Health coaching for parents of children with developmental disabilities: a systematic review

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ABBREVIATIONS
ASD Autism spectrum disorder
RCT Randomized clinical trial

AIM To determine the level of evidence on the effectiveness of health coaching for parents of children with disabilities.

METHOD A systematic review approach, comprised of a comprehensive, librarian-guided literature search; transparent study selection and data extraction; quality assessment; and synthesis of sufficiently similar data (per population, intervention nature, and overall level of evidence for each outcome using standard definitions) was undertaken.

RESULTS Twenty-eight studies (13 randomized clinical trials) were included. Three health coaching approaches were identified: child-targeted (most commonly applied), parent-targeted, and a mixed approach. Overall, there is an insufficient-to-limited level of evidence regarding the effectiveness of these approaches.

INTERPRETATION High-quality clinical trials using the parent-targeted coaching approach are warranted.

Children with developmental disabilities are facing different functional challenges due to underlying deficits in cognitive, speech, motor, behavioural, and/or social abilities. This also negatively affects their parents and ensuing family dynamics. Increased parental stress, heightened incidence of parental mental and physical health challenges, such as depression and family ruptures are some of the known undesirable consequences. Currently, worldwide healthcare service models are not standardized nor are they nimble enough to address these caregiver challenges, resulting in long waiting periods, service gaps, and duplications in service delivery.

Health coaching is an educational, content-based, structured programme that could be delivered by different, more accessible, and possibly more cost-effective means (e.g. technology/online, group exchanges). Defined as the goal-oriented, client-centred partnership that is health-focused and occurs through a process of client-enlightenment and empowerment, this strategy has recently emerged with the potential to promote parental self-management and empowerment in the presence of their child’s emerging chronic disability. Coaching, applied to adult chronic health conditions and in the context of complex paediatric care, was shown to be effective in positively influencing health status, health behaviours, and costs. For parents of children with developmental challenges, coaching is an interactive process in which the programme promotes the: (1) caregiver’s ability, readiness, and advocacy skills to navigate the healthcare system; (2) child’s development and participation in everyday experiences and interactions with family members and peers across settings; and/or (3) learning self-management skills to address their own arising mental and physical health challenges.

Traditionally, coaching is provided in the presence of the child (i.e. coaching while treating). There is a potentially more cost-effective and accessible coaching method, where it is applied to the parent (or group of parents), without the child’s presence. This particular delivery model is increasingly being implemented, studied, and advocated for as an alternative to the traditional method. To the best of our knowledge, however, there is currently no indication as to its actual cumulative effectiveness and the level of evidence of this approach (without the child’s presence) in improving parent and/or child-related outcomes.

As a preliminary step towards establishing best-practice guidelines and further advance research in this field, the purpose of this paper is to report the findings of a systematic literature review conducted to identify the existing health coaching programmes (without the child’s presence) for parents of children with developmental disabilities and...
to describe: (1) the constituents of employed strategies; (2) the impacts/effectiveness of such programmes on parent-related outcomes; and (3) the factors that potentially influence implementation and effectiveness of such programmes. The following question presents the main objective of this review, in PICO (Population, Intervention/exposure, Comparison, and Outcome) format: among parents of children with developmental disabilities (P), how does a health coaching programme (I) versus no intervention or versus a comparison intervention (C) affect parent-related outcomes (O)? Where parents refers to mothers and/or fathers (biological, step, foster) or other designated primary caregiver(s) (e.g. grandparent, legal guardian); children with developmental disabilities refers to children (0–18y) with primary motor impairments (e.g. cerebral palsy [CP], muscular dystrophies, spina bifida, spinal muscular atrophies) and/or developmental behavioural/intellectual conditions (e.g. autism spectrum disorder [ASD], intellectual disabilities); health coaching (in the context of this review) refers to a programme that: (1) is standardized with a formal structure; (2) includes predefined, interactive, content-based education and a transformation programme (i.e. contains a ‘trial-and-feedback’ element, is interactive, where the participant receives feedback and support with regard to the trained/coached skill/ability); (3) intends to facilitate behaviour change by educating parents and challenging them to transform their goals into actions with respect to their child’s disability and/or their own mental/physical health status, advocacy skills, abilities to manage family dynamics, and relations with their child; and (4) is applied solely to the parent or groups of parents, without the child’s presence; and parent-related outcomes refer to parental stress, sense of self-efficacy, knowledge-base, mood/affect/ psychological symptoms, depression, and so on.

METHOD
The systematic literature review approach consisted of a comprehensive, librarian-guided literature search; transparent study selection and data extraction; quality assessment of the studies; and synthesis of sufficiently similar data per paediatric population, nature of the intervention, and outcome for overall level of evidence using standard definitions. The American Academy for Cerebral Palsy and Developmental Medicine guidelines for conducting the systematic review were used. All elements within these guidelines were applied, apart from outcomes classification using the International Classification of Functioning, Disability and Health, to avoid repetition. (i.e. most of the outcomes were classified as Body Functions and Structures [e.g. stress] or are currently not coded [e.g. parental sense of self-efficacy]).

Search strategy
Electronic databases
The electronic database search was performed on 2nd January 2018 (set as the end date unless otherwise specified by the database) using the following seven online databases: Ovid MEDLINE In-Process & Other Non-Indexed Citations, Ovid MEDLINE Daily and Ovid MEDLINE 1946 to Present; AMED (Allied and Complementary Medicine) 1985 to December 2018; Embase Classic and Embase 1947 to 29th December 2017; PsycINFO 1967 to fourth week December 2017; CINAHL Plus with Full Text; ERIC; Social Work Abstracts 1968 to December 2017. No start date limit was set on the search criteria of the databases, unless the database already had an existing start date.

Search approach
Search terms were developed collaboratively with the senior authors of the manuscript, who have extensive experience and expertise in childhood disability, and with an associate librarian. The following keywords were used in the searches and the corresponding medical subject headings terms (Appendix S1, online supporting information) were selected and ‘exploded’ during the search.

Following the electronic database search, a manual search of the reference lists of all relevant studies and existing reviews was conducted to ensure the completeness of the search. Grey literature was not explored in this review as only peer-reviewed and published reports were included.

Study selection criteria
All the citations found in the databases were saved into EndNote (1988–2015) reference manager, where duplicates were removed. The study selection process consisted of four phases: (1) review of all identified studies by the electronic databases on the basis of their titles and abstracts. The first 10% of citations were independently reviewed by two authors (TO and WSS). Given that the agreement in this initial citation selection was 99.8%, the remaining citations selection was performed only by the first author (TO); (2) review of the full texts of all selected studies in phase 1; (3) review of the reference lists of the selected phase 2 articles; and (4) selection of citations from phases 2 and 3 based on their full texts.

Studies were included if the following conditions were met: (1) Type of publication: studies published in peer-review journals, limited to English-language reports on humans, were included; (2) Type of study: experimental studies were included and consisted of randomized clinical trials (RCTs) and non-RCTs (e.g. quasi-experimental). Published literature reviews, conference abstracts, letters to editors, and observational studies were excluded; and (3) Population: studies were included when the study population consisted of parents of children with developmental disabilities. The studies including parents of children with learning disability, epilepsy, and traumatic brain injury were excluded. In the
case where the sample included children with different diagnoses, a study was included only if it explicitly stated that 50% or more of the sample consisted of parents of children with developmental disabilities. (4) Exposure: the exposure of interest was a health coaching intervention, where the parents were coached independently of their child (without his/her presence) on different aspects of the child’s condition, evidence-based treatment strategies, self-management, and/or self-efficacy skills. All types of delivery methods were considered (e.g. group, individual, combined group and individual, face-to-face, or online). The studies explicitly reporting on ‘coaching while treating’ interventions (i.e. when the child is present during all or most of the coaching sessions [>75% of training]) were excluded. The studies employing a purely educational approach (where no ‘trial-and-feedback’ from the coach was provided on the learned skills or abilities) were also excluded. (5) Outcome: studies were included if at least one of the main outcomes was related to the parent (e.g. stress level, depression, self-efficacy, mood/affect, knowledge base). As the focus of the present review is on parent-related outcomes, child-related outcomes were extracted for completeness and comparison purposes and were succinctly summarized.

Methodological quality assessment

Quality-assessment scales

The quality assessment was performed independently by two authors (TO and WSS) on the first 10% of selected studies. Given that quality rating agreement was 100%, the first author continued independent quality ratings for the remaining selected full texts.

For RCTs, the Physiotherapy Evidence Database scale was applied.14 Its psychometric properties are well established and acceptable.12–14 The Physiotherapy Evidence Database scale rates the study quality according to 10 criteria: randomization; allocation concealment; baseline comparability; blinding of participants/assessors/therapists; intention-to-treat analysis; adequacy of follow-up/retention rate; between-group analyses; and presence of point measures. Physiotherapy Evidence Database scores are interpreted as follows: 6 to 10 out of 10, high methodological quality; 4 to 5 out of 10, fair methodological quality; 3 or fewer out of 10 low methodological quality.

The American Academy for Cerebral Palsy and Developmental Medicine guidelines were applied for the quality assessment of the non-RCTs.10 This scale rates the study quality according to seven criteria: description of inclusion and exclusion criteria; description of the intervention(s) and adherence to the intervention(s) assignment; quality of measures; assessment quality; appropriateness of statistical evaluation, including power calculations; consideration of dropouts/loss to follow-up; and whether appropriate methods for controlling confounding variables and limiting potential biases were used. The scores are interpreted as follows: 6 to 7 out of 7, high methodological quality; 4 to 5 out of 7, fair methodological quality; 3 or fewer out of 7 low methodological quality.

Overall level of evidence

The overall level of evidence (i.e. strong, moderate, limited, conflicting, or insufficient) for each intervention was determined using the guidelines developed by Phillips et al.,16 and more recently updated in 2015 (Appendix S2).

Data extraction

Studies fulfilling the inclusion criteria were used to extract data into data-collection forms. Data extraction was performed by the first author (TO) and independently verified for accuracy by the third author (WSS). The following data were extracted: (1) study (year, country, design, quality); (2) population (sample, participant characteristics: mean age and condition [children], sex [parents]); (3) exposure (name of the intervention, frequency/duration, constituents); and (4) assessment and results (statistically significant and non-significant differences in outcome measures between groups [RCTs], or improvements/lack of improvements within group(s) [non-RCTs]).

Categorization of studies and data analysis

Studies were categorized by population type (health condition), design (RCTs vs non-RCTs), and nature of the intervention.

Outcomes were considered significantly different between groups if: (1) the reported p-value was less than 0.05, including rounded values; (2) the authors reported that an association was statistically significant and provided evidence of a moderate-to-high effect size; or (3) the 95% confidence intervals around a rate ratio or similar statistic did not include 1.

In cases where multiple measures were used to measure one outcome (e.g. depression measured by two different scales), the intervention was considered ‘more effective’ (RCTs) or ‘effective’ (non-RCTs) if 50% or more of the measures used were found to be significantly different from the control group (RCTs) or with respect to baseline (non-RCTs).

Meta-analyses were not performed in this systematic review owing to the differences in the outcome measures used across studies, as well as differences in the treatment protocols (e.g. dosage, constituents).

RESULTS

The flow chart of the search strategy and studies selection is depicted in Figure S1 (online supporting information). The initial search yielded 2558 citations; 376 duplicates were removed. Following exclusion by title and abstracts, 114 citations remained, and their full texts were reviewed. Fifteen additional citations were added through reference list searches of the reviewed publications. Of these 129 publications, 28 studies were included after full-text review.9,17–44 After full-text review, 101 publications were excluded (Appendix S3, online supporting information). The main reasons for exclusion by full text were: the presence of the child during coaching intervention, no outcome of interest, or no population of interest, unclearly defined population of
interest, population of interest less than 50%, and unsuitable study design.

Overall, 13 RCTs (including one follow-up report)\(^9\)–\(^{17,26,42–44}\) and 15 non-RCTs were selected for this review (Table SI, online supporting information).\(^{27–41}\)

Included RCTs and non-RCTs were published between 1988 and 2017 and between 2002 and 2018 respectively. Countries of publication for RCTs included (in descending order): the USA (\(n=4\)),\(^{17,18,20,43}\) Australia (\(n=3\)),\(^{21,22,26}\) Hong Kong (\(n=2\)),\(^9,25\) the UK (\(n=2\)),\(^{24,44}\) the Netherlands (\(n=1\)),\(^42\) and Japan (\(n=1\)).\(^{23}\) Countries of publication for non-RCTs included (in descending order): the USA (\(n=5\)),\(^{28,31,32,27,41}\) Australia (\(n=4\)),\(^{27,29,30,36}\) the UK (\(n=2\)),\(^{34,35}\) India (\(n=1\)),\(^33\) Hong Kong (\(n=1\)),\(^38\) Iran (\(n=1\)),\(^39\) and China (\(n=1\)).\(^40\)

The methodological quality of the RCTs was (in descending order) high in nine,\(^9,17,18,20,22,23,25,26,42\) fair in two,\(^21,43\) and low in two (Table SII, online supporting information).\(^{24,44}\) All studies performed random group allocation, but only three studies concealed allocation.\(^{17,18,23}\) Groups were similar at baseline with respect to demographic/descriptive variables (e.g. age of parents, sex, socio-economic status, working status) in all but three studies.\(^{17,24,44}\) It is acknowledged that blinding of participants and therapists was not possible in any of the studies. However, blinding of assessors was performed in two studies.\(^{17,18}\) Retention rates were 85% or greater for one key outcome in all but four studies,\(^2,1,4,24,44\) as was intention-to-treat analysis.\(^{18,24,43,44}\) Between-group statistical comparisons were reported for at least one key outcome in all studies, as were point measures and measures of variability.

The methodological quality of non-RCTs was (in descending order) low in 11 studies,\(^{27–34,36,40,41}\) and fair in four quality studies (Table SIII, online supporting information).\(^{35,37–39}\) All but four studies described and followed the inclusion and exclusion criteria.\(^{27–29,41}\) All but two studies described the intervention and adherence to the intervention assignment.\(^33,40\) All but one study described the measures undertaken,\(^29\) which were reliable and valid for measuring the outcome of interest. None of the studies blinded the assessor. Only one study conducted and reported appropriate statistical analyses, including power calculations.\(^38\) All but three studies had less than 20% dropout/loss to follow-up.\(^31,32,36\) Lastly, none of the studies applied appropriate methods for controlling for confounding variables and limiting potential biases.

Interventions in the included studies targeted parents (RCT sample size range 30–209, mean [SD] 84.7 [35.9]; non-RCT sample size range 3–98, mean [SD] 37.5 [30]) of children (RCT age range 1y 6mo–16y, non-RCT age range 3mo–17y) with ASD (six RCTs, 13 non-RCTs), CP (one RCT, one non-RCT), other developmental disabilities (mixed diagnoses: four RCTs, one non-RCT), and intellectual disabilities (two RCTs). Participating parents were predominantly mothers, representing 40% to 100% (mean [SD] 88.1 [38.1]) of the included RCT samples and 49% to 100% (mean [SD] 82.6 [30]) of the included non-RCT samples. Intervention sessions were delivered individually (nine RCTs; four non-RCTs) or in groups (four RCTs; 11 non-RCTs); face-to-face (10 RCTs; 15 [all non-RCTs]) or online/at distance (two RCTs), or a combination of face-to-face and online formats (one RCT).

Nearly 68% of coaching interventions included education and support (seven RCTs, 12 non-RCTs). Fewer (32%) were manualized and also included education/support (six RCTs, three non-RCTs). Parents received anywhere from two to 12 coaching sessions (mean [SD] 7.75 [3.80] sessions). Interventions consisted of, in descending order: (1) a child-targeted approach, including educating and supporting parents in providing evidence-based treatment strategies to their child (eight RCTs; 10 non-RCTs); (2) a parent-targeted approach, including educating and supporting parents in self-management and/or stress management skills (three RCTs; three non-RCTs); or (3) a mixed approach, combining the latter two methods (two RCTs; two non-RCTs).

In terms of the person providing the coaching intervention, among studies that specified this information, 84% employed a trained and accredited healthcare professional (e.g. psychologist),\(^{9,20,21,23,25,27,28,32–35,37,41–45}\) 12% involved graduate students in the field of psychology and/or occupational therapy,\(^{18,19,22,30}\) and only one study (i.e. 5%) included mothers of children with ASD to act as coaches to other participating parents receiving the intervention.\(^41\)

Table SIV (online supporting information) summarizes the levels of evidence of results presented per population, intervention type, and parent-related outcomes of interest (including outcome measure, where appropriate) (Appendix S4, online supporting information). Twenty different outcomes were studied. Overall, the level of evidence ranged, in descending order, from ‘insufficient evidence (level 5)’ and ‘limited evidence (level 2b to 2a)’ in nearly 63% of studied outcomes to ‘moderate evidence (level 1b)’ and ‘strong evidence (level 1a)’ in 29% and 4% of studied outcomes respectively, to ‘conflicting evidence (level 4)’ in 2% of studied outcomes. When considering only level 1 (a and b) studies (i.e. high-quality RCTs), nearly 64% of those found that the applied health coaching intervention was as effective as the comparison intervention or no treatment in improving parent-related outcomes.

Table SV (online supporting information) outlines the child-related outcomes in relation to the findings of the parent-related measures (Appendix S4 presents a detailed outline). On average, 63% of selected studies also examined child-related outcomes (e.g. behaviour, engagement/play). The consistency between parent-related outcome improvements versus child-related ones was 80%. In other words, in 80% of the studies, when parent-related measures improved/did not improve, child-related outcomes changed in the same direction (improvement/no improvement).

**DISCUSSION**

The objective of this paper was to report the findings of a systematic literature review conducted to identify the
effectiveness of coaching programmes on parent-related outcomes among parents of children with developmental disabilities. This review includes 28 studies, of which 13 are RCTs, mostly of high methodological quality. We determined that coaching programmes in childhood disability have increasingly been studied over the last decade. Overall, while health coaching was meant to supplement current service delivery models by providing additional support to families in need, the lack of strong evidence is reflected by the heterogeneity of the programmes reviewed (nature of intervention and population), and the quality of reporting on those studies.

To facilitate our further interpretations, the information gained through this review assisted in the development of the coaching approach in childhood disability map (Fig. 1, adapted from Ogourtsova et al.). This map highlights the two different possible coaching teams (coaching with vs without the child’s presence), the different focuses of the interventions (parent- vs child-targeted vs mixed approach), and the outcomes of interest (child and/or parent-related). This concept map can be used by clinicians and researchers to better define the direction of the coaching intervention that they are undertaking in their clinical practice and/or their research.

Overall, it was determined that the parent-targeted approach was primarily employed among parents of children with ASD and, to a lesser extent, CP. The child-targeted approach was used with parents of children with ASD, CP, mixed developmental disabilities diagnoses, and intellectual disabilities, and was the most commonly applied health coaching method. The mixed approach was applied solely to parents of children with ASD and was the least frequently applied strategy. We identified that there is mostly insufficient-to-limited evidence supporting the effectiveness of these approaches in improving parent-related outcomes. It is therefore imperative to understand what factors lead to significant improvements in parent-related outcomes in the high-quality studies, as well as to conflicting findings in comparable-quality studies.

For example, a parent-targeted approach (six one-on-one 30–45min sessions, consisting of problem-solving education) versus usual care of regular services (e.g. speech and occupational therapy) resulted in a significantly decreased level of depression among mothers of children with ASD. However, although this intervention also resulted in lower stress levels, a comparable high-quality RCT found that 10 one-on-one 1-hour sessions of psychoeducation were as effective as the Joint Attention Symbolic Play, Engagement, and Regulation programme in diminishing stress levels and parental self-efficacy. The comparison interventions in the two studies could be at the basis of the conflicting results. The coaching intervention emerges as more effective in comparison to usual care, but as equally effective in comparison to a specific social-communication intervention delivered to parents in the presence of their child. Likewise, in studies where no treatment was received by the control group, significant between-group differences were found for parental self-efficacy and levels of stress following a child-targeted coaching approach. Correspondingly, among parents of children with mixed diagnoses, the child-targeted approach in the form of online training was shown to be more effective than usual care in improving parental self-efficacy. Therefore, it emerges that it is important to consider the constituents of the comparison intervention employed in the selected clinical trials, as when a specific and more targeted approach is used, between-group differences fade, and both methods present as equally effective. In addition, it is possible that the ‘targeted approach’ used in the comparison intervention included a form of coaching in itself (e.g. Joint Attention Symbolic Play, Engagement, and Regulation programme), thus leading to finding comparable improvements across groups. These findings are also crucial and informative. Presently, parents of children with developmental disabilities, at best, are receiving usual care (and not specific, targeted treatments), or are waiting for long time periods to receive an intervention (i.e. no treatment). Therefore, the effectiveness and further potential of coaching is promising.

**Figure 1:** Coaching approaches in childhood disability concept map.
Considering only level 1 studies, the constituents of successful health coaching approaches that resulted in parent-related outcomes improvements (depression, conflict between parents, self-efficacy, and stress) included either one-on-one parent-directed psychoeducation consisting of problem-solving/goal-setting/action-oriented sessions;\textsuperscript{15} a child-targeted approach consisting of group sessions;\textsuperscript{9,25} and individual telephone booster follow-up sessions;\textsuperscript{9} or self-administered online learning modules with telephone booster follow-up sessions.\textsuperscript{20} In addition, the duration and frequency of applied methods may also be an influential factor. For instance, two level 1 studies that did not detect any between-group differences for parent-related outcomes following health coaching versus no treatment\textsuperscript{20} or versus usual care,\textsuperscript{23} applied the intervention for eight sessions over 18 months (i.e. potentially low frequency)\textsuperscript{20} and for four sessions over 7 weeks (i.e. potentially short duration).\textsuperscript{23}

Another important finding of this review is that most of the coaching interventions were directed toward strategies to support children (i.e. child-targeted approach); very few studies used the parent-targeted or mixed-methods approaches. This warrants future research, focusing on implementation of coaching interventions that are targeted to empower parents, specifically by supporting their learning through the development of collaborative partnership, by guiding them to achieve self-set goals via different learning strategies, and by elaborating on their existing competencies as competent, confident caregivers. Moreover, summative findings of this review suggest that there is a critical interplay between the parent- and child-related outcomes, such that when parent-related outcomes improve, so do the child-related outcomes (shown by interrelated arrows in Fig. 1). This result is encouraging for parents, their children, healthcare providers, and other relevant stakeholders who are end-users of such programmes or those designing/researching this type of service delivery model in childhood disability.

This review has a limitation. Efforts were adopted to ensure that all the relevant studies were retrieved; however, it is possible that the search missed certain publications (e.g. non-English-language). In conclusion, although health coaching emerges as a potentially effective treatment strategy for parents of children with developmental disabilities and represents a great avenue for addressing the shortcomings of present healthcare delivery models, in view of existing evidence, further high-quality research is strongly suggested using all three identified health coaching approaches for parents of children with or with suspected developmental challenges.

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**SUPPORTING INFORMATION**

The following additional material may be found online:
- **Appendix S1**: Medical subject heading terms used in the search strategy.
- **Appendix S2**: Levels of evidence.
- **Appendix S3**: Excluded studies after full-text review and reasons for exclusion.
- **Appendix S4**: Detailed description of level of evidence for parent- and child-related outcomes.
- **Figure S1**: Flowchart of search and selection of studies.
- **Table S1**: Results of selected studies
- **Table SII**: Quality ratings of the selected randomized controlled trials
- **Table SIII**: Quality ratings of the selected non-randomized controlled trials
- **Table SIV**: Parent-related outcomes: effectiveness and level of evidence
- **Table SV**: Child-related outcomes: effectiveness and level of evidence

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