Transition in ADHD: attention to the lifespan

Abstract

Objectives

This paper reviews the importance of transition to adult services for young people with ADHD. Different models are described and evidence sought for their effectiveness in clinical practice.

Results

Models of care for children with ADHD include specialised mental health services, and individual paediatricians and child and adolescent psychiatrists. Although it might be expected that transition would be to equivalent adult teams or specialists, studies have shown that transition may not run smoothly and the adult services are frequently inadequate. This may result in attrition from treatment or discharge to the general practitioner.

Conclusion

Adult mental health services for transitioning young people with ADHD are under-resourced. The way of the future may be the generic ADHD specialist or service, treating ADHD across the lifespan and avoiding the need for transition.

Introduction

Transition of individuals from paediatric to adult services comes at the critical stage of life when mental disorders with a long-term impact may first become apparent. ADHD is associated with ongoing functional impairment across the lifespan and is also a risk factor for developing other psychiatric diagnoses. Therefore transition and ongoing appropriate care into adulthood is particularly important for young people with ADHD. For successful transfer, the receiving team or clinician needs to understand and be able to meet the needs of the young person.

Importance of ongoing care into adulthood

ADHD is often considered to be a disorder of childhood because the most obvious symptoms - hyperactivity and impulsivity - tend to improve with age. This may result in adults no longer meeting symptom-based diagnostic criteria. However, the executive functioning deficits persist and may be associated with lifelong impairment. This may manifest as difficulty sustaining long-term employment and relationships, more sexual partners and earlier parenthood. ADHD is common at all ages: a large German community study found a prevalence of 4.5% in adults, which was comparable to depression (8.0%) and anxiety (7.1%). Adults with ADHD have higher death rates, particularly accidental death and death associated with substance use disorder.
Although the cognitive deficits associated with ADHD tend to be very stable across the lifespan, the expression of ADHD varies according to the stage of development. Because an individual's requirement for sustained concentration is usually greatest during their years of education, many people with ADHD cease medication once they leave school. A large multicentre study of children with ADHD documented a reduction in medication use by 62% over 6-8 years of follow-up to age 13-18. However, although the symptom scores declined, there was still evidence of persistent deficits, particularly in those with comorbid oppositional defiant disorder and conduct disorder.

ADHD in adults is associated with poorer functioning across a range of occupational, social and family domains and lower quality of life. Taking on an adult role in society, with associated work and family commitments, usually requires a high level of organisational skills. Adults with ADHD experience more stress-related symptoms and have higher rates of psychiatric comorbidity, including generalised anxiety disorder, obsessive compulsive disorder, social phobia, major depression and substance use disorders.

There is evidence that ongoing and appropriate treatment is associated with better functional outcomes in adulthood. These include better personal relationships, fewer car accidents and lower crime rates. However, adherence to medication may not be consistent. Factors associated with discontinuing treatment include poorer treatment response, indicating the importance of dose optimisation. Mental health services have an important role for individuals of all ages with ADHD, many of whom require ongoing treatment across the lifespan.

Models of care
The particulars of the process of transition to adult services will depend on the available services and the model of care. There is evidence that adult ADHD is responsive to stimulant medication, therefore any service must have some provision for medical input in order to be able to optimise care.

The two main models are:

a) management within specialised mental health teams, with transition from the child and adolescent mental health services (CAMHS) to the adult mental health services (AMHS);
b) management by specialised individual practitioners, usually paediatricians or psychiatrists, with transition from a paediatrician or child psychiatrist to an adult psychiatrist.

These models may also involve the general practitioner (GP), who may share the ongoing care. The limited published data on transition in ADHD suggests that each of these models may fall short of the ideal of a smooth transition to appropriate, ongoing care for the young adult with ADHD. A third model that avoids the need for transition is:

c) care by a single specialist or service treating individuals with ADHD across the lifespan.
Transition to specialised AMHS

For childhood ADHD, management guidelines generally recommend psychological intervention, with medication when significant impairment persists\(^ {11,12}\). This multidisciplinary management may be provided in a specialised CAMHS, who would continue care until the individual is either discharged or transitioned a comparable AMHS. In some regions the AMHS may not provide an equivalent service that follows on from the CAMHS. For example the AMHS may not accept young people with ADHD, or there may be a perception that the AMHS lacks the necessary expertise to treat ADHD\(^ {13,14}\). The TRACK study evaluated the transfer process from the CAMHS to the AMHS in six UK Mental Health Trusts using specific criteria that emphasised continuity of care\(^ {15}\).

The criteria stipulated a formal plan, which included arranging a meeting with at least one clinician from each service, with discharge from the paediatric service only occurring after a transition period resulting in successful engagement with the adult team\(^ {15}\). For the majority of users, clinical practice fell short of this ideal, although in many cases it was the young person who rejected transfer and was referred back to primary care\(^ {13}\). A study of 18 Italian Regional ADHD Pediatric Centers (RAPC) found that 25% of adults aged 19-21 (95% pharmacologically treated) were still managed by the RAPC and only three (6%) had been referred to adult mental health services\(^ {16}\). The majority (69%) were being managed by their GPs although only 6% had been formally discharged from the RAPC.

Transition for young people with ADHD is often complicated by the scarcity of adult psychiatrists able and willing to treat them\(^ {17}\). This is a particular problem in rural Australia, where young people may be at higher risk of mental health disorders but have fewer services\(^ {18}\). The transition of adolescents and young adults with ADHD to AMHS may be hampered by a perception that ADHD is not really part of mainstream psychiatry. For example in Victoria the AMHS ‘are aimed primarily at people with serious mental illness,’ examples of which include schizophrenia, bipolar disorder, severe personality disorder, or severe anxiety disorder\(^ {19}\). In Queensland the state funded mental health services treat ‘common mental illnesses and disorders’ such as depression, anxiety, bipolar disorder and schizophrenia; the information given on ADHD relates only to children\(^ {20}\). The Strategic Plan for Mental Health in NSW 2014 – 2024, published by the NSW Mental Health Commission, actually states that 'developmental disabilities, such as attention deficit hyperactivity disorder (ADHD) ... are generally not within the scope of the Plan\(^ {21}\). Therefore individuals with ADHD transitioning to adult services may have their treatment options limited to psychiatrists practicing in the private sector.

Transition to individual psychiatrists

Although the multidisciplinary management of ADHD has been put forward as the ideal\(^ {12}\), in Australia most children are managed by paediatricians in private practice, often with the support of allied health therapists\(^ {22}\). As there is no adult equivalent of the behavioural paediatrician, a young person might expect transition from their paediatrician to an adult psychiatrist.

There is little published data on the transition from individual paediatric to adult specialists. However, prescribing data may provide indirect evidence of the effectiveness of transition. In NSW paediatricians are permitted to prescribe for children and young adults to the age of 25. In 2003 the proportion of currently treated
18-21, 22-24 and 25-29 year olds in NSW who had been on stimulant medication continuously for more than 9 years was 13.1%, 5.9% and 2.2% respectively. This is consistent with substantial attrition as individuals reach the age of transition.

Barriers to transition to private adult psychiatrists may include the expense of private fees. Adult psychiatrists may not be adequately trained in the management of ADHD or may choose not to prescribe stimulants. This can result in sub-optimal outcomes for individuals being treated for anxiety or depression by psychiatrists who fail to diagnose and treat the underlying ADHD. Similarly, stimulant medication may not be considered the appropriate treatment for those with substance abuse or antisocial behaviour.

The shortage of psychiatrists for transition of care can be alleviated by involvement of the GP. In NSW, care can be transferred to a GP after six months of treatment by a psychiatrist. However, this arrangement depends on the GP having ongoing support by the psychiatrist for changes in dose. In rural Australia, telemedicine may be well-accepted and considered preferable to the expense and difficulty of travelling large distances to access psychiatrists. However, telemedicine still depends on the availability of psychiatrists for consultation.

The way forward: unified ADHD services across the lifespan

Transition can be an expensive process in time and resources. It takes time for a new doctor or therapist to get to know a young person with ADHD and understand their problems. Transition might also involve a detailed re-evaluation of the diagnosis of ADHD, including a trial off medication, to give the treating psychiatrist or team an opportunity to assess the indications for continuing treatment. This whole process may be expensive, time consuming and potentially frustrating for the young person, which could explain why some decline transfer.

As ADHD is a condition which frequently requires continuous treatment extending over many years, it may be appropriate to consider a continuous service that caters for all ages, avoiding the need for transition. This is already provided by a limited number of specialists qualified in child, adolescent and adult psychiatry. These psychiatrists are also in a position to treat other family members, which may be useful given the heritability of ADHD. A trans-generational, family approach to ADHD would be able to address the difficulties that parents may have with being organised and consistent in their parenting, due to their own untreated ADHD.

Further research

Research into the views and experience of patients and clinicians is important for understanding how the current transition processes for ADHD can be improved. Regional variations in prescribing data might identify areas of particular need, perhaps highlighted by clusters of individuals stopping treatment once they reach the age of transition and subsequently restarting after failure.
Conclusion

Transition, occurring at a critical and potentially vulnerable stage of development, is a
time when the relationship with the treating doctor or team may provide much-needed
stability. Although many of the principles of successful transition of children and
adolescents with ADHD to adult services have been established, the available evidence
appears to indicate that in many regions, the resources and expertise are inadequate to
meet the demand. This may lead to retention within paediatric services, attrition from
specialised care, or discharge by default to the general practitioner, who may or may
not have the appropriate skills and support. The limited published studies appear to
indicate that adult ADHD is under-resourced. Furthermore, ADHD may not fit in well
with a model of psychiatric care that principally caters for discrete periods of intensive
intervention followed by discharge back to primary care. A more appropriate model
might consist of specialised services dedicated to the ongoing care of individuals of all
ages with ADHD. The way of the future may therefore be the generic ADHD specialist
who treats ADHD across the lifespan.

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