

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

Anna Price , Astrid Janssens , Abigail L. Woodley, Matt Allwood  & Tamsin Ford 

University of Exeter Medical School, Exeter, UK

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 that 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 United Kingdom 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 United Kingdom, including accounts from carers and clinicians.

Key Practitioner Message

- Lack of healthcare provision in the United Kingdom 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 United Kingdom 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.

Keywords: Attention deficit hyperactivity disorder; transition; systematic review; qualitative methods; health; experiences; adolescence

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a life span 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, Biederman, & Mick, 2006). The proportion of young people who access treatment declines at a greater rate than age-related decrease in symptoms, implying that some young people with ADHD do not receive the care they need as adults (Coghill, 2016; Newlove-Delgado, Ford, Hamilton, Stein, & Ukoumunne, 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, Street, Wheeler, & Singh, 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, Sameroff, & Cicchetti, 2004). This stage of development is particularly challenging for young people with ADHD because the combination of impulsivity, inattention and hyperactivity makes organising and managing change difficult (Baric, Hemmingsson, Hellberg, & Kjellberg, 2016; Gotlieb & Gotlieb, 2009; Wolraich et al., 2005).

National and international guidelines on ADHD recognise the importance of this healthcare transition (Seixas, Weiss, & Müller, 2011). In the United Kingdom, 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, Newell, Taylor, Sayal, & Hollis, 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, Randall, Longo, Nguyen, & Mulvale, 2016; Mulvale et al., 2016; Paul et al., 2015). Conclusions are limited by scarcity of data but indicate patchy provision, a need for accessible and age-appropriate services, a need to tackle stigma, unhelpful cultural differences between CAMHS and AMHS, and parents wanting more involvement (Mulvale et al., 2016; 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. 2013) confirming the lack of research and a literature review that described a number of barriers to continuity of care (Montano & Young, 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 healthcare (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 as follows: *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 online for Appendices S1 and S2. 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, Croucher, Quilgars, & Baldwin, 2004), see Table 1. This has been used in previous qualitative reviews (Greaves, Poltawski, Garside, & Briscoe, 2017; Husk, Lovell, Cooper, Stahl-Timmins, & Garside, 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 generated 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/subthemes 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

Table 1. Study characteristics

Study	Aims	Methods	Sample Description, Location (Total = N)	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.	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 ^a
Matheson et al. (2013)	Explore experiences of adults with ADHD and comparison 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, Costantino, Sequi, and Bonati, (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 ^a
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.	'Multidisciplinary team of mental health professionals, allied professionals and patients': United Kingdom				Poor ^a

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

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

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 and synthesis

Thematic analysis was used to synthesise findings (Braun & Clarke, 2006), as other qualitative systematic reviews have applied it to produce findings to inform policy and practice (Orr, Wagstaffe, Briscoe, & Garside, 2016); it is suitable for data that are 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, Heath, Cameron, Rashid, & Redwood, 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 were 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 were checked by comparing and discussing coding. A framework matrix was produced and data were summarised 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, Liberati, Tetzlaff, & Altman, 2009) shows the eight included papers selected from 2134 initial records identified. Three further papers almost met inclusion criteria (Marcer, Finlay, & Baverstock, 2008; Montano & Young, 2012; Syverson, McCarter, He, D'Angelo, & Tuchman, 2016), however, the methodology was not clear enough to identify where qualitative research findings came from, so were excluded.

Study characteristics

The majority of studies were based in the United Kingdom. For an overview of included studies and their quality, see Table 1. All studies explored experiences of

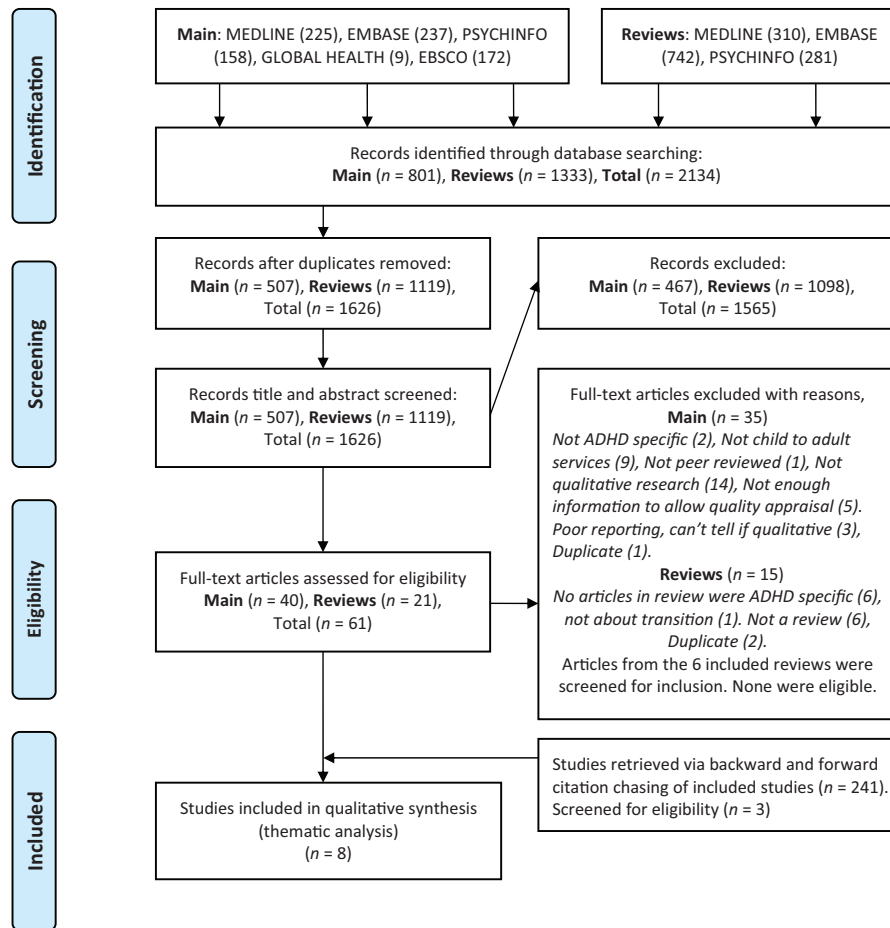


Figure 1. Flow chart of retrieved studies

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.

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, Beusterien, Amos, Jouselin, & Asherson, 2014), a consensus statement drawn from an expert workshop (Young et al., 2016) and a study using paper questionnaires (Reale, Frassica, Gollner, & Bonati, 2015). For detailed quality appraisal information, see online for Appendix S3.

Synthesis results

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

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 subthemes 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,

A bit vague 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. This was acknowledged as a highly significant factor in young people accessing adult services (Cheung et al., 2015; Swift, Hall, et al., 2013).

Table 2. Themes and subthemes identified

Main theme	Papers contributing to theme	Subtheme	Description
Transitioning	1, 2, 3, 4, 6*, 7*, 8*	Information	Multiple difficulties with transition process. Wide gap between guidelines and practice. 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.
		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	2, 3, 4, 5, 6, 7*	No adult service	Many hurdles had to be negotiated to get into adult services. Participants spoke of no adult services, which was an insurmountable obstacle to transitioning.
		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 did not include ADHD in that definition.
Limitations of adult services	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.
			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.
Inadequate Care	3, 5, 6*, 8*	Getting prescriptions	Some clinicians were reluctant to prescribe medication.
		Treatment	Treatments available were primarily medication alone, which was thought insufficient. Psychological therapies desired but not available.
	2, 5	Kept at CAMHS	When transition was not supported, inadequate care arrangements were made that failed to meet patient needs. Child clinicians hold onto patients beyond age boundary.
		Weaned off medication	Clinicians wean patients off medication then discharge.
Impact	3	Discharged to GP	Patients discharged to GP care. Lack of treatment management and specialist supervision.
			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.

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 life span 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 hurdle was no services being 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 focused 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 did not 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 nonexistent 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 workloads 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 psychosocial 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 that 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, difficulties experienced in getting a referral into adult mental health services, discharge to primary care without specialist supervision 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 the eight papers included studies that were based in the United Kingdom, these 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 stigmatising 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., 2016) 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., 2013, 2014). 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, Murphy, & Coghill, 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 which 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 & Tuomainen, 2015). Generalisation of these findings beyond the United Kingdom is not possible due to the limited number of studies detected 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 the 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 when 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.

Acknowledgements

This work forms a part of a larger study which focuses on what happens to young people with ADHD when they are too old to stay in children's services; 'The Children and Adolescents with ADHD in Transition between Children's services and Adult services project' (Ford et al., 2015). This project was funded by the National Institute for Health Research – Health Services and Delivery Research programme (project ref: 14/21/52). The authors have declared that they have no competing or potential conflicts of interest.

Ethical information

No ethical approval was required for this article.

Correspondence

Anna Price, Child Health, University of Exeter Medical School, St Luke's Campus, Room 2.07, College House, Exeter EX1 2LU, UK; Email: a.price@exeter.ac.uk

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Appendix S1. Main search.

Appendix S2. Additional search.

Appendix S3. Quality ratings for included articles.

References

- Agnew-Blais, J.C., Polanczyk, G.V., Danese, A., Wertz, J., Moffitt, T.E., & Arseneault, L. (2016). Evaluation of the persistence, remission, and emergence of attention-deficit/hyperactivity disorder in young adulthood. *JAMA Psychiatry*, *73*, 713–720.
- Banaschewski, T., Coghill, D., Santosh, P., Zuddas, A., Asherson, P., Buitelaar, J., . . . & Rothenberger, A. (2006). Long-acting medications for the hyperkinetic disorders. *European Child & Adolescent Psychiatry*, *15*, 476–495.

- Baric, V.B., Hemmingsson, H., Hellberg, K., & Kjellberg, A. (2016). The occupational transition process to upper secondary school, further education and/or work in Sweden: As described by young adults with Asperger syndrome and attention deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders*, *47*, 667–679.
- Belling, R., McLaren, S., Paul, M., Ford, T., Kramer, T., Weaver, T., ... & Singh, S.P. (2014). The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *Journal of Health Services Research & Policy*, *19*, 169–176.
- Blum, R.W., Garell, D., Hodgman, C.H., Jorissen, T.W., Oki-now, N.A., Orr, D.P., & Slap, G.B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, *14*, 570–576.
- Bolea-Alamañac, B., Nutt, D.J., Adamou, M., Asherson, P., Bazire, S., Coghill, D., ... & Santosh, P. (2014). Evidence-based guidelines for the pharmacological management of attention deficit hyperactivity disorder: Update on recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, *28*, 179–203.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Cheung, K.K., Wong, I.C., Ip, P., Chan, P.K., Lin, C.H., Wong, L.Y., & Chan, E.W. (2015). Experiences of adolescents and young adults with ADHD in Hong Kong: Treatment services and clinical management. *BMC Psychiatry*, *15*, 95.
- Coghill, D. (2016). Organisation of services for managing ADHD. *Epidemiology and Psychiatric Sciences*, *26*, 453–458.
- Embrett, M.G., Randall, G.E., Longo, C.J., Nguyen, T., & Mulvale, G. (2016). Effectiveness of health system services and programs for youth to adult transitions in mental health care: A systematic review of academic literature. *Administration and Policy in Mental Health and Mental Health Services Research*, *43*, 259–269.
- Faraone, S.V., Biederman, J., & Mick, E. (2006). The age-dependent decline of attention deficit hyperactivity disorder: A meta-analysis of follow-up studies. *Psychological Medicine*, *36*, 159–165.
- Ford, T., Janssens, A., Paul, M., Ani, C., Young, S., & Newlove-Delgado, T. (2015). Study Protocol: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (Catch-uS): A mixed methods project using national surveillance, qualitative and mapping studies. Available from: <https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/142152/#/documentation> [last accessed 11 October 2017].
- Gale, N.K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*, 117.
- Gibbins, C., & Weiss, M. (2007). Clinical recommendations in current practice guidelines for diagnosis and treatment of ADHD in adults. *Current Psychiatry Reports*, *9*, 420–426.
- Ginsberg, Y., Beusterien, K.M., Amos, K., Jousselein, C., & Asherson, P. (2014). The unmet needs of all adults with ADHD are not the same: A focus on Europe. *Expert Review of Neurotherapeutics*, *14*, 799–812.
- Gotlieb, E.M., & Gotlieb, J.S. (2009). Helping adolescents with attention-deficit/hyperactivity disorder transition toward adulthood. *Adolescent Medicine-State of the Art Reviews*, *20*, 203.
- Greaves, C., Poltawski, L., Garside, R., & Briscoe, S. (2017). Understanding the challenge of weight loss maintenance: A systematic review and synthesis of qualitative research on weight loss maintenance. *Health Psychology Review*, *11*, 145–163.
- Gwernan-Jones, R., Moore, D.A., Cooper, P., Russell, A.E., Richardson, M., Rogers, M., ... & Garside, R. (2016). A systematic review and synthesis of qualitative research: The influence of school context on symptoms of attention deficit hyperactivity disorder. *Emotional and Behavioural Difficulties*, *21*, 83–100.
- Hall, C.L., Newell, K., Taylor, J., Sayal, K., & Hollis, C. (2014). Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: A national survey of mental health trusts in England. *Journal of Psychopharmacology*, *29*, 39–42.
- Hall, C.L., Newell, K., Taylor, J., Sayal, K., Swift, K.D., & Hollis, C. (2013). 'Mind the gap' Mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*, *13*, 186.
- Husk, K., Lovell, R., Cooper, C., Stahl-Timmins, W., & Garside, R. (2016). Participation in environmental enhancement and conservation activities for health and well-being in adults: A review of quantitative and qualitative evidence. *Cochrane Database Systematic Review*, CD010351.
- Kooij, S.J., Bejerot, S., Blackwell, A., Caci, H., Casas-Brugué, M., Carpentier, P.J., ... & Fitzgerald, M. (2010). European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. *BMC Psychiatry*, *10*, 67.
- Marcer, H., Finlay, F., & Baverstock, A. (2008). ADHD and transition to adult services – the experience of community paediatricians. *Child: Care, Health and Development*, *34*, 564–566.
- Matheson, L., Asherson, P., Wong, I.C.K., Hodgkins, P., Setyawan, J., Sasane, R., & Clifford, S. (2013). Adult ADHD patient experiences of impairment, service provision and clinical management in England: A qualitative study. *BMC Health Services Research*, *13*, 184.
- McCarthy, S., Asherson, P., Coghill, D., Hollis, C., Murray, M., Potts, L., ... & Wong, I.C.K. (2009). Attention-deficit hyperactivity disorder: Treatment discontinuation in adolescents and young adults. *The British Journal of Psychiatry*, *194*, 273–277.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Reprint—preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Physical Therapy*, *89*, 873–880.
- Montano, C.B., & Young, J. (2012). Discontinuity in the transition from pediatric to adult health care for patients with attention-deficit/hyperactivity disorder. *Postgraduate Medicine*, *124*, 23–32.
- Moore, D.A., Gwernan-Jones, R., Richardson, M., Racey, D., Rogers, M., Stein, K., ... & Garside, R. (2016). The experiences of and attitudes toward non-pharmacological interventions for attention-deficit/hyperactivity disorder used in school settings: A systematic review and synthesis of qualitative research. *Emotional and Behavioural Difficulties*, *21*, 61–82.
- Mulvale, G.M., Nguyen, T.D., Miatello, A.M., Embrett, M.G., Wakefield, P.A., & Randall, G.E. (2016). Lost in transition or translation? Care philosophies and transitions between child and youth and adult mental health services: A systematic review. *Journal of Mental Health*, *6*, 1–10.
- Newlove-Delgado, T., Ford, T.J., Hamilton, W., Stein, K., & Ukoumunne, O.C. (2017). Prescribing of medication for attention deficit hyperactivity disorder among young people in the Clinical Practice Research Datalink 2005–2013: Analysis of time to cessation. *European Child & Adolescent Psychiatry*, *27*, 29–35.
- NICE. (2008). Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults (CG72). Available from <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72> [last accessed 03 April 2014].
- NICE. (2016a). Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults (CG72). Available from <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72> [last accessed 03 April 2014].
- NICE. (2016b). Transition from children's to adults' services for young people using health or social care services (NG43). Available from: <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72> [last accessed 03 April 2017].
- Ogundele, M.O. (2013). Transitional care to adult ADHD services in a North West England district. *Clinical Governance: An International Journal*, *18*, 210–219.

- Orr, N., Wagstaffe, A., Briscoe, S., & Garside, R. (2016). How do older people describe their sensory experiences of the natural world? A systematic review of the qualitative evidence. *BMC Geriatrics*, *16*, 116.
- Paul, M., Street, C., Wheeler, N., & Singh, S.P. (2015). Transition to adult services for young people with mental health needs: A systematic review. *Clinical Child Psychology and Psychiatry*, *120*, 436–457.
- Reale, L., Costantino, M.A., Sequi, M., & Bonati, M. (2014). Transition to adult mental health services for young people with ADHD. *Journal of Attention Disorders*, *22*, 601–608.
- Reale, L., Frassica, S., Gollner, A., & Bonati, M. (2015). Transition to adult mental health services for young people with attention deficit hyperactivity disorder in Italy: Parents' and clinicians' experiences. *Postgraduate Medicine*, *127*, 671–676.
- Schulenberg, J.E., Sameroff, A.J., & Cicchetti, D. (2004). The transition to adulthood as a critical juncture in the course of psychopathology and mental health. *Development and Psychopathology*, *16*, 799–806.
- Seixas, M., Weiss, M., & Müller, U. (2011). Systematic review of national and international guidelines on attention-deficit hyperactivity disorder. *Journal of Psychopharmacology*, *26*, 753–765.
- Singh, S.P., & Tuomainen, H. (2015). Transition from child to adult mental health services: Needs, barriers, experiences and new models of care. *World Psychiatry*, *14*, 358–361.
- Sonuga-Barke, E.J., Brandeis, D., Cortese, S., Daley, D., Ferrin, M., Holtmann, M., ... & Döpfner, M. (2013). Nonpharmacological interventions for ADHD: Systematic review and meta-analyses of randomized controlled trials of dietary and psychological treatments. *American Journal of Psychiatry*, *170*, 275–289.
- Swift, K.D., Hall, C.L., Marimuttu, V., Redstone, L., Sayal, K., & Hollis, C. (2013). Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): A qualitative analysis of their experiences. *BMC Psychiatry*, *13*, 74.
- Swift, K.D., Sayal, K., & Hollis, C. (2013). ADHD and transitions to adult mental health services: A scoping review. *Child: Care, Health and Development*, *40*, 775–786.
- Syverson, E.P., McCarter, R., He, J., D'Angelo, L., & Tuchman, L.K. (2016). Adolescents' perceptions of transition importance, readiness, and likelihood of future success. *Clinical Pediatrics*, *55*, 1020–1025.
- Tacconelli, E. (2010). Systematic reviews: CRD's guidance for undertaking reviews in health care. *The Lancet Infectious Diseases*, *10*, 226.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*, 45.
- Wallace, A., Croucher, K., Quilgars, D., & Baldwin, S. (2004). Meeting the challenge: Developing systematic reviewing in social policy. *Policy & Politics*, *32*, 455–470.
- Willcutt, E.G. (2012). The prevalence of DSM-IV attention-deficit/hyperactivity disorder: A meta-analytic review. *Neurotherapeutics: the Journal of the American Society for Experimental Neurotherapeutics*, *9*, 490–499.
- Wolraich, M.L., Wibbelsman, C.J., Brown, T.E., Evans, S.W., Gotlieb, E.M., Knight, J.R., ... & Wilens, T. (2005). Attention-deficit/hyperactivity disorder among adolescents: A review of the diagnosis, treatment, and clinical implications. *Pediatrics*, *115*, 1734.
- Wong, I., Asherson, P., Bilbow, A., Clifford, S., Coghill, D., DeSoyza, R., ... & Planner, C. (2009). Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY)—a pharmacoepidemiological and qualitative study. *Health Technology Assessment*, *13*, 1–120.
- Young, S., Adamou, M., Asherson, P., Coghill, D., Colley, B., Gudjonsson, G., ... & Arif, M. (2016). Recommendations for the transition of patients with ADHD from child to adult healthcare services: A consensus statement from the UK adult ADHD network. *BMC Psychiatry*, *16*, 1–10.
- Young, S., Murphy, C.M., & Coghill, D. (2011). Avoiding the 'twilight zone': Recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry*, *11*, 1–8.

Accepted for publication: 20 July 2018