The transition from children's services to adult services for young people with attention deficit hyperactivity disorder: the CATCh-uS mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

The CATCh-uS mixed-methods study

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Scientific summary

Background

Originally conceived of as a disorder of childhood, attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder patients.

A lack of evidence about the number of patents with attention deficit hyperactivity disorder who will require ongoing care as a young adult and a lack of information about the existing adult services for patients with attention deficit hyperactivity disorder hamper commissioning and the provision of services for this group. There is also little evidence about how transition is experienced and what may influence transition for attention deficit hyperactivity disorder patients. This research aimed to address these gaps and, to our knowledge, 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 attention deficit hyperactivity disorder and describe young people with attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder in transition from childhood to adulthood (map services).
- To explore the quality of service delivery during transition and identify factors that (1) influence the experience of transition and could improve continuity of care and (2) underlie (dis)continuation of treatment (utility of services).

Methods

The mixed-methods research design involved three study streams. Parents of children with attention deficit hyperactivity disorder (our Parent Advisory Group) and three third-sector attention deficit hyperactivity disorder organisations [Adult Attention Deficit Disorder-UK (AADD-UK), Bristol, UK; Cerebra, Carmarthen, Wales; and UK Adult ADHD Network (UKAAN), London, UK] 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 and the British Paediatric Surveillance Unit. These units collect data on rare conditions and processes from consultant child and adolescent psychiatrists and paediatricians through monthly cards (now e-mails) that list the conditions under study. Over a period of 12 months, consultant paediatricians and child psychiatrists reported attention deficit hyperactivity disorder patients who were prescribed attention deficit hyperactivity disorder medication, were within 6 months of the upper age boundary of their service and would require ongoing services for their medication management. The British Paediatric Surveillance Unit and Child and Adolescent Psychiatry Surveillance System 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 9 months,

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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 attention deficit hyperactivity disorder prevalence rate of 5% and applying this to the total number of 17- to 19-year-olds in the UK (2,333,035 as reported in 2016) to obtain a population at risk of 116,651, 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 the Child and Adolescent Psychiatry Surveillance System and the clinical records.

Strand 2: mapping study

The mapping study was designed to identify and locate adult health services for patients with attention deficit hyperactivity disorder. 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 e-mail lists and social media, which collected data from patients and health professionals. Freedom of information requests (based on the same questions as in the online survey) were also sent to commissioners and service providers. Responses were displayed and analysed by informant group and location using mapping software. Owing 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 'attention deficit hyperactivity disorder' or 'neurodevelopmental' in the service name (hereafter referred to as dedicated). Services were categorised into four groups: (1) 'dedicated' attention deficit hyperactivity disorder NHS services, (2) generic NHS services in which respondents had experienced care for attention deficit hyperactivity disorder, (3) NHS child services or non-NHS services in which respondents had received care for attention deficit hyperactivity disorder and (4) attention deficit hyperactivity disorder services identified but at which no respondents confirmed experiences of access to care for attention deficit hyperactivity disorder as adults.

Strand 3: qualitative study

Semistructured interviews were conducted with seven stakeholder groups to gather a better understanding of the transition process for attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder (some of whom were pre transition, some of whom were post transition and some who did not transition), (5) paediatricians and child psychiatrists, (6) health professionals working in adult mental health services and (7) general practitioners. The first four groups were recruited via clinical research nurses; the other groups were recruited from the surveillance and mapping studies, with some general practitioners also recruited via Twitter (Twitter Inc., San Francisco, CA, USA; www.twitter.com) 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 12-month surveillance period, 315 patients with attention deficit hyperactivity disorder patients were identified as requiring transition. The clinical notes review identified seven times as many eligible attention deficit hyperactivity disorder transition cases, which suggests that the surveillance figures are likely to be a significant underestimation. The annual need for young adults with attention deficit hyperactivity disorder to transition for ongoing medication needs lies between 270 and 599 per 100,000 people aged 17–19 years. The estimated incidence of successful transition was found to be considerably lower (47 to 104 per 100,000 people aged 17–19 years). In only one-fifth of cases where there was a need for transition for medication management was a referral to adult services made and accepted and the patient attended the 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

A total of 2686 survey and freedom of information responses were used to map current adult attention deficit hyperactivity disorder services. Fifty or more responses were received from each NHS region of the UK except Wales, where 40 responses were received. Respondents to the online survey were typically health professionals (61%) but patients accounted for 17% of the overall response. A total of 90% of the 236 organisations responsible for commissioning NHS mental health services in the UK responded. The responses illustrated a wide range of service models for adult attention deficit hyperactivity disorder health care and geographical variation; 294 unique services were identified, 44 of which are dedicated NHS attention deficit hyperactivity disorder services. Most (42/44) services were in England, indicating that generic services are more likely to be configured to treat adult attention deficit hyperactivity disorder in Scotland, Wales and Northern Ireland. Only 12 of the 44 dedicated NHS attention deficit hyperactivity disorder services offer a full range of attention deficit hyperactivity disorder interventions. Most provide medication management (89%) or diagnosis (77%); transitional care (55%) and psychological treatments (48%) are less frequently offered. All stakeholders identified a significantly lower proportion of general adult NHS services than dedicated NHS adult attention deficit hyperactivity disorder services. This raises questions over which, if any, generic adult NHS services provide accessible treatment for adult attention deficit hyperactivity disorder.

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 children's clinicians, 16 adults' clinicians and 14 general practitioners. Two overarching themes were found to influence the success of transition: how invested stakeholders are in continuing attention deficit hyperactivity disorder treatment and the architecture of services in local areas. The interviews with patients revealed a lack of understanding of attention deficit hyperactivity disorder, and this particularly related to impairment in adulthood. Patients often associated medication with education and assumed that 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 attention deficit hyperactivity disorder. Parents were more likely to view attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder, transition often depended on coexisting conditions and the complexity of patient needs. The interviews also revealed how general practitioners can end up with a role in transition by default, which raises questions as to the availability of specialist oversight.

Conclusions

The CATCh-uS study replicated and extends previous research on transition in attention deficit hyperactivity disorder and suggests that very few of those who need ongoing medication for their attention deficit hyperactivity disorder successfully transfer to adult services, and a very small proportion of those who transfer experience anything that approaches optimal transitional care.

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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 attention deficit hyperactivity disorder provision. Our participants reported a range of experiences including smooth transition. This seemed more likely with parental involvement and procedures that supported the promotion of understanding and self-awareness of attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder 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 attention deficit hyperactivity disorder.
3. Evaluation of different models to support transition for young people with attention deficit hyperactivity disorder specifically, and to support transition in general, including the identification of key outcomes of transition.
4. Economic evaluation of the costs of attention deficit hyperactivity disorder with and without continued care and treatment into adulthood.
5. Development and evaluation of psychological approaches to attention deficit hyperactivity disorder 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. Although the ethnicity of participants reflected the UK population, this did not allow for the systematic study of the experience of those of black or ethnic minority people, 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 attention deficit hyperactivity disorder.

Trial registration

This trial is registered as ISRCTN12492022.

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