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The Great Divide: Transition of Care from Child to Adult Mental Health Services

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Abstract

Purpose of the review: Adolescents with mental health problems often require transition of care from child and adolescent (CAMHS) to adult mental health services (AMHS). This review is a synthesis of current research and policy literature on transition to determine the magnitude of the problem, barriers at the interface between CAMHS and AMHS and outcomes of poor transition.

Recent Findings: Adolescence is a risk period for emergence of serious mental disorders. CAMHS and AMHS use rigid age cut-offs to delineate service boundaries, creating discontinuities in provision of care. Adolescent mental health services are patchy across the world. Several recent studies have confirmed that problems occur during transition in diverse settings across several countries. In physical health, there are emerging models of practice to improve the process and outcomes of transition, but there is very little comparable literature in mental health care.

Summary Poor transition leads to disruption in continuity of care, disengagement from services and is likely to lead to poorer outcomes. Some young people, such as those with neurodevelopmental disorders and complex needs, are at a greater risk of falling through the care gap during transition. Services need robust and high quality evidence on the process and outcomes of transition so that effective intervention strategies can be developed.

Key words:

Transition, Adolescent mental health, Continuity of care, Child mental health services

Introduction

There has been long standing concern about young people with mental health problems getting lost to care in their move (transition) from child and adolescent mental health services (CAMHS) to adult mental health service (AMHS). Despite the obvious importance of ensuring continuity of high quality care during transition, there is very little evidence about the magnitude of the problem, outcomes of individuals who fall through such care gaps, interventions that might improve the process, and the experience of service users and carers about transition. This review summarises recently published research evidence and policy documents (2006-2008) on transitions from CAMHS to AMHS, drawing parallels from selective transition literature in physical conditions.

Adolescence as a 'Risk Period'

The journey into adult life is a time of profound physiological, psychological and social change for young people and their families. Overall rates of mental health problems in young people increase during adolescence, problems become more complex, and serious disorders such as psychosis emerge. Besides being a risk period for higher psychological morbidity, adolescents also have greater propensity for risk-taking behaviours, falling between child and adult services, and being at greater risk of disengagement from services [1].

Young people with mental health problems have very high rates of long-term morbidity and mortality [2]. A recent UK survey found that 10% of 5 to 16-year-olds have a mental health disorder [3]. Overall, at least one in four to five young people will suffer from at least one mental disorder in any given year [4]. Comorbidity is also

common in adolescence, both in terms of psychiatric disorder and additional problems; and comorbidity among those attending CAMHS is likely to be even higher [5, 6]. The *Breaking the Cycle* report [7] found that 98% of young adults (16- to 25-year-olds) accessing services in the UK had more than one problem or need. Common comorbid problems included homelessness, problems associated with leaving care, lack of training/education opportunities, barriers to employment, crime, poor housing, drug and alcohol misuse and learning disability. Mental health problems in adolescence also predict problems in adulthood [1, 8]. The National Comorbidity Survey Replication in the USA found that 75% of people with a mental disorder had an age of onset younger than 24 years [9]. Several recent studies provide additional support that there is phenomenological continuity in mental disorder from childhood to adult age including in bipolar disorders [10], functional somatic symptoms [11] and personality disorders [12].

Defining transition

The concept of transition has two distinct meanings: developmental transition and healthcare transition. From a developmental perspective, adolescence is a crucial stage of emotional, psychosocial, personal and physiological developments as young people embark on adult roles through tasks such as separating from family, deciding on a career path and defining self in a social context. From a healthcare perspective, young people with ongoing health problems have to move from one service to another upon reaching certain age milestones. These two transitions usually occur simultaneously, but needs related to developmental transition may remain unmet if transition is seen simply as an administrative healthcare event [13]. Transition is

often too focused on service transfer rather being part of a holistic process of moving to adulthood and independence [14].

Adolescence: Stage or Age?

Adolescence is a developmental stage, rather than something defined strictly by age [15]. However, services and policies are often demarcated by rigid age boundaries. There is a lack of consensus on where CAMHS ends and AMHS begins [1, 16]. In the UK, some services use age cut-offs between 16 and 18 years while others consider CAMHS appropriate only for those in full-time education [16]. In its surveys on mental health, the UK National Office for Statistics groups 16 and 17-year-olds with adults and those aged 15 and under as children, with no separate category for adolescents [17]. It has been argued that services should consider the health and developmental needs of two groups, children under 12 years and young people between 12-24 years [4]. An alternative view, often made explicit in transition policies, is that while all age-based boundaries are ultimately arbitrary, there should be flexibility around transition based upon developmental needs of the service user [16]. Such a flexible approach may be intended in policy, but in practice busy teams struggling with complex loads often use rigid age boundaries as a way of managing capacity and restricted caseloads rather than providing what is in the best interest of the service user.

Magnitude of the problem

Child psychiatry has emerged relatively recently as a sub-specialty, and adolescent focus is an even newer concern [4, 18]. CAMHS and adult services differ in their theoretical and conceptual views of diagnosis, aetiology and treatment focus and have quite different service organisation and professional training. These differences accentuate the problems at their interface, creating barriers in transition [19]. These barriers cut across local healthcare economies; transition problems occur in diverse health care systems across different continents [1, 16, 18, 20-22] .

A recent large US study examined the patterns of mental health service use by persons of transition age (16-25 years) based on nationally representative 1997 Client/Patient Sample Survey and population data from the US Census Bureau [23]. The annual rate for inpatient, outpatient, and residential services was 34/1,000 for 16- and 17-year-olds and 18/1,000 for 18- and 19-year-olds. This confirms a precipitous decline in service utilisation just at the time when serious mental health problems are beginning to emerge. The authors recommended that resources should be specifically targeted towards shared planning between CAMHS and AMHS to facilitate continuity of care for young adults who are 'aging out' of CAMHS, as well as for those who experience their first episode of mental disorder in early adulthood.

In the USA, a survey of transition provision within 41 states found that a quarter of child mental health services and half of adult services offered no transition support. Another US study [24] found that continuity of care was hampered by separate child and adult mental health systems, marked by separate policies for access, lack of clarity in access procedures and lack of shared planning. A recent study from Australia found that many young people referred by CAMHS were not accepted by AMHS, despite having substantial mental health needs and functional impairment [20]. Despite several policy initiatives [25-27], CAMHS in England and Wales

continue to have problems in ensuring optimal transition of care [1, 16, 19]. With few arrangements in place for young people negotiating transition boundaries, some slip through the care net only to present to adult services later on, by which time they may have developed severe and enduring mental health problems [28].

Transition in Physical Health

Advances in medical care have led to increased life expectancy for young people with chronic illness or physical disability [29-32]. This in turn has led to higher numbers crossing over from paediatric to adult care;, yet transition-related research is sparse even in physical disorders [31, 33]. A recent review of transitions in diabetes reported that published studies have major limitations imposed by small sample sizes and selection bias. The review confirmed that a significant proportion of young people were lost to follow-up during the transition process. There was some evidence that implementing an educational transition programme, having a transition care coordinator and having a transition clinic attended by both adult and paediatric physicians improved clinic attendance [34] .

A recent US survey highlighted the concerns of general physicians about transition for young adults with childhood-onset conditions. These concerns clustered into six distinct categories: patient maturity, patient psychosocial needs, family involvement, provider's medical competency, transition coordination and health system issues. Adult specialists felt that paediatricians were reluctant to let go of their cases; and considerable concerns were raised about patients autonomy versus caregiver involvement [31]. Transition problems seem to cut across specialities and diagnostic

categories and embody common challenges for child and adult services across the healthcare spectrum [35].

McDonagh [15] has identified several barriers to optimal transition in physical disorders. These include changes in established, long term therapeutic relationships between young people and health professionals; differences between adult and child models of care; young people's level of maturity and understanding; differing perceptions of the adult care system; adolescent resistance to transfer; family stressors; inadequate education and training for adult care providers on adolescent disorders; and lack of organisational support. This could easily be a list of transition problems in mental health care. McGorry [18] has argued that "public mental health services have followed a paediatric-adult split in service delivery, mirroring general and acute health care. The pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest".

Transition from CAMHS to AMHS: UK Findings

A recent national review of CAMHS provision in the UK found that transition from CAMHS to AMHS caused major concerns to service users, carers and clinicians [27]. Many 16 to18 year olds did not get support and care during transition. Young people with ongoing mental health problems that did not amount to serious mental disorders were specifically excluded from adult services; this group included those with ADHD and behavioural problems. There were a few examples of good practice around the country, including specific transition workers, transition services and services such as early intervention in psychosis that operated astride the CAMHS-AMHS divide. The

review concluded that services should flexibly focus on needs rather than chronological age but recognised that such changes had significant resources and training implications.

A more recent multisite multi-methods study of transition policies, practice, procedures and outcomes in England (The TRACK study) has published its first paper [16]. Using a questionnaire to determine transition policies and practice across Greater London, the study found that most CAMHS had existing transition protocols to guide the process. Protocols were largely similar in their stated aims and policies, but differed in several key procedural details, such as joint working between CAHMS and AMHS and whether protocols were shared at trust or locality level. An enduring mental health problem was considered a key criterion for individuals requiring transition. However, many disorders that fell outside of this criterion, such as neurodevelopmental disorders (ADHD, Autism Spectrum Disorder, mild to moderate learning disability) and emotional/personality related problems were likely to fall through the care net. All protocols emphasised that service users' involvement should be central in transition planning and implementation, yet no protocol specified how users should be prepared for transition. A major omission from protocols was procedures to ensure continuity of care for patients not accepted by AMHS. The TRACK study is due to publish its final report in April 2009.

Despite policy documents and initiatives, there are still unacceptable variations in service provision for young people with mental health problems, both between regions and within local areas in the UK, leading to inequalities of care provision [27]. The challenges at the interface between CAMHS and AMHS are not all the responsibility of CAMHS services. These require strategic collaboration between all agencies providing care for adults and children and range from specific local

arrangements between CAMHS and AMHS for transition policies, the development of pathways to care and treatment protocols at the interface, to broader national initiatives to improve workforce capacity and training.

Neurodevelopmental disorders

For children with disabilities transition from childhood to adulthood is more problematic, and transition for young people with mild to moderate learning disability is particularly complex. They may not meet the eligibility criteria for either the Adult Learning Disability Service or the Adult Community Mental Health Team, yet require ongoing support and psychiatric intervention. This also occurs commonly with high-functioning young people with an Autism Spectrum Disorder or Asperger syndrome, especially in the absence of clear-cut comorbid psychiatric disorder [1, 16]. There is also growing recognition of inadequate services for young people with Attention Deficit Hyperactivity Disorder (ADHD) [36]. Only about a fifth of community paediatricians in the UK have access to dedicated clinics for adults with ADHD [37].

Young people in special circumstances

Many young people in special circumstances (such as the Looked After or those leaving Local Authority care; the homeless) and from certain minority groups such as asylum seekers may be particularly vulnerable to mental health problems. Pathways and access to mental health care are particularly problematic for people from Black and Minority Ethnic background [38, 39]. Such groups may not access either CAMHS or AMHS [28] both because of the stigma of mental illness and the perception that services are not culturally appropriate [40]. Others, such as those with a forensic history or with significant risk to others have complex needs and yet

may not meet eligibility criteria of community services. These groups are particularly vulnerable to problems during transition [1].

The effect of poor transition

The most disruptive outcome of poor transition is that young people with ongoing needs disengage from services during the transition process. Disengagement from mental health care is in many cases a major problem,[41] with socially isolated adolescents at the greatest risk of dropping out of treatment [42]. The most vulnerable therefore are at greatest risk of dropping out of care. Young people are also less likely to collaborate with clinicians about their treatment, partly because many feel that they do not have an adequate 'say' in the care they receive [43]. Poor transition simply adds to the risk of such disengagement.

In mental health care, young service users and their carers often have very different perspectives on treatment goals and outcomes from those of clinicians. Additionally, when young people turn 18 mental health services are no longer obliged to involve their parents or carers in treatment due to the assumed autonomy of the 'adult' service user. Studies show that families feel left out of the treatment process following transition and involving families collaboratively reduces the risk of disengagement as well as carer distress [e.g. 44].

Conclusion

While everyone seems to agree that good quality transition from CAMHS to AMHS is a crucial aspect care provision, the phenomenon itself is rarely studied. There are significant gaps in our knowledge about the process, outcomes and experience of transition from CAMHS to AMHS. We do not convincingly know who makes such a

transition, who falls through the care gap, what are the predictors and outcomes of successful transition, how the process of transition is experienced by users, carers and clinicians, and what organisational factors facilitate or impede successful transition. Without such evidence, we cannot develop and evaluate specific service models that promote successful transition or plan future service development and training programmes.

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