

## **“You’re 18 now, goodbye”: The experiences of young people with Attention Deficit Hyperactivity Disorder of the transition from child to adult services**

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## **“You’re 18 now, goodbye”: The experiences of young people with Attention Deficit Hyperactivity Disorder of the transition from child to adult services**

### **Abstract**

The term ‘transition’ is used to refer to the process of moving from child to adult services. Among child and adolescent mental health services attenders, young people with Attention Deficit Hyperactivity Disorder (ADHD) are less likely to transition successfully, but there is a gap in understanding their views and why they might disengage from services. The aim of this study was to explore the experiences of transition of young people with ADHD in Southwest England using semi-structured interviews and thematic analysis. Seven young people aged 17-19 years participated. Four key themes were identified: professionals’ roles and relationships with young people; the role of ADHD medication, uncertainties around transition and medication management, and identified needs and increasing independence. Although this study presents the experiences of a small number of people, their stories suggest that best practice around transition is not always being followed. There is consequently a need to better understand the facilitators and barriers to best practice implementation.

**Keywords:** Transition; ADHD; Services; Young People

## Introduction

The term 'transition' is used to refer to the process of moving from child to adult services.

This stage is characterised by multiple, often simultaneous transitions within health, social care and education, against the backdrop of social and psychological change taking place in late adolescence. For those young people with Attention Deficit Hyperactivity Disorder (ADHD), this period may be particularly challenging. ADHD is a neurodevelopmental condition characterised by age-inappropriate levels of impulsivity, hyperactivity and inattention, which may persist into adulthood in a significant proportion of young people (Faraone, Biederman, and Mick 2006). Those with ADHD are at risk of experiencing poorer outcomes across a wide spectrum of interlinked domains of function, including: education, occupation, comorbid psychiatric disorder, relationships, substance misuse, general health, obesity, criminality and accidents and injuries (Hoare and Beattie 2003; Biederman and Faraone 2006; Barkley et al. 2004; Chang et al. 2014; Uchida et al. 2015; Cortese et al. 2016).

However, the historical perception of ADHD as a condition confined to children has meant that older adolescents and adults continue to face obstacles to accessing support and treatment after the age of 16 or 18 years. In the UK, most services for children with ADHD will stop at the age of 18. Possible pathways from child services may involve referral to Adult Mental Health Services, referral to a specialist Adult ADHD clinic, or the delegation of care back to the GP. National Institute for Health and Care Excellence (NICE) guidance currently recommends that: "Young people with ADHD receiving treatment and care from CAMHS or paediatric services should normally be transferred to adult services if they continue to have significant symptoms of ADHD or other coexisting conditions that require treatment." (NICE, 2008).

This ultimate destination will be influenced by multiple factors, which include the young person's wishes, their plans for further training and education, whether they continue to need

medication, the persistence and severity of their symptoms, their co-existing conditions and the available services locally. A number of factors have been identified that may also adversely affect transition in this group, such as gaps in services, different organisational cultures in child and adult services, and a lack of professional knowledge and training regarding adult ADHD (Ahmed, Cress, and Lovett 2009; Hovish et al. 2012a; Hall et al. 2015; McLaren et al. 2013; Belling et al. 2014; Coghill 2015).

Despite the significance of the transition period, there has been a paucity of UK studies exploring the perspectives of young people with ADHD themselves on this subject, with only one recent qualitative study directly seeking their experiences (Swift et al. 2013). This may be influenced by a perception of young people in general, and those with ADHD in particular, as groups which may be 'hard to reach' in terms both of services and of recruitment for research (Wong et al. 2009; Flanagan and Hancock 2010; Singh et al. 2010). A clear gap therefore exists in understanding young people's vision of what services would help them and why might they disengage, as well as in learning about how they experience different models and structures of care. These questions are directly relevant in creating functional and acceptable transition pathways. Greater understanding of the personal experiences of service users also assists in the interpretation of the results of population studies, for example, the findings from prescribing databases that rates of ADHD medication cessation remain far greater than the estimated rate of persistence of ADHD ((Newlove-Delgado et al. 2017; McCarthy et al. 2012).

### **The current study**

We aimed to explore the experiences of young people with ADHD in transition from child to adult services in the South West Peninsula of the UK. This included their experience of using child services, of transition, and their perception of unmet needs and what services might be helpful to them in future. Qualitative methods are a particularly appropriate way to examine the perspectives of these service users, as the methods lend themselves to exploring

experiences and meaning (Strauss and Corbin 1990). As this is a little-studied field, qualitative methods also allow for an inductive approach to the data, rather than presupposing what concerns and experiences young people may have (Strauss and Corbin 1990).

## **Method**

### *Recruitment*

Participants were recruited from Child and Adolescent Mental Health Services (CAMHS), Child Health, and Adult ADHD services in Devon and Cornwall. Services for young people with ADHD in the Peninsula are provided by a variety of NHS Trusts and social and private enterprises. There is only one specialist Adult ADHD service in the region, outside of its catchment area no such service exists, so that young people may return either to primary care, or potentially be referred to a general Adult Mental Health Service if they meet local service thresholds.

Clinicians working in these services were asked to verbally introduce the study to eligible patients and with their agreement passed contact details to the research team. We then made contact to explain the study further and gain consent. We were also available during key clinics in case the young person and/or family were interested in discussing the study with us after it was introduced by the clinician.

Young people aged 17-19 who had left child services in the previous six months, or who were in the process of transition were eligible for the study. We recruited both those making the transfer to an adult ADHD service and those who were not transferring to any adult service, to gather young peoples' experiences of these different transition processes. Young people were excluded if there was a significant language barrier which meant that the interview could not be completed without an interpreter, or if their care co-ordinator or other clinician felt that taking part would be detrimental to their mental health. Those with a moderate or severe learning disability were excluded as they represented a somewhat

different population from those with mild or no learning disability in terms of their needs and the services they use.

### *Procedure*

The study used qualitative semi-structured interviews to seek the experiences of young people with ADHD in transition regarding the services they were using. The semi-structured interview format was specifically chosen as it allows the interview to be structured around the areas of service use and transition whilst enabling participants to volunteer their views and perspectives. A topic guide (see Appendix) was developed to guide the interview, but the interview was allowed to develop organically as the participant proceeded with their answers, with the interviewer responding to what was raised and using these questions as prompts to ensure that all areas had been covered. The key questions covered experiences of services in the past and the present, and asked participants what 'ideal services' would look like in the future. Interviews were carried out either at the university, or in the participant's home if they preferred.

### *Analysis*

With consent, interviews were digitally recorded. They were transcribed professionally and checked by a researcher. NVIVO software, version 10 (QSR 2012) was used as a tool to manage and catalogue the data.

Thematic analysis, described by Braun and Clarke (2006, 6) as: "a method for identifying, analysing and reporting patterns (themes) within data" was used in this study. Thematic analysis was chosen as it represents a clear and sequential method for analysing qualitative interviews to describe participant experiences relating to a defined area – i.e., going through transition.

The data were analysed by the main researcher (TND) with the support of three senior researchers (TF, KS, RG), one with extensive qualitative experience (RG). The first phase

involved reading and rereading the scripts to become familiar with the data. Then, the initial coding process led to the production of a coding frame describing and defining all the codes used across all transcripts. A senior researcher (RG), was asked to code sections from two scripts independently and compare with previously coded examples of text. This was used to discuss the nature of the emerging findings, the approach to coding and the coding scheme. The relationships between the different codes were mapped, in order to create categories. Extracts of interviews in each category were reviewed and analysed in order to develop overarching themes relating to the research questions. Coding of data and collection of new interview data also occurred contemporaneously, which allowed exploration of emerging themes. A description was written of each 'candidate' theme, all of which were then judged by Patton's (1990) criteria of external heterogeneity and internal homogeneity to determine whether they were sufficiently different from each other, and whether data within each theme was coherent and/or sufficiently demonstrated the theme. This process resulted in four final overarching themes.

Finally, each theme was written up as a narrative to tell the 'story' of transition. Quotes from the data were selected to demonstrate meaning and provide examples of the theme under discussion. In writing up this narrative, care was taken to include extracts which might contradict one another and to 'deviant cases' where one participant might hold a completely different view to the others, in order to illustrate and account for differences in experience.

Reflexivity (Mays and Pope 2000) is a term for the impact that the researcher's personal and professional characteristics can have on the interview and on the interpretation of the data. In this case, the main researcher's background as a professional in child psychiatry, with attendant experiences and prior expectations were highly relevant. Consequently, throughout the process of this study we attempted to remain conscious of our potential influences on interviewing and analysis by using memos attached to the data, and through the discussion of transcripts and interpretations.

### *Ethical approval*

Ethical approval for the study was granted by the South West Research Ethics Committee (reference: 13/SW/0162). Research and Development (R & D) permissions were also obtained for all sites involved in the study.

### **Results**

Recruitment took place from December 2013 to September 2015. Of the 22 eligible young people identified, only 12 responded to attempts to contact them by email, text message, phone and post, and four of those contacted declined, citing lack of interest and time as reasons. Qualitative interviews were therefore carried out with seven participants, as one potential participant who agreed to take part was lost to follow up prior to the interview.

#### *Characteristics of participants*

Five of the seven participants were male, and all were aged 17 or 18. There was some success in interviewing young people from across the Peninsula, with participants from Devon, Plymouth and Cornwall. Five participants had already left child services, with the remaining two still being seen by CAMHS. Three young people had Autism Spectrum Disorder as well as ADHD, and one had borderline and specific learning difficulties. In four cases, interviews took place with a parent present. See Table 2 for details. For the purposes of the analysis, participants were given a pseudonym shown in Table 1. Throughout the Results section, participants are referred to by these pseudonyms (e.g. David, 18) in order to show the gender of the participant.

*Insert Table 1 here*

### **Study findings**

Four key themes pertinent to the perceptions of transition were identified through the analysis of these seven interviews: professionals' roles and relationships with young people;



the role of ADHD medication, uncertainties around transition, and identified needs and increasing independence. The first two themes describe more general experiences regarding professionals and medication, but which were highly relevant to the process of transition, whereas the second two themes relate to specific aspects of transition.

### **Roles and Relationships**

This theme describes the experiences young people had with professionals involved in the care of their ADHD, in relation to their roles, attitudes and relationships, which form the backdrop for their transition from child to adult services.

Naturally, relationships with and personal characteristics of professionals including educators and clinicians were important to young people. Positive attitudes were valued, particularly when accompanied by an understanding of the person and their ADHD.

Consequently, participants also identified situations where they did not feel they or their ADHD were accepted or understood. '[Teachers] would say that you're a trouble-maker...I find that most mainstream schools don't get educated in ADHD and things like that...so I think all the teachers should like go on a course about it' (Rebecca, 17) .

The young people interviewed highly valued specialist knowledge about ADHD; and viewed this as an important attribute for professionals. Participants discussed how specialist care helped them to manage their ADHD medication and to change the dosage to suit them, suggesting a sense of partnership. Young people saw drug doses as something that might need to be reviewed quite frequently, and that this medication change might be a tool to help them cope with daily activities or academic schedules. 'She [the paediatrician] was really good. I was saying that the tablets don't last the whole day, they kind of wear off in the evenings and sometimes for example, during exams it can be quite important for me to be able to concentrate throughout the evening and she came up with the idea of top up once in the evening, and that's been quite useful to just be able to do more work in the evenings when I need to' (Sam, 17).

In contrast to this relationship, which was experienced as reciprocal and responsive to the YP's needs, for the young people interviewed, the GP's role was often very limited, and primarily seen as to provide prescriptions for medication, with little opportunity to develop a trusting relationship. 'We [just] go to the GP to order the repeat and then collect it' (Sam, 17).

This distant relationship that participants felt they had with their GP was sometimes contrasted with the more personal and developed relationship with CAMHS or Child Health. Such limited contact informed concerns about a transfer of care from CAMHS to primary care. 'If I've got CAMHS they know what I'm like. Doctors (the GP) don't really know. I've seen them twice in the past two years' (Joe, 18).

Another participant was particularly concerned that the GP would not provide help in managing medication, such as tailoring the dose, or being available to answer questions in the same way as CAMHS were, as he was perceived as lacking specialist knowledge. He described an appointment where he had discussed medication with his GP. 'He's not really qualified, he didn't want to change it because he doesn't really know what he's doing as much as the specialists did, so he wouldn't change it' (Patrick, 18).

The experiences of participants suggest that where the GP's role has been limited (both in terms of time and input into care), the relationship between the doctors and the young person and their family may not be one of mutual trust and understanding. Meanwhile, from the primary care perspective the GP may be suddenly faced with a patient at the age of 18 that they do not know well enough to feel able to tailor prescription requirements to their needs. This is a difficult context for transition, setting the scene for the later theme 'Uncertainties around transition'.

### **The role of ADHD medication**

Medication was mentioned far more often than non-pharmacological ADHD management by the young people interviewed, and was largely discussed in terms of medication effects, and medication purpose.

Most of the young people interviewed made a link between medication and education. 'I don't usually stay medicated when I'm not doing academic work ...I see it as an aid in situations when I need to concentrate 'cos I'm not that bad. I'm not awful without it. But I do find it hard to get on with things when I'm not medicated' (David, 18). We can also gain further understanding about young people's perception of the role of medication by listening to their concerns about what might happen without it. Most young people interviewed made the general assumption that at some point after leaving child services their medication would be stopped, possibly without any choice on their part. One interviewee had been very concerned that when he moved to adult services they would stop his medication. However, on further thought he reassured himself that professionals would be unlikely to do this whilst he was still attending school. 'I felt kind of protected by the fact that I was [still] going to school next year' (Sam, 17). The use of the word 'protected' suggests that medication may be seen as both a literal, and a symbolic, safety net for some participants, and that being still at school would provide protection against enforced cessation

However, despite saying that they took medication 'for school', the positive effects on social interactions and daily life at home and with other people were also highly valued by most interviewees. '[When I take the medication] I'm able to kind of have more of a conversation with people, I'm able to help out a bit more at home' (Sam, 17). Furthermore, occasions where medication was stopped accidentally (e.g. through a missed prescription) or deliberately, as a trial or as a 'drug holiday' had a marked emotional impact on some participants. One described his experience of a trial of stopping medication as follows. 'I was just in tears because I was just felt like everyone was having a go at me, it just felt all of a sudden everyone was just shouting at me, do this, do that' (Patrick, 17).

The quotes above suggest that motivation to use medication is likely to be more complex than purely for focus related to education. The role of ADHD medication was seen not only in terms of concentration and focus in the academic environment, but also in terms of emotional impact and ability to function. These perceptions about the purpose and value of

pharmacological therapy are relevant as they directly informed their views on needs over the transition period and beyond, which are discussed in detail in the next two themes.

### **Uncertainties around transition**

All the young people interviewed voiced a number of uncertainties and even fears around the process of transition; related to services, medication, and subsequent social and personal impacts.

As described in the previous theme, for many participants, medication played an important role in helping them manage daily life at home and at school or college. Consequently, for those who were only just leaving CAMHS, a central area of uncertainty was how their medication would be continued, and who would prescribe it. One young woman had had previous difficulties with her GP refusing to prescribe ADHD medication, and did not think they might prescribe it after the age of 18 even though she wanted to continue. When asked why, she responded 'I would think 'cos it's for kids more than anything' (Rebecca, 17). It was unclear though whether this idea about medication being 'for kids' had come from other young people with ADHD that she knew, or from professionals.

Most of the young people interviewed specifically wished to continue medication beyond the age of 18, and they linked this to their ongoing education and training at college or University. Concerns about whether they would be "allowed" to stay on medication were evident. To them, the potential consequences of stopping were envisaged as being potentially severe, including being "kicked out" of their course, and being unable to continue with education and training. 'If I don't take them I'll be clumsy, if I do take them, I'll be concentrating all the time. I know if I stop taking them and I'll just be kicked out of college, I just won't be able to handle myself...' (Joe, 18).

The sense of uncertainty experienced by some participants was further heightened by what they perceived as a lack of preparation for leaving child services, with no or little notice given or much idea of what to expect. The last appointment at child services did not always appear

to be part of a planned transition, but often an afterthought. 'It just felt like any other meeting. Apart from towards the end she said "oh, we won't be having any more meetings". I mean, I was surprised at the time because I didn't realise that was coming up, cos I've had it since I was young, I just got used to them... it was just so sudden "Oh you're 18 now, goodbye"' (Patrick, 18). 'Yeah, you get dropped when you're 18. Go to your GP now. Fill some forms in and we're leaving you' (Lauren, 18).

The language used by Patrick and Lauren above suggests that this final appointment was experienced as dismissal, or even abandonment: 'we're leaving you...goodbye' (Rebecca, 17); leaving a sudden gap. Furthermore, their accounts imply that young people found the approach to the encounter rather rushed and lacking in care, with the issue of leaving addressed suddenly, or only at the end of the appointment.

Only one of those who had left child services appeared to have been notified well in advance. He described less concern and uncertainty over leaving CAMHS than many over the other participants, which might relate to the more ambivalent attitudes towards medication which he expressed.

This theme of uncertainty leads into the final theme which elaborates on the needs identified by the young people interviewed.

### **Identified needs and increasing independence**

Participants' responses highlighted several areas where they felt services did not meet their needs over the transition period. Most of the interviewees expressed a desire for more information further in advance in order to prepare. 'I would've just liked to know a bit more about what it was going to be like [the Adult ADHD service]. I just didn't know what to expect. But yeah, if I would've known what it was going to be like I would've been so much more relaxed' (Sam, 18). 'If they said last year before I was chucked off [i.e. left CAMHS]...this time next year, this would be the last appointment, I'd be like "OK, I can prepare myself in whatever way"' (Patrick, 18).

These quotes do not appear to suggest that participants required detailed or complex information, but instead a clear indication of what happens next, where they are expected to go and contact points. This lack of information led to considerable anxiety, which young people thought could have been avoided in some cases by better communication. Most expressed willingness to take on some responsibility for preparing for transition but had not actually taken steps to find out information for themselves, perhaps needing some advance help or encouragement to do so. However, one young person had done a lot of his own research prior to leaving CAMHS and in making the move from school to university; and support in higher education was clearly important to him. 'It seems they've [the University] got a good department in place that will offer support if you need it. They've got counsellors, both very central to the university and within your accommodations and colleges. So I think that's quite nice and you'll have someone to go to that, you know, who's just there' (David, 18).

Parents still appeared to be accompanying these 17 and 18 year old children to ADHD-related appointments in many cases, but the degree to which young people took control of ADHD management also varied. 'So they [my parents] make sure I take them [pills] every morning...I think I'll take it...as long as people see a problem with me not taking it. But if people start not seeing a problem with me not taking it I'll stop taking it' (Owen, 17). 'I mean I'm getting better at determining whether or not I need medication, if I feel sort of really out of it and I can't concentrate on something, then I'd say right I'm going to have one of my meds now' (Patrick, 18). Owen felt that because others viewed him as a 'problem' when he did not take medication the onus was on them to oversee the drugs. Patrick on the other hand discussed becoming more aware of his symptoms, recognising when he might benefit from taking a dose, and therefore making his own decisions about his treatment schedule.

The timing of transition was also discussed by participants and parents in relation to increasing independence and responsibility. It was suggested that transition might occur too early, and might be better in the early twenties, for example at the age of 21. 'Like CAMHS

up to age of twenty-one and then change ... 'cos you're an adult but you're not adult adult' (Rebecca, 18).

These quotes therefore illustrate varying levels of independence and responsibility as young people and their families undergo the process of transition. Such differences seem naturally to closely relate to participants' own beliefs about the benefits and purpose of pharmacological therapy, as discussed in an earlier theme, but are also likely to be influenced by family dynamics, symptom severity and general functioning. All these accounts nonetheless supported a general narrative in which independence was seen by participants to refer to managing their own ADHD medication, rather than in a wider sense of taking charge of their interactions with services, but might represent the first step on this journey.

### ***Needs post transition***

Two participants who had actually made the transfer to an Adult ADHD service locally had already had their first appointments. These appointments with specialist nurses and psychologists were perceived as being helpful experiences. 'It was a surprise it was really nice... when I went there... I didn't know what it was going to be like but if I'd known beforehand how kind and nice they would have been and how relaxed it would have been it would have been maybe a little bit better' (Sam, 18).

The predominant focus of need identified by young people was active management and monitoring of medication post-transition. This seemed to be more of a preoccupation for those who had left CAMHS, and returned to the care of their GP, without any specialist ADHD input. These participants often perceived people with ADHD as having particular needs which might not be served by 'routine' primary care check-ups. 'I used to look forward to the [CAMHS] meetings 'cos they used to be able to change my dosage and [I could] see

what the doctor recommends, but I can't really go and see her anymore to ask questions. I've got no one to ask anymore...and it feels a bit... awkward really' (Patrick, 18).

Patrick's concern seems particularly to relate to having no-one to consult regarding his medication, in contrast to the highly valued specialist appointments he had in CAMHS. By saying that he has no-one to ask, Patrick implies that he cannot approach his GP with questions, which is linked to his earlier statement where he perceived GPs as not being qualified to help with ADHD. The result in this case is that he feels quite lost, and unable to test out changing his dosage as he would like to do.

## **Discussion**

This study directly explored the experiences of young people with ADHD undergoing transition from child services. The findings add to the very limited body of research in this area, despite considerable difficulties in recruitment.

The four themes which arose from the analysis were: professionals' roles and relationships, role of medication, uncertainties around transition and finally identified needs and increasing independence. These findings chime in many respects with other qualitative literature, but also highlight aspects of young peoples' experiences which have not been previously explored or reported.

### *Professional roles and relationships*

The importance of relationships with professionals is a theme commonly arising from qualitative research with people using health services (Swift et al. 2013; Plaistow et al. 2014).

One of the most highly valued roles professionals in CAMHS and paediatrics were perceived to have was that of an expert in ADHD who would help young people manage and optimise their medication; this was sometimes contrasted with the role of primary care.

Understandably, some compared the closer relationship they had with their psychiatrist or



paediatrician with the fact that they 'never saw' their GP, and felt that they did not know, or perhaps trust them. This lack of confidence may be influenced by various factors such as the absence of a longstanding therapeutic relationship with the GP, and real and practical constraints such as limited GP time. Furthermore, interviews also suggested that many young people and parents naturally took on the role of 'expert patients', having built up years of experience of managing their condition, in common with young people with other chronic health conditions. They may therefore have been more critical of primary care, and the knowledge or qualifications of GPs relating to ADHD. Research amongst young adults has found that this group report issues with trust and communication in primary care, with some believing that GPs dealt exclusively with physical disorders and lacked training in or understanding of psychiatry (Biddle et al. 2006; Davey et al. 2013).

Perhaps surprisingly, given their key role, to date in the UK there have been no published studies of GP attitudes towards ADHD in this age group specifically. An international systematic review (Tatlow-Golden et al. 2016) suggested that some GPs may be reluctant to become involved in shared care arrangements for ADHD and may hold sceptical attitudes regarding the validity of the diagnosis. Furthermore, NICE guidance (2008) currently recommends that ADHD medication requires occasional review by a specialist, and where such services are not available this will limit the GP's ability to prescribe, or to offer non-pharmacological interventions even where they might wish to do so. GPs may therefore be cautious in taking on prescribing responsibilities in ADHD after patients reach 18 years, especially given that the stimulants that are most often prescribed for this condition are controlled drugs (Bolea-Alamanac et al. 2014).

Misunderstandings and stigma surrounding ADHD itself as a condition, as well as controversies around ADHD medication, might further contribute to difficulties in relationships, not just with GPs but with other professionals too. Whilst some young people had a positive experience of ADHD support in schools, other interviewees reported encountering negative attitudes, such as an assumption that children with ADHD would be

'trouble makers'. Polarised or ambivalent attitudes towards ADHD amongst educationalists have been highlighted in the literature (Anderson, Watt, and Shanley 2017; Richardson et al. 2015). Richardson et al.'s review found some teachers tended to perceive the disorder as being of a wholly sociological origin rather than being of multifactorial aetiology, relating it to 'naughtiness' and to the environment in the home.

### *The role of medication*

A commonly expressed idea by the young people interviewed was a strong link between medication and education. They described the purpose of medication in various ways: as helping them to be calm in the classroom, to concentrate, to complete homework, and to take exams. This, of course, is possibly the most common reason for taking medication cited across the literature (Travell and Visser 2006; Wong et al. 2009; Brinkman et al. 2012). Although education appeared to be considered to be the 'purpose' of medication, the benefits of medication on social relationships were also prominent in young peoples' accounts. Indeed, in Singh et al.'s (2010) qualitative study with young adolescents with ADHD, participants reported that medication had more of a beneficial effect on their social relationships than on their academic work. The interviewees in our current study seemed to value these effects on social relationships, and appeared to use relationships with people to test out whether their behaviour was appropriate, and whether they might need to take or change medication. Interestingly, no participant gave social relationships as the main reason for wanting to continue medication. It is possible that education was seen by young people and parents as being the most worthy or acceptable purpose for medication; and one that would be harder for professionals to argue with.

### *Transition*

Two of the themes focussed on experiences and needs around transition and beyond: 'uncertainties around transition' and 'identified needs and increasing independence'. Participants' views on medication, discussed above, contributed to the uncertainties around transition that they faced. A major anxiety expressed by some participants appeared to be

the fear that if their medication was stopped, their training and education might consequently suffer, even to the extent of being expelled from college, or having to leave University. Most interviewees also appeared keen to continue to take their medication after the age of 18. This contrasts to some degree with other qualitative studies with adolescents about ADHD medication where a significant number of participants perceived that the negatives of medication outweighed the positive, and where many reported making their own decision to stop medication (Wong et al. 2009; Brinkman et al. 2012; Charach et al. 2014).

The need to prepare young people for transition is well recognised from previous research and forms a key part of the guidance on optimal transition across physical and mental health services (NICE, 2016). Consequently, one of the more striking findings was how important information was to participants; and that this remained a central unmet need identified by interviewees in this study.

The second major unmet need identified relating to care over the transition period and beyond was for support in managing ADHD medication. This has implications in terms of the acceptability of different models of ADHD care for young people. In particular, participants who were not transferring to an Adult ADHD service to appeared to have concerns about lack of specialist advice and review. They felt that they required regular review of dosage and type of drug in order to optimise the management of their symptoms. Similarly, in Matheson et al.'s (2013) study of adults with ADHD, those that received only repeat prescriptions from their GP wanted extra support with adjusting their medication and dealing with adverse effects, suggesting this might not be a role that primary care is always able to fulfil.

In contrast to the anxieties voiced regarding medication, needs for non-pharmacological management were less prominently expressed during interviews. Non-pharmacological interventions were generally referred to in more vague terms such as 'someone to talk to' or 'support' with further or higher education. Given that those interviewed had only just left child services, the issue of medication may have been a more urgent concern; but the relative

lack of emphasis placed on other interventions might also reflect uncertainty about the role of non-pharmacological management. Adolescents interviewed by Singh et al. (2010) reported the view that medication was the most efficacious treatment for ADHD; and many also could not recall memorable or helpful non-pharmacological interventions. Such perceptions may indicate both a lack of awareness and a lack of availability of non-pharmacological options for young people with ADHD, leaving medication as their only 'safety net' over the transition period.

A number of young people also indicated that they would value advice from schools about managing their ADHD in further and higher education, including how to choose supportive Universities. Therefore, teachers and lecturers have the potential to play a major role in helping students through these multiple simultaneous transitions; but may face a number of challenges to fulfilling such a role, including multiple conflicting demands on their time (Taggart H 2014).

#### *Strengths and limitations*

One of the strengths of this study was that we were able to interview young people using a variety of services across the South West Peninsula, encompassing four different service providers and configurations. It therefore describes the perspectives of service users from both CAMHS and paediatrics that transferred to Adult ADHD services as well as those for whom no such service was available and who were returning to primary care. Their experiences may therefore be applicable to young people in other areas of the country where similar arrangements are in place.

However, the young people interviewed in this current study were all still being seen in specialist services at the age of 17-18 years and were all on medication; which suggests that these participants both recognised the need for medication and were engaged with healthcare services. The study is therefore unable to reflect the experiences of young people who might disengage from services earlier in adolescence; a group who may face different challenges and report different priorities and needs.

One of the key limitations was the difficulty in recruiting this hard-to-reach group. Young people in general can be difficult to recruit to research studies, and the nature of ADHD led to added challenges in recruitment and retention (Flanagan and Hancock 2010; Wong et al. 2009; Singh, Kendall, et al. 2010). Most of those who eventually took part required repeated contacts, sometimes over the course of weeks or even months. The study design also involved making contact with service users at the disruptive and potentially chaotic time of transition.

Although qualitative studies are not predicated on reaching a specific sample size ((Mays and Pope 2000) the small number of young people interviewed means that the data may not reflect the full range of experiences of transition, and therefore should be generalised with some caution. Nonetheless, few studies have successfully managed to recruit to plan when carrying out research with this population and most achieved similar sample sizes (Wong et al. 2009; Hovish et al. 2012b; Swift et al. 2013; Matheson et al. 2013).

## **Implications**

Although this study presents the experiences of a small number of young people at a specific point in time, their stories suggest that best practice around transition is not always being followed and also have implications for the design of models of care. The findings are in keeping with those of the 2010 TRACK evaluation of transition from CAMHS to AMHS, which found that only 5% of cases experienced 'good transition' (Singh, Paul, et al. 2010). This gap between policy and practice is also evident in recent mapping surveys of healthcare professionals and mental health trusts in England, which highlighted a lack of transition protocols and care pathways for young people with ADHD (Hall et al. 2015; Hall et al. 2013). There is consequently a need to better understand the facilitators and barriers to best practice implementation. Exploration of the views and attitudes of commissioners and professional groups who are responsible for implementing guidance should therefore be a central component of future transition research.

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The authors declare no conflict of interests.

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**Appendix: Summary of topic guide for qualitative interviews**

<b>Topic Area</b>		
<b>Past</b>	<b>Present</b>	<b>Future</b>
Could you tell me a bit about your experience of Child and Adolescent Mental Health Services/Child Health services in the past?	Could you tell me a bit about the services you are using now (if any)?	How do you see your ADHD affecting you in the future (if at all)?

Could you tell me what it was like leaving CAMHS/Child Health?	Is there anything you find helpful at the moment about services?  Is there anything you find unhelpful?	In an ideal world, what tools, services or support do you think would be available for you in the future to help you manage with your ADHD?
How did / do you feel about moving on into adult services?	In an ideal world, what services or support do you think would be available for you now to help you manage with your ADHD?	
Was there anything that could have made this process easier/better?		

**Table 1: Characteristics of participants**

<b>Participant number and pseudonym</b>	<b>Age and gender</b>	<b>On ADHD medication?</b>	<b>Psychiatric co-morbidities</b>	<b>Transition stage</b>	<b>Parent present at interview</b>
P1 David	18 M	Yes	None reported	Care transferred to GP from CAMHS	No

P2 Joe	18 M	Yes	Borderline and specific learning difficulties	Leaving CAMHS	No
P3 Rebecca	17 F	Yes	None reported	Leaving CAMHS	Yes – mother
P4 Sam	18 M	Yes	ASD	Care transferred to Adult ADHD service, from Paediatrics	Yes – mother
P5 Lauren	18 F	Yes	ASD	Care transferred to GP from CAMHS	Yes – mother
P6 Patrick	18 M	Yes	None reported	Care transferred to GP from CAMHS	Yes – mother
P7 Owen	17M	Yes	ASD	Care transferred from Adult ADHD service from CAMHS	No