Hall, Charlotte L. and Newell, Karen and Taylor, John and Sayal, Kapil and Hollis, Chris (2015) 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 (1). pp. 39-42. ISSN 1461-7285

Abstract

Transition from child to adult mental health services is considered to be a difficult process, particularly for individuals with neurodevelopmental disorders such as Attention Deficit/Hyperactivity Disorder (ADHD). This article presents results from a national survey of 36 mental health NHS Trusts across England, the findings indicate a lack of accurate data on the number of young people with ADHD transitioning to, and being seen by, adult services. Less than half of Trusts had a specialist adult ADHD service and in only a third of Trusts were there specific commissioning arrangements for adult ADHD. Half of Trusts reported that young people with ADHD were prematurely discharged from CAMHS because there were no suitable adult services. There was also a lack of written transition protocols, care pathways, commissioned services for adults with ADHD and inadequate information sharing between services. The findings advocate the need to provide a better transition service underpinned by clear, structured guidelines and protocols, routine data collection and information sharing across child and adult services. An increase in the commission of specialist adult ADHD clinics is needed to ensure individuals have access to appropriate support and care.

Declaration of Interest: This study forms part of the wider TRAMS (Transition to Adult Mental Health Services) project and is funded by NIHR (National Institute of Health Research) CLAHRC-NDL (Collaborations for Leadership in Applied Health Research and Care – Nottinghamshire, Derbyshire and Lincolnshire). On behalf of all authors, the corresponding author states that there is no conflict of interest.

Introduction

Recent research has acknowledged the need for young people diagnosed with a neurodevelopmental disorder to have continued access to mental health services during adolescence and into adulthood (Hall et al., 2013b; Singh et al., 2008; Singh et al., 2010). However, the process of transition is complex and there are many known barriers that hinder transition from one service to another, including different service thresholds, cultures, and boundaries (Bruce and Evans, 2008; Singh et al., 2010; Munoz-Solomando et al., 2010).

One of the most comprehensive investigations of transition within mental health services found a lack of clarity on transition protocols operating in Greater London (Singh et al., 2008). Specifically, protocols differed on age of transition, flexibility of boundaries, protocol sharing and joint working between CAMHS and AMHS. A longitudinal study conducted across six mental health Trusts (MHTs) in England revealed that less than 5% of young people transitioned to adult services received optimal transition, consisting of joint working, transition planning and information transfer across teams (Singh et al., 2010). These findings have been confirmed by recent interviews with psychiatrists working across CAMHS and AMHS (McNamara et al., 2013).

These problems are often exacerbated when the young person has Attention Deficit/Hyperactivity Disorder (ADHD) (Young et al., 2011) where the National Institute for Health and Care Excellence (NICE, 2008) state that most young people with an ADHD diagnosis will continue to have significant difficulties in adulthood and will require ongoing support. Research has found that young people with neurodevelopmental disorders (such as ADHD) are less likely to meet the acceptance criteria for AMHS than individuals with a severe mental health disorder (Singh et al., 2008), or those taking medication (Singh et al.,

2010). Furthermore, young people with ADHD have high chance of being discharged or lost during follow-up (Ogundele and Omenaka, 2012).

NICE (2008) and the updated British Association for Psychopharmacology (BAP) guidelines (Bolea-Alamañac et al., 2014) recognise the importance of continuing care into adulthood for individuals with ADHD and highlight the importance of transition timing, planning and joint working for ADHD cases.. However, few studies have investigated transition or the provision of care for ADHD in adult services.A survey of Community Paediatricians found that 40% felt their patient would need continuing care into adulthood, with 90% highlighting the need for a specialist ADHD clinic (Marcer et al., 2008). Other surveys (Ahmed et al., 2009) have identified a lack of confidence and experience in AMHS clinicians' ability to diagnose and manage ADHD and a lack of structured guidelines, protocols and boundaries for transitioning cases with ADHD (Hall et al., 2013b). To date, no research has mapped the national process of transition or provision of care for adults with ADHD.

We present findings from the first national survey to investigate the transition process and current services for adults with ADHD across MHTs in England, with the aim of identifying gaps in care and areas for service improvement.

Method

Procedure

All NHS mental health Trusts (MHTs) in England were invited via an email to participate in an on-line survey hosted by www. surveymonkey.com. This was designed to be completed by a Clinical or Medical Director or a nominated senior healthcare professional with particular knowledge of ADHD services within the Trust. Questions centred on transition protocols,

pathways and commissioned services (see Appendix A for survey questions). Data were collected between May and August 2013 and downloaded from the website at the end of the study. Descriptive statistics were used.

Respondents

The survey was sent to all 53 NHS MHTs (www.nhs.uk) in England, of which 36 Trusts (68%) responded. One large NHS Trust allocated two respondents dealing with different geographical parts of the Trust, giving a total of 37 respondents. Non-responding Trusts were contacted up to seven times with reminders. Three R&D departments did not provide necessary approval.

The respondents comprised 36 Consultant Psychiatrists (97%) and 1 Principal Psychologist (3%). Ten of the Trusts covered were urban areas, one a rural area and 25 both urban and rural areas. Twenty-three Trusts provided information about staffing numbers; ranging from 850-9,000 staff. Twenty provided information about population size, ranging from 464,000-1.8million. Many Trusts indicated difficulty in ascertaining number of patient contacts, 13 Trusts provided data on this, estimates ranged from 2,500-276,000 patients per annum. Ethical approval for the study was granted by the East Midlands-Derby Ethics Committee and the Research and Development Departments of all participating Trusts.

Results

ADHD cases and barriers to transition

Over half of respondents (59%, 22/37) did not know how many adults with ADHD were currently being seen by their Trust. Of those who provided figures, estimates ranged from less than 10 adults to up to 400 adults. A similar number of Trusts (54%, 20/37) were unsure

how many young people with ADHD transition from child to adult services within their Trust per annum. Estimates ranged from no transitioned cases to up to 100 young people transitioning per annum. Table 1 shows the respondents' perceptions of the current barriers to transition.

[INSERT TABLE 1 HERE]

Transition Protocol

Across participating NHS MHTs there was little evidence of formal protocols. Table 2 shows the number of Trusts with written transition protocols for transitioning young people and shared care protocols for medication in adults. Additionally, only one-third of Trusts had shared care protocols (SCPs) in place for ADHD medication in adults. There was no relationship between the presence of a SCP and transition pathway.

[INSERT TABLE 2 HERE]

Only 38% (14/37) of transition protocols were reported to specify a formal period of joint working between CAMHS and AMHS and 89% (33/37) of respondents reported having no staff with a dedicated role to support young people during the transition period.

Transition care pathway

In contrast to the low number of transition protocols, more Trusts had a written transition care pathway (65%, 24/37), although the majority of these were not specific to ADHD (76%, 28/37). Half of respondents (51%, 19/37) reported that CAMHS teams often have to discharge young people with ADHD because there is no appropriate adult service to accept them Table 3 indicates that the most common transition pathway for young people transitioning from child services was into adult mental health services or a specialist ADHD clinic.

Less than half of Trusts (43%) had access to a specialist adult ADHD clinic Fifty per-cent (8/16) stated that their specialist clinic offered a tertiary level of assessment and management to AMHS (hub and spoke service model) and 38% (6/16) reported the clinic offered a secondary level of care for all adult cases.

[INSERT TABLE 3 HERE]

Commissioned services

Sixty per-cent of respondents (22/37) did not currently have any formally commissioned services for adult ADHD. However, all those who reported having a commissioned service (n=13/37) stated that the service included a specialist ADHD clinic and 46% (6/16) reported a commissioned transition service.

Just under half of respondents (46%, 17/37) indicated that their Trust was planning a formally commissioned service for adults with ADHD, the majority of which were for a specialist adult ADHD clinic (88%, 15/17) and 47% (8/17) for a transition service (e.g. a distinct service for young people aged 16-24 years which is aimed at facilitating the transition process).

Discussion

Our findings specifically highlight a lack of defined transition protocols, care pathways and inadequate information sharing between services, as well as a lack of commissioned services for adults with ADHD. To our knowledge, this is the first time that information on ADHD transitions between children's and adult services has been systematically collated across the NHS in England.

This survey revealed a nationwide lack of knowledge on the number of adult cases with ADHD and the number of cases with ADHD transitioning from child to adult services. This may reflect poor Trust information systems (Hall et al., 2013a) and poor recording of diagnosis (Singh et al., 2010). In support of the findings of Hall et al. (2013b), staff training in adult ADHD was considered the largest barrier to successfully transitioning young people with ADHD. This may stem from the only relatively recent acceptance of ADHD as a valid diagnosis in adults (Young et al., 2011; Wilens, 2004), Given the findings from Hall et al. (2013b)that a lack of training on ADHD may be responsible for adult clinicians' lack of confidence on prescribing ADHD treatments for adults, there is a need to improve their ability to assess and manage ADHD.

Our findings corroborate previous reports indicating a lack of transition protocols (Hall et al., 2013b; Singh et al., 2010), and identify a particular lack of ADHD specific protocols oror protocols for individuals transitioning from paediatric services. Although we found a higher number of Trusts with a written transition care pathway, the majority of these were not specific to ADHD. The findings further support the need for a more extensive and comprehensive set of guidelines on how best to transition young people with ADHD, such as those created by Young et al. (2011). Based on our findings, we support the need for local services to commission a single, clear transition pathway that is implemented regardless of whether the young person is transitioning from paediatric services or CAMHS (Young et al., 2011).

The previously reported lack of joint-working between services (Hall et al., 2013b; Singh et al., 2010; Singh et al., 2008; McNamara et al., 2013) was also noted in this national survey One way to improve the transition from CAMHS to AMHS could be to encourage the development of designated transition staff positions that would hold a shared post between the two services (Singh et al., 2010), or improve the training of generic staff. As also

concluded by Singh et al. (2010), information sharing between CAMHS and AMHS could be improved through nationally standardised electronic databases which would facilitate an easier transfer of case information between teams and services. Improving the transition process is one step to ensuring better care for young people with ADHD, but it is equally as crucial that there is an appropriate service to transition on to. We found approximately half of CAMHS teams having to discharge young people due to a lack of appropriate service to transition them on to, suggesting that young adults with ADHD may not have appropriate access to clinical care. It should be noted that not all young people with ADHD would need to have the assistance of AMHS or a specialist service; some cases could be managed by primary care, providing GPs are appropriately trained and shared care protocols (SCPs) are in place. The fact that specialist adult ADHD clinics were present in less than half of the responding Trusts highlights the national shortage in the provision of such services. However, the indication that the majority of future planned commissioned services were for a specialist ADHD clinic may be particularly valuable for adults who do not currently meet the criteria acceptance for AMHS.

This is the first survey to investigate the national provision of services for young people diagnosed with ADHD transitioning into adult services and yielded a high response rate. However certain caveats need to be taken into consideration. It is possible that some respondents may not have had the specific knowledge necessary to complete the questions, or they did not have enough time or interest in the study to complete the survey fully. Alternatively, this may genuinely reflect poor database keeping acknowledged in similar studies (Singh et al., 2010). Additionally, we cannot say whether our findings are representative of all Trusts or determine the number of transitioning cases in relation to Trust size. The likelihood is that responding Trusts will be those with better services and access to information. Future studies should use clinical records to ascertain information about

numbers of ADHD cases. Our study only investigated transitions between services within MHTs; we chose this specification in order to assess organisational barriers of transferring care within the same Trust. However, there are some Trusts where children's mental health services are provided by Primary Care or Paediatric Trusts which will have been excluded from our survey. In identifying the presence of formal protocols and care pathways, we do not report on adherence to these or how the lack of transition protocol may lead to transition failures. A qualitative investigation into ADHD transition has revealed that a lack of clear, structured planning and approach to transition often led to young people feeling let down by their clinician and under-prepared for leaving child services (Swift et al., 2013), suggesting a potential link between the two. Additionally, we did not collect data on the number of cases discharged from child services (to transition adult services) each year. In order to improve the transition process future studies may wish to build on this by further understanding the nature, content and adherence to these protocols and investigate which factors s hinders joint working between child and adult services.

Our findings identify a nationwide gap in service delivery for young people diagnosed with ADHD who are leaving child services. Systems and protocols need to be developed in order to facilitate a smoother transition process and there is a need for increased commissioning of adult ADHD services to provide continuity of care for this developmental disorder across the lifespan.

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Tables

Table 1. Respondents' perceptions of the current barriers to transitioning young people with ADHD

Barriers to transition	**Trusts responding positively (%)** ***N* = 37**
Staff training in adult ADHD	65% (24)
Lack of specialist services	62% (23)
Lack of defined care pathway	54% (20)
Lack of shared care protocol	43% (16)
Lack of transition protocol	24% (9)

Note. Respondents could chose more than one option

Table 2. Presence of transition protocols and shared care protocols (N = 37)

	Yes	**No**	**Don't Know**
Written transition protocol from CAMHS to AMHS	54% (20)	43% (16)	3% (1)
Written transition protocol from Paediatrics to AMHS	22% (8)	57% (21)	22% (8)
Shared care protocol (SCP) for ADHD medication in adults	35% (13)	46% (17)	19% (7)

Table 3. Available pathways for young people transitioning from child services

Available Pathways	**Respondents (%) (*N* = 37)**
General adult mental health teams	65% (24)
Specialist ADHD clinic	43% (16)
GP	14% (5)
No commissioned services	14% (5)
Learning disability services	3% (1)
Social care services	3% (1)

Note. Responses represent the percentage of respondents who reported that these were available options. Respondents could tick more than one option.