

An evidence synthesis of risk identification, assessment and management for young people using tier 4 inpatient child and adolescent mental health services

Short title: The risk study in CAMHS (RiSC)

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Scientific Summary

Title

An evidence synthesis of risk identification, assessment and management for young people using tier 4 inpatient child and adolescent mental health services.

Background

Inpatient child and adolescent mental health services (CAMHS) are one part of a complex system, and exist to meet the needs of young people with the greatest difficulties.

Objectives

The overarching research question was: ‘What is known about the identification, assessment and management of risk (where ‘risk’ is broadly conceived) in young people (aged 11-18) with complex mental health needs entering, using and exiting inpatient child and adolescent mental health services in the UK?’

Objectives for the overall project were:

1. To summarise and appraise the evidence for the identification, assessment and management of risk for young people: as they make the transition into inpatient CAMHS; as they are cared for in inpatient CAMHS; as they make the transition from inpatient CAMHS to the community; and as they make the transition from inpatient CAMHS to adult mental health services.
2. To identify and describe any underlying theoretical explanations for approaches used in the identification, assessment and management of risk.
3. To understand the views and experiences of risk of young people (11-18 years) with complex mental health needs using inpatient mental health services, and of those involved in the identification, assessment and management of risk in these settings.
4. To synthesize the evidence for the identification, assessment and management of risk in young people (aged 11-18) with complex mental health needs entering, using and exiting inpatient services.

5. To synthesize the evidence on the costs and cost effectiveness to the NHS of different approaches to identifying, assessing and managing these risks.
6. To identify the future priorities for commissioning, service development and research for young people (aged 11-18) with complex mental health needs entering, using and exiting tier 4 inpatient services.

Methods

The two-phase Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) approach to evidence synthesis was used. This stresses the importance of transparency and rigour, and effective engagement with concerned people typically through work with a stakeholder advisory group.

In phase 1 searches were made using Medline and PsycINFO to scope English language citations at the intersection of young people, mental health, inpatients and risk. No attempts were made to assess the quality of materials. An end date for these searches was March 2013. A series of descriptive maps were produced summarising this phase.

A collaborator working for the national charity YoungMinds conducted five consultative conversations with young people previously admitted to inpatient CAMHS. Conversations were recorded, and young people were asked to identify risks which the project team should focus on in the in depth phase of the project. A summary of these conversations was written up. A similar consultative conversation took place with the mother of a child who had been in hospital.

Participants at a project team/stakeholder meeting, independently chaired and held in April 2013, included: project team members; the collaborating representative from YoungMinds (who had previously completed the series of consultation conversations); young people with experiences of using child and adolescent mental health services; practitioners; and a senior managers. Phase 1 descriptive maps were presented, and a presentation given drawing on the consultations with young people. Informed by the principles of nominal group technique participants generated independent lists of the risks for young people making the transition into, through and out of inpatient mental health care. These were collated and displayed.

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Participants then ranked, in writing, their personal priorities for the categories of risk to take forward into the second, in-depth, phase of the project.

Individually generated, ranked, phase 2 priority categories of risk were put alongside the carer priorities previously identified and a composite list of priorities from the YoungMinds consultation. Items were coded and themed, and a list of ranked priority risk categories created. A summary document was produced and circulated for a final round of comments.

The concept of 'dislocation' was introduced by the project team to describe the first priority risk category for phase 2. The second priority risk category was 'contagion'. Phase 2 centred on the search, appraisal and synthesis of English language citations relating to the risks to young people in these areas. A final search strategy comprised three arms, and had high sensitivity: (1) young people; (2) mental health and (3) inpatient. Searches were made using the following databases, with time limits from 1995 to September 2013: EconLit; ASSIA; BNI; Cochrane Library; CINAHL; ERIC; Embase; HMIC; Medline; PsycINFO; Scopus; Social Care Online; Social Services Abstracts; Sociological Abstracts; OpenGrey; TRIP Plus; Web of Science. Members of the team reviewed all citations retrieved and manually identified those also addressing the risks of dislocation and contagion, from which any papers also addressing costs and cost effectiveness could simultaneously be located. Government and other websites were searched, a call for evidence was circulated and references of included citations were reviewed.

All types of evidence relating to outcomes, views and experiences, costs and cost-effectiveness, policies and service and practice responses in the areas of 'dislocation' and 'contagion' for young people (11-18 years) using inpatient mental health services were considered. A staged approach to screening and selection of citations was used, involving all members of the project team. Data from included citations were extracted into tables formatted following guidance issued by the Centre for Reviews and Dissemination or tables developed for the purpose of the review. Quality was assessed using one of a number of agreed appraisal checklists from the Effective Public Health Practice Project, the Critical Skills Appraisal Programme or devised by previous published reviewers. No papers were

excluded on the grounds of quality alone, and all materials identified were brought together in a series of narrative syntheses.

Results

In the phase 1 scoping an initial 4,539 citations were found, from which 124 were finally included. These were displayed in a series of maps focusing on ‘harm to self’, ‘suicide’, ‘harm to others’, ‘longer-term risks found at follow up’, ‘early disengagement from services’, ‘risk factors influencing admission and length of stay’, ‘predictors of restraint or seclusion’, ‘risk of harm from the system’, ‘responding to and managing risk’ and ‘other’.

In phase 2 an initial 15,662 citations were found, from which 40 were finally included. These were supplemented by 20 supporting policy and guidance documents. Included materials were brought together in a series of individual syntheses. Each focused on a priority risk category. Materials were synthesised in narrative fashion, using a series of broad risk categories directly reflecting the project’s phase 2 priorities and a series of sub-categories derived from the material retrieved.

The categories and sub-categories were: *Dislocation: Normal Life* [i) Everyday life and interactions in hospital ii) Missing out on life outside and transition home]; *Dislocation: Identity* [i) Mental health problems as identity-changing ii) Responding to threats to identity]; *Dislocation: Friends* [i) Relationships with young people outside hospital ii) Relationships with young people in hospital]; *Dislocation: Stigma* [i) Young people’s experiences during admission ii) Young people’s experiences post-discharge]; *Dislocation: Education* [i) Education provision and facilities ii) Quality of inpatient education iii) Academic progress iv) Re-integrating with school post discharge]; *Dislocation: Families* [i) Impact on family relationships ii) Family involvement iii) Maintaining contact with families]; and *Contagion* [i) Experiences of contagion ii) Evidence of contagion].

In the areas of risks to normal life and identity policy and guidance was sparse but did recognise that young people undergoing treatment within inpatient settings should be able to lead as normal a life as possible. Views and experiences were reported in rich detail and

young people and health care professionals described boredom, stringent ward rules and

routines and a lack of opportunity for everyday interactions. Feeling separated from life outside and the subsequent difficulties experienced on returning home were identified as pressing issues by some young people and health care professionals. Young people with eating disorders talked about mental health problems eroding their identities, along with the experience of not being treated as individuals. For other young people it was a struggle to manage threats to the sense of self during admission and treatment. There were no intervention studies found which focused on the testing of actions to mitigate the risks to normal life or to identity.

In the case of risks associated with friendships and peer relations policy and guidance is limited to making recommendations on inpatient units having space for visitors. The evidence included in this segment of the project pointed to the difficulties (and ambivalence) young people can experience in maintaining home friendships at a distance and in reconnecting with their friends after discharge. In some cases connections with friends were significantly associated with levels of post-discharge depression and suicidal ideation. No intervention studies were found investigating actions to help young people in hospital maintain good relations with their peers at home. Evidence was found pointing to young people's positive views of being with others in a similar position during hospital care and treatment, in terms of mutual support and companionship. Young people also spoke of the negative aspects of living with other young people with mental health difficulties. Some parents were found to be concerned about their children's sharing of living space with other vulnerable people and at least some young people expressed ambivalence (and even fear) in their relationships with other inpatients. No studies were found investigating actions to promote positive peer relations amongst young people who were inpatients.

Managing the risks of stigma and discrimination are high priorities for policymakers. Young people felt that stigmatising experiences can occur as a result of being admitted, as well as during their inpatient stay and at discharge. Being with similar young people can also lead to feelings of acceptance, in contrast with the experience of being rejected in the community.

No intervention studies were found evaluating actions to mitigate the risks of stigma or discrimination to young people admitted to mental health hospital.

Hospital admission poses risks to young people's schooling. Health care professionals, parents and young people all recognise the importance of educational provision with appropriate facilities for young people in inpatient CAMHS, which is also identified as a policy and guidance priority. Smaller class sizes utilising a multi-class format with specialist teaching has been shown in a study involving young people in an RTC in the US to be effective in increasing the amount of work young people are able to produce whilst in hospital. In the UK education is provided as standard across inpatient units, but in a majority of hospitals only core national curriculum subjects are taught. Improving quality and maintaining good communication and coordination across hospitals and schools feature prominently in policy. Within units in the UK varying teacher/student ratios are found in NHS and non-NHS units, and good (but not universally so) relations between parents and teachers have been reported.

One of the disadvantages of inpatient care recognised in policy and guidance is the effects of admission on family life. Training inpatient staff working with young people and their families through the use of role plays or mindfulness did not have a significant impact on the family friendliness of the admission process. Whilst on an inpatient unit young people often feel homesickness and experience a range of negative feelings. Associations between family connectedness and post-discharge depression and suicidal ideation have been reported. Some family members need additional support during their children's admission.

Partnership with families during inpatient care is strongly recommended in policy and guidance. Young people whose parents do get involved make significant improvements across a range of treatment and post discharge outcomes but health professionals report that a number of obstacles exist to enable this to take place.

Whether families are fully involved in a young person's care or not the evidence suggests that units should have procedures on visiting and that flexible arrangements should be made for family contact. A particular risk of family dislocation is reported in instances where young people are admitted to hospitals located far from home, in terms of keeping in touch and cost.

For some, the quality of care at inpatient units is considered to be more important than the distance from the hospital to the family home. Some young people also appreciate being away from the home environment.

The risks of young people in hospital learning harmful behaviours was a priority area for phase 2 of this project, but no policy or guidance was found addressing this. Health professionals and parents have concerns about young people acquiring unhelpful, destructive, behaviours whilst they are inpatients. Young people with eating disorders very quickly copy the behaviour of those around them with the same condition. There is mixed evidence of recorded contagion in inpatient mental health facilities for young people, with no fixed definition of what constitutes 'contagion'. No evidence was located investigating actions to mitigate the risks of contagion in inpatient settings.

None of the studies reported above included an economic analysis or an economic evaluation of alternative ways of identifying, assessing and managing less obvious risks for young people using inpatient CAMHS. The data derived from these studies could not be used to inform an economic modelling exercise of likely NHS costs and cost effectiveness analysis.

Limitations

Included studies were of variable quality. Limitations of the review were the search for English language-only materials, and a further potential limitation related to the use of umbrella terms and concepts ('dislocation' and 'contagion'). Degrees of interpretation were needed in the identification of evidence judged to make a contribution to knowledge in these broad, constructed, areas.

Conclusions

This review has focused on a series of 'less obvious' risks which are important to people with stakes in the child and adolescent mental health system, but about which little evidence exists. Service providers need to pay close attention to the identification, assessment and management of these less obvious risks but a programme of research is needed to generate new knowledge underpinning the best ways of doing this.

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Plain English Summary

In our two part study we brought together evidence in the area of risk for young people admitted to mental health hospital. First we searched two electronic databases, finding 124 articles. Most were concerned with clinical risks, such as the risks of suicide. Using diagrams we grouped these articles together under a number of themes.

Young people who had been inpatients in mental health hospital, carers, managers and professionals helped us prioritise the types of risk we should concentrate on in the second part of our study. Our top two priorities were the risks of dislocation and contagion. We used the word 'dislocation' to refer to the risks of being removed from normal life, of experiencing challenges to identity and of being stigmatised. We used it to refer to the risks to friendships and to families, and to education. We used 'contagion' to refer to the risks of learning unhelpful behaviour and making unhelpful friendships.

We searched 17 databases and a large number of websites for evidence in these areas. We asked hospital staff to send us information on how they managed these risks and we searched journals and reference lists. We identified 40 items to include in our review and 20 policy and guidance documents. The quality of the studies varied. We grouped the evidence together under seven categories.

We found little evidence to guide practice. The risks of dislocation and contagion are important, but research is needed to inform how staff might identify, assess and manage them.

Plain English summary word count: 249