healthcare services. Data could be collected from young people, their parents/carers, clinicians, educational support workers, or service providers. Study design included primary qualitative research with a recognised methodology (such as interviews or focus groups), mixed methods including a qualitative element (such as questionnaires with free text comments) or consensus statements from stakeholders.

Studies were excluded if they did not report on young people with ADHD or if findings were not reported separately for young people with ADHD.

Search Strategy

Five databases were searched (Medline, Embase, PsychINFO, Global Health and Cinahl) from 2000 (given older studies are less generalisable to current healthcare systems) to 19th Jan 2017. Areas targeted were: *Attention Deficit Hyperactivity Disorder, Transition, Age, and Qualitative Research*. A supplementary search looked for reviews of ‘*mental health*’ or

'neuro-disability' healthcare transitions which were screened for research including an ADHD population. For detailed search strategy and syntax see appendix A. Experts in the field were consulted and a one-stage forward and backward citation search was carried out for included articles.

Study Selection

Title and abstract of all unique citations were screened against the eligibility criteria by two reviewers (AP and AW or MA). The same procedure was followed for the full text screening. Disagreements were resolved through discussion or adjudicated by AJ.

Quality Assessment

Quality was appraised using the Wallace criteria to determine the appropriateness of the method and quality of reporting (Wallace et al., 2004), see table 1. This has been used in previous qualitative reviews (Greaves et al., 2017; Husk et al., 2016; Moore et al., 2016), and covers research question, theoretical perspective, study design, context, sampling, data collection, data analysis, reflexivity, generalisability and ethics. Studies were assigned 'yes', 'no' or 'can't tell' for desirable and essential criteria which generates an overall score of 'good', 'moderate' or 'poor' (Husk et al., 2016). Quality appraisal was not used to determine eligibility for inclusion, but to inform judgements about the strength of the evidence.

Themes/sub-themes were only included if they emerged from at least one paper rated 'good'. Evidence stemming from 'moderate' or 'poor' quality papers was clearly marked in results and used to support/extend existing themes. Quality appraisal was completed by AP and MA; discrepancies were resolved by discussion with AJ.

Data Extraction

Data on sample, study details, research methods and findings were extracted using a checklist adapted from a recent systematic review (Gwernan-Jones et al., 2016) by AP and checked by MA.

Data Analysis & Synthesis

Thematic analysis was used to synthesise findings (Braun et al., 2006), as other qualitative systematic reviews have applied it to produce findings to inform policy and practice (Orr et al., 2016); it is suitable for data that is mainly descriptive (Thomas & Harden, 2008)..AP and AJ independently familiarised themselves with all papers. AP indexed all included papers and AJ indexed two (also called, open coding) (Gale et al., 2013). Papers were purposefully selected to include comprehensive coverage of the subject (Swift, Hall, et al., 2013) and a study with wide research aims (Wong et al., 2009). Qualitative data (in the form of quotes, themes and concepts) were identified by the authors and extracted from the results and discussion sections of included articles. The extracted data was coded using NVivo version 11. Codes were compared and discussed before creating a working analytical framework to be applied to all papers. Aptness of the framework and reliability of its application was checked by comparing and discussing coding. A framework matrix was produced and data were summarized by code for each paper (AP); cells also included references to interesting or illustrative quotes and researcher's comments. Finally, a summary was produced by AP for each code, based on the cell summaries, which was reviewed by AJ and led to the development of the conceptual model and decision on final themes.

Results

The PRISMA flow chart (see Figure 1) (Moher et al., 2009) shows the eight included papers selected from 2134 initial records identified. Three further papers almost met inclusion criteria (Marcer et al., 2008; Montano et al., 2012; Syverson et al., 2016) however the methodology was not clear enough to identify where qualitative research findings came from, so were excluded.

>>*Insert Fig 1 here*<<

Study Characteristics

The majority of studies were based in the UK. For an overview of included studies and their quality, see table 1. All studies explored experiences of ADHD specific mental health populations, except Belling et al. (2014). The aims of two studies (Belling et al., 2014; Wong et al., 2009) differed from those of this review, so only relevant aspects were extracted.

>>*Insert Table 1 here*<<

Study Quality

Methodological quality of included papers was moderate; five scored ‘Good’ and three scored ‘Poor’ (see table 1). Studies scoring poorly were not primarily qualitative. They included a literature review supported by evidence from a web forum (Ginsberg et al., 2014), a consensus statement drawn from an expert workshop (Young et al., 2016) and a study using paper questionnaires (Reale et al., 2015). For detailed quality appraisal information see appendix B.

Synthesis Results

For a summary of themes emerging, see table 2. The five main themes are described below.

>>*Insert Table 2 here*<<

Transitioning. Multiple struggles with healthcare transition processes were reported, which, combined with difficulties ADHD patients face with self-organisation and managing change, left some unable to cope. Key sub-themes were lack of appropriate information, importance of preparation, relationship with clinician, transition age, and parental role.

Lack of appropriate *information* on what to expect during healthcare transitions was an extensive and consistent theme across studies. This included uncertainty about which services AMHS provides, where services are, and living with ADHD as an adult. In several studies CAMHS clinicians reported lack of clarity on availability, while difficulties in

identifying appropriate AMHS made it difficult to support patients. Several respondents discussed negative impacts of not knowing what to expect,

“bit vague to me what’s available.” (Nurse, CAMHS) (Belling et al., 2014)

“When she gets to 18 is there gonna be somebody there that can talk to us and talk to her? ... We just don’t know. And it worries you” (Parent) (Swift, Hall, et al., 2013)

Importance of *preparation* emerged as a key factor. Some reported feeling ill-prepared and let down, while those receiving joint working felt prepared and typically reported more positive transition experiences. Parents and clinicians identified lack of shared transition planning between services and a lack of parallel care as a barrier (Reale et al., 2015). Requests included introductions to new clinicians, seeing a photo and being given written information about next steps. Authors recommended formal protocols, jointly developed with service users, commissioners, paediatricians, AMHS providers and primary care clinicians.

Parent/Carer involvement was acknowledged as a highly significant factor in young people accessing adult services (Cheung et al., 2015; Swift, Hall, et al., 2013). Most clinicians found parental input was important and some parents reported lack of support for families in adult services as a barrier to transition (Reale et al., 2015).

“I can see where they’re coming from ‘cos he’s an adult, but ...they know he won’t go out the house and won’t do certain things on his own yet he’s got to go all the way up there and that’s the point he won’t do that” (Parent) (Swift, Hall, et al., 2013)

Most young people accepted the need for continued parental support (Swift, Hall, et al., 2013). The expert consensus statement described parental involvement as essential but noted the tension with the young person’s need for increasing autonomy (Young et al., 2016).

The question of *transition age* for young people was the only theme where there was significant variation between and within studies. Several young people expressed ambivalence about healthcare transitions, preferring to stay with familiar services (Cheung et al., 2015). They found transition unsettling and an annoying inconvenience.

“I don't see what age has got to do with who you're seeing and where you see 'em. ..., we're used to coming here, but now we've got to change ... so that's a bit annoying”

(Patient) (Swift, Hall, et al., 2013)

Italian clinicians said 18 years made sense for transition (Reale et al., 2015). Many clinicians described transition as a process not an event, while others mentioned lifespan clinics that avoid transition at 18 (Young et al., 2016). Flexibility may be the key to the accommodation of young people's needs.

Hurdles. Respondents across studies shared experiences of ‘hurdles’ that they had to overcome in order to transition. Difficulties were experienced in accessing adult services, obtaining referrals and meeting acceptance thresholds. The most insurmountable and common was when no services were available.

Lack of *adult services* was reported in most studies; it was viewed negatively and often had traumatic effects.

“There are places you can go as a kid, but not as an adult, it's kind of swept under the carpet as soon as you reach 18” (Young Person (YP)) (Matheson et al., 2013)

“A common experience of our patients is that once they reach 17, 18, they finish with Child Psychiatry and GPs stop prescribing without any preparation, ... for some of them they experience that as quite traumatic because suddenly they couldn't take medication” (Clinician) (Wong et al., 2009)

Authors recommended adult services should provide care consistent with child services and in line with NICE guidelines (Matheson et al., 2013; Swift, Hall, et al., 2013; Young et al., 2016).

Patient-clinician relationship could support or hinder transition, either directly through levels of practical support or indirectly by making the young person more or less likely to engage. Patients liked clinicians who listened and went beyond their job role to support them, but reported negatively on staff changes and brief consultations focussed on routine questions.

"No relationship with doctor at all...and he has not followed the case regularly so he just asks those routine questions" (Patient) (Cheung et al., 2015)

Gaining referrals was another difficulty according to young people and clinicians. This was attributed to lack of belief in, understanding of, or knowledge about adult ADHD.

"The GP may or may not have detailed knowledge of ADHD. I don't think the majority of GPs will have ADHD [as a possible diagnosis] in mind" (Clinician) (Wong et al., 2009)

"She [GP] basically said that because I got really good grades in school and am at university doing pretty well that I do not have ADHD." (Web forum) (Ginsberg et al., 2014)

The ability to re-enter services was considered important.

Difficulty *meeting thresholds* for adult services was a barrier in most studies, with some adult services only accepting referrals for 'severe' conditions, a definition which didn't include ADHD. Stakeholder experiences were that more 'complex' problems made transition smoother.

“...of course they think he, he’s got autism/ADHD but he’s not self-harming or anything so he can go to his own doctor if he’s got no problems” (Parent) (Swift, Hall, et al., 2013)

Clinicians said differing eligibility criteria between child and adult health services, exacerbated by a perceived lack of resources, aggravated this, with some reporting that patients were 're-labelled' at transition:

"most of them are given a different label, taken off their medication and sent out into the community and goodbye" (Clinician) (Wong et al., 2009)

These findings were consistent across all studies including parents or clinicians. Notably, they were not mentioned in the two papers that only interviewed young people (Cheung et al., 2015; Matheson et al., 2013).

Accessibility of adult services concerned some young people, including distances to travel and feeling comfortable in the environment.

“Yeah, will there be like people with the same disability, or people with like schizophrenia or any other serious illnesses - Yeah, and will it be a one-on-one as well” (YP) (Swift, Hall, et al., 2013)

Limitations of adult services. Once in services, barriers to treatment included attitudes and experience of adult clinicians, issues with funding and resources, difficulty in getting prescriptions and limitations on available treatments.

Competencies: the need for more education, training and skill development in clinicians supporting adults with ADHD emerged in every paper. Many patients experienced negative attitudes and scepticism about adult ADHD from health professionals, making accessing services and getting medication ‘*an uphill struggle*’ (Ginsberg et al., 2014; Matheson et al., 2013). Participants recalled doctors refusing to prescribe, which was often

attributed to presumed negative attitudes towards ADHD and/or medication or uncertainty over licensing.

"Colleagues in General Psychiatry are usually not too keen on diagnosing ADHD because if you diagnose it you need to treat it and the treatment is unlicensed."

(Clinician) (Wong et al., 2009)

Trusts recognised a need to develop skills and confidence in ADHD diagnosis and treatment in adult mental health professionals (Belling et al., 2014). Encountering negative attitudes sometimes led to severe emotional distress and functional impairment in patients (Matheson et al., 2013).

Contrastingly, experiences with specialist ADHD care were associated with provision of more informative advice on medications and coping strategies. This helped patients feel informed about treatment and led to greater patient involvement in decision making (Matheson et al., 2013). Authors suggested fostering engagement in clinical providers through discussion and psychoeducation (Ginsberg et al., 2014) and recommended training clinicians to provide relevant information to service users (Young et al., 2016); several recommended providing specialist consultation or services.

Some UK forum users (Ginsberg et al., 2014) said ADHD was still seen as solely a childhood condition, leaving many adults untreated, while patients from Hong Kong reflected on needs to raise public awareness and prevent stigma:

"If there is more public awareness, less people will delay their treatment" (YP)

(Cheung et al., 2015)

Resources: problems of high demand combined with restrictive or non-existent funding emerged across most studies.

“...commissioners do not commission services for adults, so that is another fall off point” (Clinician) (Wong et al., 2009)

“We have ... between 350 and 400 cases of ADHD and with that population 50% of them will have had ADHD after the age of 16 ... it would be good if there was a service to be provided.” (Psychiatrist, CAMHS) (Belling et al., 2014)

Staff shortages and high work-loads in AMHS, including reported losses of transition workers, explained some barriers (Belling et al., 2014). Young people said more investment was needed to reduce waiting times (Cheung et al., 2015) and reported health trusts refusing to fund medication (Matheson et al., 2013).

Reluctance to prescribe led to difficulties *getting prescriptions*:

"the psychiatrists but often mostly pharmacists act as if [ADHD drug] is plutonium and it's, like, ridiculous" (Patient) (Matheson et al., 2013)

"...colleagues say it is not recognised, the products aren't licensed, so why should we? We are prescribing something that isn't licensed." (Clinician) (Wong et al., 2009)

Treatment was usually limited to medication, which many saw as insufficient (Cheung et al., 2015; Matheson et al., 2013).

"beyond medication I am not getting any interactive care [CBT] which I have always found is as important as the medication" (YP) (Matheson et al., 2013)

Some respondents valued psychological therapies less than medication, but several authors recommended wider access to psychological treatment (Matheson et al., 2013; Young et al., 2016) as some saw this as essential to meet needs of adults with ADHD (Cheung et al., 2015).

Inadequate care. Many stakeholders reported inadequate care when transition was not possible. Some patients were *kept at CAMHS*, often unofficially, while others were *discharged to GP care*, with some ‘*weaned off*’ medication.

The doctor said my case is special so she will continue to follow” (YP) (Cheung et al., 2015)

“There isn’t a service for them. I don’t know what will happen if we get caught.”

(Clinicians) (Wong et al., 2009)

“You sometimes find yourself in a position of having to cut back on medication and see if a child can do without.” (Clinician) (Wong et al., 2009)

Some patients were placed in primary care, without monitoring or support, leading to feelings of abandonment, lower self-efficacy and poorer self-management of their condition. This contrasted with valued specialist service support.

“Participants whose primary interaction was with a GP strongly desired support with adjusting their medication type and dosage, or advice regarding coping with side effects, but did not receive it.”(Author Comment) (Matheson et al., 2013)

Impact. The majority of studies included reports of significant negative *impacts* on wellbeing associated with lack of access to treatment and support. One author observed, *“exacerbated...feelings of disempowerment, distress and helplessness...led to a downward spiral in functioning”* (Matheson et al., 2013). Unsupported transition experiences for those already living with the accumulated psycho-social burdens associated with ADHD were extreme. Some dropped out of treatment, others went through *“seven years of hell”* (Wong et al., 2009) trying to access services, or described feeling left out and like no-one cared. One young person said,

"Putting somebody with ADHD through a bureaucracy is torture.... it's like treating a diabetic in a bakery" (YP) (Matheson et al., 2013)

Authors commented delays accessing treatment left young people unable to cope (Ginsberg et al., 2014; Matheson et al., 2013).

Data from the six UK based studies contributed to all themes. The two other studies, from Italy and Hong Kong, contributed to themes of; transition difficulties, hurdles experienced, the need to develop ADHD specific competencies in adult clinicians and experiences that medication was the primary treatment available. However, challenges gaining referrals, discharge to primary care and poor accessibility of adult services were reported on only in UK papers (see table 2).

Discussion

This systematic review explores the experiences and perceptions of key stakeholders involved in healthcare transitions for young people with ADHD. As six of eight included studies were based in the UK, findings cannot be generalised beyond this context. Of the five main themes emerging from the synthesis, three allude to the transition pathway: experiences of the transition process, structural steps needed in order to transition and the inadequate adult services that are currently available. The fourth relates to inadequate care provided when the pathway is blocked. The fifth reflects impact on the young person. All draw on patient, parent and clinician reports and highlight barriers and facilitators to successful and appropriate transitional care for these young people. Experiences of distress and inadequate support were shared across all themes.

Included studies revealed patchy provision, unmet need for accessible and age appropriate services, parents wanting more involvement with adult services and a need to tackle stigma, all of which echo findings from a recent systematic review of mental health

transitions (Paul et al., 2015). When compared with mental health transitions across mental health conditions (Paul et al., 2015), ADHD specific experiences appeared to emphasise the essential nature of parent/carer involvement and reveal difficulties caused by a serious lack of appropriate adult services and reluctance of clinicians to prescribe ADHD medication. There is some indication that specialist adult services were seen as more acceptable and less stigmatizing to young people with ADHD than generic provision.

Previously described differences between care philosophies of children's services (emphasising family) and adult's services (focussing on autonomy) (Mulvale et al., 2015) explain the importance of preparation and the provision of information about adult services to facilitate transition. These cultural differences may also explain why parents report lack of involvement in adult services as a barrier to continuity of care.

Healthcare transition experiences specific to ADHD included lack of training and resources in AMHS, rejected referrals for ADHD patients without comorbidity, and premature discharge (Hall et al., 2014; Hall et al., 2013). When added to inherent difficulties young people with ADHD face around organisation and managing change, these help explain lower than expected transition rates and high levels of drop out from services (Young et al., 2011). Implementation of existing NICE (2016a) guidelines would address many barriers to transition identified in this systematic review.

For improved organisation and planning of ADHD services, NICE (2016a) recommends greater integration of CAMHS, Paediatric and AMHS with specialist ADHD teams. Mixed opinions of the optimal age for transition indicate a need to evaluate the different service models such as transitional ADHD services or extending CAMHS to treat 0-25 year olds (Singh & Tuomainen, 2015). A flexible approach to age boundaries that is developmentally appropriate should be adopted (NICE, 2016b).

Strengths and Limitations

This review was conducted with a clear protocol following established guidelines (Tacconelli, 2010) with double data extraction. Analysis and synthesis were developed iteratively. The supplementary search, expert consultation and citation chasing aimed to detect studies missed by our literature search, yet we only detected eight studies.

To fully explore healthcare transition experiences of this group, evidence from different settings, locations and from a range of countries, similar to that being gathered in the European Union Funded MILESTONE study would be needed (Singh et al., 2015). Generalisation of these findings beyond the UK is not possible due to the limited number of studies elsewhere. Nevertheless, evidence included views from a range of stakeholders. We were able to report on clinician, parent and patient perspectives. Future research needs to address limited research involving clinicians and absence of studies involving educators.

Themes tie in with existing quantitative research indicating lack of healthcare provision for adults with ADHD, (Coghill, 2016; Hall et al., 2014) and poor awareness of or adherence to transition protocols (Hall et al., 2013). Further qualitative and quantitative research is needed to assess levels of need and to map provision of adult ADHD services.

There is a potential limitation of mixing study types in the synthesis of evidence as individual study aims may have been quite different. However the consistency of themes across different respondent groups and studies builds confidence in generalisability of findings even from this small selection of studies. The only sub-theme with mixed opinions between respondents was *transition age*. No clear consensus emerged. Some clinicians supported age 18, many respondents and authors recommended flexibility and a few patients questioned the need for any transition.

Conclusions

The qualitative evidence included in this systematic review ties in with existing quantitative evidence, indicating that UK guidelines are not being implemented. The

importance of providing service users with information about adult services is a novel finding that could easily be provided and evaluated. Positive experiences of specialist adult ADHD services should also be noted.

Table 1.

Study Characteristics

Study	Aims	Methods	Sample	Participant type (n)			Quality Score
				YP	P/C	CI	
Belling et al. 2014	Investigate organisational factors that impede/facilitate transition.	Semi-structured Telephone interviews, TA.	Description, Location (Total = N) Clinicians: England (34)	34	0	0	Good
Cheung et al. 2015	Explore experiences of YP with ADHD accessing treatment, coping with impairment, and expectations of future treatment.	Semi-structured F2F interviews, TA.	Patients aged 16-23 receiving pharmacological treatment for ADHD: Hong Kong, China (40)	40	0	0	Good
Ginsberg et al. 2014	Review to discuss unmet adult ADHD needs in Europe.	Systematic analysis of data from web forum, TA.	All postings in two threads in an adult ADHD web forum: United Kingdom				Poor*
Matheson et al. 2013	Explore experiences of adults with ADHD and compare between patients diagnosed during adulthood and childhood.	Semi-structured F2F interviews, TA.	Adults with ADHD recruited through ADHD charity or hospital outpatient clinics: United Kingdom (30)	30	0	0	Good
Reale et al. 2014	Describe experiences of parents and clinicians in relation to transition.	Postal qualitative questionnaires, TA.	Parent/carers of YP aged 18+; Child Clinicians: Lombardy, Italy (51)	0	24	27	Poor*
Swift et al. 2013	Explore experiences of YP with ADHD during transition.	Semi-structured F2F interviews, TA.	YP with ADHD aged 17+; <i>Some parents/carers present at interview:</i> England (10)	10	0	0	Good
Wong et al. 2009	Explore process and outcomes of ADHD medication cessation.	Semi-structured F2F interviews, TA.	YP aged 15-24; Clinicians from London, Liverpool, Nottingham and Dundee: United Kingdom (25)	15	0	10	Good
Young et al. 2016	Consensus statement to discuss transition of ADHD patients. Formulate recommendations for successful transition.	Presentations followed by discussion.	<i>“Multidisciplinary team of mental health professionals, allied professionals and patients”</i> : United Kingdom				Poor*

Notes. YP = Young people with ADHD; P/C = Parent or carer of young person with ADHD; Cl = Clinicians; F2F = Face to face; CAMHS = Child and Adolescent Mental Health Services; AMHS = Adult Mental Health Services; TA = Thematic Analysis

*NB. Although qualitative evidence was rated poor for purposes of review, research was appropriate for articles' intended purposes

Table 2.

Themes and sub-themes identified

Main Theme	Papers contributing to theme	Sub-theme	Description
Transitioning			Multiple difficulties with transition process. Wide gap between guidelines and practice.
	1,2,3,4,6*,7*,8*	Information	Uncertainty about processes caused distress. More information wanted on how to access services, what would happen, differences between child and adult services and experiences of living with ADHD as an adult.
	1,4,6*,7*,8*	Preparation	Quality of preparation was key. Poor preparation led to feeling let down and in the dark. Requests made to meet adult clinicians in advance or see a photo and for written information to be provided.
	2,4,7*,8*	Transition age	Some patients felt transition was unnecessary and wanted to stay with familiar services. Some clinicians found 18 a logical age, others emphasised the need for flexibility, saying transition should be a process not an event.
	2,4,7*,8*	Parent/carer involvement	Parent/carer input seen as essential in transition process. The fact adult services not set up for family involvement was experienced as a barrier.
Hurdles			Many hurdles had to be negotiated to get into adult services.
	2, 3, 4, 5, 6, 7*	No adult service	Participants spoke of no adult services, which was an insurmountable obstacle to transitioning.
	2,4,5	Patient-clinician relationship	This relationship supported or hindered transition. When a doctor ' <i>went the extra mile</i> ' and listened, this supported transition, but frequent staff changes and too many routine questions made it difficult for the patient to maintain engagement.
	3, 5, 6*, 8*	Gaining referrals	Getting a referral to transition into or enter adult services was difficult. This often related to GPs' limited understanding of ADHD.
	1, 4, 5, 6*, 7*, 8*	Meeting thresholds	High rates of unaccepted referrals were a barrier. Some adult services only accept cases of 'severe' mental health, and didn't include ADHD in that definition.

	1, 3, 4, 6*	Accessibility	Long waiting lists and significant distances to travel were a barrier to access. Young people worried about feeling comfortable in generic adult mental health settings.
Limitations of adult services			Once in adult services, young people found support patchy and insufficient.
	1,2,3,4,5,6*,7*,8*	Competencies	Negative attitudes and lack of understanding led to difficulties gaining appropriate treatment and support. A need for specialist ADHD training and skills development in clinicians treating adults.
	1,2,3,5,6*	Resources	High demand coupled with inadequate funding led to limited services. Trusts commissioned very limited services.
	3,5,6*,8*	Getting prescriptions	Some clinicians were reluctant to prescribe medication.
	2,3, 6*,7*,8*	Treatment	Treatments available were primarily medication alone, which was thought insufficient. Psychological therapies desired but not available.
Inadequate Care			When transition was not supported, inadequate care arrangements were made that failed to meet patient needs.
	2, 5	Kept at CAMHS	Child clinicians hold onto patients beyond age boundary.
	5	Weaned off medication	Clinicians wean patients off medication then discharge.
	3	Discharged to GP	Patients discharged to GP care. Lack of treatment management and specialist supervision.
Impact	1, 2, 3,4,5, 8*		Combined with challenges ADHD patients already face, poor transition experiences were associated with intense distress, uncertainty and feeling abandoned. Some were unable to cope.

Key: 1 = Belling, 2 = Cheung, 3 = Matheson, 4 = Swift, 5 = Wong, 6 = Ginsberg, 7 = Reale, 8 = Young, * = Poor quality paper

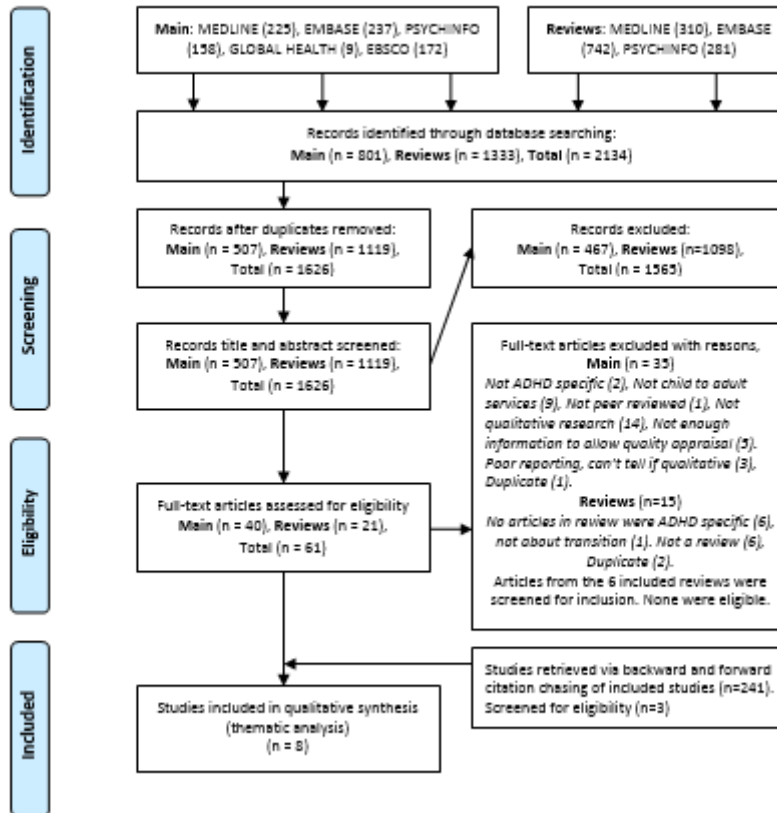


Figure 1. Flow chart of retrieved studies

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Conflicts of interest

The authors have declared that they have no competing or potential conflicts of interest.

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