

Transfers and transitions between child and adult mental health services

Moli Paul, Tamsin Ford, Tami Kramer, Zobia Islam, Kath Harley and Swaran P. Singh

Background

Transfer of care from one healthcare provider to another is often understood as a suboptimal version of the process of transition.

Aims

To separate and evaluate concepts of transfer and transition between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS).

Method

In a retrospective case-note survey of young people reaching the upper age boundary at six English CAMHS, optimal transition was evaluated using four criteria: continuity of care, parallel care, a transition planning meeting and information transfer.

Results

Of 154 cases, 76 transferred to AMHS. Failure to transfer resulted mainly from non-referral by CAMHS ($n=12$) and refusal by service users ($n=12$) rather than refusal by AMHS ($n=7$). Four cases met all criteria for optimal transition, 13 met none; continuity of care ($n=63$) was met most often.

Conclusions

Transfer was common but good transition rare. Reasons for failure to transfer differ from barriers to transition. Transfer should be investigated alongside transition in research and service development.

Declaration of interest

None.

Healthcare transition has been described as ‘a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centered to adult-oriented healthcare systems.’¹ It may be one of a number of developmental transitions that young people face as they move through adolescence into adulthood. Healthcare transition planning and management are key elements in the organisation and delivery of health services.^{2–4} Transition is particularly important between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS),³ because failure results in service delivery being weak when the needs of young people are most pressing, as illustrated by other papers in this supplement.^{5–7} Transfer is often discussed as a suboptimal version of transition⁴ but, in our hypothesis, it is distinct from transition and should be investigated alongside transition. Transfer is the termination of care by a children’s healthcare provider and its re-establishment with an adult provider,⁸ i.e. more of an event or transaction between services. Transition is a process requiring therapeutic intent, which may be expressed by the young person’s preparation for transition, a period of handover or joint care, transition planning meetings (involving the young person and carer, and key CAMHS and AMHS professionals) and transfer of case notes or information summaries. Transition ultimately results in established engagement of the young person with adult services and therefore includes vital aspects of continuity of care.⁹

The TRACK study was a multistage, multicentre and multimethod study of adolescents’ transitions between CAMHS and AMHS, undertaken in the English National Health Service (NHS). It included an audit of the policies and procedures relating to transition,¹⁰ a case-note survey and organisational analysis,¹¹ and a qualitative study of the views of service users, carers and mental health professionals on the process of transition.¹² This paper analyses data from TRACK’s case-note survey of adolescents’ progression through CAMHS/AMHS boundaries in order to separate the concepts of transfer and transition and to evaluate each process.

Method

Full details of the study method have been published.¹³ This retrospective case-note survey was undertaken in six mental health trusts (NHS provider organisations): three in Greater London and three in the West Midlands. The West Midlands trusts merged during the study. Together these trusts deliver specialist mental health services, free at the point of delivery, to a socio-demographically diverse population of 8.1 million in urban and rural areas. All specialist (secondary care) CAMHS teams referring to local AMHS were included. Highly specialist tertiary services, e.g. condition-specific services with a national catchment area (such as specialist national eating disorder services), were excluded because of atypical populations served and logistical problems created by their interface with AMHS spread nationally. To identify a cohort of adolescents reaching the age boundary for transition to AMHS in the preceding year (from September 2003 in London, from January 2006 in the West Midlands) we intended to use service databases and cross-reference with CAMHS clinician-generated lists.

Separate data extraction tools, available online,¹³ were used for cases transferred to AMHS (CAMHS and AMHS notes) and those not transferred (CAMHS notes only). Data on sociodemographic, clinical, transition pathway and outcome variables were extracted. Two researchers independently extracted data from five transferred cases from a different trust to test interrater reliability. Comparing 491 non-text variables, the error rate was less than 2%. The data extraction tools collected information on presenting problems rather than diagnoses, because non-psychiatrists within multidisciplinary CAMHS do not always use diagnoses in their practice. Subsequently, presenting problems were independently assigned to seven diagnostic groups by three CAMHS psychiatrists (M.P., T.F. and T.K.). When required, discussion facilitated consensus. Comorbidity was defined as the presence of more than one diagnostic category. The diagnostic groups were serious and enduring mental disorders (including schizophrenia, psychotic disorders, bipolar affective disorder, depression with psychosis);

emotional/neurotic disorders (including anxiety, non-psychotic depression, post-traumatic stress disorder, obsessive-compulsive disorder); eating disorders (anorexia nervosa, bulimia nervosa, atypical eating disorder); conduct disorders (including other behavioural disorders); neurodevelopmental disorders (including pervasive developmental disorders, attention-deficit hyperactivity disorder, intellectual disabilities); substance use disorders (alcohol and/or drug misuse); and emerging personality disorder.

There were four criteria for optimal transition: continuity of care (either engaged with AMHS 3 months after transition or appropriately discharged); a period of parallel care or joint working between CAMHS and AMHS; at least one transition planning meeting, involving the adolescent, with or without a carer, and key AMHS and CAMHS professionals, prior to the handover of care; and information transfer (any of the following transferred from CAMHS to AMHS: referral letter, summary of CAMHS contact, CAMHS notes, a contemporary risk assessment). These criteria were developed from literature on continuity of care and CAMHS transition protocols.^{10,14}

The term 'cases' is used as only case notes were consulted. The term 'transferred' is applied to cases referred to and seen by AMHS, and the completed process of data extraction from case notes is referred to as 'tracking'. Wandsworth Research Ethics Committee approved the study.

Results

Databases did not exist at two sites and were poorly functional in relation to case ascertainment at four sites. Collating clinician-generated lists was a protracted process and, given the budget and time frame of the study, data extraction was completed on 155 of 186 cases identified in total. There was some variation between sites in relation to proportions of cases for which tracking was completed: 27/27 for London site 1, 50/60 for London site 2, 36/44 for London site 3; 5/5 for West Midlands site 1, 6/8 for West

Midlands site 2, 31/31 for West Midlands site 3. One case was excluded from subsequent analysis as transition was to a neurology service.

The sample consisted of 78 (51%) males and 76 females, with a mean age of 18.1 years (s.d. = 0.8) at the time of data collection. The majority ethnic group was White (31%), followed by Black (23%). No ethnicity was recorded in 27% of cases. The majority of individuals (76%) spoke English as their first language. Most adolescents lived with their parents (71%) and were in either education or employment (60%). Most presenting problems at the time of transition fell into the diagnostic category of emotional/neurotic disorders (51%, $n=78$), followed by neurodevelopmental disorders (25%, $n=38$), serious and enduring mental disorders (22%, $n=34$), substance misuse (9%, $n=14$), conduct disorders (4%, $n=6$), eating disorders (4%, $n=6$) and emerging personality disorder (3%, $n=4$). In five cases (3%) the presenting problem was not recorded. Almost a fifth had comorbidity (19%, $n=29$).

Transfer

Of the 154 cases that crossed the transition boundary (i.e. the age boundary between CAMHS and AMHS), 131 (85%) were thought suitable by CAMHS clinicians for transfer to adult services, 102 (66%) were referred and 90 (58%) were accepted by AMHS (Fig. 1). In 76 (49%) cases, at least one appointment at AMHS was attended, i.e. transfer was achieved. The reasons for non-referral to AMHS were refusal by the adolescent or parents/carers; CAMHS clinicians thinking AMHS would not accept the referral or had no appropriate service; or CAMHS still planning to refer to AMHS. Adult mental health services refused to accept 7 (5%) and a decision by AMHS was pending in 5 (4%) cases.

Table 1 summarises what happened to the 90 cases referred to and accepted by AMHS. Seven (8%) had no appointment arranged, for reasons including non-response to AMHS attempts to arrange the appointment (3%, $n=3$), the adolescent's

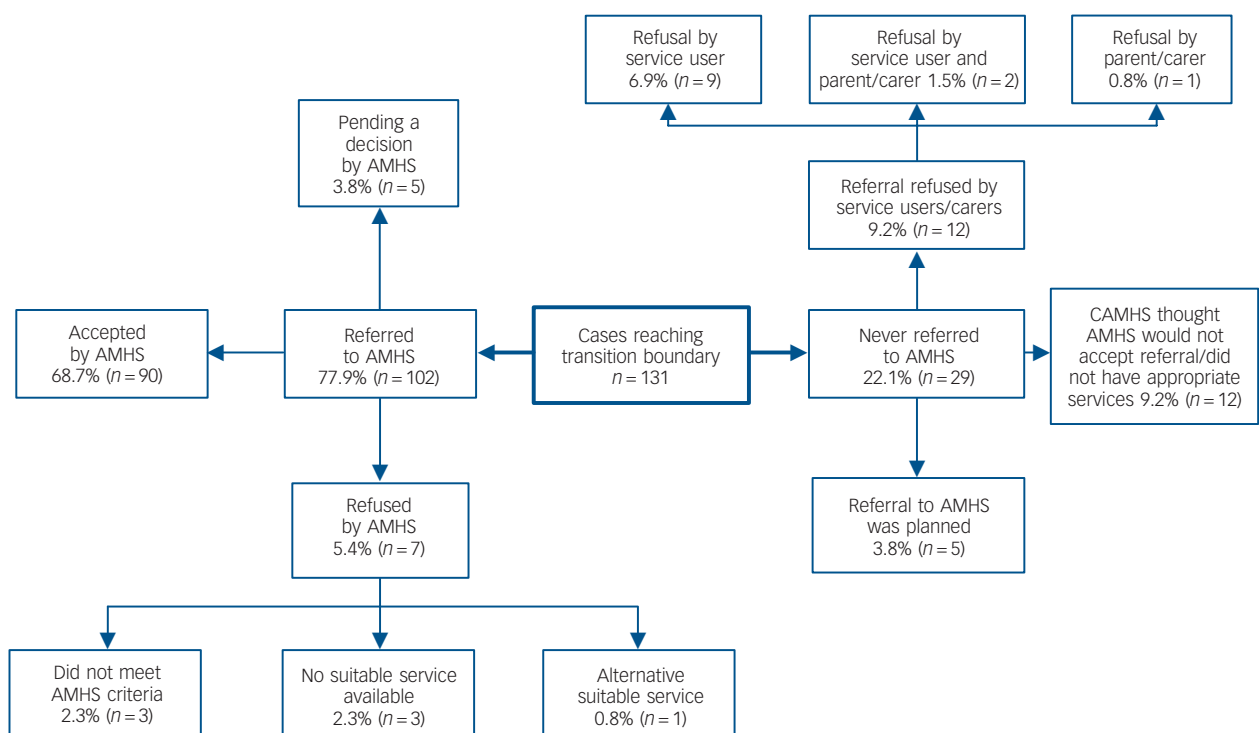


Fig. 1 Crossing the transition boundary between child and adolescent mental health services (CAMHS) and adult mental health services (AMHS) with ongoing clinical need.

Table 1 What happened to cases accepted by adult mental health services

	Cases accepted by AMHS (<i>n</i> = 90) <i>n</i> (%)	Cases offered appointments by AMHS (<i>n</i> = 83)		
		Initial assessment appointments attended <i>n</i> (%)	Subsequently offered assessment appointments attended, <i>n</i> (%)	Any assessment appointments attended <i>n</i> (%)
Appointment arranged	83 (92)	63 (76)	13 (16)	76 (92)
Appointment not arranged	7 (8)	NA	NA	NA
Subsequent contact				
Attended follow-ups	58 (64)	50 (60)	8 (10)	58 (70)
Discharged	15 (17)	12 (15)	3 (4)	15 (18)
Disengagement followed by a return to care under mental health legislation	1 (1)	1 (1)		1 (1)
Discharge followed by a return to care under mental health legislation	1 (1)		1 (1)	1 (1)
Lost to follow-up	1 (1)		1 (1)	1 (1)
Failure to attend appointments offered	7 (8)			

AMHS, adult mental health services; NA, not applicable.

disengagement with CAMHS (1%, *n* = 1) and administrative failure (3%, *n* = 3). Of 83 initial AMHS appointments offered, 63 (76%) were attended. In 20 (24%) of the 90 cases accepted by AMHS the person did not attend the first appointment offered. Of these, 16 were offered second appointments and 4 discharged. Only a quarter of the 16 second appointments were attended. The remaining 12 were offered a third appointment, 9 of which were attended. No fourth appointment was offered. The adult service succeeded in seeing 13 of 20 cases (65%) where the initial appointment was not attended. Transfer was therefore achieved in 92% of cases offered appointments by AMHS, 84% of cases accepted by AMHS, 74% of cases referred by CAMHS and 58% of cases crossing the transition boundary with ongoing clinical need. By the end of the study, of the 131 cases crossing the transition boundary with ongoing clinical need, 60 (46%) remained open to follow-up by AMHS and 15 (12%) had been discharged following attendance at AMHS.

Transition

Among the 90 cases accepted by AMHS, the element of optimal transition most often met was continuity of care (70%, *n* = 63), followed by having had at least one transition planning meeting (40%, *n* = 36), good information transfer (27%, *n* = 24) and a period of parallel care (24%, *n* = 22). No criterion for optimal transition was experienced in 13 (14%) cases, only one criterion in 33 (37%), two criteria in 24 (27%), three in 16 (18%) and all four criteria in 4 (4%) cases. In the four cases that met criteria for optimal transition, two of the individuals were male, three were 18 years old at the time of transfer and one was 19, and all four were from ethnic minority backgrounds. Three had a diagnosis of a serious and enduring mental disorder and had been admitted to hospital at some point while attending CAMHS (two under mental health legislation). All four were on medication at the time of transition and came from London (two each from London trusts 2 and 3).

Discussion

In our sample more than five-sixths of young people leaving CAMHS were thought to have ongoing clinical need. Transfer of care was common but good transitional care was rare. Many individuals transferred successfully to AMHS without experiencing good transitional care. Transfer failed more often because of young people's refusal to accept referral to adult

services, and CAMHS clinicians' failure to refer, than AMHS refusing to accept referrals or discharging young people who did not attend the first appointment offered; the latter two reasons have been assumed to be the main reasons in the past.^{15,16} The majority of transferred adolescents experienced continuity of care but other elements of good transition such as transition planning meetings, periods of joint care and good transfer of information were far less frequent. Transfer does not, therefore, guarantee successful transition. Moreover, poor transition, in the context of successful transfer, does not necessarily bode ill: TRACK's case-note survey and qualitative study findings indicate that despite suboptimal transitions most young people stayed engaged with AMHS and reported improvement in their mental health.^{11,12} Small sample sizes indicate that further investigation of the relevance of key elements of good transition to better outcomes is necessary. The requirement for a better-quality, more generalisable evidence base is reiterated by recent reviews of the broader paediatric to adult transitions literature.^{17,18}

Transfer

On the whole transfers were found to be successful in this study, although a small minority of those referred were not accepted by AMHS. An Australian study of a CAMHS with different referral criteria, however, found that many adolescents were not accepted by a youth mental health service (for 15–24 year olds).¹⁹ One of the two main reasons for a quarter of the TRACK cases with ongoing clinical need failing to be transferred was CAMHS clinicians thinking that AMHS would reject the referral or would not have appropriate services. We cannot say whether these assumptions, based on experience or knowledge of AMHS referral criteria, were correct. We can say that the majority of those referred to AMHS in this sample were accepted and, by the end of the study, almost three-quarters of transferred cases remained open to AMHS, sometimes following multiple offers of an 'initial' appointment. Overall, more cases were 'not referred' than 'not accepted'. Making referrals based on need, regardless of assumptions about whether adult services will accept them, may highlight the types of adult service that are inadequate or non-existent. This should aid the development of appropriate services for young adults.

A second reason for failure to transfer despite ongoing need was the young person's refusal to be referred to AMHS. Future research, policy and service development should separate cases of young people who fail to transfer for other reasons from cases

of those who (or whose parents) choose not to engage with adult services even though professionals think this would be of benefit. Some young people or parents/carers might prefer private or voluntary sector care. Lack of transfer to AMHS is therefore not necessarily equivalent to needs remaining unmet. We do not know, however, what proportions find alternative suitable care, and we need to remain concerned about those who fail to transfer to AMHS.

Poor adherence to health supervision around the time of transition is also noted in relation to young people with chronic physical health problems such as diabetes.²⁰ Disengagement with services may result from developmental characteristics such as emerging autonomy and distrust of authority figures, changing family relationships and heightened influence by peers alongside young people's need to acquire many life skills,²¹ or concerns about confidentiality, knowledge about and accessibility of the service proposed.²²

Equitable, accessible, acceptable, appropriate and effective youth-friendly services, as promoted by the World Health Organization (WHO),²³ or separate youth services, as suggested by user-oriented research,²⁴ might help with acceptance of referral to adult services. There remains debate, however, about whether separate youth mental health services are preferable.^{25,26} There may be specific reasons why young people and carers are reluctant to be seen at AMHS, such as stigma²⁷ and lack of insight into some mental health problems.²² Also, some young people do not seek help for mental health problems, are not referred to CAMHS,²⁸ or disengage with the service; adult services may therefore need to engage adolescents who never engaged with CAMHS. Push and pull factors remain important beyond the transition boundary between CAMHS and AMHS – for instance, the proportion of young people receiving public mental health services in the USA declines from the age of 17 years, and only a quarter of those aged 18–20 years who want services receive them.²¹

Transition

Our study provides evidence of extremely poor quality of transition: less than 5% of transfers fulfilled all four criteria of optimal transition. This is despite the use of tight definitions of transition and continuity of care, the latter compatible with the wider literature.^{9,14} A broader definition of transitional care for young people with serious mental health conditions was used in a study from the USA of transitional services providing options such as supported housing, vocational support, preparation for independent living and the availability of dual diagnosis services, e.g. mental health and substance misuse services.²⁹ It found that a quarter of child and a half of adult State mental health systems offered no transitional service of this broad type. Most options were available in less than 20% of states.²⁹

The paediatric evidence base has produced guidance on how to 'do' transition well, for instance, by focusing on the 'four Ps' of people (the young person, parents or caregivers, a transition coordinator and keyworker, interested adult services, primary care, multidisciplinary/multi-agency networks and professional training), process (written transition policy, transition programmes, and evaluation and audit), paper (informational resources and administrative support) and place (youth-friendly spaces).³⁰ It highlights paediatric and adult service staff needs for training and attitudinal changes towards each other's services, while young people need to be trained and empowered to become effective partners in their own transition.³¹ Addressing transitions in education and employment, adolescent health (fertility and sexual health), ethical and legal issues (consent, competence and

autonomy) and societal factors (health inequalities and urban/rural differences) at the time of transition between paediatric and adult services may also be key.³² This might indicate the need for generic adolescent health services rather than condition-specific (e.g. psychosis-specific) or youth mental health services.

This analysis of the TRACK data indicates that transition and transfer are related, but different, processes. Differences have implications for services, which are seeking to improve experiences and outcomes for individuals crossing the paediatric/adult service interface, and for researchers, in relation to the methodology of future transitions research. Transfer can be of use even if transition has been poor;¹¹ transition processes and policies may be followed impeccably yet still result in failure to transfer (e.g. if the patient chooses not to go to adult services for some reason). There may be barriers to transfer that are quite different from barriers to transition. Services and researchers need to address both aspects.

Limitations of the study

There were significant problems in case ascertainment. Databases either did not exist or could not provide accurate and suitable information. This reflects the poor level of data collection (at the time) in the NHS. Information technology has a low priority within the NHS, which is funded from a public service budget, with no need to bill for individual contacts, as in private practice or insurance-dependent services. Some clinicians felt too busy to provide relevant information, some could not be contacted because of high staff turnover, and some could not accurately recall appropriate cases because of high case-loads. Some case notes were difficult to locate or access. Clinicians might be most likely to recall cases where transition had been problematic. Even if every unascertained case had an ideal transition, we still document a worrying number of poor experiences. Also, case notes may not accurately reflect the quality and content of services delivered. The population studied was large and diverse, making findings generalisable to other services in the UK. The main conclusion of this paper, that future service development and research need to explicitly address barriers and facilitators of both transfer and transition, should be of interest to those working in different service structures internationally.

Moli Paul, MRCPsych, PhD, University of Warwick, Warwick Medical School, Coventry; **Tamsin Ford**, MRCPsych PhD, Peninsula Medical School, University of Exeter; **Tami Kramer**, MRCPsych, Imperial College London, St Mary's Campus, London; **Zoebia Islam**, PhD, University of Warwick, Warwick Medical School, Coventry; **Kath Harley**, DClinPsy, South London and Maudsley National Health Service Foundation Trust, London; **Swaran P. Singh**, FRCPSych, DM, University of Warwick, Warwick Medical School, Coventry, UK

Correspondence: Dr Moli Paul, Room B153, The Medical School Building, Gibbet Hill Campus, University of Warwick, Coventry CV4 7AL, UK. Email: moli.paul@warwick.ac.uk

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