Developing a model of mental health self-care support for children and young people through an integrated evaluation of available types of provision involving systematic review, meta-analysis and case study

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Scientific summary

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Background

The mental health of children and young people (CYP) is a major public health concern in the UK. Around one in five CYP will have mild to moderate mental health problems; around 1 in 10, a diagnosable mental disorder.

Regarding the delivery and organisation of mental health services for CYP, recent policy reviews suggest that service provision is not always as comprehensive, consistent or effective as it could be, nor is it especially responsive, accessible or child centred. There is, therefore, clear scope for improvement in the delivery and organisation of mental health services for CYP in England and Wales. This study explores the potential of self-care support in enhancing such service provision.

There is a notable amount of research and literature on self-care support in long-term physical health conditions, both in adult and, to a lesser extent, children's services. There have also been some inroads in adult mental health. For example, the recent growth in self-help for common mental health problems has been captured by England's Improving Access to Psychological Therapies (IAPT) initiative. There has also been National Institute for Health Research (NIHR)-commissioned research work on self-care in adult mental health, and the emphasis on 'recovery', which maps well onto a framework of self-care, is a key philosophy of contemporary adult mental health care. The role that self-care support can play in the mental health of CYP is a largely unexplored area. It is not known, for example, whether or not self-care support interventions and services are being commissioned and provided in England and Wales, nor whether there exists a substantive body of literature in this area.

The need for this study was thus based on three principal factors: the relative paucity of research on mental health self-care support for CYP; the potential to change and enhance service provision in this area, to the benefit of both the NHS and the service user; and its capacity to build upon and complement existing work on CYP's mental health, including work already carried out by members of the study team.

Aims and objectives

The aims of the study were to identify and evaluate the types of mental health self-care support used by, and available to, CYP and their parents, and to establish how such support interfaces with statutory and non-statutory service provision.

These aims were operationalised via a series of specific objectives, namely:

1. the provision of a descriptive overview of mental health self-care support services for CYP in England and Wales, including a categorisation of these services according to a self-care support typology developed in a previous study
2. an examination of the effectiveness of such services
3. an examination of the factors influencing the acceptability of such services to CYP and their parents
4. an exploration of the barriers to the implementation of mental health self-care support services for CYP
5. an exploration of the interface between such self-care support services and the NHS and other statutory and non-statutory service providers, in order to guide future planning in health and social care
6. the identification of future research priorities for the NHS in this area.

Methods

The study comprised an evidence synthesis combined with primary research, conducted as two overlapping stages over a 2-year period. Stage 1 consisted of two inter-related elements that ran concurrently: (a) two systematic reviews of the literature (an effectiveness review and meta-analysis, and a perceptions review); and (b) the mapping of self-care support services in CYP's mental health across England and Wales. Stage 2 involved a case study of service provision and involved empirical research at six case study sites chosen to represent a 'typology' of self-care support that emerged from the service mapping exercise.

Stage 1a (literature reviews)

Data sources

MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, All Evidence-Based Medicine (EBM) Reviews, Applied Social Sciences Index and Abstracts (ASSIA) and Education Resources Information Center (ERIC), searched from January 1995 to July 2011.

Study selection (inclusion criteria)

Population

Children and young people, defined as those under the age of 18 years. Studies with populations that included young people up to 25 years of age were included so long as there was evidence that the mean age of participants was, or the majority of participants were, under the age of 18 years.

Interventions

Any health, social care or educational intervention or service designed to support or facilitate CYP (or their parents) to take action to promote their mental health, prevent mental ill health, or maintain or enhance their mental health and well-being following recovery from mental ill health.

Comparators

For the effectiveness review, we were unsure whether or not we would find sufficient trials with a control or other such comparison group and so did not specify a comparator at the outset. Since the perceptions review was concerned with absolute, rather than relative, service user views of specific self-care support interventions and services, this aspect of the Population, Interventions, Comparators, Outcomes and Study (PICOS) designs framework was disregarded for the perceptions review.

Outcomes

For the effectiveness review, included studies needed to contain a valid standardised mental health measure. Where available, a range of relevant secondary outcomes (measures of general functioning, general well-being and self-esteem, for example) were considered. For the perceptions review, qualitative and quantitative data that captured service user or service provider views rather than outcomes per se.

Study design

For the effectiveness review, initially studies containing trials, with 'trial' being defined as any study in which there was, at minimum, a relevant pre- and post-intervention outcome measure. However, sufficient randomised controlled trials (RCTs) were available to restrict the effectiveness review solely to RCTs. For the perceptions review, any empirical study (qualitative or quantitative) in which service user and/or service provider views about any element of the self-care support intervention or service were available.

Data extraction and quality assessment

For both reviews, data were extracted by two independent assessors and any disputes were referred to a third reviewer for arbitration. For the effectiveness review, data were quality assessed using the concealment of allocation element of the Cochrane risk of bias tool. For the perceptions review, qualitative data were quality assessed for inclusion via an appraisal tool used in a previous NIHR study. Quantitative

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perceptions data were obtained from satisfaction surveys nested within trials of which there were several hundred; in order to manage the number of quantitative perceptions studies, we used the PICOS criteria from the effectiveness review as a quality filter.

Data synthesis

For the effectiveness review, the principal data synthesis was meta-analysis, with the primary outcome measure being a measure of CYP's mental health symptomatology. For the perceptions review, the qualitative and quantitative elements data were analysed independently before being integrated, along with the effectiveness review and meta-analysis results, into an overall mixed-methods synthesis.

Stage 1b (service mapping)

Data sources

Contacts and networks deemed to have potentially relevant information about current services, augmented by an internet search. In addition, any English or Welsh services identified during the literature reviews stage.

Service selection (inclusion criteria)

For consistency, the same population and intervention definitions from Stage 1a were used, although the term 'services' replaced 'interventions'. Additional inclusion criteria were that the service had to operate in England and Wales and that it had to be 'live' during the 9-month data collection period, October 2011 to June 2012.

Data extraction and selection of services

Basic details of potential services obtained from any source were logged by a study team member who obtained any necessary further information by telephone or e-mail. When there was sufficient information to make a judgement on inclusion, the service was discussed with a second team member and a decision was made on its inclusion in the service map.

Stage 2 (case study)

Design

A collective case study involving six case study sites selected from those identified in the mapping exercise.

Participants

A purposive sampling strategy was used to select both the case study sites and the participants at each site. Fifty-two participants (17 CYP, 16 family members and 19 staff) were interviewed across the six case study sites.

Research ethics

A favourable ethical opinion was obtained through a National Research Ethics Service (NRES) proportionate review in March 2012. Two substantial amendments needed to be made and were approved during the lifetime of the project. All identifiable participants received an age-appropriate information sheet informing them of the study's nature and purpose. Written consent was obtained from all adult participants. In line with NRES guidance, all CYP participants aged 15–17 years provided their own written consent. Parents provided written consent for children under 15 years old, although written assent was also obtained from these children. At each case study site, all specific research governance requirements were adhered to.

Data collection and analysis

Data were obtained through semistructured interviews, documentary review and virtual non-participant observation and, wherever possible, from all three participant categories: CYP, parents and staff. The data were analysed using the framework method.

Results

Stage 1a (literature reviews)

Seventy-one studies were included in the effectiveness review; 65 were meta-analysable. These 65 studies elicited 71 comparisons which, when meta-analysed, suggested that self-care support interventions were effective at 6-month [standardised mean difference (SMD) = –0.20; 95% confidence interval (CI) –0.28 to –0.11] and 12-month (SMD = –0.12; 95% CI –0.17 to –0.06) follow-ups, though the generally low quality of the studies considered and asymmetry in the funnel plots means that this statement has to be made with reservations. Regarding specific dimensions of self-care support that might influence the effectiveness of an intervention, there is some evidence that individual interventions may have an advantage over group interventions; that those delivering and facilitating interventions need not necessarily be trained in mental health; that more contact time with the self-care support agent may be beneficial; and that the setting of the intervention (home, school, etc.) is largely irrelevant.

Key elements of self-care support identified in the perceptions review were the acquisition of knowledge and skills, peer support and the relationship with the self-care support agent. CYP also had different perceptions from adults about what is important in self-care support.

Stage 1b (service mapping)

The mapping exercise identified 33 self-care support services across England and Wales, delivered by 27 providers. Almost all of the services targeted CYP; only a few targeted parents or the family as a whole. Around two-thirds of providers were in the voluntary sector. Few services were condition-specific and no particular theoretical approach dominated the services. A wide variety of professional and lay people facilitated the services. A typology of self-care support from a previous NIHR study was modified on the basis of the service mapping data and the literature reviews, the modifications pertaining principally to the provider of the intervention or service, the process of self-care and the platform through which it was delivered.

Stage 2 (case study)

Themes arising from the case study were: having a mental health problem; providing self-care support; accessing self-care support; and facilitating self-care support. A common feature across all the case study sites was the perceived accessibility of the services provided. The services appeared to offer convenient locations and appointment times and to maintain engagement with between-session support, and were staffed by people who were caring and compassionate. Where barriers were mentioned, they tended to be discussed in the context of criticisms of standard NHS and local authority services and were broadly related to the inflexibility of those services. In addition to flexibility, effective mental health self-care support services for CYP appeared to be built on straightforward access; positive staff and organisational attributes that are non-judgemental and welcoming; the provision of time and attention; the chance to learn and practise skills relevant to self-care; and systems of peer support which include opportunities to share experiences and practical tips. The interface of the self-care support service with other statutory and non-statutory services worked best in relation to referral; though only a few services had extremely well-integrated referral pathways, all had some degree of interface, even if it was as simple as merely signposting into, or out of, the self-care support service, or using networks among the sectors to promote self-referral.

Conclusions and implications

This study makes a contribution to the knowledge base by being the first to formally explore self-care support in the context of CYP's mental health, an area that is generally under-researched. Through two inter-related systematic reviews, a mapping exercise and a case study, the aims of the study have been achieved. In achieving these aims, a model of self-care support is proposed that can help policy-makers and practitioners make decisions about the organisation and delivery of mental health self-care support for

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CYP, and help researchers identify gaps in the knowledge base. Key features of this model include its conceptualisation as a long- rather than short-term process, involving the acquisition of knowledge and skills, which require input and motivation on the CYP's or parent's part; opportunities to practise and consolidate these requisite skills, with support and facilitation from a self-care support agent; and some identifiable positive outcomes for the child or young person and his or her family.

Recommendations for future research in this area include work on the potential for self-care support in the more serious mental health problems of psychosis, eating disorders and self-harm; research into the use and role of technology in self-care support; more work on unpicking the factors associated with satisfaction in self-care support services; work exploring the role of readiness and leadership in self-care support; research on how self-care is conceptualised in CYP's mental health, in particular its links to concepts such as recovery and resilience; conducting a more systematic and comprehensive mapping exercise; work on the cost-effectiveness of providing self-care support in CYP's mental health; and more research testing interventions and services in real-life environments.

The following observations provide some implications for policy and practice.

- Self-care support in CYP's mental health requires a partnership between service providers, the CYP and those who provide care for them.
- CYP and their families want ongoing support from, and contact with, services.
- The means by which professionals can support CYP and their families to self-care is not generally considered in the education and training of those working in child and adolescent mental health services.
- Effective services need not necessarily be delivered by mental health-trained staff or by NHS organisations (it being the child-centred skills and attributes of the individuals and organisations that are important).
- Choice and flexibility are important aspects of self-care support in CYP's mental health.
- Practitioners working in CYP's mental health rarely consider readiness to engage with a service or commence an intervention.
- Outcomes other than those relating to mental health symptoms need to be considered.

Study registration

This study is registered as PROSPERO number CRD42012001981 (for the effectiveness review).

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