

Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children's services to adult services (CATCH-uS): a mixed methods national scoping study

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Scientific summary

Background

Originally conceived as a disorder of childhood, attention deficit hyperactivity disorder (ADHD) is now recognised as a long-term health condition, with poor outcomes associated with adult patients whose ongoing impairment is not treated. This recognition highlights the importance of continuity of care for ADHD patients with ongoing needs who become too old for child services. Transition is important to reduce disengagement; however, adult mental health services are not typically configured to care for ADHD patients.

A lack of evidence about the number of patients with ADHD who will require ongoing care as a young adult and lack of information about the existing adult services for patients with ADHD hampers commissioning and provision of services for this group. There is also little evidence about how transition is experienced and what may influence transition for ADHD patients. This research aimed to address these gaps and is the first in-depth study of these issues in the UK.

Objectives

- to assess the current need for adult services for young people with ADHD and describe young people with ADHD in need of a transfer to adult services (*level of need*)
- to identify the range and type of services that are currently available for young people with ADHD in transition from childhood to adulthood (*map services*)
- to explore the quality of service delivery during transition and identify factors that (i) influence the experience of transition and could improve continuity of care and (ii) underlie (dis)continuation of treatment (*utility of services*)

Methods

The mixed methods research design involved three study streams. Parents of children with ADHD (our Parent Advisory Group) and three third-sector ADHD organisations (AADD-UK, Cerebra & UK-AAN) advised and supported the research throughout the project.

Strand 1: Surveillance Study

To assess ongoing service needs, we collected surveillance data via the Child and Adolescent Psychiatry Surveillance System (CAPSS) and the British Paediatric Surveillance Unit (BPSU). These units collect data on rare conditions and processes from consultant child and adolescent psychiatrists and paediatricians through monthly cards (now emails) that list the conditions under study. Over a period of twelve months, consultant paediatricians and child psychiatrists reported ADHD patients who were prescribed ADHD medication, were within six months of the upper age boundary of their service and who would require ongoing services for their medication management. BPSU and CAPSS informed the research team of the clinicians who reported cases, and the researchers sent these consultants a baseline notification survey to collect details of patient treatment and planned transition. After nine months, a follow-up questionnaire was sent to the reporting clinician to confirm the outcome and details of the transition. We calculated the needs estimate by taking an ADHD prevalence rate of 5% and applying this to the total number of 17 – 19 year olds in the UK (2,333,035 as reported in 2016) to obtain a population at risk of 116,651, and adjusting for non-response and case ascertainment. To check case ascertainment, we also undertook a Clinical Notes Review at one mental Health Trust, which enabled us to triangulate the total number of cases reported as eligible for transition and the details of transition between CAPSS and the clinical records.

Strand 2: Mapping Study

The mapping study was designed to identify and locate adult health services for patients with ADHD. We made the map publicly available to improve information about services, help access to ongoing care and identify gaps in service provision. The map was created from responses to an online survey distributed via organisational email lists and social media, which collected data from patients and health professionals. Freedom of information (FOI) requests (based on the same questions as the online survey) were also sent to commissioners and service providers. Responses were displayed and analysed by informant group and location using mapping software. Due to difficulties in differentiating

specialist services from specialist clinics operating within a generic adult mental health service, services were described as 'dedicated' if they had 'ADHD' or 'neurodevelopmental' in the service name. Hereafter referred to as dedicated. Services were categorised into four groups a) 'Dedicated' ADHD NHS services b) Generic NHS services where respondents had experienced care for ADHD c) NHS Child Services or Non-NHS services where respondents had received care for ADHD and d) ADHD services identified but no respondent reported experience of ADHD care from them.

Strand 3: Qualitative Study

Semi-structured interviews were conducted with seven stakeholder groups to gather a better understanding of the transition process for ADHD patients. These groups were 1) patients pre-transition 2) patients post-transition 3) patients who did not transition but returned to adult services 4) parents of children with ADHD (some of whom were pre-transition, some post transition and some who did not transition) 5) paediatricians and child psychiatrists 6) health professionals working in adult mental health services 7) GPs. The first four groups were recruited via clinical research nurses, the other groups were recruited from the surveillance and mapping studies, with some GPs also recruited via Twitter or through a snowball method. Data from each stakeholder group were analysed separately using a Framework Analysis approach and then compared to look for consensus and differences in views and experiences of transition.

Results

Level of Need

During the twelve-month surveillance period, there were 315 confirmed cases of ADHD patients who required transition. The Clinical Notes Review identified seven times as many eligible ADHD transition cases, which suggests that the surveillance figures are likely to be a significant underestimation. The annual need for young adults with ADHD to transition for ongoing medication needs to lie between 270 and 599 per 100,000 people aged 17- to 19 years old. The estimated incidence of successful transition was found to be considerably lower (47 to 104 per 100,000 people aged 17 – 19 years). Only in a fifth of cases where there was a need for transition for medication management was a referral to adult services made, accepted and the patient attended first appointment. The completed surveys also indicate a relative lack of adherence to recommended guidance for transition, with fewer than 30% of cases involving a care plan and joint handover meeting.

Map Services

2,686 survey and FOI responses were used to map current Adult ADHD services. Fifty or more responses were received from each NHS region of the UK except for Wales, where 40 responses were received. Respondents to the online survey were typically health professionals (61%) but 17% of the overall response rate was from patients. 90% of the 236 organisations responsible for commissioning NHS mental health services in the UK responded. The responses illustrated both a wide range of service models for adult ADHD health care and geographical variation; 294 unique services were identified, 44 of which were dedicated NHS ADHD services. Most (42/44) were in England, indicating generic services are more likely to be configured to treat adult ADHD in Scotland, Wales and Northern Ireland. Only 12 of the 44 dedicated NHS ADHD services offered a full range of ADHD interventions. Most provided medication management (89%) or diagnosis (77%); transitional care (55%) and psychological treatments (48%) were less frequently offered. All stakeholders identified a significantly lower proportion of general adult NHS services compared to dedicated NHS adult ADHD services. This raises questions over which, if any, generic adult NHS services, provide accessible treatment for adult ADHD.

Utility of Services

We interviewed 144 individual stakeholders from across all regions of the UK. Our sample comprised: 64 patients (21 pre-transition, 22 post-transition and 21 who did not transition but returned to adult services), 28 parents, 22 child clinicians, 16 adult clinicians and 14 GPs. Two overarching themes were found to influence the success of transition – how *invested* stakeholders are in continuing ADHD treatment and the *architecture of services* in local areas. The interviews with patients revealed a lack of understanding of ADHD and particularly related impairment in adulthood. Patients often associated medication with education and assumed treatment would end when their schooling ended. The medication focus of services meant that those who did stop medication before transition did not transfer to adult services. Those going on to higher education were more likely to transition but still expressed a view that they would stop their medication once they had finished university. Those who did not transition, but after a period without routine care, returned to services as a young adult, were often prompted to seek help after a profoundly negative event in their lives which emphasised the ongoing influence of ADHD. Parents were more likely to view ADHD as an impairment that needed ongoing support prior to transition and their active involvement was viewed by all stakeholders as essential for transition to be successful. How prepared a patient and parent were for transition, the

quality of patient information handover, accessibility of adult services and the fit of patient needs with the remit of adult services available were all interlinked factors influencing the success of transition. With comorbidities frequently observed in patients with ADHD, transition often depended on coexisting conditions and the complexity of patient needs. The interviews also revealed how GPs can end up with a role in transition by default, which raises questions as to the availability of specialist oversight.

Conclusions

CATCh-uS replicated and extends previous research on transition in ADHD and suggests that very few of those who need ongoing medication for their ADHD successfully transfer to adult services, and a very small proportion of those who transfer experience anything that approaches optimal transitional care. All stakeholders perceive psychosocial approaches as essential, although there is a lack of evidence-based approaches and a real need to evaluate various models of transitional care and adult ADHD provision. Our participants reported a range of experiences including smooth transition. The latter seemed more likely with parental involvement and procedures that supported the promotion of understanding and self-awareness of ADHD as a long-term condition, and solid information transfer.

Recommendations for Research in order of priority

1. Updating the estimates of need for transition; there are likely to be continuing increases in the number of young adults with ADHD who need and want ongoing care, given the history of rising childhood prescriptions over time
2. Development of a national level understanding of the roles of primary care within current service models, and examination of the evidence for implementation of training or tools to support primary care in managing young people with ADHD
3. Evaluation of different models to support transition for young people with ADHD specifically, and to support transition in general, including the identification of key outcomes of transition
4. Economic evaluation of the costs of ADHD with and without continued care and treatment into adulthood
5. Development and evaluation of psychological approaches to ADHD in adolescents and young adults; the needs of these two groups may differ

6. Exploring the experience of important groups missed by this research; such as people who left children's services but did not return to services in their mid-20s, people presenting for the first time in adulthood, those accessing private care, and university students. While the ethnicity of participants reflected the UK, this did not allow for the systematic study of the experience of those of Black or Ethnic Minority, which may differ.
7. Empirical exploration of the role and constitution of 'dedicated' / specialist services versus delivery of care via generic teams for adults with ADHD

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