

Interventions to improve the mental health of children and young people with long-term physical conditions: linked evidence syntheses

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Scientific summary

Mental health of children with long-term physical conditions

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Scientific summary

Background

Having a long-term physical condition (LTC) places a strain on children and young people (CYP) and their families. Having a LTC can adversely affect the mental health and well-being of CYP, which can in turn affect aspects of the physical condition such as treatment adherence and symptom severity. The overall risk of diagnosed mental health difficulties is reportedly around four times greater in CYP with LTCs than in their physically healthy counterparts. Although an extensive evidence base informs guidelines for the treatment of mental health disorders in CYP generally, there is a lack of evidence focusing on the treatment of mental health in CYP with LTCs. Therefore, we aimed to address this gap by conducting two linked evidence syntheses and integrating the findings from these two reviews in an overarching synthesis.

Objectives

Two systematic reviews and an overarching synthesis of these reviews were conducted:

- Review 1 aimed to evaluate the clinical effectiveness and cost-effectiveness of interventions aiming to improve the mental health of CYP with LTCs and elevated symptoms of mental ill health.
- Review 2 aimed to explore the factors that may enhance or limit the delivery of interventions aiming to improve the mental health and well-being of CYP with LTCs.

The overarching synthesis aimed to integrate the findings from reviews 1 and 2 using a deductive approach.

The project aimed to integrate end-user involvement throughout the project in the form of input and feedback from topic experts, CYP with LTCs and their parents, as well as consultation on preliminary findings with a range of interested parties.

Summary of review 1

Methods

Thirteen electronic databases were searched: MEDLINE, EMBASE, PsycINFO, Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CENTRAL), Database of Abstracts of Reviews of Effects (DARE), Health Technology Assessment (HTA) database, NHS Economic Evaluation Database (NHS EED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), British Nursing Index, Health Management Information Consortium (HMIC), Conference Proceedings Citation Index and Science Citation Index. This was supplemented with forward and backward citation-chasing, searches for sibling articles, website searching, author contact and searches for grey literature.

Two independent reviewers were involved in study selection, data extraction and quality appraisal. The inclusion criteria specified randomised controlled trials (RCTs) or economic evaluations involving CYP aged 0–25 years with LTCs and symptoms of mental ill health. A LTC was defined as any diagnosed physical health condition with an expected duration of at least 3 months for which a cure is considered unlikely and which results in limitations in ordinary activities and necessitates the use of medical care or related services beyond what is usual for someone of the age of the affected individual. Participants needed to have received an intervention that targeted their mental health, but there was no restriction on the type of

intervention. Clinical effectiveness had to be measured in terms of impact on at least one measure of the young person's mental health.

Interventions and outcomes of included studies were categorised. Effect sizes for each study were calculated post intervention using Cohen's *d*. When multiple studies considered the same intervention type, a similar comparator, similar participant LTC and the same outcome category, random-effects meta-analysis models were fitted to pool effect sizes (*d*) across the studies.

Findings

A total of 25 RCTs (31 articles) that assessed the clinical effectiveness of interventions aiming to improve the mental health of CYP with LTCs and elevated symptoms of mental ill health were synthesised. These studies evaluated 11 types of intervention, sampling CYP with 12 different types of LTC. Outcomes were organised into 28 categories, 17 of which related to CYP's mental health; the rest were categorised as 'other outcomes'. Of the 11 reported interventions, the greatest volume of research focused on the clinical effectiveness of cognitive-behavioural therapy (CBT), with 10 papers (reporting on seven studies) evaluating this type of intervention. These studies provide tentative evidence that CBT-based interventions could be beneficial for the mental health of CYP with inflammatory bowel disease (IBD), chronic pain, epilepsy and persistent functional somatic complaints, but not type 1 diabetes mellitus (T1DM). Some of the clinically effective CBT interventions featured content that was adapted to the specific LTC prior to intervention delivery. Four parenting programme interventions were evaluated in three studies. Group play therapy interventions were also assessed in three studies. Other intervention types were seen in only one or two studies. Trials were typically small, meaning that effect sizes across the included studies were characterised by wide confidence intervals. Therefore, the evidence for particular interventions used with similar samples of CYP is very limited. There were relatively few opportunities for meta-analysis.

Review 1 highlighted the lack of trials aiming to address the issue of mental ill health in CYP with LTCs. In particular, there were no relevant trials in the UK. The quality of the relatively small number of studies was generally poor. The quality of future research in the field should therefore be improved. Although findings from review 1 are tentative, there was some support for the findings from previous research.

The findings of review 1 point to the need for large, high-quality trials with consistency in intervention, design and outcome reporting. The development of manualised interventions would allow for rigorous testing of interventions across a range of conditions and locations and would aid comparison of the components of different interventions. It would be particularly useful to examine whether or not broad intervention types are effective across a range of LTCs, including whether or not (and how) they should be adapted to specific LTCs. Although we included studies of interventions aiming to improve mental health, the majority also targeted other outcomes, particularly LTC symptoms. Therefore, future research might consider integrated treatment and its effects across a wider range of outcomes, rather than focus primarily on mental health in terms of population, intervention and outcome.

Summary of review 2

Methods

The databases MEDLINE (including MEDLINE in-process), PsycINFO, and CINAHL were searched. This was supplemented with forward and backward citation-chasing, searches for sibling articles, author contact, website searching and searches for grey literature.

Two independent reviewers were involved in study selection, data extraction and quality appraisal. The inclusion criteria specified primary qualitative studies that explore attitudes and experiences regarding interventions aiming to improve the mental health and well-being of CYP with LTCs from the perspectives of CYP, their families and/or practitioners. Data analysis and synthesis broadly followed the principles of metaethnography.

Findings

In review 2, 57 studies were synthesised, evaluating 21 types of intervention, a broader range than seen in review 1. The LTC most frequently examined in the 57 included studies was cancer. Studies involving participants who were human immunodeficiency virus (HIV) positive or participants with a variety of LTCs were common, which differs from review 1. Included studies commonly explored the perceptions and experiences of interventions aimed at improving coping, self-esteem and emotional support rather than targeting symptoms directly related to a mental health disorder such as depression or anxiety. Interventions often aimed to improve symptoms related to the LTC and social skills as well as mental health constructs. Included studies represented views from a range of different participants involved in the delivery and receipt of relevant interventions.

We used metaethnography to synthesise the included studies. The synthesis was presented as five main constructs: 'a therapeutic foundation', 'social support', 'a hopeful alternative', 'resilience' and 'getting in and staying in'. A number of themes contributed to each construct. We developed a line of argument that offers an explanatory model of the experience of interventions to improve the mental health of CYP with LTCs.

The model describes the process by which CYP with LTCs access and maintain engagement with a relevant mental health intervention. Some interventions helped CYP to acquire a sense of hope for the future and increase their resilience. Interventions were often perceived to be effective when they offered participants a safe space and social support. The relationship between these constructs is tentative, as other factors may affect the experience of interventions and participants' attitudes.

The quality of included articles was generally good. At least 10 high-quality articles contributed to each theme in the synthesis. The general weaknesses in this literature included a failure to make the theoretical perspective of the author explicit and to adequately describe the context or setting of qualitative research and a lack of clarity in the description of interventions.

We believe that this is the first attempt to examine the experiences of CYP with LTCs receiving interventions that aim to improve their mental health. However, our synthesis shares features with some previous literature. We identified only one study in which qualitative data collection and analysis occurred alongside a RCT; there is a need for this type of mixed-methods evaluation to improve our understanding of how interventions are experienced and how this may link to effectiveness. Our synthesis suggests that availability, access and engagement with interventions are crucial, and that physical and mental health difficulties can pose unique challenges. Other aspects of interventions, such as social support, relationships with those who deliver interventions and hope for the future, are considered important by the range of people who received and deliver these interventions.

Summary of the overarching synthesis

Methods

The overarching synthesis integrated the findings from review 1 and review 2. A deductive approach was used whereby questions based on the findings of each review were generated and used to interrogate the other review for information that could potentially inform the findings or explain gaps in the literature. Despite the different research questions, mental health inclusion criteria, methods of synthesis and types of interventions seen across the two systematic reviews, the overarching synthesis allowed us to raise a number of tentative implications.

Findings

Nine categories emerged from the analysis:

1. degree of overlap between the two reviews
2. availability of up-to-date, good-quality research

3. what works for whom
4. adaptations to interventions and flexibility
5. accessibility and delivery
6. stress and coping
7. working with family and peers
8. therapeutic relationships
9. holistic approach.

There was a limited amount of overlap between the reviews, particularly when focusing on interventions used for particular populations. Much of the research included in both reviews was published in the 10 years prior to the review, but there was a relative lack of studies conducted in the UK, and we were unable to identify any clinical effectiveness studies. Although there is some evidence of benefit for interventions in CYP with particular LTC populations, for example CBT in populations with IBD, neither the quantitative nor the qualitative evidence can go further to explain why this may be or suggest how intervention clinical effectiveness may vary between individuals.

There is some evidence from both reviews that interventions responding to the needs of individuals, particularly in relation to their LTC, may be beneficial. An intervention's setting, use of technology and flexibility can have an impact on perceived clinical effectiveness and it may be valuable to consider how such issues affect clinical effectiveness. Alongside symptoms of mental health disorder, the overarching synthesis indicated elements of interventions that may support CYP to manage stress and coping related to their LTC. There was evidence from both reviews that interventions that include family, particularly parents, may be beneficial. Interventions that enable CYP to meet peers with similar health needs also appears to have more benefits than disadvantages. There is an indication that relationships between CYP with LTCs and their therapists and peers are important. Although both review 1 and review 2 include interventions that aim to improve mental health in some way, the majority of interventions also targeted other outcomes including LTC symptoms, social support, knowledge and self-management.

Discussion and conclusions

In review 1, the lack of similarity in terms of the combination of interventions, LTCs and outcomes studied often meant a reliance on small trials for clinical effectiveness findings. Little meta-analysis of similar trials and no moderator analyses could be performed. This limited the strength of conclusions that could be made about intervention clinical effectiveness. Despite conducting an additional database search and targeted searches, no economic evaluations were located. No UK studies were included in review 1, therefore limiting the applicability of review findings.

None of the studies included in review 2 sampled participants with a diagnosed mental health disorder and only two considered the current mental ill health of participants on study entry. The number of CYP who received the interventions who were experiencing active mental health difficulties is uncertain, and this limits comparability with review 1. The overarching synthesis was challenged by the different inclusion criteria across review 1 and review 2. This may have partly explained the different intervention types seen in each review, which presented a challenge to comparison. Review 2 interventions were more often focused on improving coping, stress and self-esteem than review 1 interventions.

There is some tentative evidence that CBT may be beneficial in some of the LTC populations in which it has been evaluated. Further research on what specific methods are currently used within paediatric health-care services to recognise the mental health needs of CYP with LTCs, and their clinical effectiveness, would be useful in helping to plan future interventions to address this apparent need. The delivery of interventions in both reviews indicates that it may be possible to deliver mental health interventions outside clinical mental health settings. However, the training and support needs of intervention deliverers would need to be considered alongside the resources required for setting up and sustaining the intervention.

Given the importance of social support, relationships that CYP establish with those who deliver interventions, and with family members and peers, would seem to be an important component of interventions.

The findings of review 1 suggest the need for further large, high-quality, well-reported RCTs. In particular, improved reporting of the methods used to randomise participants and achieve allocation concealment, as well as blinding of outcome assessors, is required. Review 1 suggests that it would be useful to examine whether or not broad intervention types are clinically effective across a range of LTCs, including whether or not (and how) they could be adapted to specific LTCs. Interventions aiming to improve the mental health and well-being of CYP with LTCs often take a holistic approach; future research might therefore focus on integrated physical and mental health treatment and its effects across a wide range of outcomes, rather than focus primarily on mental health in terms of population, intervention and outcome.

Study registration

This study is registered as PROSPERO CRD42011001716.

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