

Effectiveness of resilience interventions for parents of children with complex care needs: a systematic review

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Citation

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Review question

(1) What is the effectiveness of interventions that aim to promote individual resilience in parents of children with complex care needs, compared to no intervention or a comparison intervention?

(2) Do these individual resilience interventions impact child health outcomes?

Searches

PsycINFO, PsycArticles, EMBASE, CINAHL, MEDLINE (via PubMed), Cochrane Database of Systematic Reviews, and JBISIR. We will also search organizational websites, trial registries, and dissertation and theses databases for grey literature to include unpublished studies or ongoing studies/reviews, including NIH Trial registries, Cochrane Database of Systematic Reviews, Google Scholar, and Proquest Dissertations and Theses Global. All sources will be searched between August 2019 and August 2020 for articles in English, French, German and Arabic, with no restriction on publication date.

For PubMed:

((parent*[Title/Abstract] OR mother*[Title/Abstract] OR father*[Title/Abstract] OR maternal[Title/Abstract] OR paternal[Title/Abstract] OR caregiv*[Title/Abstract] OR guardian*[Title/Abstract]) AND (child[Title/Abstract] OR children[Title/Abstract] OR youth*[Title/Abstract] OR adolescent*[Title/Abstract] OR infant*[Title/Abstract] OR teen*[Title/Abstract]) AND (resilient*[Title/Abstract] OR resilience*[Title/Abstract] OR resiliency[Title/Abstract] OR "resilience training"[Title/Abstract] OR hardiness[Title/Abstract] OR Hardy[Title/Abstract]) AND (intervention*[Title/Abstract] OR programs[Title/Abstract] OR program[Title/Abstract] OR RCT[Title/Abstract] OR "randomized control trial"[Title/Abstract] OR "randomized clinical trial"[Title/Abstract] OR "randomized trial"[Title/Abstract] OR therapy[Title/Abstract] OR therapies[Title/Abstract] OR training[Title/Abstract] OR treatment*[Title/Abstract] OR "psychological intervention"[Title/Abstract]))

Types of study to be included

This review will seek to include all randomized controlled trials (RCTs) evaluating the efficacy of individual resilience interventions for parents of CCCN because they are ranked as the highest level of evidence available for intervention effectiveness. In the absence of RCTs, we will include other study designs, such as quasi-experimental studies (non-RCTs) and observational studies (with or without a comparator). This pragmatic approach will ensure the inclusion of the best available evidence within our review. Eligible study designs may be before and after studies and interrupted time-series studies, cohort studies (prospective or retrospective), case-control studies, and cross-sectional studies. Eligible studies will be empirical, using quantitative or mixed methods (i.e., qualitative and quantitative), so long as there is one quantitative measurement of resilience (discussed in main outcome).

Condition or domain being studied

Children with complex care needs (CCCN) is a hypernym for infants, children, and youth whose medical, technological, social, emotional, educational, or nutritional needs exceed that of the general population of children, and who often require extra health and/or other professional care, often from multiple care providers

at different locations. CCCN is an emerging term encompassing both severe and non-severe, chronic and non-chronic physical and mental health needs.

Participants/population

Parents of children with complex care needs (CCCN): "Parents" = biological parents, adoptive parents, guardians, and primary caregivers. "Children with complex care needs" = infants, children, youth with multidimensional health, social and/or educational needs beyond those required by general population of children; may include one more physical, mental, behavioural, neurological, and/or developmental conditions or disabilities.

To be included in the review, the child's or youth's age must be between 0 and 25 years. There are no restrictions on the diagnosis (including a lack of diagnosis), so long as the child has complex care needs, as per the definition above. The included intervention studies in this review may also support the children, but the primary target of the individual-focused interventions must be the parents. Finally, there are no restrictions on parental or child demographics (e.g., age, gender, ethnicity, SES, condition type).

Intervention(s), exposure(s)

This review will consider studies that will evaluate the effectiveness or efficacy of an intervention, program, treatment, therapy, or service aimed at parents where a specific goal/aim of the study was to improve, enhance, or develop individual resilience. There are no restrictions on the nature of the intervention (e.g., medical, psychological, pharmacological, complementary and alternative medicine (CAM), social, spiritual, or nutritional in nature) so long as it includes at least one validated measure of individual resilience (discussed in main outcome).

Comparator(s)/control

There may or may not be a comparator in the included studies. In cases of a comparator for the parents or children, there will be no restriction on the type of this comparison group (e.g., placebo, standard care, no treatment, matched, or unmatched control group).

Main outcome(s)

The primary outcomes will be the parents' resilience, as measured by a valid instrument of individual resilience. For both primary and secondary outcomes, positive negative, and neutral outcomes will be included.

* Measures of effect

A valid measure of resilience is defined by Joyce et al.'s (2018) criteria: First, the measure must assess a person's "ability to adapt to change" (Joyce et al., 2018), cope effectively in the face adversity, and avoid negative adjustment patterns (Joyce et al., 2018; Mullins et al., 2015). This may include their ability to maintain positive or better than average wellbeing despite difficult circumstances and their ability to "bounce back" from hardships (Masten & Powell, 2003; Moyle et al., 2010; Tugade & Frederickson, 2004). Second, the measure must be psychometrically sound (reliable and valid) whilst adhering to our definition above. As Joyce et al. (2018) determined a priori, examples of reliable and valid measures of individual resilience may include the Connor-Davidson Resilience Scale (CD-RISC), the Brief Resilience Scale and/or the 14-item Resilience Scale.

Additional outcome(s)

The secondary outcomes will be the child's physical and mental health outcomes. as measured by quantitative or qualitative assessments relevant to the child's care needs. For both primary and secondary outcomes, positive negative, and neutral outcomes will be included.

* Measures of effect

Measured by quantitative or qualitative assessments relevant to the child's care needs.

Data extraction (selection and coding)

Data will be extracted from the eligible studies by two independent reviewers (LM, RA) using the standardized JBI data extraction tool. Extracted data will include specific details about the population, sample size, study methods (e.g., type of trials, designs, comparators), interventions, and outcomes of resilience measures and child health outcome measures. Disagreements that may arise between reviewers

will be resolved through discussion. If no consensus is reached, a third reviewer will be consulted. Authors of papers will be contacted to request missing or additional data, where required.

Risk of bias (quality) assessment

The Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach for grading the certainty of evidence will be followed and a Summary of Findings (SoF) will be created using GRADEPro GDT (McMaster University, ON, Canada). The SoF will present the following information where appropriate: absolute risks for the treatment and control, estimates of relative risk, and a ranking of the quality of the evidence based on the risk of bias, directness, heterogeneity, precision and risk of publication bias of the review results. The outcomes reported in the SoF will be: (1) the change in the resilience outcome of parents according to the resilience measurements and (2) any quantitative effects on the child's health according to the appropriate measurements (e.g., blood-glucose levels), where possible.

Strategy for data synthesis

Studies will, where possible, be pooled in statistical meta-analysis using JBI SUMARI. Effect sizes for resilience outcomes will be expressed as either odds ratios (for dichotomous data) or and weighted (or standardized) final post-intervention mean differences (for continuous data) and their 95% confidence intervals (CI) will be calculated for analysis. Due to the heterogeneity of health outcome indicators across health conditions, child health outcomes will be synthesized in a narrative form. Statistical heterogeneity will be assessed using the standard chi squared and I squared tests. Statistical analyses will be performed using the random effects model (Tufanaru et al., 2015). Sensitivity analyses will be conducted to test whether decisions such as including youth over the age of 18-19 or including lower-quality studies will significantly impact the results. Where statistical pooling is not possible, the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate. To assess the risk of publication bias (when there will be 10 or more studies included in the meta-analysis), we will use statistical tests for funnel plot asymmetry (Egger test, Begg test, Harbord test) where appropriate (i.e., Egger's test with continuous data; Harbord and Begg tests with dichotomous outcomes, as odds ratios). Additionally, to visually illustrate the presence of asymmetry, we will generate a funnel plot, which will plot effect sizes against a measure of variance (e.g., standard errors).

Analysis of subgroups or subsets

There are no planned subgroup analyses, but subgroup analyses will be performed if there is sufficient data.

Contact details for further information

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Type and method of review

Intervention, Meta-analysis, Systematic review

Anticipated or actual start date

31 August 2019

Anticipated completion date

31 August 2020

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Conflicts of interest

Language

English

Country

Canada

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Child; Humans; Parents; Resilience, Psychological

Date of registration in PROSPERO

16 December 2019

Date of first submission

20 August 2019

Stage of review at time of this submission

| Stage | Started | Completed |
|---|---------|-----------|
| Preliminary searches | Yes | Yes |
| Piloting of the study selection process | Yes | Yes |
| Formal screening of search results against eligibility criteria | No | No |
| Data extraction | No | No |
| Risk of bias (quality) assessment | No | No |
| Data analysis | No | No |

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

16 December 2019

PROSPERO

This information has been provided by the named contact for this review. CRD has accepted this information in good

faith and registered the review in PROSPERO. The registrant confirms that the information supplied for this submission is accurate and complete. CRD bears no responsibility or liability for the content of this registration record, any associated files or external websites.